

THE SCHOOL EXPERIENCE: PERCEPTIONS OF LONG-TERM SURVIVORS  
OF PEDIATRIC SOFT  
TISSUE AND BONE SARCOMAS

By

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Chairperson

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THE SCHOOL EXPERIENCE: PERCEPTIONS OF LONG-TERM SURVIVORS  
OF PEDIATRIC SOFT  
TISSUE AND BONE SARCOMAS

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## Table of Contents

Acknowledgements .....	6
Abstract .....	7
Introduction and Literature Review .....	8
Purpose .....	10
Methods .....	11
Participants .....	11
Table 1 .....	14
Table 2 .....	15
Setting .....	16
Procedures .....	16
Analysis of the Data .....	22
Findings .....	25
The Phenomenon of Being a Student with Sarcoma .....	25
Identifying Common Themes .....	27
Discussion .....	40
Investigator Journalling and Discussions with Independent Reviewer .....	43
Implications .....	48
References .....	51
Appendix I – Adult Consent Form .....	54
Appendix II - Minor Child Parental Consent and Child Assent Form .....	59

Appendix II – Demographic Questionnaire .....	67
Appendix IV - Interview Question and Probes/Domains .....	69
Appendix V – Recommendations for Education Professionals .....	70
Appendix VI - Exhaustive Description of Perceived Supports to Academic Success and Psychosocial Well-being of Students with Sarcomas .....	74
Appendix VII – Clustered Theme .....	76
Appendix VIII – Formulated Meanings .....	79
Appendix IX – Significant Statements .....	85
Appendix X – Comprehensive Exam .....	98
Appendix XI – Comprehensive Exam II.....	149
Appendix XIII – Comprehensive Exam III.....	209

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The School Experience: Perceptions of Long-Term Survivors of Pediatric Soft  
Tissue and Bone Sarcomas

**Abstract**

**Background.** Students with sarcomas my experience supports or barriers to academic success and psychosocial well-being at school. **Purpose.** The purpose of the study is to examine the lived experience of students that have been treated for bone or soft tissue sarcomas. More specifically, this study attempts to find answers to and extract meaning from the following questions.

1. What is the lived experience of a student with bone or soft tissue sarcoma?
2. What does the lived experience of students with sarcomas, as described by survivors, reveal about the perceived supports and barriers to academic success and psychosocial well-being that they experienced?

**Findings.** The lived experience of the phenomenon of school has many facets for the young person with cancer. Memories of survivors included descriptions of supports and barriers that exist in 1) support teams, 2) fitting in, 3) physical factors 4) absence from school and 5) communication. **Practical Implications.** Knowledge of the areas where survivors experience support and barriers will assist educators in designing programs to support students with sarcoma.

## **The School Experience: Perceptions of Long-Term Survivors of Pediatric Soft Tissue and Bone Sarcomas**

Even though long term survival of children and adolescents with cancer has steadily improved over the past 50 years, this population of young people continues to struggle to achieve academic success and psychosocial well-being. When treatment is completed, physical, psychological or social sequelae may continue to result in challenges to achieving goals in school and social settings. Despite the existence of federal educational and civil rights legislation enacted with the intent to protect the rights of persons with disabilities in school and society, barriers continue to affect the school experience of students with cancer. When compared to siblings, survivors of childhood sarcomas, both amputees and nonamputees, were significantly less likely to graduate from high school, to have a job, or to be married and were significantly more likely to report insurance problems overall (Nagarajan, Neglia, Clohisy, Yasui, Greenberg, Hudson, Zevon, Tersak, Ablin, & Robison, 2003).

As a result of increased survival after pediatric cancer, interventions to improve long term outcomes have become important (Hammond, 1992). Several quantitative investigations suggest that survivors of childhood malignancies experience psychosocial and learning challenges (Bressoud, Real del Sarte, Stiefel, Mordasini, Perey, Bauer, Leyvraz, & Leyvraz, 2007; Stam, Grootenhuis, Caron & Last, 2006). Most of these inquiries focus on outcomes of youngsters who received central nervous system treatment for leukemia or brain tumors. Research on the

effect of the cancer experience and treatment on academic success and psychosocial well-being of sarcoma survivors is limited.

Survivors of osteosarcoma were determined to generally recover good functional performance but one third of the patients present depressive symptoms and posttraumatic stress disorder (Wiener, Battles, Bernstein, Long, Derdak, Mackall, & Mansky, 2006). This study of thirty-four long term survivors of sarcomas found that the majority of young people experienced significant persistent psychological distress including difficulty readjusting to work/school after treatment, and enduring worries about health.

Students who are survivors of malignant solid tumors such as Ewing's sarcoma, osteogenic sarcoma, rhabdomyosarcoma and synovial sarcoma have evidenced school problems while on treatment and afterwards. Information has been gathered via quantitative methods from parents, teachers, and school administrators about how to help students with cancer succeed in school (Barrera, Shaw, Speechley, Maunsell & Pogany, 2005). There has even been some quantitative work done with young people with sarcoma, themselves. Citing the lack of investigations of quality of life from the perspective of long term survivors (LTS) of sarcomas, Langeveld, Grootenhuis, Voute, deHaan & van den Bos (2004) studied that topic. Their findings suggest that LTS of pediatric sarcoma worried significantly more about their fertility, getting/changing a job and obtaining insurance. Further, the investigators concluded that further research exploring determinants and indices of quality of life and worries in LTS is warranted.

It is hypothesized that unavoidable barriers such as the physical effects of cancer and high rates of absenteeism may be causative factors. However, other, yet unidentified, barriers may exist which, if identified and removed, could enable students with cancer to realize increased academic and psychosocial success. One possibility is that quantitative methods may not adequately capture the survivor's school experience, and so fail to detect the factors most critical to school success.

Research has not included qualitative inquiry that affords the survivor of sarcoma an opportunity to share their experience of the phenomenon. There may be something about the lived experience of the student that changes the school experience for them, so that trying to "help" them by traditional means is ineffective. Identifying the specific nature of supports and barriers, by hearing the lived experiences of students with soft tissue and bone sarcomas, is the goal of this study. The inquiry will take a qualitative approach to understanding the school experience of children with sarcomas. Understanding the lived experience of students with sarcomas may lead to the identification of specific factors which were perceived by the survivor of sarcoma as beneficial or detrimental to school success and psychosocial well-being. This knowledge will provide understanding of the phenomenon which can shape future interactions and interventions at school, thus resulting in improved long term outcomes for students who are survivors of sarcomas.

#### *Purpose*

The purpose of the study is to examine the lived experience of students

that have been treated for bone or soft tissue sarcomas. More specifically, this study attempts to find answers to and extract meaning from the following questions.

3. What is the lived experience of a student with bone or soft tissue sarcoma?
4. What does the lived experience of students with sarcomas, as described by survivors, reveal about the perceived supports and barriers to academic success and psychosocial well-being that they experienced?

### Methods

This qualitative inquiry employs a phenomenological style which seeks to study the problem by entering the field of perception of the participants; seeing how they experience, live and display the phenomenon; and looking for meaning of the participants' experience (Creswell, 1998). Colaizzi (1973, p.28) supported the importance of phenomenological description when he stated,

“Without thereby first disclosing the foundations of a phenomenon, no progress whatsoever can be made concerning it, not even a first faltering step can be taken towards it, by science or by any other kind of cognition”.

### *Participants*

Participants in the study were selected from a group of long-term survivors of pediatric sarcoma previously treated at a university tertiary care hospital in the Midwest. With assistance of the Pediatric Hematology/Oncology clinical nurse specialist, the researcher identified potential participants by reviewing charts of long-term survivors in the pediatric hematology/oncology department. Seventeen participants who met participation eligibility requirements were identified in this manner. The researcher was involved with the psychosocial and educational care of

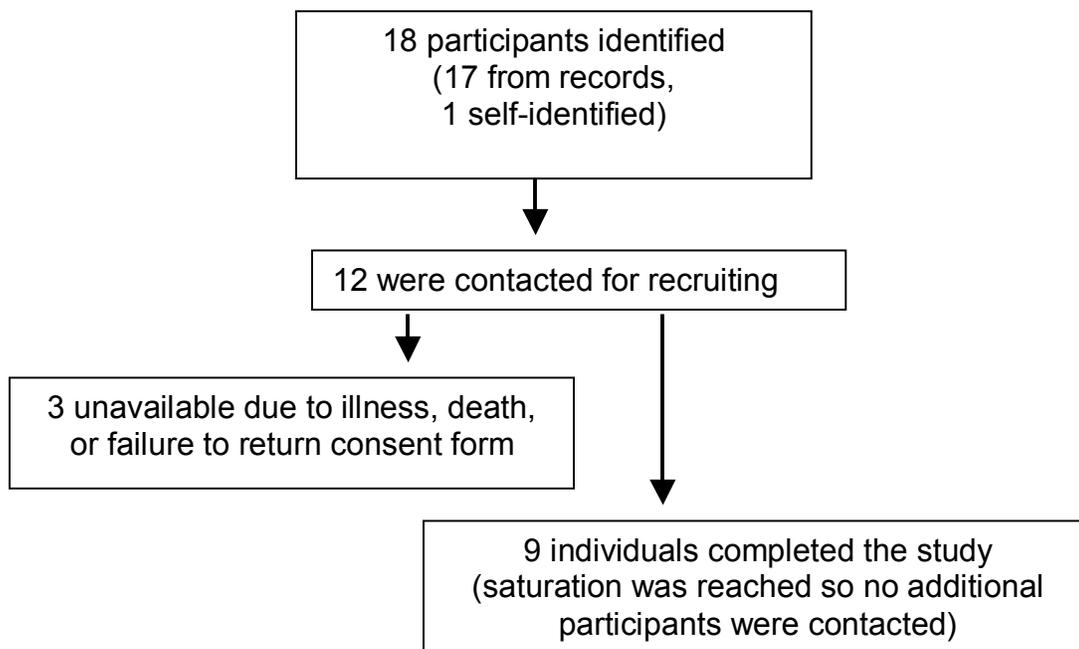
these 17 potential participants during their treatment for cancer. One other participant, who learned of the study through her status as a medical student, approached the researcher with a request to be included on the list of eligible participants, bringing the total number of potential participants to 18.

Phenomenological methodology dictates that information be collected until saturation occurs; that is, until participants' themes are repeated and new information is not being presented. In the present study, saturation had occurred in common themes, among two divergent groups, after interviewing 9 young adults, 8 of whom were female. Eight participants were individuals with whom the investigator had a previous clinical relationship during the time of treatment for sarcoma. One participant was a medical student who the investigator met in the workplace. Participants ranged in age from 16 to 28 at the time of the study (11 to 18 at time of diagnosis). All had been treated during late childhood or adolescence for sarcomas of the soft tissue or bone, including osteogenic sarcoma, Ewing's sarcoma, synovial sarcoma or rhabdomyosarcoma. The length of time since diagnosis ranged from five to fifteen years. Five participants were from rural towns in Kansas; one from an urban area in Kansas; one from an urban area in Missouri; one from rural Missouri; and one from an urban area in Florida. A chart of participants is presented in Table 1.

At the time of interview, three participants were high school students; one sophomore and two seniors. In addition, two participants were in undergraduate programs at universities in Kansas, and one had just completed the first year of medical school, planning to specialize in pediatrics. Two participants were employed

full-time after high school graduation and one had attended 3 semesters of college and was currently unemployed. Participants came from high schools with graduating classes ranging from 12 to over 500 students.

**Table 1: Selection of Participants**



**Table 2: Demographic Information for Potential Research Participants**

Table 1: Research Participants

Participant	Diagnosis	Sex	Age at dx	Current age	Time since dx (years)
1 *	Ewing's sarcoma	F	15	20	5
2 *	Ewing's sarcoma	F	12	17	5
3 **	Osteosarcoma	M	15	17	2
4 *	Ewing's sarcoma	F	11	16	5
5 *	Synovial cell sarcoma	F	12	17	5
6 *	Ewing's sarcoma	F	15	21	6
7 ***	Ewing's sarcoma	M	15	21	6
8 +	Osteosarcoma	F	11	18	7
9 *	Ewing's sarcoma	F	14	25	9
10 **	Rhabdomyosarcoma	M	12	25	13
11 **	Ewing's sarcoma	M	17	27	10
12 **	Rhabdomyosarcoma	M	10	26	16
13 **	Rhabdomyosarcoma	M	10	26	16
14 *	Rhabdomyosarcoma	M	13	28	15
15 **	Ewing's sarcoma	F	5	12	7
16 **	Ovarian teratoma	F	12	24	2
17 *	Ewing's sarcoma	F	15, 19	24	9,5
18 *	Synovial cell sarcoma	F	18	23	5

Key:

- \* = participant
- \*\* = could not be found
- \*\*\* = present physical condition precludes inclusion
- + = deceased

OS = osteogenic sarcoma  
 ES = Ewing's sarcoma  
 RS = rhabdomyosarcoma  
 SS = synovial cell sarcoma

### *Setting*

Interviews occurred in the hometowns of most participants. Participants were invited to identify a location that would provide quiet and privacy and that was convenient for them. Interview sites included four homes, a library, a restaurant, a coffee shop, a hospital room and the investigator's office. All interviews were face-to-face in the hometown of each participant with the exception of a telephone interview of the participant in Florida and the interview in one individual's hospital room. Interviews were conducted between February and May of 2007.

### *Procedures*

#### Ethics Review

The initial step was the submission of the research proposal for approval by the Kansas Masonic Cancer Research Institute and, upon approval there, the Human Subjects Committee. Approval was received from both departments.

#### Independent Reviewer

The next step was to identify and invite an outside reviewer to assist in the investigation. This researcher opted to invite an outside reviewer to ensure that the researcher was vigilant in the identification and recognition of personal prejudgments prior to the onset of the study and that there was verification of the findings of the study. The outside reviewer was a physician in the pediatric department of the hospital where the researcher worked and where the participants had been treated. Her expertise, in a variety of areas, made her an invaluable resource in the research process. The reviewer is an experienced researcher with qualitative expertise. The

reviewer is the co-chair of the Pediatric Ethics Committee at the hospital where the research took place. In addition to her strong research and ethics background, she was enthusiastic about serving as the outside reviewer to this study.

The researcher met, on two occasions, with the outside reviewer to discuss the prejudgments prior to the onset of the research. In addition, the researcher's prejudices were clearly delineated in the research journal. A third meeting was held with the outside reviewer to discuss and confirm study findings.

#### Recruitment and Consent

Participant contact information was obtained through the initial chart review to identify potential participants. Due to the previous clinical relationship with potential participants, initial contact was made by the researcher. To invite potential participants to this study, procedures included an initial phone call from the investigator to either the adult survivor of pediatric sarcoma or, in the case of the two participants who were age 16 and 17 at the time of the interview, their parents. Potential participants or parents were asked if they would be interested in learning about the study and considering participation. All potential participants contacted agreed. Recruitment information included: an overview of the study, including description of the purpose; anticipated length and style of the interview; discussion of the consent and assent processes; a description of the voluntary nature of the study; possible risks and benefits; and explanation of interview location. In the case of the minors, information was provided to both parent(s) and minor child.

Upon the decision to participate in the study, a packet of information was sent to the participant including an introductory letter welcoming the participant to the study, a copy of the study protocol including consent and assent forms, and the demographic form. Participants were asked to read over the study and consent/assent forms but to wait until the initial meeting to sign the consent/assent form. In the case of the minor children, parents were asked to attend the beginning of the meeting so the consent process could be completed with both minor child and parent(s). A thorough explanation of the purpose of the study and the interview process was provided to participants and parents, where indicated, at the initial meeting. The consent process was explained thoroughly. Due to the prior teacher-student relationship between the investigator and participant, the researcher was vigilant in ensuring that each individual understood that their participation was completely voluntary. The consent and/or assent form (Appendix I and Appendix II) was signed and the participant was asked to complete the demographic questionnaire (see Appendix III) if they had not already done so. To protect anonymity in reports of this study, the participant was assigned a number and a pseudonym.

#### The interview

The interview was then conducted as described previously. Participants were offered breaks every half hour, however no one opted to take a break. In phenomenology, the intent is to hear the perceptions of the individual who lived the experience. Thus, the interview began with the open-ended question, “What was it like to be a student with cancer?” This question was designed to elicit an elemental

description of the lived experience of a student with sarcoma. Questions that may be considered to be leading questions or which suggest the type or form of anticipated response are avoided. During extended delays in the respondent's answer, the researcher would often respond "Can you tell me more about that?" If no further explanation was given, the researcher would provide probes, or questions that might encourage further responses (Appendix IV). These probes were developed to extract responses about perceived supports and barriers to academic success and psychosocial well-being; the roles and the reactions of peers, teachers and others in achieving academic success and psychosocial well-being; and the role of social interactions in academic success and psychosocial well-being. Each interview concluded with the question, "What else would you like to make sure you have the opportunity to tell me about being a student with cancer?" This question was included to ensure that participants had the opportunity to address all aspects of the school experience that they felt were important to achieving academic success and psychosocial well-being.

Each interview was tape recorded and transcribed verbatim as soon as possible after completion of the interview. Initial interviews ranged from 42 minutes to 91 minutes in length. Clarification of the participant's intent in a response or assistance in identifying speech on the tape recording was conducted by telephone and e-mail. Each participant was contacted 1-2 times after the initial interview to ensure accuracy in their responses. In addition, the verbatim transcript of their interview was sent, by e-mail, to each participant. Upon completion of data analyses,

participants were e-mailed an overview of the exhaustive description, or essences, gleaned from compiling information from all interviews and asked to indicate whether their experience was adequately described.

In addition to the tape recording of the interview, the researcher kept notes related to each interview. These served to help identify important concepts, body language, facial expressions and other incidents of significance that later aided in analysis of the data.

### Ethical Considerations

Ethical issues in qualitative research share some similar characteristics when compared to ethical considerations in quantitative research. Certainly, confidentiality, anonymity, human subjects considerations, careful adherence to study protocol and respectful treatment of research participants must be a priority when conducting both types of inquiry. In addition, qualitative research presents some unique ethical issues for consideration due to the close relationship that may develop between the researcher and the participant and the vulnerability of some individuals who are research participants.

In general, ethical considerations in qualitative inquiry include participants' feeling of obligation to participate in the research, especially among vulnerable populations; participants who may provide responses that they believe are socially desirable, even if they are not completely accurate; and concerns regarding the disclosure of personal information that, later, the individual may regret sharing.

Therefore, it is very important that the researcher address possible ethical considerations with participants prior to initiation of interviews, focus groups, etc.

In this study, the researcher was very aware of special ethical concerns. First, the participants had, previously, been students of the researcher. Thus, there was the opportunity for a perception of unequal power between researcher and participants. The researcher emphasized the completely voluntary nature of the study and encouraged participants to carefully consider their participation and to discuss it with a parent, spouse, or other trusted individual prior to consenting/assenting and engaging in the research.

Next, the prior relationship between the researcher and participant had often been one where the teacher would help the student with problem solving, coping strategies and other techniques to aid in navigating the cancer experience. In this setting, however, the researcher was a listener as each survivor shared the individual lived experience of being a student with cancer. As a result, it was necessary for the researcher to discuss the difference in the dynamics of the interpersonal interaction prior to the interview.

In addition, the use of the outside reviewer to assist in bracketing of prejudgments and validation of study findings ensured that ethical considerations were addressed further. These meetings enabled the researcher to examine ethical considerations that could be readily identified by an individual who was not as close to the research. This was an invaluable addition to the study.

Finally, another way ethical issues were addressed came, in part, from the nature of the study design. In this phenomenological study, the participants became co-researchers, participating in validating themes and the exhaustive statement and providing concurrence regarding final conclusions. This served to provide participants with a scholarly exposure to research, while giving them a voice as co-investigators.

### Analysis of the Data

The research question was stated as follows: What does the lived experience of students with sarcomas, as described by survivors, reveal about the perceived supports and barriers to academic success and psychosocial well-being that they experienced?

#### Colaizzi's Method of Phenomenological Analysis

Colaizzi's Method of Phenomenological Analysis (1978) was used to analyze the data. The transcribed verbatim interviews of each subject were treated as raw data. Colaizzi's Method was selected because it provides a clear account of the procedural steps involved in analyzing the data in phenomenological research. These steps include:

1. Each interview was transcribed, verbatim, by the researcher. During this process, the participant was contacted, if necessary, to provide verification of the speech or to respond to meaning in the event of lack of audio clarity.
2. The researcher read each interview transcript several times in order to gain an overall sense of the content of the text. Particular attention was paid to the

- context of the response as well as speaker tone, expression and researcher notes regarding researcher observations during the original interview.
3. Significant statements directly pertaining to the experience of a student with sarcoma were identified and extracted from the text. Repetitious statements were eliminated and a list of significant statements was compiled. The significant statements became the raw data. To assist in handling the large quantity of raw data, significant statements were grouped according to common traits including family, friends, school, hospital, psychosocial and physical. Significant statements are presented in Appendix IX.
  4. The analysis then requires the researcher to move away from the language of the participants and to focus on the meaning and intent of each significant statement. The researcher read and reread each significant statement carefully and asked questions such as “What does this really mean?”, “What was the participant’s intent in this statement?” and “Does this describe a support or barrier to academic success or psychosocial well-being?” Formulated meanings are presented in Appendix VIII.
  5. The formulated meanings were then organized into clusters of common themes which represent the concepts of supports and barriers in a more focused fashion. This allowed for the emergence of themes that were common to multiple participants. Five common themes related to supports and barriers to academic success and psychosocial well-being were identified. Clusters of common themes are presented in Appendix VII.

6. An exhaustive description of the phenomenon was developed from the clustered themes. The exhaustive description provides what is commonly referred to in phenomenology as the essence of the phenomenon of being a student with sarcoma. In the present study, the essential structure of the phenomenon was formulated in both the area of supports as well as a separate statement for barriers to academic success and psychosocial well-being. The exhaustive description can be found in Appendix VI.
7. Since the research question asked “What does the lived experience of students with sarcomas, as described by survivors, reveal about the perceived supports and barriers to academic success and psychosocial well-being that they experienced?” Separate analyses were done to identify both supports and barriers to academic success and psychosocial well-being.
8. The outside reviewer was invited to examine significant statements, formulated meanings, clustered themes and the exhaustive descriptions to validate the findings.
9. Final validation was sought by returning the exhaustive description to the participants and asking if the description was representative of the phenomenon as their memory of their lived experience recounted.
10. In addition, the qualitative research data analysis software, QSR’s N6 (Qualitative Solutions and Research, 2002) was utilized to verify the findings of the manual data analysis. In N6, the researcher enters the raw text, in plain text format, of the interview transcripts. The researcher then enters search terms to simultaneously

search the text of transcripts for similarity in terminology used by participants. The software enables text to be saved in nodes, or smaller units of text. Nodes are then coded to identify common themes. The outcome of the computerized analysis validated the significant statements and themes produced during the manual data analysis.

## Findings

### *The phenomenon of being a student with sarcoma*

Of utmost importance in this research is the realization that the lived experience of the phenomenon of school has many facets for the young person with cancer. The researcher's perceptions of what survivors might have experienced and considered significant was not always what the participants reported. Further, it is not enough to say that the participants were *willing* to share their story. Rather, they appeared to have a *need* to tell their story. Few completed their recollections without significant emotional expression, including frustration, laughter and tears. Several sent communications after the interview thanking the researcher for the opportunity to relive their experience. Upon receiving the copy of her interview transcript for verification, one participant wrote:

I cried all over again remembering all that I had told you and the memories were as if I was living in all of them again. Thank you so much for getting me to open up and re-live the memories... good and bad they all have made me who I am today! (4)

### Dual saturation

Saturation occurs when redundancy of information is achieved or, in other words, when no new themes are being presented. The researcher anticipated that saturation may occur along one single direction. In this investigation, young peoples'

experiences fell into two distinct groups related to perceptions of academic success and psychosocial well-being. One group perceived that they had achieved academic success and psychosocial well-being which were supported by a large circle of friends, family, teachers and others. The other group did not perceive the achievement of academic success or psychosocial well-being and, in addition, did not perceive the same level of support from family, friends, teachers, etc. Overall, the latter group reported more negative outcomes including poorer academic success, fewer friends, more teasing and rejection by peers and fewer accounts of close relationships with parents. This dual, or two-pronged, saturation began to manifest after 4 interviews. At that early stage, there were two participants who described academic success and psychosocial well-being with significant statements about family, friends, educators and others who provided them with support. For example, one of the participants who perceived academic success and psychosocial well-being stated,

So I think that it just – you just - if you luck – if you’re lucky enough to have those people in your life who will cut you some slack but will also just not let you become, like a pity party, you know, kind of thing – then you are lucky. (8)

However, another participant described her feeling of lack of academic success and psychosocial well-being when she stated,

“I remember them (peers) calling me a “b” because I received extra help. It’s so hard to look past what I don’t like about the past and see my really good friend standing right by me or to be with me. All I see is the same faces that hurt you so bad. (1)

Saturation, or repeated themes not accompanied by new information, was realized within each of these two groups after 4 participants in each group. Both those students who perceived academic success and psychosocial well-being, as well as

those who did not, identified supports and barriers along a continuum of the following, common themes.

### *Identifying common themes*

It is suggested by phenomenologists that each study represents a way that the data can be analyzed for presentation. There are other ways to analyze the data or arrange common themes resulting in additional findings which also offer valid knowledge and directions for future research. The present study provides information about common themes related to participants' experiences with perceptions of academic success and psychosocial well-being. There are additional themes that were borne of this investigation. However, this researcher has analyzed the data which addresses the original research question.

Five common themes were identified which were described in the experiences of the participants. Those themes include: 1.) Support teams 2.) Fitting in 3.) Physical issues 4.) Absence from school and 5.) Communication.

#### 1. Support teams

A pervasive theme in the data was related to the wide source of support encountered by some youngsters with sarcoma. Students who perceived that they had good school outcomes reported support from a variety of sources and across multiple settings. Those supporters will be referred to as the survivor's support team. When parents, friends, peers, siblings, teachers, health care providers and others were all working as a team, across the youngster's environments, participants perceived a greater sense of success and well-being. These "support teams" provided necessary

physical, educational and psychosocial accommodations across a variety of environments. There were many significant statements that described support and lack of support. For example, one participant shared:

I really – I always say (laugh) I had wonderful doctors and nurses. But, if I didn't have my mom, I don't know what I would have done. Because she's the one that really had to be in the trenches with me. And she's the one that, like when I had those fevers like, "You're going in the hospital" kind of thing when I don't want to go back. So it's all those things that my mom – I really feel almost bad for her – all the things she had to do (laugh). But, yeah, we're really, really close now. (8)

For one participant, support was obvious from the start. In response to a question about what classmates did that was supportive:

Umm, they pretty much just, like, gathered around me – like from the beginning. So they didn't make me feel left out. They talked to me and made sure I was doing okay. And they helped me out with school. (1)

And yet another who simply stated:

I can't think of just one particular thing, you know. Just support from everybody. Like, the community came out. (5)

A participant expressed appreciation for her broad base of support by sharing:

So I think that it just – you just - if you luck – if you're lucky enough to have those people in your life who will cut you some slack but will also just not let you become, like a pity party, you know, kind of thing – then you are lucky. (8)

And for another, big support came in small packages.

I went to a small school so all the little kids knew who you were and everything. And they'd come up and go, "Why don't you have any hair?" It was just so cute. I mean, they didn't care. (5)

Often, a very important member of the support team is the youngster's mother or father.

My mom and I have always been really – we've always been close. But she's definitely the person who had to go through – all of it with me. I definitely am closer to my mom. (2)

Relationships with fathers became closer as well.

Umm, I noticed that I got closer to Dad because he was... we did a lot of bonding just going back and forth (to the hospital) because he's the one that was taking me the most. (1)

Parents sometimes became role models and parents to their teen with cancer.

I bonded with my parents really good through it all. I look up to them (parents) like no other (family). I want to be just like them. (4)

Support sometimes was very pragmatic:

We didn't really emotionally talk about it. We were afraid to talk about it because it would take you off course. We were like, "We know it's bad. Just do what we have to do". It was either "get the cancer treated" or "falling apart". We went for "get the cancer treated". (5)

And for others, a bit more complex:

I think it's – for my friends, or my nurses, or my mom – whoever – it was just kind of finding a balance where they let me talk about things when I wanted to. They didn't force things. But there's also that part where they didn't let me, like get too far into it. You know, like my mom cut me slack but she didn't like, give me the whole rope kind of thing (laugh). My husband – but then boyfriend, he was kind of the same way. Like, he would do stuff for me, but then after awhile he was like, "Okay, like you're pushing the sick thing here". (laughter) (9)

Another very important part of the support team is comprised of friends with the same or similar diagnosis. Saturation on this topic occurred early in the interview process as each individual mentioned hospital friends and nurses.

You know my friends are there (school) but it is completely different. Like when (friend at hospital) and I talk, I feel complete different when I'm talking to her. (3)

Several young people attended summer camp along with friends from the hospital.

It's very fun. You're not afraid to do anything there - to embarrass yourself in front of somebody or anything. Because everybody's - everybody has the same thing and has something different about 'em and it's just - you open up. Very well. (2)

And simply stated,

It was kind of hard because you wanted to make friends at the hospital, but then it really hurt when your friend died. That happened a lot. They were really special friends, too. (7)

Support also came from the nurses at the hospital.

Like I felt like they put a lot of time into getting to know you and when you don't feel good and it's not medical – it's mental – they will sit down and talk to you. I always felt so comfortable around them. (3)

The hospital was referred to as “our home-away-from-home” (3) and a place “where I felt great comfort” (9). Youngsters grew to view the hospital as a place where they were safe in many ways.

When I was in the hospital, everyone knew what was going on with me. I didn't feel like I had to put up any fronts. When I was at school, even if I was feeling crummy I wanted to be like, “I'm fine; I'm good; I'm not sick; I don't feel bad”. Because I didn't want people feeling sorry for me. But when you are in the hospital all those nurses are used to you and they don't feel bad for you. It was just easier to be myself around those people than it was at school. (9)

But for others, barriers were erected when support was not available from all team members or in all of the youngster's environments. Even the relationship with parents did not always feel supportive.

I didn't personally want that (homebound education) because I wanted to be able to go somewhere to get away from home – from Mom – because it seemed like she was always with me..... With my mom, it seems like her and I get frustrated with each other a lot easier. I think that's because we had all that time together. (3)

And

At the time, it brought me really close to my dad. But we're not – I wouldn't say we're very close anymore. At all. (2)

Sometimes, youngsters perceived barriers to the support they wanted and needed.

My brother never wanted to come up to the hospital because he told me, “When you're in a hospital bed, you're not my sister. You are a body in the hospital bed... sick”. That hurt. I needed him then. (3)

One might anticipate that someone who was a cancer survivor would be very supportive of a student going through that experience.

And my history teacher – he did a lot of movies and stuff and I never had time to make 'em up or anything like that so I just didn't know the stuff. He was... he was a real jerk about it, pretty much. And we thought he'd understand because he had had cancer. But, he was the worst out of them all. (2)

Peers and friends may struggle with supporting a friend with cancer.

And, I mean, it's (going back to school) just really awkward. And my best friend – she was scared to death when I was diagnosed. We didn't talk for three years. And then, we finally got back in touch and it's just not the same as it was. At all. (2)

And a survivor who was 12-years-old at diagnosis describes the lack of perceived support from friends:

I wasn't happy. I couldn't get a friend if my life depended on it. No body wanted to be friends with me. (2)

## 2. Fitting in

Erikson (1963) considers identity formation to be the cornerstone of adolescent psychosocial development. An alternative to identity achievement is identity diffusion, which occurs when adolescents are not able to commit to definite life choices. Students with sarcoma are in a situation where uncertainty and inability to commit to life choices are daily occurrences. After a cancer diagnosis, youngsters struggle to answer the question "Who am I now" and to determine how to fit in with friends again.

Perhaps the most consistent message of all participants was their intense desire to just be normal, to not be treated different and to not have people feel sorry for them. Fitting in was enhanced by peers who helped survivors feel like part of the group.

It was really important that they (peers) treat me like they did before. I mean, I didn't feel I was any different than before. That helped me out and kept me up with the positive attitude that way. Because they didn't treat me any differently and that's what I wanted to happen. (1)

And some peers just seemed to know how to help a friend fit in.

I thought it was really nice when my very close friend would call me up at the hospital. She would fill me in on what went on at school 'cause, you know, I wasn't there. (3)

What students with cancer did not want was pity or to be perceived as different.

I didn't like it when I thought people were feeling sorry for me. I felt uncomfortable because I felt different. (9)

Similarly:

Instead of being able to develop who I was, to develop my own personality, I was “the girl with cancer”. I mean I was the absolute minority. Like I was the only one in my school kind of thing. (8)

For some, the changes caused by cancer made it difficult to fit in with friends in some of the most basic adolescent ways.

So, when... it's totally different whenever, you know, you're all excited because you *have* hair and they're excited because they went and got a hair *cut* or they got their hair *colored*. It's... it's two totally different worlds. I'm still friends with all of the girls. We don't... you know, we don't talk on a regular basis like we did before. (6)

Fifteen years after treatment for rhabdomyosarcoma, one young man shared,

The worst part of the whole thing was having to miss the freshman back-to-school party. I was diagnosed the summer between 8<sup>th</sup> and 9<sup>th</sup> grades so I was going in to my first year of high school on chemo. My school had this big party for incoming freshman. I couldn't go. Everybody went but me – I couldn't be there. And everyone was talking all about the party for the whole next year. I felt so left out. I was really hard. (7)

The process of fitting in is complicated when teachers and peers at school are not perceived as being welcoming and supportive. The adolescent who does not feel “normal”, who feels different or does not feel that they fit in with their peers may have difficulty going to school and being productive and, therefore may perceive an effect on academic success and psychosocial well-being. A young man expressed, “Just because someone looks different doesn't mean they are different”. (2) Some youngsters anticipated that school would provide some comfort and familiarity, but were disappointed when they returned.

And you know the clinic and the hospital became, like my home. And school became like a place that... it was like I couldn't really relate to those people the way I could (at the hospital) (8)

Or the poignant reflection of a young woman who was 12-years-old when she was diagnosed with sarcoma:

If we ever had a class project or group projects, I was never picked at all. Because I would do it wrong or maybe they touched me and they would get cancer or something. I was never

picked for anything. I was always the last one there. You get used to it (the participant laughs, but her voice tone became lower as she made this statement). (2)

The problem of fitting in and being comfortable with peers sometimes continues long after the cancer experience. Six years after cancer treatment a participant shared:

It didn't go back to normal. I didn't... I didn't really hang out with them (classmates) either. I mean, I would see 'em during class and that was it. Then, I'd go straight home. I didn't... I pretty much didn't want to have anything to do with them anyway. We really didn't talk or anything like that. (2)

And a 24-year-old who continues to perceive a sense of challenge related to fitting in explained:

I still kind of struggle making friends because - I tease my mom. You know, my mom and I kind of tease about it, but it's almost like I feel you know, like I'm 24 but trapped inside a 45-year-old's body. (8)

The following survivor summarizes what several participants expressed in regard to their desire to fit in and for others to perceive them as normal. "You can't feel normal anyway, having to go through treatment." (2)

### 3. Physical factors

Transition from childhood to adulthood is complex and involves the development of one's own identity (Erickson, 1963). A key component of identity development is body image (Eiser, 1996). Schilder (1950) defined body image as "the picture of our body that we form in our mind... the way in which our body appears to ourselves" (pg. 11). That picture may be altered by the effects of chemotherapy, radiation and surgery and, as a result, body image changes affect identity development in sarcoma survivors. Young people seek acceptance from peers and understanding from the members of their support team about the unique challenges posed by hair loss, in-dwelling catheters, surgical manifestations and other

physical changes. In a study of cancer survivors, a significant proportion of participants experienced psychosocial distress in relation to their visible difference (Rumsey, Clarke, White, Wyn-Williams & Garlick 2004).

The aversion to being different and the desire to be normal appears again as young people talk about the physical factors associated with sarcoma and its treatment. Physical concerns resulted in several perceived barriers to participants.

I was scared, initially, that I wouldn't be able to be a physical person. And being a young male, that's not a good idea – to not be a physical person, you know. And I overcame that as quick as I could. The main thing was, at the beginning of my freshman year, is I had my Infus-a-port in. So I couldn't do anything. I couldn't really be physical. I couldn't take PE; I couldn't take weight training class. And I had lost a lot of weight and such and that was something I really wanted to do – to take a weight training class. And I couldn't do it. (7)

And sometimes physical concerns exist long after the experience of cancer. A survivor

who experienced an radical surgery that removed a significant portion of her buttocks and

resulted in significant deformity stated:

I have a semi-serious boyfriend. That has definitely been interesting to explain a lot of the intricacies of what I've been through. And how I am now and how my body functions now because it is definitely different from many young women. (9)

Another young woman reflected:

It defines a very big part of who I am. It... it definitely does. Because I have a reminder every single day of what I went through. I have a – I think it is a 14-inch scar on my left butt cheek, basically. (6)

The same participant later asked, “Who’s gonna want to date me? Nobody. I’m a freak. (6)”

Hair loss was mentioned, at some point in the interview, by every female participant.

Ummm... at first I kind of felt like an outcast, with my limp and everything, and no hair from chemo. (1)

And another response regarding hair:

One of the hardest things... first my hair fell out. And that was horrifying. I was 14-years-old and when everybody... we were all concerned about, you know, how we looked and wearing cool clothes and everything like that. And then my hair falls out. I was mortified. I bawled like a baby. I bawled for a very long time. (6)

However, hair loss was also seen as an advantage by one participant.

You know, it was cool to have your head shaved. I had wanted to shave my head and my dad wouldn't let me. So, this was my way of getting to wear my hair the way I wanted. (7)

In addition to hair loss, fatigue during and after cancer treatment was a recurring physical issue of concern. In regard to what happened if she got very tired at school, one young woman said:

If it (fatigue) did happen, I would just leave. If I wasn't feeling that great I would just go home and lay down. 'Cause you don't know that you feel bad. It's kind of like being sick for a long time. Whenever I'd get platelets and stuff and I'd be like, "Man, I tell ya... that past couple of weeks I felt bad". But you don't know. And then when you feel good you're like, "Man, I felt bad before". (5)

And another participant agreed by saying, "I was just so drained. I couldn't do it any more". (3)

And yet another included:

My physical - you know, I got tired a lot faster. I, well, even still to this day if I don't rest enough I start getting sick. (9)

Participants often expressed concern about teasing as a result of their physical differences. The possibility of teasing was as much of a threat as the actual occurrence. The following account is, perhaps, the most distressing account of teasing.

I remember I had this teacher my senior year, um, who would tease me about my limp. And he would like - in the hallway, if he passed me - he would, like, mimic my limp. And it always really bothered me. Because, like, I knew that everyone could see that I'm limping. But to me it's something I *really* thought about. So, I didn't like people - I didn't like him, like, teasing me about it. "Cause I was very self-conscious about my limp. It was much more pronounced then. And, um, so - but I just did not feel comfortable approaching a teacher and saying like, "You're hurting, you know, like I think this is rude". 'Cause I just - it was like I, I, like I felt comfortable talking to them about assignments or I can do this or that, but I didn't

feel comfortable saying like, “I think you’re out of line”. So, that’s the only time my mom stepped in. (8)

In addition to outward physical signs of cancer, participants spoke of invisible physical sequelae such as difficulty with concentration, memory and attention.

I don’t remember anything from my junior high; I don’t remember freshman; I don’t remember sophomore year; I don’t remember dates; I can’t remember numbers – nothin’ like that. At all. (3)

The potential affect on the school experience becomes apparent when a young woman shares:

During that time (chemotherapy) to sit down and read, you know, 15 pages in a book at a time was just – it was too much for my brain to comprehend. (9).

And:

Concentration was a very big issue. Um, part of the time because of the medication that they gave me. There were just different ones that made it hard for me to think – hard for me to remember. I did my best, you know, I did what I could (audible sigh). And when you can’t think straight, it’s hard to do your homework. It’s hard to even think about your homework when you’re so sick. (6)

Memory was also reported to be affected by the cancer experience.

I have, I guess, lost some of my memory of that time – during treatment. I just can’t remember some things. (7)

Although infrequent, there were some factors related to physical issues which participants considered to be supports. Identified supports came from within the individual. One participant discovered a way to put a positive spin on the physical issues with which she was uncomfortable. She made signs for her Student Council campaign which read “Bald is Beautiful”. Later, after being elected, she and her mother found other ways to address physical differences in a positive manner.

When you are on Student Council you have to go out to all the school dances and stuff. I remember that being of concern too because I was like, “I’m not going to go to these dances”. I was on crutches and I was having to wear scarves and stuff at that time. But I think it was one of those things - everyone knew that I didn’t have hair. I never wore wigs. So, I just kind of found ways around it. My mom made me a dress that would cover my catheter because I

couldn't find a dress that was high enough, you know. And, like, we put flowers on my crutches (laughter). She made me a little thing with flowers to wear on my head and stuff. So, you know, I went and I think, in the end, it was nice. I'm glad that I didn't miss out on those things. I'm glad that I made – I think it was good that I had to go because I had to figure out a way to make it work. And, you know, it ended up being fun. (8)

#### 4. Absence from school

Academic success and psychosocial well-being are challenged when student is absent from school a significant amount of the time. The experience of frequent absences was universal.

I was absent most of the time (2)

And

Every other week I was in school. (9)

For some, absence resulted in the placement of barriers which students perceive as difficult to remove as illustrated by a survivor who stated, "You always felt behind and not as smart as everyone else"(2). Some survivors managed to get to school, but still experienced what they perceived to be barriers.

I think, um, I remember being sick a lot in school and that was a big drag. You know, having everybody sit there and look at me because I'm sick in school. Especially at that age when I'm looking for acceptance from all my peers. (7)

However, some youngsters manage great success despite frequent school absences.

I got all As that year, with being there less than 46 days. (5)

Another student who perceives herself as being successful shared:

I was on the fast track. It (chemo) was every other week. I'd have a 3-day treatment and then I'd go home for seven days and then I'd have a 5-day treatment. We were traveling from (name of home town). It was 5 hours and 10 minutes without stopping. I ended up with all As and Bs. I just think it kind of made it easier because then I learned how to study on my own and everything. That way, I could find someone if I needed help but I also learned how to just do it on my own. (1)

Another student, who made good grades despite frequent absence from school, points out some of the other challenges of being away from school.

The hardest thing for me though... I went back to school... I think I went back twice the whole second semester ... just to visit. And it was really strange because everybody... nobody knew what to say around me. Nobody knew how to act. (6)

The cancer experience resulted in absence not only from the school day, but also from extracurricular school activities.

I couldn't participate in Freshman Fun Night, which was the big freshman welcoming thing. I went, and I watched everybody but I couldn't do anything. My dad discussed it with them (school) and they went ahead and moved me forward so I could stay with my peers. (7)

For other students, absences result in barriers during treatment and for years beyond treatment. In addition to the unavoidable absences for cancer treatment and side effects, cancer patients miss school days for reasons other than cancer or its treatment.

I would just start crying and saying, "I don't want to go" and I'd do anything and everything to drag my feet so I wouldn't have to go. I mean I'd do *anything*. (2)

And:

Like, I don't enjoy going to school. Like right now I don't want to go to school tomorrow. I always have that feeling: I don't want to school. I'd rather do something else, even though I want to go to college and get a degree, I don't want to go to high school. (3)

## 5. Communication

Effective communication is a challenge to many adolescent situations. That experienced is not improved by the cancer experience. Some survivors, however, were able to develop communication which enabled them to achieve goals, advocate for themselves and to continue developing independence despite having cancer. Effective communication which enabled self-advocacy and developing independence was perceived to be a support in goal attainment.

I was, um, pretty comfortable dealing with any of those issues (school related). That was really more me working with my teachers. And I felt comfortable doing it because my – for the most part my teachers were very kind about it. So I felt comfortable talking to my teachers but I also knew that I had a counselor who was kind of working with me - if I ever needed to talk to her. (8)

Some survivors believed that their willingness to communicate with others about their cancer determined how others responded to them. Effective communication may be fostered by a person with cancer who encourages questions and who is not afraid to talk about it.

People... you know, as long as you let people know that they can talk to you, you know. 'Cause some people want to ask but they're like oh, you know, they're not sure if you want to talk about cancer. But if you just go ahead and act like, "Hey, you know, I just want 'em to know how it is". Be like, "Oh, like this is what I have to do and this is what happens and these are the kinds of drugs with five syllable names that I have to take". 'Cause they don't know about cancer. I don't really care if you want to ask me – just ask me. (4)

Some students were able to identify communication methods that were helpful to them, but had to put forth ensure barriers were not placed by others.

There was a couple of times when another student or somebody would start asking me questions. Some teachers would be like "Don't ask him about that" and others would be like, you know, just sit back and let us talk. And that was, to me, was better – was when I could sit down and speak to another student when they had all these questions. I could just spill out to them, "Hey, it's not weird. That's what happened; this is what happened". And it was just better to relate. And people related better with me that way. But when I couldn't speak to another student and the teachers were trying to, you know, shy other students away from me – that was something I didn't like. (7)

However, ineffective communication imposed barriers for other participants.

The following excerpt was offered by a young woman who was concerned about her parents' belief that psychologists and psychiatrists are "quacks".

I didn't feel like I could talk to them (parents). They were going through enough, you know. So I didn't have anybody to talk to, you know. Nobody knew what I was going through. Nobody knew what I was feeling. I wrote a lot. I wrote a *lot*. But, it was still... you know, I couldn't get those feelings out and I couldn't deal with those emotions because I didn't want to freak out my parents. And, sometimes you don't feel comfortable – or I did not feel comfortable talking to my friends. Because, it's like, I don't want to put all that on them. (6)

Not only was communication difficult with parents, but with other support team members

as well. One young woman showed great insight when she shared:

And there was a guy that I had really liked and that we had talked a lot on the phone and he rode my bus and stuff. And then after I was diagnosed it was just too weird talkin' to him on the phone. Because we... he was just like... he didn't know what to say and he didn't know now to act. And after I was diagnosed and went through some chemo and stuff, you know, the conversations were just never the same. It was never the same 'cause, like I said, he just didn't know how to act. And, well, really ... I don't think I would have either. (6)

And another participant expressed sadness that people at school did not understand what she was experiencing.

I went to such a small school and it's not anything that they'd ever had to deal with before. And I almost feel like (audible sigh) it would have made a difference if, somehow, the administration and the educators, I guess you could say the teachers or whatever, had been more educated about what was – what was exactly going on. I mean, they had no idea. But nobody was really in touch. (4)

There are many psychosocial issues embedded in the five identified themes.

Sarcoma during adolescence significantly affects psychosocial issues. Participants spoke, with passion, about many of those issues and the affect on them. In the interest of focusing on issues which may be addressed in school settings, a more in depth psychosocial analysis has been reserved for future investigation.

## Discussion

There are lessons to be learned from the unique experiences of these two groups of survivors of pediatric sarcomas. Survivors of pediatric sarcoma fell into two groups: 1) those who perceived that they had achieved academic success and psychosocial well-being despite their experience with sarcoma and 2) those who perceived that they did not achieve academic success or psychosocial well-being as a result of their experience with sarcoma. Five themes were identified which represented the responses of the lived experiences of the two groups, and these were

developed into Exhaustive Descriptions which provide a synthesis of the commonalities of supports and barriers to academic success and psychosocial well-being as elucidated by all participants in this study..

Supports and barriers were remembered by youngsters in both groups. It appears that those individuals in the group that perceived success and well-being were not deterred by the barriers, while the youngsters who did not perceive success and well-being were more significantly affected by barriers. This was expressed in the interviews by length of responses and by the emotion and expression that accompanied some reactions. In addition, youngsters who perceived their achievement to be lower remembered avoiding school, ending relationships with friends and having difficulties in relationships with parents and siblings. Exhaustive descriptions for perceptions of supports and barriers are given in Appendix VI.

From this investigation we learned that youngsters who sense that they have achieved academic successes and psychosocial well-being have extensive support from a wide variety of sources and across various environments. They perceive that parents, siblings, friends, teachers, school administrators, peers and others are helping them in a variety of ways. They also perceive that this support occurs in all areas of their environment including home, school, community and hospital. That support is characterized by effective communication and an understanding of the young person with cancer. These components of support are perceived as enabling the young person to survive and, at times, thrive during the cancer experience and beyond. Due to this support, youngsters with sarcoma feel better able to fit in with peers and to

minimize physical differences. They are better able to achieve academic success despite frequent absences. Relationships and communication with friends and family can be strengthened. The input from their support team translates into a range of accommodations that enables the young person to realize academic success and psychosocial well-being.

Conversely, young survivors of sarcoma who did not perceive that they had achieved academic success and psychosocial well-being described an absence of support from parents, siblings, friends, teachers, school administrators, peers or others. Their responses suggest that gaps in support, either from specific groups or in specific environments, may have deleterious effects on how they experience cancer and its treatment. Without a wide net of support, young people feel that they do not fit in with peers and classmates and are very aware of their physical differences. Frequent absences due to health related issues are augmented by additional time away from school because it no longer feels like a place the student with sarcoma wants to be. Relationships and communication with family, friends, teachers and others begins to decline and the young person perceives pervasive lack of success in academic and psychosocial arenas.

This research provides important information about the lived experiences of students who are survivors of pediatric sarcomas. They perceive that their school experience is much more than *academic* assignments. In addition, even those who fared well in their school experience had significant concerns about body image changes, being different, not being normal and being the object of pity from others.

Across the board, families suffered; some became stronger from the experience and others never seemed to recover. The survivors told us that fatigue is a problem, both during and after treatment. And many shared what the quantitative research has not revealed: that they perceive cancer and its treatment to have a negative effect on concentration, attention and memory in students with sarcoma.

In addition to these insights about the lived experience of students who were treated for sarcomas during late childhood or adolescence, this study identifies possible directions for future research with this population. During the research, unique discoveries were made regarding bracketing, journalling, and the role of the independent reviewer in a phenomenological inquiry.

*Investigator journalling and discussions with independent reviewer*

Phenomenological research seeks to return to the Greek conception of philosophy as “a search for wisdom before philosophy became enamored with empirical science” (Creswell, pg. 52). In this search, phenomenological design calls for the researcher to openly discuss the prejudgments which exist at the onset of the inquiry. Bracketing, as this practice is called, is intended to help the investigator recognize personal biases at the onset of the inquiry in order to suspend all judgments about what is real until the real issues are founded on a more certain basis by studying the phenomenon through the lived experiences of those who are experts. This researcher and the outside reviewer discussed prejudgments on two occasions. In addition, the researcher journalled about thoughts, biases and expectations that accompanied the research.

The researcher anticipated that the interviews would, uniformly, suggest that being a student with sarcoma was a very difficult task. Further, it was assumed that survivors would universally recount experiences of frustration and disappointment related to academic experiences; describe difficulties with friends and peers that resulted from the young person being absent from shared activities; describe teachers and school systems that failed to provide sound educational opportunities to them while they were on treatment; complain that teachers were “too easy” on them; and express that participants’ had not been able to achieve their childhood dreams or aspirations, or had significantly modified goals, as a result of these barriers. Further, the investigator believed that the root of concern and disappointment for students with cancer originated from barriers to achieving academic success. In other words, the researcher thought that the foundation of problems was related to students’ lack of academic success which, in turn, led to the challenges to achieving psychosocial well-being. All of these biases were discussed with the outside reviewer and recorded in the research journal.

The initial bracketing discussion with the outside reviewer occurred prior to the onset of the interview process and consisted, essentially, of a verbal listing of those things that the researcher had identified as personal biases. The researcher could not perceive, at this stage, how the bracketing exercise would affect the course of the research. However, the second meeting with the outside reviewer was very meaningful. By this time, the first two interviews had been conducted and transcribed. In doing the interviews, the researcher had come to better understand the

role of personal bias in the research process and had become aware of biases that had not been recognized before.

In addition, biases emerged which could have affected the data, if the practice of bracketing had not been employed. These biases were ones which were related to the personal traits of the interviewer and which reflected components of prior relationships with the participants. The researcher and participants had enjoyed a teacher-student relationship during participants' treatment for sarcoma. These relationships were founded on a great deal of dialogue and interactive communication. During the first interview, it appeared that the participant was waiting, at times, for the researcher's response. The natural tendency of the researcher was to want to be responsive and supportive to the individual. The researcher felt unfriendly and unsupportive to the participant due to the limited verbal input which was offered during the interview. A similar situation ensued during the second interview, although to a lesser degree. It was after the second interview that the researcher met again with the outside reviewer. At this time, a discussion evolved regarding this phenomenon and the researcher's need to describe to participants, prior to the interview, the different nature of the interview interaction. The solution was to schedule time to have a more interactive conversation at the conclusion of the interview. These steps solved this problem and subsequent interviews seemed effortless.

During data analysis, the researcher was aware and journalled about a personal bias regarding the definition of the concepts of "academic success" and

“psychosocial well-being” that might differ from that of participants. Participants who graduated from high school certainly are likely to feel a great sense of accomplishment and success. Thus, it is with caution that references are made to success or failure of study participants. It is important to note that this discussion focuses on the *perception* of their personal academic success and psychosocial well-being.

Journalling helped the researcher appreciate the distinction between probing the respondent and guiding the respondent. The fundamental nature of phenomenological interviewing is to ask as few questions as possible and to maintain open-ended queries that do not lead the participant in a certain direction. This is in an attempt to gain insight into the participant’s lived experience only as they remember it. Ideally, in this study, the researcher would have asked only, “What was it like to be a student with cancer?”. Each participant had plenty to say and readily provided ample information in the areas of physical challenges, psychosocial issues, family, friends and the hospital. For example, in response to the question “What was it like to be a student with cancer?” most respondents talked immediately about friends and peers. The researcher would probe with “Can you tell me more about what school was like” or “Can you talk about how that affected your schoolwork”. The response still did not include much information about academic issues.

Journalling about the way participants answered questions and the topics about which they spoke led to some of the significant conclusions regarding the approach used to analyze the data and the manner in which youngsters with sarcoma

remember their school experience. First, youngsters wanted to talk about many topics more than they wanted to talk about academics. Although there was enough data to analyze academic success, there was significantly more data regarding friends, dating, physical changes, family members and the hospital. One participant, when asked if she remembered anything in particular that a teacher did that was helpful, stated, “Um, I don’t know of any, really, as far as really helped me with school or anything”. The significance of this may be that survivors of sarcomas did not have memorable experiences of an exclusively academic nature or that they did not frame their cancer experience in the context of academic outcomes.

It was through journaling that the researcher became aware of the bias regarding the belief that participants would express frustration and disappointment related to academic experiences. Perhaps the psychosocial issues were more compelling than academic ones due to the adolescent age of participants at the time of their cancer diagnosis and treatment. Participants mostly talked about their experience related to *school*, rather than their experiences related to *academic success*. The participants wanted to talk about school in the context of friends, peers, family support, discomfort with physical changes and body image issues and their intense desire to “be normal”, “not be treated differently” and “not have people feel sorry for me”. It was important for the researcher to put away, or bracket, the bias of focusing on academics as this was not the lived experience of the participants.

Finally, the experience of meeting with the outside reviewer to validate the research findings was very beneficial. The reviewer confirmed that the findings were

relevant and that they were representative of the significant statements of the transcribed interviews. In addition, the discussion gave rise to the potential for other papers which could come from this data and future research directions emerging from this study.

Journalling and discussions with the outside reviewer both contributed significantly to data analysis. The research journal became a map, of sorts, providing both an historical path of how the research unfolded and another route delineating where the research was heading. The act of writing about the researcher's experiences along the way gave birth to ideas and directions that, otherwise, might not have been considered. It was a powerful tool. Likewise, the outside reviewer served as a compass along the research route, providing validation that the course traveled was leading in the right direction.

### Implications

Navigating the school experience may prove challenging for even the most able-bodied of students. In addition, the broad base of quantitative research has concluded that central nervous system treatment for leukemias and brain tumors result in cognitive changes which further challenge the school experience. This study of survivors of solid tumors suggests that unique challenges to academic success and psychosocial well-being also exist for this population of learners. A youngster on treatment for sarcoma can experience increased difficulty due to physical and psychosocial factors during treatment and beyond. This phenomenological study sought to identify the perceived supports and barriers to academic success and

psychosocial well-being of young people who are long-term survivors of pediatric sarcomas of the bone or soft tissue.

Reasons for the differences in perceptions of success and well-being require further study. Interesting research might include both qualitative and quantitative investigations to determine causative factors. Internal and external locus of control, parent coping styles, school performance prior to diagnosis of sarcoma and many other topics could be studied to determine if those factors are related to survivors' perceptions of academic success and psychosocial well-being while a student with cancer.

A significant implication of this inquiry resides in lessons learned that can shape future education practice, research and teacher training. Appendix V provides specific suggestions for ways that post secondary programs can prepare teachers to work with students with sarcomas; ideas for education research to diffuse the topic into the field of education; and strategies for educators to incorporate in their practice to better serve young people with sarcomas. These interventions are not specific to students with cancer and are likely to benefit students with other chronic illnesses, as well. Educators can use the information reported by survivors of sarcoma to begin increasing supports and eliminating barriers for any student with similar concerns and needs.

Future quantitative research may look at these qualitative findings to help shape study directions. This research sheds light on the necessity of clearly defining what is to be studied in regard to the school experience. The difference between

perceptions of “academics” and “school” which has been suggested by this research provides an important consideration for future inquiries. It is important to ensure that there is clarity in the definition of these concepts and in what is being measured in future investigations. As this researcher learned, merely referring to “school success” or “academic achievement” may not have meaning to the participant and, therefore, may not capture all of the information which the researcher is seeking. .

Further, this research provides information about the various groups and settings that young sarcoma survivors deem necessary for achieving academic success and psychosocial well-being. A variety of inquiries could use the information gleaned here to further investigate supports and barriers for students with sarcomas or other chronic conditions; the various relationships that affect the youngster’s well-being; and the interrelatedness of the youngster’s experiences at school and outside of school.

By hearing and understanding their experience, it is hoped that educators will identify ways to ensure that students with chronic health conditions have supports in place and barriers removed, thus affording the best possible opportunity for academic success and psychosocial well-being (see Appendix V for suggestions). The goal is to enable all students with sarcoma to embrace the following statements:

I would tell her to go to school as much as she could. Because I think it really helped. I just really liked going to school. I thought that it made me feel normal. And it gave me, like, a break from cancer. Not completely, but in a way. (17)

And,

I think I felt more of a success after I completed it (cancer treatment) than I may have before. This is more like, “Hey, you know, I had this obstacle and I did it and hurray for me”. I was more proud of myself. (5)

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## **Appendix I: Adult Consent Form**

### **Adult Subject Consent Form**

**Title:** The School Experience: Perceptions of Long-Term Survivors of Pediatric Soft Tissue and Bone Sarcomas

#### **INTRODUCTION**

As a person who was treated for cancer while you were a student, you are being invited to participate in a research study which will give you the opportunity to share what it was like to be a student with cancer. It is hoped that the experiences you share will help identify ways help students with cancer manage school challenges. This research study will be conducted at the University of Kansas Medical Center with Kathy Davis, Ph.D. candidate, as the principal investigator. We will enroll approximately 5 - 10 subjects in the study.

You not have to participate in this research study. It is important that before you make a decision to participate, you read the rest of this form. You should ask as many questions as needed to understand what will happen to you if you participate in this study.

#### **BACKGROUND**

Students with cancer often report that there are challenges to keeping up in school and maintaining social opportunities while they are on treatment. There are factors such as higher rates of absenteeism, fatigue, effects of medications and low infection fighting abilities that may affect a student with cancer and his/her ability to be at school and to succeed in school. There have been a number of studies which have looked at the effects of cancer in childhood. There have not been research that has asked former students with cancer to tell what their experiences were like in order to help identify what needs to be studied to see if the school experience for students with cancer can be improved. We want to see if we can identify what former students with cancer consider to be the things that were the most helpful, and the things that made it more difficult to achieve school success and psychosocial well-being.

#### **PURPOSE**

The purpose of this qualitative study will be to develop a better understanding the school experience of children with cancer. Understanding the lived experience of students with cancer may lead to the identification of specific factors which were perceived as beneficial or detrimental to school success and psychosocial well-being by the child. This knowledge will lead to a better understanding of the child's

experience, which can shape future interactions and interventions at school, thus resulting in improved long term outcomes for students with these diagnoses.

**PROCEDURES**

Your participation will require one 2-hour interview about your experience as a student with cancer. The interview may take place before or after a regularly scheduled appointment at the University of Kansas Medical Center or in your home community. You may determine where the interview will occur (i.e. a library, coffee shop, your home, KUMC, etc.).

After the initial interview, you will receive a summary of our interview via e-mail or regular mail. You will be asked to review the summary and verify my interpretation of your statements for accuracy. This process will occur at least 2 more times, as I check of accuracy on what appear to be common themes between your responses and the responses of other participants, and, finally, as I identify the most essential meaning of your experience.

The interview will consist of asking you to describe experiences, of your choice, that occurred when you were a student with cancer. In addition, you will be asked to describe what it was like to be a student with cancer, and what interventions or factors you perceived as supportive; and what interventions or factors you perceived as resulting in barriers to school success and psychosocial well-being.

You will be allowed to take breaks whenever you feel you need one. You may choose not to answer specific questions or discuss specific topics. You may also choose to stop the interview at any time or to cease participating in this study.

**RISKS**

There are minimal risks to participating in this study. You may experience a negative emotional response when recalling what it was like to be a student with cancer. If you (parents, in the case of a minor child) would like to talk to someone about these feelings, we will help you schedule an appointment with Behavioral Pediatrics at KUMC or with another psychologist or counselor in your area.

*There may be other risks that have not yet been identified, and unexpected side effects that have not been previously observed may occur.*

**NEW FINDINGS STATEMENT**

You will be informed if any significant new findings develop during the course of the study that may affect your willingness to participate in this study.

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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**BENEFITS**

You may experience a positive emotional response as a result of having the opportunity to discuss your lived experience as a student with cancer. It is hoped that information gained in this research study may be useful in the developing school programs for future students with cancer.

**ALTERNATIVES**

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you receive at University of Kansas Medical Center.

**COSTS**

There are no costs to you for participating in this study.

**PAYMENT TO SUBJECTS**

*You will not receive any money for participating in this study.*

**INSTITUTIONAL DISCLAIMER STATEMENT**

Although the University of Kansas Medical Center does not provide free medical treatment or other forms of compensation to persons injured as a result of participating in research, such compensation may be provided under the terms of the Kansas Tort Claims Act. If you believe you have been injured as a result of participating in research, you should contact the Office of Legal Counsel, Mail Stop #2013, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

**CONFIDENTIALITY AND PRIVACY AUTHORIZATION**

Efforts will be made to keep your personal information confidential. Researchers cannot guarantee absolute confidentiality. If the results of this study are published or presented in public, information that identifies you will be removed.

The privacy of your health information is protected by a federal law known as the Health Insurance Portability and Accountability Act (HIPAA). By signing this consent form, you are giving permission (“authorization”) for KUMC to use and share your health information for the purposes of this research study. If you decide not to sign the form, you cannot be in the study.

To do this research, we need to collect health information that identifies you. We will collect information about the type of cancer that you had and the length of treatment.

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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Your study-related health information will be used at KU Medical Center by Kathy Davis, Ph.D. candidate and Joan McDowd, PhD and other members of the research team at KU Medical Center, the KUMC Human Subjects Committee and other committees and offices that review and monitor research studies. Study records might be reviewed by government officials who oversee research, if a regulatory review takes place.

All study information that is sent outside KU Medical Center will have your name and other identifying characteristics removed, so that your identity will not be known. Because identifiers will be removed, your health information will not be re-disclosed by outside persons or groups and will not lose its federal privacy protection. If your specific comments are used in the publication of results of this study, there will be no personal identifiers associated with those statements.

Your permission to use and disclose your health information remains in effect until the study is complete and the results are analyzed. After that time, information that personally identifies you will be removed from the study records.

### **QUESTIONS**

You have read the information in this form. Kathy Davis, Dr. McDowd or their associates have answered your question(s) to your satisfaction. You know if you have any more questions after signing this you may contact Kathy Davis at (913) 588-6305 or Dr. McDowd at (913) 588-0646. If you have any questions about your rights as a research subject, you may call (913) 588-1240 or write the Human Subjects Committee, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

### **SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY**

You understand that your participation in this study is voluntary and that the choice not to participate or to quit at any time can be made without penalty or loss of benefits. You understand that not participating or quitting will have no effect upon the medical care or treatment you receive now or in the future at the University of Kansas Medical center. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

You have a right to change your mind about allowing the research team to have access to your health information. If you want to cancel permission to use your health information, you should send a written request to Kathy Davis. The mailing address is Kathy Davis, Mail Stop 4003, University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160. If you cancel permission to use your health information, you will be withdrawn from the study. The research team will stop

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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collecting any additional information about you. The research team may use and share information that was gathered before they received your cancellation.

**CONSENT**

Kathy Davis, Dr. McDowd or their associates have given you information about this research study. They have explained what will be done and how long it will take. They explained any inconvenience, discomfort or risks that may be experienced during this study.

I freely and voluntarily consent to participate in this research study. I have read and understand the information in this form and have had an opportunity to ask questions and have them answered. **I will be given a signed copy of the consent form to keep for my records.**

\_\_\_\_\_  
Type/Print Subject's Name

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Time                      Date

\_\_\_\_\_  
Type/Print Name of Witness

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Type/Print Name of Person Obtaining Consent

\_\_\_\_\_  
Signature of Person Obtaining Consent

\_\_\_\_\_  
Date

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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## **Appendix II: Minor Child Parental Consent and Child Assent**

### Parental Permission/Child Assent Form

**Title:** The School Experience: Perceptions of Long-Term Survivors of Pediatric Soft Tissue and Bone Sarcomas

#### **INTRODUCTION**

As the parent of a child who was treated for cancer while he/she was a student, you are being asked to give permission to allow your child to participate in a research study which will give your child the opportunity to share what it was like to be a student with cancer. It is hoped that the experiences your child shares will help identify ways help students with cancer manage school challenges. This research study will be conducted at the University of Kansas Medical Center with Kathy Davis, Ph.D. candidate, as the principal investigator. We will enroll approximately 5 - 10 subjects in the study.

You do not have to give permission for your child to participate in this research study. It is important that before you make a decision to allow your child to participate, you read the rest of this form. You should ask as many questions as needed to understand what will happen to your child if you allow him/her to participate in this study

#### **BACKGROUND**

Students with cancer often report that there are challenges to keeping up in school and maintaining social opportunities while they are on treatment. There are factors such as higher rates of absenteeism, fatigue, effects of medications and low infection fighting abilities that may affect a student with cancer and his/her ability to be at school and to succeed in school. There have been a number of studies which have looked at the effects of cancer in childhood. There have not been research that has asked former students with cancer to tell what their experiences were like in order to help identify what needs to be studied to see if the school experience for students with cancer can be improved. We want to see if we can identify what former students with cancer consider to be the things that were the most helpful, and the things that made it more difficult to achieve school success and psychosocial well-being.

#### **PURPOSE**

The purpose of this qualitative study will be to develop a better understanding the school experience of children with cancer. Understanding the lived experience of students with cancer may lead to the identification of specific factors which were perceived as beneficial or detrimental to school success and psychosocial well-being by the child. This knowledge will lead to a better understanding of the child's

experience, which can shape future interactions and interventions at school, thus resulting in improved long term outcomes for students with these diagnoses.

**PROCEDURES**

Your child’s participation will require one 2-hour interview about your experience as a student with cancer. The interview may take place before or after a regularly scheduled appointment at the University of Kansas Medical Center or in your home community. You and your child may determine where the interview will occur (i.e. a library, coffee shop, your home, KUMC, etc.).

After the initial interview, your child will receive a summary of our interview via e-mail or regular mail. Your child will be asked to review the summary and verify my interpretation of his/her statements for accuracy. This process will occur at least 2 more times, as I check for accuracy on what appear to be common themes between your child’s responses and the responses of other participants, and, finally, as I identify the most essential meaning of your child’s experience.

The interview will consist of asking your child to describe experiences, of his/her choice, that occurred when he/she was a student with cancer. In addition, your child will be asked to describe what it was like to be a student with cancer; what interventions or factors he/she perceived as supportive; and what interventions or factors he/she perceived as resulting in barriers to school success and psychosocial well-being.

Your child will be allowed to take breaks whenever he/she feels he/she needs one. Your child may choose not to answer specific questions or discuss specific topics. Your child may also choose to stop the interview at any time or to cease participating in this study.

**RISKS**

There are minimal risks to participating in this study. Your child may experience a negative emotional response when recalling what it was like to be a student with cancer. Kathy Davis, who will be conducting the interviews, has 32 years of experience with young people with special health conditions. She will be alert to any uncomfortable feelings your child may have, and will help your child with that experience. If you or your child would like to talk to someone else about these feelings, we will help you schedule an appointment with Behavioral Pediatrics at KUMC or with another psychologist or counselor in your area.

*There may be other risks that have not yet been identified, and unexpected side effects that have not been previously observed may occur.*

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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**NEW FINDINGS STATEMENT**

You and your child will be informed if any significant new findings develop during the course of the study that may affect your willingness to participate in this study.

**BENEFITS**

Your child may experience a positive emotional response as a result of having the opportunity to discuss his/her lived experience as a student with cancer. It is hoped that information gained in this research study may be useful in the developing school programs for future students with cancer.

**ALTERNATIVES**

Participation in this study is voluntary. Deciding not to participate will have no effect on the care or services you receive at University of Kansas Medical Center.

**COSTS**

There are no costs to you for participating in this study.

**PAYMENT TO SUBJECTS**

*You or your child will not receive any money for participating in this study.*

**INSTITUTIONAL DISCLAIMER STATEMENT**

Although the University of Kansas Medical Center does not provide free medical treatment or other forms of compensation to persons injured as a result of participating in research, such compensation may be provided under the terms of the Kansas Tort Claims Act. If you believe your child has been injured as a result of participating in research, you should contact the Office of Legal Counsel, Mail Stop #2013, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

**CONFIDENTIALITY AND PRIVACY AUTHORIZATION**

Efforts will be made to keep your child’s personal information confidential. Researchers cannot guarantee absolute confidentiality. If the results of this study are published or presented in public, information that identifies your child will be removed.

The privacy of your child’s health information is protected by a federal law known as the Health Insurance Portability and Accountability Act (HIPAA). By signing this

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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consent form, you are giving permission (“authorization”) for KUMC to use and share your child’s health information for the purposes of this research study. If you decide not to sign the form, you cannot be in the study.

To do this research, we need to collect health information that identifies your child. We will collect information about the type of cancer that your child had and the length of treatment.

Your study-related health information will be used at KU Medical Center by Kathy Davis, Ph.D. candidate and Joan McDowd, Ph.D. and other members of the research team at KU Medical Center, the KUMC Human Subjects Committee and other committees and offices that review and monitor research studies. Study records might be reviewed by government officials who oversee research, if a regulatory review takes place.

All study information that is sent outside KU Medical Center will have your child’s name and other identifying characteristics removed, so that your child’s identity will not be known. Because identifiers will be removed, your child’s health information will not be re-disclosed by outside persons or groups and will not lose its federal privacy protection. If your child’s specific comments are used in the publication of results of this study, there will be no personal identifiers associate with those statements.

Your permission to use and disclose your child’s health information remains in effect until the study is complete and the results are analyzed. After that time, information that personally identifies your child will be removed from the study records.

### **QUESTIONS**

You have read the information in this form. Kathy Davis, Dr. McDowd or their associates have answered your question(s) to your satisfaction. You know if you have any more questions after signing this you may contact Kathy Davis at (913) 588-6305 or Dr. McDowd at (913) 588-0646. If you have any questions about your child’s rights as a research subject, you may call (913) 588-1240 or write the Human Subjects Committee, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

### **SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY**

You understand that your child’s participation in this study is voluntary and that the choice not to participate or to quit at any time can be made without penalty or loss of benefits. You understand that not participating or quitting will have no effect upon the medical care or treatment your child receives now or in the future at the University of Kansas Medical center. The entire study may be discontinued for any reason without

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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your consent by the investigator conducting the study.

You have a right to change your mind about allowing the research team to have access to your child's health information. If you want to cancel permission to use your health information, you should send a written request to Kathy Davis. The mailing address is Kathy Davis, Mail Stop 4003, University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160. If you cancel permission to use your child's health information, your child will be withdrawn from the study. The research team will stop collecting any additional information about your child. The research team may use and share information that was gathered before they received your child's cancellation.

**CONSENT**

Kathy Davis, Dr. McDowd or their associates have given you information about this research study. They have explained what will be done and how long it will take. They explained any inconvenience, discomfort or risks that may be experienced during this study.

I freely and voluntarily consent for my child to participate in this research study. I have read and understand the information in this form and have had an opportunity to ask questions and have them answered. **I will be given a signed copy of the consent form to keep for my records.**

\_\_\_\_\_  
Type/Print Subject's Name

\_\_\_\_\_  
Signature of Subject's Parent

\_\_\_\_\_  
Time                      Date

\_\_\_\_\_  
Type/Print Name of Witness

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Type/Print Name of Person Obtaining Consent

\_\_\_\_\_  
Signature of Person Obtaining Consent

\_\_\_\_\_  
Date

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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Principal Investigator: Kathy Davis

Department: Therapeutic Science Ph.D. Program

Telephone number: X86305

Title of Project: **The School Experience: Perceptions of Long-Term Survivors of Pediatric Soft Tissue and Bone Sarcomas**

Participant's name:

**CHILDREN'S ASSENT FORM FOR PARTICIPATION IN RESEARCH ACTIVITIES**  
**(ages 7-18 years)**

*We are asking you to be in a research study. This form will tell you all about the study and help you decide to be or not to be in the study. Read this paper carefully and ask any questions you have. You might have questions about what you will do, how long it will take, if anyone will find out how you did. When we have answered all of your questions, you can decide to be or not to be in the study. This is called "informed consent."*

**What the study is about:**

There is a lot of research that looks at ways to make it easier for kids with cancer to go to school, to stay caught up on their assignments, and to have the opportunity to spend time with friends from school. Most of that research has asked teachers and parents what they think about going to school when you are a kid with cancer. There is not much research that asks kids who have had cancer what it was like to be on treatment and to try to keep up on assignments and have chances to spend time with friends. We want to hear from you and other kids who have had cancer, to help us understand what that experience was like. If we understand your experiences better, we hope we can find ways to make it easier for children who will have cancer in the future to do well in school while on treatment. You may take breaks at any time during the conversation, or you may ask to stop if you do not want to talk about your experience any more. It is fine if you choose to take breaks or stop, and no one will be upset if you choose to do that.

**What I'm being asked to do:**

We would like you to tell us about what it was like to be a student while on treatment for cancer. You will be asked to tell us some of your experiences, both those that you thought were helpful and those that you thought were not helpful, while you were a student with cancer. We will talk for about 2 hours about your experiences. If you agree, our conversation will be tape recorded.

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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That is so we do not forget any of the important information you share with us. After the interview, we will send you an e-mail, or a letter in the regular mail, reviewing the most important things you shared. You will be asked to check those points to make sure we are getting them right. If not, we will talk again, over the phone, until we do get it just the way you meant it.

**Risks and Benefits:**

Talking about the experience may make you feel sad or upset. If it does, you may ask to take a break, to stop the conversation or to stop participating in the study. You may want to talk to the researcher, Kathy Davis, about how you feel. Kathy has been a teacher working with students with health conditions for 32 years, and she will be happy to help you if you want her to do so. If you want to talk to someone else about how you feel, we will share the names of some people who can talk to you more about your feelings.

Talking about your experiences as a student with cancer may also make you feel better. Some people find that it helps to talk about situations that were difficult. You may realize certain strengths that you developed as a result of your experiences. We hope that this research will also help future students with cancer. You are an expert on being a student with cancer, and your experiences are very important in helping us understand what others in a similar situation may be feeling and what may help them.

**Prizes:**

There are no prizes, gifts or money given to you for participating in this study.

**Privacy:**

If you participate in this study, we will not tell anyone else how you did. We will keep all information about your participation in a locked cabinet without your name on it so that only we can see how you did. We will use this information to write a big paper on the experiences of students with cancer. Your name will not be used in that paper. After we write the paper we will throw away all of this information.

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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**Your Rights**

- You have the right to carefully read this paper and ask questions before deciding to be or not to be in the study.
- You have the right to choose not to be in the study and nobody will be mad at you.
- You have the right to stop participating anytime you want, and you will still get the prize.

**If You Have Questions**

If you have any questions about the study, call Kathy Davis at (913) 588-6305.

If you have any questions about your rights, or are upset in any way about the study, you can call the Human Subjects Committee at (913) 588-1240.

Signing this paper means that you have read this or had it read to you and that you want to be in the study. If you don't want to be in the study, don't sign the paper. Remember, being in the study is up to you, and no one will be mad if you don't sign this paper or even if you change your mind later.

If you want to be in our study, fill in your name and sign below.

Your Name \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

Investigator's Name \_\_\_\_\_ Date \_\_\_\_\_

Signature of Investigator \_\_\_\_\_

HSC #: Approval Date: _____ to _____ Assurance #: FWA00003411
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### Appendix III: Demographic Questionnaire

ID Number \_\_\_\_\_ Pseudonym \_\_\_\_\_

Current age \_\_\_\_\_ Age at diagnosis \_\_\_\_\_ Type of cancer \_\_\_\_\_

Duration of treatment (years/months) \_\_\_\_\_

**I currently live:** (please put a check mark at the appropriate response)

at home with parents \_\_\_\_\_ at college \_\_\_\_\_ apartment/house of own \_\_\_\_\_  
other \_\_\_\_\_

I am:

married \_\_\_\_\_ single \_\_\_\_\_ have children \_\_\_\_\_ ages \_\_\_\_\_

**Current activities:** (please fill in blanks with appropriate response)

K-12 school: \_\_\_\_\_ Grade level \_\_\_\_\_

College: \_\_\_\_\_ Year \_\_\_\_\_ Major \_\_\_\_\_

Extracurricular activities

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Job: yes \_\_\_\_\_ no \_\_\_\_\_ Part time (hrs/week) \_\_\_\_\_ Full time (hrs/week) \_\_\_\_\_

**History:** (please fill in the blanks with the appropriate answer)

I was in \_\_\_\_\_ grade when I was diagnosed with cancer.

I was in \_\_\_\_\_ grade when I finished treatment for cancer.

I attended school: (please check all that apply)

in my regular school \_\_\_\_\_ at the hospital school \_\_\_\_\_ homebound \_\_\_\_\_

I had to repeat: a class \_\_\_\_\_ a semester \_\_\_\_\_ a grade \_\_\_\_\_ as a result of my diagnosis and treatment for cancer? This occurred in grade \_\_\_\_\_.

### Appendix IV: Interview Question and Probes/Domains

Primary inquiry:

1. What can you tell me about what it was like to be a student with cancer? (probes will follow this question)

Interview Probe	Domain
a. Were there things at school that worked well for you?	Perceived support (all sources; social and academic)
b. Were there things at school that did not help you?	Perceived barriers (all sources; social and academic)
c. Were there things at school that caused problems for you?	Role of teachers/others Peer reactions Social activities
d. Were there things that teachers did that made it easier to succeed in school?	Perceived teacher support
e. Were there things that teachers and other school staff did that made it easier to succeed in school?	Role of teacher in perceived supports Peer reactions Reactions of others
f. Were there things that teachers and other school staff did that made it more difficult to succeed in school?	Role of teacher in perceived barriers
g. Were there things that your friends and other classmates did that made you uncomfortable or feel different?	Peer reactions Social activities
h. Were there things that you wish would have been different at school when you had cancer?	Peer reactions Reactions of others Perceived teacher support Social activities
i. What was your school experience like after you were finished with cancer treatment?	Peer reactions/reactions of others Perceived teacher support/barriers Social activities
j. What else would you like to make sure you have the opportunity to tell me about related to being a student with cancer?	Peer reactions Reactions of others Perceived teacher support Social activities

## **Appendix V: Recommendations for Education Professionals**

This research offers the opportunity to affect teacher education, research and practice as a result of the findings. Other disciplines such as psychology, nursing and medicine may also find benefit in a similar context specific to those disciplines.

### Teacher Education

Undergraduate and graduate teacher education may benefit from the findings of this study. With some understanding of existential philosophical concepts, as afforded by a phenomenological study, teachers may begin to build their teaching practice on a meaningful, philosophical base. This model offers opportunities for teacher education on a wide variety of topics. Enabling teachers to understand the lived experience of students may better enable them to consider the uniqueness of their students, as emphasized as a need by the survivors of sarcoma. Understanding students with a variety of special health considerations, as well as students with learning challenges, social concerns, family challenges, mental health diagnoses, etc. may direct teaching to include those exceptional components that better “reach” individual learners.

Due to the increase in the number of students with chronic physical and mental health conditions, students who are technology dependent, children who have been exposed to alcohol or drugs in utero, and youngsters who have survived traumatic brain and spinal cord injuries, there is a growing need to provide teachers with necessary information to meet the complex needs of these youngsters. Teacher pre service and in service curricula should include information on the 5 common

themes that survivors of sarcoma have provided in this research. Further investigations of other populations of students with chronic illness may show similarities of perceptions across illness and injury categories. Further, information regarding where to go for additional information or community resources would be a valuable addition to education curricula.

Developing a knowledge, understanding and appreciation of students' unique characteristics and experiences is an attribute which should be modeled for education students. Developing skills in building support teams for all students is a valuable asset for teachers and their students.

#### Education Research

The research related to students with cancer and other chronic illness and their school experiences is almost exclusively found in health care publications.

Therefore, findings related to educating students with chronic health conditions are not often found in professional publications of educators. Concurrently, education professionals are being encouraged to conduct research in their field.

Phenomenological inquiry offers a good "fit" as a research design well-suited to educators and education. Educators are used to talking to students, are familiar with the telling of stories, and are adept at analyzing the responses of students. Therefore, phenomenological studies may provide the field of education with information which will enhance teaching and learning.

### Education Practice

Even if formal phenomenological research is not conducted by educators, the techniques used may offer benefits to teaching practice. Teachers may use phenomenological approaches to find out about the lived experiences of, for example, a student who is having difficulty in math. Identifying the youngster's perceptions and memories of previous encounters with math may shed light on ways to remove barriers or institute supports to enhance achievement. In working with a student with a chronic health condition, a teacher may learn that barriers to success in math were erected due to a student's absences, fatigue, or inability to sustain concentration due to the diagnosis or medication.

Phenomenological inquiry could also be used for data collection. Asking students to discuss their lived experience in a finite form may provide data that can enhance the experience of the student. For example, a question such as "What do you perceive as the reason you get in trouble at school?" may afford the student with an opportunity to describe his/her perception of supports or barriers to appropriate behavior. This information may provide data that can be valuable in the subsequent development of a behavior plan.

Finally, the findings of this investigation may serve to better equip educators with skills necessary for providing appropriate education for a wide range of students, including those with sarcoma. The participants spoke of their need for extensive support, effective communication, a sense of "fitting in" and being normal, concern about their physical differences and the devastating impact of missing a great deal of

school. Educators are in a unique position to be able to help the young person and family address these concerns and seek meaningful solutions. Peers, other faculty, school administrators and the community can be influenced by the direction of the informed educator who is aware that each of these themes may significantly effect academic outcomes and psychosocial well-being.

## **Appendix VI: Exhaustive Description of Perceived Supports to Academic Success and Psychosocial Well-being of Students with Sarcomas**

Academic success and psychosocial well-being of the young person with cancer are affected by multiple factors and interactions occurring in several environments besides the school building. Support for the youngster is needed in all environments in order to afford the opportunities necessary to recognize success and well-being. Students with sarcoma perceive support as coming from parents, siblings, teachers, school administrators, and peers, friends at school and hospital and health care providers. Effective communication enables the survivor to access and utilize supports in his/her environment. Supporters should recognize the significance of the youngster's cancer experience and focus on the individual's "normalcy" and strengths, rather than on his/her illness and limitations. Appropriate accommodations and consideration of the developmental issues that occur in concert with cancer provide the young person with opportunities to attend school whenever possible, to enhance emerging independence and self-advocacy and to be able to "fit in" with peers and others despite their cancer experience.

### *Exhaustive Description of Perceived Barriers to Academic Success and Psychosocial Well-being of Students with Sarcomas*

Barriers to academic success and psychosocial well-being of the young person with cancer are affected by multiple factors and interactions occurring in several environments besides the school building. Students with sarcoma perceive support as coming from parents, siblings, teachers, school administrators, and peers, friends at school and hospital and health care providers. Barriers to success and well-being are

prevalent and must be removed from the youngster's path. Barriers exist when support for the youngster does not exist in all environments and when he/she is not given opportunities necessary to recognize success and well-being. Opportunities may be missed due to absences, physical limitations or not "fitting in" with peers. Ineffective communication denies the survivor to access and to supports in his/her environment. Supporters should recognize the significance of the youngster's cancer experience and focus on the individual's "normalcy" and strengths, rather than on his/her illness and limitations. Appropriate accommodations and consideration of the developmental issues that occur in concert with cancer provide the young person with opportunities to attend school whenever possible, to enhance emerging independence and self-advocacy and to be able to "fit in" with peers and others despite their cancer experience.

## Appendix VII: Clustered Themes

### Clustered Themes - Supports

1. Support from many people, many places. Support for the youngster with sarcoma comes from a wide range of sources, called the support team, including parents, siblings, teachers, administrators, peers, school friends, hospital friends and health care, each of which is essential in providing unique input which enables the youngster to realize academic success and psychosocial well-being.
2. Fitting In. It is of utmost importance to adolescents to “fit in”. This includes being treated normally, not being seen as “different” and not receiving pity from others. The sarcoma experience, due to physical issues, communication challenges and frequent absences results in requiring more effort on the part of the youngster with sarcoma and the support team to ensure that the youngster “fits in”.
3. Physical issues and self-concept. As a result of effective communication , the support team members recognize and understand the individual’s body image concerns and uniqueness, as well as his/her need to be treated with dignity and as normally as possible in order to enhance his/her ability to achieve optimal growth and success.
4. Absence from school. The sarcoma experience results in a significant unavoidable absence from school. Absences increase the youngster’s risk by not having access to his/her support team, not having an opportunity for effective communication, and missing opportunities to “fit in” with peers.

5. Communication. Effective communication is essential to the young person with sarcoma realizing that he/she has supports; knowing how to access and utilize those supports; understanding how to use those supports to help take down barriers; and helping the young person develop a positive self identity including increasing skills of independence and self-advocacy.

*Outcomes When Supports Exist*

Supportive actions and effective communication among all who care for the student with sarcoma results in the student feeling secure, capable and successful.

Clustered Themes - Barriers

1. Lack of support from many people in many places. Support for the youngster with sarcoma is negatively affected when it does not come from a wide range of sources, called the support team, including parents, siblings, teachers, administrators, peers, school friends, hospital friends and health care, each of which is essential in providing unique input which enables the youngster to realize academic success and psychosocial well-being.

2. Fitting In. It is of utmost importance to adolescents to “fit in”. Barriers develop when a young person with sarcoma does not perceive that he/she “fits in” with peers or when others do not treat him/her normally, perceive and treat them as “different” and show pity to the young person with sarcoma. The sarcoma experience, due to physical issues, communication challenges and frequent absences results in requiring more effort on the part of the youngster with sarcoma and the support team to prevent the development of barriers and to ensure that the youngster “fits in”.

3. Physical issues. As a result of ineffective communication , the support team members do not recognize or understand the individual’s body image concerns and uniqueness, as well as his/her need to be treated with dignity and as normally as possible resulting in enhance his/her ability to not achieve optimal growth and success.
4. Absence from school. The sarcoma experience results in a significant number of unavoidable absences from school. Absences increase the youngster’s risk and impose barriers due to not having access to his/her support team, not having an opportunity for effective communication, and missing opportunities to “fit in” with peers. Accommodations which support success can help ensure that the youngster doesn’t miss even more school than is necessary.
5. Communication. Lack of communication or ineffective communication negatively affects the youngster’s perception of support in his/her environment. Effective communication is key to the young person with sarcoma realizing and utilizing existing supports; knowing how to access those supports; understanding how to use those supports to help take down barriers; and in helping the young person develop a positive self identity including increasing skills of independence and self-advocacy.

*Outcomes When Barriers Exist*

Absence of supportive actions and effective communication among all who care for the student with sarcoma results in the student feeling insecure, incapable and unsuccessful.

## **Appendix VIII: Formulated Meanings of Significant Statements**

### *Family*

“It was either “get the cancer treated” or “falling apart”. We went for “get the cancer treated”.

### *Supports*

1. Children with cancer may develop an increased sense of appreciation, respect and closeness to their mother, father or siblings.
2. Children with cancer may experience the ability to speak openly with their mother, especially after treatment for cancer is completed.
3. Parents act as supporters, decision makers and coaches to their child with cancer and are “there for them” throughout the cancer experience.
4. Siblings may be sources of support to the child with cancer and their relationship may become more positive as a result of the experience.
5. The youngster with cancer recognizes that siblings have a difficult experience, too.

### *Barriers*

1. Children with cancer may perceive that their siblings are angry and aggressive, get less attention than they do, have difficulty handling the cancer experience, reject them, and that siblings must make personal sacrifices while they are on cancer treatment.
2. Communication between family members may be challenged by the child’s perception that they must spend too much time with a parent or by not feeling that they can speak about emotional issues or express fears and concerns about their cancer experience.

### Friends and Peers

“Find a friend who’s gonna stand with you through the whole thing”.

#### *Supports*

1. Young people appreciate that some friendships become stronger during the course of their diagnosis with cancer.
2. Inclusion in activities, treating the young person with cancer as normally as possible and not showing sorrow or pity for them are perceived as helpful.
3. It is beneficial for friends and peers to find balance in communication, reading their friend’s cues and allowing them to talk about their cancer experience when desired but not forcing them to do so.
4. Special bonds develop between the youngster with cancer and a peer or adult with cancer due to the perception of a special understanding of one another.
5. The young person with cancer appreciates all forms of communication including e-mail, phone calls, cards and letters, etc. and enjoys hearing about what went on at school.

#### *Barriers*

1. Both extremes of response to the young person’s cancer may have negative effects, so friends should avoid talking only about the cancer experience as well as never talking about the cancer experience.
2. Teasing and rejection about physical changes caused by cancer is very hurtful.
3. Friendships may be strained by difficulty by one or both parties in knowing what to say, what to do or how to act after a friend is diagnosed with cancer.
4. Some friendships become strained or end altogether after the diagnosis of cancer.
5. There is little in common between friends after one is diagnosed with cancer.

### Physical

“I don’t see how people can do drugs or harm to their body to die, when I sat there and I fought for my life – to stay alive”

“Who’s gonna want to date me? I’m a freak”

#### *Supports*

1. Some children with cancer, particularly those who have a short course of treatment, may not feel excessive fatigue.
2. The return of hair growth after chemotherapy treatment is an exciting and celebratory event.

#### *Barriers*

1. Hair loss, physical changes, surgical interventions that result in scars and disfigurement and other changes in body image can make the young person feel out of place, devastated, horrified or cause them to “freak out”.
2. Fatigue may occur during or after treatment for cancer and may interfere with a student’s ability to stay awake in school, to concentrate at school or to stay in school.
3. The physical effect of cancer may result in missed activities, inability to play sports and some children with cancer may not realize that they felt bad until they feel good again.
4. Physical disability and post surgical issues, such as limping or large scars, may cause embarrassment, pain, teasing and reduced self esteem.

## School

“Hurray for me”

Two groups: those who were successful in school and those who were not

### *Supports*

1. Some students with cancer perceive a benefit of becoming a better learner which is derived from being primarily responsible for their learning during the time of treatment by teaching themselves, advocating to teachers regarding their learning needs, and being responsible for understanding what they needed to accomplish.
2. Teachers were perceived as being a support if they took time to help the student catch up on work, understood what the student was experiencing or were lenient with negotiating work requirements.
3. Survivors perceive success and accomplishment to be possible despite significant absence or impaired health; to be important to survivors’ overall outcomes; and to be enabled by extra help at school, leniency by teachers and understanding of peers and educators.
4. Just being in school offers normalization in the life of the student with cancer.

### *Barriers*

1. Students with cancer do not want to be treated differently by peers or educators and may experience discomfort in being identified as sick, “the girl/boy with cancer”, the absolute minority or in receiving treatment that is perceived as special or different.
2. School attendance and physical stamina are significantly impacted during cancer treatment and sometimes afterward, resulting in missed activities, extra curricular opportunities, school work and opportunities for socialization.
3. Educators, peers, parents and others create barriers to success when they do not have adequate information about or understand the youngster’s experience with cancer, were out of touch with the youngster, did not know what to do to help the youngster or teased or excluded the youngster at school.
4. Frustration after diagnosis is associated with not feeling as smart as peers, feeling that school work is harder than before, being unable to be present to do all schoolwork, perceiving lowered expectations from teachers, the school experience not being as fun as before, and feeling behind in school work.
5. Return to school after the diagnosis of cancer is characterized by being difficult, not being what the student had hoped, feeling of being left out, teasing and rejection, at attempt to get out of going and a situation to which it is difficult to relate.

6. After cancer, some students experience difficulty with concentration, memory, thinking, reading speed and comprehension, attention and not feeling as smart as they did before having cancer.

### Psychosocial

“It happened to me and I lived through it”

#### *Supports*

1. Cancer experience resulted in the acquisition of positive attributes and feelings such as being more open to people, using the experience positively, caring about others who have had challenges, not taking things for granted, enjoying each day, seeing my life as a blessing, increased knowledge, being proud of my accomplishments and knowing that I got through it.
2. Coping with cancer treatment and the cancer experience is exemplified by accepting that it is something that one has to do; accepting support from various sources; and moving forward with life goals.
3. Having cancer forces one to face their own mortality and reassess goals, beliefs and attitudes.

#### *Barriers*

1. Young people with cancer are adamant about their desire to be treated “normally”; their aversion to being identified as different; their discomfort with being known as the girl/boy with cancer; and their dislike for having people feel sorry for them. (comprised 22% of statements in psychosocial category)
2. Survivors are constantly aware of their status as a survivor of cancer, worry about their health, are anxious when having scans or follow-up exams and worry about the recurrence of cancer.
3. Young people with cancer express a range of negative feelings and disappointments including missed opportunities, not being able to experience adolescence in a typical manner, not being chosen for school groups, anger, isolation and horror regarding body image changes such as hair loss and surgical disfigurement.
4. Survivors wish that they had had somebody to talk to about their feelings or a way to “get out” their emotions during cancer treatment.
5. Transitioning between the hospital and school is difficult due to the differences in how peers and adults in each setting understand the young person’s cancer experience.

*Neutral*

1. Survivors acknowledge that the cancer experience was life changing, was not fully understood at the time, affected their sense of who they are, defined themselves, made them grow up and mature more quickly, was nothing to be ashamed of, has made them more emotionally expressive, resulted in missed experiences and was something they had to do.

## Appendix IX: Significant Statements

### Family

- My family is just as close as we always were.
- We didn't really emotionally talk about it
- Afraid to talk about it because it would take you off course
- We know it's bad. Just do what we have to do
- It was either "get the cancer treated" or "falling apart". We went for "get the cancer treated"
- Mom and Dad wouldn't let me give up
- I just wanted to succeed and I want to make them (parents) happy
- Having my sister there – she made sure – she looked after me. That's what big sisters are for
- I noticed I got closer to Dad
- We (Dad) did a lot of bonding just going back and forth (to hospital)
- My sister and I got really close
- My parents had to make all the major decisions
- I bonded with my parents really good through it all
- I look up to them (parents) like no other
- I want to be just like them
- My mom helps me a lot
- My brother wanted to have nothing to do with me
- He (brother) was very angry and aggressive
- It was more all the attention was on me, then him
- They never allowed him to go out to parties anything like that
- It brought me a lot closer to my mom
- At the time it brought me a lot closer to my dad
- I wouldn't say we're (me and dad) close anymore
- Me and my mom – I can tell her whatever I want
- I'm not ashamed of my mom
- My brother never wanted to come up to the hospital because he told me, "When you're in a hospital bed, you're not my sister. You are a body in the hospital bed... sick"
- It bothered him (brother) a lot
- I don't know what I'll do if you leave me (said by brother)
- It always seemed like I was being treated different by him (brother)
- You have cancer. What am I (brother) supposed to think of you now?
- Mom – her and I get frustrated with each other a lot easier
- We spent so much time together
- Right now, I'm more connected with my dad than my mom. We talk

- A lot of us survivors have learned at an early, early state why we appreciate our parents. They're there for us.
- My brother and I – we weren't – you know.
- He gave up a lot so he could spend time with me (brother)
- He sacrificed a lot for me (brother)
- But now we're inseparable, it seems like (brother)
- My parents are the best in the world
- I love 'em to death (parents)
- They shaped me into who I am after chemo (parents)
- To me and my parents, every day was a special day
- I was attached to my mother at the hip
- My parents did not believe in psychologists or psychiatrists.
- I didn't feel like I could talk to them
- I couldn't deal with those emotions because I didn't want to freak my parents out
- Friends, mom, boyfriend didn't let me get too far into it
- Mom and I have always been close
- Mom and I are very close now
- I can tell my mom anything
- I had wonderful doctors and nurses but if I didn't have my mom I don't know what I would have done
- My dad was always the male figure, strong you know
- The thing that changed was that I saw my dad being sad. That really bothered me
- I think my brother really got the short end of the stick in the whole deal
- It was really, really hard on him (brother)

### *Physical*

- All I wanted to do was sleep
- No hair
- Sick looking
- There were days when you were too tired
- You just wanted to sit there
- You don't want to do anything
- If I was tired I would just leave (school)
- You don't know that you feel bad
- Man, I felt bad (before getting blood transfusion)
- You don't have any eyelashes
- I just didn't feel good
- I was tired and wanted to sleep all the time
- Every day I was there (school) I would go to the nurse's office
- Because I was just so drained
- I couldn't do anymore

- I would just sleep until the rest of the day was over
- Different? Physically, yes. Mentally, no
- By the end of the day I'm still drained
- Just walking from classes; I'm drained
- I can't even walk normal
- Let alone play sports
- I was always tired
- I don't see how people can do drugs or harm their body to die, when I sat there and I fought for my life – to stay alive
- And then the sports – I missed out on the first year of sports (high school) (physical)
- I couldn't do it physically
- 2 hardest things – when my hair fell out and they took the gluteus maximus muscle out
- (Sleepover with friends). I was absolutely exhausted. I screamed at them for no apparent reason
- I was so excited when hair came back in. Friends didn't understand that
- I have a reminder every single day of what I went through – a 14 inch scar on my left butt cheek
- I got tired a lot faster
- I definitely did feel out of place, not having hair

### *School*

- It (brain) wouldn't function to read a book
- I couldn't concentrate enough to read
- I was a studious person before I got cancer
- Never wanted to get behind in school
- School was very lenient
- Missed a lot of school
- I got all As that year, being there less than 46 days
- Do all of this math, even though the problems are all the same
- It (repetitious school work) just took up my time
- If I hadn't stayed up in school, I would have cared after cancer was over. It would have made cancer just go on for another year.
- The whole outcome could change if kids didn't make it through school
- They could feel more sorry for themselves
- They may not even be as successful if there are school problems
- Hardest part was having to miss out on the activities and extracurricular stuff
- Every other week I was in school (sophomore year)
- My economics teacher wouldn't send out anything (assignments)
- Cancer kind of made school easier 'cause I learned how to study on my own

- You always felt behind and not as smart
- I was unable to do everything they do
- I always missed class and everything
- You have to figure it (homework) out on your own
- It just wasn't fun that way
- I didn't feel as smart as everyone and up to their speed
- I had a lot of excused work
- I did less work than most sixth graders
- If I was in class I wouldn't understand what they were talking about
- So I pretty much stayed in the resource room
- My English teacher was helpful
- I couldn't keep attention to anything
- My math teacher would stay after school to help me
- In science I had to do all the book work and everything else
- The history teacher – he did a lot of movies and stuff and I never had time to make them up
- I was there (school) maybe 2 or 3 days and then back in the hospital
- Going back (to school) was really different
- It's really awkward
- It didn't go back to normal (school after tx)
- I don't remember anything from my junior high
- I don't remember freshman
- I don't remember sophomore year
- I don't remember dates
- I can't remember numbers
- If I didn't write it down I wouldn't do it because I couldn't tell you what it was
- If they did a lecture in the morning and by afternoon I'd have to go back and reread two or three times
- Nouns, pronouns, adjectives, adverbs. I don't know how to pick any of that stuff out
- I have to have somebody explain
- Like every little detail before I'll get anything out of it
- I can't read fast
- I have to sit there and I have to reread stuff
- I won't know what I read two minutes ago
- I'll be frustrated cause there's things I can't remember
- I'd have homework and I wouldn't understand it
- It's really frustrating
- I'd do everything and anything to drag me feet so I wouldn't have to go (to school)
- I would do anything to avoid school

- It wasn't what I wanted it to be
- I saw that it was going to be really hard academically
- To me it seemed like I was left out
- There was a table in the back of the room where I would work
- Why even come (school)?
- It was tough
- There were times that I just didn't want to go
- I wasn't ready to go on but I did go on (to next grade)
- I got put on the Learning Resource room because I was having so much difficulty
- High school teachers would help during seminar
- I always feel like I'm at least a grade behind
- I didn't want homebound because I wanted to be able to go somewhere to get away from home, from Mom, because it seemed like she was always with me
- Like, I don't enjoy going to school
- I always have that feeling: I don't want to go to school
- I think it's because I have all those people there who knew me when I was going through treatment and made fun of me and they still make fun of me
- I would fall asleep at school
- Like all I can really picture is me being bald (looking back at school with cancer)
- "You have four legs", because I had crutches
- Calling me a "b" because I received extra help
- It's so hard to look past what I don't like about the past and see my really good friend standing right by me or to be with me
- I see the same faces that hurt you so bad
- I'm getting treated completely different. I don't like it
- Being a student with cancer wasn't any different. Well, at first that year it was really different. Kind of intimidating
- The school system was awesome. They were really lenient
- Before cancer I was an average student. Afterwards, it was hard
- It was all self-taught
- I had those days where I was really frustrated
- Everyone in my class was very understanding
- A lot of 'em were scared out of their minds
- Since cancer, it's different. It's harder
- Everything is harder and just... just different
- Like, it doesn't just come natural any more
- I did all the work myself
- I think I went back twice the whole semester – just to visit
- I wore a wig and two girls made some really nasty remarks to me
- Concentration was a very big issue
- Hard for me to think

- Hard for me to remember
- It's hard to do your homework when you can't think straight
- I went to school about half the time
- I was anxious to get back to school
- School gives you something going on besides just treatment
- I wanted to be in the honors class (school) but the teacher would not let me
- I was frustrated because I had read all those stupid books over summer
- I was on student council so I had to go to school functions
- Mom made me a dress to cover my port; we put flowers on my crutches; she made me a flower wreath for my head
- I'm glad I had to go because it all turned out good
- "Bald is Beautiful" signs for stucco campaign
- School became like a place that I couldn't really relate to
- At school, even if I felt crummy, I would say "I'm fine; I'm good' I'm not sick' I don't feel bad"
- Really disliked being the 'cancer kid' at school
- Being the girl everyone knew had cancer
- Got old being the girl with cancer
- I was the absolute minority – the only one in my high school with cancer
- I just taught myself out of the books and did the worksheets
- Teachers just kind of left it (school) up to me
- I kind of worked it out on my own
- I had a homebound teacher but she never came since I was not having any problems
- I wanted to do everything at school

*Teachers (subcategory of School)*

- Thought maybe he'd (principal) understand because he'd had cancer but he was the worst of them all
- Assistant principal would make sure I had all my homework
- Stepped up and helped out
- Will always remember math teacher. She was really cool
- Gave me origami books and paper because she knew I liked it
- I would get confused because they taught me a different way
- She would take time during recess and walk backwards with me to where I understood and then go forward
- The next teacher – she didn't know what to do with me
- It seemed like some of the teachers tried to push me away because I took so long (to understand)
- I think that (teachers not helping) was the most frustrating thing
- I don't know of any teachers who helped me with school or anything

- My principal at the time had cancer
- Teachers were really understanding
- I took the tests and did the basic course work
- I felt a connection with my principal who had cancer
- Would have made a difference if teachers and administrators had been more educated about what was going on
- Teachers had no idea about what I was going through
- Nobody was really in touch
- Teacher who teased me about my limp really hurt my feelings, really bothered me
- Didn't feel comfortable telling teacher, "you're out of line"

### *Hospital*

- Our home-away-from-home
- Hospital teacher and nurses helped a lot
- Nurses helped out – just having someone to talk to who understood
- We know what each other's went through
- We know what it feels like
- We know what each other's thinking
- Camp is very fun
- You're not afraid to do anything there
- They understand more than a normal group of senior girls would
- I started talking about my friend up there
- When I had friends from the hospital who were going up for a check-up and don't feel good - I kind of get that fear like I have when I'm going up (to hospital for check-up)
- My friends are there but it is completely different
- I feel completely different when I talk to her (another patient)
- You don't get these looks like "what does that mean?" (at camp)
- People don't stare at your leg or at your body (at camp)
- Nice to go somewhere where you can feel comfortable
- I want to go to college and be a nurse because I always felt so comfortable around them
- With nurses, it's mental - they will sit down and talk to you
- You become close to people with cancer and they take a turn for the worse and they die
- It made me uncomfortable when I finished treatment
- Finishing treatment – Okay, what now?
- How do I go back to having a normal life?
- When you finish treatment, your normal life is alien to you
- Clinic and hospital became like my home
- Everyone at hospital knew what was going on with me

- At hospital I didn't feel like I had to put up any fronts
- Hard to leave the people at the hospital

### *Friends and Peers*

- Learned who my really true friends were
- Stuck by me
- My friends let me talk about it when I wanted to but didn't force me
- Couldn't go out or hang out
- Hard on my friends
- If it gets too tough for you, I totally understand (to boyfriend)
- Your feeling rubs off on the people you're talking to
- Don't beat around the bush – just ask me
- Close friends got closer
- Acquaintance or classmates became farther away
- Close friends surrounded me
- They didn't ask me to do things because they didn't know if I should
- Friends gathered around me
- Didn't make me feel left out
- Really important that they treat me like they did before
- They didn't tease me in front of me
- Sometimes felt that they (peers) were kind of scared of me
- Maybe if they touched me they would get cancer or something
- I may talk to 'em but I didn't say I'm friends with them – social
- Support – not so much my classmates
- I didn't really hang out with them
- I would see 'em during class and that was it
- I pretty much didn't want to have anything to do with them
- We really didn't talk or anything like that
- I couldn't get a friend if my life depended on it
- Nobody wanted to be friends with me
- They would turn their back on you and wouldn't help
- Never really knew who was your friend and who wasn't
- I had one really good friend. She stood by me through all of it
- She understood how I felt
- We're just not as close as we used to be
- We just don't have the bond we used to have
- Oh well, I don't know them; I don't want to hear about it
- I don't think I'll ever catch up to them
- People that said they were my friends had kind of ventured away
- The ones that really were my friends stuck by me

- Then again, I don't want them not to know. It's part of me ...my maturity level
- Find a friend who's gonna stand with you through the whole thing
- Walk up to me like I was just sort of a foreign object
- I just wanted to be with my friends
- There wasn't anybody that made fun of me. If they did, I did not never hear it
- There wasn't one time that they said anything about my hair or my hand
- There's about 3 or 4 girls that stuck by me
- Best friend kept me up to date on just about anything and everything you dreamed
- Talking to her everyday
- Take time to write personal letters
- They made me uncomfortable sometimes
- Nobody knew what to say around me
- Nobody knew how to act
- Two or three girls told me my personality was so much different – less inhibited
- Best friend stayed really good friends throughout the whole thing
- Guy that I had really liked- after I was diagnosed with was just too weird talking to him on the phone
- He didn't know what to say and how to act
- Others – I don't know if they just didn't know how to handle it or if they didn't know how to deal with it
- They didn't know what to say to me
- Fun to hang out with the girls but not as fun as it used to be
- Still friends with all the girls. Don't talk on a regular basis like we did before
- How do you deal with death of another person with cancer?
- Who will want to date me? I'm a freak
- There was, and still is, a struggle to maintain friendships
- People want to understand and they want to be very kind
- Maintained a few close friends
- Other friends didn't understand
- Not a lot that you have left in common with friends
- Friends tried to include me in things
- Friends got to be a much smaller group
- Close friends good at finding a balance between treating me the same way they always had but not minimizing the experience
- Amazing that friends that were able to do that at 15 and 16
- Envious that they could ever forget because I always lived with it
- Envious that my friends got to put it away for a little while
- I have trouble relating to people my age
- They didn't treat me any differently and that's what I wanted to happen
- Happy to go to college where no one had to know if I didn't tell them

## *Psychosocial*

- Postponed everything
- Cancer completely changed everything
- Lost feeling
- Made me more open to people
- Not just all about me anymore
- Try to use my experience positively
- Not made me bitter; made me better
- Can't let it get you down
- Too much for my brain to comprehend (re: reading)
- It (cancer) definitely opened me up
- Relate more to people who have had hard times
- Don't take things for granted
- Look at people differently
- Wanted everybody to act just the way they were
- Didn't want anybody to treat me any different
- I didn't feel that I was any different
- It's no big deal – I've got to go take some medicine and then I'll be back
- Come on let's go. I've got things to do
- Man, I'm missing out
- Man, this really stinks
- Kind of like a bump in the road
- Support from everybody
- The community came out
- Find out who the people are who you can depend on
- People are fascinated by it (cancer)
- I was more emotional after the fact
- Give back a little
- Hurray for me
- I was more proud of myself
- It's always in the back of your mind – it could come back, you know
- At first I kind of felt like an outcast with my limp and everything
- I didn't feel any different than before
- I had to have a positive attitude all the way through
- You've got to do it so do it
- Frustrating – very frustrating
- You never felt up to everybody else
- I feel like I'm looked different upon and I don't want to be looked at different
- I was never picked at all
- You get used to it

- I was still something wrong
- My support is from my boyfriend, parents. And other kids who have had cancer
- I don't know how to explain it
- You begin to live with it but there's just so much you miss
- Wantin' to go for a home cooked meal in your own living room on your own couch
- I didn't understand at the time what was going on
- I just went with the flow
- I felt like I knew more than a normal person would
- Freshman and sophomore year I was really mad
- I'd go home and I'd yell at my mom
- I'd have my days
- I didn't want to be around other people very much
- I didn't want to be seen the way I was
- There's still days I don't even want to think about it and really remember what happened
- Wow, that did happen and I really did get through it and I am okay
- I can go to school and I can get a job and I can have a life.
- A lot of feelings got hurt
- You always felt like you're being left out
- Why can't I just be like them?
- Why did I end up with cancer?
- Just crying because I wanted to be out there
- Very, very frustrating because you didn't know who you were anymore
- You never know how long you're gonna live so live it happy and live it mature
- What if it comes back?
- What are we going to do?
- Are we going to take treatment or are we not?
- Every time I go back for my check-up you've just got that thought in my head
- This year I realized that I need help
- I can't go through this alone anymore
- Just skip the year that I had cancer
- You know, I'm a survivor
- You have to go out and find that guy that doesn't care that you have had cancer
- I'm always trying to go forward – to achieve something in life
- Having cancer has influenced everything I do so much
- I never knew (before cancer) that I could feel so much
- I think about life a lot different than someone – a lot of teenagers nowadays
- I've been down that road where you don't know what's gonna happen. I don't want to go down that again
- Living day by day by day. Now I don't have to live one day at a time

- I have a goal or something every day
- I'm very independent
- I just as strong as an ox
- I was stubborn
- I wasn't gonna cry. Anymore, that is all I do
- I could be still sitting in the hospital not knowing what.... you know. This is like a gift to be able to do something
- If I've gotta do it again, I gotta do it again. But, I'm hopeful that I'm not going to, But....
- I just wanted to be normal
- Don't treat me any different – that was my biggest fear
- I think of having cancer at least once a day. Oh yeah, at least
- Little things remind me (of cancer)
- I'm not ashamed (of cancer)
- I was a little bit self-absorbed
- Chin up. Be strong. Have faith. You'll get through it
- Always worried about health
- Scared to death I'd get bad infection and that would be the end of it all
- First my hair fell out and that was horrifying
- Muscle removal horrifying as well. The first time I actually saw it, I lost it
- I completely lost it
- I lost my medical insurance so there's no way I could even afford going up there for a visit
- Don't feel sorry for me
- There is nothing to feel sorry for
- Always mature for my age
- I didn't have anybody to talk to
- I wrote a lot
- Nobody knew what I was going through
- Nobody knew what I was feeling
- I couldn't get those feelings out
- Cancer kind of defined my sense of self
- Instead of me being able to develop who I was, develop my own personality I was 'the girl with cancer'
- Cancer defines a very big part of who I am
- It happened to me. And I lived through it
- Don't feel sorry for me
- There is no reason for you to feel sorry for me
- I didn't like it when I thought people were feeling sorry for me
- I felt uncomfortable because I felt different
- You can't feel normal anyway, having to go through treatment

- I became an expert on medical things
- You live in a world where everything evolves around your health and bodily functions
- You eat, drink, breathe medical science, basically
- Medical science becomes very comfortable, very soothing
- You just freak out (when finished with treatment)
- It's like you've gone from one life to another and then you have to go back again.
- Just because I look different doesn't mean I am different inside.
- I see my life as a blessing
- I'm still here – I could not be here
- People really don't understand
- I didn't want people feeling sorry for me
- Happy to go to college where no one had to know if I didn't tell them (psychosocial, friend)
- I really did want to be normal
- Feel like you are representing something other than yourself
- I didn't want people to worry about me
- I didn't want to portray a bad, sickly image
- Didn't want people to think of me as being really sick
- It was just in an effort to have people treat me normally
- I wanted to be normal and wanted people to think of me as normal
- And I wanted people to forget
- Hard to find the balance between being treated normal but not ignoring this big thing going on in your life
- Cut me some slack but not let me have a pity party kind of thing
- I think my cancer affected the way I grew up
- I relate better to adults
- I just had to grow up. You don't really get an option
- Maybe I did miss out on some of those teenage years
- I don't regret it
- Forced to figure out what's important to you
- Think of those things when faced with your own mortality
- Cancer has really defined me and the things that are important to me
- I think about being a cancer survivor a lot
- It's one of those things in my life that I always worry about (cancer)
- When things get really good I start thinking, "Okay well now the other shoe's gonna fall and then I'm gonna relapse again"
- Every time I have a scan I'm terrified
- I really disliked people feeling sorry for me
- It might be helpful to talk to someone
- All things pass

## **Appendix X: Comprehensive Exam I**

Challenges in Identification and Eligibility of Students with Chronic Health  
Conditions for Special Education Services

Kathleen Tyler Davis

A written comprehensive paper completed as partial fulfillment of the Ph.D.  
requirement

## Introduction and Overview

During recent years, federal legislation has been enacted which guarantees a public education for all children (“children” includes the population of adolescents), regardless of disability or illness. As a result of advances in medical treatment and improved technologies, children with chronic illnesses are living longer and are often able to participate in school and other activities. Young people with chronic illnesses, who once spent most of their time in the hospital or at home, are now more frequently involved in social and sports activities, family experiences and school. These factors have led to an increase in the numbers of children with chronic health conditions, both in general as well as in the classroom (Thies, 1999). As a result, schools face new challenges as they address the needs of this population of learners.

An estimated 40% of children with chronic health conditions, such as cancer, diabetes mellitus, sickle cell anemia and asthma, experience school-related problems (Thies & McAllister, 2001). The learning needs of students with chronic health conditions are individual, diverse, and differ in varying degrees from those of healthy children. Cognitive and learning issues may accompany chronic illnesses for a variety of reasons, such as frequent absences, lethargy, disease symptoms, or side effects of medical treatments (Thies et al, 2001). Students with chronic health conditions are often in need of special education supports and services. However, due to the focus on health, rather than education concerns, many children living with a chronic illness may not be assessed to determine if they are eligible for traditional special education programs, leaving many students with unmet learning needs.

Obtaining the appropriate type of support is complicated by the lack of a uniform definition of students with chronic health conditions, as well as by other gaps that exist between the medical and education professions concerning this population of learners (Perrin, Newacheck, Pless, Drotar, Gortmaker, Leventhal, Perrin, Stein, Walker, & Weitzman, 1993).

### *Challenges in Identification & Eligibility*

There are several reasons that schools are challenged in addressing the needs of students with chronic health conditions. First, there has been much controversy in determining a working definition of chronic health conditions, leading to uncertainty regarding the prevalence of this population. Educators frequently perceive that children with chronic health conditions have a diagnosis that results in health and physical activity limitations, rather than a disability that may impact learning and academic achievement (Thies, 1999).

The Individuals with Disabilities Education Improvement Act of 2004

(IDEIA) defines special education as:

“...specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability, including--

(A) instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings” (IDEIA 2004)

Lack of agreement regarding a uniform definition of chronic illness also leads to problems determining which learners with chronic illnesses may be identified as “a child with a disability” and, therefore, qualify for special education services. Within the field of education, professionals use a variety of terms to describe children with health conditions, including chronically ill, medically fragile, special health care

needs and other health impaired, based on legislation, health or education mandates, special interest groups, or philosophies. The result is that children with chronic illness receive special education services only when their needs “fit” into the program guidelines (Thies, 1999), rather than when they might benefit from “specially designed instruction that fit the student’s unique learning needs” (IDEIA, 2004). With a more functional working definition of chronic health conditions, educators and health care providers could better identify students who might be eligible for special education services. Since chronic health conditions can have both health and education challenges, educators and health care providers could collaborate to determine what types of “specially designed instruction” would best meet the student’s unique needs.

Another reason that schools have difficulty identifying the educational needs of students with chronic health conditions may be due to what has been called the “med-ed gap”. The “med-ed gap” is the chasm that exists between two disciplines which deal with the same population but that operate with different policies and practices (Koenning, Benjamin, Todara, Warren, & Burns, 1995). There is often such a gap between health care professionals and education professionals in regard to the educational needs of students with chronic health conditions. Even in school re-entry programs designed to support the student with a chronic illness at school, the focus is on identifying and managing health issues, rather than integrating health and education needs into a more holistic program (Yeo & Sawyer, 2003). Upon return or reintegration into school, educators primarily view children with chronic illnesses as

having health care needs, while educational needs may be overlooked (Ireys, 1994). Educational services for students with chronic health conditions need to address the youngster's learning needs. Cooperation and collaboration between the child's health care providers and educators is essential in ensuring that the student's needs are addressed in a comprehensive manner (Thies, 1999).

An additional concern is that both medical and education professionals do not appear to have developed an inclusive understanding of the learning issues that may impact students with chronic health conditions. For example, when the child is very ill, no one considers education a priority. Conversely, during times of disease remission or stabilization, professionals and families shift their focus to education, and health issues become a lesser concern (Symons, Cinelli, James, & Groff, 1997). The intricate relationship between health, wellness, and learning has been acknowledged in research and societal expectations (Center for Disease Control, 2002; Ireys, 1994; & U.S. Department of Health and Human Services, 2000). However, it is often unclear who bears responsibility for addressing the actual or potential impact of a health condition on learning (Thies, 1999).

Finally, as parents, educators and health care providers struggle to determine how to best meet the education needs of students with chronic illnesses, these learners experience separate challenges managing social, emotional, psychological, and academic demands of childhood and adolescence. Traditional health care focuses on disease outcomes; however, young people do not necessarily share the same focus (DiCroce, 1990). Children with chronic illnesses must strive to succeed in two

different worlds: the healthcare environment and the community, including school. Frequently, there is a lack of communication between healthcare and education. (Koenning, Benjamin, Todara, Warren, & Burns, 1995). If children with chronic health conditions are to have the opportunity to realize success in those two worlds, it will require collaboration and cooperation between the disciplines of health care and education. It is more likely that positive outcomes will be realized if the two disciplines communicate effectively and understand one another's roles and responsibilities, the various definitions of "chronic illness", and the legislative mandates related to chronically ill children (Kliebenstein & Broome, 2000).

The educational experience of students with chronic health conditions may be positively impacted by an enhanced agreement between health care and education professionals regarding definition and educational needs of the population. The first step is to reach agreement between the medical and education professions regarding a definition of chronic illness in childhood. An effective definition will identify those students who have chronic health conditions that may result in disability and, therefore, require special education services or additional educational supports in the form of accommodations or modifications. In addition, a collaborative definition may enable educational professionals to recognize the educational need of children with chronic illnesses. In achieving consistency in defining the population of students with chronic health conditions and its numbers, educators may succeed in supporting the "commitment to ensure that all children receive a high quality

education so that no child is left behind” (U.S. Department of Education website, 2005).

The following examination will review some of the key factors that impact the educational programming for students with chronic health conditions and access to additional educational support for this population. Topics will include quantitative issues that identify the growing significance and numbers of students with chronic illness and the qualitative issues that complicate identification of students in need of additional education support; the various definitions of chronic illness including those that have emerged from civil rights, education and health care; and the gap in communication between the professions of medicine and education that may result in further difficulty in access to special education for students with chronic health conditions.

#### Defining Chronic Illness and Special Health Care Needs

Defining which students comprise the category of students with chronic illness or special health care needs is filled with potential challenges. In order to adequately address the educational needs of the population, the population must first be clearly defined. Quantitative issues related to defining the parameters of the population, qualitative issues that address the characteristics of the population, and issues specific to the interests of various involved disciplines should be considered. The definitions that have evolved from civil rights legislation, education legislation, and the field of health care contribute unique to the development of an effective, working definition.

### *The Quantitative Issues*

Students with special health care needs are increasing in number. Mortality rates in childhood have fallen from 870 per 100,000 children aged 1 to 14 years in 1900 to 33 per 100,000 children in 1987 (Newacheck & Taylor, 1992). The survival of some children who previously would have died from chronic illnesses results in the potential for additional young people with special needs to attend school. For example, most youngsters who had acute lymphocytic leukemia at the turn of the twentieth century did not survive. Now, long-term survival rates are around 64.8% overall and 89.1% for children under the age of 5 (The Leukemia and Lymphoma Society, 2005). As a result, the number of students with chronic or special health care needs is also on the rise, and the educational needs of students who previously were not in school, may need to be identified and defined for educators. For example, youngsters with leukemia may experience treatments that have been linked to cognitive challenges or may have to miss a substantial amount of school, resulting in loss of learning opportunities or learned skills (Thies, 1999). Similarly, the prognosis for young people with cystic fibrosis (CF) has improved dramatically over the past quarter of a century. Previously, the prognosis for children with CF included a life expectancy into the teens. Today, approximately 40% of children with cystic fibrosis live beyond age 18. The average life span for those who live to past adulthood is 30-40 years of age (Mayo Clinic, 2005). The price paid for extended longevity for children with chronic health conditions may be medical care that results in time

missed from school, compromised social functioning, psychological and emotional difficulties, as well as direct impact on cognitive development.

Improved survival means that there are more children who require special education services at a time when school districts are often unable to find resources to support growing needs of students. Oberg, Bryant, & Bach (1994) suggest that there are approximately 6.2 million children with disabilities in the United States, or slightly more than half of all eligible students with disabilities, who may not be receiving needed services at school. Further, a 1989 Harris poll of public school teachers found that 38% have students who need special education and have not been evaluated to enable them to receive such services. Oberg et al (1994) further explain that “Eligibility – financial and/or categorical – is the gatekeeper to publicly financed services” (for children with disabilities) (pg. 223). Thus, children with chronic health conditions may be denied access to appropriate education services both as a result of not being recognized as having special education needs and also as a result of the fiscal limitations of school districts.

In addition to the increased numbers and educational needs of students with chronic health conditions, there may be additional disparities in funding for the education of low income students in the population. Studies suggest that children from low income families and those who are minorities are at higher risk for having a chronic illness (van Dyck, Kogan, McPherson, Weissman & Newacheck, 2004). Further, these children already face less fiscal support for education. During the 1999-2000 school year, the national average expenditure on students in districts with higher

child poverty rates was \$5,846.00 per child, compared to \$6,812.00 per child in districts with lower poverty rates (Orlofsky, 2002). Van Dyck, et al (2004) conclude, “To address these disparities, we need systemic change that establishes universal, sustainable community systems of services for all affected children and their families.” (pg. 888, van Dyck et al, 2004).

### *Qualitative Issues*

As the number of students with chronic health conditions increases in schools, the quality of life issues imposed by chronicity are more often experienced in regard to education. Students with chronic health conditions are at risk for school difficulty in two dimensions: (1) academic achievement may be impacted by absences, medication side effects, fatigue, psychosocial issues, and more and (2) some diagnoses and treatments have a cognitive impact to learning. Identification students’ needs and subsequent provision of education services are further complicated by education law which, historically, has limited access to special education and related services to those students whose health impairments directly affect educational performance in an adverse manner. School districts may adhere to the concept of “adversely affects educational performance” (IDEIA, 2004) by determining eligibility based on standardized test scores. However, the terms “educational performance” and “adversely affects” are not defined in IDEA, and the Office of Special Education Programs (OSEP) has directed school officials to consider both academic and nonacademic skills and progress when evaluating a child and determining if the child’s impairment adversely affects educational performance (Grice, 2002). In

addition, an opinion letter written by OSEP states that even students who are making progress within the general education environment may require special education services, and that the terms “educational performance” and “adversely affects” must be determined on a case-by-case basis after considering all facts and circumstances (OSEP, 1995). The gap between education and health care is evidenced by the differing opinions regarding identification of students with chronic health conditions as learners in need of additional educational support. While educators may be hesitant to identify a student as in need of special education or related services, health care professionals may be more likely to recommend to parents that the child be considered for such support. Professionals in the health care field believe that strict eligibility definitions often are discriminatory to children whose health care needs were not being met at school (Koenning, et al,1995).

#### *Specific Definitions from Federal Civil Rights Legislation*

The root of the problem of identifying young people with chronic illnesses who may need special education is defining the term “chronic illness” itself. Various disciplines, such as civil rights law, education, and health care, have attempted to define “chronic illness” in children. Federal civil rights laws that determine eligibility for health and social services have historically defined “chronic illness” in a variety of ways. The Social Securities Act of 1985 identifies “children with special health care needs” as three overlapping groups under age 21, including those with: (1) developmental disabilities, mental retardation, and learning disabilities; (2) chronic medical illnesses, such as diabetes and asthma; and (3) emotional/behavioral difficulties, including attention deficit disorder (ADD) (Americans with Disabilities Act, 1990). Inclusion of these three groups in a single definition has not served to provide cohesiveness to the population of children with special health care needs, as children in these three categories have very diverse needs and are more dissimilar than similar to one another in terms of educational needs (Terman, Lerner, Stevenson & Behrman 1996). In addition, individual states have some discretion in their interpretations of the term “special health care needs”. Some states emphasize service provision for children with developmental disabilities but not those with chronic

medical conditions. In addition, services may be restricted to covering only medical and health care needs and not include educational needs (Thies, 1999).

Two other federal civil rights laws which attempt to define a chronic health condition are Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (ADA). In each of these laws, a “disability” includes:

- (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment (Americans with Disabilities Act, 1990, United States Department of Health and Human Services, 1973).

Major life activities include “caring for one's self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning”. Some examples of impairments listed in this law which may substantially limit major life activities, even with the help of medication or aids/devices, are: AIDS, alcoholism, blindness or visual impairment, cancer, deafness or hearing impairment, diabetes, drug addiction, heart disease, and mental illness (Americans with Disabilities Act, 1990). However, students with chronic illnesses are eligible for protection under the American Disabilities Act to be guaranteed the rights of a person with a disability. However, these civil rights laws are not typically used to define “chronic illness” within public school systems, thus potentially denying students with chronic illnesses of equal protection under the law. The existence of the ADA definition, and the lack of utilization of the definition for defining which students are eligible for additional school support, may contribute to confusion and lack of clarity among both education and health care professionals.

*Specific Definitions from Education Legislation*

The second method of defining chronic health conditions in childhood is via education law. Typically, these pieces of legislation utilize a more narrow definition of disability and chronic illness than civil rights legislation, and are very specific regarding which students may qualify for special education and related services. Within the public education system, students with special needs are those students who cannot learn through general education methodologies, and who require instruction to meet their unique needs (Symons, Cinelli, James, & Groff, 1997). The Education for All Handicapped Act (P.L. 94-142) was enacted in 1975, guaranteeing a free, appropriate public education, at no cost, to all children. The purpose of the Act was:

... to assure that all handicapped children have available to them, within the time periods specified in section 612(2) (B). a free appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist States and localities to provide for the education of all handicapped children and to assess and assure the effectiveness of efforts to educate handicapped children (Public Law 94-142, 1975).

Later reauthorized as the Individuals with Disabilities Education Act (IDEA) in 1997 and the Individuals with Disabilities Education Improvement Act (IDEIA) in 2004, this law guarantees a fair and appropriate education, at no cost to parents, to students with a wide variety of special education needs (Public Law 94-142, 1975, Individuals with Disabilities Education Improvement Act, 2004). Students must be determined to be eligible for special education services before such services will be initiated (IDEIA 2004). Eligibility is determined based on whether or not the child meets the criteria

of being “a child with a disability”. In general the term “child with a disability” means a child--

- (a) with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this title as “emotional disturbance”), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and
- (b) who, by reason thereof, needs special education and related services (Individuals with Disabilities Education Improvement Act, 2004).

Although the special education definition does not specifically include students with chronic health conditions or special health care needs as groups who are eligible for classification as students in need of special education, there is a reference to students with health impairments. The category of “other health impaired” (OHI) refers to a student “having limited strength, vitality or alertness, including heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that

- (a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and
- (b) adversely affects a child’s educational performance” (Individuals with Disabilities Education Improvement Act, 2004).

Recent changes in education systems’ practice regarding inclusion criteria for qualifying for OHI have further complicated the process. In 1991, children and adolescents with attention deficit hyperactivity disorder were included as individuals who may qualify as a student who is OHI due to the evidence that ADHD is a neurobiological disorder. Although this student population is an appropriate group to include in the category of OHI, the number of youngsters with ADHD served under

OHI, which remained steady for many years, has grown dramatically since ADHD was included as a qualifying diagnosis. For example, in the 1988-1989 school year, 50,000 students were identified as OHI; in 1993-1994, the second full school year after inclusion of ADHD in the OHI category, that number rose to 83,000. The increase in numbers of students classified as OHI has risen steadily, with 292,000 students classified in that category during the 2000-2001 school term (Digest of Education Statistics, pg. 66, 2002). Any acute or chronic health condition may meet the definition and eligibility criteria for OHI if the condition results in limited alertness to the environment. Limited alertness may be evidenced by a low level of strength, vitality or alertness, as may be the case in a child with a chronic health condition. In addition, the manifestation of limited alertness, as in ADHD, may be heightened attentiveness to environmental stimuli. Thus, educators and school psychologists, who are those responsible for identifying students in need of special education services, may be wise to ensure that OHI eligibility is made on a case by case basis (Grice, 2002), rather than considering OHI to be synonymous with the diagnosis of ADHD.

The President's Commission on Excellence in Special Education acknowledges the problems that exist in regard to the definition and subsequent identification of special needs students. The report, "A New Era: Revitalizing Special Education for Children and Families", published in July 2002, states that the subdivision of students in certain special education categories is not perfect. Further, the report explains that the complexity of IDEA reflects the proliferation of categories

and assessment guidelines that vary in their implementation, often with little relation to intervention. Many of the 13 disability categories emerged as a result of advocacy group efforts to promote recognition for their specific constituency. The category of “other health impaired” is unique in that there have not been efforts to promote the category, a physician’s input is required to validate diagnosis and student needs, and the individuals in the group are highly variable as a result of the multiple chronic conditions that comprise “other health impaired”. Students with physical disabilities or chronic illnesses are often referred by parents and physicians for eligibility determination through medical histories (President’s Commission on Excellence in Special Education, 2002). However, that does not guarantee that special education services will be provided to the student. As with all special education categories, only after extensive assessment will the student qualify as a student who is “other health impaired” and in need of special education services (Dalton, 2002). In the case of a student with a chronic illness, the assessment process may be complicated by the child’s frequent absences, fatigue and lethargy or compromised health condition. In addition, the perception among education professionals that the group of students who may qualify for special education as a result of a health impairment is a “low-incidence” population has resulted in a reduced focus on this group’s needs (President’s Commission on Excellence in Special Education, 2002).

The lack of a uniform definition of chronic illness of childhood results in the subsequent lack of educators’ knowledge about the learning needs of children with special health care needs (CSCHN). Educators’ knowledge, regarding other special

needs groups, often was fueled by parent groups who were active lobbyists for their children's needs. For example, the Arc of the United States is an organization that was established 50 years ago as the result of families, primarily parents, who wanted services and supports for their children. The organization worked to educate the community about the little known condition, mental retardation. Children with mental retardation usually did not go to school and there were virtually no programs and activities in communities to assist in the development of children and adults with mental retardation and to help support families. By lobbying, parents' goals focused on changing the public's perception of children with mental retardation and other developmental disabilities and to enable children to access school and other programs (The Arc website, 2005). Other parent advocacy groups, such as those for students with learning disabilities, have garnered more attention due to better organized, larger and more active advocacy groups (Political Advocacy Groups, A Directory of United States Lobbyists, 2005).

However, educational lobbying at the federal level for students with chronic illnesses has not been an organized effort in the past. Often, parents of chronically ill children are consumed with the care of their ill child and other family issues, and do not have the opportunity to participate in formal advocacy efforts (Dalton, 2002). There has not been a forum for parents of children with various chronic illnesses (e.g. cancer, cystic fibrosis, diabetes, sickle cell anemia) to work cooperatively to assure educational support for all children with chronic conditions. Rather, any groups that have been formed have been disease specific, and the numbers have, thus, been small.

Thus, parents of CSHCN have not always been a source for information and advocacy for their children's educational needs.

Finally, limited funding for education, in general, and special education, specifically, does not create an environment that supports the identification of additional students who need the already stretched resources. When P.L. 94-142 was enacted in 1975, Congress promised to pay for 40% of the National Average per Pupil Expenditure for every child receiving special education services. Although Congress has made improvements in funding over the past few years, it is still only funding IDEA at 19%. The result is a \$10.6 billion shortfall, and that state and local taxpayers are funding much of special education. In addition, districts have been forced to reduce services under their general education budgets as they redirect funds to cover the lack of promised federal dollars (IDEA Funding Coalition, 2004). Oberg et al (1994) argue that "such constraints at the front end (the school level) only multiply our expenditure at the back end (maintaining life-long dependence on public support) among a population of whom most have the capability to achieve economic independence" (pg.227).

#### *Specific Definitions from the Health Care Community*

In addition to the discrepancy between civil rights and education definitions of chronic health conditions, there are further differences in definitions utilized by the health care community. The terms "chronic health conditions" and "special health care needs" and the populations of children they represent in health care are similar

but are not synonymous. The latter refers to a population legally entitled to certain services; the former does not (Thies, 1999).

Within healthcare, children with special health care needs (SHCNs; hereafter referred to as children with SHCN) have been recognized as an important population from a variety of perspectives including health care services, economics, and policy (McPherson, Arango, Fox, Lauver, McManus, Newacheck, Perrin, Shonkoff, & Strickland, 1998). However, until recently, no national data utilizing a uniform, commonly accepted definition, existed on the prevalence and health care service needs of this unique group. Recent epidemiologic studies have resulted in better definitions to identify the population of children with SHCN (McPherson et al, 1998).

In an attempt to create definitions that provide more clarity in identifying children with SHCN, researchers utilized several conceptual approaches (Perrin, Newacheck, Pless, Drotar, Gortmaker, Leventhal, Perrin, Stein, Walker, & Weitzman, 1993). For the past 40 years, the three most common approaches have included condition lists, which define populations of children according to their underlying health condition; functional status assessments, which identify children whose chronic conditions cause impairments in basic functions such as hearing, seeing or higher level functioning required to conduct activities of daily living; and limitations in socially defined roles, such as school or play, due to chronic conditions.

(Newacheck, Strickland, Shonkoff, Perrin, McPherson, McManus, Lauver, Fox, & Arango, 1998; Newacheck & Taylor, 1992; Haggerty, 1983; Walker, Gortmaker, & Weitzman, 1981; Aron, Loprest, & Steuerle, 1996). One result of using these

differing concepts has been a lack of consistency in defining the population and, therefore, variations in estimating its prevalence in the context of health care and education needs. Early epidemiologic studies estimated the prevalence of chronic illness in childhood in the U.S. from 5% to nearly 30%. Lower estimates included only children with disabling chronic conditions, while higher estimates included children with chronic illness which resulted in no significant medical or functional consequences (Aron, et al 1996; Cadman, Boyle, Szatmari, & Offord, 1987, Collins, 1983-1985, Adams & Marano, 1995, Westbrook, Silver, & Stein, 1998).

Classifying children by medical diagnoses reflects a problem-oriented approach to treatment. (Thies, 1999) Focusing on a medical diagnosis alone cannot capture the full scope of the chronic illness. Disease severity, progression, and outcomes may vary greatly among children. For example, cancer is now considered a chronic illness of childhood. Its course may last months or years and survivors may experience no significant outcomes or serious long-term effects of disease and treatment. Likewise, asthma may be an occasional, seasonal nuisance for one child, while posing life-threatening ramifications in another. Thus, a diagnosis alone cannot predict the need for health or educational support for a child.

The need for education services may vary greatly from child to child within specific education diagnostic categories (Thies, 1999). Thus, clear definitions of qualifying special education categories are required prior to identifying which students in a given category may be eligible for special education services. As a result, policy makers in pediatrics and public health have suggested the use of a

multicomponent, noncategorical approach to a definition of chronic condition based on that condition's consequences as well as its origins. In this approach, a chronic health condition is defined as one that is expected to last at least 3-12 months and has a biological basis. Further, it is accompanied by one or more consequences: (1) limitations in routine day-to-day functioning; (2) reliance on compensatory modalities such as medications, special diets, and assistive devices; and (3) a need for services beyond routine medical care (Stein, Bauman, Westbrook, Coupey & Ireys, 1993). This definition offers clarity and is devoid of medical jargon. An advantage for students with educational needs related to a chronic health condition is that the definition accentuates the individual nature of chronic health conditions and draws attention to the potential need for special education supports.

More recently, Newacheck and Halfon (1998) summarized the effect of activity-limiting chronic conditions on children with diseases and injuries in the tabulations of data from the 1992-1994 National Health Interview Survey. A cross-sectional descriptive analysis of the data from 99 513 children included in the survey estimated that 6.5% of all US children experienced some degree of disability caused by chronic conditions. The outcome of childhood disability is estimated to result in 66 million restricted activity days annually, including 24 million days lost from school (Newacheck et al, 1998).

The research of Newacheck et al (1998) and the findings that chronic conditions resulted in such a significant number of days lost from school helped to emphasize the need for a definition that would lead to improved planning and

advocacy for children with chronic health conditions (DiCroce, 1990; Boyle et al, 1994; Fowler et al, 1995). In response, the federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs developed the following definition:

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson, et al 1998).

In 2001, this population of children was estimated to comprise 12.8% of non-institutionalized with a chronic illness which resulted in a functional limitation. This translates to an estimated 9.3 million children in the United States under the age of 18 (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). This definition has been widely accepted among health care providers.

Epidemiologic studies also suggested that young people with chronic health conditions experienced school related challenges. A study by Newacheck et al (1998) focused on presenting an epidemiologic profile of children with SHCN using the Maternal and Child Health Bureau's definition of such children. They found that 18% of children <18 years of age in 1994, or 12.6 million children nationally, had a chronic physical, developmental, behavioral or emotional condition and required health and related services of a type or amount beyond that required by children generally. This estimate includes children with existing special health care needs, but excludes the at-risk population. Newacheck et al (1998) recognized the potential impact on education as the research showed that children with existing special health

care needs had three times as many bed days and school absence days as other children, adding an additional component of potential educational need.

This association between education and chronic health conditions was also reported by Msall, Avery, Tremont, Lima, Rogers, & Hogan (2003). They examined the 1994 and 1995 National Health Interview Survey and Disability Interview Supplement which provide the *International Classification of Diseases, Ninth Revision* medical impairment codes (ICD codes) for children with functional limitations or school activity limitations in a nationally representative US sample. They categorized the ICD codes reported in conjunction with medical usage as physical disorders (including leukemia, heart failure, Type 1 diabetes, cystic fibrosis, sickle cell anemia and other episodic, intermediate and injury categories); asthma; neurodevelopmental disorders; and learning-behavior disorders (including ADD, learning disability and anxiety) for children with functional or school activity limitations. Of the total number of children with functional limitations reviewed, 18.1% had physical disorders and 4.2% had asthma. They found that among children requiring special education, physical disorders accounted for 9.4%, neurodevelopmental disorders for 16.7%, learning and behavior disorders for 17%, asthma for 3.4%. However, the 53.4% of the youngsters who did not have an identified medical impairment had not received medical services within the previous year. Thus, it was unknown whether they may have had a medical impairment which simply had not been identified. Results indicated that severe functional disabilities were found in 23.3% of those children with physical disorders and 14.5% of those

with asthma (Msall et al 2003). This evidence suggests that the number of students with a chronic health condition (physical disorder or asthma) who also have a functional impairment constitutes 22.3%, or almost a quarter of the children with functional limitations. Thus, a condition which has long been perceived by educators to comprise a low-incident population of students may be, in fact, a much larger population that has not been adequately identified or assessed for possible eligibility for special education services.

In addition to learning, cognitive, and academic problems that result from chronic health conditions, such children are also at risk for school problems. Hogan, Rogers, & Msall (2000) reviewed the national representative data from the 1994 and 1995 National Health Interview Surveys on Disability (NHIS-D) (N = 41 300) and the Year 2000 Health Supplement to the 1994 NHIS-D (N = 9530). They found that children with functional limitations more often had unfavorable family resources, less healthy home environments, poorer health status, and less health service access than other children. They concluded that these circumstances resulted in making the children more likely to experience additional difficulties, including school-related problems, beyond those associated with their specific functional limitations.

As the Federal Bureau of Maternal and Child Health definition of a child with special health care needs suggests, children with chronic health conditions require more services than other children. Specifically, children with chronic or disabling conditions use health, education and social services at a higher rate than their healthy peers. These children use more ancillary (e.g., audiology, occupational, physical or

speech therapy, or social work) and enabling (e.g., special equipment, personal care assistance, respite care, transportation, or environmental modifications) services. The purpose of these services is to improve a child's quality of life and enable a family's adaptation to their child's special needs, particularly when the functional consequences of a condition cannot be ameliorated. In the school setting, children may demonstrate functional limitations that impede learning, but they may not qualify for ancillary or enabling services, as they do not meet the criteria established through educational statutes. Unless a student fits the criteria for eligibility for ancillary and enabling services, the student will not receive services (Benedict & Farel, 2003). Thus, the need to determine a working definition which will result in eligibility for special education is imperative to enable children to have access to needed services.

The definition of Bureau of Maternal and Child Health definition of "special health care needs" provides clarity regarding who comprises the group of children with chronic health conditions (McPherson et al, 1998; Walker et al, 1981; Haggerty, 1983; Newacheck et al, 1992; Perrin et al, 1993; Stein et al, 1993; Aron et al, 1996; Newacheck et al, 1998). However, there is still disagreement in determining need for special education services, resulting in diminished or nonexistent educational support for students with chronic health conditions (Thies, 1999). Chronic health condition is not a term that is commonly understood or utilized by educators. Thus, invisible diagnoses such as asthma, diabetes, and sickle cell anemia are perceived as conditions requiring medical treatment rather than educational intervention (Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004). The definition needs to encompass a broad

base of youngsters and diagnoses to ensure policy and programming that will cover the needs of this population.

### *Section Summary*

In summary, multiple agencies at the federal, state and local level provide services for children with SHCN or children with chronic illnesses. There is a wide variation in eligibility criteria for such services. Epidemiological studies show that 3.8% - 32% of children could be classified as children with special health care needs, depending on the definition and method of determination for eligibility used.

The Bureau of Maternal and Child Health estimated that 12.8% of non-institutionalized children have special health care needs that place them at risk for chronic health conditions and who require a greater amount of health and related services than their peers. Agencies need to be more explicit with eligibility criteria so that the definitions are meaningful to those making referrals and determining eligibility for services (Beers, Kemeny, Sherrit, & Palfrey, 2003).

### The Med-Ed Gap

Defining “chronic health condition” is but one of the factors that may impede a student with a chronic health condition from receiving optimal support and services in school. In addition to the difficulty defining chronic illness, additional differences exist between the medical and educational communities that may impact education support and access to services for students with chronic illness. Koenning et al (1995) coined the phrase “med-ed gap”, describing the gap that exists between medical and education communities’ perceptions of what constitutes eligibility for

special education services and educational needs of children with health-related disabilities. The authors describe the gap that exists as one that is due to education law, which, historically, has limited access to special education and related services to those children whose health impairments adversely affect educational performance. Koenning et al (1995) state “Regardless of whether the comparability in disability estimates is accurate or not, the issue (of underserved students with chronic health conditions) typifies the long-standing controversy between the medical and education communities concerning the eligibility of children with health-related disabilities for special education services” (pg. 207). Conversely, the medical community has lobbied for more intensive education support for students with chronic health conditions, arguing that strict eligibility criteria for special education services results in discrimination to some chronically ill children whose learning needs have not been identified due to lack of educators’ knowledge, altered expectations of students with chronic illness or insensitive assessment measures. This lack of consistency in identifying who is eligible for special education has contributed not only to a widening gap between the two professions, but also confusion and mixed messages to parents and students. Families may be told by health care providers to request special education support for their child, and educators may respond that the child is not eligible for additional education services or that other interventions may be attempted prior to evaluating further.

Despite the fact that eligibility for special education services is determined by educators, it is important to have input and cooperation from health care providers in

the process of providing essential information to educators regarding issues that may impact learning. Several studies have shown that educators feel poorly prepared to provide the support needed by students with chronic illnesses due to lack of information (Thies, 1999; Yeo & Sawyer, 2003; Symons et al, 1997). Other researchers cite educators' desire to have more information about an individual child's diagnosis and treatment and better communication with health care providers (Rehm & Rohr, 2002; Olson et al, 2004; Mukherjee, Lightfoot & Sloper, 2002; O'Keeffe & McDowell, 2004). Effective communication and collaboration between educators and health care professionals may enable educators to go about the business of educating the child, while health care issues are clearly defined and delegated to the school nurse. The result is one that benefits educators and health care professionals and, most importantly, the child and family.

Cooperation between health care and education professions and interdisciplinary efforts may lead to more effective program planning for the estimated 40% of children and adolescents with chronic health conditions experience school-related problems (Bloch, 1986). Students with chronic health conditions exist at the intersection of the health and education systems. Traditionally, these systems operate in separate realms with differing political agendas and philosophical bases. As a result, students' health and education needs at school are often not well integrated. The school nurse – if one exists – is designated as the one to attend to health problems, while classroom teachers focus on academics. Better coordination within the school setting is recommended as this practice of separating health and

education services further serves to limit the cohesiveness of supports for students with chronic health conditions (Thies, 1999).

There are several issues that perpetuate the ways health care providers and educators perceive the needs of students with chronic health conditions. Issues that will be addressed in this writing include poor communication between the two fields, a lack of understanding of one another's disciplines, differing beliefs about school safety issues for students with chronic health conditions, and a lack of pre-service or in-service education opportunities for educators regarding students with chronic health conditions may cause problems in developing effective educational programs for students with chronic health conditions.

#### *Communication Between Professionals in Health Care and Education*

Communication between medical and educational communities regarding a student's health status and education needs does not often occur and, when it does, lacks consistency. Magrab (1985) suggested that a linkage system between education and medical venues be created as a method of bridging the med-ed gap. Specifically, the author proposed that a "liaison" special educator having systematic and regular contact with the classroom teacher and special resource programs be included on the interdisciplinary team to better address individual needs of the child. The role of the special educator included: assessing the educational needs of the chronically ill child, developing linkages between the health and education systems, planning educational programming, and assisting teachers in educational settings to implement appropriate educational programming.

For students with chronic health conditions, health and education are interrelated, with one impacting the other. Effective communication between the two professions becomes integral to the student's continued school success. A physician may send a report to the child's school with the assumption that what is written will be interpreted in the same manner by a child's teacher as it does to the physician. If there are significant, unrecognized differences in interpretations, collaborative management between education and health care professionals is likely to be compromised (Koenning et al, 1995). In addition, reports from physicians often contain medical information, but lack specifics that would enable educators to be more cognizant of the student's unique learning situation. Lightfoot, Wright and Sloper (1999) suggest providing basic information for school staff about such things as pain, tiredness, poor concentration, and other factors that may impact educational performance, in order to ensure that these factors are considered when planning for the child's education and necessary supports.

Health care providers and educators have difficulty establishing and maintaining effective communication, and parents are not the best candidates to bridge the gap between the two professions. Communication may be further compromised when parents are expected to provide medical and health related information to schools. It is well recognized that it may take parents several weeks or months to adjust to the diagnosis of a chronic illness in their child, and that repetition of key information is integral to parental understanding of their child's disease and treatment (Roemer, 2003; Clarke, 2004; Lowes, Gregory, & Lyne, 2003; Janse,

Sinneman, Uiterwaal, Kimpen, & Gemke, 2005; Mukherjee et al, 2002). Parents may overemphasize their child's needs in order to ensure that optimal care is given (Roemer, 2005). In other research, it has been suggested that parents may feel that their power and authority are being usurped by physicians when a child is diagnosed with cancer. Thus, accurate reporting of information may be compromised (Clarke, 2004). A parent's grief or perception of their child's diminished quality of life as a result of a chronic health condition may further interfere with communication with school staff regarding their child's need. Mukherjee et al (2002) found that parents as conduits of information to the school was correlated with difficulty in communication between health and education staff, thus resulting in misinformation that complicated the planning for education services for the student with a chronic health condition.

Other sources of difficulty in communication between health and education staff identified by Mukherjee et al (2002) included the practical difficulties of arranging meetings and lack of knowledge about other professionals' roles. The ethos of the school with regard to health matters, and the flow of information within health services, also had an impact on the communication process. Recommendations of physicians and educators in the study focused on two key issues: clarification of the roles of health and education staff with regard to this group of pupils; and how information should flow from health to school staff. It was suggested that clarification of roles of different professionals in health and education with respect to students with special health needs was a good place to begin communication. In addition, both sides expressed a preference for face-to-face meetings, and

acknowledged the difficulty of scheduling for health care providers, due to demands of the profession. A positive observation was the apparent recognition that better communication and understanding was integral to ensuring that the student's needs were best addressed.

### *Understanding One Another's Discipline*

In addition to poor communication, health care providers and educators often do not understand one another's role or the limitations and constraints of the system within which each works. Early research regarding the challenges of school reentry for students with chronic health conditions investigated the attitudes of both groups of professionals. Each group accused the other of arrogance, lack of follow-up, and a lack of knowledge of the other's field of work (Beck, Edgar, Kenowitz, Sulzbacher, Lovitt, & Sweibel, 1978). Health care providers may perceive that schools are able to provide more services than is fiscally possible. To implement a school-linked services approach, schools must use existing funding sources for programs in health, social services, juvenile justice, and other areas rather than adding social workers and nurses to the school payroll (Kirst, 1993). Hiring additional nursing, education, or social work staff to support the school programming for students with chronic health conditions is not likely in this time of declining school budgets.

The misconceptions of health care providers regarding school-related issues may also be counterproductive. A lack of knowledge regarding such things as current classroom conditions, available resources, and assessment and evaluation processes may result in incorrect assumptions about what is achievable within schools (O'Keefe

& McDowell, 2004). For example, homebound education services, sometimes requested by physicians of students unable to attend school, typically consists of 3-5 hours of instruction per week (Sid Cooley, Kansas State Department of Education, personal communication, June 13, 2005). However, physicians and others outside the school system may believe that homebound instruction consists of significantly more teacher contact time per student.

Similarly, educators may be unaware of the limitations placed on health care providers in the age of managed care and capitation. Bilenker, Weller, Shaffer, Dover, & Anderson (1998) reported that,

“Unless managed care organizations and capitated pediatricians receive payment rates that reflect the higher expected expenditures of caring for these children, access to and quality of care may suffer. Analyses of practice guidelines and utilization patterns suggest that newborn screening, regular access to specialty facilities and comprehensive education programs are critical areas that are vulnerable to reductions under capitation.”

The comprehensive education programs referred to typically include those that provide information and education to the schools of young patients. One study concluded that teachers are generally happy with the diagnostic accuracy of medical practitioners, though are less satisfied with their input to schools after diagnosis. The majority of teachers (75%) would not ask the child's doctor for more information about a child with a disability, despite the feeling that they are under-trained and under-resourced to be able to deal with children with special conditions (O'Keeffe et al, 2004). In the same study, doctors commented on teachers' lack of information about medical conditions as being a barrier to collaboration. However, only 4% of doctors (pediatricians) commented on the importance of information going from

physician to the school. Results suggest significant lack of communication originating in both professions.

*Educators' Access to Information and Training on Chronic Health Conditions of Childhood*

Several investigators have reported on the lack of sufficient information and research that is available in education literature in regard to the needs of students with chronic health conditions. In addition, these analyses have suggested that educators are poorly trained to collaborate with health care providers (Fowler, Johnson, & Atkinson, 1985; Johnson, Lubker, & Fowler, 1988; Magrab, 1985; Weitzman, 1984; Walker & Jacobs, 1984). Differing professional jargon used by both teachers and physicians was also noted as causing misunderstanding and confusion between the disciplines (Cransoun, Olfey, Hansen, Hudler, Marshall, & Wuoir, 1988).

Attitudes regarding school safety are another area of difference between educators and health care providers. Rehm & Rohr (2002) studied the perceptions of parents and health care providers with regard to their school concerns about the safety and health of children with chronic illness. Informants all believed that attending school provided benefits to most children who are medically fragile/technology-dependent, including opportunities for skill acquisition, socialization, and respite care for families. However, they also perceived that there were real risks involved, including obtaining appropriate care, exposure to infection, and social isolation or teasing.

Bradford, Heald and Petrie (1994) described the delicate balance between the health care and educational needs of a student with a chronic illness in the school setting. Their study emphasized the importance of school nurses having access to information about students with chronic illness for whom they provide care. The authors state that the individuality of chronically ill children in schools must be understood: some have chronic illnesses with disabilities that create medical and educational problems; others have conditions with attendant treatments that affect the school environment. Without adequate communication between the health care provider and the school, the student's physical and educational needs cannot be appropriately addressed at school.

#### *Section Summary*

In summary, Koenning et al (1995) state that collaboration between health care providers and educators is recommended, allowing for individualized assessment of the child's needs and enhanced communication among families, health providers, and schools. However, recent literature suggests that the opposite trend or a broadening of the "med-ed gap" has occurred (O'Keeffe & McDowell 2004). Koenning et al assert that physicians do not routinely participate in collaborative efforts with schools, teachers are poorly trained for this collaborative role, and, as a result, parents are frequently placed in the less than optimal role of translating complex medical recommendations into educational programming. Among the barriers to a successful school experience are non-overlapping service systems (health and education) staffed by school providers who lack knowledge of specific illnesses

and their effect on educational performance and participation, and health providers who fail to communicate to school providers the health needs of their patients in ways which make clear the educational implications of the child's health-related disability (Koenning et al 1995).

### Summary

There has been significant disparity between the policies, positions, and beliefs of health care and education professions in regard to the educational needs of children with chronic health conditions. The controversy is fueled by differences in definitions of a special health care need or chronic health condition. Lacking a uniform definition of the target population of students, there is a significant communication gap between the two professions.

In education, confusion exists between such definitions as other health impaired, medically fragile, special health care needs, orthopedically handicapped, and physically impaired. The definition of "other health impaired" (OHI), in the Individuals with Disabilities Education Improvement Act, requires that a child's health condition "adversely affects educational performance" in order to consider the youngster for special education eligibility. Conventional assessment measures, such as achievement and academic evaluations, may not be sensitive enough to capture the impact of a chronic health condition on learning. Such effects as pain, lethargy, medication side effects, the impact of the disease process itself, or the psychological, social or emotional ramifications of illness are not easily measured, but may have a significant impact on educational achievement. With the knowledge that

approximately 40% of children with chronic health conditions experience school-related problems, the need for a working definition that leads to access to services would seem to be warranted.

Most of the research regarding possible educational problems and needs of students with chronic health conditions originates from health care and medical fields. Educators do not have ready access to the research and information about how to support learning issues for such students. Common sources of reporting on research related to the educational needs of students with chronic illness include peer reviewed journals in medicine, nursing and pediatric health care. Educational journals, however, are lacking in research on this topic.

Conversely, health care providers do not have an adequate understanding of the educational processes utilized in identifying and determining eligibility for students with chronic health conditions. The process is formal, often long in duration and requires that specific requirements for eligibility be met before services can be provided. However, health care providers are not always aware of what is entailed in the eligibility for special education services process within schools. For example, on a website for pediatric oncology nurses it is suggested that a health care provider write a letter to the school outlining the health care needs of the child that may impact education. The fact sheet goes on to advise that parents, after the faculty has had the opportunity to read the letter, “To help your child keep up in school, you need to request special education eligibility. Then the child can qualify for an itinerant teacher. Without an IEP or 504 plan, the child is legally entitled to nothing except

what the school voluntarily provides, and this is not enforceable.” (Onconcourse website, 2005). In reality, the IEP meeting would only be held when, and if, the student had previously gone through the rather rigorous process that leads to possibly being determined to be eligible for special education services, a process that may take weeks or months.

Bridging the “med-ed gap” may be fostered by the definition of “special health care needs”, as drafted by the federal Maternal and Child Health Bureau’s Division of Services for Children with Special Health Care Needs. This definition possesses the potential to more readily define and, thus, identify students with chronic health care conditions in need of special education support. The definition requires that children be at risk for chronic physical conditions and that they require health and related services of a type or amount beyond that generally required by children. Further, the definition is broad enough to ensure inclusion of all children who may benefit from additional services and supports, but specific enough to ensure that the population is perceived as consisting of those youngsters who have significant health needs. The reference to the need for services beyond those required, generally, by most children further tightens the target group to those who have the greatest need for services. Utilizing this definition, it is estimated that 12.8% of students are SHCN children, a number that is likely to be recognized by the education community as one that is significant and which defines a population in potential need of special education support. In this era of limited resources, it is imperative that the children most in need of services be clearly identified.

It is imperative to achieve, across disciplines, a uniform, consistent definition of a student with a health condition which warrants educational intervention. Thies (1999) suggests that, in regard to students with developmental or learning disabilities, eligibility criteria for services is something that evolved over a generation of experience, lobbying, legal action, and educational research. The result is that educators recognize these students as learners in need of educational intervention and there is an understanding of what interventions may help learners with developmental or learning disabilities. However, the educational needs of students with chronic health conditions have received less attention and are, therefore, less well-defined, have not received as much attention in the research, and are not well understood by educators. While federal law prohibits discrimination and affirms the need for accommodations for all students with disabilities, it does not specify how the learner with a chronic health condition should be identified as in need of additional support. “Chronic illness” and “other health impaired” are defined differently. The definition for OHI requires that the health condition “adversely affects educational performance” (IDEIA, 2004). It is not uncommon for students with asthma, diabetes, or cancer to not fit the eligibility criteria for or philosophies of traditional special education as defined by “other health impaired” under IDEA (Thies, 1999). However, they may be considered, by the health care field, to be students with chronic health conditions which impact learning and by the ADA as a person with a disability which affects one of life’s major life functions – learning.

In order to ensure optimal learning experiences occur for students with chronic illnesses, educators and health care providers must work toward unification of a definition of the population and improved communication between the disciplines that may lead to shared beliefs regarding the need for services and support. In addition, collaborative and collective research and information dissemination may result in greater prospects for appropriate education leading to improved opportunities beyond K-12 education. Such efforts will enable students with chronic health conditions to engage on a level playing field with peers, provide them with the opportunity to realize the goals that sustain them throughout periods of illness and disability, and allow the opportunity for productive adult lives.

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## **Appendix XI: Comprehensive Exam II**

Education Challenges for Students with Chronic Health Conditions

Kathleen Tyler Davis

A written comprehensive paper completed as partial fulfillment of the Ph.D.  
requirement

## Introduction

Children and adolescents with chronic health conditions must navigate both health care and education environments. Chronic conditions of childhood and adolescence such as asthma, leukemia and other cancers, cystic fibrosis, diabetes, epilepsy, juvenile rheumatoid arthritis, sickle cell anemia and others have long been considered only to result in health care needs, at the expense of considering the additional needs of children with these conditions. As a result of advances in medical treatment and improved technologies, children with chronic illnesses are living longer and are often able to participate in school and other activities. Young people with chronic illnesses, who once spent most of their time in the hospital or at home, are now more frequently involved in social and sports activities, family experiences and school. These factors have led to an increase in the numbers of children with chronic health conditions, both in general as well as in the classroom (Thies, 1999).

Historically, accessing public education has been a challenge for students with chronic health conditions, despite the fact that both education and health care professionals have expressed support for the continuation of school involvement for these learners. Poor academic performance due to chronic health conditions may impose challenges on how, or if, the student will succeed in school. Students in grades K-12 with chronic illness experience more academic difficulties than their healthy peers. Forty five percent (45%) of students with chronic illness have been reported to fall behind in their school work due to absences and illness, leading them to dislike school (Lynch et al, 1993). Fowler, Johnson & Atkinson (1985) examined

270 sixth graders with chronic health conditions in regard to school achievement and absenteeism, discovering that the mean national achievement score for students with chronic health conditions was at the 51<sup>st</sup> percentile, compared with the 63<sup>rd</sup> percentile for healthy peers. At the high school level, 35% of students identified as "other health impaired" report failing grades (Valdes, Williamson & Wanger, 1990). Valdes et al (1990) reported that only 6% of secondary students with chronic illnesses have Individual Education Plans (IEPs) that address postsecondary educational or vocational goals, and 36% worry they will not get a job and, thus, may not be eligible for health insurance. Defining appropriate education services for students with chronic illnesses may result in increased access to appropriate education services and, therefore, improved academic achievement.

Public education has not always been guaranteed to students with chronic health conditions and other disabilities. In 1948, only 12% of all children with disabilities received some form of special education. By the early 1950s, most school districts offered some sort of special education, but often services consisted of learning to weave or string beads (National Association of Special Education Teachers, 2003). The Education for the Handicapped Act (EHA - P.L. 94-142), passed in 1975 and reauthorized as the Individuals with Disabilities Education Act in 1997 and 2004, assured a free and appropriate public education, at no expense to parents, for all children with exceptionalities (Individuals with Disabilities Act, 1997). The result of that legislation is that 6.6 million exceptional children with a variety of disabilities, or 10% of all children in public schools, now receive special

education services under IDEA (Council for Exceptional Children, 2003). However, students with chronic health conditions often are recognized as persons with health care needs, but not as individuals with education needs resulting from the chronic illness or related factors.

Students with chronic health conditions have the right to attend school and to experience all of the associated benefits. The Individuals with Disabilities Education Act (IDEA) guarantees a free and appropriate public education (FAPE) to every school-aged child (“child” is used to denote both children and adolescents) regardless of degree of disability or special need (IDEA, 1997). The social and developmental advantages provided by a youngster’s direct involvement in school support the benefit of education in a school setting for all children (American Academy of Pediatrics, Committee on School Health, 2000). However, it is often difficult to ensure that a student with a chronic health condition has full access to the advantages afforded by school.

The contributing factors for these challenges are two-fold: (1) characteristics unique to the child with a chronic illness, the family and school community and (2) issues inherent in the education system which may limit the provision of a FAPE for students with chronic health conditions. The education of the child with a chronic health condition is impacted by multiple influences. Just as a plan is developed to ensure optimal health outcomes for the patient, so must a plan be developed to guarantee that educational opportunities are maximized for the student. In order to ensure that the student with a chronic health condition has access to appropriate

educational supports, each potential issue or problem must be examined and addressed. The following discussion will review these factors and the unique challenges that may be encountered when navigating school reentry and reintegration for a student with a chronic health condition. Primary areas of discussion will include: (1) an examination of the current issues which may result in challenges to access to appropriate services; (2) the perspectives of the student with a chronic illness, (3) concerns of the student's parents in regard to school reentry and reintegration, (4) and attitudes and concerns of educators and peers which may affect the student's school experience. The integration of these concepts serves to identify major areas of difficulty related to school success for students with chronic health conditions.

#### Current Issues

Several current issues in education result in school related challenges for young people with chronic health conditions. Included are the increase in the complexity of needs and the size of this population of learners, challenges in identifying which students meet the eligibility criteria for special education and the subsequent identification process, and awareness and acknowledgement in the education community of the unique learning challenges of students with chronic health conditions. Each of these challenges may limit a student's access to appropriate education services.

### *Increasing numbers of students with chronic health conditions*

The number of students with chronic health conditions who are attending school and who may require additional education support is growing. This population of students has long been considered to be a low-incidence population. However, that assumption may be the result of a lack of awareness of the unique learning needs of students with chronic health conditions, rather than actual low numbers of students with educational needs that result from chronic health conditions. Newacheck and Taylor (1992), using the National Health Interview Survey on Child Health, found that there were 18 million young people, or 31% of all children under age 18, who had at least one chronic condition. Further, an estimated 12.8 percent of noninstitutionalized children aged 0 through 17 have a special health care need which limits normal activities or results in a functional limitation (vanDyck, Kogan, McPherson, Weissman & Newacheck, 2004). If a student has a functional limitation, it is likely that there may be a consequent impact on school activities. However, during the 1996 -1997 school year approximately 11% of all students received special education services. Of those students, 4% were classified as “other health impaired”, representing .44% of all school age children (U.S. Department of Education, 1998). Thus, it appears that many children who have been identified as having a “functional limitation” have not been identified as being “other health impaired”, the latter requiring educational intervention.

In addition, survival and longevity for young people with chronic illnesses has improved significantly due to medical advances. Medical complications that used to

present in childhood now often can be delayed until adolescence or adulthood, resulting in many students in school who, previously, would not have been able to attend (Breslau, 1992, pg. 58). As a result, the population of children with chronic health conditions now includes individuals who are surviving, but with more severe handicaps (Breslau, 1992). Thus, it may be advantageous to address the educational challenges of this growing, more significantly disabled population. Next steps in education might include developing better descriptions of the population's educational needs and improving recognition of students with chronic health conditions as a growing and changing population with potential education needs.

#### *Identification and eligibility for special education services*

An education challenge encountered by students with chronic health conditions is lack of access to special education due to ambiguity in identifying which learners qualify for special education support. Although the history of special education would suggest that all students with special needs or exceptionalities are eligible for special education services, the process of identification is not uniform and varies from state to state and from school district to school district. The federal programs outlined in the IDEA were initially intended to address the education needs of the most severely disabled students. However, today approximately 90 percent of special education students have less significant disabilities, such as mild mental retardation, learning disabilities, speech and language delays or an emotional disorder (Horn & Tynan, 2001, pg 44). A more uniform approach to identifying learners in need of special education services and consistency in determining the level of

disability that constitutes eligibility for special education services could result in access to services for students with chronic health conditions who may, otherwise, be overlooked.

*Acknowledgement of educational needs*

Another current issue in education is an exclusive focus on these youngsters' health needs, and lack of attention to their education needs. The school nurse is often the staff member who is identified as the case manager and the individual with primary responsibility for overseeing the school reentry of a student with a health condition. The role of the nurse is important in regard to ensuring the child's health care needs at school are addressed. The school nurse, however, is not the professional to address education needs. In addition, educators are often unaware that the student has education needs (Sexson & Madan-Swain, 1993). The increased risk for education challenges in children with chronic health conditions has been well documented in health care research (Sexson et al, 1993). The Isle of Wight study (Rutter, Tizard & Whitmore, 1970) was one of the first, and most comprehensive, studies of the educational impact of chronic health conditions in childhood. The researchers examined both the direct and indirect impact of chronicity in students and concluded that both consequences impact school achievement. This research, and similar findings, have originated from investigators in the health care professions, rather than from educators. Because the professions rarely read one another's literature, there is a lack of awareness among educators of this research and of the education implications of chronicity in childhood. Despite these and similar later

findings (Lynch et al, 1993; Sexson et al, 1993; Weitzman, 1986; Thies, 1999), educators, physicians and school nurses often fail to discuss the impact of chronic health conditions on a child's ability to learn (Thies, 1999), impacting the potential for optimal educational outcomes.

### *Section Summary*

Increasing numbers of chronically ill students in schools create a challenge for school systems in the provision of special education and other support services. The number and health severity of students with chronic health conditions who attend school is increasing. At the same time, research from health care disciplines such as has identified education challenges for many youngsters with chronic health conditions. Access to special education services may be compromised by the ambiguity in identifying which students with chronic health conditions are in need of education support. Further, the school focus on children with chronic health conditions has long been one that addresses health related needs, rather than education needs. This focus is difficult to redirect, as educators have limited access to health care research that identifies academic and cognitive issues of children with chronic health conditions. An understanding of these current issues, which may impose educational challenges for children with chronic health conditions, may provide the foundation for a better understanding of the obstacles encountered by these learners at school.

## Attitudes and Perceptions of the Student and Others

The student with a chronic health condition is impacted by her perception of self, as well as the perceptions of parents, peers, educators and others. As a result of the illness, young people are at risk of being negatively valued by self, family members, peers and educators. These diminished perceptions may result in feelings of frustration and failure in the youngster (DiNapoli & Murphy, 2002). Sexson et al (1993) identified the need for successful school reintegration of students with chronic health conditions, citing that school adjustment is highly significant in a child's overall adjustment. A positive overall adjustment may impact the child's attitudes and perceptions of self in a manner that may lead to improved school functioning.

When compared to healthy peers, most research suggests nearly double the prevalence of emotional, developmental, and educational problems among children with a chronic health condition (Pless & Pinkerton, 1975; Cadman, Boyle, Szatmari & Offord, 1987; Drotar & Bush, 1985; Eiser, 1990; Lavigne & Faier-Routman, 1992). Interviews of young adults with chronic health conditions since childhood reported that school absences, exclusion from school life, teachers' reactions to the illness, and peer relationships were the most troublesome memories of being a child with a chronic health condition (Lightfoot, Wright & Loper, 1998). However, the impact of frequent absences, exclusion from or limited participation in activities, educators' reactions to the child's illness and peer relationships are rarely addressed in educational planning for students with chronic health conditions at school. Understanding the attitudes and perceptions of youngsters with chronic health

conditions, their parents, educators and peers may assist in determining what types of education, advocacy, supports and services are needed by students with chronic health condition.

### *Attitudes and Perceptions of Students with Chronic Health Conditions*

The attitudes and perceptions of students with chronic health conditions reflect the highly individualized internal challenges of the individual with a chronic health condition. Social concerns, psychological morbidity, physical and activity limitations and frequent absences may pose education challenges that are not easy to quantify in terms of the impact on education. In addition, these concerns are often immune to alteration.

#### *Social concerns of students with chronic health conditions*

The socialization process at school and during childhood and adolescence determines a young person's ability to engage in appropriate social interactions in the future. Socialization is the process through which a child acquires personality and learns the way the society and culture operates. A child spends a significant amount of time at school involved in socialization and its many components. In addition to learning about themselves and others while at school, children also learn how to interact with a variety of people including teachers and other students (Akos, 2000). This process may be interrupted by frequent absences associated with chronic health conditions.

Due to significant absenteeism, children with chronic health conditions face a variety of school-related challenges including difficulties in socialization with peers

(Schuman & La Greca, 1999). Specifically, children with chronic conditions have been noted to worry about being forgotten when they are away from school, teasing and rejection when they return to school, and not “fitting in” with peers after the diagnosis of a chronic illness or a lengthy absence from school (Nash, 1990). There are a variety of ways that socialization may be impacted by illness and treatment, including interruption of normal daily activities due to absences, restrictions on physical activities such as physical education and recess, altered physical appearance such as hair loss or amputation, and lifestyle modifications (Donnelly, Donnelly & Thong, 1987; Nocon, 1991; Padur, Rapoff, Houston, Barnard, Danovsky, Olson, Moore, Vats & Lieberman, 1995).

One of the foremost interruptions of normal daily activities is lengthy or frequent absences from school. Lightfoot et al (1992) reported that young people with chronic illnesses identified absences as leading to frustration regarding missed school work, as well as feelings of isolation from peers. In another study, students reported getting behind peers in schoolwork and difficulty in maintaining relationships with peers as areas of significant concern related to their chronic illness (Bolton, 1997). Similarly, inability to engage in social activities, attend clubs or extracurricular activities, or engage in sports activities has been reported to result in feelings of hopelessness and despair in young people with chronic illness (Lee, Phoenix, Brown & Jackson, 1997). Children who have restrictions on physical activities encounter more peer social difficulties than healthy peers or children with a

diagnosis that does not limit activities (Dorner, 1976, Hurtig & White 1986; Padur et al, 1995).

Social concerns may also arise from changes in body image after the diagnosis of a chronic illness. Alterations in physical appearance may lead to feelings of difference or not being “normal” (Erkolahti, Ilonen, Saarijarvi, 2003). Adolescents with chronic conditions were found to have lower emotional well-being scores, worry more about appearance, dying, school or future work, and have poorer body image (Wolman, Resnick, Harris & Blum, 1994). Of note is the fact that differences were not found between adolescents with visible and invisible conditions (Wolman et al, 1994). Thus, students with diagnoses which have no obvious physical characteristics, such as asthma, diabetes or sickle cell anemia may be at as great of risk of experiencing lower emotional well-being as those who have more visible diagnoses such as cancer or epilepsy.

Socialization at school often occurs at recess, physical education class, or after school activities. Children with chronic health conditions may not be afforded the same opportunities as healthy peers to participate in age-appropriate social activities as a result of illness-related restrictions (Wallander, et al 1998). Restriction on activities may result from various factors including limitations due to the child’s disease status, the advice of health care providers, school policies or concerns for the child’s safety, determination of limitations by the parent, or reluctance on the part of the child to participate in physical activities. Despite the cause, socialization is further compromised by the youngster’s inability to participate in activities shared by

peers (Anthony, Gil & Schanberg, 2003). Participation in extracurricular activities has been found to facilitate learning, academic achievement, self-esteem and social relationships (Eiser & Vance, 2002). Disruption to attendance and participation may result in further challenges to school success.

The benefits of school attendance and participation have been recognized by adults associated with the chronically ill student. Despite challenges to school attendance and participation when a student has a chronic health condition, parents, teachers and health care providers have recognized benefits of school including skill attainment in daily living activities and academic areas, socialization with other children and adults, and respite care for families. School may prove to be a normalizing experience that helps students with chronic health conditions learn to manage issues of socialization and self-concept (Rehm & Rohr, 2002). One result of school attendance may be enhanced achievement at school. Opportunities for socialization comprise one component of school success. Thus, such issues as absenteeism, attendance and participation, which may impact socialization, should be considered in planning for school reentry and reintegration for the student with a chronic health condition.

*Coping and psychological concerns of students with chronic health conditions*

Young people with chronic illnesses have been shown to be at increased risk for psychological morbidity (Bennett, 1994; Lavigne et al, 1992; Noll, Gartstein, Vannatta, Correll & Bukowski & Davies, 1999; Roizen, Blondis, Irwin, Rubinoff, Kieffer & Stein, 1996). Psychological morbidity has been shown to result in school

avoidance, behavior problems, or academic performance problems (Wray, Long, Radley-Smith & Yacoub, 2001).

The number of youngsters with chronic health conditions who experience morbidity in psychological functioning is significant. Compared to healthy peers, psychological maladjustment is 10% to 15% higher among children with chronic conditions (Pless, Roghmann & Haggerty, 1972). Over 40% of students with chronic illnesses are estimated to have problems at school including problems with social adjustment, peer relationships and learning, even when cognitive ability and assessments of achievement remain stable (Wray, et al 2001). Most studies show no indication that disease severity affects adjustment (Wallander & Varni, 1998), nor do studies show that condition type is related to children's psychological adjustment (Thompson & Gallagher (1996). Therefore, youngsters with a variety of chronic health conditions, from those with very visible characteristics to those that are indiscernible, may be at risk for psychological morbidity.

Identifying the psychological impact of a chronic health condition may be complicated by the potential for a delayed exacerbation. Psychological problems may become evident months or years after the onset of a chronic health condition. Problems at school were found in a study of children who had undergone successful heart transplantation. Although it was anticipated that more school related problems would surface shortly after the transplant, it was found that a great number of difficulties were evidenced 3-5 years after the surgery and such problems were not related to the child's functioning before the transplant (Wray et al, 2001).

Recommendations include early intervention and close liaison with educators in an attempt to reduce the child's psychological morbidity and to improve the child's adaptation to the school environment (Wray et al, 2001).

Research has been conducted to determine what types of psychological problems may be associated with chronic health conditions. Several studies have suggested that young people with chronic health conditions evidence more internalizing behaviors (Boekaerts & Roder, 1999; Rosina, Crisp & Steinbeck, 2003; Laufersweiler-Plass, Rudnik-Schoneborn, Zerres, Backes, Lehmkuhl & von Gontard, 2003; LeBovidge, Lavigne, Donenberg & Miller, 2003). Specific internalizing problems that may impact young people with chronic health conditions include depression, anxiety and social withdrawal (Anthony et al, 2003). Post traumatic stress disorder (PTSD), or post traumatic stress symptoms (PTSS) may also be associated with chronic health conditions of childhood (Magal-Vardi, Laor, Toren, Strauss, Wolmer, Bielora, Rechavi & Toren, 2004).

In addition to anxiety, depression, PTSD and PTSS, children may also have more immediate concerns which do not constitute a mental health diagnosis, but which may impact the child's ability to concentrate and focus in the classroom. These concerns include fear of failure, a desire to "fit in", not wanting to be different from peers, and needing to navigate the normal developmental issues of childhood and adolescence (Roemer, 2005). Education challenges may result when students who experience these feelings develop a discomfort with being at school, leading to increased absences or school avoidance behaviors. Like socialization concerns,

psychological morbidity and other concerns of the student should be considered when education planning is undertaken.

*Physical limitations and concerns of students with chronic health conditions*

The physical limitations imposed by a chronic health condition may lead to additional education challenges. Young people who are more physically impaired and, thus, experience significant physical limitations tend to have more adjustment difficulties than those with less impairment (Cadman, Boyle, Szatmari & Offord, 1987; Stein & Jessop, 1984). In addition, children with chronic health conditions who have physical restrictions on activities combined with pain also have associated restricted social activities (Donnelly et al, 1987; Nocon, 1991; Padur et al, 1995). Meijer, Sinnema, Bijstra, Mellenbergh & Wolters (2000) recommend that youngsters with physical restrictions on activities receive extra attention from care givers at school as they are especially vulnerable for problems in social development.

In addition to severity of physical limitations, lethargy and fatigue may affect academic performance of students with chronic health conditions. Several pediatric chronic conditions list lethargy and fatigue as possible side effects of the disease and/or treatment, including leukemia and other cancers, diabetes, asthma, juvenile rheumatoid arthritis, Crohn's disease, AIDS and others (Thies, 1999) [See Appendix for more detailed discussion of some of these specific conditions]. For example, children with rhinitis and snoring have been shown to evidence poorer school performance compared with controls (Fisher, Ghaffari, Davies & Craig, 2005). The impact of fatigue on students with cancer was evidenced in a study of adolescents

who reported “fatigue” to be the concern which resulted in the highest level of distress, and “worry about missing school” was rated as one of the overall worst aspects of having cancer (Hedstrom, Ljungman & von Essen, 2005). Stores, Ellis, Wiggs, Crawford & Thomson (1998) studied children with asthma who were reported to be fatigued and found that they had significantly more disturbed sleep, tended to have more psychological problems, and performed less well on some tests of memory and concentration compared to matched controls. The conclusion was that their poorer performance on the test was attributable to fatigue, as improvement was seen as treatment was changed, resulting in improved sleep. These investigations suggest that fatigue and physical restrictions related to chronic illness may impact school achievement. Thus, school reentry planning should include each of these areas of concern.

*Absenteeism and related concerns of students with chronic health conditions*

Physical limitations, doctors’ visits, fatigue, disease and treatment symptoms, and psychosocial concerns may lead to excessive absenteeism from school. Studies show that 58% of youngsters with chronic health conditions routinely miss school, and 10% are absent for more than 25% of the school year (Lynch, Lewis & Murphy, 1993; Sexson et al, 1993). It has been reported that one in three 7-year-old children with asthma had missed more than 50 days of school due to asthmatic symptoms (Speight, Lee & Hey, 1983) . More recently, it was reported that asthma is the most common chronic disease in children in the U.S. today, and is the leading cause of absenteeism among students, accounting for nearly 20 million lost school days

annually (Telljohann, Dake & Price, 2004). Children with cancer were found to miss an average of 91 days of school in the first year after diagnosis (Charlton, Larcombe, Meller, Morris Jones, Mott, Potton, Tranmer, Walker, 1991).

The challenges imposed by excessive absences on academic progress is considered to be significant, but difficult to measure (Fowler, Johnson & Atkinson, 1985). Several studies have linked high absentee rates to decreased academic performance (Fowler et al 1985; Cook, Schaller & Krischer, 1985; Charlton, Larcombe, Meller, Morris Jones, Mott, Potton, Tranmer, & Walker, 1991; AAP Committee on School Health, 2000). The American Academy of Pediatrics, Committee on School Health (2000) reports that “Absence from school for any period will disrupt the educational process” (pg. 1154). Thus, any absence, beyond that which is anticipated for a typical student, should be recognized as having the potential for resulting in school challenges.

The impact of frequent, brief absences on school achievement is difficult to measure. Most absences experienced by students with chronic health conditions are not long, consecutive periods. Rather, minor medical problems such as a cold, medical appointments and restrictions on activities account for the majority of days missed from school (Cook et al, 1985; Weitzman, 1986). Some studies have suggested that neither the severity of the youngster’s illness nor the total number of days absent is directly linked to the student’s academic achievement. Instead, it is the pattern of absences and the chronicity of the condition itself that results in a situation in which it is difficult for students with chronic illnesses to achieve academic success

(Sexson et al, 1993; Dworkin, 1985). The absence pattern exhibited by students with chronic illnesses is, typically, one of multiple, brief absences comprised of half days, a few hours for a doctor's visit, or a several days in succession, as opposed to longer absences that are likely to be noticed and result in academic support. In addition, it is not uncommon for students with chronic illnesses to spend a small part of each day in the nurse's office, rather than in the classroom, for catheterization, rest periods, blood glucose monitoring, or medication administration (Thies, 1999). As a result, gaps in learning may exist that are not recognized at the time of absence, but which may cause problems as subsequent learning builds on previous requisite skills.

The impact of frequent, even short-term absences is highlighted in the research of Rumelhart & Norman (1980). The author emphasizes that in order for learning to occur, new information must be integrated with what the learner already knows. Although problems can manifest in any subject area, deficits in learning and problems with academic achievement are most likely to occur in subjects that build on previous knowledge, such as math and foreign languages (Sexson et al, 1993). In addition, absences lead to falling behind academically and, subsequently, the need to catch up. Catching up precludes keeping up, which may undermine academic motivation and self-concept (Thies, 1999). Thus, education challenges that result from absences tend to be cumulative and may affect motivation, leading to additional education challenges (Rumelhart et al, 1980).

### *Section Summary*

Students with chronic health conditions may experience social, psychological and physical concerns and absenteeism which present major challenges related to academic success. Understanding the potential needs and concerns of the student with a chronic illness may provide a sound foundation for program planning. Further, such an understanding may be beneficial when integrated with the perceptions of parents, educators, peers and others into a cohesive framework of education programming.

### *Attitudes and Perceptions of Parents of Students with Chronic Illnesses*

Parents' attitudes toward school are important to consider, as they will likely set the tone for the perceptions of others who are involved with the child with a chronic health condition. Parental perception of the increased vulnerability of their child with a chronic health condition is related to increased social anxiety in children and increased school absences (Anthony et al, 2003). Parental coping styles, stress and concerns about their child's well-being may influence how school issues are addressed by others, including the child, educators and peers. Parents' concerns may be viewed in the context of (1) coping and stress of parents, (2) issues related to school reentry, absences and academic concerns, and (3) parents' concerns regarding the safety of their child at school.

### *The impact of parental stress and coping on a child's school reentry*

Parents of children with chronic health conditions experience a variety of stressors and a variety of coping strategies (Katz, 2002). Coping behaviors of parents

may be impacted by many factors including social support, previous coping strategies, socioeconomic status, the family's subjective perception of the illness, adaptation to the child's illness and other factors (Beckman, 1991; Eiser, 1993; Wallander, Varni, Babani, Tweddle Banis, & Wilcox, 1989). In addition, witnessing their child's pain and fear, in combination with parents' own fears about the possible death of their child, may make it difficult for the family to function normally (Haas, 1990; Rolland, 1994; Sloper, 2000). McGrath (2001) reported that the stress of caregivers of children with cancer may be more significant than that of the child himself.

Often, parents may find it overwhelming to put forth the effort required to successfully include their child with a chronic health condition in school. The task of successful school reentry and reintegration requires coordinating school attendance with clinic visits and absences due to illness, staying abreast of class work and homework, and negotiating and implementing necessary treatments at school while dealing with the considerable personal stress of having a child who has a chronic health condition (Sexson & Dingle, 2001). Such coordination requires cooperation between parents, educators and health care providers to reduce or eliminate the education challenges encountered by the student. It may seem easier to parents to keep the child home or to utilize homebound education services, rather than attempting to navigate school reentry (Rehm et al, 2002).

Children with chronic health conditions may be influenced by their parents' concerns or coping style. If the parent is having concerns regarding school reentry,

the child may be similarly influenced. Investigations have shown a strong correlation between a parent's stress and coping style, and the subsequent impact on the child. A study by Hobdell (2004) identified chronic sorrow as a condition that exists in parents of a child with a chronic health condition, and suggests that chronic sorrow is a potential barrier to the parent's ability to understand necessary components of their child's care and diagnosis. Other studies suggest interventions to support maternal coping patterns lead to improved maternal functioning and emotional coping outcomes, which, in turn, result in significantly fewer adjustment problems in the child (Barakat & Linney, 1992; Melnyk, Alpert-Gillis, Feinstein, Crean, Johnson, Fairbanks, Small, Rubenstein, Slota, Corbo-Richert, 2004). The perceptions by parents of increased vulnerability in their child with a chronic health conditions was found to be related to an increase in social anxiety in children (Anthony, Gil & Shanberg, 2003). These findings were consistent, even when controlling for the severity of the disease and the child's age. Further, interactional issues between a mother and child are linked to the child's subsequent physical health (Mantymaa, Puura, Luoma, Salmelin, Davis, Tsiantis, Ispanovic-Radojkovic, Paradisiotou & Tamminen, 2003). These investigations highlight the complex relationship between parents, especially mothers, and their children with chronic health conditions, and suggest the importance of considering parental coping when examining issues that may affect a child's coping strategies, social anxiety and school performance.

Parents often must make decisions regarding school issues that may be influenced by the stress and concern that they experience related to their child's

diagnosis and illness. Separation anxiety, of both the parent and the child, has been studied in children with cancer. Findings suggest that school avoidance may exist when parents are concerned about their child's safety and well-being at school (Lansky & Gendel, 1978; Hollenbeck, Susman, Nannis, Strobe, Hersh, Levine & Pizzo, 1980). If parents are fearful about their child's health condition or the possibility of death, those fears may result in difficulty separating from the child and relinquishing the care of the child to another adult, and, therefore, may impact the child's school experience. In order to ensure that children with chronic illnesses have access to appropriate education opportunities, they must first be present at school and engaged in learning. An understanding of specific parental concerns may provide a better understanding of factors which may influence the child's opportunities for school attendance and achievement.

*Parental concerns regarding school reentry, attendance and academic issues*

All children with chronic health conditions may be at risk of parental over-protectiveness, as the concerns of parents regarding school reentry do not appear to be related to the degree of severity of the child's illness (Anthony et al, 2003). If parents do not have adequate information from health care providers, they may believe that their child is vulnerable, and that school attendance may be overly tiring or lead to illness complications (Shapiro, Dinges, Orne, Bauer, Reilly & Whitehouse 1995). In a study which examined parents' perceptions regarding the unmet needs of their children with chronic illnesses, 91% of parents reported that they would like to obtain more information about the child's condition, its treatment and its long-term

implications (Walker, Epstein, Taylor & Tuttle, 1989). Additional investigation and research of these issues may help determine effective methods to address parental concerns that impact a child's successful school reentry or reintegration.

A lack of parental involvement in decision-making regarding education for the chronically ill student may lead to additional challenges. Parents report that they often lack the opportunity to be involved in the school reentry planning process. Kliebenstein & Broome (2000) report that only 14% of parents of children with chronic health conditions had been involved in a multidisciplinary team to determine educational needs and whether special education services were recommended. In addition, those parents who were involved felt that the process focused on the deficits of the child, rather than on identifying what the youngster had achieved or was capable of achieving. Parents reported that they felt that the negative focus had an impact on how the teacher interacted with their child. Rehm et al (2002) described parents' frustration with schools' failure to follow through with plans set out in the child's IEP. In the same study, other parents described a lack of planning regarding school reentry and the resultant dissatisfaction experienced when their child's needs are unanticipated or unmet upon return to school. Vigilance and on-going advocacy for the educational rights of their child was described by parents as essential. Parents' solutions to these concerns were varied, including frequent visits to the school, on-going communication to advocate for the child's educational rights, and contacting a lawyer (Rehm et al, 2002). Parental involvement in decision making for school reentry may reduce or eliminate some of the concerns.

Some parents may not value the social and developmental benefits of the school experience and may prefer that their child receive homebound education services. However, school attendance may offer needed supports to the child with a chronic health condition. It has been suggested that a positive school experience for a child with a chronic health condition may result in improved self-esteem, provide peer relationships which are positive and fulfilling, and enable the child to develop a sense of mastery and control while decreasing possible emotional trauma that is caused by the disease (Worchel-Prevatt, Heffer, Prevatt, Miner, Young-Saleme, Horgan, Lopez, Rae, Frankel, 1998). The American Academy of Pediatrics (2001) Committee on School Health recommends that “It must be clear that homebound instruction is meant for acute or catastrophic health problems that confine a child or adolescent to home or hospital for a prolonged but defined period of time and is not intended to relieve the school or parent of the responsibility for providing education for the child in the least restrictive environment” (pg. 1154). Thus, a thorough review of the child’s academic and social needs should be conducted regularly, and decisions about where to deliver services made in light of that review.

*Parental concerns regarding physical and psychosocial well-being at school*

Parents often report apprehension about the safety of their child at school. Two areas of concern expressed by parents include lack of effective communication between parents and school staff and educators’ inadequate information about chronic illness in childhood. In addition, parents believe that minimal communication occurs between themselves and educators due to lack of time, resources and ancillary staff to

support teachers (Kliebenstein et al, 2000). School reentry and reintegration requires constant attention from parents of students with chronic health conditions, as well as on-going communication between parents, educators and health care providers (Thies, 1999). Parents in one study felt that they should be the person to instruct school personnel about the care needed by their child (Thies, 1999). However, 91% of the parents in another investigation (Perrin, Lewkowica & Young, 2000) reported that they felt that they did not know enough about their child's diagnosis, treatment and prognosis and, therefore, would like their child's physician to provide them with more information on those topics. Some researchers believe that parents acting as a conduit of information between health care providers and educators interfered with effective communication between the two professions (Mukherjee, Lightfoot & Sloper 2002). The investigators suggested that inaccurate information was presented by parents to teachers. In light of these conflicting results, additional investigations may be indicated to determine the most effective methods for sharing diagnosis and treatment information with educators.

Concern about physical injury and the possibility of contracting an infection at school are additional concerns of some parents of students with chronic illnesses. Parents in one study described situations where their child was excluded from school due to the management of his/her illness or concern about physical harm (Notaras et al, 2002). Rehm et al (2002) found that parental anxiety about physical well-being intensified as the length of the child's school day increased from early childhood to elementary school settings. Due to multiple teachers, parents of junior and senior

high students felt an increased sense of vulnerability for their child when they entered secondary school. They were concerned that teachers would not know what interventions were necessary in an emergency situation (Kliebenstein et al, 2000).

In addition to concern for their child's physical well-being, parents were also worried about their child's psychosocial well-being at school. Teasing, rejection and isolation of their child with a chronic health condition was a concern for parents in several studies. Parents surveyed by Rehm et al (2002) expressed concern about teasing and isolation from classmates, especially as children grew older. Parents reported that these problems were more significant when teachers did not advocate for the child or did not make concerted efforts to include children with chronic health conditions in the classroom and on the playground. Some parents expressed concern that exclusion from school activities, segregation and ridicule by other students and education personnel create a learning environment that is detrimental to their child's growth and success (Turner-Henson, Holaday, Corser, Ogletree & Swan, 1994).

Parents are likely to be more concerned about their child's safety at school if they do not have confidence in the knowledge of those providing care for their child. Evidence suggests that many parents feel that educators are not knowledgeable about chronic health conditions in children and, therefore, do not have the skills to adequately care for their child at school. An investigation of 161 parents of children with chronic illnesses reported that 86% of the parents surveyed indicated that the teacher or teacher's aide working with their child needed in-service education about chronic illnesses and the education issues associated with them (Notaras, Keating,

Smith, Cordwell, Cotterwell and Nunn, 2002). Further, 56% of those parents did not feel that their child's teacher had the information necessary to care for their child during the school day. Similarly, Kliebenstein et al (2000) described the school setting as continuing to pose major barriers for students with chronic illnesses due to the fact that school personnel are not well informed about chronic illness, receive little or no training, and feel unprepared to deal with children in the classroom who have chronic health conditions. Some parents go as far as to say that their child with a chronic health condition is a victim of discrimination at school. A study of parents of school-aged children with chronic conditions identified the perception of parents that barriers to effective education for their child were "human made barriers" and not the child's chronic illness itself. In the same study, parents described their children's exclusion from school activities, segregation and ridicule by students and school personnel. Mothers felt that their children were the victims of discrimination evolving from the school system, the child's peer group, and community and governing institutions (Turner-Henson et al, 1994). Despite the fact that a free and appropriate education is mandated by federal law for all students, it is suggested that many youngsters with chronic health conditions are still the victims of educational discrimination (Ratliffe, Harrigan, Haley, Tse and Olson, 2002) and experience the resultant challenges to receiving an appropriate education. The concerns of parents regarding school may reduce education opportunities for students with chronic illness.

### *Summary*

There are many issues of concern that may impact parents' perceptions and subsequent decisions related to school reentry, reintegration and attendance of their child with a chronic health condition. Parental stress and coping, perceptions regarding the importance of school attendance for their child, and concerns about physical and psychosocial well-being are among some of the issues that may impact parents' decisions related to school attendance. The school-related attitudes encountered by parents of children with chronic illness are of great importance, as they will, ultimately, impact perceptions and decisions of the child, educators and others. Consideration of parental perceptions and concerns are important in the attempt to ensure that access to equitable education opportunities are afforded the student with a chronic health condition.

### *Attitudes and Perceptions of the Education Community*

Students with chronic health conditions are at the intersection of education and health care, and possess both health and education needs at school. These separate, but related, needs are not always well integrated. Although educators acknowledge that good health is a prerequisite to learning, there appears to be a lack of understanding of the connection between good health and school progress. The National Action Plan for Comprehensive School Health Education, developed by representatives of over 40 health, education, and social service organizations, found that professionals viewed education and health as independent systems, although they determined that healthy children learn better (Symons, Cinelli, James & Groff, 1997).

There is often a lack of awareness among educators of the school related implications associated with chronic health conditions (Thies, 1999). The perspectives and attitudes of teachers, school administrators responsible for final decision making regarding programming and planning for students with chronic health conditions, and legislators who impact policy regarding educational rights of young people with chronic health conditions may create or intensify the challenges faced by this population of students. Providing these individuals with opportunities to increase knowledge regarding the education needs of students with chronic health conditions may lead to better access to appropriate education services.

*Teachers' concerns regarding need for information*

Access to appropriate education services and supports may be negatively impacted when educators lack sufficient knowledge about the learning needs of the student with a chronic health conditions (McCarthy, Williams & Eidahl, 1996; Harrison, Faircloth & Yaryan, 1995; Krier, 1993; Lynch et al, 1993). It is reported that, during their careers, teachers work with many children with serious health conditions and that these professionals are asked to perform health care tasks in the classroom that they feel unprepared to do. The teachers report receiving inadequate training, and express a desire for further education to assist them in dealing with students' needs (Krier, 1993). A survey of 147 experienced teachers indicated that they felt they did not have adequate knowledge about pediatric chronic illnesses, and that they were not prepared to deal with medical emergencies or the repercussions for the child's peers (Eiser & Town, 1987). Further, although 76% of teachers indicated

that they had taught students with chronic health conditions during their career, only 38% reported having coursework related to the needs of students with chronic health conditions and only 7% felt that their certification requirements adequately prepared them to work with this population of learners. Knowledge and preparation about health conditions was cited as the most significant concern of teachers in that study (Johnson, Lubker & Fowler, 1988). Seventy-five percent of teachers in another investigation believe it is important and should be mandatory to increase awareness of chronic illness in the school setting (Brook & Galili, 2001). Educators and school nurses have cited the need for additional information about chronic illness in students and a desire for effective communication with health care providers. Both teachers and school nurses report similar needs: information dissemination, resource integration and communication (Esperat, Moss, Roberts, Kerr & Green, 1999). Such information would enable the school nurse to address health care needs and the teacher to focus on the learner's education needs.

Bowen (1996) investigated whether preservice or inservice training existed that provided information to prepare teachers to address the needs of students with chronic health conditions, or better enable teachers to know how to respond to medical emergencies. No such staff development program was found to exist, but teachers in the investigation indicated that they would appreciate regular updates on the issues related to students with chronic health conditions. In the same study, teachers also reported a lack of available training on the needs of students with chronic health conditions.

Teachers and health care providers agree that there is the need for additional information for educators about students with chronic health conditions. However, there is not consensus regarding how, or by whom, this information should be provided. Often, the school nurse is expected to provide information to teachers about a child's chronic health condition (McCarthy et al, 1996). Although the school nurse may be an appropriate source for information in some instances, there may be other circumstances in which the educator needs more comprehensive information than the school nurse is able to provide, either due to inadequate staffing or the insufficient knowledge. If staffing issues are inadequate, the school nurse may not have time to educate school staff about a specific child's illness. For example, nationally there is one school nurse per 1,500 children who is responsible for addressing acute, chronic, episodic, emergency health care needs, as well as record maintenance, health promotion and health screenings (Barrett, 2000). Some schools do not have a nurse or have limited access to a nurse who is shared between schools. The National Association of School Nurses recommends one school nurse for every 750 students in the general school population, a 1:225 ratio for mainstreamed students and a 1:125 ratio for students with severe disabilities (Proctor, Lordi & Zaiger, 1993).

Also of note are findings that indicate that nurses' information about specific aspects of pediatric chronic illness may not be adequate. When surveyed about their knowledge of asthma, school nurses indicated that most of their information resulted from communication with parents. However, they also acknowledged that obtaining such information from parents was considered to be a major challenge (Calabrese,

Nanda, Winklestein, Quartay & Rand, 1999). In addition, school nurses may or may not have had recent experience in an acute care, intensive care or clinic setting. If they have not had recent experience, they may not have the knowledge necessary to educate the educators (Rehm et al, 2002). The role of the school nurse focuses on the provision of routine care and screening, record keeping, attending to the demands of school nursing, and providing care to a wide variety of children, including those with typical health and development and children with a wide variety of chronic conditions (Rehm et al, 2002). School nurses may have limited personal experience or knowledge about chronic health conditions of childhood

Finally, school nurses are not educators and, therefore, are not able to support teachers in the development of IEPs or other plans that would address the educational needs of students with chronic health conditions. Nurses sometimes do not feel that they have adequate skills or sufficient preparation to evaluate a student's eligibility for special services and, thus are not comfortable participating in special education meetings (Koenning, Todaro, Benjamin, Curry, Spraul & Marer, 1995). Enabling the nurse to address health care issues and the teacher to focus on education may result in improved access to appropriate education programming.

Educators, parents, and health care professionals have each indicated that they do not believe teachers have enough information regarding the needs of students with chronic illness. Provision of additional training may enable educators to understand the various factors that impact learning when a child has a chronic health condition and, therefore, be better prepared to address the learning needs of students with

chronic health conditions. Education challenges may be reduced, and the needs of students with chronic health conditions can be more addressed in a more comprehensive manner by combining the expertise of all service providers.

*Educators' concerns regarding addressing students' needs*

Additional education challenges for students with chronic health conditions may result when teachers are concerned about the ill child's or classmates' well-being at school. Knowledge about chronic conditions may result in enabling teachers to focus on the student's education needs, rather than feeling overwhelmed by unfamiliar medical and health care matters. In addition, addressing the demands of teaching which are increasingly focused on student achievement and adequate yearly progress may enable the teacher to address all learners' needs, rather than feeling overwhelmed by the needs of a single student. In contrast, introducing a student with a poorly understood, demanding health condition may result in failure for all concerned.

Investigations have suggested that educators' concerns about the education needs of the student with a chronic health condition are related school reentry and subsequent reintegration. Kliebenstein et al (2000) found five themes that exemplified the concerns of educators in a comprehensive manner. The first, "sharing the news", evidenced educators desire to have on-going communication with parents and hospital staff regarding a child's physical status. The second theme, "making the transition", focuses on the school reentry process after diagnosis or an exacerbation of the chronic health condition. Educators highlighted the lack of

information from health care providers or parents during the period of “sharing the news” and “making the transition”. In the study, several teachers responded, “We are not nurses, we need to focus on the educational and social needs of the child” (pg. 581), and expressed frustration when they felt unable to address the needs of the child with a chronic health condition, as well as the needs of other students in their class. The third theme, “watching the child”, elicited similar concerns to the first two themes; a response from educators that they were seldom fully informed about the needs of the child before the child returned to school or when there were changes in the child’s health status. The fourth theme, “teaching the teachers”, elicited the recurrent theme from educators of the need for adequate and on-going information. The majority of educators expressed the desire to have in-services about the illnesses their students had as soon as possible after the child’s diagnosis, and that on-going in-services about common chronic illnesses of childhood would allow education professionals to gain and maintain knowledge. The final theme, “working with the child”, reflected educators’ expressions of concern that they may “overmother” the child, and that they did not expect as much work from a child with a chronic health condition as they did from other students.

Prolonged or frequent absences were identified as another area of concern when working with a child with a chronic health condition. Educators spoke of the difficulty in helping the child “catch up” upon their return to school, and the subsequent challenge of “keeping up” while working on previously missed work. Knowing how much they should “push” students with chronic health conditions to

complete assignments was another common concern among educators. Finally, all educators felt that they were poorly prepared to deal with the death of a child in their class (Kliebenstein et al, 2000). Concerns included their personal response to the child's death, as well as uncertainty about how to help the child's classmates deal with the death of a friend. Other results yielded similar findings, indicating that teachers were most concerned about unanticipated medical emergencies, increased absence rates and how to access information about students with chronic health conditions (McCarthy, et al 1996). For some educators, academic issues or the impact on peers were not reported as problematic but, rather they cited the personal impact of having a student with a chronic health condition in the classroom (Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004). The extra burdens on the teacher, additional time and attention required to care for the child, and feeling personally at risk or uncomfortable having a student with a chronic health condition in the classroom were identified as the greatest source of concern among a group of 384 educators. Over half of the teachers in this study expressed the need for additional training and most indicated that they had not received training about chronic conditions of childhood during their education nor do they have the opportunity for training in in-service or postgraduate venues (Olson et al, 2004). Some teachers decided to limit their knowledge of certain skills, such as resuscitation, in order to limit their responsibility or liability in situations in which they were uncomfortable (Notares et al, 2002). Addressing educators' concerns will serve to better enable teachers to go about the business of teaching the child.

Educators may be unaware of diagnoses that may result in serious or life-threatening exacerbations at school. For example, when surveyed about their comfort with specific chronic health conditions, educators expressed the diagnoses that made them feel the most personally threatened were epilepsy or congenital heart disease (Olson et al, 2004). Asthma and diabetes mellitus were perceived as diagnoses that had little impact on the child, their peers and the teacher. The authors expressed surprise at these findings, as both asthma and diabetes mellitus are common pediatric conditions that have the potential to greatly impact the child's life and which can result in life-threatening acute events in school. They concluded that the lack of concern about these asthma and diabetes may suggest ignorance of the life-threatening potential associated with those diagnoses. There is a fine line in ensuring that educators have adequate information about chronic illnesses of childhood, while ensuring that they are empowered to teach the student, rather than feel that they must treat the child. Providing accurate information about disease symptoms and support may serve to remove the mystery and fear that educators report having when a student comes to school with a chronic illness. The result may be improved access to appropriate education services and supports.

*Educators' concerns regarding identifying students with chronic health conditions*

One of the greatest challenges to an appropriate education for children with chronic health conditions is the difficulty educators often have in identifying these children. This group of students often have invisible diagnoses and, as a result, may not readily

identify itself as a population of learners in need of education intervention (Thies, 1999). Parents and children may not come forward with information about the diagnosis, either due to the desire for confidentiality or because they do not perceive the diagnosis as having education relevant components (Thies, 1999). Educators express concern regarding parents who intentionally choose to keep information from them, and indicate that they feel more comfortable when able to speak with health care providers directly (Kliebenstein et al, 2000). Those educators who have the opportunity to meet with parents and health care providers prior to the student's reentry describe a process that is smoother and less stressful to all (Kliebenstein et al, 2000). In addition to relevant health information, in many medical settings youngsters with chronic health conditions are referred to psychologists for an evaluation of concomitant cognitive impairments that warrant further evaluation and recommendations to other health care providers (Kazak, 1989). However, information about these referrals may not reach the school setting.

In order to be eligible for special education support, the IDEA requires that a child's health condition "adversely affects academic performance" (IDEA, 1997). Guidelines for defining what constitutes an adverse effect on academic performance remain unclear and ambiguous, and some effects of disease, treatment, or other factors may take months or years to become evident (Thies, 1999). Thus, a child with a chronic health condition may not be recognized, referred or identified as a student with academic or learning needs resulting from the health condition. Educational assessment of learners with chronic health conditions is a complex process, which

warrants careful selection of measurements, both general and specific to the child's diagnosis, to provide a comprehensive picture of the student's abilities and areas of need. There are multiple testing instruments, used to assess educational functioning in children, which are well standardized. However, the standardization is based on physically healthy children or for clinical populations with psychopathology (LaGreca, 1994; Thompson et al, 1996). Typically, there is no normative data for children with chronic health conditions. In addition, there are situations where assessment is needed that encompasses areas not covered by standardized measures, and does not answer the questions for which the child was referred for evaluation (Kupst, 1999). Kupst suggests that standardized measures may be necessary, but not sufficient, and compares relying on data from the Weschler Intelligence Scale for Children (WISC) and the Child Behavior Check List (CBCL) when assessing learners with chronic health conditions, as the equivalent of a Type II error: One may conclude that there are no cognitive or behavioral problems when there may be more subtle difficulties present for which the measures are not sufficiently sensitive to detect.

Thus, the identification of students with chronic health conditions which may impact learning should be individualized and on-going. The health status of the child may change over time, or the exacerbation of learning problems may be evidenced months or years after the diagnosis or treatment of the disease. The reference in the IDEA to a health condition which "adversely affects academic performance" is not

clearly defined by the law (IDEA, 1997). In the identification of a student who is “other health impaired”, this qualification criterion warrants careful consideration.

*Concerns of school administrators*

The research regarding the perceptions and attitudes of school administrators - from building principals to special education directors to superintendents – is extremely limited. However, the beliefs of this population may be important to examine, as they make programming and placement decisions, appropriate funding for various needs, and are instrumental in policy development related to the education needs of students with chronic health conditions. Thus, education challenges may be significantly impacted, either positively or negatively, by the input of school administrators.

Eligibility for special education services is generally limited due to limited finances and personnel in school districts (Notares et al, 2002). Such strains are exacerbated as schools and districts work to determine ways to serve students whose chronic conditions are more severe and who, therefore, need more sophisticated and expensive health-related supports to enable them to attend school. For example, the cost of educating a student who requires mechanical ventilation at school is impacted by the need to have special bus or ambulance transportation to and from school and an individual nurse to provide care for the student (Gilgoff & Gilgoff, 2003). School districts admit that funding issues comprise a primary challenge for addressing the educational needs of students with chronic health conditions (Lynch et al, 1993).

School boards, administrators and legal counsel are faced with determining policies that impact children with chronic health conditions. One such issue is the districts legal responsibility to maintaining life in a student who is terminally ill, and whether or not the school can honor out-of-hospital Do Not Attempt Resuscitation (DNAR) policies at school. Despite medical advances, there are some children living with life-limiting diagnoses who may want to attend school at end-of-life without the additional concern about attempted resuscitation in the event of cardiopulmonary arrest at school. Eighty percent of school districts sampled in 2004 did not have policies related to DNARs (Kimberly, Forte, Carroll & Feudtner, 2004). The survey found that many school district policies are in conflict with state laws that govern DNARs at school. Thus, families are faced with the difficult decision of whether to send a child to school when the child may be harmed by cardiopulmonary resuscitative (CPR) efforts. School boards, administrators and school district legal counsels are also challenged by determining how to adhere to federal law that guarantees all students the right to an education in the least restrictive environment, while adhering to state laws and local policies that do not honor the DNAR request (Kimberly et al, 2004). The decisions of how to proceed regarding DNAR issues in public schools may determine whether or not a student with a terminal illness or severe disabilities has access to education services in school.

Educators, administrators and school boards must consider a variety of issues that impact all students within the school. The challenges of students with chronic health conditions may be better addressed if necessary information is provided to

education professionals and if on-going communication ensues among all parties regarding the needs of the student.

*The concerns of student peers*

Peers play a very important role in the emotional and social development of all youngsters, and take on a special significance in the life of a child with a chronic health condition (La Greca, Auslander, Greco, Spetter, Fisher & Santiago, 1995). The support of friends can lessen the impact of stressful events, such as coping with unpleasant medical procedures or adjusting to a chronic illness (La Greca & Prinstein, 1999). Conversely, children with chronic health conditions sometimes forgo medical treatments or recommendations of health care providers due to their desire to “fit in” (Christian & D’Auria, 1997).

Research suggests that, although young people with chronic illnesses express much concern about their peer relationships, youngsters with chronic illnesses such as asthma, cancer and diabetes generally have not been found to have more significant difficulties with social relationships than age-mates (Noll, Bukowski, Davies, Koontz & Kulkarni, 1993; Noll, Bukowski, Rogosch, Leroy & Kulkarni, 1990; Noll, LeRoy, Bukowski, Rogosch, Kulkarni, 1991; Noll, Vannatta, Koontz, Kalinyak, Bukowski, Davies 1996; Noll, Garstein, Vannatta, Correll, Bukowski, Davies 1999). However, those diagnoses that are associated with cognitive impairments, such as HIV, sickle cell anemia, epilepsy, spina bifida, cerebral palsy, and cancers that involve the brain, do present significant challenges for peer relations. This may be due to cognitive deficits that impact socialization, more significant degrees of physical handicaps

associated with those diagnoses, or limited opportunities for socialization for those young people in special education classes (Nassau & Drotar, 1997). Several studies have suggested that friends may play an important role in aiding the child with a chronic health condition in adaptation to a chronic illness (Wallander & Varni, 1989; Varni, Katz, Colegrove & Dolgin, 1994). Better adaptation to a chronic illness may result in increased school attendance and reduction of education challenges, leading to improved education outcomes.

Peers may be more readily able to support the child with a chronic health condition when they are knowledgeable about their friend's illness (Sherman, Bonanno, Wiener & Battles, 2000). Sharing intimate concerns, worries and fears is an essential component of friendship (La Greca & Prinstein, 1999; La Greca, 1990). Not only might the child with a chronic health condition miss an important source of support if they choose not to share information about their diagnosis, but keeping the secret may negatively impact close friendships (Brown & Demaio, 1992). Sherman et al (2000) found that young people with HIV who shared their diagnosis with friends had a significant increase in immune functioning as compared to those patients who did not disclose similar information. This suggests that peer understanding and support may lead to improved socialization and, possibly, even enhanced physical well-being.

Further research may be needed in order to determine, however, which young people with what specific diagnoses may benefit from disclosing information about their diagnoses with classmates and friends. Studies suggest that young people with

visible conditions may be rejected by peers when their diagnosis is made known. For example, Bell & Morgan (2000) found that giving classmates medical information about obesity resulted in classmates being less likely to later share academic activities with the child with obesity. After a lesson that explained the scientific and biologic bases of obesity, obese children were chosen by classmates less often for group academic activities. The study included children in grades 3-6 and found that the older children (grades 5-6) were less likely to choose the peer with obesity than younger (grades 3-4) children. Similar findings were presented in studies of young people with epilepsy, diabetes and Tourette Syndrome (Friedrich, Morgan & Devine, 1996; Potter & Roberts, 1984). It has been suggested that medical information about the child's condition may result in peers not holding the child personally responsible for the condition, but did not change how the peers liked the child (Bell et al, 2000). In addition, older children may have experienced more stigma related to the child's condition, resulting in less tolerance even if they became aware of the causative factors of the disability.

#### *Section Summary*

Further study is indicated to determine which diagnoses, behaviors or other factors may be associated with positive and negative peer reactions to disclosure regarding a youngster's diagnosis. In addition, studies of healthy peers' concerns, which may impact relationships with a friend with a chronic illness, are recommended. At this point, the issues that worry or cause discomfort to peers, in regard to their friend's chronic illness, remain unknown. Better understanding of

these issues may result in improved relationship between children with chronic health conditions and their peers, and the subsequent reduction of education challenges resulting from peer related issues.

### Summary

Children with chronic health conditions face a number of school-related challenges that may impede their ability to enjoy an appropriate education experience. The challenges are based in issues such as the perceptions of the child, parents, peers and educators as well as in system components of K-12 education including identification of students with special needs, eligibility determination for education support, and funding and policy determinations. These challenges may be evidenced anywhere along the education continuum including at the time of diagnosis, school reentry, referral for evaluation, identification for eligibility for education support and throughout the ensuing years.

A variety of strategies may effect positive change in reducing the education challenges of youngsters with chronic health conditions. In a broad context, improved outcomes may be realized by providing psychosocial support for the young person with a chronic health condition and their family members and by increasing opportunities for communication between student, parents, educators and health care providers. In addition, ensuring that adequate resources are available to educators for knowledge attainment regarding this unique population of learners is recommended.

The education ramifications of these challenges are great: the mean national achievement score for students with chronic health conditions was found to be at the

51<sup>st</sup> percentile, compared with the 63rd percentile for North Carolina state's sixth graders (Fowler et al, 1985). Further, 35% of high school students with chronic illnesses were found to be failing in school (Valdes, Williamson & Wanger, 1990). Additional research is necessary to determine evidence-based policies that can be developed to begin to address these challenges.

Success in school for students with chronic health conditions is difficult to achieve and poses challenges in identification. Symptoms and side effects of the diagnosis may result in challenges to school success. This is complicated by the difficulty in identifying what factors may be impacting a student who is dealing with a wide variety of social, emotional, psychological and physiologic side effects of the diagnosis. Evaluation may be made difficult by the child's physical limitations, absence from school, side effects of medication and many other potential factors. Therefore, assessment should be frequent and on-going. A student's learning behaviors should not be considered to be stagnant, and reevaluation should be conducted throughout the learner's school career. Finally, effective and frequent communication between the student, parents, educators and health care providers is a requisite component of ensuring that the student's needs are addressed. The focus on a comprehensive and cohesive team approach may enable students with chronic health conditions to realize more success in academic endeavors in the future.

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## **Appendix XII: Comprehensive Exam III**

Telehealth: Past, Present and Future

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A written comprehensive paper completed as partial fulfillment of the Ph.D.  
requirement

## Introduction

The “house call” by the family physician is a thing of the past. In contrast, patients, especially those living in rural areas, often travel many miles to see the family doctor, and hundreds of miles to see a specialist, typically located in areas of high population concentration (Brown, 1995). Telemedicine provides an alternative to traveling long distances to seek medical care. The early vision of telemedicine continues to be the same today as it has always been: to overcome the huge liability of distance in patient care (Merrell, 2004). For individuals living in rural communities telemedicine often ensures access to health related services that otherwise would not exist.

Telemedicine is the use of telecommunications technology for medical diagnosis and patient care (Currell, Urquhart, Wainwright & Lewis, 2000). This method of health care delivery affords the opportunity to take health care back to rural communities, in terms of direct health care, consultation and continuing education for rural health care providers. As a result of telemedicine, it is predicted that, in the future, patients in remote areas may not be at a disadvantage resulting from living in areas with physician shortages (Myers, 2003).

The ability to use telemedicine technology, in a variety of ways, to link rural communities to health care resources in larger metropolitan areas is the focus of this discussion. Current advantages to using telemedicine include greater accessibility to health care services for patients, and increased opportunities for staff development for professionals in health care. However, the literature on staff development has been

limited to professionals in health care and medicine. Children and adolescents with chronic health conditions or special health care needs spend a great deal of their day in the school setting. Existing telemedicine technology may enable educators to have access to information necessary for planning and programming for these students' education needs. The present discussion will address the potential utilization of existing telemedicine technology to link health care providers with educators serving students with chronic health conditions. Such collaboration would provide needed information to educators regarding chronic health conditions of childhood and the potential impact on learning. In addition, an interdisciplinary approach would afford an opportunity to address both health and education needs of students with chronic health conditions in the school setting.

Telemedicine is not a delivery system which enjoys familiarity with most educators. Therefore, this discussion will offer a comprehensive definition of telemedicine and telehealth, an overview of the history of the delivery system, current trends and issues, future directions and applications that have been used in pediatrics. An additional focus will be on the use of telemedicine technology in distance learning and continuing education applications in health care disciplines. Although telemedicine technology has been used to provide continuing education opportunities for health care providers, the same is not true for educators. A significant opportunity presents to use existing telemedicine technology to offer needed staff development and in-service opportunities to educators of students with chronic and special health care needs. The final section of this discussion will address the potential benefits for

youngsters with chronic and special health conditions, and the collaborative possibilities between education and health care.

### The Definition of Telemedicine and Telehealth

The prefix, tele, is from the Greek *telos* and implies distance (McLaren & Ball, 1995). Telemedicine is defined as providing health care services, at a distance, by utilizing information and telecommunication technologies. The exchange of information for diagnosis, treatment and prevention of disease and injury, research and evaluation, and for the continuing education of health care providers constitute additional possibilities as components of telemedicine (Scalvini, Vitacca, Paletta, Giordano & Balbi, 2004). Reid (1996) expands the definition by adding that telemedicine services take place across geographic, time, social and cultural barriers. A committee of the Institute of Medicine considered at least 10 definitions of telemedicine before settling upon “the use of electronic information and communications technologies to provide and support health care when distance separates the participants” (Field, 1996).

Although often used interchangeably, there are differences between the definitions of telemedicine and telehealth. Telehealth is an umbrella term, referring to all services utilizing telemedicine equipment and offered at a distance, one of which is clinical care. Telemedicine is a component of telehealth and refers to the use of telecommunications and information technologies for the provision and support of clinical care to individuals at a distance and the transmission of information needed to provide that care. The U.S. Department of Health Resources

and Services Administration (HRSA) established the Office for the Advancement of Telehealth (OAT) to serve as a leader in telehealth, and to emphasize HRSA's telehealth activities and to work toward more comprehensive adoption of advanced in the provision of health care services and education. HRSA defines telehealth as

“the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration” (Office for Advancement of Telehealth, 2005).

Thus, the term telehealth will be used in this writing, unless a specific telemedicine application is being discussed.

Defining telemedicine and telehealth may be complicated by the various methods used in communicating over a distance. For example, telemedicine may include a variety of equipment including telephone, radio, facsimile, modem, and video (Grigsby & Sanders, 1998). Further, it may occur in real time, as in the case of interactive video, or it may occur asynchronously, as in the transmission of text or graphic data, still images, video clips or full-motion video (Grigsby et al, 1998). Although telemedicine includes a broad range of services and technologies, all telecommunication applications share the common characteristic of utilizing some form of electronic transfer of information. Most telemedicine interactions today use narrow and high bandwidths for information transmission, broadcast video, compressed video, full motion video and virtual reality (Myers, 2003). There are two basic forms of technology which comprise most of telemedicine applications: store and forward and two-way interactive televideo. These are sometimes referred to as

asynchronous and synchronous forms of telemedicine. Store and forward is often used for transferring information from one location to another. For example, a digital image may be taken using a digital camera, (“stored”) and then sent (“forwarded”) by computer to a physician in another location (Brown, 1996). Typical uses may be for teleradiologic images (x-rays, CT scans, MRIs), sending images of skin lesions to a dermatologist or sending images of pathology slides to the pathologist (Perednia & Allen, 1995). This is typically used for non-emergent situations, when a diagnosis or consultation may be completed in 1-2 days and information sent back to the referring physician (Brown, 1996). Thus, the methodology and equipment employed in telehealth endeavors may include a wide variety of options.

The other widely used technology is used when a “face-to-face” consultation is necessary. Telemedicine consultations using two-way interactive televideo connect two sites, often separated by miles, with one another. The patient and sometimes their provider, a nurse practitioner or telemedicine coordinator, are present at the one site, often in a rural area. The connection is made with a specialist who is often at an urban medical center. Videoconferencing equipment at both locations allow a “real-time”, or live, consultation to take place. In addition, there are also peripheral devices which can be attached to computers to aid in an examination of the patient. For example, an otoscope allows a physician to “see” inside a patient's ear; a stethoscope allows the consulting physician to hear the patient's heartbeat, or a camera can project images of skin lesions (Brown, 1996).

It is not unusual for health care professionals involved in telemedicine to use a combination of applications and equipment. Store-and-forward, interactive televideo, audio and video or digital still images may be combined to provide patient care in telemedicine. Using wireless technology in ambulances enables the provision of mobile telemedicine services (Brown, 1996). Interactive televideo is the technology that is often used to provide continuing education opportunities for health care professionals.

Thus, the various technologies, equipment and uses of telemedicine present challenges in providing a singular definition of this delivery method. Focusing on specific uses of equipment or applications may result in difficulty in understanding the variety of ways telemedicine and telehealth may be incorporated to support patients and their needs. Rather, embracing the broad definition may provide a better overall understanding of telemedicine and telehealth and provide the opportunity to examine the possibilities for future expansion of services utilizing telehealth technology.

### The History of Telemedicine and Telehealth

The history of the field of telemedicine and telehealth is relatively brief and only recently has it been recorded in writing (Merrell, 2004). The exact origin of the field is unknown. Zundel (1996) speculates that the concept of sharing medical information may have originated centuries ago. Information about war and famine was transmitted across Europe by bonfires and heliographs, and it is possible that information about bubonic plague was shared in the same manner. It is known that,

during the Civil War, medical supplies were ordered and casualty lists were shared by telegraph. Thus, although the terms “telemedicine” and “telehealth” may be in their infancy, sharing health information over distances is an ancient concept.

Historically, telehealth has utilized a variety of technologies and applications as health care information has been shared over distance. The rapidly advancing field of technology has created an ever-changing picture of telehealth. This section will examine several of the factors that have given way to what constitutes telemedicine and telehealth today. The pioneers in the field helped shape the current components of telemedicine and telehealth. Further, such factors as space exploration, the invention of television, government funding of telemedicine demonstration projects and additional factors have contributed to the parameters of the delivery method. An examination of the changing technology and of the manner in which this young field has emerged may enable a conceptualization of the future of telehealth endeavors and ways to expand services to include staff development for educators of students with chronic and special health care needs.

#### *The early years of telemedicine*

Prior to the existence of the more sophisticated interactive video technology that is currently used for telemedicine, medical information was shared over distances by such methods as telephone, radio and facsimile. Physicians were among the early adopters of the telephone, for sharing patient information, in the early 1900s (Zundel, 1996). Radio communication was established by World War I and was used to transmit medical information to remote areas like Australia and Alaska. Facsimile

transmission of medical information has been utilized since the 1980s for sharing medical information (Doarn, Ferguson and Nicogossian, 1996) and continues as a component of telemedicine today.

The first generation of telemedicine using video conferencing was limited to the specific applications of telecardiology, telepsychiatry and teleradiology. Experiments were conducted in the 1910s using radio telecardiology. In the 1920s, telephone-mediated telestethoscopy was used on a limited basis (CTEC, 2005). Early reported telemedicine applications are reported in the late 1950s with microwave-mediated rural telepsychiatry and cable-mediated teleradiology. In the late 1980s, point-to-point interactive videoconferencing was possible from and to anywhere that had access to T1, fractional T1, or ISDN lines. Since the mid-1990s, telemedicine technology has become more prevalent and programs have become common throughout the world (CTEC, 2005). Currently, telemedicine applications occur in nearly every specialty and area of healthcare including radiology, pathology, continuing education, homecare, emergency care, mental health, rehabilitation, cardiac monitoring, and every medical and surgical specialty (CTEC, 2005).

#### *Pioneers of telemedicine applications*

The evolution of telemedicine has been fueled by health care professionals who use the technology. There were early adopters of telemedicine technology who continue to use telemedicine applications, and there were also later adopters who have recently included telemedicine applications to their practice. Throughout the history of telemedicine, some clinical specialties have used telemedicine more than

others, but almost every specialty has used it in some way (Grigsby et al, 1998). Among the most actively involved clinical specialists have been cardiologists, dermatologists and psychiatrists. Grigsby et al (1998) describe a “founder’s effect” suggesting that physicians in these specialty areas continue to utilize telemedicine significantly since these subspecialties were among the first clinicians to practice using telemedicine. As telemedicine emerged, the quest was to ensure greater clarity of images and faster transmission (Zundel, 1996). Significant advances in telemedicine resulted from research in the space program, the invention of television and federal support of telemedicine research.

#### *The space program*

First, telemetry research and development was undertaken in the 1950s by the National Aeronautics and Space Administration (NASA) as a component of the manned space-flight program (Zundel, 1996). NASA’s scientists, engineers and contractors developed biomedical telemetry and telecommunication systems designed to monitor the health and physical status of astronauts. Physicians on earth were, therefore, able to monitor the physiological functions of astronauts in space. Initial uses of telemetry in space flight were to monitor effects of launch, flight, zero gravity and reentry on the human body (Doarn et al, 1996). The incorporation of telemedicine enabled the constant monitoring of other physiological functions such as heart rate, blood pressure, respiratory rate and body temperature. As flight times extended, scientists utilized telemedicine to develop medical support systems to diagnose and treat in-flight emergencies (Zundel, 1996). Technology used today in emergency

rooms and intensive care units was developed based on the 1960s applications in space (Doarn et al, 1996).

#### *The invention of television*

A second contribution to the development of telemedicine applications was afforded by the introduction of television. In the late 1950s, closed circuit television applications were used in clinical settings. The first interactive video link, in 1964, was established between Nebraska Psychiatric Institute in Omaha and the Norfolk State Hospital. A distance of 112 miles separated the two facilities. In 1967, the first complete telemedicine system was established, linking the medical station at Boston's Logan Airport to Massachusetts General Hospital. The advent of the television monitor led to the ability for visual images to be transported from one site to another and, thus, be seen by medical specialists in distant locations. Soon, researchers were able to show that it was possible to make diagnoses and transmit x-rays, medical records and laboratory data across distances (Zundel, 1996).

#### *Federally funded demonstration projects*

In addition, federal government support of telemedicine also enabled growth to proceed rapidly. Much growth has occurred through federally funded demonstration projects (Crump & Pfeil, 1995), contracts, and NASA and Department of Defense (DOD) budget line items (Grigsby et al, 1998). Demonstration projects offered the chance for the capability of telemedicine to be evaluated in relationship to specific medical care issues. Due to inadequate medical staffing in rural areas, many demonstration projects were developed in those areas (Zundel, 1996). Although the

projects did not offer comprehensive definitive conclusions, as desired, they did verify that telemedicine was feasible and could be utilized as a substitute for traveling to obtain medical care (Zundel, 1996). Further, the projects supported the ability of telemedicine applications to increase coordination and extend medical and administrative functions in large institutions, and to provide an alternative form of emergency care when a physician is not accessible (Zundel, 1996). The U.S. Federal Communications Commission developed rules for the implementation of changes in the universal service program under the Telecommunications Act of 1996, providing subsidies for telecommunications services for which some rural health care providers are eligible (Grigsby et al, 1998). The Act ensured that rural areas have access to broad-bandwidth networks that offer high quality resolution and images in interactive video.

Merrell (2004) points out that telemedicine may be coming of age, as the field is just now developing mainstream written histories of its components, past failures and accomplishments. During the previous 30 years, the history telemedicine was oral, shared among visionaries and technophiles. The vision in telemedicine, according to Merrell, has always been to create an electronic continuum between the location of need and the location of expertise related to distance in patient care.

#### Current Trends and Issues in Telemedicine

The trend in telemedicine has been rapid and constant growth marked by technology that has consistently become more advanced and powerful. Telephone, radio and facsimile transmission have been replaced by more high speed modalities.

The technologies used for telemedicine now range from high-bandwidth with interactive video to low-bandwidth wireless (CTEC, 2005). Increased utilization and growth of telemedicine has been fueled by several improvements in equipment and capability of systems. Technologically advanced communication systems have become more widely available and, thus, the cost of telemedicine service has decreased (CTEC, 2005). Similarly, computer equipment is characterized by higher performance and lower cost. During the past several years, both the general public and health care professions have developed greater confidence in computer technology and, therefore, embraced greater acceptance of this form of medical care provision (CTEC, 2005). The perceptions and the reality of the capabilities of technology for the provision of health care are becoming more consistent in similarity to one another and, thus, health care professionals can communicate about technology that is similar from site to site (CTEC, 2005). Telemedicine is a program that is recognized as having a broad range of service targets, and multiple applications in supporting the health of Americans. The continued growth of telemedicine is challenged by the wide variety of forms the field includes, funding issues and conflicts regarding reimbursement for services.

#### *Forms of telemedicine and technology*

Through the early 1990s, telemedicine was characterized by real-time, broadband, synchronous consultations. In the subsequent decade and a half, telemedicine practice has assumed one of two basic forms: computer-based technology or video teleconferencing. In the store-and-forward process a digitized

image (either taken with a digital camera or a digitized CT scan) is sent to a remote location for review (Myers, 2003). This application can be used in non-emergency situations such as to forward medical records, laboratory results, radiographs and other diagnostic images to the appropriate consultant. This enables consultants to utilize a readily available, accessible and inexpensive internet platform that can be easily modified to accommodate one's schedule (Grigsby et al, 1998).

Video teleconferencing is the most commonly recognized form of telemedicine (Myers, 2003). Video teleconferencing is not unique to health care, as the technology is used by many major corporations to aid in daily operations (Myers, 2003). In health care, this technology enables real-time consultations with patients and distance learning. It also enables the health care provider at a remote site to use adjunctive tools such as an electronic stethoscope to assess breath and heart sounds, an electronic otoscope to examine the ear or a high-resolution camera to magnify and examine skin lesions (Myers, 2003). The expert can, therefore, observe important clinical signs and symptoms first hand, enabling the physician to consult with the health care provider and patient at the remote site. Video teleconferencing has also been reported to be highly effective in psychiatry and psychology applications (Pesamaa, Ebeling Kuusimaki, Winblad, Isohanni, Moilanen, 2005).

As equipment becomes more reliable and sophisticated and costs decline, the possibilities of telemedicine and telehealth expand (Ferrante, 2005). The field is experiencing emerging technologies which support the rapidly changing and expanding scope of applications in telemedicine and telehealth. The focus is on such

aspects of services as wireless systems, emerging broadband, nanotechnology, intelligent agent applications, and grid computing (Ferrante, 2005).

Telemedicine has been used to improve access to care, increase contact between physicians, contain costs through limiting travel of patients and physicians and to provide continuing education. Despite the various forms of telemedicine, there is a common telemedicine model. Such a program is comprised of a medical center, staffed by a physician or physicians, equipped with a two-way communications link. The center is connected with the communication link to multiple satellite medical offices staffed by doctors, nurses, nurse practitioners or physician assistants, often in remote areas. The patient may be seen by a health care provider at the satellite site while the medical center physician provides consultation (Zundel, 1996). In addition to traditional physician consultations, another typical telemedicine use is for the transmission of digital images such as x-rays, computed tomography (CT scan) and magnetic resonance images (MRIs) between sites. Adequate funding is needed for the continuation of traditional telemedicine applications, as well as for developing broader uses of telemedicine technology.

### *Funding*

As the applications of telemedicine continue to evolve, the brief history of telemedicine gives rise to continued changes and new applications of current telecommunication technologies. In addition, telemedicine has also experienced significant challenges resulting from funding issues. A 1992 literature review revealed the fluctuating interest in and funding of telemedicine in the past. The

review discovered that from 1975-1982, the National Library of Medicine information system included 127 articles on health care uses of telemedicine and 55 articles on educational uses. However, the period from 1983–1990 showed a change in focus with only 75 articles related to health care uses and 117 articles that focused on educational applications of telemedicine (Crump and Pfeil, 1995). The high cost of telemedicine transmission is cited by the authors as the primary cause for the declining interest in telemedicine in the early and mid-1980s. Improved technologies and lower costs are suggested as the reason that interest in telemedicine began to revive in the late 1980s (Scannell, Perednia & Kissman, 1995).

Many of the new applications of telemedicine are funded by federal dollars. It is estimated that the Federal Government will spend approximately one billion dollars this year on research, activities and grants related to telemedicine, telehealth and informatics (Federal Telemedicine Update, 2005). The Telemedicine Information Exchange (TIE) provides information on telemedicine grants available from a variety of federal sources, including the U.S. Department of Health and Human Services, The National Libraries of Medicine, The National Institutes of Health, Centers for Medicare and Medicaid Services, U. S. Department of Agriculture, Centers for Disease Control, Food and Drug Administration, Agency for Health Care Research and Quality and various foundations and corporations (TIE, 2005). Research by the TIE has determined that funding is a significant challenge for telemedicine programs of all descriptions (Brown, 2005). Federal dollars are the primary source of funding

for the TIE itself. Thus, telemedicine programs continue to seek additional sources of funding.

#### *Reimbursement for services*

Another challenge to the growth of telemedicine was realized in the limitations of third party reimbursement for services. Until recently, most insurance companies did not pay for telemedicine or telehealth services, especially if there was face-to-face contact (Myers, 2003). Reimbursement for such services as interpretation of electrocardiograms (EKGs), CTs, x-rays or MRIs was the exception. The Balanced Budget Act of 1997 included a small change that resulted in a positive impact for the future of telemedicine. The Act changed the manner in the Medicare payment structure which allowed limited reimbursement for face-to-face telemedicine services (Puskin, 2001). In October 2001, the Medicare, Medicaid and SCHIP Benefits Improvement Act of 2000 went into effect, eliminating the presenter and fee-sharing requirements while also expanding eligible locations to health professional shortage areas (HPSAs) and counties which were not part of a metropolitan statistical area (MSA) (Myers, 2003). The result was full reimbursement to specialists providing telemedicine consultations to rural areas with limited access to specialists. Several states followed Medicare's lead by approving telemedicine services for Medicaid reimbursement. In addition, many private insurers now also cover some telemedicine services. However, telemedicine services are still not, typically, reimbursed on the same level as face-to-face services (Whitten, 2002).

A telemedicine system is likely to result in additional fiscal benefits. For example, if the system is initiated by a government agency, other government agencies are likely to realize related benefits (Brown, 1996). Time and cost savings will be realized by patients and time conservation is likely to be a benefit to health care providers. Further, economic development in rural areas is often difficult when medical services are not readily available. Telemedicine may bridge that gap in services for rural residents (Brown, 1996). Further, the establishment of telemedicine services could aid in attracting employers to rural areas (Brown, 1996). Funding, cost effectiveness and several other aspects of telemedicine will contribute to the future growth of telemedicine services that are available to patients, health care providers and other consumers.

#### Future Directions in Telemedicine

In addition to funding concerns, four other key issues which will impact the use of telemedicine in the 21<sup>st</sup> century were identified in the 2001 Telemedicine Report to Congress (Puskin & Kumakawa, 2001). Those issues include (1) legal concerns related to cross-state licensure. States are working toward establishing laws that regulate out-of-state practitioners. Another concern is related to (2) safety standards in telemedicine. Technical standards which will facilitate interconnectivity between sites, clinical standards that lead to safe, effective care and inclusive standards of telemedicine care developed by the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) constitute separate components of safety in telemedicine. In addition, the Food and Drug Administration, the Federal

Trade commission and the Center for Devices and Radiologic Health are also involved in ensuring safety and effectiveness and telemedicine devices and computer software. The assurance of (3) confidentiality and security of electronic transmission of patient information has been addressed by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and standards have been mandated that govern electronic data transmission, protects privacy of identifiable health information and secures electronic signatures. Finally, (4) infrastructure maintenance in telemedicine comprises the greatest expense to those organizations promoting and developing telemedicine and telehealth programs. The Federal Communications Commission was made accountable by the Telecommunications Act of 1996 for the Universal Service Program. The purpose of this program is to ensure that rural health care providers are granted discounts on telecommunication charges and to assist rural programs with the expenses involved in maintaining telemedicine infrastructure (Puskin & Kumakawa, 2001). The future of telehealth has been further defined by world events and the potential of communication over distance to assist in times of national need. For example, the possibilities of bioevents of terrorism that may require national, coordinated communication have led to increased new telehealth applications. Such events would require that officials possess knowledge on how to collect, analyze, and deliver information in a timely manner, develop a single set of terms, rules, and practices so that organizations will have a primer for response plans (Federal Telemedicine Update, 2005). As a result of terrorist activity, the United States currently faces the potential of several new, concurrent large-scale health crises

such as anthrax, plague, and smallpox (Morse, Edelson, Rosenfield, Lipkin & Smith, 2003). The specific major health issues which currently receive public and government attention include bioterrorism, the threat of widespread delivery of agents of illness; mass disasters, local events that produce large numbers of casualties and overwhelm the usual capacity of health care delivery systems, and the delivery of optimal health care to remote military field sites (Teich, Wagner, Mackenzie & Schafer, 2002). Informatics unquestionably plays a significant role in this effort, and current trends and funding are being directed to these efforts.

In addition, it is predicted that two other key issues will impact how telemedicine affects the delivery of health care in the future: the rapidly changing technology and the aging population. The demand placed on the health care system by the number of aging baby boomers makes a strong case for telehomecare. Issues related to access to care in both rural and urban settings and reimbursement will influence policy-making decisions. The future of telemedicine in the United States may be determined by the cost-effectiveness of telehomecare and, therefore, whether third party payers are willing to reimburse for such care (Myers, 2003).

#### Pediatric Applications of Telemedicine and Telehealth

Telemedicine offers great promise for pediatrics, as virtually every pediatric service can be provided by telemedicine technology (Spooner & Gotlieb, 2004). Pediatrics has long incorporated one of the earliest forms of telemedicine, the telephone. Telephone triage systems have been shown to reduce the number of referrals without resulting in adverse outcomes for patients (Kempe, Dempsey,

Hegarty, Frei, Chandramouli & Poole, 2000). However, some professionals question the efficacy of telephone systems, as it is unlikely that the call is recorded for training purposes or that the person on the other end of the line has had any training in providing telephone advice (Oberklaid, 2002). Nearly twenty years ago, this type of telemedicine was described as a neglected area of health service delivery (Oberklaid, Bell & Duke, 1984). Yet, it does not appear that the practice has changed much, if any, since that suggestion (Oberklaid, 2002). Other forms of telemedicine in pediatric settings, such as interactive televideo conferencing, may offer an alternative that is consistent and offers more significant medical options.

Interactive telemedicine applications have been incorporated into pediatric care in a variety of additional ways. Interactive televideo conferencing has been incorporated with families of very low birth weight infants, to provide support and education after the baby goes home (Gray, Safran, Davis, Pompilio-Weitzner, Stewart, Zaccagnini & Pursley, 2000). This investigation and others have indicated that there are fewer neonatal hospital transfers, shorter admission time in neonatal intensive care units, and an improvement in efficiency and quality of care (Rendina, Carrasco, Wood, Cameron & Bose, 2001; Sable, Roca, Gold, Gutierrez, Gulotta & Culpepper, 1999). Further, improvements have been shown in the quality of care for adolescents with asthma who receive support and education by telemedicine (Bynum, Hopkins, Thomas, Copeland & Irwin, 2001). Economic advantages and cost savings for both health care providers and families have been suggested in pediatric subspecialty consultations such as for pediatric congenital heart disease.

Telemedicine and telehome models have been utilized effectively with children who have life-threatening or life-limiting diagnoses such as cancer, asthma and other chronic illnesses. This technology offers connection with other young people with similar diagnoses when other sources of support and education for patients and parents may be limited (Battles & Weiner, 2002).

In addition to traditional medical applications of telemedicine, mental health and developmental applications of telemedicine are applied to pediatrics. For example, telepsychiatry and telepsychology have been widely utilized in pediatric care. Some families face barriers to cognitive-behavior treatment for children which can be addressed by connecting the clinician and young patient using interactive televideo (ITV) (Nelson, 2004). Another advantage of telepsychiatry/telepsychology is cost-effectiveness. Hyler and Gangure (2003) reported that this mode of treatment is cost-effective in certain settings and offers the greatest financial viability when used beyond the break-even point as compared to face-to-face services.

Pediatric telemedicine has even enjoyed success in public school settings. Access to health care for children may be limited by such barriers as distance, lack of transportation, poverty and unemployment, inadequate health insurance coverage and shortages of providers (Young & Ireson, 2003). Some school districts utilize telemedicine in schools to extend the range of services and to enable medically disadvantaged children to have access to health care (Whitten, Cook, Shaw, Ermer & Goodwin, 1998). School-based health centers (SBHCs) offer comprehensive health services at the location where young people spend the majority of their day. Thus,

SBHCs have been identified as an appropriate place for telemedicine services and as an effective tool in overcoming many of the barriers to health care (Kaplan, Brindis, Phibbs, Melinkovich, Naylor & Ahlstrand, 1999). In addition to affording improved access to primary care through telemedicine, SBHCs also have the potential for improving access to mental health services, especially in rural areas where access is very limited (Young & Ireson, 1999). Over 20% of children in the United States have been identified as having mental health problems which require services at any given time (Report of the Surgeon General's Conference on Children's Mental Health, 2001). Thus, a greater number of children may have access to mental health services through school-based telemedicine services.

The typical model of school-based telemedicine is an interactive televideo system in the office of the school nurse with the capacity to connect to a university medical center for physician, psychologist or psychiatrist consultation (Miller & Miller, 1999). Several advantages to school-based telemedicine have been reported. In addition to improved access to care for rural or disadvantaged children, school-based telemedicine results in decrease absenteeism for children and less time off work for parents (Spooner & Gotlieb, 2004). Parents and patients have reported satisfaction with this method of health care delivery. In an investigation of 940 telemedicine encounters, parents indicated that 91.2% of telemedicine contacts allowed them to stay at work and that 93.8% of problems managed by telemedicine would otherwise have led to an appointment at the doctor's office or emergency department visit (McConnochie, Wood, Kitzman, Herendeen, Roy & Roghmann,

2005). In addition, physicians, residents and nurse practitioners reported feeling very confident in the use of telemedicine equipment to provide health care to children (Young & Ireson, 2003).

The various applications of telemedicine and telehealth may be particularly beneficial to children with special health care needs. This population of young people is at risk of not receiving appropriate or adequate health care due to limited access to subspecialist care and the specialized services they require. Often, the concerns of children with special health care needs are complex, and may include areas of growth and development, cognition, communication skills, daily living skills, social competence, and behavioral adjustment (Farmer & Muhlenbruck, 2001).

Telemedicine care for children with special health care needs in rural areas is suggested as an effective and cost-saving way to provide subspecialty care to children who live a distance away from a tertiary care facility, especially when incorporated as a part of an integrated health care program, as opposed to use as the sole medical care delivery method (Spooner & Gotlieb, 2004).

As a result of the complexity of their needs, a youngster with chronic or special health care needs benefit from an interdisciplinary model of care, often not available face-to face in rural areas. Telehealth and telemedicine programs offer the possibility of access to the specialized services needed and the potential to improve community-based services for children in rural or underserved areas. In addition to conventional telemedicine applications, children with special health care needs may benefit from evaluation for developmental disorders. In an investigation of young

people with special health care needs, telehealth was used to assess and treat neurodevelopmental disorders such as cerebral palsy, developmental delays, learning disorders, autism, brain injuries and others in 55% of the children in the sample (Farmer & Muhlenbruck, 2001). Telemedicine offers the potential to provide education and training for educators and to enhance collaboration between education and health care throughout the United States.

Telemedicine programs have been suggested to have the potential to advance the agenda for children with special health care needs by improving communication and continuity of care, developing partnerships between primary and specialty care providers, and by enhancing the capacity of the community to meet the needs of this special population and their families. The potential for health care providers, educators and community service agencies to collaborate on the child's health care needs is enhanced by the increased opportunity for communication afforded by interactive televideo meetings via telemedicine (Farmer & Muhlenbruck, 2001).

The existing model of school-based telemedicine and the potential to expand telemedicine applications for children with chronic and special health care needs are significant. There is the potential for additional interdisciplinary services to support health and education needs of this population of learners. In addition to direct care for patients, telemedicine technology offers a link between the primary sources of care for a child with a chronic or special health care need: the family, health care providers (rural and urban) and the child's educators. Telemedicine and telehealth technology has already been used to provide information and education for families

of seriously ill children and for local care providers. Schools have utilized telemedicine to provide acute health care for children. Now, those schools afford prime locations to use existing telemedicine technology to provide staff development on special health care issues for school staff members working with seriously ill students.

#### Telehealth, Distance Learning and Continuing Education

Distance between student and teacher has complicated learning for many centuries. It is reported in ancient literature that Ulysses was away at the Trojan War for many years, thus rendering him unable to provide guidance and training to prepare his son, Telemachus, for adulthood. As a result, Ulysses asked Mentor to act *In Loco Parentis* and guide Telemachus toward adulthood (Merrell, 2004). Thus, solutions to educating at a distance have long been an issue of concern.

Current distance learning applications include CD-ROM, computer based and interactive televideo (ITV) delivery options (Mattheos, Schitteck, Attstrom & Lyon, 2001). CD-ROM and computer based learning offer the advantage of asynchronous, on-demand capabilities. The learner may choose to watch a presentation, previously recorded, on the disk or internet at a time of convenience. This type of distance learning does not offer the opportunity for real time interaction. ITV enables interaction between teacher and learners during real time broadcasts. Personal contact between the teacher and the students is recommended and noted to be a motivating factor which enhances the effectiveness of learning (Mattheos et al, 2001). An additional advantage of ITV for continuing education is the significant cost

savings due to reduction of travel. Thus, ITV presentations may afford advantages over computer based and face-to-face learning for continuing education. This discussion will focus on learning through interactive televideo technology.

### *Distance Education Research and Theory*

Distance education research has not yet been subjected to repeated review and synthesis and, as a result, it is important to investigate which delivery methods are most effective and if distance learning improves student performance (Cavanaugh, 2001).

Theories have been developed to help shape the direction of needed investigations. Holmberg (1985) developed a theory of distance teaching which suggests that distance teaching is most effective and impacts student motivation when learners are engaged in discussions, decisions and engaged in communication with other learners and the instructor. Further work on developing a theory of distance education determined that learning by interactive televideo enables not only education across geographic distance, but also is a pedagogical concept which forces one to rethink the traditional meaning of education and learning and the roles of instructor and student (Moore, 1991). The theory of transactional distance, articulated by Moore (1991), describes the universe of teacher-learner relationships that exist when time or space separates the two. This theory embraces elementary constructs of education, including (1) the structure of instructional programs, (2) the interaction and dialog between teachers and learners, (3) the nature and degree of autonomy and self-directedness of the learner, and (4) the concept of transaction (interplay between

individuals, environment and behavior in a situation). The importance of transaction in distance learning is illustrated by the need for special teaching and learning strategies due to the distance between teacher and learner (Moore, 1991). Thus, the interactive nature of televideo presentations may offer the needed motivation for students learning at a distance.

### *Applications of Distance Learning in Health Care*

Education for health care professionals is being conducted more frequently in community based teaching sites outside the traditional medical setting (Langlois & Thach, 2003). One such model is distance learning utilizing telehealth equipment. Wheeler (1998) observes that, since its inception, telehealth and distance learning have been natural partners. The author suggests that if telemedicine technology is in place to connect rural and urban physicians for consultation or treatment purposes, it is logical to use the equipment for educational purposes. A question which drives new telemedicine applications is “what does this patient community lack that can be solved with telemedicine technology?” (Wachter, 2000). In many rural communities, what is lacking is the means to access continuing education. Telemedicine offers access to resources and experts unavailable through other channels. Interactive televideo allows communication to flow in both directions. Educational information may be provided by an expert on the topic and participants can ask questions or request clarification of information.

Telemedicine technology has been frequently used to provide continuing education opportunities for health care providers, including physicians, residents,

medical students, nurses, and allied health professionals (Varga-Atkins & Cooper, 2005; Ricci, Caputo, Callas & Gagne, 2005). Continuing education via telemedicine equipment is an effective and convenient method of obtaining Continuing Medical Education (CME) units for physicians or continuing education opportunities for nurses, social workers, psychologists, educators and others (Zundel, 1996). The application is especially important in rural or remote areas. In a survey of physicians, telemedicine was used to obtain continuing medical education units (CMEs) more frequently by rural physicians than physicians living in metropolitan areas (Sargeant, Allen, & Langille (2004).

Several factors are suggested as impacting the utilization of telemedicine for distance learning or continuing education applications in health care. First, the changes that are occurring in social, professional and lifestyle dynamics impact how and where individuals seek educational opportunities. No longer is a commute to a distant college campus the norm for accessing continuing education opportunities (Maclean, McShane & Etchason, 2001). In addition, the rapid evolution of educational principles in health care further ensure that there will be a significant demand for lifelong learning. These factors result in differing needs of learners today as compared to the traditional student of the past (Maclean, et al, 2001). The greatest influence on a learner's decision to attend an educational offering delivered by telemedicine technology include interest in the topic and the perception of utility of the information (Krupinski, Lopez, Lyman, Barker & Weinstein, 2004). A feeling of connection and interaction between students and instructor has been identified as an

important factor affecting the decision to participate in interactive televideo presentations. Resident physicians who participated in an interactive videoconference teaching session did not believe that their ability to interact with the presenter was inhibited by using telemedicine technology, and all agreed that they would use the technology again (Cook, Salle, Reid, Chow, Kuan, Razvi, Farhat, Ragli & Khoury, 2005). Finally, cost effectiveness is cited as an attraction of distance education using existing telemedicine technology. Distance learning, in the past, has often been expensive and time consuming (Cavanaugh, 2001). When existing telemedicine or interactive distance learning equipment is used for staff development, the cost of purchasing equipment for that purpose can be eliminated presentations (Zundel, 1996). Such presentations save money spent on travel, lodging and meals when attending a conference. Further, time is often saved, allowing a health care provider to have access to continuing education without the need to travel and miss a significant amount of work. Rural nurses participated in an interactive televideo continuing education series reported that the experience provided an effective teaching tool resulting in learner satisfaction and cost effectiveness (Weber & Lawlor, 1998). Consumer demands ensure that the quality and availability of distance learning opportunities is improving.

#### *Applications of Distance Learning in Education*

In addition to continuing education applications for health care providers, telemedicine technology and equipment have the potential to offer an opportunity for continuing education for other professional groups. One such application may be in

the provision of continuing education, or staff development, for educators, especially those in rural areas. As early as 1981, Helge cited inadequate staff development as a major contributor to the personnel retention problems experienced by rural schools. The author suggested that rural educators, due to a lack of accessibility to experts for staff development, may become discouraged and leave the profession early. Further, in 1991, Galbraith suggested that staff development may be the key in addressing the problems of attrition in rural schools. He pointed out that rural educators are challenged by limited resources and, thus, must seek alternative methods to address continuing education needs.

Rural schools experience significant shortages and high attrition rates in special education and, as a result, often face difficulty in providing for the needs of students requiring special education (Theobald, 1991). National attrition rates for special educators in rural areas are reported to be between 30% and 50% (Gamble, 1995). Oftentimes, a special educator may be further isolated from colleagues with similar situations, as rural school districts may employ a single special education teacher. Williams, Gold & Russell (1995) report that the isolation experienced by small and rural schools often results in a lack of attention paid to the needs of those schools. There are unique attributes of the concerns of rural and small schools. Such schools have fewer educators in each specific teaching area, resulting in a lack of opportunity to interact with other educators working in the same type of education setting. Further, challenges to traditional staff development or in-service opportunities for small and rural schools result from transportation barriers,

geographic isolation, cultural differences, lack of available personnel to provide education modules, limited financial resources and the feeling of being cut off from the resources of larger or urban schools. (Williams et al, 1995).

The significance of the problem of providing continuing education to small and rural schools has resulted in attempts to find solutions. The Office of Technology Assessment (OTA) of the United States Congress was commissioned in 1989 to analyze various technology options that could be used for distance learning among schools (Linking for Learning: A New Course for Education, 1989). The results found that (1) many rural schools still did not have access to distant experts and information, (2) technology was advancing rapidly, resulting in powerful, flexible and affordable technology applications, (3) that distance learning, in most cases, was as effective as face-to-face instruction, (4) that distance learning would be the method of reaching the teaching force of tomorrow, (5) that state education agencies were both the catalysts and the gatekeepers for distance education, (6) that federal and state regulations governing the telecommunications infrastructure significantly impacted distance education, and (7) that federal funding was emerging, but still modest. These findings suggested that the potential for distance learning applications in education is significant.

Despite the recommendations of OTA thirteen years previously, a study in 2002 found similar challenges to the provision of distance education for educators in rural and small schools. The United Nations Education, Scientific and Cultural Organization (UNESCO) issued Teacher Education Guidelines which were developed

for teacher training institutions to address ways to expand teacher education through distance learning (Perraton, Creed & Robinson, 2002). The report highlights that there is a shortage of qualified teachers, and that many existing teachers are under trained. Continuing education resources are cited as being limited for educators in rural and small schools. The report suggests finding ways to utilize resources differently and recommends using distance education for continuing education development.

The UNESCO report suggests that there are obstacles related to the infrastructure and funding that require further consideration. The funding for staff development within rural school districts is, typically, inadequate (Helge, 1985). Schools have a fiscal advantage by often having equipment that can be utilized for accessing distance learning staff development presentations. There are three basic methods which schools may use to access distance learning presentations. Access to telemedicine equipment exists in some public schools, as telemedicine is used to provide health care consultations for students who may not, otherwise, have ready access to care (Whitten, Kingsley, Cook, Swirczynski & Doolittle, 2001). Other schools may be able to utilize the equipment of a local hospital telemedicine program. Finally, schools often have existing equipment and technological resources in the form of interactive distance learning (IDL) equipment used for K-12 student courses. During the 2002–03 school year about one-third of public school districts (36 percent) had students in the district enrolled in distance education courses (National Center for

Education Statistics, 2005). Each of these options enables school staff to have access to staff development at a distance.

Another fiscal advantage for schools may exist in the opportunity to collaborate with experts in a wide range of professional fields. Partnering with businesses, universities and agencies may provide a cost-effective option for continuing education presenters for rural school districts. The potential exists for additional teacher training resources by utilizing members of the community, non professional staff, business and industry and shared teaching efforts (Helge, 1985).

An additional resource exists in university and health care professionals who may use telemedicine equipment to broadcast to rural schools. This application presents significant potential benefits to students with chronic or special health care needs, those who educate them, and the peers. Students with chronic or special health care needs are at the intersection of health care and education. The opportunity for the marriage of health care and education, benefiting the student with a chronic or special health care need offers exciting potential. In addition, telemedicine technology may provide patient education, consultation for caregivers of patients with developmental disorders, offer in-home hospice support, or provide monitoring for understanding and compliance with medical recommendations (Zundel, 1996).

There are some continuing concerns that may limit the use of ITV for educators' staff development. One criticism is that distance learning applications do not include a solid theoretical framework. In addition, distance learning applications have not included adequate evaluation (Mattheos et al, 2001). Thus, further

investigation is needed to determine if distance learning is as effective as traditional teaching methods.

Further, the consumers of distance learning must be comfortable with the technology. There are two typical methods of identifying how users develop a level of acceptance of the technology used in distance learning. The technology acceptance model (TAM) suggests that users accept distance learning technology after they have determined that the technology is useful to them and easy to use (Davis, 1989). The opposing model, the social information processing model (SIPM), presumes the opinions, information, and behaviors of important others are what determines an individual's acceptance of distance learning technology (Salancik and Pfeffer, 1978). Individuals who develop the technology which supports distance learning recognize that a lack of acceptance by the user of technology can result in loss of money and resources (Lee, Cho, Lee, Davidson & Ingraffea, 2003). In order to ensure that educators will adopt distance presentations it is important to determine if the effectiveness of distance learning is impacted by their perceptions related to technology. Acceptance of the technology used for distance presentations may be less problematic in schools where telemedicine applications are familiar. An examination of the perceptions of teachers, nurses and administrators in schools with telemedicine revealed that, once these professionals had experienced telemedicine first hand, the technology was seen as an effective and important asset (Whitten, Cook, Kingsley, Swirczynski & Doolittle, 2000).

In summary, continuing education opportunities for rural educators are complicated by lack of access to experts in areas of interest. Staff retention in rural schools has been reported to be negatively impacted by the lack of access to staff development opportunities. Distance presentations may afford the opportunity for educators to learn from experts to whom they may not, otherwise, have access. The utilization of telemedicine technology which may be present in the school offers a cost-effective mode of receiving continuing education presentations. By providing staff development opportunities which may not be accessible by traditional methods, a decrease may be realized in teacher attrition in rural districts and the needs of kids may be more likely to be met.

#### Summary

Although a field still in its infancy, telemedicine and the accompanying technology have experienced significant development and change. All telemedicine usages share the common characteristic of providing care or information at a distance. Telemedicine technology has evolved over time in ways that have altered not only the effectiveness, but also the applications of the delivery method. The exchange of information for diagnosis, treatment and prevention of disease and injury, research and evaluation, and for the continuing education of health care providers constitute current applications of telemedicine.

The history of telemedicine is comparatively brief and the current trend in the field is one of rapid and constant growth. Communication related to health care issues is significantly enhanced by telemedicine capabilities. Distance and continuing

education applications constitute emerging applications in the field. Challenges to the continued growth and viability of telemedicine include funding and cost effectiveness of various uses. Continued focus on funding sources is indicated. Applications such as telehomecare and distance learning may emerge in the future as primary components of the field. Utilization of existing telemedicine for related and expanded purposes may enhance continued growth and expansion in telemedicine.

Telemedicine technology can be used in most pediatric services. Pediatric telemedicine has already enjoyed success in public school settings, enabling teachers, school nurses and education administrators the opportunity to become familiar with the technology. Thus, the potential for health care providers, educators and community service agencies to collaborate on a child's health care needs is enhanced by telemedicine applications of care.

Using telemedicine or distance learning equipment to link educators and health care providers could enable better communication and lead to enhanced support for students with chronic health conditions or special health care needs. Their needs, in the school setting, include health care and medical care as well as assessment to determine how learning may be affected by the health condition, treatment or concomitant psychosocial implications and, subsequently, appropriate education supports and services to address educational needs. Educators do not, typically, receive training to aid in either the education or health care assessment and services for students with chronic or special health care needs. In a survey of 147 experienced teachers, only 7% felt that their certification requirements adequately

prepared them to work with students with chronic health conditions (Eiser & Town, 1987). Continuing education opportunities for rural and small schools on topics of medical and educational needs of students with chronic and special health care needs, utilizing existing distance learning or telemedicine equipment in the school and telemedicine equipment in the tertiary care center offers significant possibilities. The technology is in place, thus creating a cost effective method of presentation delivery. In addition, the expertise in relevant topics would likely be available in most tertiary care facilities. The potential for significant outcomes is remarkable.

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