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Coping with Isolation: A Case Study of an Elementary School Student with Cancer

Brian C. Ante

New York City Public Schools

Brian C. Ante is a social studies teacher in the special education program of New York City Public Schools. He received his doctorate in educational psychology from The Catholic University of America.

Abstract

In this article, Brian Ante describes the education of a child diagnosed with neuroblastoma. Factors relating to educational services provided, physical effects of treatment, and socioemotional state are explored over the nearly six year progression of this cancer. The author suggests that the persistent good will of providers and the community, more than an educational plan, ensured a sound education for the child, given the uncertainty of the medical treatment and side effects; and that additional peer interaction would ameliorate depression during periods of isolation due to treatment or neutropenic status (low white blood cell count).

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The Lockharts (Rowlings, 2005) had it all; they were living the American Dream. Dad retired young from the Army, as they often do in the military, and had an assured income for life. Mom left her job as an Army lawyer to be with her man. Dad, Mom, and little Ron (Rowlings, 2005) spent half a year in their camper, seeing all of the U. S., Canada, and much of Mexico, before deciding that they would spend the rest of their lives in beautiful Avalon, Atlantis.

They bought a house with a pool. Dad started a second career with an information technology company. Mom got a job with the Atlantis Attorney General's office. Little Ron was enrolled at Little Whinging Academy (Rowlings, 2005).

Ron looked forward to beginning kindergarten at Hogsmeade Elementary School (Rowlings, 2005) in the fall, which he and Mom had visited to meet the "graduating" class, and to check things out. Ron, however, was becoming increasingly easily fatigued, and had bruises that had nothing to do with ordinary playground activities. In May, 1999, he was diagnosed with the most advanced stage of neuroblastoma (stage 4), a rare form of childhood cancer, with little time left to live. The Dream was over.

As is usually the case with such a diagnosis, Mom and Dad initially experienced shock and grief, and immediately were placed in circumstances where they had no prior experience (Daverson, 2001; Clarke, Davies, Jenney, Glaser, & Eiser, 2005). They were determined that their Ron would survive this, and were given some hope, because recent medical research indicated that more children with cancer were surviving longer (e.g., Clarke et al., 2005; Mukherjee, Lightfoot, & Sloper, 2000; Spinetta & Collins, 1993). Among their many concerns, was how they were going to continue Ron's education.

Would he attend public school, and, if so, what would happen when he was hospitalized or homebound? Would they have to homeschool him? They wanted Ron to know that he was an ordinary boy who just happened to be dealing with extraordinary circumstances.

Factors that affected Ron's education and development can be understood as interrelationships, if some theoretical assumptions are made, such as which follow. Cancer created a complex and changing environment that shaped the Lockharts' behavior, requiring them to be very flexible. Choices they made were based on maximizing the best quality of life for Ron, and the eradication of his cancer. They had to make uncertain inferences throughout the progression of the disease and its treatment, and Ron's maturation (Anderson, 1995).

Ron's battle with cancer also took place within a larger social context (Bronfenbrenner, as cited in Santrock, 1995). For example, computed tomography (CT) scan results at Children's Hospital in Dragoon (microsystem; Rowlings, 2005) might lead to his being transferred (mesosystem) to Memorial Sloan Kettering Cancer Center ("Sloan") in New York for surgery (exosystem), because everyone would assume that a curative treatment was desirable (macrosystem), and Ron would see it as yet, or just (Stewart, 2003) another cancer treatment (chronosystem).

The purpose of this paper is to describe how the education of a child with cancer might progress, by using the case of Ron Lockhart to explore factors relating to educational services provided, physical effects of treatment, and socioemotional state that emerged over his survival period of nearly six years. The term "educational services" is meant to encompass the curriculum, role of technology, assessment, and extracurricular activities, as well as health and counseling services. Physical effects of cancer treatment

can not be ignored, since, for example, neutropenic status "blood counts" determine school attendance, and chemotherapy involves such side effects as vomiting and diarrhea. Psychological effects are important because a child with cancer might not be able to concentrate on academics if s/he is preoccupied with, for example, loneliness due to isolation, or sadness, because the treatment never seems to end.

Cancer has not been eradicated. When parents receive the anguishing news that their child has been diagnosed with it, they will want to know how this diagnosis will affect their child's education. A place to begin is by looking at the legal responsibilities of school systems.

Creating an Individualized Education Plan (IEP)

The Education for All Handicapped Children Act of 1975 (extending from Section 504 of the Rehabilitation Act of 1973, and now known as The Individuals with Disabilities Education Improvement Act of 2004, or IDEIA), mandates that states provide a free and appropriate education to children with disabilities. Chronically ill children who are determined to need special education and related services qualify for these services as students with "Other Health Impairments" (OHI). As such, any student categorized as OHI must have an IEP developed by a multidisciplinary team which can include parents, educators, medical, and psychological staffs (Resnick & Zurawsky, 2005; Santrock, 1995; Spinetta & Collins, 1993; Worchel-Prevatt, Heffer, Prevatt, Miner, Young-Saleme, Horgan, & Lopez, 1998).

How states have implemented this has varied. Georgia, for example, provides three hours of hospital/homebound instruction per week, citing limited funding. Core courses are emphasized to prepare students for standardized tests (Madison County

School System, 2005; Cobb County School District, 2005). Massachusetts, however, prohibits school districts from presetting the number of instructional hours per week provided, stating that the decision must be individualized, based on the student's medical circumstances, the benefit of one-to-one home instruction, etc. Massachusetts requires that students keep up with their courses of study, and that these include the same academic content as would be found in regular school-based programs (Massachusetts Department of Education, 2005).

An IEP is required before special educational assistance can be provided. The process of creating an IEP goes something like this: parents (perhaps with the help of a social worker) send a letter of request to the school principal, who forwards it to the school district. The school district also needs a physician's written order, verifying the student's medical condition and estimating the amount of schooltime that will be lost. Once the school district approves, an IEP meeting is scheduled with the parents, a school district official, a representative of the district special education office, school administrators, teachers, and a hospital representative.

An IEP typically includes the following information: dates when the educational services will be needed, although this can be phrased as "intermittent" because of the nature of the medical treatment; the child's medical condition, and any medical precautions or special needs; an academic assessment of the child, a statement of academic goals, and objective criteria for evaluation; who is responsible for implementing the IEP; and most importantly, a statement of what educational services will be provided, along with a justification (CureSearch, 2005; Peckham, 1993; Massachusetts Department of Education, 2005).

The effect of the requirement to have parents, teachers, administrators, etc. all have a scheduled meeting together was that Ron's education was delayed by four to six weeks each year. Mom and Dad were told that this was because the homebound office did not have the staff to work any faster. When they did meet, the administrators wanted to mainstream Ron. They did not seem to know how to write an IEP for his situation. They also did not know where funding for his textbooks would come from.

Mom and Dad had to explain to them that his medical condition precluded this. They suggested having video teleconferencing established with Ron's regular class whenever he was homebound. Dad's recent employer, Ollivander, Inc. (Rowlings, 2005; he resigned to become Ron's full time caregiver) donated computer hardware. Mom heard from the principal that GlobeTel Communications Corp. (GTE) had some kind of small grant for such purposes. The Supervisor of Homebound Education was not enthusiastic, citing several bureaucratic obstacles. It was not unreasonable to think that teleconferencing might be done; this is an option in Baltimore (Baltimore County Public Schools, 2005).

The IEP that resulted, stated that Ron would be "dual-enrolled;" he would attend regular class whenever he could, and have a homebound teacher visit for one and a half hours, twice a week, focusing on language arts and math, when he could not. Also, the regular, homebound, and hospital teachers were to coordinate with one another. Mom and Dad were disappointed, referring to this as a "bare minimum plan." As time went on, however, they found that individual teachers were more generous with their time than the state required. But they found that subjects other than language arts and math only

received "spotty attention," and that Ron's regular, homebound, and hospital teachers often did not know what the other was doing.

Mom and Dad tried to fill in the gaps, while Ron moved around from city to city, hospital to hospital, to receive various cancer treatments. They referred to this as Ron's "fly by the seat of your pants education", adding that "meeting Ron's educational needs falls on our shoulders more than it does on the agencies which try to provide the service." They wondered how other parents, or single parents, with less insurance, and other children, managed at all. The agencies did try, though. At one point, the principal assured Mom and Dad that the "system" was, and would continue to do whatever was needed for Ron. Mom and Dad acknowledged that they knew this to be true, because of what they had already seen of the personal dedication and generosity of the teachers who worked with Ron on a regular basis.

What to Expect from Educational Services

The Atlantis Comprehensive Assessment Test (ACAT) is not first administered to children until they are in the third grade. The primary benchmarks for Ron's success up to that point were finishing grade-level workbooks, in part, because he spent so much time at Sloan in New York. As the school year began in mid-August in Atlantis, Dad made Ron begin the workbooks in New York. Ron called these workbooks "boring" and he "moaned about the injustice" of having to do them. Sometimes he would not focus, so had to be repeatedly reminded about the possible loss of "fun things" (Premack Principle; Anderson, 1995) like watching television or playing games, or about having to take a nap, if he did not get his schoolwork done.

But, the workbooks did help tide the downtime between treatments, providing something to do when Ron was bored. Often, rather than doing a single assignment from each of several subject workbooks (e.g., reading, writing, spelling, math, science, and art), Ron would concentrate on just one. He felt a sense of accomplishment when he finished a workbook that allowed him to advance to the next grade level - ahead of the regular school kids. Dad or Mom were "quality control", making him re-do whatever was wrong or sloppy.

When Ron did spend time with his homebound or hospital teachers, sometimes Dad wondered if any work was being done at all, because it sounded like they were having so much fun (It is a legal requirement that parents be present, but Ron's parents did not stay in the same room.). Work was being done, though. A game of blackjack was really a math drill, a film storyboard and script about dinosaurs and aliens was really writing practice, and Ron's making his own slides to look at under a microscope that the teacher brought was definitely science. Just as important, Ron had someone to talk with, other than only Mom and Dad.

Once Ron entered the third grade, the ACAT push was on. Reading was to be assessed every year. Ron's regular school had an accelerated reading program that offered parties and prizes for students who successfully met the standards. Students had to select from an approved list, stay "on-level," and pass ready-made tests. Ron found this frustrating, in part, because he was ready for more advanced reading, but also because he often missed the parties due to his treatments. He placed in the 95th percentile for reading on the ACAT.

Math was also assessed every year. Ron stayed caught up with his regular class in the textbook. Shortly before the test was administered, there were days when entire afternoons at the regular school were spent doing math. This continued into the evenings on those days, because Ron's homework was to explain to Mom and Dad how he derived answers to problems done at school during the day, or how he would interpret a graph or chart. He also placed in the 95th percentile for math on the ACAT.

Writing was assessed during the fourth grade. One of Ron's homebound teachers had, early on, described him as being a "lazy writer," who had gotten too comfortable only doing homebound workbooks. Following this, Dad became the enforcer of new, higher writing achievement goals (Santrock, 1995) for Ron, resulting in such stories as "The Adventures of Superguy," "Pixies: The Chamber of Stinkies" (Rowlings, 2005), and a story about Santa fighting a mutant Santa. Just before the test, Ron received a motivational letter from his regular teacher, indicating that he was well prepared, and very capable of doing well on the test. As best as Mom could remember, he scored at the equivalent of a "B" on this writing component.

Supplementing Educational Services

Supplementing the educational services provided has to be accomplished in a way that is conducive to the inherently unpredictable course of the neuroblastoma (Stewart, 2003; Wishnietsky, D. B. & Wishnietsky, D. H., 1996). During times of sustained remission, when Ron was in relatively good health, Dad would shuttle Ron by camper between the Children's Hospital Avalon Clinic ("the clinic") and his school, mornings and afternoons, for blood tests and platelet transfusions. During periods of intensive medical treatment, Dad would either take Ron by camper to Children's Hospital in

Dragoon, or fly with him to New York for another visit to Sloan (He went to hospitals in other cities, as well. Flights were often provided by major airlines, paid for by individuals who donated their frequent flyer miles, or by private flights with the Corporate Angel Network). If Ron was in-patient, he was either isolated to his room, or allowed to study in various rooms on the ward floor. If he was outpatient, he stayed at the Ronald McDonald House, and received instruction at the hospital. Ron's educational materials had to fit into baggage, along with his medical and personal supplies, that could be carried from the camper, through airport security, into a taxi, and finally to his bedside.

Given this highly mobile lifestyle, anywhere a laptop computer could be set up and plugged in became an impromptu classroom. Educational software had the advantage of being lightweight and easily transportable (Much of the initial software that Ron used was donated by Florish & Blots; Rowlings, 2005.). Dad also packed books, videos, and games to supplement the homebound instructional materials.

Ron and Mom read stories together every night before he went to sleep, even if only by telephone. On weekends and holidays, the family took excursions, to, the Museum of Science and Industry in Avalon, the Metropolitan Museum of Art in New York, to a dance performance by a troupe made up of members of various Native American tribes, or to a Caribbean street festival. While driving, Dad would ask Ron quiz questions, sometimes adding the incentive that he would increase Ron's allowance if he got the "hard" ones right. Marbles were easy to pack, so Mom would use them as manipulatives to demonstrate solutions to math problems. In so many ways, Mom and Dad did the best they could to ensure that Ron was not only mastering language arts and

math, but also receiving exposure to science, social studies, and the arts. The cancer itself provided Ron with an introduction to medicine.

Physical Effects of Cancer Treatment

It is harder for children with cancer to study than it is for healthy children, because of hospitalizations, treatments, and side effects. They often feel sick to their stomach, vomit frequently while on certain medications, develop mouth sores, find it difficult to eat, and are often fatigued (Peckham, 1993). They try their best to get used to the adverse effects, becoming familiar with various bodily sensations, as they experience treatments repeatedly, but this requires effort, intention, and vigilance (Stewart, 2003).

Ron experienced these side effects and more. Sometimes he had to make "mad dashes," cutting in front of entire class lines to get to the restroom, due to nausea or diarrhea. Sometimes he fell asleep at his desk, because the drugs induced drowsiness, or left him feeling depleted, or because he was up much of the night before, sick, in the bathroom. He was also often thirsty, had fevers and dizziness, had a profound loss of hearing (difficulty distinguishing primary sounds from background noises), lost his hair, and sometimes had to wear a surgical mask at school. There were times when he was sullen, irritable, tearful, or defiant; what Mom and Dad called the "chemo blues" (e.g., Ron's reaction to Benedryl with Vancomycin). Over the course of six years of treatment, his body just wore down. His hospital teachers had the added challenge of sometimes trying to teach him while he was on codeine or morphine.

Attending Regular School

If a child with cancer has never been to regular school, or has not been there in a long time, much confusion, and ensuing problems, can be alleviated by having a member

of the child's healthcare team give a presentation about cancer and its treatment, guide discussion, and distribute literature to students and school staff (Wishnietsky, D. B. & Wishnietsky, D. H., 1996; Peckham, 1993). The school staff need to know what medications are administered when, under what conditions, as well as what special precautions to take. Students will want to know that cancer is not contagious. Hopefully they will gain an appreciation of the cancer ordeal, and will not tease. Everyone needs to understand that the affected student has a suppressed immune system, so should not be exposed to illnesses that spread around the school, such as shingles, chicken pox, or measles (Worchell-Prevatt et al., 1998; Wishnietsky, D. B. & Wishnietsky, D. H., 1996; Spinetta & Colling, 1993; Mukherjee et al., 2000).

A week prior to Ron's Spring, 2003 integration, his homeroom teacher made a courtesy call to Mom and Dad. A week after the term began, the school psychologist played the video, Why Me, Charlie Brown?, which explains cancer, to Ron's class. A couple of days later, the homebound teacher spoke with his class, and before the end of January, a nurse and child therapist from the clinic also spoke with them. They emphasized that cancer is not contagious, demonstrated how a mediport works, and let the students try on surgical masks. Ron shared a treatment journal that he kept, and Dad brought in four photo albums of Ron, through various stages of treatment.

Generally, Ron's integration went well, with only a few minor exceptions. One time he got in trouble in the cafeteria, when he did not hear what a teacher, who he did not know, said from behind him, because of his hearing loss. Another time, some giggling girls from another class asked Ron, in jest, if he had "brain cancer or something." He found them bothersome, but provided matter-of-fact answers to their

questions. The biggest concern was when a classmate came to school with chicken pox, and Dad had not been told.

There were no problems in gym, aside from Ron's own awareness that he could not keep up with the other students. The coach allowed Ron to do whatever he felt up to, or to sit out if needed. Sometimes, other teachers used the gym period to help Ron catch up on missed work. Mom and Dad ensured that Ron received physical activity: they played with him in the pool, took him on long walks when he was well, and encouraged him to get out of bed, take his IV pole, and walk the ward corridors when he was hospitalized.

Prior to being diagnosed with cancer, Ron had been enrolled at Nimbus Karate (Rowlings, 2005). Mom and Dad took a relaxed approach to encouraging the continuation of this. Ron often said that he did not feel up to it, but they would coax him in the door for a social visit. Next, a classmate or instructor might talk him into "hanging out" at the mat, which often lead to his participating. The on-again, off-again nature of this karate instruction continued for three years, with only one kidney, and through two relapses. Eventually Ron was officially awarded his first-degree black belt by the American Tae Kwon Do Association.

Stuck in Isolation

Children with cancer spend a lot of time in isolation, due to their blood counts and treatment. This has an effect on their emotional well being, because they have basic social needs that are not being fulfilled. Visits, telephone calls, or cards from classmates are much appreciated distractions from their condition. They serve as reminders that they have a social role as students, they have not been forgotten, and there is hope for the

future (Worchell-Prevatt et al., 1998; Wishnietsky, D. B. & Wishnietsky, D. H., 1996; Santrock, 1995).

Decisions whether Ron would remain in isolation were made daily, based on blood test results, with the isolation sometimes running for weeks at a time. The longer the isolation continued, the more Ron longed to go to the hospital playroom or return to his regular school. Continued isolation resulted in tears, while the lifting of isolation caused Ron to become very excited and talkative; "thrilled," with "pure joy resonating in his voice." Mom and Dad once noted that so much prolonged isolation had an effect on Ron's socialization; when he was around peers, he sometimes acted "goofy."

Ron did, at times, receive cards from classmates, as well as an occasional telephone call from a friend, but these were poor substitutes for actually being with children his own age. On the occasions that children did visit him, Ron received a morale boost, like when his friend Percy (Rowlings, 2005), from Atlantis, popped out of a package in front of the Christmas tree at the New York Ronald McDonald House. Once a couple of teenage nieces of one of Dad's friends visited, perking Ron up, because they were "almost" kids. The hospital friendships involved an air of sadness. For example, Ron felt empathy for Oliver (Rowlings, 2005), who wanted the Sloan "classroom" (a converted closet) to feel more like a normal school, so he stayed after his scheduled session with the teacher to read, just so Oliver would not feel so alone. Over time, so many of the children with cancer, that Ron made friends with in the hospitals, died.

There were many adults who did whatever they could to try to help Ron, or to cheer him up. Friends, neighbors, teachers, school staff, people Mom and Dad knew from work, friends of all these people, and other people who had heard about Ron's

neuroblastoma, made directed donations of platelets, had their bone marrow typed and placed on the national directory, and paid visits. After Ron and his teacher worked together on a story, "Me and My Big Fat Treehouse," volunteers from Granger Construction Associates Inc. and Trelawney Glass and Mirror Inc. (Rawlings, 2005) used lumber and supplies donated by Home Depot to build this treehouse as a surprise when he returned from his bone marrow transplant.

The adults who visited Ron while he was hospitalized, or homebound may have been "boring", but they were better than no visitors at all. There were also celebrity appearances at the hospitals and Ronald McDonald Houses, such as by Lance Armstrong, astronaut Eileen Collins, Harrison Ford, skateboarder Tony Hawk, and Hulk Hogan. Ron said about Avalon Hockey player, C. D., "I never thought I could have so much fun talking to a hockey player."

Of the adults who helped Ron throughout his cancer treatment, aside from Mom and Dad, who were always with him, no one had more impact than his teachers. His regular schoolteachers prepared work prior to his absences, and spent their free time helping him catch up when he returned. They also visited and sent gift packages while he was homebound or in the hospital.

[Insert table about here.]

His hospital teachers were flexible and persistent. They roamed rooms and corridors at both the hospital and the Ronald McDonald House to locate Ron, at times. They returned later if he was not well. They waited while treatment was being done. They made up for missed or abbreviated sessions later. They stopped by his room just to visit or to say "hi" or "bye". His New York teachers even tried to fill the role of surrogate

Mom, as the real one was frequently not there, dealing with the financial crisis and insurance burden in Atlantis.

When Ron's medical condition was especially bad, at Sloan, his teacher took on another role, distracting him from his thirst and pain. Once during instruction, Ron's chest tube had to be removed. While this was going on, his teacher left to make a photocopy. When she returned, Ron was trembling and hyperventilating. The nurse tried to distract Ron by asking what he had been reading with his teacher. She picked up on this, quipping that he had already forgotten, then made him get right back into the classwork again. She even later reminded him to take his medications.

Child Life/Therapeutic Recreation Services

Child Life/Therapeutic Recreation Services, which are generally available, upon doctors' orders, to children receiving treatment for cancer in hospitals, may not sound like education, but they consist of activities like music, art, play, and dance, which children do in regular elementary classes. In hospitals, they take on an added significance, providing opportunities for choice and self-expression, when there is so little in these children's lives that they have any control over. When these children are in these sessions, whether at bedside or in a playroom, they can choose between whichever instruments, mediums, toys, or props they want to use. They have the opportunity to be actively engaged; to use their minds, express their emotions, be spontaneous, and discover what abilities and potentials they have, rather than just their limitations (Children's Hospital, Richmond, 2005; Daveson, 2001; Robb, 2000; Mendelsohn, 1999; Jones, 2001).

Ron responded well to music therapy. The first time the music therapist visited him, he was in no mood or condition for her. She kept returning, from time to time, hoping, maybe, for a breakthrough. Ron eventually acquiesced, because he had nothing better to do than to sit in bed all day. He started off singing along quietly with her, but by the end of the session, he was playing a bongo off the top of his head. The therapist was not always this successful, though. One time, Ron was crying when the therapist came in, so she left to get a keyboard, then spent an hour with him. He only felt a little better, but was still quiet and distant. Music therapy was not just about emotion releasing improvisation; a "Musicians on Call" piano instructor gave Ron several "real" lessons keyboarding and reading sheet music.

Psychological Effects of Cancer

Children undergoing cancer treatment exhibit a gamut of behaviors and emotions, such as throwing temper tantrums, being uncooperative, moody, withdrawn, clingy, confused, anxious, fearful, or depressed. Often this is because they need to ask questions about their illness and its treatment, and need people to be open and honest with them about it, or the information they received is erroneous, diminishing the credibility of whoever provided it, or they've learned about another child's death or setback, and they realize that the same could happen to them, or that they are afraid of separation and death. What seems to reassure them is that an effective plan to treat their cancer is in place (Clarke et al., 2005; Stewart, 2003; Judd, 1995).

For most of his six years, Ron was upbeat and emotionally healthy. He was happy, optimistic, witty, entertaining, kind, generous, sweet, and lovable. He ran in the New York Road Runners' Kids Charity Fun Run several years, raising thousands of

dollars for the Ronald McDonald House. He was also very helpful, talking with and providing advice to newly diagnosed children and their parents.

However, occasional incidents caused Mom and Dad to worry about Ron's emotional state. Explanations provided by school and hospital psychologists seemed inadequate. One time, Ron was so mad that he beat his head with a hard plastic pencil box. Another time, he screamed that he did not want to be alive; wanted to be dead, then flung Lego pieces around the hospital room. When he got into one of his moods, he would not want to do anything. He'd become quiet and sit in a corner or go to his room to sulk and cry. After much work from Mom to elicit his feelings, he explained that he was tired, frustrated, and angry about having had to fight cancer for so long; that he wanted it to be done with. There were times when he woke up in the middle of the night, crying almost to the point of hyperventilating. He could not say why, but by a year and a half after his initial diagnosis, Mom and Dad noticed that his mood spells seemed to disappear with additional medication.

Mom and Dad tried to shield Ron from news about just how many of his hospital friends were dying. Sometimes they would tell him, though, because he asked, or because these were very close friends. When this happened, he became quiet; absolutely stunned, then cried, while fighting to hold himself together. He was sad for them, but he also wanted to know if he was going to die.

Each time Ron asked Mom and Dad whether he was going to die, they explained to him the medical treatment he was receiving (he was present while doctors discussed these with Mom and Dad, as well), how his situation was different than that of his friends who died, and how many people with all sorts of chronic illnesses receive their

treatments, but go about leading long and active lives. When they could no longer say any of these things, Mom and Dad answered his question with a question, asking him if he felt any different than previously, then reminded him that he was a seasoned veteran in his battle with cancer. During his last month or so, he sobbed repeatedly that he felt he was in the dark, lost, and holding onto hope by a thread. What he wanted more than anything else was a definite plan. Mom and Dad felt that what was needed, more than anything else, was to get home; to a "normal" environment and routine; away from the big city hospital.

Receiving Palliative Care

Ron returned to Atlantis and to school for a month, until he was no longer able to do so. During his final stay in the hospital, Mom and Dad stayed by his side. Ron's hospital teacher also continued to make regular visits. During the last week of his life, when his teacher stopped by, thinking that she would read to him for a while, he seemed especially alert. She asked if he would like to take a portion of the ACAT. Ron said yes, but he was too weak to read. His teacher read to him a passage about astronaut Sally Ride, then asked him some comprehension questions. He scored 100%. It is as if this were his little way of saying the same thing as Descartes, in his Meditation II

(1641/1901):

...Am I, then, at least not something?

...Am I so dependent on the body and the senses that without these I cannot exist?

...thinking is another attribute...This alone is inseparable from me.

I am - - I exist: This is certain; but how often?

As often as I think...

Discussion

The intent of this study was to give parents of a child who has recently been diagnosed with cancer, an idea of how they can continue the education of their child. The case used was of an elementary-aged child who survived cancer for six years. His parents provided the best possible education, given that their first priority was his medical treatment, and that his school district did not want to commit to providing for more than basic instruction to pass state exams.

In this case study, the IEP, aside from minimally obligating the school district to provide special educational services, was less important than the cultural capital of committed parents, teachers, administrators, family and friends in providing the best possible education for the sick child. The parents described this as others "getting on board," and not letting this child with cancer "slip through the cracks." Educating this child became something of a stochastic process, except that so many people were trying to help. What follows are some generalizations of things that parents, who receive the diagnosis that their child has cancer, can do to provide for their child's education:

- Ensure that all special educational services that your child needs are documented in an Individualized Educational Plan (IEP). Otherwise, states are not obligated to provide any services.
- Take your child to school, if blood counts allow, because more "time-on-task" leads to a better education, as well as more socialization. Otherwise, schedule (and adjust)

class sessions with the homebound and hospital teachers, who are often very flexible and generous with their time.

- Supplement provided educational services, by ensuring that homework is completed properly; provide reading books, educational software and movies; take fieldtrips to museums, zoos, and cultural events; ask impromptu quiz questions, etc.; "minute-manage" opportunistically.
- Keep track of where your child's regular classes are in their coursework and assignments, as well as all work completed by your child, in order to assist the regular, homebound, and hospital teachers in coordinating instruction.
- Encourage your child to eat and exercise as much as possible, to store up strength for when medical treatment becomes difficult.
- Coordinate visits (preferably, depending on blood counts) or telephone calls from classmates, while your child is homebound or hospitalized. Your child will want to play and talk with children her/his own age, not just adults.
- Assemble a team of healthcare and service providers to speak at your child's school about cancer and its treatment, so staff and students will understand, know how to help, and not make problems.
- Provide the school nurse with medications, medical supplies, instructions for usage, and contact telephone numbers, as well as updates on you child's medical status.
- Encourage your child to participate in play, music, art, dance, or other therapeutic services. S/he will feel better afterwards.
- Consult with doctors and psychiatrists about your child's moodiness. This may reflect a drug reaction, or depression.

As a final note, it is very hard for children who are diagnosed with chronic illnesses, like cancer, to undergo the social role change from "student" to "patient." A parent may be with them, they may receive visits from nurses and other adults, but they really miss their classmates. Is it possible to find a better way to bridge the gap between schools and hospitals?

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Selected Charitable and Resource Websites

Alex's Lemonade Stand

Raises money to fight childhood cancer. Includes history of the little girl who began the effort, how to run a stand, grants given, and sponsors.

<http://www.alexlemonade.com>

CaringBridge

Caringbridge offers free, easy-to-create websites to help connect patients to friends and family to communicate current condition, complications, improvements, treatments, etc.

<http://www.caringbridge.org>

CureSearch

CureSearch unites the world's largest childhood cancer research organization, the Children's Oncology Group, and the National Childhood Cancer Foundation through our shared mission to cure childhood cancer. Research is the key to cure.

<http://www.curesearch.org>

Corporate Angel Network

Matches cancer patients in need of travel with private corporate jet schedules.

Information for patients and potential corporate sponsors.

<http://www.corpangelnetwork.org>

Hope Street Kids

The mission of Hope Street Kids is to eliminate childhood cancer through cutting edge research, advocacy and education.

<http://www.hopestreetkids.org>

Ronald McDonald House Charities

Provides comfort and care to children and their families by supporting Ronald McDonald Houses in communities around the world and by making grants to other not-for-profit organizations.

<http://www.rmhc.org>

National Marrow Donor Program

Information and resources for donors, patients, and physicians about bone marrow and cord blood transplants and the latest news about the National Marrow Donor Program.

<http://www.marrow.org>

N-BLASTOMA: Neuroblastoma Discussion Group

N-BLASTOMA is an unmoderated discussion list for patients, family, friends, researchers, and physicians, to discuss clinical and non-clinical issues and advances pertaining to neuroblastoma.

<http://listserv.acor.org/SCRIPTS/WA-ACOR.EXE?SUBED1=n-blastoma&A=1>
