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***From the Mouths of Babes:*
Narratives of Children and Young People
with Advanced or Terminal Illnesses**

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From the Mouths of Babes:
**Narratives of Children and Young People
with Advanced or Terminal Illnesses**

by

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Dissertation

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Dedication

To the children and young people, and their parents,
willing to share their intimate stories on behalf of all those
in similar situations;

To those in the healthcare field who care for them
with their hearts and souls; and

To the person and perseverance of Jeanne Chatelle.

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From the Mouths of Babes:
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with Advanced or Terminal Illnesses

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Death is the only certainty in life. Everyone dies eventually. Yet despite its inevitability, death and dying scenarios represent one of life's most challenging areas of communication. This study delves into this important area of research by focusing a narrow lens on possibly the most unwanted deaths of all: those of children and young people.

Using a narrative methodology, the research presents the stories of 13 children and young people with terminal or advanced illnesses, and the stories of some of their family members. Thematic findings include (1) acceptance and determination; (2) communication and 'straight talk'; (3) sense-making; (4) isolation; (5) spiritual talk; (6); client control; (7) natural alliances; and (8)

individuality. The study suggests applied perspectives within the context of interpersonal and organizational strategies, including conceptualizations of presence, listening, uncertainty expectation, internal sense-making, and language phraseology. The study concludes by offering future considerations within the realm of public policy and specific future research questions within the theoretical contexts of symbolic interactionism and identity.

Table of Contents

List of Figures	xi
CHAPTER 1: THE JOURNEY	1
The Challenge	8
The Process	14
CHAPTER 2: THE STORIES	30
A. Minister Mike Foretells	30
B. The Hooters Guy	48
C. Intellectual Capital	60
D. Praising Life: The Final Chapter	71
E. Leonzo's Lead	88
F. Authenticity	96
G. Unfiltered Harry	106
H. Waiting	131
I. It Happens	143
J. Blistered	155
K. Good News, Mijito! What The Hell!	166
L. Quiet Considerations	184
M. Enough	199
CHAPTER 3: THEIR STORIES: OUR LESSONS	219
Acceptance and Determination	222
Communication / 'Straight Talk'	231
Unnecessary and Undesired External Sense-making	237
Isolation	241
Spiritual Talk	242
Client Control	247
Natural Alliances	250
Individuality	254
CHAPTER 4: ENVISIONING AN APPLIED PERSPECTIVE	257
Interpersonal Strategies	258
Organizational Strategies	272
Future Considerations	275
Conclusion	284

APPENDICES	287
Appendix A: Agency/Entity Contact Listing	287
Appendix B: Newsletter Solicitation Copy	291
Appendix C: Data Collection Letter	292
Appendix D: Interview Decision Tree	293
Appendix E: Interview Protocol	294
Appendix F: Respondent Profile.....	296
REFERENCES	300
VITA	307

List of Tables

Table 4.1. Language of Rhetorical Care—Suggested Phraseology.....	268
Table E.1. Interview Protocol.....	294
Table F.1 Respondent Profile.....	296

List of Figures

Figure 3.1. Conversational Flow from Dying/Ill Young People.	251
Figure D.1. Interview Decision Tree.	293

CHAPTER 1:

THE JOURNEY

Within a 12-day period I had the privilege of sitting next to 2 women as they took their last breaths. The women were mother and daughter. Combined they were 2 of the most influential and loved individuals in my life, my 72-year-old mother, Irma Jeanne Chatelle, and her mother, my 92-year-old grandmother, Faye Farley.

Up until age 42, I had never actually seen anyone die. Nor had I ever held the hands of someone as she breathed her last breaths, and then waited to see if anything else happened. Never before had I looked at a medical professional and said through my tears, “Is she actually dead now?” Nor had I ever helped funeral home people put a person in a body bag. The deaths and lives of these 2 remarkable women fundamentally changed my own life.

One of the deaths was expected, that of my beloved mother. She had battled cancer intermittently for 17 years with a strong will, unimaginable perseverance, a heart of gold, and the gift of humor until the bitter end. She used to tell my father he was going to be very popular with the ladies after she died because he was one of the few *old men* in their town who could drive at night. After undergoing her second mastectomy, she would often laugh and say, “Thank

God that's over." Later, when she was diagnosed with lung cancer despite having quit smoking more than 30 years before, she said with a sad and ironic smile, "Perhaps I spoke too soon."

We were first told in August of 1999 that my mother would probably die that month. She did not. She held on to soak up days of going to a few more garage sales, winning a few more hands of poker, telling a few more jokes, spending a little more time with her treasured granddaughters Lauren and Rachel, celebrating her 72nd birthday, and living through—albeit in a very compromised physical state—one last Thanksgiving.

In this last stage, my father, sister, nieces, and I would sit together with my mother just to be near her because she was always the life of the party—and we all knew the party was quickly coming to an end. We would tell jokes, play cards, remember stories, create Beanie Baby puppet shows with my nieces, laugh at stupid things on television, listen to music, and so on. Yet as the days and weeks turned into months during which my mother steadily declined, no longer could our own stamina or schedules sustain a 24-hour group vigil. Thus we began taking turns.

My mother actually died on November 30—3 months after she was supposed to. In what appeared to be another *routine* evening of handholding, touching, and monitoring her breathing, I whispered to my mother, who was comatose at the time, that dad was going out for a quick walk around the block,

and that he would be right back. No sooner had my dad left the house and shut the door behind him than I noticed a change in my mother's labored breathing. Although this had happened before, something seemed different this time. Mom's breathing seemed thinner than usual.

I did not know whether to leave my mother and run after my dad, but I was afraid that Mom might die alone. So I stayed and continued to hold her hand and tell her everything would be fine, hoping my dad would walk back in the door.

Throughout the next several minutes I thought to myself how inadequate I felt in terms of what to say to Mom through my tears, even though I had dutifully poured through a stack of how-to-care-for-the-dying books. All I could seem to spit out was "I love you," "We'll take care of each other here," "We'll see you again," "It's OK to let go if you want to," and "Everything will be fine." In a few minutes my mother took one last stutter of a breath. As I continued to hold her hand, my eyes went back and forth from her contorted face to the ticking of the clock to see if anything else would happen. Nothing did. After 5 or more minutes had passed, I knew it was really over this time.

A few minutes later, my dad returned. When he came into the room, I told him I thought Mom had died. We both held her hands for a long time to see together if it really was over. Then I quietly stepped out of the room to give my father some time alone with my mom, and to call my sister. Later we waited,

together with a dear friend who happened to stop by, for the funeral people to come and take my mother's body.

My grandmother's death had been entirely unexpected even though she was 92 years old. She was in excellent shape for her age, although she had been fretting for weeks about my mother's health. Yet always before, my mother had managed to get better, even after having breast and lung cancer twice. No doubt my grandmother was hoping and praying for yet another miracle from and for her grown daughter. We all were.

Thirteen days before my mother died, we went to tell my grandmother that my mother wasn't likely to survive this bout with cancer. My grandmother looked straight at me that morning and emphatically said, "I do not want to be here to watch one of my girls die." We all told her how badly we felt about everything. I made arrangements to pick her up the next day to take her to visit my mom for perhaps the last time. As we left my grandmother, we asked to have a social worker look in on her periodically because she was really sad.

Later that same day, the nursing home staff called. They said my grandmother had somehow broken her hip and was beginning to slip in and out of a coma that would likely kill her. No one had seen her fall, nor would she ever tell us if she had actually fallen. We were incredulous. When I reached her bedside and asked her if she were somehow making herself sick because of Mom, she would just smile slightly and remain quiet.

Later that evening my grandmother died. After a several hour period, her breaths simply became more shallow and distanced in time. At the very end she took one last little breath, and then nothing else. She and I were the only 2 people in her room. A nurse's aide came into the room a little while later to check on us. When I asked her if my grandmother were dead, she nodded.

The nurse's aide then asked me if she could spend some time alone with my grandmother. I did not know what she intended to do, but I knew I needed to make some calls to my family, so I stepped outside the room. When I walked back in, my silver-haired precious grandmother lay there with her eyes shut in a new nightgown and robe. Her hands were folded across her stomach. She lay on top of fresh bed linens.

My grandmother looked absolutely beautiful, just like a 92-year-old Sleeping Beauty. Her body was full of grace and poise. I will always feel indebted to that nurse's aide. She had fully bathed, redressed, and changed the bed sheets of a person who was already dead. Maybe that was nursing home protocol. To me, it was an act of amazing grace from a guardian angel.

As we waited together for the funeral home personnel to arrive, the aide stayed with me as I brushed my grandmother's hair and told stories about this wonderful woman. When the funeral directors arrived, I helped them put my grandmother into a body bag, something I could not later bring myself to do with my mother.

We then walked quietly and slowly down the long nursing home corridor. There were 4 of us—myself, 2 people from the funeral home, and my grandmother in a body bag on a gurney. As we walked down the corridor, I saw several residents standing quietly at their doors, almost as if to pay their last respects. I thought to myself how hard it must be, when you are elderly, to see one of your fellow nursing home residents being taken out in a body bag. I was sad for them and sad for us.

To this day there are many unanswered questions that remain in my mind about death, despite having watched 2 very significant people in my life die. I wonder how people truly make sense of their own losses. I wonder how those who have lost entire families in an instant due to accidents manage to cope and carry on. I continue to think about the devastating and massive losses from the September 11th tragedy.

Amidst all of the uncertainties of life and death alike, what I do know is that my grandmother's death helped prepare me for my mother's death 12 days later. It was also a stark personal revelation to me that losing a child, even a child the age of my mother, is just not the way it is *supposed* to be.

As I sat at the funerals for my grandmother and then my mother, I began my own personal journey into thinking and wondering extensively about death. The thought struck me about the unconditional love of a mother for her children (or a father for his), and the dire need to avoid the pain of losing a child. I began

to think how we as a family might feel even more consumed with grief, if that was possible, had the caskets been smaller and contained the remains of the younger members of our family. The thoughts and questions stayed with me long after the funerals ended. Thus began this dissertation journey.

At times while creating this document I have dreamt about the babies or children or young people who were dying—especially those whom I’ve had the privilege of interviewing along with their family members and healthcare professionals. I have thought about them not in terms of what they have accomplished, but of what they may have missed or perhaps are going to miss. I have asked myself repeatedly: *What is it like for a mother to push her baby out of her body, and then have to bury that baby before he or she reaches adulthood?* A part of me believes all the research in the world will never fully answer that question.

I think about children and young people who may never put their first teeth under their pillows, reach their first birthdays, go swimming, pack a satchel for the first day of school, draw giant cursive letters on Big Chief tablets, perform at their first recitals, drive a car, get nervous about their first dates, experience their first kisses, go to the prom, or cross the stage of their graduations. I think about young people who, at some level of their emotional being, know they will eventually be leaving their loved ones behind, sooner rather than later.

What takes place when our worst nightmares are realized and the dying are children? What should be said to them? How do they make sense of their lives? What can they teach others?

Much is written in the literature about death and dying from a general, academic perspective. Yet much less is offered from the specific perspectives of those who have the greatest story to tell: the children and young people themselves who are personally facing life-threatening illnesses. The hope of this research is to expand upon the literature in this area. We begin with a brief overview of current scholarship.

The Challenge

Talking about death in general seems to be hard. Talking about death with persons who are actually dying is even harder in that it represents one of the biggest communicative challenges we all face.

Miller and Knapp (1986) point to one of life's most difficult discursive situations as the need for communicating with a person who is known to be dying. This particular sphere of communication represents a skill many do not want to think about, although most would like to have instant expertise when faced with such an encounter. It often elicits an increase in avoidance strategies along the lines of being *upbeat*, *updating*, and *recounting* (Miller & Knapp, 1986).

The Unthinkable

If we find such difficulty in dealing with dying individuals who are grown, then what happens when children are the focus? Thus far a majority of extant scholarship is predicated upon a chronological order of reality in which adults usually die first.

Yet expected life scenarios do turn to the unexpected, in which the natural and expected chronological order of death turns upside down. What happens when the very people who are dying are children and young people? Are we *dying to know* this information? Extant research suggests not.

Milo (1997) argues losing a child is out of the normal order of things to the point of being *unthinkable*. My grandmother wanted no part of the unthinkable, for there is no doubt in my mind that she willed herself to die in order to avoid the pain of losing a child—even a child who was 72 years old.

As a society, we contemplate the deaths of parents, grandparents, siblings, and friends as generally accepted and natural—if sad—facts of life (Fletcher, 2002). In contemplating death, dying, or bereavement, however, few of us are willing to consider children dying before their parents, given the death of a child is unfamiliar, uncomfortable, and outside the natural order of generational progression (Fletcher, 2002). Judd (1989) calls such a death *out of season*.

Un-Silencing Children's Voices

Children's voices are noticeably silent in extant research on pediatric illness, pain, and death. In a extensive, though non-exhaustive, review of more than 200 articles and books published since the 1960s, I found 12 studies containing sample populations comprising sick children (Bluebond-Langner, 1978; Burton, 1975; Hunt, 1990; Goldman & Christie, 1993; Issner, 1973; Katz, Kellerman, & Siegel, 1980; Ljungman et al., 2003; Morrissey, 1963; Natterson & Knudson, 1960; Ritchie, Caty, & Ellerton, 1984; Spinetta, Rigler, & Karon, 1973; Waechter, 1971).

Most of the studies related to children's conceptualizations of adults' death. This reaffirms Thompson's (1989) notion that researchers place greater weight on studying the challenges and ramifications of helping children adjust to the deaths of *others* as opposed to their *own*, given the degree to which researchers themselves are uncomfortable even thinking about the subject of children dying.

Bricher (1999) suggests children's voices are distinctly missing in research surrounding children and pain. Goodman and McGrath (1991) found that a comprehensive analysis of pain problems often associated with terminal illnesses in childhood and adolescence continues to be void of the perspectives of the children themselves, although chronic pain is conservatively estimated to affect 15 to 20 percent of the pediatric population.

In thinking about death and dying, I am making the argument that if researchers struggle with willingness to listen to children who are in chronic pain then the challenges in listening to children who may be dying are even greater. Even in scholarly writings on death and bereavement pushing for *full* communication with individuals who are terminally ill, specific references to dying children are noticeably absent.

For instance, in an otherwise excellent compilation of articles on end-of-life issues from interdisciplinary and multi-dimensional perspectives, de Vries (1999) offers a wide range of viewpoints in an effort to address the complexity of life and death, and to promote dialogue among those whose personal and professional interests bring them into contact with the dying and the bereaved. The compilation includes articles from the perspectives of grandparents in times of bereavement and even the perspective of animals as neglected members of families coping with death. Yet no specific mention is made of the perspectives of dying children.

Why is this so? Fowler-Kerry (1990) argues that if we are to develop a true understanding of pediatric healthcare issues, we must do so by hearing directly *from* children, as compared to hearing *about* them from parents, representatives, or advocates.

Knowing

We need to hear from seriously ill children because they know a great deal about what is happening to them when they become ill. Nagy's (1948) pioneering empirical work set the foundation for understanding more about how children thought about death in stages based on specific ages. Bluebond-Langner (1977) found in her seminal work with children who had leukemia that children became stronger in their personal awareness of their own deaths as those deaths became imminent, despite physical and cognitive limitations of disease progressions that might normally dictate otherwise.

Silverman (2000) found there comes a time when children realize they will die from their conditions. When this happens, parents need to be able to follow their children's emotional and cognitive development in an effort to recognize the changes their children will experience in death conceptualizations, as well as their own ways of relating to the world.

Extant literature suggests children from the ages of 6 to 10 years generate a sense their personal illnesses are no ordinary illnesses, despite frequent efforts of parents and medical personnel to keep the children unaware of their prognoses (Spinetta & Deasy-Spinetta, 1979). Faulkner (1993) argues children's perceived nuances of death, including their own, stem from personal experiences and environments that vary greatly from those of adults. Koocher (1974) found that children are far from being miniature adults in terms of the quality of their

cognitive capabilities; thereby suggesting adult literature on death and dying presents an incomplete and thus inaccurate picture of children's perspectives in dealing with their own illnesses.

There is both a uniqueness and commonality in death experiences. Children who are seriously ill and their parents share many common experiences and feelings (Spinetta & Deasy-Spinetta, 1979). As well, there are significant differences among experiences, personalities, economic and social standing, and political and religious orientations. Such expected richness in *similar* and *different* perspectives alike is worthy of in-depth examination through the voices of the children themselves.

A Limited Goal

The intent of this research is to delve into an important and expansive area of study using a limited and narrow lens. The research is deliberately designed *not* to change any outcomes or make sweeping predictions. It is *not* designed to end with a new communication theory or model or suggest how someone should or should not die. In sum, it is not designed to culminate into one grand narrative.

Rather, the study is predicated upon individual stories, each containing its own messages. These messages collectively reflect an observer's look at how language plays a role in the lives of children and young people with diseases considered incurable and in the lives of those around them.

In essence, given their unique messages, the narratives themselves serve as stand-alone data. Such individualized offerings of self-disclosure give greater voice to a special segment of society missing from extant literature, while shedding new light on a difficult topic. In sum, this dissertation offers the stories themselves as a beginning framework upon which additional theoretical questions can and should be pursued.

The Process

In keeping with the limited intent of having the stories speak for themselves, this study began with the following research questions:

- | | |
|-------------|---|
| RQ1: | What can scholars and society alike learn from hearing the personal stories and narratives of dying children or children facing life-threatening or advanced illnesses? |
| RQ2: | What meaning and sense-making are these individuals constructing during this time in their lives, and toward what ends? |

Additional research questions stemming from the data collection are identified in chapter 4, in the section titled “Future Considerations.”

Bricolage

Denzin and Lincoln (1994, p. 2) describe qualitative research as multi-method in focus, involving an “interpretive, naturalistic approach to its subject matter, suggesting that qualitative researchers study things in their natural

settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.” A picture of qualitative research and its multiple methodologies is painted as *bricolage*, from the French word for *bricoler*, meaning to putter about or to construct something by using whatever comes to hand. Levi-Strauss (1966, p. 17) calls this multi-faceted form of qualitative research a commingled, close-knit set of practices providing solutions to a problem in a concrete situation as offered by the *bricoleur*, a “Jack of all trades or a kind of professional do-it-yourself person.”

The notion of *bricolage* is offered given the reliance upon qualitative research as an important methodological foundation for this study. Pauly (1991) argues that the topic of all qualitative research is the making of meaning. Qualitative inquiry lends itself to a research plan that is like the methodology itself: It does not reduce the process to some simple set of procedures in support of a conceptualization. Lindlof (1995) says qualitative researchers are seeking to preserve the form and content of human behavior while analyzing its qualities, rather than subjecting it to mathematical or other formal transformations.

Wright and Flemons (2002) argue researchers who wish to predict and control, measure variables, test hypotheses, and make refutable truth claims will find little of interest in most qualitative methods; but social scientists who are searching for meaning rather than laws can find much in qualitative research to inspire and intrigue them. In sum, my attempt is not to find the ultimate truths

from the children and young people's stories, but rather to (1) let the stories speak for themselves, and (2) examine similarities and uniqueness contained in the stories from which we can all gain knowledge about an inevitable human situation: death.

The Preparation

Prior to undertaking this study, I conducted research in other areas involving healthcare or end-of-life communication using qualitative interviews. Included in this research were interviews with clergy persons from multi-denominational churches who minister to dying individuals and interviews with spouses whose partners died following many years of marriage. I have also studied healthy children and their experiences with dental pain and immunizations from a communicative perspective. In most of these cases, I used a narrative approach involving open-ended questions. I use a similar approach in this particular study, as I discuss in greater detail in subsequent subsections of this chapter.

My additional exploratory research and preparation included becoming certified as a hospice volunteer in a large municipal hospice organization catering to both adults and children. As a part of this certification process and the studies mentioned above, I conducted preliminary interviews with hospice clinicians, clergy, and other volunteers, as well as with healthcare professionals and volunteers in various hospital, pediatric palliative care, and nursing home settings.

As a part of my own civic interests and academic scholarship, I also participated in a 3-day camp for children who had experienced the deaths of loved ones. I conducted no interviews during this time; nor did I attempt in any way to use the event as a data-gathering opportunity. No written data, transcriptions, or notes were taken during the retreat, although I did hold informal conversation with various hospice professionals trained in pediatric research and with other community volunteers.

Before I participated in the children's bereavement camp, I also attended an orientation session that focused on the stages of grief for children from the perspective of chronological age. Results of the orientation session validated much of the bereavement literature in suggesting that age matters in children's conceptualizations and understandings of death, including their own. At this orientation session, the hospice professionals also highlighted the importance of understanding community support systems in examining this topic from familial perspectives.

Data Collection

Judd (1989) asserts that although theories help form a useful structure, actually working with a child brings forth the excitement of discovery. In my work with children and young people, their parents, and healthcare providers, I used participant interviews as the basic data collection methodology for the study.

Rubin and Rubin (1995) claim that interviews work best if the interviewer and his or her conversational partner are in a small room—maybe sipping coffee—while quietly discussing an event or exploring some aspect of their culture. For this study, repeated attempts were made to replicate such settings in quiet and conversational interview fashion with the children and their parents and with healthcare professionals. Such attempts met with varying degrees of success, especially when the interviews were conducted in hospital rooms during the administration of medical treatments.

Geertz (1973) affirms there is much to learn about cultural interpretations from what he calls *thick descriptions* in the interviewing process in terms of inscribing meanings around particular social actions. For purposes of this study, data analysis was conducted based on thick descriptions resulting from conversations with children who have serious or terminal illnesses from advanced diseases, and from conversations with their parents. An assumption was made from the onset that if children and their parents were voluntarily giving of their time for interviews, they were willing to tell their stories and experiences in detail.

Recruitment

Thirty interviews were conducted for the purposes of this study. Thirteen interviews were conducted with seriously ill children and young people primarily identified by physicians who practice in areas involving advanced or terminal

illnesses. The remaining interviews were conducted with parents and healthcare professionals working in the field of pediatric care, including pediatric palliative care in which children are simply being kept comfortable in preparation for their expected deaths.

The sample size recommended for this study was in keeping with other scholarly work in this general area based on qualitative methodologies. Yedidia and McGregor (2001) conducted a study based on semi-structured interviews with 30 patients as close to their times of death as they determined possible. Brinchmann, Forde, and Nortvedt (2002) conducted 20 in-depth interviews with parents making life-and-death decisions regarding premature and/or critically ill infants. Fletcher (2002) used a sample of 2 families as a way in which to theoretically compare events, incidents, or happenings to determine variances in families grieving the losses of their children.

Age matters in children and young people's death conceptualizations. As such, careful consideration was given to the requested age of the children and young people in the sample population. For purposes of this study, children and young people in the data set fell within the range of 5 to 20 years of age. Spinetta and Deasy-Spinetta (1979) found children in this age range, or more narrowly in the range of 6 to 18, have a fuller sense of the magnitude of their own illnesses. Another justification for selecting this particular age range for the sample

population related to the children's abilities to verbally express their feelings, beliefs, and experiences.

One of the important distinctions of this research was a sincere attempt to conduct stand-alone interviews with as many children and young people as possible, specifically without the presence of parents or family members. Such a protocol was attempted, with varying degrees of success in this study.

Appendix A contains a listing of all of the agencies and key individuals I personally contacted for the purpose of finding individuals to interview. I made an additional but unsuccessful attempt to secure respondents via advertising in publications such as newsletters for the Texas Nurse Practitioners and the National Association of Social Workers (Texas Chapter). Appendix B represents newsletter copy placed in both publications at my expense. No respondents were directly recruited via this method.

Finding willing respondents took approximately 3 months of intensive work, not including the time invested in preparing a second research application. That step in the recruitment process is described in the following section.

Institutional Review Board (IRB) Approvals

Two Institutional Review Board (IRB) approvals were obtained for this study. The original proposal, IRB Protocol Number 2002-11-0038, went through The University of Texas at Austin. The UT-Austin Office of Research Support and Compliance approved the study request on December 18, 2002, prior to the

proposal defense for a time period lasting until November 25, 2003. The study was re-approved from September 3, 2003, to September 3, 2004.

When I was making initial contacts for data collection purposes, numerous individuals referred me to Dr. Javier R. Kane, M.D., Associate Professor and Head of the Palliative Care Program, Division of Hematology/Oncology/Immunology, Department of Pediatrics, The University of Texas Health Science Center at San Antonio. Dr. Kane works with children who have advanced illness and/or children who are in the active stages of dying. In July of 2003, I met with Dr. Kane and toured his clinic, which is located on the 8th floor of the Christus Santa Rosa hospital facility in San Antonio, Texas.

Dr. Kane and his pediatric palliative care team were extremely excited about the prospects of working on a qualitative study involving communication aspects of ill children and young people with advanced illness. Dr. Kane suggested that I undergo a second IRB approval process so that he and his associates could serve as a referral source.

The second IRB was approved through The University of Texas Health Center in San Antonio, IRB Protocol Number 034-0099-105. It was approved on November 5, 2003, with an expiration date of November 4, 2004.

Dr. Martha Morse, M.D., Pediatric Pulmonary Specialist from San Antonio, Texas, was also instrumental in referring patients to me. Dr. Morse was featured in a *San Antonio-Express News* article titled “Doctor says it’s all right to

be human: Physician Martha Morse shares her experiences on dealing with dying patients (Pisano, 2003).”

I formed partnerships with Drs. Kane and Morse and other individuals listed in Appendix A to find willing interview respondents. Respondents were also identified via a convenience sample in collaboration with physicians and representatives of healthcare provider organizations such as hospice entities and children’s hospitals.

Once the parents of prospective respondents were identified, I requested that staff members of the healthcare facilities or professional agencies make the initial contact via a cover letter with information on how to contact me if individuals were interested in participating. This process was in keeping with the IRB specifications. Appendix C shows a general letter given to individuals working in the field who were willing to share information about the study with potential respondents. Once individuals indicated a willingness to consider being interviewed, or to having their children interviewed, names were passed along to me by healthcare physicians or individuals working in the field for follow-up purposes. I made no direct contact with potential respondents until permission had been granted by participating physicians or healthcare providers.

Given the complexity of working with individuals during this particular time in their lives, I developed an interview decision tree prior to data collection. Appendix D shows a general model of the decision tree.

Appendix E shows a typical Interview Protocol, including the general outline used as a starting point. I made modifications as warranted. The primary interview criteria beyond medical diagnoses were that (1) the children or young people be able to communicate, and (2) that in the case of children 18 or younger, their parents be agreeable to the interviews.

Both male and female children were recruited. Serious attempts were made in working with various healthcare professionals to find gender and ethnic diversity within the respondent pool.

Interviews

I solicited interviews with pediatric, parental, and medical personnel. Regarding parental involvement, repeated attempts were made to separate parental participation between mothers and father to the extent possible so as to maximize gender participation.

Interviews ranged in length from approximately 20 minutes to well over 2 hours. Locations for the interviews varied, predominantly between the respondents' homes and the Christus Santa Rosa Pediatric Palliative Care Center, in both the clinic and hospital settings. Other interview locations included retail outlets such as restaurants and coffee shops. I used semi-structured, open-ended questions in the interviews in support of the identified Research Questions. Such questions are shown in Appendix E as asked of both children and parents.

Appendix F is an overview of the respondent profile including children/young people, their parents, and healthcare providers. As noted, some children and young people were in remission from their diseases. Some were in the active stages of dying. One of the identified respondents was too ill to be interviewed at length beyond an initial brief conversation. He subsequently died a few weeks later. However, his mother was willing to be interviewed to give voice to her dying son.

Some of the children and young people were struggling with advanced illnesses in various stages, e.g. cancer or Cystic Fibrosis, from which full recovery or life longevity was not expected. In sum, the overall criteria for being included in the project required first, that the children/young people and parents were willing to participate in a voluntary capacity, and second, that such participation on the part of the children and young people would in no way make difficult situations worse. In keeping with IRB specifications, it was stipulated in advance that if, at any time, a patient's ongoing participation in the project was thought by any involved party to be detrimental to the patient's situation, interviews would be discontinued or not pursued. This situation did not, however, occur at any time in the data collection.

I recorded all interviews via cassette tape, and made extensive field notes along with the taped conversations. An outside professional service transcribed

the tapes. Confidentiality was maintained at all times in keeping with both IRB protocols.

Data Analysis

For this study, I used a thematic approach to compile and analyze data by conducting an ongoing content analysis of the interview transcripts (Patton, 1990). As Patton recommends, I conducted data analysis based on various strategic options, such as categorization via chronology, key events, various settings, people, processes, and issues. I developed and expanded emerging themes as a result of the interviews using Glaser and Strauss's (1967) constant-comparison method to create categories of relationship between data units.

Validity

Babbie (2001) states that simply “being there” is a powerful technique for gaining insights into the nature of human affairs in all their rich complexity. He uses an example of an interview with a nurse discussing impediments to patients' abilities to cope with cancer in suggesting that observations and conceptualizations are valuable in their own right, and provide the basis for further research—both qualitative and quantitative.

Kirk and Miller (1986) propose that one way to help ensure validity with research is to constantly evaluate the data by spending considerable time in the field and with resource persons in order to check and recheck for accuracy.

Throughout the study, I periodically made checks and rechecks with various respondents in the field regarding the data being received.

Reliability

Babbie (2001) addresses the reliability issue by suggesting that researchers should use the benefit of colleagues in a communal sense of science to sort out their own biases and points of view. Bochner and Ellis (1996) argue that qualitative researchers are hard-pressed to stand above and outside what they are studying. To help ensure reliability, I periodically used physicians and other healthcare providers and professionals from hospice and other healthcare entities as communal colleagues for the purposes of checking both data reliability and validity. I discussed emerging themes with these various resource individuals on a periodic basis while maintaining confidentiality of participants in the sample population at all times.

In studying terminally ill persons, Wright and Flemons (2002) call for the establishment of *relational integrity* in which relationships being studied are held to be inviolable. Researchers must not impose themselves on the person or thing being researched, but must allow the researchers' informants, experiences, data, and analyses to speak for themselves.

Two components of Wright and Flemons' (2002, p. 268) choices for ensuring relational integrity include (1) treating interviews as conversations in which respondents are invited but not pulled or pushed into an exploration of

experiences; and (2) allowing data analysis to become a process of composing stories about participants' stories in the way of creating "meta-stories that retain the uniqueness of individual participants' voices and that weave these voices contrapuntally." The importance of storytelling as a core methodology for this study is discussed in the following section.

Narratives and stories

The core foundation upon which this dissertation is based points to the value of stories. Everyone has a story to tell. At the beginning of this chapter, I told part of my own story, involving my mother and grandmother. Browning (1992) says that stories are communications about personal experiences told in everyday discourse that do not require a technical specialist to understand what they mean. He argues the telling of stories gives coherence to a group subculture (Browning, 1992). Fine and Sandstrom (1988) state that working with children presents opportunities for researchers to step back and learn from those who are constructing their own worlds in the moments of creating monuments.

Gilbert (2002) says the terms *narrative* and *story* are generally found to be synonymous in a world in which we live in stories, not statistics. I use the terms as such for the purposes of this section and within this study.

The telling of personal narratives is one form of presenting self to others that begins early in life and crosses racial, ethnic, and cultural boundaries (Markham Shaw, 1997). Not only do we present ourselves through narrative,

those with whom we are involved present us to others through narrative. Bruner (1990) and others offer narratives as a way in which individuals make sense of experience. The story metaphor emphasizes that we create order and construct texts in particular contexts. Because narratives help create plots from disordered experience, they become essential meaning-making structures that must be preserved and not fractured by investigators, who must respect respondents' ways of constructing meaning (Riessman, 1993). Situational contexts such as difficult life transitions and personal trauma lend themselves to order making (Beck, 2001; Riessman, 1993). Beck (2001) argues the public presentation of personal narratives can accomplish coherence and consistency through the description of some personal trauma. Storytelling is simply what we do with our research materials, and what informants do with us (Riessman, 1993). Browning (1992) points to stories as messages that unfold naturally; and that stories are known to be flexible, evolving, and changing. People learn to give context to what is said in a story (Browning, 1992).

For purposes of this research, knowing more about ill or dying children in particular can and should teach us a lot about understanding the future generations of children who face life-threatening illnesses and their parents who live through those situations vicariously and experientially. Such information should also be of assistance from a public policy perspective as societal policy leaders continue to struggle with the issue of dying children from a myriad of contexts. At a

minimum, hearing from ill children and young people should arguably help shed additional light on what Sprang and McNeil (1995) define as one of the most avoided topics of conversation in society: our own deaths.

Puchalski (2002) argues that of all life's difficult yet important experiences, dying may be the most difficult; thus a critical need exists to ensure that society enhances the dignity of all people, especially those made vulnerable by illness and suffering. Puchalski identifies listening as one of the primary ways of ensuring this dignity.

When I have told people about the topic of my dissertation, the response, quite often, has been the same: a non-verbal contorting of the face in grimace like fashion. A verbal response usually followed along the lines of "Why in the world would you want to study that? It's so depressing."

Yet listening to my own inner compass following the deaths of my mother and grandmother told me to make this journey, which has been far from depressing, although there have been many sad days. Through it, I have become convinced there is much to learn about living and dying from talking with those whose lives may be coming to a close, most especially the children and young people who are experiencing the unthinkable.

CHAPTER 2:

THE STORIES

Stories are important within research. Gilbert (2002, p. 235) suggests that storytelling is integral to study in that it affords the opportunity to hear respondents speak in their own words, as filtered through choices made by the researcher. The approach “taps into the emotional as well as the intellectual experience of the participants.”

The stories contained in this study come from the hearts and minds of those seriously ill. They contain as much raw transcription as possible in an effort to maximize the accuracy of the respondents’ emotional experiences. I present them here in chronological order of my interviews, beginning with Minister Mike.

A. Minister Mike Foretells

My first interview resulted from a referral by a pediatric pulmonary specialist who had heard of my research. She sent me the name of the young man, Mike, who was affectionately known as “Minister Mike.”¹ The young man and

¹ Unless otherwise noted, the names I use in this dissertation are the actual names of the people involved, used with their permission. In keeping with IRB requirements and healthcare rules and regulations, I have changed the names of some people in some narratives. In this story, I have changed the names of the people I call “Mike/Minister Mike,” “Little Sam,” “Dr. Esperanza,” and “Rosie.”

his mother were anxious to tell me of their lives in the spirit of witnessing. Their story began with a tale of a vision.

In the Beginning: A Brotherly Vision

Minister Mike foretells a vision: “My brothers and sisters in Christ, I bring you good news of great joy. For I have seen a great light. And the great light is that of my brother, Little Sam.”

A young, seriously ill, 12-year-old boy, Mike remembers the vision. While sitting in his wheelchair in a small, contained, and humble apartment he shares with his mother, the handsome young man with puppy-dog eyes and a full head of straight black hair tells me what transpired during one of many hospital visits.

In his vision, Mike clearly saw his older brother, who had been affectionately known as Little Sam. Little Sam died at the age of 4, of the same disease that afflicts Mike now. No one had ever talked very much about Little Sam with his younger brother because they shared the same disease. Everyone tried to protect Mike.

Yet on this particular hospital visit, Little Sam visited Mike in the hospital in the vision. “He came. I saw him in a vision with 2 other angels. I didn’t know who they were. I couldn’t really visualize them. But he had come and he told me: ‘Get Mom out of there—it’s a trap.’” So Mike insisted that he and his mother leave the small South Texas town that had been their home in order to receive better medical care and escape worrisome family problems. The vision

transported the family to a large metropolitan area of Texas where they willingly agreed to tell me their story.

Mike and Minister Mike

Mike spends his days sitting in a wheelchair, riding a special transport van that picks him up in the wee hours of the morning, going to school, playing video games, watching television, talking to friends who call him “Dude,” and visiting with his mother and grandmother. To pass the time while glorifying his God, he sings Christian songs in a rich deep voice with a full vibrato in sweet harmony with his mother. His nights are spent sleeping on a small bed tethered to oxygen.

His birth name is Mike. His self-appointed name is Minister Mike. His mother uses that name as well for her son. He foretells his own life story, as short or long as it may be.

Children with Special Needs

Mike moves around predominantly by using a wheelchair. He has been stricken with Neuro-Muscular-Dystrophy (NMD), or more specifically, Spinal Muscular Atrophy (SMA). Spinal muscular atrophy is a genetic mutation that destroys nerve cells in the spinal cord, leading to muscle weakness and atrophy (wasting).² For Mike, the disease has specifically robbed him of his ability to

² MDA Diseases (2001, May 18). *Spinal-bulbar muscular atrophy MDA fact sheet*. Retrieved January 4, 2004, from http://www.mdausa.org/disease/fasheet_sbma.html.

walk, and so he remains confined to a wheelchair, relies heavily on oxygen, and is surrounded by machines to help him maneuver through the day. Amidst the many celebrity posters and computer games, Mike's bedroom looks like a mini-hospital room.

The disease is no stranger to Mike or his mother. Four years after Little Sam died, Mike was born with the same affliction. Mike's mother calls her boys "children with special needs."

Twelve years ago physicians told Mike's mother he would not live to his first birthday because of his physical plight. Today he defiantly contorts his body and thrusts a clenched fist in the air from his wheelchair to proclaim his longevity at age 12. "Against all odds" seems a fitting mantra for Mike, especially as compared to the very short life of his older brother.

Little Sam and the Family

Despite dying so young, Little Sam seems to have paved much of the way for his younger brother, Mike. Little Sam was treated in a small community where medical technology and innovation at the time were quite limited. "[There] they didn't have the technology like we have now, like the IPV machine, the VPAP machine, they didn't have all that," Mike explained. The Intra-Pulmonary Percussive Ventilation (IPV®) machine helps clear individuals' lungs and improve overall breathing. The Variable Positive Airway Pressure (VPAP®) machine is designed to help with breathing overall and specifically assist in

alarming patients and caregivers when respiratory pressure is too high, too low, or there is a power failure involving any of the breathing assistance machines.

Mike's vision of Little Sam gave him the impetus to insist that a move be made. In about 1995, they say, Mike and his mother made the move across Texas and settled near a large hospital serving pediatric residents where physicians were learning more and more about his disease.

The move from a small community to a metropolitan area also helped Mike solve family issues, primarily for his mom. "I just kept telling Mom that we have to move away, and that it's [the smaller town] a trap, and we need to get out of there." Mike says his dad wasn't the "right kind of person" for the family. "Although this is where most of my family lives [in the smaller town], I just kept telling Mom that we have to go to the bigger place. It's a trap, and we need to get out of there," Mike kept saying, over and over again.

After the move, when Mike's father sent his mom divorce papers saying their marriage was nothing more than "a big show," Mike responded by encouraging his mom and viewing the dilemma as a mother/son partnership problem, saying that "*We* had to go through that part, and *we* got through it." Mike continues to be estranged from his father. "Up until now, ever since we left the house to come down here [to the larger city], I haven't seen him ever since. I don't want no contact. I don't want to, I don't. . . . I don't really want contact with him because I don't want him to give my mom trouble."

Golly Dude: Minister Mike and His Legacy

Mike and his mom reminded me of an important Biblical teaching to them (John 3:16, New Revised Standard Version): “For God so loved the world He gave his only son, so that everyone who believes in Him will not perish but will have eternal life.” Young Mike and his mom believe in that message wholeheartedly. It embodies the very heart and soul of the way they live their lives, and carry out their mission of service to others.

Mike explained his belief to me that God had given him a highly privileged and very special agency with Him, proclaiming him “Minister Mike.” Mike laughs when he talks about his friends who say: “Golly, dude; you’ve got a special relationship with God. You’ve got a real relationship with God.” He responds by saying: “Yeah, even though I may look like I’m playing my [computer or video] games or I’m doing something else, I’m talking to God actually. That’s my time alone when I’m playing my games. I just talk to Him in the mornings when I’m just there.” When asked if God talks back to Mike, he responded without looking up and without elaboration, “Yeah.”

Carrying on a conversation with Mike means sometimes you are talking with 12-year-old, all-boy Mike, whose favorite movie is *Finding Nemo*, and who blushes when he talks about meeting a beauty contestant winner from his large city. At other times, talking with this child with special needs means you are receiving The Word from Minister Mike. He is quick to quote Bible verses. He is

a soloist in his church choir, and he actively solicits food and toy donations for the underserved, all as callings from God.

Both Mike and his mom wholeheartedly feel that Mike has lived 11 years longer than expected for a variety of reasons, including the love and care of outstanding physicians and the benefit of research and technology surrounding him in the bigger city. Yet the primary reason Mike believes he is still alive is because God has called him to minister to others. This special calling has allowed, and mandated, that Mike live in order to become Minister Mike, and be in service and outreach to others. God “helps me out,” Mike explained, thus giving back because of that help is important to him.

Mike defines this outreach as his “legacy,” a word that many 12-year-old boys could arguably not even know—much less feel a burning desire to *create* before they die. Mike likes to tell his story over and over again so that he can sustain the legacy he is ardently trying to create as fast as he can, especially given his limited life expectancy.

During the Christmas season, Minister Mike actively solicits funds in order to dress up as Santa Claus. He hands out toys to younger children less fortunate. When asked how his legacy building was proceeding, he replied: “Oh, it’s going good. I still haven’t reached as many as I had over there [in his small hometown]. We are still getting our feet wet here. We’re still trying to get more people here [in his larger city].”

People, Not Animals

Mike wants to make others understand how to relate to people like himself. He wants people to understand there is a definite demarcation between “people” and “animals.”

“I like it when people treat people with disabilities as people—like regular people. Because we are, we’re not just animals, we’re not anything like that. We’re normal human beings. We are just like any normal person.”

Mike firmly believes that “even though we do come in different shapes and sizes and colors and everything, we’re just like everybody else. It’s no different.” The bottom line is that “we’re still human beings.”

Mike and Dr. Esperanza

One of Mike’s favorite people is his physician, Dr. Esperanza. Mike loves Dr. Esperanza, and his face lights up with a smile when anyone mentions her name. Mike loves to talk about her, and tell stories of how they work together to keep Mike from dying.

Dr. Esperanza is well known in the large city for her work with young people and children. After 16 years of medical practice as a pediatric pulmonary specialist, she says now that she can love a patient and lose a patient and survive and “be better for it.”

Together Dr. Esperanza and Mike fix his lungs—over and over and over again for the time being. Like so many young people with spinal muscular atrophy, Mike repeatedly finds himself knocking at death’s door because of lung fluid problems. Dr. Esperanza has repeatedly saved him. They work together as a team, and they “shoot straight” with each other about the severity of each situation.

“We openly speak of him dying sooner rather than later, although unlike cancer there is no timetable,” Dr. Esperanza said. “As long as he doesn’t get an infection, he can go on a while, but when he gets a cold, he just goes downhill,” she added.

During one particularly difficult time within this past year, Dr. Esperanza repeatedly tried to eliminate fluid from Mike’s lungs so that he could breathe, but without complete success. Mike described the procedure: “They have a special tube . . . and this procedure takes about 20 or 30 minutes. They have this tube, and they go in and it has a real small camera, and they see inside the lung. There’s a hole for suctioning, and there’s a hole for putting medications in there, and there’s a hole to blow in oxygen.”

Mike calls the procedures “bronchs.” During this particularly difficult time, Dr. Esperanza had already completed at least 4 or 5 bronchs on Mike, each of which could be life threatening because of the medical risks associated with sedation and other potential complications. While Dr. Esperanza had been

successful in getting out much of the phlegm and mucus and other problem fluids in Mike's lungs, too much fluid still remained, which would eventually kill him.

"She [Dr. Esperanza] told my mom to prepare for the worst, and to start thinking reality," Mike said. Prior to the 5th or 6th procedure, Mike had told his mom that he wasn't ready to leave yet, although he knew that Dr. Esperanza had tried everything humanly possible to clean out his lungs. He even told Dr. Esperanza before the procedure took place not to feel badly if it didn't work this time around because she had tried everything possible.

He also specifically called Dr. Esperanza over to his hospital gurney prior to the procedure to say "thank you" to her for all of her efforts. "I want to thank you, and I know you have done and you are doing everything in your power that you can, and I want to tell you that I love you," Mike told Dr. Esperanza. "I saw my mom turn around and she started to cry. Dr. Esperanza put her head down, and she turned red, I saw her," Mike remembered. He specifically requested that Dr. Esperanza watch over his mother because he knew that she would be sad when he died.

"And finally it came to her [Dr. Esperanza], and God gave her this idea," Mike said explaining the innovative procedure that Dr. Esperanza had created specifically for Mike as a last-ditch attempt to keep him alive. "What she did [a variation of the standard procedure], took her a little bit longer, this one took 40 to 50 minutes," Mike explained. "But what she did with this procedure was [to first

go] in there, and she sucked out as much as she could. Then she massaged the lung to push all the stuff to the top, to the upper lung, so that it would be easier to drain. She had sucked it all, and got it all, and then she blew oxygen in there, she opened it up and made it blow up so it would get full of air. Then she told me that she had blown some of her breath into me. She had blown some of her oxygen into me.”

When the procedure ended Mike told Dr. Esperanza that her “breath must have been anointed because it sure got up in that lung. And she just smiled at me. I told her: ‘Dr. Esperanza, God gave you the grace and the knowledge and the power to get through this,’” Minister Mike said.

Avoiding the Tubes

Like so many other ill children and young people, Mike is keenly aware of his illness, and the ramifications of certain situations. One of his biggest worries is the possibility of tubes being inserted into his body that would hinder his ability to talk and eat on his own.

In 2002, Mike experienced severe throat complications. He could not swallow. He encountered a new minor procedure to him called “swallowing therapy,” in which lemon swabs were used in his mouth to help stimulate the muscles. Through this stimulation Mike was eventually able to increase his facial flexibility and open up his mouth more to increase his abilities to communicate and eat. Talking and eating are important to Mike. “It was a little crazy because I

almost had to get a feeding tube, almost, it was close. . . . It was God again. He helped me out,” Mike proclaimed.

Shooting Straight

Mike believes talking about his illness is a way of helping others. When asked if Dr. Esperanza always “shoots straight” with him, he replied: “Mmhmm. She’s a really good doctor, and I have a really good relationship with her.”

Talking directly is important to both Mike and his mom. Mike’s mom affectionately remembers the time when he told another doctor besides Dr. Esperanza, “You know what? This is *my* body. You are going to do the things to *my* body. . . . So you speak to me,” Mike demanded. He was 11 or 12 years old at the time.

“Sometimes I tell other people about it [the illness], and I think it sort of helps them to understand,” Mike said. Even when asked about a possible preference at times for not talking about being sick, Mike responded: “Oh, it’s OK, it’s not really that bad.” He especially prefers to hear directly from all his doctors, as opposed to some physicians’ practice of asking the parents to first step outside the room for conversation, leaving the young patients alone to wonder what is being said about them. Mike despises this outside-the-room dialogue practice that he again likens to inhumane treatment of the less-than-human: “I tell people that I don’t like people who treat us like animals,” he stated.

A Mother's Perspective

Mike's mom, Rosie, knows the heartbreak of losing a son, having said goodbye to Little Sam when he was 4. She is now reliving a similar story with Mike.

Being honest and straightforward with Mike has always been important to Rosie. Yet as a mother she first tried to protect her younger son from thinking about death. She did not talk with Mike about Little Sam because of the disease they shared. When Mike told her he already knew about Little Sam from his vision in the hospital, communication lines between Rosie and her son were strengthened even more.

"I thought he [Mike] wasn't ready to know of his first brother and that he had passed on," Rosie commented. . . . "Then Mike told me he had spoken to him [Little Sam]. . . . It was at that time that he [Mike] knew and understood what was going on. It was through that experience that he started being more open and also talking about if he himself were to pass on. We are very open about that [dying]."

Rosie also told another visionary and prophetic story in which Mike somehow learned of the death of a fellow church member and Catholic sister long before the news was actually delivered to the family by a minister. As the story goes, Mike was in the hospital, and had asked to be taken outside for some fresh air, and to look at the buildings. While he and Rosie were sitting outside, they saw an eagle soaring. Rosie felt an overwhelming peace fill her heart and soul. "I

know about coming under the shadows of the Almighty, and that His wings will cover us,” she said.

After seeing the eagle, both Mike and Rosie then saw a dove fly by and sit on a window ledge. The dove began staring at the two of them. Rosie comments: “And then Mike says to me: ‘You know, Mom, this is no coincidence,’” referring to seeing the eagle and the dove. ““There is a message behind this.””

Rosie continued: “Then Mike says to me: ‘Do you remember the sister from church? . . . The sister passed away already.’”

Later that day when the church pastor called to check on Mike, Rosie asked about the sister. Actually, she commented to the pastor that she already knew the sister had died. The pastor asked Rosie how she had already become aware of that situation. She answered: “Mike told me.”

To this day, both Mike and Rosie believe that the sister sent the eagle and the dove to appear to them in the hospital garden so that together they might pray for her as she made her transition from life to death. They cherish that memory.

Rosie believes she and Mike have a natural and a spiritual understanding that will sustain them both, regardless of the future. She affirms that as Mike grows older, he should become more of an advocate for his own needs.

No longer will Rosie allow physicians to pull her aside to talk away from Mike about her son’s grave medical situation. She stated: “Mike, I don’t need to

teach you no more. You are an advocate on your own.” Slowly she is beginning to release her son, just as she had to do with Little Sam.

Despite relying fully on God, sometimes her faith waivers, given that both of her children were born with spinal muscular atrophy, which will most likely take them both away from her eventually. “It’s not to say in the natural I don’t feel the angers or . . . say, ‘Why me?’ Because those questions did come, and those feelings did come,” Rosie explained. “However, I knew that I was not in control of our lives, and I knew that our lives were only passing through here. I knew that I needed to trust and depend on the Lord,” she added.

Rosie lives for the moment. She fully accepts that only through God’s grace will she be able to handle what is yet to come her way. For now, she wants and needs to live each day in the moment, knowing that, as the saying goes, tomorrow will be another day.

Be Still My Soul

“Staying still” is the bottom line for Rosie. Despite a reality that could have easily buckled other parents, Rosie prepares for the future with her remaining and terminally ill son by staying still. “Sometimes things are so challenging. Life is so challenging and hard, and not knowing about the unknown. We need to know that if we are emotionally reacting to the situation, then we need to stay still, and The Answer will come. The peace comes to us right as we are leaving. In the meantime, each day is God’s masterpiece.”

The Future

Like so many sages who have lived much longer lives before him, Mike has visions about his life as it stands today and his future. He still continues a relationship with Little Sam through his dreams. Little Sam would be 16 now if he were still alive. Perhaps the brothers are preparing for a reunion in a different realm.

Mike continues to talk with his mom about his illness. Most of the time, however, they prefer to just go about “enjoying their lives, enjoying God together,” Mike said. “We usually do things together, like eat and we play games,” he added.

Yet the notion of life and death is still fraught with high stakes and weariness for Mike and his mom. Sometimes talking or thinking about the future is difficult for Mike. He changed the subject only once during the entire interview. When I asked him a question about his future, he said “Sounds like it’s going to rain or something.”

Nonetheless, perhaps talking about the future is something Mike *chooses* not to do, as opposed to avoiding the topic entirely. Like the angel Gabriel in the Christmas story who foretells the coming of a special birth, Mike seemed to know how things were going to shake out in terms of his own life and death story. At age 12, he appeared not to be unfolding his entire life story—at least not at this time during the interview.

He does, however, seem to gingerly suggest a premonition for his own future: “Well, there’s some stuff coming in the future. Next year I don’t know the whole story. Only God knows what’s in store for me next year. Yeah, there are things coming in the future—probably this month or next month. It will be quite a few weeks from now. I’m just praying about it,” he confided.

With that, Mike begins to sing Christian songs with full vibrato using his much-coveted lungs to praise his God. His mom joins in. Together they make beautiful harmony. “Against all odds.” That is The Word proclaimed through the life being led by 12-year-old Minister Mike.

Epilogue

Five months after this interview was held, Minister Mike’s mother called me to say that Mike was in the hospital and not doing well. The last time I saw him, he was about half the size as before. The circumference of his arms and legs was about the size of a quarter. He could barely speak, much less sing. He smiled slightly and said hello when I walked into the room.

While Mike rested, his mother walked me around the hospital wing. She showed me the Tree of Life plaque commemorating those children who died within the previous few years. Each child had a gold square with his or her name engraved on it, signifying the branches of the tree. About one-half of the squares were blank.

Rosie pointed to the gold square at the very top of the tree: “That’s the one Mike picked out for himself,” she explained. Mike picked out the square when he had arrived at the hospital a few days before.

A few days after our visit, Mike was discharged from the hospital to die at home. Before he was released, Mike fulfilled his dream of giving his mom a surprise birthday party in his hospital room, and meeting a San Antonio Spurs basketball star. The basketball star said afterwards that this special 12-year-old boy ministered more to him than anyone ever had, according to Mike’s mom.

Three weeks later on an early Saturday morning, Mike asked his mom to physically lift him up in bed so that he could reach out to God and the angels. He was ready to go. He died a few minutes later, telling his mom that he loved her with his last breath. The local newspaper ran a story about his death and his ministries.

At his funeral, the 12-year-old boy/minister looked handsome and distinguished lying in a gray casket clothed in a black tux, complete with cummerbund and bowtie. People spoke of a reality in which this young man was simply running a race ahead of his time. His beloved Dr. Esperanza gave one of the many eulogies. She remembered a time when she had to lobby Mike hard to get him to wear an oxygen mask at night so that his lungs could rest. Finally she told Mike that if he wore the mask, he would be like an astronaut who could fly to the moon at night. The next time he saw her, he told her that her ploy had worked. He had

worn the mask and been to the moon – and that the moon was indeed made of cheese.

In true form, Mike had the last written and spoken word at his own funeral. The funeral program contained a message from him that read:

Thank you for spending this special day with me for the laughter and memories this day will bring I thank my dear lord for the blessings like you and I hope that in time, you'll reminisce of this day and say to yourself, "Oh, what a glorious time."

His aunt played a cassette tape toward the end of the service in which Minister Mike said goodbye to everyone in a clear, firm voice: "Bye, everybody. I shall miss you all."

B. The Hooters Guy

For his 16th birthday in the fall of 2003, Richard³ wanted to go to a place called Hooters, a restaurant chain known specifically for its physically endowed and scantily clad waitresses, and that he did—wheelchair and oxygen and all—along with his mom and his beloved hospice friends who cared for him. The entourage even included the hospice chaplain, "Reverend Lois" as Richard called her. Reverend Lois proclaimed the outing as a "monumental and joyful and wonderful celebration of life."

³ In this story, I have changed the names of the people I call "Richard," "Reverend Lois," "Dr. Johnson," "Bob," and "Alonzo."

A short time later Richard's mom sent me a message via electronic mail. The message said: "I just wanted to let you know that Richard went home to be with his Lord, yesterday morning."

Richard's Story

Richard embraced life with a smile that rippled off the sides of his face and down his thin body in the wheelchair like water from an edgeless swimming pool. He laughed at the humor, or attempted humor, of others around him almost as much as he laughed at himself.

Life, for Richard, was ridiculously funny, embarrassing, joyful, ironic, and full of love. Life was also quickly slipping away. He died less than eight weeks after this interview was conducted, a little more than one month after his 16th birthday celebration at Hooters.

Despite the Prognosis

Richard was born with Ataxia-Telangiectasia (A-T), but did not officially receive the diagnosis until he was 11 years old. A-T is a progressive, degenerative illness that attacks many body systems. Children with this disease usually appear normal at birth yet begin showing signs of the disease in the second year of life.

Initial signs may include slurred speech that stems from a lack of muscle control called *ataxia* or “wobbly balance.”⁴

In the disease progression, a second clinical hallmark occurs after the onset of ataxia in the form of *telangiectasia*, tiny red spider veins, usually appearing on the surface of the ears and cheeks or corners of the eyes exposed to sunlight. Approximately 70 percent of children experience a third major clinical moment in the form of recurrent respiratory infections which often become life threatening.

Several times during his 16 years of life, Richard nearly died. Yet he kept bouncing back. He never failed to see the irony or humor of the situation.

Richard’s mom: *[To Richard.]* Do you want to tell her *[myself as the interviewer]* what the doctor told you who put you in hospice?

Richard: Yeah. I had 6 months.

Question: Six months to live? How long ago was that?

Richard: Six years ago. *[A huge smile engulfs Richard’s face.]* And I’m still here.

Richard led a full and active life during his few years. He loved to watch football on television. He loved to bowl, and he says he was a darn good bowler who loved to throw strikes. (Funny how we think children and young people with physical challenges might be different in their thinking from all the rest of us).

⁴ A-T Children’s Project (2004, n.d.). *What is A-T?* Retrieved January 4,

He loved to go to the Special Olympics, where he competed in the softball throw. He was good at throwing the ball. He loved the movie *Star Wars*. The small bathroom he shared with his brother and mom was covered with movie paraphernalia and posters of Luke Skywalker in action.

Richard's body may have been physically challenged, but his ego was healthy. He was proud to have been featured in a newspaper article about his own physician and her work with dying children and young people.

This particular cover story featured a beautiful color photograph of an exuberantly smiling Richard in a crisp black and white golf shirt. He was sitting in his wheelchair, having his breathing checked by his beloved physician, Dr. Johnson. Even though he exuded shyness and humility, he loved the attention.

Richard would happily yet sheepishly grin when you showed him a copy of the newspaper article. He would then scribble an illegible autograph that at least he said was his name on your copy. He would only return it to you if you gave him some dollars or at least some spare change—a proverbial and loveable con man. In this case the con man was a 16-year-old boy sitting contorted in his wheelchair with a twinkle in his eye, a smile that would not quit, and a bottomless heart of gold.

Oxygen Hater

Despite his positive countenance and brilliant sense of humor, Richard did not like being noticeably sick. He did not want people to know when he was getting oxygen. He fought the physical progression of his disease to the bitter end.

His mom said Richard's reliance on a wheelchair came all of a sudden, as if he had willed his legs to hold him up for as long as he could. The same was true for other medical necessities. "He never had a feeding tube, a G [gastrointestinal] tube, and [all of a sudden] he had to have one of those. And we never had to have nursing care before, and now we're going to have to," his mom explained. In Richard's house, things seemed to be a certain way for the 16-year-old for 1 minute, and then a completely different way the next.

Richard detested being seen with oxygen although he knew it kept him alive. When he was forced to use oxygen, Richard often refused to go to school or church. Before he died, he often asked one of his hospice workers how many more times she thought he would have to be on oxygen, because "there are times when he thinks that he will no longer bounce back from being on oxygen or antibiotics," his mom commented.

Although the oxygen tubes going into his nose gave him the breathing assistance he desperately needed when necessary to stay alive, they made Richard feel horribly embarrassed and self-conscious. Interestingly enough, Richard lived in modern western civilization where permanent body piercing and demarcation

over all parts of the face are arguably typical and prevalent signs of individuality, if not popularity. Yet for Richard, somehow the removable, clear, and noiseless tubes unnoticeable to the adults around him became like a giant noose around his neck. He wanted no part of being different.

Yet Richard was unmistakably different. He was 16 years old and dying. Despite that reality, he was almost magical in the love he constantly poured out to his mother, his brother, and to those who cared for him. The “Richard is amazing” stories overflowed.

The Contentious Worrywart

As amazing as he was, Richard worried a lot—not about himself, but about those around him. When he did not go to school because he was really sick or was forced to use oxygen, he worried about Bob, his friend and hired aide at school. Bob was one of the individuals with whom Richard talked most about his illness, in a fraternity of male bonding.

“He is very fond of Bob,” said Richard’s mom. “When he didn’t go to school this week, he [Richard] was worried for Bob—that Bob would be out of a job, because he didn’t have anything to do. I tell him, don’t worry about Bob—they’ll find something for him to do,” his mom added.

Look Ma, No Hands!

Scholarship suggests humor is a critical coping mechanism during end-of-life times. Such was the case for Richard and his community. Although talking at times was difficult given his breathing issues, he never failed to tell his hospice care workers that they could *only* come back to his house and see him when they had first stopped by Toys-R-Us on the way.

His mom told the story of when Richard first had his G-tube inserted for eating. “He was in the hospital. His cousins came over to see him, and he said: ‘Watch. I’m going to show you a trick. Look, I’m eating: no hands!’”

The Dirt Nap

Not only did Richard make fun of his own physical situation, he made fun of how society as a whole talks about the plight of those like him who are dying. Richard quite often used the word *death* in talking about himself and his situation. What he also enjoyed talking about even more were all the words or phrases people used in place of the “D” word. His list was priceless, and his smile unending as he shared each one:

Kick the bucket

Buy the farm

Cross the river

Pushing up daisies

Taking a dirt nap

Even the hospice workers delighted in picking up on Richard's rhetorical cue. It was as if Richard set the tone about the language parameters for talking about his situation. Without a doubt, he was comfortable with the word *death*. He never seemed to deny the reality of his situation.

Protectionism: The Man of the House

Within their family structure, Richard and his mom, and his little brother, Alonzo, spent a great deal of time and energy protecting each other. Alonzo was born perfectly healthy in 1998.

Richard and Alonzo, who looked much the same, acted like normal brothers. They wrestled and boxed with one another, played jokes on one another, got on each other's nerves, and most of all: protected one another. When the family was sent a new hospice nurse, Richard and his mom told the nurse she need not be offended when Alonzo tried to take over the situation to protect and help Richard. "I said, please don't get offended. I said that sometimes, like when he [Richard] was coughing, and she [the new nurse] was saying, 'Do you need your bucket [to cough into]?' Well, Alonzo, he thinks that's his job. He'll go and get it. [When mechanical] alarms go off [signaling Richard is in physical trouble] he [Alonzo] goes and . . . says: 'That's my job, that's my job to take care of my big brother!'"

The tireless hospice workers who help Richard love to tell about Alonzo's parting words and rituals every evening when they finished taking care of his brother. "Thank you for taking care of my brother," he would always say to them. After walking them out of the modest mobile home with the long blue wheelchair ramp, Alonzo checks under their cars for strange things, or scans their cars with flashlights to make sure all is well for the evening. The hospice workers thank him.

Alonzo then asks them to beep their car horns at him so he will know they are safe as they drive away. The same words are said, and the same actions taken almost every evening. The noise of car horns beeping repeatedly brings simple comfort and solace to a very grown-up 5-year-old boy named Alonzo—a young boy who loves his dying brother.

Richard also worked hard to try and protect his mother from sadness and crying, no easy task, she readily admits. "He doesn't like for me to cry for anything," Richard's mom commented. To which Richard replied, "She cries at everything. You big baby!" Richard then flashes his huge smile, and gazes affectionately at his mom, who does not disagree with the assessment. She readily admits the tears flow easily, and always have. She uses much the same self-effacing humor as her son in responding: "I cried the first day of school. I cry the last day of school. I cry when he goes into another pant size," she laughed. She described her oldest son as being her protector—"my man of the house."

The Dying Talk

Richard was extremely close to his grandfather. “I love my grandpa,” Richard commented. It was Richard’s grandfather who would always hold him tight when Richard was feeling as if he were going to die.

During these times, Richard’s grandfather would console him by saying, “When the time comes, who’s going to be waiting for you on the other side? Remember? Who’s going to be waiting there for you?”

“Grandma,” Richard would reply.

Fight or Flight / Fight or Freedom

One of Richard’s ultimate goals was not just to have a 16th birthday party at Hooter’s, but also to have a high school graduation party. His goal was to graduate with his class of 2006. He told his mom just recently: “You know, Mom, instead of a birthday party, I want a graduation party. Oh, wow!”

Yet Richard never made his goal of graduating in 2006. He died in late November of 2003, in the early morning hours of a Thanksgiving weekend.

Perhaps for Richard there is a notion of “fight or freedom,” as compared to the proverbial notion of “fight or flight.” Although his body failed to let him reach his high school graduation goal in 2006, in no way did Richard run away from death. In fact, he embraced his dying in the same way he embraced living. He talked about it with grace and humor far beyond his 16 years of age. Richard’s

long-time school mentor, a gentleman far older than the 16-year-old, said as a part of his eulogy, “I did not mentor Richard. Richard mentored me.”

Physical freedom now abounds for Richard. No longer does he have to be tethered to or embarrassed by oxygen. No longer does he have to cough into a bucket. Perhaps life on the other side, in whatever shape or form that may take, represents the final and truest form of freedom for Richard. His mother believes so.

Before he died, Richard asked Dr. Johnson about her notion of Heaven. He explained to her that he wasn’t worried about dying, but he was concerned about missing all of his favorite television shows. Dr. Johnson reassured Richard that televisions would be turned on 24 hours a day in Heaven. He could watch anything he wanted, anytime.

Epilogue

The Hooters guy who embraced life, and taught so many others how to do the same in the process, died quietly in his own bed at age 16, with his mother sleeping on the floor next to his side. The evening of his death, on the Saturday after Thanksgiving, he seemed to feel much better than earlier in the week. He wanted to watch a movie, and said very clearly, “I need a candy bar.”

He spent time with his adored grandfather, mother, and little brother. He was unusually concerned on that particular night about being clean. He wanted to make sure his fingernails were all clean. He wanted his face to be perfectly clean-

shaven. He even asked his cherished grandfather to hand shave him after already being shaved with an electric razor. This was unusual behavior. His mom said it was as if he were preparing for a new life in which he wanted to make a good first impression.

When his mom awoke on her own accord in the middle of the morning, she immediately knew Richard was not breathing. For some reason he did not have any coughing fits right before his death, unlike so many times before. His eyes were closed, and his mouth was no longer open as if fighting for his last breaths. His mom kissed him, and said at least now he would never have to wear oxygen again.

During the funeral visitation time, Richard's treasured protector brother, Alonzo, worked the crowd in his crisp white button-down shirt, black creased pants, and shiny patent shoes. Every few minutes Alonzo would glance at his mother, as if to make sure she was still standing. He would then return to the open casket and touch the hand of his champion and departed brother, clothed in a blue high school sports jersey. Richard would have been, or was, proud.

Perhaps the night of his death Richard knew what was going to happen. Maybe an unusual cleaning ritual became one way for Richard to prepare for what was to come. Maybe he wanted to look his very best to see others. Whatever the reason, being clean and extra-handsome on this one particular night seemed of critical importance.

In the words and beliefs of his grandfather, Richard most assuredly was going to see his grandmother again, his guardian angel. She would reach down to give him a big hug and kiss, and say, “Hi.” The Hooters guy had indeed graduated.

C. Intellectual Capital

In a capital city of a large state, a very smart and loving family rests a little easier now that their son, Marcus,⁵ age 5, is in remission from a rare and potentially deadly form of leukemia. The cancer struck Marcus when he was 24 months old.

Web MD: The Ugly Stuff

Marcus’s mom, Sandy, knew something was wrong. “Marcus had been sick. He had been on antibiotics. We thought that he had an ear infection,” she stated in a matter-of-fact manner. He was only 24 months old, and could not verbalize a lot. “But you know, he just didn’t look good,” she added.

Sandy was the first to diagnose Marcus as having leukemia. She continued to be concerned about his overall appearance, and his inability to come back from the ear infection, or what could possibly have been the flu. “I had actually gotten

⁵ In this story, I have changed the names of the people I call “Marcus,” “Mom/Sandy,” “Dad/John,” “Debra,” and “Dr. Jones.”

online thinking: *What could this be?* and had come across, you know, it's funny, because most kids, if they don't have the measles, mumps, flu, the basic stuff, then it goes immediately to the really ugly stuff. You know, like cancer," she explained.

Sandy searched the web in detail. On one particular search engine, called Web MD, she entered Marcus's specific symptoms. The word *leukemia* appeared.

"I had a doctor's appointment for him to go back to the pediatrician, but the night before, I went to a book store, and saw a book on leukemia. I just picked it up, and just looked at the symptoms, and freaked out," Sandy said. The book presented the symptoms of leukemia in great detail, including joint pain that can manifest itself in preventing children from wanting to walk. That was Marcus. "That really triggered fear in my mind," she commented.

The next afternoon was Marcus's appointment with a local pediatrician. Early that morning, Sandy called the pediatrician and asked: "Can we just come in now?" That morning the pediatrician told Sandy he did not think Marcus had leukemia, but he would do a blood test just to make certain. "He had this little machine in his office. Then he said 'This is definitely some kind of leukemia,'" Sandy said. That was all the information he would give her at the time.

Sandy took Marcus straight to the pediatric hospital. Dad (John) met them there. Thus began the family's chaotic journey into the world of cancer. It began

almost as fast as Sandy had searched Web MD, and pulled up the word leukemia.

Planes, Trains, and Automobiles

Marcus and his parents spent the first night at a local children's hospital trying to make arrangements for the future—or at least the next 24 hours as they redefined their new future. John commented: “We thought that it was bad, but more our take on it was, we need to find the best place in the world, and get on a plane and go there.” The next day the family left for St. Jude Children's Hospital in Memphis, Tennessee.

Marcus's older sister, Debra, stayed behind with friends so that her fifth birthday party scheduled that very day would not have to be cancelled. “I went in my imagination,” sister Debra remembered. Parents John and Sandy did remember to cancel the dinner party they were having that evening, but they forgot to notify everyone whom they had invited. While a few unaware dinner guests stood on a darkened front porch, the family was well on its way to St. Jude. Chaos is an initial part of most pediatric cancer diagnoses.

Low Tones

Like most families, hearing the word *cancer* for a child triggers the onslaught of a waking nightmare. For some, the word is among the most ugly in the English language. Like memories of that notable day in Dallas when President John F. Kennedy was assassinated, nearly every parent of a child with an advanced illness seems to remember the *exact* day and time when they were first

told of the situation. Some parents wet their pants, as one mother shared with me; some simply drop to the floor. Others have to have the message repeated, sometimes again and again.

In the case of Marcus's family, the physician initially telling them the diagnosis of leukemia for certain said the word in such a low tone in an attempt to be soothing that the family missed the diagnosis at first. "I remember he [the physician] was very soft spoken—we couldn't hear him. I probably had a wiggling toddler on my lap and some chattering. I remember not hearing anything," Sandy said. She asked that he repeat what he had just said.

Research has long indicated that physicians struggle with the delivery of bad news. Physicians working in pediatric care suggest that only in recent years has training been initiated in relatively small scales in medical schools whereby they are taught how to work with the families of dying patients. Such was not the case in the early 1980s. "Doctors were taught to distance themselves emotionally, and I think that's wrong," a pediatric pulmonary physician states. "You can't let it impair your judgment, but I no longer fight it," she says.⁶

Perhaps speaking softly is one way of attempting to soothe a family or to distance a person emotionally from the necessity of having to deliver devastating news. Whatever the reason, the physician spoke so softly that Sandy was forced to

⁶Pisano, M. (2003, August 18). Doctor says it's all right to be human. *The San Antonio Express-News*, pp. 1D, 4D.

have the word *leukemia* repeated at least once more before it finally soaked in to her psyche, literally and emotionally.

Talking Down

Marcus's parents are well-educated individuals. Both have strong academic and professional credentials. Tackling Marcus's cancer from an intellectual capacity will always be a core strategy for the family. Included in that process is the way in which Marcus's physicians communicate with Sandy and John as they direct their son's care. They respectfully contrast their hunger for straightforward, smart, and recent detailed medical information with other families who may only want a thumbs up/thumbs down response.

Plain talk, as John and Sandy call it, does not work with them, but they recognize and appreciate everyone's diversity in the range of information desired. "Something that I know they [the physicians] struggle with, and it's a fine line, is not to overwhelm the parent. There is just so much information to be reported," Sandy commented. "My brain was just trying to reach back to college biology, you know, when you are talking about white cells and platelets. It can be very technical, trying to understand it," she added.

Sending cues is important. Sandy commented: "In talking with doctors, I find myself doing this when I encounter a new physician, is kind of sending them cues, you know, that we are educated. There is so much [to grasp]. They [the physicians] are trying hard to make this understandable . . . putting things in very

simple terms. And we get frustrated with that because we both feel like we've earned honorary degrees," she stated.

In remembering the initial and subsequent conversations with the soft-spoken physician, Sandy recalled: "I remember doing that [sending cues] with Dr. Jones. We told him very straight out: 'Look, we are both educated. Please don't talk down to us.'"

Options and Answers

John and Sandy wanted messages that delivered three things: (1) current and detailed information; (2) answers; and (3) options. Generalizations and platitudes became shrill violations against their self-images as young professionals, and most especially as educated parents of a young child who had cancer. Making decisions based on personalities or trite sayings was not an option for them.

"I remember I was talking with Dr. Jones on the phone that day, telling him that we had made the decision to go [to move Marcus from their hometown hospital to St. Jude Children's Research Hospital in Tennessee], and I said, that's my advice from my sister who has the most medical training in my family. She's an oncology nurse, and I just have to trust that," Sandy stated. "And his response was, 'I wish you would trust me.' I was just like, I so don't need this right now."

Once the family arrived at St. Jude, they were given many options, answers and very detailed information as to how specific medical protocols would

be used on Marcus. Upon the family's initial arrival, the front-line medical staff spent at least 10 minutes simply explaining the features of the room in which Marcus had been placed, long before conversations began about actual treatment.

Even when the conversations did not represent options or answers for the family, somehow the St. Jude staff managed to deliver the messages in such a way so as to avoid the gross generalizations and small talk that had initially frustrated the parents. Both Sandy and John attributed the change in communication style at St. Jude to a focus on research as opposed to practice.

"The doctor came in that night [the first night they arrived at St. Jude]. He was a resident. Not even a leukemia guy—he's a solid tumor guy," Sandy explained. "He took a lot of information. That was part of what he was doing. But he also explained so much," Sandy recalled.

"And he wasn't hurried, he was just there. I think we probably spent about 2 hours with him," she added. John quickly interjected, "Which was funny because, the gist of what he really had to tell us was: 'We are not going to do anything until Monday morning.' I think it had to do with the difference of a human being and a focus on practice versus research," John said. "These are people [at St. Jude] who actually do spend all their time when they are not treating patients thinking about better ways to treat patients—better ways to fight the disease," Marcus's dad explained.

A Language of Weirdness

Marcus spent many months at St. Jude. To this day, he and his parents continue to travel back and forth for follow-up treatments. He also continues to see physicians in his hometown.

When asked how the parents communicated with 2-year-old Marcus during this initial time and during subsequent periods, both Sandy and John acknowledged doing “weird” things to both continually entertain and distract Marcus. Finding word substitutions became an important part of that language of weirdness.

For example, Marcus has always loved “choo-choo” trains. The pajamas he was wearing on the day of the interview, which he proudly showed to everyone in the room, were covered in colorful trains. He likes to make the sound of trains.

Thus when Marcus first began treatment at age 2, the port that was surgically placed into his body for the purpose of delivering his chemotherapy became his *choo-choo*. The dressing placed on top of the port became the *train station* or the *route*. The little pillow that holds up the port became the *platform*.

As he grew older Marcus began to send the family signals that he knew what was going on with his body. He began to understand what the actual medical words meant, and what certain treatments would entail. Sandy recalled: “And then one time, you know we would always [in front of Marcus] call it [the port] *choo-choo*, and we would talk to the nurses about the port,” she explained. One time

Marcus turned to his mother out of nowhere and said: “That’s not my choo-choo, that’s my port!” Marcus was approximately 3 at the time.

Marcus also quickly picked up a lot of the medical terminology beyond the word *port*. When the time came for Marcus to receive shots or take medicines, Sandy would usually say to her husband in front of Marcus: “I think it’s time to administer his *pharmaceuticals*,” a way to say *medicine* without him running. Yet she explained that even as early as age 3, Marcus knew what was coming when he heard the phrase *administer his pharmaceuticals*. “He knew. He caught on very quickly,” Sandy said.

Statistics, Sanctuary Spots, and Verb Tenses

Knowing the details associated with pediatric cancer and leukemia data is critically important to Sandy and John. They view themselves as intellectuals and continually study and learn the many statistics associated with their son’s disease.

Without looking at a sheet of paper, they succinctly told me that 1 in 2 million children is diagnosed each year with the same kind of leukemia Marcus has experienced. This figure represents what they call *nightmares* for 1 in every 10,000 children just like their son. The stakes are high, and the chances for reoccurrence prevalent.

Fortunately Marcus remains in remission to date. The parents are quick to correct me when I mistakenly refer to Marcus’s disease in the present tense. They do not want Marcus described as a young person who *has* leukemia.

“Actually Marcus doesn’t have leukemia. He’s in remission. Well, he’s still on treatment, so it’s kind of a personal choice on words—ones that we think are important, and we certainly emphasize with him,” Sandy explained as she corrected me. “He probably went into remission day seven of treatment, which most kids with leukemia do. But they still think that on a molecular level, he still might have leukemia, so they continue to treat him for about 3 years. But their clinical definition of remission most kids reach in the first month,” she added. The family remains ever vigilant in keeping up with the latest technology and information on the disease as their son continues to receive treatment on a prevention basis.

Reassurances and Choices

Despite being frequently frustrated with physicians who deliver messages in ways perceived too simplistic or patronizing, both John and Sandy are grateful for the medical care and technology they have found both in Memphis and their hometown. It has kept Marcus alive so far.

This time in their lives is spent holding each other close, enjoying lazy Saturday mornings, reminiscing, looking at photographs, and reading the latest information on leukemia. Marcus and his 8-year-old sister, Debra, seem exceptionally close. They look out and take care of each other.

People tell John and Sandy they are parents to be admired for their unending reliance on intellectual capital in responding to Marcus’s cancer. They

are told they come across as extremely poised and graceful in the many ways in which they have faced this chapter in their lives. They suggest otherwise:

Mom/Sandy: It's not always that graceful.

Dad/John: —graceful, nor pretty.

Mom/Sandy: Stress brings out a lot of ugly.

Revisiting their son's initial cancer diagnosis and the early days and months of Marcus's cancer at age 2 is not something Sandy nor John care to do. However, they *choose* to do so in an effort to provide both education and reassurance to other parents in similar situations.

“I know there have been studies on what kind of information parents wish they had heard, and one thing that doctors don't tend to address, that parents really want to hear—it's like the 4th most requested thing: reassurance,” Sandy explained. “You need a lot of assurance that you caught this as soon as you possibly could have. That this wasn't neglect—every parent I know completely beats themselves up over it.”

She added: “That's funny, it's really like a first stage thing. You really are caught up in *why*. Then it goes out the window. And you don't think about *why*, ever again. That's the way it is,” she declared.

D. Praising Life: The Final Chapter

Shannon and David Ede and their children are individually and collectively one of the most physically beautiful families I have ever seen. Together they look much like an ensemble cast on a Hollywood movie screen. Mom Shannon looks like Nicole Kidman, complete with long, wavy red hair and porcelain skin. Dad David looks like Kevin Klein. Their 3 children, Patrick and his siblings, Daniel and Ellen, are equally beautiful with translucent smiles, smooth complexions, and sparkling eyes. The family smiles and laughs a lot. They obviously enjoy being together.

Yet their world of physical beauty and happy times became an emotional nightmare on November 26, 2002, when 12-year-old Patrick was diagnosed with Acute Myeloid Leukemia (AML). Here is their story, beginning with a look at the disease that hit their family.⁷

Growing Pains and Visceral Responses

The American Cancer Society and the National Cancer Institute identify leukemia as the most common form of cancer in children and adolescents. It

⁷ At the suggestion of The Ede family, information from various Internet sites such as the Patrick Ede *CaringBridge* web site retrieved from <http://www.caringbridge.org/tx/patrickede>, along with a review of a videotaped church celebration led by his parents to thank friends and supporters, has been used to supplement the interview commentary.

accounts for nearly one-third of all cancers in children under the age of 15, and one-fourth of all cancers occurring before the age of 20.⁸

Acute Myeloid Leukemia (AML) is a rare form of pediatric leukemia. It is a cancer of the blood-forming tissue usually found in the bone marrow and lymph nodes. The bone marrow of persons with leukemia begins producing large numbers of abnormal and immature blood cells that are usually white blood cells. These bad cells are often called *blasts*. Blasts flood the blood and lymph streams, and then may invade vital organs such as the brain, testes, ovaries, or skin. In some rare cases, AML tumor cells may form solid tumors called Isolated Granulocytic Sarcoma (IGS) or Chloroma.

Early signs of AML may include fever, chills, bleeding or bruising, swollen lymph nodes, and other symptoms that are flu-like such as weakness, chronic weariness, or aching bones and joints. In Patrick's case, 2 days before Thanksgiving in 2002, he went to his physician. He was hurting badly.

"My bones had been hurting more. My arms and legs had really been hurting, and I couldn't sleep at night because it hurt so much. And I thought it was growing pains. So we went to the doctor, and asked if we could see blood work. And later, he diagnosed me," Patrick calmly stated at age 12.

⁸ Cancer Reference Information (2003, n.d.). *What are the key statistics about childhood leukemia?* Retrieved Jan. 2, 2004, from <http://www.cancer.org/docroot/cri/content/>.

Parents use a variety of words and phrases to describe their reactions to hearing the news for the first time that one of their children has cancer. Some calmly rattle off long names of specific diseases. Others take a chronological, journal-like approach. They tell you where they specifically went each day, what they did, who saw them, where, and what the physicians, nurses, and others said at every point of the journey. In some cases, the reactions are beyond words and descriptions.

“Just for the record, I mean, we all had moments,” Shannon, Patrick’s mom explained. “When I first heard [Patrick’s diagnosis], I had a visceral response,” she added. She explained that in actuality she wet her pants and the carpet in the physician’s office, for which she later apologized. The physician told her not to worry—it had happened before with other parents.

Patrick’s father, David, also had his moments of despair and darkness. Shannon describes a memorable moment for her husband that occurred later on in their son’s illness when the pain for Patrick was excruciatingly horrible. “David laid out on the hospital floor one time, in tears, because he [Patrick] was in pain, and the morphine wasn’t touching his pain, and the nurses weren’t responding, and it was so frustrating.” There is a sense in talking with this family that father David seldom loses his composure.

Regardless of what came the family’s way, the young boy at the center of the storm seemed to rise above it all. “I think Patrick is given a special grace

because I have seen him respond more negatively emotionally to algebra before and since cancer, than he did the whole thing [the cancer journey]. I'm not kidding you. I think he was really given a special grace," she said.

Shannon also talks about her son and his philosophy regarding his illness within a schema of control. She is proud that Patrick remains in control of his own decision-making and life living, to the extent humanly possible. Shannon suggests Patrick sees himself in being in control of his destiny: "Not to get boring, he's just fairly in control, of thinking 'OK, this is my responsibility in setting this thing.'"

Another verbal exchange reaffirmed much the same sentiment. It also added a perspective held by the whole family: They are not alone in the journey.

Mom/Shannon: We explained to him that he has cancer, . . . but he was shockingly accepting right from the start.

Question: *[Asked of Patrick.]* Any idea why?

Patrick: I knew that it was in God's hands.

In a Matter of Hours

Parents of children with advanced diseases view time differently. Time frames are much shorter and bound by upcoming treatments and physician visits.

Weeks may seem like an eternity in the worlds of children and young people who have cancer. Minutes and hours seem to dictate a cancer family's calendar as they try and cope with what has now become a different type of long-term future. The Ede family web site, www.caringbridge.org/tx/patrickede/,

described one particular day in the almost-daily postings of Patrick's progress in terms of hourly time limits:

December 5, 2002: Patrick gets to go home for about 30 hours.

Upon the initial diagnosis, the family remembered that Patrick started on chemotherapy within a matter of hours. The simple difference in expectations from one hour or one day to the next can bring major highs or lows.

Patrick and his parents also remembered an especially joyful time in which he ran ahead of schedule. "He [Patrick] surprised us the day that he got out of isolation. This time, day 21 would be the earliest that he should ever come out. But he had recovered enough to where it was safe for him to come on out," Shannon said. "But Patrick, on day 14, his white cells rebounded, and [he] made a great recovery, so he was a week earlier on getting out of isolation. I was going to get my mask and gloves on, and he said, 'No, Mamma.' Then those tears just started coming, and he came in and hugged all of us, and we're all boo-hooing," she added.

Cybersphere Prayers: The Birth of Communication

The Patrick Ede web site is one of the saving graces mentioned repeatedly by the family. Patrick's Uncle Johnny created the site. It is a part of the Caring Bridge organization, an organization designed to help seriously ill children and young people and their families stay in touch and be informed throughout their healthcare journeys. Shannon describes the web site and the communication

available to her at her fingertips as the “birth of communication—it’s just huge. He [Patrick] can communicate with other people. So now it will allow us to rally support, and can also tell us what we need. People right away started sending us e-mails and stuff, telling us jokes, and to try and reach him,” she added.

Patrick enjoyed the web site because it allowed him to hear from not only his healthy friends, but also other cancer kids and seriously ill kids who made him smile. When asked if he personally looked at the e-mails, he responded: “Yeah, a whole bunch. There are little 6 year olds, you know, saying, ‘Now I’ve got a joke that I would like to tell,’” Patrick added.

Shannon viewed the web site as cathartic both for her husband and Patrick. “He [David] would sit down there and daily, see what’s going on. It was more than . . . just a lot of medical facts. There were some spiritual things that we were learning, or things that we all needed. So it was really a helpful thing. It was nice for me to not have to carry that because with any burden, I get impatient. For now, he [husband, David] could just do that, and it took some of the stress off Patrick, too,” she explained.

Patrick’s parents perceived a variety of benefits from the web site. Shannon suggested the web represented a method for people all over the world to write to the family, and “at our leisure we could read through them. The guest would write, and they would send prayers and jokes and stories and so that way, it

was a no hassle way of communicating effectively. Like we could look at that if we wanted to, or we didn't have to," she added.

The family also believes this new birth in communication is a way for patients such as Patrick to avoid becoming isolated in an environment where sometimes direct contact can be costly, if not deadly. "When he [Patrick] was really so sick, he did not get out and interact with the kids at the children's hospital here," Shannon says. "He's kind of introverted. He never felt well enough to get out there. We did see this one boy who was the same age who was out there yukkin' up with the nurses. We were going, 'What, are you really sick?' In the MDA [MD Anderson Cancer Center], he (Patrick) had never really felt well enough to go there and make friends with the kids, but there you are in isolation where you are not allowed to be outside. It was kind of, he got peer support from the web site because it was easier to write to people that way," Shannon stated.

David also says that the web site, which contained daily updates on Patrick's condition, as well as his whereabouts, represented a much-preferred method of communication for families like his. "It's so much better than e-mail because e-mail is sort of a push type of communication: *Here I'm pushing this to you*. But the web site was more pull. It was basically: *Here it is if you are interested*. So, it wasn't very intrusive communication," he added.

The web site also became a way to ask for help, and to sort through emotions throughout the hospital vigils. The family routinely asked for people to

rally on Patrick's behalf in terms of prayers when times became really tough. David also used the routine of connecting with the web site as a form of sense-making. "That was actually an exercise in discipline for me to have to sit down at the end of the day, and do all the events, all my emotions, all my thoughts," David said. "It sort of made sense. . . . So that was real good for me. Also, people want to know [what is happening, moment by moment]," he commented.

The Three-Finger Roller Coaster

Real-life activities of daily living remind us that conversing with children and young people in the best of times is frequently challenging. Thus when children like Patrick are thrust into a foreign and frightening world like that of cancer, parents often search for new and simplistic ways to explain to their children harsh and complicated scientific realities. In Patrick's case, nonverbal communication became an increasingly important way of understanding what was happening on a daily basis, and what was to yet come.

"We were trying to get him ready for Houston [the MD Anderson Cancer Center]. First of all, we were trying to give him a scope for a different environment," Shannon said. "I showed him three fingers, and that was three different phases that we were going through," she added.

Both Shannon and David used the three-finger method throughout the journey to help Patrick gauge where he was in his treatment plan, and what was awaiting him around the corner. The three-finger method became an explanatory

tool for helping Patrick understand the initial phases of his treatment which included induction therapy, in which chemotherapy is used to try and kill as many of the leukemia cells as possible so that the disease will go in to remission, and then the second and third phases, intensification and consolidation therapy, designed to kill any remaining leukemia cells once the leukemia is in remission.

The three-finger method became a calendar for the family in terms of holiday and major events. Because Patrick was first diagnosed during Thanksgiving week, treatments were being given in the midst of the Thanksgiving and Christmas seasons. Shannon would anticipate Patrick's questions, such as "Where is Christmas going to be?" She explained: "Christmas is going to be right around here. You will still be in the hospital, just so you kind of know," she replied. Throughout the conversation, she again referenced a certain number of fingers along with specific points along her fingers and the areas in between. Shannon's nonverbal, picturesque method of communicating using this three-finger method almost seemed to parody a roller coast ride, with higher moments at the tops of the tracks, and then the inevitable extreme dips or lows that were just ahead of the curves in each stage of the treatment. "I would say: 'So, Patrick, here is where we are right now: We're this far, and you still have this far you need to go.' We kind of always had a scope ahead of him," she explained.

Bone Marrow Transplantation

One of the more successful moments of the journey that eventually led to Patrick's remission came in the form of a bone marrow transplant (BMT). According to the National Cancer Institute, bone marrow transplantation is a newer type of treatment against AML in which a patient's bone marrow is replaced with healthy bone marrow from another person whose tissue is the same or almost the same as the patient's. Bone marrow transplantation takes place once high doses of chemotherapy are given in order to destroy all of the bone marrow in the diseased body.⁹

Again the family turned to the web to make an appeal for individuals to volunteer so they could be tested for possible matches with Patrick. On December 14, 2002, many people came forward. Within that population, one individual wanted desperately to help Patrick more than anyone: his little brother, Daniel. As Shannon explained, "All Daniel wanted to do was be the donor, that's all he wanted to do."

It's Me! It's Me! It's Me!

On December 17, 2002, a match donor for Patrick was identified. Over 150 people, including Patrick's brother and younger sister, Ellen, had willingly

⁹ National Cancer Institute (2002, Aug. 19). *Childhood acute myeloid leukemia/other myeloid malignancies*. Retrieved Jan. 2, 2004, from http://www.cancer.gov/templates/doc_pdq.

agreed to be tested as possible bone marrow matches for Patrick. Human nature suggests that some of them, including sister Ellen, breathed a sigh of relief when someone else was identified.

Less than one month after Patrick's first diagnosis, younger brother Daniel found out he would get his Christmas wish: to be a bone marrow donor for his brother. When Daniel first heard the news, his mom said the reddish-haired exuberant boy went running through the house, jumping up and down, and shouting over and over at the top of his lungs: "It's me!!! It's me!!! It's me!!!"

On the afternoon of March 11, 2003, Daniel underwent a bone marrow aspiration in which bone marrow was taken from his body in one part of the MD Anderson Cancer Center, while Patrick waited in another. The boys' parents said the first words out of Daniel's mouth after the procedure were as follows: "[Did] I help my brother?" "Then," as Shannon laughingly remembered, "he just blows chow all over the place, you know, because he's feeling awful."

Nonverbal communication again became important to the family. "They let Daniel out of his procedure. We went straight up to see Patrick, and to let him know that his bone marrow was coming," Shannon explained. "There wasn't a lot of fanfare from the doctors [in terms of Daniel's donating his bone marrow]. I was walking through while the doctors were finishing their paperwork, and the nurses were over there. I was like, 'Hey, let's give it up for the donor!' I made everybody applaud," she said.

Patrick received Daniel's bone marrow beginning early that same evening. Twelve days later his blood counts improved to the point he could be removed from isolation. On March 25, 2003, Patrick was released from MD Anderson.

As of this writing, Patrick remains at home in remission. His head is now full of beautiful dark hair, and he no longer looks like Gollum from *The Lord of the Rings* trilogy, as another young boy called him when he went bald from receiving massive amounts of chemotherapy. If not for the white surgical mask Patrick occasionally wears in public, one might never know of his ordeal or that he has had any experiences different from any other healthy 12-year-old boy.

On Wednesday, October 29, 2003, the family posted the following update on their web site:

Patrick is doing really well. We're back from 2 weeks in California and we had a great time, thanks to the Make-a-Wish Foundation (www.wish.org). We arrived in Burbank on October 11, spent several days in Ventura with Shannon's brother, then rented a 25-foot motor home and drove up the coast along Highway 1 north. We camped along the way at Morro Bay, Big Sur River, then Carmel for 2 nights, then landed in Yosemite where we stayed 5 days. It was absolutely gorgeous. We were all in awe of the beauty of God's creation and could not stop looking up at the tall trees and huge mountains all around. The weather was perfect. We slept about 10 hours per night. We could not have asked for more.

Patrick continues to do well. He has not had any serious illness since being released from MD Anderson 7 months ago! One reason that we chose to rent an RV and go camping was because we wanted to avoid large crowds and too many public places, due to Patrick's immune suppression. Although all of his clinic visits and lab tests have been positive, he is only 7 months past his bone marrow transplant, and he is still at risk for illness, infection, and relapse.

Eye on the Storm: Beginning with Data

Patrick's parents talked about a variety of responses both have observed from other parents experiencing the horror of having children with cancer. They talk about the anger response, which Shannon suggested stemmed largely from the "nag of feminine frustration." They talked about the running-and-hiding response, in which you continually say "God help us."

Through their own emotional roller coasters, they continue to experience both anger and an intense desire to run and hide. Shannon remembered the time when the family went by the MD Anderson chapel to pray. A statue of an angel was in the room. At the bottom of the statue were the words: Fear Not.

Shannon recalled: "And so my heart is going boom, boom, boom. I'm terrified at this point. God, you know how your first encounter with something is usually the right way and everything else seems to be wrong? Even though we know that, we were like, *Do this right; do this right*. We were kind of irritated. And I see this 'Fear Not,' and I'm about to come unglued, and I think it's OK to fall apart. And I said [to Patrick], 'Don't be scared. It says "fear not."' But he was fine," she added.

Patrick has sustained his family throughout this trauma; and they have sustained him. The family holds tight to each other, physically and emotionally, and continues to work hard to keep focused on the situation at hand, as they did

when Patrick was in the three phases of his treatment. They refuse to continually hide. Even when they do, they know that “God will hear us,” David said.

“There are a number of emotional features that helped me—gave me focus and direction—helped me make sense,” David said. . . . “And one of them was, you know, on a daily basis, we would talk to a doctor, and get certain numbers of certain statistics,” he described. “Well, you know, our latest test shows this and that means this, and there is this percent chance that this might happen. These numbers are important.” Data became an increasingly important component for the family’s ability to remain focused on the eye of whatever storm was coming their way. Data also became an ongoing mechanism for a more spiritual understanding of the family’s definition of truth.

Truth and Reality

Patrick’s dad used a Biblical illustration to convey his family’s notion of real truth beyond data-driven numbers and statistics. It’s the story of Peter’s challenge of Jesus to prove His identity by walking on water.

David gave an overview of the story: “They [the disciples] were on a boat in a big storm. And they were scared, and they said, ‘What is that, his [Jesus] ghost?’ And he said ‘No, it’s ours.’ And Peter said, ‘OK, if it’s really you, then you step out of the boat.’ Peter walks out and, do you remember the story, he’s doing OK. Then, the Bible says he starts to see the waves, and he takes his eyes

off his goal. He starts to look at that stuff that gets in his way. And when this happens, he starts to sink.”

David continued with the analogy by explaining that once when someone asked him how he copes with his family’s situation, he responded: “We have all these facts and all this junk, all this medical junk. You can’t focus. Then you sink. It’s not that you don’t consider it—you don’t ignore it. The question is, what are your eyes going to focus on? So Peter had a choice, and he made the wrong choice. So we had a choice too. Now, are we going to look at the facts? These are medical facts, they are statistics, but they are not the truth. The truth for us is that God loves us, and that He is always with us, no matter what happens to us,” David said.

Shannon is quick to add that for her family, spirituality is not like a bandage or a pat on the back. “It was what your next breath was based on,” she stated. She is also fully aware that sometimes there is a different outcome. “We saw some other reality checks. They [MD Anderson Cancer Center] lost some 31 kids In these next 3 months, things can change on the turn of a dime. So the reality is out there. We were just thankful that he [Patrick] is still here, and we get to do these new things,” she added. In the midst of whatever new things come their way, the family members will continue to rely on the help and grace of others that has sustained them thus far.

It Takes a Village

Following Patrick's release from MD Anderson Cancer Center, the Ede family stood center stage on July 27th in a *Praise Celebration* at their church in front of approximately 250 friends, family, and general well-wishers who came to celebrate Patrick's remission and homecoming. These were individuals who had literally circled the family's Round Rock, Texas home in a prayer vigil. They were men and women who had donated blood. They were folks who had offered to give up some of their bone marrow. They had mowed the family's lawn, cleaned their home repeatedly, home-schooled Patrick's siblings, and delivered casseroles on top of casseroles. They had prayed and acted without ceasing. They were valiant heroes to these 5 individuals.

Shannon and David spoke to the crowd, at times crying and at other times talking in clear united voices, firm and full with gratitude. They named individuals by name, and by deed. They thanked groups of people. They remembered the day when they first drove to Houston, to a new and unknown cancer hospital in a much larger city, only to find their local pastor from back home sitting in the lobby waiting for them to arrive. He was there simply to be on hand if they needed anything, including the comfort that comes from seeing a familiar face in a strange location during times of angst.

For Shannon and David, and countless other families in which a child has a life-threatening illness, reliance on the outstretched hands of others may seem at

first to be a sign of weakness or at a minimum, unfamiliarity. Soon enough, however, it becomes a matter of necessity and survival. As the family posted on their web site: “We continue to find reasons to praise God, and that includes each of you.” As the family tearfully hugged each other before the auditorium crowd, Patrick said simply and quietly into the microphone: “Thank you all.”

The Last Chapter

Data from the American Cancer Society show a 40 percent chance for a 5-year survival rate for children with AML like Patrick. Advances in treatment continue to improve the odds, as may be the case for Patrick, so that he may live well beyond his 12 years of age. For now, the family celebrates small yet significant victories—like nine plus months of remission.

David and Shannon fully understand the correlation between data and the truth. They know now is a critical time. “Although all his clinic visits and lab tests have been positive, he [Patrick] is only seven months past his bone marrow transplant. He is still at risk for illness, infection, and relapse. For the next 4 or 5 months, we will be going to MD Anderson once every 3 or 4 weeks. This is a critical time. One of Patrick’s physicians told us that patients who relapse within the first year usually relapse at the very end of their first year period. This may be due to the fact that any residual chemotherapy drugs have been eliminated from the patient’s body toward the end of the first year, and that may allow any remaining leukemia to reformulate,” they wrote on their web site.

Yet in their minds and hearts this is not the final chapter for the Ede family, regardless of the data, the odds, or the possibility of a relapse for Patrick. The final chapter, for this beautiful family, is one that is yet to come. It represents the real truth of life for them: God saves you.

Patrick knows God will save him in some form or fashion, even if it means departing this earth following a relapse. His parents and siblings wholeheartedly agree that their collective final chapters are yet to come, and show little resemblance to life on this earth. For the time being, Patrick and his family are grateful for the present moments in their lives. As they posted on their web site:

Again, this is a great reminder that there are no guarantees regarding our future on this planet, and that applies to all of us. Although we know our ultimate destination, we do not know how or when we will be ushered from this life to the next, or how much pleasure we will enjoy or suffering we will endure until that time. We are grateful for today, and grateful for the guarantee of life eternal in Heaven.

E. Leonzo's Lead

Leonzo¹⁰ is 13 years old. For more than half of his life, he has wrestled with cancer. He was 6 when initially handed the diagnosis of leukemia. Leonzo's specific form of leukemia is called Acute Lymphocytic Leukemia (ALL). The

¹⁰ In this story, I have changed the names of the people I call "Leonzo" and "Dr. Pete."

American Cancer Society predicted in 2003 that approximately 2,200 children in the United States would be diagnosed with ALL. Because of the advances being made in treatment over time, the 5-year-survival rate for ALL patients is now nearly 80 percent.¹¹

Triste

Despite his young age, Leonzo wears many hats and juggles many balls in his battle with cancer. He is a first-generation English speaker. His mom speaks only Spanish. Because most of his healthcare staff members speak only English, Leonzo has assumed the primary role of decision-maker and translator regarding his own healthcare.

People all around Leonzo seem to rely heavily on him. For a young boy who does not care to talk very much, he is frequently placed at center stage, at least as observed on the afternoon of our interview. He consistently translated messages for his mother and directed the staff regarding his medical needs. He seemed to be familiar with the role of a take-charge, albeit quiet, leader.

At age 6, Leonzo had a sense that something was physically wrong with him, but no one initially said anything directly to him. When asked how he knew something was amiss, he replied, “Because I looked at my mom, and she was

¹¹ Cancer Reference Information (2003, n.d.). *What are the key statistics about childhood leukemia?* Retrieved Jan. 2, 2004, from <http://www.cancer.org/docroot/cri/content/>.

sad.” When I responded to that statement using the Spanish word, *triste*, for sad, Leonzo’s mom, who was sitting quietly nearby, said faintly, “*Si, triste.*”

Perhaps she is referring to sadness then *and* now, and all the years in between during which Leonzo has battled cancer. On this particular day, the sky is gray and gloomy, and Leonzo has just completed another week in a pediatric palliative care hospital—his home away from home. He hoped to leave the hospital that night. He will most likely return again.

Just a Word

Leonzo is the first to tell you he has leukemia. He understands the importance of blood cultures and numbers, and the worry that comes with the onset of a slight fever, like the one that put him back in the hospital. However, things have changed over time in that Leonzo was not always told what was happening with his body, especially when he was much younger.

Initially several days passed before Leonzo was first told he was sick, even though he already knew something was wrong. Although he was only 6 at the time, he distinctly remembered the first time he officially learned he had leukemia:

Question: So, a few days passed [*during which he noticed his mom being sad*], and your mom came in, and said . . . ?

Leonzo: [*Finishing the question*] —she told me I had leukemia. And I took it as just a word.

Question: Just a word? Did you know what that meant?

Leonzo: No.

Question: What did you think?

Leonzo: Nothing.

Question: Did you ask her what it meant to you?

Leonzo: No.

Even though he asked little at the time, Leonzo seemed to remember a great deal. He remembered not talking about his illness at the onset. He recalled closely watching his mom for a cue as to how things were going with him. He remembered, although somewhat vaguely, talking periodically to his primary physician, Dr. Pete, whom he calls “a nice guy.” “He’s been nice to me,” Leonzo explained. His physician seems to be one of the few persons with whom Leonzo talks about his illness, even to this day.

Talking in general is not something Leonzo likes to do. He answered interview questions in brief form, usually with a yes or no answer, although he was extremely polite in conversing. Despite his brevity, however, he seemed genuinely interested in and willing to tell his story—perhaps for no other reason than his friend Dr. Pete asked him to. “Do you ever like to talk about it [his illness]?” I asked. “No. I don’t talk that much,” he replied.

Diversions and Memories

Leonzo has both older and younger siblings. They visit him in the hospital, where “we just play,” he explained. They like to tell jokes and most of all, play Nintendo on the computer. Sometimes Leonzo wins. Sometimes he loses.

Leonzo and his siblings prefer game playing and joke telling in lieu of direct conversation. Outside the sibling circle, Leonzo sometimes uses humor about his own illness as a way to find new friends. “If I didn’t have this illness, I couldn’t meet more persons,” he stated, explaining that his illness presents a way for him to meet new people—“at least, I think, a few of them,” he added. He avoided going into greater detail on his thoughts in these areas, despite probing on my part.

Sometimes Leonzo likes to hear stories. Yet most of the time he prefers avoiding such conversation. “It brings memories,” he says quietly, looking *triste*, much like his mother.

Dragons and Tigers

Leonzo sits in his home away from home, one of the rooms at the pediatric hospital. He spends a lot of the time looking out the window of what he calls his “second living room.” He likes to play Nintendo and tell jokes. He likes to draw. Specifically he likes to draw cars and flowers—and dragons and tigers.

Much of his time is spent keeping up to date with his healthcare status for the day. He listens closely to the numbers being given to him by his physicians and nurses about blood counts, bodily temperatures, cell levels, culture results, and on and on. He is told by people who are quickly moving in and out of his room that certain treatments will happen for that particular day provided previous tests turn out the way they are expected. Intravenous (IV) fluids and antibiotics are hung, and then taken down when the beepers go off. New bags are hung. Everything happens almost automatically, yet the talk is often tough.

Tough Talk

Leonzo seemed to be like many other young cancer patients in that he preferred to hear “straight talk” about his condition. During that particular afternoon of the interview, that was exactly what he was given—straight talk from the hospital staff:

Staff Nurse: I talk to Leonzo like he’s my son. I tell him, and I’d be honest with him, I’d tell him: You need to take this medicine, this medicine sucks, it tastes nasty, but you are going to have to take it. You know that. And that’s it, don’t I? *[Staff nurse looked at Leonzo, and Leonzo nodded]*. And then when he doesn’t get up in the morning, I would take him my little normal saline and start dripping them on his head. Then he wakes up. Don’t I? *[Staff nurse again looked at Leonzo, who said, “Yeah.”]* [I] tell him he’s going to eat his breakfast. If he doesn’t, I’m going to eat it. His mama always brings him food. I don’t know why we even have meals for him. Huevos and potatoes, and his mom brings him tacos with hot sauce.

The tough talk from the staff continued in front of Leonzo:

Staff Nurse: *[Looking at Leonzo]* You know you have leukemia. That took over the transplant. There is nothing more we can do. When the leukemia takes over, you are going to go to Heaven. And only God is going to decide when you go to Heaven. When is that going to happen to you? Maybe in 3 months, maybe 3 years, maybe 30 years. It's when you get sick, you could die. So that is why we have to give you these drugs, these antibiotics, to keep you from getting sicker. . . . I know you have ALL [a serious form of leukemia], and I know you are going to die. But I don't care. I'm going to spend the time that I have with you having fun.

Looking Ahead

Leonzo wonders about the future. He prefers to think of himself now and in his future as a “normal” rather than a “sick” person. At times throughout the conversation he seemed more willing to think ahead. At other points, he became quite reticent.

Someday Leonzo hopes to become a physician. When asked what kind of physician he wanted to be, he replied: “Like Dr. Pete.” Dr. Pete is the tireless head of the hospital where Leonzo spends much of his time. He has taken care of Leonzo for the past seven years. One suspects Dr. Pete as being Leonzo's closest confidant. He is certainly his role model.

Leonzo's reticence about the future stems from one kernel of truth: things are uncertain. What the future holds for Leonzo is highly ambiguous. He himself holds his cards close to his chest in the form of brief answers and few

explanations. The uncertainty is troublesome and at times, sad, for Leonzo. It continues to make his mom *triste*. She is turning to the Bible for help and understanding.

Leonzo says hearing the staff talk about his dying makes him sad at times, but it does not worry him. He still sleeps well at night. He may draw dragons and tigers, but he does not seem to dream about them.

As his staff nurse said, Leonzo could live for 3 more months, or maybe 30 years, although the latter is unlikely given the ALL disease, and his present medical problem of fever spikes and frequent hospital visits. The hardest part is in the not knowing. Leonzo says he prefers not to talk to his mother or sisters or brothers at times because “Sometimes they ask me questions I can’t answer. Because I don’t know.”

In the meantime, Leonzo will continue to lead the way on directing his own healthcare journey, regardless of how much longer he lives. The staff says he continues to have a good handle on his situation. As the afternoon of treatments and waiting draws to a close, a staff member says to the 13-year-old who has known sickness longer than not:

OK, I’ve got other patients, guy. So at 5 o’clock, in a few minutes, we will start our report, and I’m going to come back by and take some blood, and you will be discharged. A few minutes from now the doctor should be here, so I’m looking at a quarter of seven you should go home. So you will need to let your mama know.

The directions to Leonzo continued to flow from the adult to the 13-year-old:

There was some morphine, some boxes of morphine the pharmacy won't send up, so you will have to stop and get them on the way out. One of the healthcare nurses will come to your house to take care of you, and give you more medicines. So let's say seven o'clock. It looks like you are already packed. Are you ready to go?

As Leonzo nodded affirmatively, he again looked around the room, and glanced at his mom who was eagerly awaiting the latest translation from her 13-year-old son. Leonzo has grown up fast. The scene represents an acute case of role reversal.

Before the interview closed, I asked Leonzo another question about his own 7-year journey of illness and what others might learn from his experiences. "If there was another patient in here who had just been diagnosed with leukemia like you were in 1997, what would you say to him or her?"

"Never give up," Leonzo replied with a smile.

F. Authenticity

At age 18, Eduardo¹² is a wise sage who sat cross-legged in the middle of his hospital bed and philosophized about his life. Although he wishes he could live up north in the cold with the benefit of being "bundled up in blankets," he actually lives in an area that is usually warm. He lives with his mother. Because of the weather, he does not particularly care for living where he does because it is

¹² In this story, I have changed the name of the person I call "Eduardo."

“summer year around.” Living up north also appeals to Eduardo because there “ain’t millions of people” crowded into a small space.

Although he loves the idea of living in the cold, Eduardo does not actually like to *be* cold. He shivered frequently during the interview, and asked that his hospital room temperature be raised from 70 to 85 degrees to ease his chilled body.

Reality

Shivering is a function of Eduardo’s life in that he has a form of cancer called Acute Lymphocytic Leukemia (ALL). He described it as a “basic blood disorder.” Although his initial diagnosis in the spring of 2001 came with what he was told was a “high rate of being cured,” he relapsed 2 months prior to the interview.

Cancer is not new to Eduardo’s family. When his parents divorced, Eduardo, an only child, said he had to move out. He did not elaborate why. He lived a big part of his life with his aunt who currently comes to see him frequently in the hospital. Two months before Eduardo was diagnosed with leukemia, his father died of liver and lung cancer.

Remembering

Instinct told Eduardo he was sick. He initially went to see a dentist because his mouth would not stop bleeding when he brushed his teeth. The dentist

noticed a lot of bumps around Eduardo's neck, and told him to go see a physician. "Then I was always tired; I was getting weak," Eduardo explained. Eduardo's dentist told him it was his lymph nodes. That night, he told his mom what the dentist said. She took him to a physician the very next day, Friday, where blood work was done. The medical staff told him to come back on Monday.

On Saturday, the physician's office staff called, and asked that he come in immediately. Eduardo would have preferred waiting until the following Monday because he had plans for the weekend. When asked why he preferred waiting, Eduardo replied: "I'm just that type of person. I don't know. It wasn't really bothering me. I had dealt with it up until that time, so another couple of days isn't really going to matter."

Emergency Transfer

His mother prevailed, and she and Eduardo went back to the physician's office on Saturday. Eduardo remembers that the physician's office was on the west side of the city. The physician was waiting for Eduardo, who was then transferred immediately to the emergency room of a local hospital. "They already had a room for us, and everything," he said. He knew something was wrong.

Eduardo remembered being more "upset" than "scared." "I was a little bit upset that I was sick, and they ruined my time," he explained. Since the initial diagnosis, Eduardo has lost more time to being sick with ALL, although he initially went into remission with hopes for a full recovery.

Waking Up

One of the first procedures Eduardo underwent because of his disease was a spinal tap. He remembered waking up during the procedure. He also recalled waking up during a bone marrow aspiration. “Yeah, it hurt,” he said simply. Two months ago he was told cancer cells were found in his spinal fluid. Now Eduardo is going through more chemotherapy until a suitable bone marrow donor can be found.

He is also taking antibiotics for an infection that caused mucus buildup in the form of blisters in his throat. Both the throat infection and the need for more chemotherapy have necessitated Eduardo’s most recent return to the hospital.

During this part of the conversation, a nurse walked into Eduardo’s hospital room. He told her he was busy right then. “Do you want me to come back?” she asked. “Yes, please,” he responded. She turned and left the room. Eduardo runs his own show.

Confusing Talk

Talking about his illness with others is not something Eduardo likes to do. He finds talking about his situation, especially with his mother and aunt, frustrating because of the complicated nature of medical issues involving cancer.

“I don’t really like to talk with them about it. They don’t really understand. My aunt doesn’t really understand, and she will get confused. She

will start saying wrong things, and telling other people different,” he explained. He also says that medical situations in general lend themselves to confusing talk. “It’s really confusing if you don’t know anything about it. Just the whole terminology and the ways things are called. And she [his aunt] has that Mexican accent and a lot of things sound [differently] like that,” he described.

When asked if he remembers the specific language used by the physician to tell him he was sick, he distinctly recalled the specific phrase: “Hey Eduardo, you have leukemia.”

The physician then started “breaking it down, telling me I had ALL. It’s acute lympho . . . leukemia, or something like that,” he said. “I don’t remember,” he added.

The Bottom Line

After being given the initial diagnosis, Eduardo inquired little. “I didn’t really ask any questions. I just wanted to know if I could be cured or not. Because I didn’t really want to know what it was,” he recalled.

Eduardo was told there was a high rate of being cured. Then he explained: “I just recently relapsed like 2 months ago.” When I responded, “I’m sorry,” Eduardo replied: “Me, too.”

Although he may not have wanted to know the full name of his disease when initially diagnosed, Eduardo is now acutely aware of what is being done to his body to try and keep him alive. He knows which intravenous bags are full of

fluid, which are full of chemotherapy drugs, and which contain morphine. He is fully cognizant of which bags are being hung for him at which times, and why. He says he is feeling “pretty good” today because he is on morphine. “It takes the pain away,” he explained.

Giving Back

Eduardo’s recent relapse derailed his plans to start college in the fall. He is a high school graduate who hopes to attend a local community college and someday become a nurse. Before becoming sick initially, he had set his sights on being a pediatrician. “But now that I’m here [in the hospital], it takes longer to be a pediatrician,” Eduardo explained.

In the next couple of days, Eduardo hopes that he will be released from the hospital. When he gets home, he looks forward to watching cable television, channel surfing, and eating pizza or anything Italian. He loves rap music and rhythm’n’blues, or “whatever sounds good.”

Eduardo converses easily about the movies he loves. *Finding Nemo* (“Ellen’s crazy,” he said, referring to Ellen Degeneres; he loves her acting as Dorie and speaking whale), *A Beautiful Mind*, *Radio*, and *Titanic* are among his favorites. He suggests that the film, *A Beautiful Mind*, is one you “can’t see twice.” When asked why, he replied: “because you have already spoiled it” by knowing the ending.

Half Full / Half Empty

Eduardo said he is not certain as to the ending of his own story:

Question: Do you have an idea of how this is all going to work out?

Eduardo: Do I have an idea? No. I don't really know what is going to happen.

In the meantime, Eduardo continues to call things as he sees them. He focuses on what is real, as opposed to what may be imagined in a happenstance of hope. "I'm not real optimistic. I'm pessimistic. I focus on the negative. Yeah, I've always been like that," he said.

He wishes other people would do the same. In fact, he resents people who hand him an optimistic view of his situation, meaning that "You are going to live, and everything is going to be all right," Eduardo said. He goes on to explain: "You know how people tell you: You are going to be all right. God has to know, you don't really know what is going to happen to you?" Eduardo hates that kind of talk.

Eduardo takes a more practical, authentic approach to his way of thinking. "I focus more on the reality part of it, that I may die. And my life may come to an end. It just happens. I'm sure other people who pray and say that they are going to do good, don't end up living. That's mostly how it is," he said.

When asked specifically if he wished other people would talk to him using an optimistic or pessimistic point of view he replied: "pessimistic. I don't like it

when they tell me what they think, and they tell me what they think like they know what is going to happen. “You know how people are like, ‘Stay up,’ saying that it is going to be alright. I always found it so corny. And now that I’m in the position, it sounds even more corny,” he added.

Eduardo continued to emphasize his perspective. As he is talking I noticed he changed his subject reference from *they* to *you* almost in midstream. Perhaps as he continued his dialogue, he switched from talking to me, to talking directly to an imagined or remembered audience: “*You* [as opposed to *they*] don’t know what my future holds. Don’t talk to me like *you* do,” he declared angrily.

Does he ever tell people directly not to talk to him in that way? “No,” he replied, “I just let them talk. I don’t want to be rude or anything.” He says people who take an optimistic view of situations they are not directly living may think they are saying the right thing, but “They’re just not.”

Boundaries

Although Eduardo may hold strong feelings about how people should and should not talk with him, he is quick to place tight boundaries around how much talking he himself does with others. Not only does he prefer to remain silent in talking about his illness with his mom (because she cries a lot) and his aunt, he also prefers not to talk about his illness or his feelings with his friends. He said: “I wouldn’t talk with anybody about it because most people don’t want to hear what I have to say, because it’s so negative.”

His feelings are negative, they change very fast, and are often hard to pinpoint. When asked to describe how he feels emotionally, Eduardo responded with honest clarity about an ambiguous and unsettling situation: “I don’t know. Right now I feel good. But when I feel sick, it’s like I think I’m going to die, it’s just . . . it’s not a good feeling what you go through.”

Eduardo also has no interest in defining other people’s stories, not even other young people who have cancer just like him:

Question: Is there anything you would say to parents of children, or young people, with cancer?

Eduardo: Me personally? No. Because you are going to feel the way you feel about it. And nobody can make you feel anything. You don’t know how other people feel. I mean, they can tell you, but at the end of the day you are still going to feel what you feel. So it doesn’t really matter what anybody says. You have that mindset already.

Eduardo says it would be hard for other young people to learn from him. “I’m sure they are going through something worse than I’m going through. How do I talk to them? I don’t want to say something that might hurt them, or that might get them thinking negative. I don’t want to affect them like that,” he explained.

Hypocrites

Even though Eduardo does not outwardly talk much about his illness with anyone, he does pray at times, albeit infrequently. “Sometimes [I pray],” he says.

“But I didn’t really pray before [he got sick], so I don’t really want to start praying now. I don’t want to be one of *those* people,” he added.

Those people are people who “just come to God when something bad happens,” Eduardo explained. “Hypocrites,” he called them. He added: “You know, like those people who only go to church on Easter and at Christmas time.” Eduardo does not believe that you have to go to church all the time. “Yeah, you don’t, but damn. Yeah, but don’t try to preach if you only go 2 times a year,” he commented.

Sense-Making

When Eduardo first got sick, he would lie in bed at night in the hospital. His mind would swirl. “But I don’t ask questions anymore, like ‘Why?’ Everything happens for a reason,” he says.

He understands people may be afraid to use the word *death* around him because “deep down inside they might see that I may die. And they don’t want to bring it up, which is perfectly fine with me. I don’t really want to talk about it. I’m real to the fact that I may die. We’ve all got to die,” he said.

No longer does Eduardo feel a need to make full sense of his situation or behave a certain way or even talk to others. He is periodically bothered by the reality that leukemia is “just taking time out of my life that I can never get back because I would much rather be out there doing something else,” he stated.

There

When asked what the last few years have been like for him, Eduardo replied simply: “There.”

“I’m still alive, so I guess they’ve been alright,” he continued. When asked what could be worse than his present experiences, he replied: “death and suffering. I haven’t really been suffering. I’m in a much better position than a lot of other kids that have been here.”

In the meantime, he continues to think about his life in terms of his philosophy that it is important to “just be patient, and let it play out. I don’t want to rush it. Because it might not be what I want it to be.”

G. Unfiltered Harry

Twenty-year-old Harry¹³ sits on his front porch on a cold and gray Saturday afternoon in the fall of 2003. The afternoon in no way lends itself to being outside for any reason. It is damp, cold, and miserable. Not a single individual can be seen outside on the entire block. No birds are chirping, and the sky is void of color or character other than dreary. When I asked Harry if the cold might bother him because of his illness, he shot me a look that crossed between

¹³ In this story, I have changed the names of the people I call “Harry,” “Dr. Carter,” “Lucas,” and “Ted.”

the inquisitive—*Have you always been stupid?*—and the cynical—*Who me?*
What have I got to lose?

Harry is an incredibly direct yet courteous young man. He is also fast in sizing up his audience. When he realized the weather might be too miserable for sitting outside, he quickly asked if I wanted to do the interview inside. I said I wanted to do the interview wherever he preferred. He sat down in a dirty plastic chair on his porch.

Then he asked if his smoking would bother me. Again I responded in a positive yet deceptive way by saying “Of course not,” fully appreciating the fact that we are sitting on *his* front porch. Harry began talking by saying he did not sleep very much the night before because he and his girlfriend drove a family member out of town to a camp for the autistic. The trip took almost all night. Yet Harry is gracious in keeping his interview appointment and giving a total stranger part of his time on a miserable Saturday afternoon. His story began. . . .

Harry’s Deal

Harry has lived with leukemia, Acute Lymphocytic Leukemia (ALL), almost all his teenage years. He remembers first being diagnosed in the early part of 1998 when he was 14 years old. He knew something was wrong when the physician [in a “weird tone” that Harry knew meant bad news] asked his father to step outside the hospital room where Harry was undergoing tests. “If he [the physician] can’t say it in front of me, it can’t be good. We would have talked in

my room if it had been like, ‘Oh, by the way, he’s fine, send him back to school tomorrow’; but it wasn’t like that. They weren’t fooling anybody,” Harry said.

At the time Harry had never heard of ALL, but he had a vision about what the future meant in terms of the diagnosis. “I never really knew what leukemia was. I just knew that you would be bald if you had it,” he commented.

Even after all these years, keeping track of his disease has not been easy. It seems like a never-ending on-again, off-again saga. Harry battled leukemia, and first went bald, between 1998 and 2000. “Or 2001, maybe. Either 2000 or 2001,” he tried to remember precisely; “2001, I think. And then I got over it, and it came back in 2002,” he added.

Sugar-Coating

Harry is smart in a commonsensical, no-nonsense kind of way. He knows his long-term prognosis is not good, despite constant talk from his medical staff that he described as *sugar-coating*. “They always tell me the good stuff. But that’s what they’ve always done the whole time, and it’s come back twice already, and my chances are down to 50-50,” he stated.

Harry knows there is a major potential wrinkle in his long-term life plan. Although he realizes his physicians and nurses “never tell me nothing bad, I figure when you’ve got a life-threatening illness, there’s got to be some kind of catch somewhere, you know, and they are just trying to tell me that it’s all good,” he said.

With that in mind, Harry made a pact with his physician whom he admires and relies on heavily. The pact is that if “he [the physician] thought I wasn’t going to make it,” then he would answer me honestly: “What do you think from a professional point of view?” Harry asked. “And he will always tell me, ‘Well, I think it looks good,’ and all that,” he added.

Despite the pact, Harry understands things may not always be what they are set up to be. He recognizes the complexities and ambiguities that often generate changes in people’s good intentions, like honoring a pact, while communicating with individuals who may be at the end of their lives. “But I think that’s what he [the physician] tells everybody. He’s a doctor, that’s what he’s supposed to do - sugar-coat it all,” Harry said.

Harry also believes the entire medical staff is adept at sugar-coating his situation in a genuine effort to make him feel better. “They always tell me, well, the first time [Harry was diagnosed] they told me the same thing: ‘It looks good,’ and this and that,” he said. “And now that I’m back they tell me, ‘We, we kind of saw it back then when we thought it was going to go away, but there was some stuff that showed otherwise,’” he explained.

Even during this latest time when the staff was sugar-coating the situation, Harry saw reality. “You know, the fact that my blood count didn’t drop, I never needed blood products. At the end, I was on like a year of just getting a shot in the leg, and seriously, like 4 or 5 times to try and drop my blood count, and it

wouldn't drop. And then finally they just had to, they reached the maximum they could be giving me, so, which was like 4 or 5 times what they started with," he explained. "And it still wasn't even touching my count. So that was a bad sign right there. All this time, my blood count is supposed to be lower, because the chemo is supposed to be affecting them [the bad cells], and it's not for like a year," he recalled.

When asked if he perceives sugar-coating as a form of lying, Harry said no. "No, because they tell me pretty much straight-forward. If they told me, 'Well, look, you're going to live,' with a 50-50 chance, 'You're going to live, everything is going to be fine,' that's lying," he stated. But his physician told him, "'Look, you have a real serious disease again. It's really bad that you got it a second time.' That's not a really good sign at all. What that tells me is that the medicine is not working, which is very bad," Harry said. "You know, so he tells me the truth, that it's very bad," Harry distinguished.

Flying Solo

When Harry was first diagnosed at age 14, he participated to a much lesser degree than now in conversations and decision-making regarding his care. As he recalled, "the real important stuff when I was 14, they would usually talk that over with my dad. They would kind of talk it over with him first, and then they would kind of team up on it, like my dad, and then Dr. Carter, and they would figure it out: 'OK, this is what we should tell him, and this is how we should tell him.'"

Harry also remembered that the medical staff perceived him as having a greater laissez-faire attitude when he was younger, an incorrect assumption he is quick to add. “I guess that when I was 14, I was always different in their eyes. Like I was always happy-go-lucky, so it didn’t really bother me, you know?”

But the staff was wrong, according to Harry. It did bother him to a greater degree than they realized. “I mean, it did because it sucks, but other than that it would have been fine. I guess they figure that now that I am more of an adult, I can cope with the truth more than when I was younger,” he added.

Over the years, Harry has become adept at being more of a decision-maker and conversationalist in his own healthcare situations. For the past 2 years, he has been going to the hospital by himself for his treatments. Since he has been wrestling with leukemia for over 6 years, the routine of treatments, decisions, and medicines has become second nature to Harry. “Like most people, you go to the doctor and you think about it a couple of times, *OK, well I’m going to the physician, and this is what I am going for,*” he explained.

“Me, it’s like, *OK, it’s Monday. I’m going to the physician.* [I] just get up, and go about my business, like you would get up and go to school or work. That’s how I get up and go to the doctor. Not like every day, but basically, pretty close to it. And if I wasn’t in the hospital for chemo, I was in there for pneumonia or low blood counts, or, what’s the word I’m looking for, Neutropenia, when you have

an unexplained fever and your blood counts are low,” he described. “Just like it was my daily routine,” he added.

The Null

Harry is quick to express his appreciation to his medical staff. At times, he seems to rely more on them than his family. Although it may frustrate him, he understands their reasoning for sugar-coating his situation by sometimes saying very little. “If he [his physician] doesn’t really have any [hard evidence], almost like a criminal investigation, you don’t go kick somebody up without any hard evidence,” he stated. “That’s the way I’m thinking he’s thinking about it. If he’s not real sure that it’s going to come back, why get me worried? As if I don’t worry enough,” Harry commented as he smiled wryly.

Harry believes his physician takes the long-term approach of just letting things ride out for a while in an effort to help make life less of a worry for him. “Because right now he says that everything is looking good. So, as long as nothing is showing up bad, there is really no reason for him to say nothing to me anyway,” he theorized.

Crapshoot

Harry’s odds of long-term survival are continuing to worsen. They will not get better. At a minimum, he hopes, over time his body will stop the current statistical spiral downward from his initial diagnosis of 70-30 (70 percent cure/30

percent return rate) down to his current odds of 50-50. If his leukemia returns for a third time, however, his odds will drop even further to 30-70 (30 percent cure/70 percent return rate). As his odds have worsened, so has the talk associated with his disease, or at least the way in which Harry has heard that talk.

“It’s kind of like the first time that everybody made it sound like a breeze, which I guess it was supposed to be, because I had a 70-30 chance, so I guess it was supposed to be pretty simple. Since they made it out to be so simple, like, I went through it and once I finished my last treatment, in my mind, that was it, *OK cool, I’m over it*,” Harry recalled. “*Live my life like a normal person now*,” he commented.

“And then a year later, I got a job. I got everything going. I got car payments, just like any adult would. And then it just comes back out of nowhere, and I’m like, *Man, it came back, how does that happen? Wait a minute. It’s not supposed to do that. Seventy-thirty means it don’t come back*,” he said. “Kind of jumps up and slaps you in the face,” he said.

Harry continued: “And you realize that it does come back. My mentality about it is: I had a 70-30 that didn’t work. Now I have a 50-50. If your luck ain’t good enough for a 70-30, you really ain’t going to make a 50-50. And then if it comes back again, he [his physician] said that I drop down, he said to, probably under a 30-70,” he reflected.

Harry is also extremely frustrated with the ambiguity that comes with 50-50 odds. “Fifty-fifty doesn’t tell me much. That’s another thing. Not only do my odds suck, it doesn’t really tell me anything. You know, if I had a 20 percent or a 10 percent or a 30 percent even, then I would pretty much know what to look forward to,” he said. “Now I’m kind of like, *Well shit, what’s going to happen, am I going to make it, or am I not going to make it? What’s going on?*” he wondered.

Yet he is resolute at times. “If I go through my life thinking I’m going to die, then obviously, no matter how strong-willed you are, you’re going to. It’s going to affect you. So I just try to [stay strong], until they tell me otherwise,” he stated.

Flexible

If Harry’s odds continue downward, and the ALL comes back again, he anticipates having some very tough decisions to make, like undergoing a bone marrow transplant. The side effects of transplantation can be “really horrible,” he said, especially “if I find out that I have a 1 percent chance.” Side effects that worry Harry include skin graphing, where “your skin falls off,” he described. He also mentioned platelet dependency, where “every day you have to go in there, and get infusions of platelets, like everything. So you don’t even really have a normal life anyway,” he said. “What else?” he asked himself. “All kinds of stuff.

Yeah - like all kinds of stuff. Real bad horrible stuff that I had never heard of or that I had never thought about because nobody had ever told me,” he commented.

“But then again, that’s their job because they aren’t really supposed to talk me out of it [getting whatever additional treatment he may need should the cancer return],” he added. “They are supposed to try to talk me into any hope there is. You know what I mean? If there is the slightest bit of hope, they are supposed to talk me into going for it,” he stated.

Circular Depression

People marvel at Harry’s ability to stay upbeat amidst his life situation. People say to him repeatedly, “You’re never depressed?” He responds: “And what I always tell everybody is, I’m like, ‘If I’m depressed, would that cure me?’ That would just give me a miserable life along with a deadly disease. Two wrongs don’t make a right. I’m not going to be able to fix it, so I might as well enjoy my life the best I can,” he said.

He continued: “I tell everybody that. I say it’s not going to cure anything by me being depressed or sad about it, or me dwelling on it. I might as well live my life the best I can, and be as happy as I can while I’m here, you know, and appreciate these people who are with me,” he stated. “And if I’m depressed, you know, what is that going to do? It’s going to make my dad depressed. It’s going to make my girlfriend depressed. The kids are going to be depressed. My whole family, you know what I mean? My outlook, I think, that’s the reason why they

have a good outlook on it, and . . . because I go through it with such ease, kind of, it's like, they don't really even get sad. They see how I'm strong, and they say, 'Oh yeah, he's going to make it.' You know what I mean?" he asked.

Political Ironies

Harry used the word *weird* a lot. He used it in terms of how he thinks about life in general, including his own. He used it to describe how people talk to him, around him, about him, and down to him. He especially thinks about the way in which public policy and political decisions are made regarding research for his disease.

"I don't think they have enough research going on for leukemia," he said. "Like I just heard on the news the other day, they spent, like a billion dollars or like a hundred million dollars on figuring out about Alzheimer's. I figure, that's cool, I mean, I'm really glad that you are going to make a lot of older people remember stuff they forgot," he explained. "But meanwhile, you got 2-, 3-, 4-, 5-year olds dying every day. What about them?" he asked.

The weirdness and irony in Harry's mind is not just placed in the public arena. It is also personal. He knows the 2-, 3-, 4- and 5-year-old children who are dying and for whom he lobbies. "And that's pretty hard to deal with too, because I am pretty good friends with a patient who just passed away. Not so long ago, I went to his funeral, his viewing. I still hang out with his family, and so it's kind of rough to deal with," he described. "I've seen a 10-year-old boy get turned into an

only child from diseases like this. So it's kind of hard to deal with. Like, I've seen, the same case with my friend, his parents now only have, they had 2 boys, now they only have 1 boy. You know, like, imagine, you grow up with just you and 1 sibling, and then all of a sudden, you're by yourself. They get taken from you. It's kind of weird," he explained.

Smokin'

Harry prays more now than he used to in an attempt to curb some of his anger. When he was young and "a lot more immature," he said, "I kind of had that attitude of *God did it so I'm mad at Him*." Now he thinks he is smarter. "It's like when you're little, you know, and your parents don't let you get something. Well, telling them something, getting rude with them is not going to help you any. You know what I mean? So you might as well be nice," he philosophized. "Now I've gotten more into praying instead of being mad," he added.

Yet he is particular about what he prays for at this time in his life. "Usually I'm not a very selfish person at all, like if you knew me you would know that. So the [usual] way that I pray is like, to let me be healthy and to keep me around. But if He doesn't, I know that there is a reason, that I probably don't know but that I will find out when I get up there, wherever I'm going. I'll probably find it out," he said. "But I just tell them that, you know, if He does end up taking me, just to make sure that my family is OK," he explained.

In the meantime, he is still wondering about his future in terms of where he will end up. “Yeah, show me,” he challenges. “Who can tell me, ‘Oh, I’ve been there; Heaven’s the *coolest* place around, you know, it’s happening!’ Nobody can tell you that,” he says.

“All you know is that there’s a hundred old books of people who used to get all high off something, and write down stuff. That’s all it is,” he said, referring to books and philosophies about Heaven as described in the Bible. “Who’s to tell you what those people were on back then? You know? They were on acid or something. Yeah, there’s this guy, he’s in the sky, I’ve seen him,” he ponders.

Harry also wonders about Hell, especially since he says he has made some “bad choices” in his life. “They can’t let everybody in [referring to Heaven], so there’s got to be some [referring to Hell],” he explained. “Everybody always tells me, ‘All you’ve got to do is ask for forgiveness for any bad things you’ve ever done, and you’ll get right in.’ If it were that easy, Hell would go out of business. The devil would get out and become an angel again,” he argued.

Harry suggested many of us make our own Hell on earth. “The way people live their life is a big part of it. Like I said, a lot of people would feel like this is Hell, you know—the worst, going through a real bad disease,” he stated. [But] “I make the best of it. I still got the people I love—you know what I mean? Knock on wood. There’s wood laying around here somewhere,” he said searching.

Quality of Life

Of all the phrases used in a cancer hospital with seriously ill young people, the one Harry hates the most is *quality of life*. “I don’t like that term, it makes me sound like a used car,” Harry explained. “Quality of life. That means my resale value isn’t too much, kind of, you know?” he explained.

He remembered the phrase was used repeatedly, especially when he was younger. “I don’t remember how they used it, but I remember them using the term, *quality of life*,” he said. “What does that mean, my life sucks, what are you trying to say? What does that mean, my life is not worth living? Fill me in. Explain it to me slower. I’m 14 now. Come on now,” he challenged.

He continued: “I don’t know, it just gets to me. It’s nothing fancy, but to a 5-year-old or a 14-year-old, they might think, *Well, what is that?* And a lot of time when they used to tell me that, I used to just skip right over it and not think about it. I would just go on about my thing because I didn’t understand it,” he added.

The Perfect Place

Harry is suspicious, if not cynical, about death. He is suspicious about the notion of Heaven as an end-all nirvana. The hospice chaplains reminded him that God is not fair, and that life is not fair. They asked him to think about things in ways that are not always easy for him, like “everything happens for a reason, and

that in the Bible it says that everybody is supposed to go through trials and tribulation and suffering,” he explained. He is not certain about the logic or comfort that comes from hearing such words.

He is also still puzzled about the loss of life at such a young age. Ironically, he is not referring to himself, although he was only 14 when first diagnosed, but rather to those much younger children with cancer whose situations seem to crawl under his skin, given their injustices and insanities.

One day the hospice chaplain asked Harry how he knew that a 5-year-old passing away was such a bad thing. “[This] kind of struck me,” Harry replied. “It kind of upset me at first, but then she [the chaplain] went on explaining by saying: ‘How do you know that God’s not actually God, because, at 5 years old, God’s taken them to Heaven? You know he’s not going to get judged or anything, he’s just going to go straight up to Heaven.’ Even if he did get judged, it is obvious where he would go, because he was the sweetest boy, and the chaplain said, ‘You know he’s going to go to Heaven because he’s 5 years old,’” Harry recalled.

The hospice chaplain challenged Harry to think about death in a different way. Harry remembered the chaplain asking him: “How do you know that God is not actually saving him from something bad going on in his life?” The question certainly made Harry think. In fact, Harry thinks the only plausible explanation for why young children die from illnesses like his is maybe because they are being saved from something bad that was going to happen. “You never know

what would have happened in his [a young child's] life, if he would have lived," he theorized.

Yet he still remains unsure. "See, that's the thing too. I kind of have mixed feelings about it. I've gone through a lot of rough stuff in my life, the leukemia, a bunch of other stuff, you know, I've had a pretty rough life," Harry explained. "And, you know, everybody says that 'Oh, Heaven is the perfect place, it's paradise,' this and that. That's probably true, but to me, it's not. I don't think that it's the perfect place. Just because of the fact that, it may be the perfect place in the end, but to me, even though I have been through so much, this is the perfect place for me. I love my family, I love my environment, I love the people around me," he said.

Choices

Harry firmly believes cancer patients initially have few choices. They are bound by a practical reality suggesting a need to reach out and grab hold of whatever treatment is offered to them. He thinks this is especially true of the younger cancer patients whose treatment decisions are being made by their parents. "They don't have no choice," he said.

In that process, those younger patients and their parents inspire the 20-year-old Harry. "There's nothing amazing about me," he suggested. "Just to be able to go through it is amazing," he said. "Those patients down there [in the palliative care center area for the younger patients], they inspire me. I don't think

I would have made it all through my treatment if it wasn't for seeing all those little kids and stuff," he added.

Being a role model to the younger patients is something that has always been important to Harry, although he is not sure he is particularly up for the challenge. "When I was in-patient, I kind of felt that I had to be a role model for those kids. You know what I mean? Granted, I never came out of my room because I was too busy throwing up, but I always felt, just being there, you know, they see an older person being there, they feel like, *Man, look at him, he's older. I want to be older, too.* They kind of look at it, and they try and be stronger, because they see somebody older in there, and they want to be older. They want to be my age someday," he explained.

Harry feels the same about his own family. Harry's father is his role model. "That's kind of what keeps me going too, because, I see my dad, and I want to be a grandfather one day. I want to go through all that stuff," he added.

Lucas

Almost every example of a young cancer patient Harry mentioned specifically referred to a 5-year-old boy. That little 5-year-old boy Harry thinks about almost all the time is his friend, Lucas. Harry worships Lucas. Lucas is Harry's role model. The only time in a several-hour interview that Harry came even close to crying was when he talked about Lucas. Cancer killed little Lucas.

Harry talked to one of the hospice chaplains about Lucas in his ongoing attempts to make sense of things. “It was more of a religious talk than anything else. I told her [the chaplain]: ‘I don’t seem to understand.’ I was like, ‘You hear about on the news about people robbing banks and stuff, they get shot 3 or 4 times in the head, and they still live, and get out of jail a year later,’” he wonders. “And you’ve got the sweetest little boy I’ve ever met in my whole life—5-year-old boy, sweetest little boy you’ll ever meet in your life,” he said again. He continued: “He is so sweet. And he just dies. You know what I mean? I just don’t think it’s fair,” Harry stated sadly.

Harry is firmly convinced Lucas “got gypped.” “You know, all the fun stuff that we take for granted, he never got a chance to do. He never got a chance to just, make his own decisions. You know? You wake up on your day off or something and you are like, *Where am I going to go today, what am I going to do?* Nobody’s telling you what to do because you are not 5 years old,” he commented. “You just go about your day, wherever you want to go, you go. If you want to get in your car right now and drive to Canada, you’ll do it, just because you want to. And he never got to drive a car. Have a girlfriend. Go to high school. Actually have a group of friends that he went out and had fun with. He never got to do nothing,” he lamented.

Tears well up in his eyes for the first time. They glisten beyond the smoke from his cigarette. He looks away, and shifts his body forward in the patio chair,

as if to push the tears back into his face. Harry has not cried once before—not even when talking about the prospects of his own death.

Blessed Assurance

Harry rhetorically pushes the envelope. He does not mince words. He is like the movie character Dirty Harry. He tells it like it is. You keep waiting for him to snarl: “Make my day.” He is also direct in saying what he needs. He thinks cancer patients like himself, especially those who are younger, need to hear “more reassurance from the physician that everything is going to be fine,” he said. And yet he does not say in particular what that reassurance might entail. Does it mean being cured, living a long time, being less sick today than tomorrow, finding a suitable bone marrow donor? Harry does not elaborate.

Harry suggests reassurance is the most important message needing to be conveyed to people who are possibly staring at the end of their lives. He is also especially adamant that such reassurances need to be conveyed over and over again to younger patients with life-threatening illnesses.

Rated PG-13

In thinking about how to tell people they have cancer, Harry pontificated: “I think, as you get older, unless it’s a baby or somebody really, really young who really doesn’t know much, I think the older you get, the easier it would probably be to tell somebody,” he said. “I think when you are 5, it’s real hard to.”

He continued: “But then again, when you’re older, you can tell a 5-year-old boy he has cancer, and he’s like, ‘OK.’” Then Harry paused, as if to wonder about the theory that ignorance is bliss.

“He [a 5-year-old patient] doesn’t know what he’s in for. But if you break it down for him, and tell him, ‘Look, you have this disease called cancer. It’s probably going to end up killing you. But if it doesn’t kill you, you are going to wish it did because you are just going to end up spending year after year throwing up in the hospital.’ But other than that, I don’t think that a 5-year-old can really understand what’s going on,” he said. “You know what I mean?”

He continued: “And then it would be more of a thing, *Well, let me tell him so that at least he knows*. He may not understand exactly, and then once he starts going through treatment, he starts feeling weird and stuff. Then try to be his best friend. Try to talk to him and be real friendly with him so he trusts you. And just be straight-forward with him,” he added.

Harry also believes delivery is important. Pauses are a cuing factor, along with his defined weird tones from the physicians, although he cannot fully describe what qualifies as a weird tone. “Just the way he [his physician] said it [that Harry’s cancer had returned], you could tell bad news was coming,” Harry remembered. He gives an example: ‘Well, Harry, I would like to tell you that, uh *[pause]*.’ “You know, when somebody keeps pausing, it’s not a good thing that’s happening,” Harry explained.

Reruns

When he found out his cancer had returned after experiencing severe headaches at work, Harry recalled receiving the news: “They looked at my blood, and told me I had it again. And they go, ‘OK, well, we’ve got a room saved for you on the in-patient side, and we need you to start tonight.’”

Harry protested. “The disease needs me to start tonight on chemo? Well, the disease can wait until tomorrow. That doesn’t meet up with my schedule. I don’t feel like starting tonight. I’m not going to live my life depending on what I need to do to beat that disease. It’s not going to work,” he told the medical staff and his family, many of them crying softly. “Either the disease is going to work my way, or it is just not going to work, and that’s just not the way it was meant to be,” he explained. “I told him [his physician] that I wanted to go home and think about it. I was like, ‘I don’t even know if I want to go through this again,’” he added.

Harry went home that night for time to “count his blessings” and “see why I’m going to put myself through all of that trouble again,” he said. Later that night he went out and partied with friends. In the end, he decided to start treatments again largely on the advice of his physician and the nursing staff at the cancer hospital. “I’ve been going there so long, I trust them. If Dr. Carter tells me there is nothing wrong, then nothing’s wrong. If Ted [one of his favorite oncology nurses] tells me he thinks that I’m going to get cured, then that’s what I’m going to

believe. They've just built up that trust with me. You know, everybody down there has. They've made it to where, as far as I know, they've never just lied to my face. They've sugar-coated stuff in the past like I said, but, that's their job, they're supposed to do that," he mentioned.

Straight-forward vs. Cut-throat

Harry also distinguishes between talking in a straight-forward manner, as opposed to a cut-throat manner, to use his words. "Cut-throat? No. Not to a 5-year-old. I was just saying . . . that's what you would have to say for them to understand exactly what they are going to go through. Because you tell a 5-year-old boy that he has cancer, you've got ALL—leukemia—he's going to look at you like, *Is that good? Do I get some candy or a toy?* They're not going to understand exactly what that is," he explained.

"But you tell a 20-year-old, you got cancer, they are like, 'Aw, shit.' You know what I mean? They are like, 'Damn,'" he said.

When Harry was first told he had cancer at age 14, he said he just "kind of laughed about it. It wasn't serious to me, but then again, I didn't really know what I was in for either. And that's one thing I think: Cancer really sucks. Because, most diseases and stuff, you know how to get rid of them. You take antibiotics or something that makes you feel better," he said. "Because usually you have a disease that medicine makes you feel better," he added.

“Well, with cancer, you’ve got a disease that makes you feel like crud, and they give you something that makes you feel even worse—a lot worse. That’s kind of how I think you get ripped off. Any other thing, your treatment makes you feel better. This thing, your treatment just, it’s kind of like, in a fight, the leukemia knocks you on the ground, and then the chemo just kind of gives you those last few kicks while you’re laying there.”

As the interview drew to a close, Harry stubbed out the last of many cigarettes. The cold and damp air seemed worse now because it was late afternoon. The sky remained dark.

Harry thinks again of little Lucas, his role model. “To be honest, he inspired me more than I inspired him, I think. He went through [it], then he relapsed, too, so he went through what I went through too, if not worse. I think he really went through worse honestly. Actually, I know he went through a lot worse,” he clarified. “How am I going to be scared or not willing to do something that a 5-year-old boy does? That’s another reason that I did it too [began treatments again]. I’m figuring, if these children can go through it without [a say so], then so can I—they don’t have the say so of whether they want to or not, they are made to go through it. It’s kind of like when you are in the army, you stick up for your army. When you’re a police officer, you stick up for other police officers. If there are little kids dying everyday, and they went through everything they could, and they still pass away, you never know, I would hate to give up on it, and

then find out, when I get to Heaven or whatever, that if I didn't give up on it, I would have lived—because to me that would have made me feel like *that small*. Because I don't think that [it] would be right for somebody my age to give up such a wonderful opportunity to continue their life, when there are people who get that life taken from them, they have no choice. And I figure that, I think, that's the most horrible thing I could do, from my position, is just give up an opportunity that I'm given," he commented.

"As far as now, even if I do die, I still have time, I would at least probably say a year or two. Worst-case scenario, you know, I'm open," he pondered. With that, he proceeded to introduce me to his girlfriend's four young children who came onto the porch, whom he views as his own. "You could imagine what it would be like to lose a father—especially at a young age," he said, thinking of his own family.

For more than 2 solid hours, this young man, who knew at age 14 he would periodically be bald and sick because of leukemia, has told the story of his life for the last 6 years. The good, the bad, and the ugly. He has spoken with the utmost candor. He has asked many tough questions and challenged many perceptions that come with few clear answers.

Many of Harry's viewpoints, feelings, and pontifications are mixed and contradictory. Without a doubt, they are all frank and raw. He is incredibly generous in giving of his time in order to help other people through the telling of

his own story. There is a sense in which he seems to be wondering why he is still alive, and his dear 5-year-old friend, little Lucas, is dead.

For now, he lives with an internal view of abundance and gratefulness. “For the most part, my suffering has come from the chemo and stuff, you know what I mean? And that just has to do with me, and like I said, I’m not a selfish person. So if that’s what I have to look forward to, my pain and suffering during life, then I’ll take it with a grain of salt, and just be thankful that my family is OK,” he said. “Because, that’s the only thing I’m worried about is, the people I love. I’m pretty strong-willed, too. I can pretty much go through anything. I can go through 6 years of this stuff, you know. I don’t think there’s anything out there I can’t do,” he said convincingly.

In the meantime, he will make the most of every single day that comes his way. “And if God does take me young, then I enjoyed what I had. That’s just the way it is,” Harry said.

Driving back from the interview I was reminded for some reason of the song from “Carousel” that comedian Jerry Lewis sings at the end of each annual Muscular Dystrophy Association (MDA) fundraising telethon. It begins:

When you walk through a storm, hold your head up high

*And don’t be afraid of the dark.*¹⁴

¹⁴ Richard Rogers and Oscar Hammerstein, lyric from “You’ll Never Walk Alone,” in the 1945 musical *Carousel*.

Perhaps from Harry, the message is somewhat similar: When you walk through a storm, tell it like it is.

Make my day: Unfiltered Harry.

H. Waiting

In the butterfly room of a children's hospital cancer ward, Corazon¹⁵ sits waiting and watching. She sits alone in the small living room adjacent to her son's hospital bed. Her son, 6-year-old Marcelo, fidgets in the bed nearby, seemingly watching cartoons. There is no sound coming from his television.

Marcelo is extremely restless. His eyes, although sunk deep back into his face, are open. He stares at you piercingly and hauntingly when you smile and say hello. He does not smile back.

Both eyes are blackened from internal bleeding. His lips are chapped and the skin is cracked and torn. He does not smile, but groans periodically at low tones. His mother leans down closer to his body, and softly asks her *mijito* (son) if he is hurting. He says no, yet continues to squirm in bed. With his emaciated legs, he tosses his white bed sheet on and off his rail-thin body. He is bleeding from the lips, along with many other parts of his body, his medical staff explains later. He continues to moan.

¹⁵ In this story, I have changed the names of the people I call "Corazon," "Marcelo," and "Manuel."

At age 6, time is slipping away for Marcelo. Perhaps his groans suggest he is aware of the intensity and brevity of his situation. Maybe he is angry. Or perhaps he is in pain, despite what he has said to his mother and the morphine drip that hangs nearby—perhaps all of the above.

To myself I wonder if the presence of a third unknown party in the room, despite Corazon's approval, is making a bad situation worse. When I offer to leave, Corazon quietly responds, "It's OK." She wants to tell her story and give voice to her dying son who is too ill to talk.

The Butterfly Room

Many hospice programs and pediatric cancer centers have what are called butterfly rooms like the one in which Marcelo is staying. The rooms represent areas for transitioning from this life to the next, much like the morphing of a cocoon into a butterfly.

Butterfly rooms are usually decorated in bright yet soothing colors, as is the case with the rooms in which Corazon and Marcelo are located. Butterfly rooms are usually much larger than traditional hospital rooms, and are designed to accommodate entire families with separate living areas, kitchenettes, pull-out couches, and similar other items. To say that someone is in the butterfly room usually means that person is getting ready to die.

On this particular Friday afternoon, Corazon and Marcelo are alone in the butterfly room. No family members are huddled nearby. The 2 sections of the

butterfly room are cheerful and bright. Yet everything in the room is quiet and seems to move at a slow pace. Marcelo's groans are quiet. The television noise is drone-like. Corazon speaks quietly. Medical staff personnel come and go, softly and unobtrusively. Corazon sits, waits, and watches while she tells her story.

A Mother's Vigil

Corazon and Marcelo, whom she watches from across the room, are both beautiful. Their eyes are dark, expressive, and sad. They both have dark hair, and are extremely youthful despite the weariness showing on their faces.

Corazon sits by herself in the living area of the butterfly room. Like her son, she is watching television with the sound barely on. She is watching a segment from *Oprah* in which a husband in Florida is appealing to a court to end his suffering wife's life. Corazon says the show takes her mind off of Marcelo's situation. At the risk of placing unintended judgment about a situation in Florida I know little about, I am struck by the irony in which a young mother sits helplessly alone watching a television show about a person actively pursuing death for a loved one, while her son lays dying in the next room. Her conversation with me over the next hour suggests she would do anything to make things different.

Her First Born

Marcelo is Corazon's first-born child. As if life were not challenging enough with Marcelo's situation, Corazon's other younger son has severe autism.

Corazon distinctly remembers the day in the fall of 2001 when she was told Marcelo had cancer. She was alone at the time. “It wasn’t what I was expecting—being your first-born. He was never sick at the time. [It was] very scary,” she explained. Her eyes filled with tears, but she does not make a sound.

Marcelo has lived for the past 2 years with a form of cancer called Neuroblastoma. The National Cancer Institute and *CancerIndex* describe Neuroblastoma as one of the most common solid tumors of early childhood. It customarily is found in babies or young children, with two-thirds of the cases occurring in children younger than 5 years of age. The disease usually originates in some area of the nervous tissue, the most common site being the abdomen. It can also be found in the chest, neck, pelvis, and other body areas.¹⁶

Approximately 70 percent of all patients with the disease have *metastatic* (or spreading) disease at diagnosis. For children of any age whose evidence of the disease is localized as opposed to spreading, and for infants younger than 1 year of age with advanced illness, there is a high likelihood of long-term survival. However, survival chances for older children with advanced-stage Neuroblastoma are significantly decreased despite intensive therapy. As an example, the National Cancer Institute reports a two-year survival rate of only approximately 20 percent in older children with end stages of the disease.

¹⁶Children’s Cancer Web (2003, Jan. 11). *Neuroblastoma*. Retrieved Jan. 10, 2004, from <http://www.cancerindex.org/ccw/guide2n.htm>.

Little Words, Big Problems

When physicians initially told Corazon that Marcelo had Neuroblastoma, they used what she described as “little words,” the words *mass* and *tumor*. They did not initially use the word Neuroblastoma.

“They showed me how Marcelo had a tumor the size of two fists in his abdomen.” She holds up her fists to show the large size. “He’s a very petite little boy,” she said. The physician explained to Corazon that the mass in Marcelo’s stomach was not supposed to be there.

Telling Dad

Much is written about the strong matriarchal role of women in the Hispanic culture. Such seems to be the case in this family. Corazon’s husband, Marcelo’s father, was working at the time the news about Marcelo was delivered. One of the hardest parts of the initial ordeal for Corazon was telling her husband about their son. “That was hard because he lost his mom like a year and a half before to cancer,” she said softly. She looked away and down at her lap, as if to hide extremely painful memories. There also seemed to be an unstated projection from her that somehow she had let her family down because of the multiple deaths.

At first, Corazon and her husband asked few, if any, questions. “You kind of just stay stunned, in shock, I guess. And then you kind of say, ‘Well, what

should we do, what is there to do?’ And then they sit down with you, and tell you, these are your chances. And this is what is going to take place. He will get sick from chemo. They are very straight-forward with you,” she recalled.

Reality Time

Corazon appreciated the candor of the medical staff, despite the pain of the message. “We had a conference, and we asked ‘What are his possibilities of getting better?’ And you know, it was told to us, 10 to 20 percent, that he might,” she stated. “That’s a very small amount,” she added.

She continued: “We had some hope, but I think deep inside you are kind of like, *Oh, OK*—kind of trying to get the reality in there,” she said. “But it takes time,” she remembered.

The initial treatments were the hardest on everyone, especially Marcelo and Corazon. “The first time it’s really bad, because by the second day, he has the nausea—and then to see him, because he’s so petite. The first session, because you hear of the nausea and you are like, *Oh, he didn’t get it the first day*. But then the second day, ‘I’m going to throw up,’” Corazon recalled Marcelo saying.

By the second session, Marcelo began losing his hair. “It was on his pillow, and he was kind of like, ‘Why is my hair falling out?’ I’m like, ‘Well, you know. . . ,’” she added, without finishing the sentence.

One of the hardest parts of Marcelo’s journey over these past 2 years for his mom is watching his body physically waste away. Marcelo has always been

small. At age 4, before he became ill, he already weighed approximately 10 pounds less than national parenting statistics suggest an average 4-year-old weighs.¹⁷ He continues to drop well beyond the national averages on a daily basis. In fact, Marcelo's frame unfortunately looks like that of a little old man.

The Devil

Another of the biggest challenges faced by Corazon relates to what to say to her son. While she appreciates the directness of the medical staff, she struggles with putting reality into words for Marcelo. As conversations have taken place over these past 2 years, Marcelo has created his own visual images of what he is being told.

"And that's the other thing, explaining to him what is going on," she said. Her eyes filled up with tears that she quickly wiped away. She is careful not to make a sound other than the low tones of her voice.

"He wasn't in the room," when she was told he had cancer, she explained. "I had to tell him later, and it's hard to explain. You know, he turned 5 [just recently] so, to a 5-year-old, to tell him, 'You have cancer.' And he's like, 'What's that, is that what's making me puke?'" she recalled Marcelo as saying.

Corazon explained to Marcelo: "I told him, there's little rocks in your body, baby, and they are in different places. And they are not supposed to be

¹⁷BabyBag.com (2004, n.d.). *Height and weight averages for children*. Retrieved Jan. 10, 2004, from www.babybag.com/index.htm.

there. It's called cancer," she stated. "And he himself said: 'It seems like the devil.' And I never We're Catholic, it's mostly like, we haven't gone [to church] in a long time because of Manual [her young son with autism]. You can't take an autistic little boy to church on Sundays. It's like one parent has to watch him. You know, so it's very hard. So, where did he [Marcelo] get that," she shrugs with a smile, "'It's like the devil?'" she repeated with wonder. With that, she asked to pause the interview in order to get Marcelo some chocolate. He continued to groan, but said he needed nothing.

Disinfectants

Corazon has had a lot on her plate for many years. At age 29, she seemed an extremely strong and caring individual. When she was a small child, she took care of her parents, both of whom were ill. Her mother later became afflicted with cirrhosis of the liver, although ironically she recalled, "My *dad* drank, which was odd."

The last few years of her life have been extremely challenging. The spring of 2001 was when Manuel was diagnosed with severe autism. Later that same year, Marcelo was diagnosed with cancer. In the spring of the following year, Corazon's mother became acutely ill at age 55 and in need of liver and kidney transplants. She eventually survived. During her mother's illness, the petite Corazon cared for the incontinent woman, "a big woman, just big everywhere," in her home, along with her two boys, one with autism and the other, cancer.

The scene was not pretty, nor sanitary, an important medical element in the environmental lives of struggling cancer patients. “I was a Clorox and Lysol freak; it was very hard,” Corazon recalled. Corazon is also currently raising her sister’s oldest daughter who is about the same age as Marcelo.

Lady God / Hungry God

Throughout his illness, Marcelo has not talked very much, although he can be talkative at times. He has only once asked about the devil, yet he does continue to wonder about many things. He wonders if the female hospice chaplain is the “Lady God”? His mom tells him that although she isn’t God, she is the hospice chaplain and does *know* God. That seems to have pleased Marcelo, as Corazon recalled.

Corazon also recalled that the more the hospice chaplain would visit her son, the more Marcelo would ask about God, and what God was doing. Corazon once told Marcelo that God was in him. “Again I ran into that problem where I am not the expert, so, you know, I’ll kind of say what I think is right,” she explained. Such dialogue resulted in interesting questions from Marcelo.

Marcelo asked his mom if she thought God was in his stomach. “Do you think He’s eating my hamburger?” he used to say. Corazon remembered: “He’ll say, ‘I think He drank my punch because I’m thirsty again.’ Just things like that. He would say, ‘Well, he’s probably thirsty. He could take a drink in my stomach, that’s OK.’”

Attitude: Hear No Evil, See No Evil, Speak No Evil

One of the reasons Corazon believes her son prefers not to talk very much is because he is shy around strangers. She says that over time he has changed his perspective on the medical personnel who deliver his chemotherapy. “When we first started chemotherapy, he was talking to everybody. But then he found out that when he’s in the hospital, he gets sick with his chemo. So I guess in his mind, these people are making him sick, and they are talking to [him].” *So I’m not going to talk to them*, she thinks Marcelo might be thinking.

She continued: “He told me at home: ‘They want to hear me talk, and I’m not going to talk to them,’” she stated. Corazon recognizes her son has what she describes as *attitude*. “So, when we would come here [to the hospital], he would just close his lips,” she described. When the medical staff asked him something, Marcelo would not respond. “He would say, ‘I don’t want them to hear me talk. They’re not going to hear my voice.’ So he had that attitude. . . . He had that thing where he wasn’t going to talk to anybody,” she added.

Keeping His Word

Corazon and her son seem to worship each other. From across the width of the butterfly room, they visually connect with each other, with few words ever being exchanged. Corazon is extremely cautious about how she behaves in front of Marcelo.

“He might have gotten a little bit [of that attitude] from me, but you know, he was a very happy-go-lucky kind of guy,” she recalled. Corazon thinks part of Marcelo’s attitude that resulted in him telling her he would not talk, now means that sometimes he only talks to the medical staff when she is not in the room. “I don’t know if he’s like, *I already told my mom I’m not talking, so I’ve got to keep my honor*,” she conjectured. “Even with the nurses, he would talk to some of them, but as soon as I walked in, he wouldn’t talk,” she suggested.

A Straight Face

Marcelo’s physical cancer pain is bad. He requires a great deal of morphine to minimize the discomfort. Sometimes his groans suggest the morphine is not working, as he continues to thrash in his bed.

Marcelo’s emotional discomfort is always very bad when he sees his mother cry. “Marcelo doesn’t want me to cry. If he hears me, he just gets hysterical,” Corazon explained. “He get mad, and he starts to cry, and he says, ‘Stop crying!’ He loses it; he just loses it. So, it’s like, it’s hard because I have to keep that straight face with him,” she commented. “Sometimes I just can’t,” she added quietly, with tears filling her eyes. She looks down and away from Marcelo.

What If the Devil Wins, Mommy?

Marcelo has told his mother he thinks both God and the devil are in his stomach, and that God is fighting the devil, which is the cancer. At times he asks her: “What happens if the devil wins?” She tells him that “the cancer will win, and that you are probably going to die and go to Heaven.”

Marcelo has worried not only about his own future, but also the other children he knows who have cancer like him. Corazon is convinced that at times her son has pretended to be asleep in the hospital room while listening to the nurses and physicians, and other parents around him. Later he would ask his mom about what he had heard, “Like, all these kids have cancer, are all of them going to die?”

Maybe Tomorrow

Corazon does not hesitate to use the word *death* in front of Marcelo if she thinks straight talk is in order. Humor is important within the family in that sometimes family members will tell Marcelo that even after he gets to Heaven, he can come back to earth and turn off the television sets so that no one will be able to see his or her favorite shows. “He’ll say [to his cousin] ‘I’m going to go take out the cables when you are watching *Kim Possible* [a television show]. Yeah, I’m going to take them all out, and you’re not going to be able to see it,’” his mom recalled.

Sometimes Marcelo directly asks Corazon, “Mommy, am I going to Heaven?” He will ask her to explain once again what is Heaven. Then the 6-year-old will respond: “Well, I don’t want to go to Heaven right now. Maybe tomorrow.”

Epilogue

After this interview was conducted, Marcelo unexpectedly regained enough strength to leave the butterfly room, and return home with his mom. He lived several more tomorrows, and died a month later.

I. It Happens

Trudy¹⁸ is a 15-year-old teenager with long blonde hair who sits in an International House of Pancakes booth next to her mom, Kathy. The restaurant is busy with patrons on a Saturday morning right before Thanksgiving.

Trudy’s parents are divorced. Three weeks before the interview, Trudy came back to live with her mother after spending 10 months living with her father.

The 15-year-old looks like a normal teenager who could easily be a high school homecoming queen or head cheerleader. At this moment in her life, Trudy

¹⁸ In this story, I have changed the names of the people I call “Trudy,” “Kathy,” “Michele,” and “Dr. Dixon.”

is busy pushing a single order of hash browns around on her plate, awaiting the arrival of catsup. Her mom tells me she cannot eat hash browns without catsup. Trudy tells me she cannot even take a single bite before receiving the condiment. We all wait.

After the catsup arrived, Trudy began eating. Together Kathy and Trudy told me their story.

CF

Trudy is the first to tell you she battles Cystic Fibrosis (CF) on a daily basis. The disease “has to do with your lungs and pancreas,” she explained. With the exception of the end of an intravenous needle holder poking through her bandaged forearm, Trudy appeared the picture of good health. Such is not the case.

Trudy was first diagnosed with Cystic Fibrosis at age 8 weeks. One in every 3,900 babies in the United States is born with CF, considered one of the most common fatal genetic disorders in the country.¹⁹ Approximately 30,000 American children and young adults have the disease. It is an incurable hereditary disorder in which the body secretes abnormally thick, sticky mucus clogging the

¹⁹ Encarta Encyclopedia. (2004, n.d.). *Cystic Fibrosis: Multimedia*. Retrieved Jan. 11, 2004, from http://www.encarta.msn.com/encyclopedia_761567047/Cystic_Fibrosis.html.

pancreas and the lungs. This secretion leads to breathing and digestive problems, infection, and untimely death.

Thirty years ago Cystic Fibrosis killed most babies before they reached early childhood. Despite medical advancements, the disease remains incurable. However, the long-term outlook has improved over time. Now more than 60 percent of babies born with the disease reach adulthood. The journey, however, is not without hardships and struggles.

Early Trouble

Trudy's pediatrician knew something was wrong, especially given the fact that Trudy was always breathing heavily and frequently vomited right after eating. At age 6 weeks she was referred to a pulmonary specialist.

Sweating and Patting

Confirming a Cystic Fibrosis diagnosis for certain involves conducting a *sweat test*. Sweat tests measure the amount of salt in a person's body. Kathy remembered the day well. "They wanted to sweat test her [Trudy] just to make sure that it wasn't CF. She [the physician] knew something was wrong because of the weight gain, the vomiting, and the chronic respiratory problems. But she didn't, of course, suspect CF," Trudy's mom recalled.

"They did a sweat test on her, which was like a watch, a little watch they put on her arm. And it gathered sweat. CF patients have high doses of sodium in

their system. It was like a 20-minute test. Then we had the results later that day,” she said. “After she [the physician] got the positive back on the test, they called us back in, and they told her father and me. They said she had CF because she had a high dose of sodium in her system,” she recalled.

Kathy vividly remembered being told Trudy’s life span would be limited because of CF. “She [the physician] had told us at that time that they expected the life span to be under 20 years. Ten years before that, it wasn’t more than childhood,” she stated. “It took a while for the information to soak in. She [the pulmonary specialist] immediately hospitalized her, and kept her for about a week. And they treated her for her symptoms,” she recalled. “All they could do at that time was treat the symptoms, you know, get the mucus out of her lungs,” she added.

“At that time, we started on a regiment of nebulized [breathing] treatments, and patting her body at different places 2 or 3 times a day [much like is done on the backs of babies needing to burp], in order to clear out the mucus in her lungs,” she stated. Kathy then began patting Trudy in various places on her body to show me the ritual she has done since her daughter was 6 months old.

Always Knowing

At this point in the interview, Trudy finished her hash browns. I asked Kathy when exactly she first told Trudy she had Cystic Fibrosis. She replied quickly, “She always knew.”

“How is that?” I asked. “Because we had a son, 2 years older than her, so there was another child who didn’t have all of that,” she recalled. Trudy does not contradict her mother’s assessment.

Everyday Occurrence

Even as the patting and medical treatments for Trudy continued, her growing up years were relatively normal, with certain exceptions. During her eighth and ninth grades, she was homebound for a majority of the time because of her illness.

Trudy is a good student who seems to enjoy going to school. When asked what school is like for her in the midst of periodic hospital visits and routinely needing to be patted, Trudy replied: “It’s—I don’t know how to explain it. It’s just something that I’ve always done. It’s not bad, sometimes it is—sometimes it’s bad. But, I have to do it, so. . . .”

Trudy prefers not to dwell on her illness. Kathy says the family has spent less time talking about the illness than simply taking it as an “everyday occurrence.” As medical advancements have been made over time, Trudy’s expected life span has increased from 20 to 30 years.

“I just try not to think about it. If I dwell on it, I will probably make it happen [make the situation worse]. So I just try not to think about it,” Trudy stated. She said she talks to only one friend about her illness - her best friend, Michele, who lives on her street. They have lunch together every 2 or 3 days.

Michele is the person whom Trudy called the night before she returned to the hospital on her last visit because she was “pissed off, sad, depressed, all of it,” Trudy described.

An Answered Prayer

During her eighth and ninth grades, Trudy’s body began to give way to the Cystic Fibrosis. As Trudy and her mom recalled, the 15-year-old began a slow death march while she waited for a must-have lung transplant in order to live.

The 14 months of waiting were incredibly hard on the 15-year-old and her family. At times Trudy was uncertain whether she wanted to live or die. “For a while there, I didn’t care,” she explained. “It didn’t feel like I was ready [for a transplant]. The first time that we got the call [that lungs had been found for her], I wasn’t ready at all. I didn’t want to go through the surgery. I wasn’t physically, emotionally ready,” Trudy explained.

Perhaps Trudy’s reticence was visionary. As the situation unfolded, the lungs initially found for Trudy were not medically appropriate for her. A similar situation happened a second time, again after the family rushed Trudy to a large metropolitan hospital for another possible transplant.

As the saying goes, the third time worked like a charm. After spending an afternoon talking with hospice chaplains and praying to God, Kathy received a call that once again a new set of lungs had become available that might work for Trudy. “We had talked that afternoon, and we had prayed and everything, and

sure enough, we got the call that night,” Kathy explained. For the third time, Trudy’s parents rushed her to the hospital in the fall of 2002. This time the lung transplantation was successful.

When asked how that makes her feel, Trudy says she feels both happy and sad. “I can do a lot more. I can do a lot more running than I used to be able to,” she commented.

Home Schooling

Even though she may miss school from time to time, Trudy is required to work daily with a computer for medical purposes. Using a laptop, Trudy takes a deep breath and blows into a mouthpiece that has a sensor connected to the computer. Looking at the screen, Trudy can immediately see the lines from her breathing indicating lung capacity.

The numbers from the breathing test that Trudy hopes to see on the computer screen range from 105 and 115—acceptable and usual numbers for her. If the numbers are bad, Trudy knows to immediately call Dr. Dixon. Prior to her most recent hospital stay just before the interview, her numbers dropped to 70 and then even lower because of a cold. Even a common cold can be deadly for individuals with CF like Trudy.

Therapy

Talking about Trudy's illness within her family unit is complicated. Both of her parents have remarried. They converse together, and share in the responsibility of caring for Trudy. Both sets of parents are capable of handling her intravenous (IV) fluid and medication needs at home as warranted. "We just transported her from house to house. I guess we ran a portable hospital out of the house," Kathy recalled.

Over the years the entire family has undergone psychological therapy in a variety of ways to try and better cope with Trudy's medical situation along with the challenges of simple, everyday living within blended families. Kathy says Trudy's illness has placed pressure on an already struggling and tenuous family communication system, including her parents and the new stepparents and "the dislike they have for each other."

Yet therapy seems to have helped. "We talked about the fact that she was dying because she was. I think the fact that we had a therapist for a year and a half or 2 years is the only reason the 5 of us got through it," Kathy explained. "The therapist helped the 4 adults do a lot. And I highly recommend a non-partial therapist for the child and then for the adults," she added.

Decision-Making

Like most teenagers, Trudy is looking forward to her future independence. She is excited about getting her driver's license when she turns 16. When she begins dating, she plans on talking with her boyfriends about her illness, but wants to avoid making a big deal of the matter. "It's hard to tell, but eventually it [the illness] just comes out. I'm scared of rejection," she stated.

In the meantime, the 15-year-old and her mother seem to experience tension between them when talking about who is in control of Trudy's healthcare decisions. Trudy suggested that "no matter what," her physician decides her course of treatment now. Her mom chimes in quickly, "Her father and I decide the course of treatment with Dr. Dixon."

Zingers

Parent-child relationships are challenging in the best of times. For young people with CF like Trudy, perhaps the stark reality of living with the disease can make parental relationships even more complicated for numerous reasons, including the fact that the disease itself is handed down to children from a defective gene carried by each parent.

For whatever the real reasons, things seemed strained between Trudy and Kathy during the interview. How much of their tension stemmed from Trudy's illness as opposed to usual mother-daughter, teenager challenges is unknown.

Tensions are evidenced during several points of the interview, as would be expected. Although she is seated next to her mom, she told me: “I’m closer to my dad, I’m a daddy’s girl so I’m closer to my dad. But I have to talk to my mom, too,” Trudy said. She also commented that regardless of her relationships with her parents, “It always comes down to my best friend [Michele].”

Kathy replied: “Her whole entire life, she’s lived with me. She’s only lived with her dad these last 10 months. But she’s still a daddy’s girl. But that’s OK,” she explained.

Isolation

Germes are a constant worry for individuals like Trudy who live with life-threatening diseases. Many children and young people battling serious illnesses in pediatric hospitals are seen wearing masks as they walk around the units pushing IV hanging bags on steel carriers.

While Trudy was living with her father, she met another young girl with Cystic Fibrosis, but was unable to talk with her because of the worry of spreading germs between them. “She could have some bacteria she could give me. I could have some bacteria I could give her,” she explained. Her mother added, “They could talk if they sat 4 feet away from each other. But I don’t think either of them made the attempt,” she explained. Handshakes can also be problematic and are to be avoided, according to Kathy and Trudy.

Sibling Reality

Although Trudy identified her friend Michele as her closest confidant in talking about her illness, she does at times reach out to her 18-year-old brother. In fact, she seemed genuinely happy and surprised that her brother recently visited her in the hospital with a friend of his. “He came up and saw me the other day before I left the hospital, which is unusual. He doesn’t like hospitals too much. It shocked me,” she explained.

When asked if Trudy ever wonders why she has CF and her brother does not, she replied: “I’ve asked him that before.” “His response,” I asked? “It happens,” she stated with a shrug.

Jaded

Trudy readily admits to becoming jaded while battling CF her entire lifetime. The situation has changed over time depending on her age and emotional state. “The first time that I ever went in [to the hospital], I was 7 and I hated it then,” she recalled. “When I was 12, I went in, and I was all happy because I was missing school. And then I got older and felt jaded—too much was going on in my life,” she explained.

When asked if she views her life as short, medium, or long, she replied: “I don’t look at it that way,” she responded. “I just do what I do—what I can do—with my friends,” she replied.

Moving On

Medical scientists point to Cystic Fibrosis as one of the more promising areas of research in modern medicine. On a personal note, Trudy and her mom are continuing to pursue any and all available opportunities for new knowledge.

After finishing the conversation at the IHOP, they were driving to a larger city to attend a seminar on CF being led by Trudy's primary physician. Kathy uses such support group educational sessions as ways to "pick up what other parents are going through," she stated. "You give them suggestions on things that you went through because there are a lot of new patients with small babies. And you can tell them things that we remember when our children were small," she added. On a daily basis, Trudy and Kathy continue to move through their lives, viewing the challenge presented by Cystic Fibrosis as an "everyday occurrence." "We're just like a normal household," they added.

Whether she lives for a few more years until she is 20 or 30, or defies the odds and lives much longer, Trudy sees her life as a composite of mixed blessings and future uncertainties. She prefers not to talk about her illness, and does not care what words other people use when they do. She often seems especially frustrated over being sick. She fondly remembers her years before her lung transplant as "having a good life," she commented. She continues to pray to God, "just for health," she explained.

For now, Trudy seems grateful to be a normal teenager who just happens to have another person's lungs in her body, although at times she is sad as a result of the transplant. She recommends that other CF patients "do the treatment as much as they can because even though it may seem like something really good, to get new lungs, it's not really all that good," she stated. Trudy hopes to begin feeling better to avoid another hospital stay like the one she just completed because of a cold.

The future for Trudy is uncertain. Her transplanted lungs are expected to last around 5 or 10 years. At that time she can ask to receive another set of lungs if she desires. In the meantime, regardless of how normal her life may be or appear, she thinks about the future in a unique way. "I just wonder how long the lungs are going to last," she pondered.

J. Blistered

Today is a good day for 15-year-old Oscar²⁰ because he is "not tired or anything," he explained. Oscar is a stoic young man who responded in short answers, and used the word *yeah* a great deal. He had just spent Thanksgiving week in the hospital.

Oscar is wearing a shiny earring in one ear, given to him by his dad. His father and mother are sitting on each side of him in his small hospital room. Oscar

²⁰ In this story, I have changed the name of the person I call "Oscar."

is 1 of 15 children. His dad, a large man, is sitting in a wheelchair for lack of another regular chair. His mother is sitting in a straight chair. I sat down on a physician's stool that had a tendency to roll. Oscar watched out for the tape recorder so that it did not fall. Doctors and nurses came in and out of the colorless hospital room, one right after the other. The scenario was chaotic at best.

On this particular hospital visit, Oscar had a roommate a few feet away—a tiny baby girl receiving chemotherapy through intravenous bags hanging on a short little roller. The baby was wearing a large pink bow around her balding head. The bow gave the room the only visible bright color. Otherwise things were steel and black and gray.

The day before, this same little baby, with the same bow on her head, was sitting in her stroller at the nurses' station. Her short IV hanging-bag stand was next to her. She was laughing and giggling and holding court with all the nurses.

Today things have changed for the baby. She hollers mightily—evidently nothing is wrong with her lungs. She fusses and frets constantly. With a chronically pained expression, her mother does a variety of things to try and comfort her baby as the baby jerks about on her lap. Her mother tries to hold her tight, ever mindful that the baby's intravenous drip must remain stable. Nothing seems to help this little one on this particular day.

As the baby bow girl continued to fuss, Oscar and his parents told me about their lives.

Murphy's Law

Murphy's Law suggests anything that can go wrong will go wrong. Such is the case for Oscar.

Although he has been coming to the hospital for chemotherapy treatments for over 10 years, Oscar is getting progressively worse. In 1994 he was first diagnosed with Acute Lymphocytic Leukemia (ALL), a cancer of the blood.²¹ Since that time, his condition has deteriorated. Just recently he relapsed with brain cancer.

Murphy's Law of Thermodynamics

Under pressure, things get worse. So suggests Murphy's Law of Thermodynamics.

During every interview I have conducted, there always comes a moment when I am overwhelmed by the perseverance and attitudes of those who are sharing their stories. This was also true for my interview with Oscar and his parents.

Having said that, the other side of the coin is more tarnished. The family is struggling mightily. Perhaps they have always struggled. Before the actual interview began and the tape recorder was turned on, the nurses asked Oscar to go

²¹ See *Leonzo's Lead* for more detailed information about this particular form of leukemia.

down the hall for a brief medical procedure. His mother went with him. I remained in the hospital room with Oscar's father as the baby continued to holler in her mother's arms.²²

Oscar's dad proceeded to tell me how difficult things are for the family. They are not communicating or getting along well. In fact, he said that Oscar has told him on previous days to "Get away, or I'll kick you in the face." Throughout the interview, Oscar's father used a familial term, "Daddy," to refer to his son.

Knowing No Difference

The first 5 years of Oscar's life were normal. The next 10 years have been anything but, given the amount of time he has spent in and out of hospitals battling leukemia and now brain cancer. Oscar is incredibly astute in knowing the specific details of his medical treatments, including what his statistical numbers and counts mean in terms of future treatments.

When asked how he feels to have spent over 10 years battling cancer, he responded: "I've been here so many times, I'm used to it."

Anticipation

Although Oscar does not talk very much in general, he says that hearing what his nurses have to say about his condition is helpful because then he knows

²² The interview with Oscar and his family was obtained with each participant's willingness to speak in front of the baby's mother who agreed to confidentiality in what she may or may not have heard.

what is coming his way. Although he has been coming to the hospital for years, battling brain cancer is different in some respects than battling leukemia.

Anticipation is challenging. Knowledge makes things easier. For now as always, the family will continue to take things one day at a time. At this point in the conversation, Oscar's father interjected a comment to his wife: "Your money comes in today, remember? The check. It should come in today." No one responded.

Asking

Oscar is especially appreciative of the physicians and nurses who ask him what he wants. Not only do they ask him if he needs anything in the way of basic items such as water or a blanket, they also ask him how he wants to hear the latest news involving his condition.

"They ask me first if I want them to tell me straight out," he explained. He prefers "regular, straight-out" words, but does not elaborate.

Punching Bags

Oscar's father spoke at great length about his ongoing frustration over his son's situation, including the inconveniences on the family of his receiving medical care away from home. Remembering a time that treatment was not delivered to his son despite a trip to the hospital, the father said, "I had to drive 28 miles. And then, basically there was no reason for him [referring to his son] to be

here. And then, my wife, she has a hard time taking care of him, working, paying bills. It's really an inconvenience," he commented. "You know, the time he [Oscar] spends in here, she could be working, earning money. Like I said, she can deal with it. It bothers me a lot," he added.

The father continued, "He [Oscar] never talks to me about it [his illness]. Him and I never talk about it, and I don't know if Mom does or not. But, I try to get close to him, but there is, I don't know, he just . . . I guess, in situations like this, somebody is a punching bag, and that happens to be me," he stated.

Oscar's father also related a scenario in which he feels he was wrongly accused of being dishonest in claiming disability benefits because of his bad knees. "That's part of the things that I've got to deal with. When I ask questions, she [pointing to his wife] gets mad." At this point, his wife got up and left the room. She returned a little while later and said nothing about her departure. Body language suggested she was extremely upset and angry with her husband.

Oscar's father continued while his wife was gone and his son remained in the hospital bed: "A lot of times, he's in the hospital, I come in, and she gets up and walks out. I don't know. I guess I'm supposed to be superman and not hurt and not have any pains," he stated. "I don't know. I've got Spondelosis (old age, fused vertebrae, joint problems). You know, your bones start developing bone spurs. I've got 5 herniated discs, I've got torn tendons, and I got nerve damage in my legs from an injury. There are days when I feel like my legs are just going to

give out on me,” he commented. “I guess I’m just not supposed to deal with those kinds of things,” he questioned.

“All men are strong. All men set aside their problems,” the father suggested. “[But] I’ve been where he’s at,” he said, looking over at his son. “I’ve been through it. And no amount of words can comfort someone,” he commented. My belief was that Oscar’s father was referring more to his own healthcare and perceived unfair life situation than he was to the plight of his son who was sitting in the hospital bed near him battling leukemia and brain cancer.

Foul Play

Oscar’s father talked more during the interview than did either Oscar or his mom. Only infrequently did the family members refer to each other by personal names, as opposed to *he* and *she*, and *her* and *him*. They seldom looked at each other. There was a sense on my part that if the father had not been in the room, the interview would have been quite different.

Communication lines were definitely complicated, if not at times nonexistent within this family unit. Once Oscar’s dad recalled asking his son what the physician had said. His son replied, according to the dad: “Why don’t you go ask him?”

Both Oscar’s mother and father remembered their son’s initial diagnosis of leukemia in 1993 when Oscar had barely started school at age 5. His mother commented: “I remember my mother [Oscar’s grandmother] saying, ‘You know,

this doesn't look right, this doesn't look right.' I guess she was telling me that because she at that time wasn't working full-time, and I guess she was seeing shows [television shows about diseases] or something like that," she added. "And then I went to work and he [her husband] went to work, and then he came back from what I remember, and he took him [Oscar] to the physician and found out what he had. And then he went to my job to let me know so we could tell him [Oscar]," she added.

Oscar's father recalled: "I took him [Oscar] to school that morning to tell them that I was going to pick him up at 10 o'clock because if they are in school until 10, they are counted for the whole day," he explained. "I was told somebody from Child Protective Services wanted to talk to me because of his bruises. I told the lady, 'Well, that's why I'm taking him to the doctor.' I said, 'Well, you don't think I'm hurting my son, do you?' And she said, 'Well, we need to make sure.' And I said, 'Well, he's my only son; I wouldn't do that.' 'Well,' she answered loudly, and she said, 'sometimes parents single them out.' And I'm like, 'I don't need this.' So when she turned her back, we took off, and I took him to the doctor," he recalled. Then he turned to his son and asked, "Do you remember, Daddy?" Oscar did not respond.

Oscar's mother explained that her son's severe bruising had started the week before his initial diagnosis. "Then it was finally when we came home, and we saw him on top of the fence by the tree, remember? He said that he had fallen

and hurt himself. And that's where I thought the black eyes had come from. And it wasn't even from that," she commented.

When the initial diagnosis was made, the physician first asked Oscar's parents if they would go into his office to sit down and talk. "I said 'No, you need to tell me right now where we stand,'" Oscar's father said. The physician told them that Oscar had leukemia. The family went straight to the pediatric cancer hospital.

Murphy's Constant

Murphy's Constant suggests that matter will be damaged in direct proportion to its value. Oscar and his family are damaged. Scholars suggest receiving a terminal diagnosis can be likened to the effect of looking directly at the sun: It blinds, it is intense, and it can cause damage.²³

For Oscar and his parents, this is the second time in their lives they are looking directly at the sun. Leukemia first, now brain cancer. They are hurting, in their own ways. Oscar's mom said she will maintain her vigil in "faith and trust," and will continue to "pray for the people who are helping you. Give them knowledge and wisdom. That God may, you know, that the hands may be His hands as far as the healing and the care," she stated.

²³ Hutchings, D. (1998). Communicating with metaphor: A dance with many veils. *The American Journal of Hospice & Palliative Care*, 15, 282-284.

Imagine

Listening to this family's conversation is a challenge. These individuals do not like each other, or at least they struggle with each other much of the time. Yet no doubt the parents both love their son. Perhaps leaving the room as Oscar's mother did for much of the interview is a way to keep the peace or minimize the discord during these tough times.

For me personally, I imagine a great deal of anger and pain on the part of 15-year-old Oscar who has leukemia and is now facing brain cancer. Because Oscar has refused to say very much in front of his parents, I can only imagine his internal thoughts when he hears his father complain about bone spurs and having to drive 28 miles to the hospital, all the while trying to convince his son that he knows exactly what the younger boy is experiencing. In my opinion, the attempt at such an empathetic comparison seems ludicrous and mean-spirited, but certainly I have not walked in these individuals' shoes. Nor is the story mine to tell.

John Lennon wrote, "Life is what happens to you / While you're busy making other plans."²⁴ For Oscar and his family, I get the strong sense based on both conversation and observance that Murphy's Laws are wearing them down.

²⁴ John Lennon, lyric from "Beautiful Boy (Darling Boy)," on the 1980 John Lennon/Yoko Ono album *Double Fantasy*.

They are tired and weary after 10 years of fighting on a variety of fronts. Yet for whatever their reasons, they have shared part of their story with a total stranger.

Within the nucleus of the family unit, a 15-year-old boy whose future remains highly unsettled imagines a better and more hopeful world for others like him. As I asked Oscar one of the final questions, it is one of the few times in the conversation he does not shrug, and say “Yeah” or “Nah” or nothing at all. Instead, he deliberately pulls a silver necklace with a cross on it from underneath his shirt, and responds:

Question: What would you say to other newly diagnosed cancer patients your age?

Oscar: Everything will be all right.

Epilogue

As his situation grew worse, Oscar decided to stop going to the hospital for chemotherapy treatments. His physician indicated to me that the decision was against the wishes of his parents. The stoic young man with the shiny earring died in the early part of 2004.

K. Good News, Mijito! What The Hell!

Frequently there are good moments and days in a children's cancer hospital, like when positive news is delivered to a patient. On this particular day, 16-year-old Arthur²⁵ is doing wheelies in his wheelchair in a hospital room, having just received some good news: His blood counts were doing fine, and "there is no trace of leukemia anymore," said his mother, Iris. Iris was grinning from ear to ear when she said those words.

Arthur is anxious to tell his story about when he first learned he had leukemia in 2001, and his life up until that day when he received his good news. Even though the hour is later, and the mother and son have a 3-hour drive ahead of them, both are willing to stay and be interviewed.

Arthur was grinning from ear to ear as he continued to circle around the center of his little hospital room in his wheelchair. His mother talked a lot, which seemed to frustrate the 16-year-old. Yet Arthur wanted to tell his own story, his way. He persevered.

Interruptions

Throughout the dialogue, the give and take between Arthur and his mom was consistently funny and poignant. Iris is a happy-go-lucky large

²⁵ In this story, I have changed the names of the people I call "Arthur," "Iris," "Dr. Rose," and "Laura."

woman with an ample bosom. She switches from English to Spanish and back again in the blink of an eye. One immediately senses she is the definite ringleader and matriarch of her family, for whom the saying was written: “Mama ain’t happy? Nobody’s happy.” Iris repeatedly referred to her son in loving terms of Spanish endearment such as *mijito* (my son).

While Arthur and his mother played point-counterpoint, I felt as if I was watching a tennis volley or a television episode of *Everybody Loves Raymond* in which Raymond’s meddlesome and martyrdom mother, Marie, is bugging her fully grown sons by telling them what to say and when, interrupting them when they try to say what she’s told them to say, and then re-explaining what they said because they said it all wrong. Like Marie, Iris even periodically pinched her son on the cheek and played kissy-face with him, which finally made Arthur explode in total exasperation, “MAAAAAA!” Arthur could be a young Raymond.

An example follows of one of many exchanges between the 15-year-old Arthur, who looked like Raymond, and his mom, who reminded me of Marie:

Question: *[To Arthur.]* Do you remember when they first told you about the leukemia?

Arthur: *[Arthur began to answer. His mother immediately interrupted.]*

Iris/Mother: We all went to pick him up from school and that’s when he saw us, and then all of us went to the doctor’s office. All of us entered the doctor’s office. And they were ready for us with a room and everything, and I said ‘Oh my God, what’s happening?’ But then we came into the room, and we sat down, and he was on the table, right,

the examining table? And then the doctor came in. And then *[to Arthur]*, what did the doctor say?

Arthur: You're telling the whole story. *[He looks in frustration at his mother.]*

Iris/Mother: No, please. *[She sits back in her chair, pouts, and puts her purse on her lap. She motions for her son to speak.]*

Arthur: *[to his mother]* Say what you want to say.

Iris/Mother: Well, that's all I wanted to say.

Iris then stoically looked away with no animation for the next few seconds, as if she was mad and was not going to say another word whatsoever. Within a very few minutes, however, she became animated again, interrupted her son, and another conversation just like the one above took place. This type of exchange happened over and over throughout the interview.

Oh, *+#!

Nosebleeds were among several indications that something was wrong with Arthur. One day when he was nearly 15, he recalled feeling especially sick. He had awakened with a nosebleed, and was dizzy. "I woke up, and I went to get a glass of water, and I was walking," he recalled. "I felt real dizzy, and I hit the wall on the side of the garage. I spilled the water, and was like, 'Oh, shit.'" With that, his mother quickly interrupted and said to her son: "Don't say bad words." He replied: "Well, that's what I said." Iris glared at her son.

At this point in the interview I explained to both of them that total honesty during the interviews in remembering the way things truly happened was preferred. I also tried to reassure them their actual names would not be used in any final documents. Iris continued to glare at her son and act embarrassed.

What the F---!

Despite feeling badly, Arthur went on to school on the day he finally found out about his illness. His mother awaited test results from a physician's appointment the week before. The physician's staff called Iris mid-morning, and told her Arthur needed an additional test called a CA 125. Iris distinctly remembered the term CA 125. As a former medical office assistant, she knew CA meant cancer.

While Iris was talking with the physician and nurse about the CA 125 test, Arthur continued to have a rough morning at school. "I had like first period, and it was reading. I had a reading class, and I told my teacher that I wasn't feeling too good, and she said that I looked pale. I went to the nurse and I told her, 'Hey, I feel bad.' And she said, 'Oh yeah, you look real bad, you look pale.'" During the second period class, Arthur was called on the intercom, and told to go to the office. "I was like, *Cool, OK,*" he said.

He waited for his mother in the office. "I was just waiting there, and my mom, it took her like 10 minutes to get there," he recalled. "She came in, and she signed something, and it was like, 'Well. . . .'" Arthur hesitated before saying

what he wanted to say. Then he spoke and said what he thought to himself at the time: “*What the fuck?* I said; *What the fuck?*”

Now Arthur’s mother looked as if she was going to have a heart attack. I said nothing. Iris shot her son another look, and pleadingly said to him: “*Mijito*, please.” Arthur continued: “And I thought someone had died because of the way she was . . . , and we were all. I got into the Dodge Ram truck, and we were on the way to the clinic, and it was all serious.”

Leucemia

Together the family made the 3-hour drive to a nearby metropolitan area. Medical personnel were waiting for Arthur. “We’re in this room and then I sat down on this table where they do all this stuff,” he recalled. “And the doctor sat down and he said, ‘Your son, *tu hijo tiene leucemia*.’ And all of a sudden my dad just started crying and got very freaked out, and I got freaked out,” Arthur remembered.

“I was like, ‘What the hell? What is that?’ And he [Arthur’s father] was crying for like 5 minutes or something, and we were all quiet. My brother was just like quiet and my mother was like, ‘Stop it—you are going to make him [Arthur] cry. You are scaring him.’ And the doctor was like, ‘OK, cry it out,’” Arthur recalled. “I said, ‘OK, doctor, what is, *que es, lucemia?*’ And he said, ‘*Es cancer en tu sangre*.’ And I’m like, ‘It’s cancer in my blood? Oh, what the shit. Me? Cancer. What the hell.’”

The Word

Arthur specifically remembered hearing the word *leukemia* for the first time. “I didn’t know leukemia. I didn’t know that word. But I did know what cancer meant. Cancer is like for old people. I’m not old; what the hell,” he reflected.

Go Right Now. Pack No Bags.

The immediacy and severity of the situation was not lost on the 14-year-old. “They said ‘OK, you guys are supposed to . . . , I’ve already called the doctors over there, and you have to go [to the cancer clinic in the larger hospital] right now. Don’t even go home and pack—right now, real serious, just drive over there.’” He continued, “And then we went and we were driving on the way, and then my dad and everyone was all crying, and my mom, she was all nervous. I don’t know what she was thinking,” he recalled. Then he turned to his mom and asked her: “What were you thinking?” The exchange at that moment indicated they had never re-lived together the important experience of a few years earlier.

A Liquid Diet

Iris’ mind was racing at the time. “Everybody was [crying]. My husband was crying the 2 hours, 3 hours, in the back of the car, the truck, he was with him [Arthur] and hugging him and crying and crying and crying and crying. And I was like, *Oh my God*,” Iris recalled.

She continued: “I’m always too hungry, because I always like to eat too much—back then,” she joked and laughed, inferring that she does not eat too much now. “No, but anyway, I was not even hungry. I didn’t even want to eat on the way. We stopped to get some hamburgers, but we just ordered some Diet Cokes or whatever. But we were not able to eat, because we were not hungry,” she added.

The family raced to the large hospital during which time Iris hoped and prayed for a good doctor. “And I said, ‘Oh my God, I hope that we find a good doctor.’ We didn’t expect nothing, we did not know too much about leukemia. He [Arthur] knows what cancer is. I know cancer. Cancer of the lungs, or whatever. But to me, I didn’t know what was involved with leukemia to the extent that I do now,” Iris said.

“So when we got here they do the spinal tap right away, and they said that he didn’t have any leukemia in the spinal tap, but that the white blood cell count was very high. It was 300,000—the normal is 5,000 to 10,000 white blood cells—and he had 300,000, so it was very high at risk. So they gave him very aggressive treatment to cure the leukemia, and that’s what they said they would do,” she added.

Episodes

The family stayed at the large hospital for a month during their initial visit. The weeks were hard, especially when Arthur hallucinated because of the

chemotherapy and steroids. His mother began: “One time in the middle of the night. . . .”

Arthur interrupted her because it was his story to tell. “There was this one time that I woke up, like, I had a dream that I was going to kill everybody on earth but, like, with my eye, like Cyclops—kind of like XMEN. But like if I opened my eyes, I would kill everything,” he remembered. “And I woke up screaming and I was like, *Oh, wow*,” he added.

There were other episodes in the midst of never-ending vomiting. Arthur recalled another time when he was back at home in his own bed: “I woke up, and I thought I was dead. I was. I woke up, and I still thought I was dreaming. But it was real—I was just in my bed. I was like, *Oh, what am I doing, is this where I’m supposed to be?* And like, *I’m dead. What am I doing here?* I know I’m in my room, but it’s not my room. And I was like, getting up, and moving around and trying to know where I am,” he added. His mom quickly interjected, “It was terrible.”

Arthur continued: “I was like, *What the hell?* And then I looked out the window, and I was like, *I’m still here, but I’m not here*. I was banging on my door and saying: *Help me, someone help me*. I just got on my bed, and made myself into a ball, and was like, *What the hell, what the hell?* I remembered, *Hey, well, open the door*. And if I remembered and if it opened, I would be alive. And so I opened the door and I was like, *Oh, OK*. Then I went to my mom’s room and my

dad's room and I was like, 'Hey,' and that night I was all scared." Iris quickly interjected: "Yeah, he was all scared."

TGIA

When he was diagnosed 2 years ago, Arthur wondered every day what was going to happen to him. He wondered about his treatments, where he would spend his time, and how sick he would be on any given day.

Over time Arthur has become less concerned about his daily issues. He is now more philosophical. He appreciates the help of the medical staff in that they "make you feel comfortable in knowing what's going to happen to you. And they make you more open-minded about what's going on. They prepare you for what's coming next," he added.

When asked what he thinks about now in terms of his life, he replied: "Uh, I don't know; thank God I'm alive."

Straight Up

Arthur is practical in his thinking about how young people should be told they have cancer. "Well, now, I think there is no other way [than straight-forward] to tell you that you have cancer because, I mean, because you think at that time, *Oh gee, 12-year-old, real harsh, could you tell me in a nicer way?*" He continued: "How well or nice can it be told?" He makes his voice cheery, then grave: "'Gee,

hee hee, you've got cancer,' or like, 'You've got cancer.' I mean: *you've got cancer.*"

This 16-year-old straight-talker continues to be practical and bodacious, much to his mother's periodic chagrin. "If you just have it [cancer], there is nothing else they can do. Like, you're paralyzed, what do you do, you go to the doctor, 'Gee, doc, I'm paralyzed, what do you got for me?' The response: 'Why don't you take this wheelchair and roll your ass around town?' And like blind people, 'Oh, I'm blind; oh I'm blind, what do you got for me?' 'Why don't you take this dog, and let him drag your ass around.' I mean, what the hell? If you just got shit, shit, there is nothing else. There is nothing else you can do," Arthur commented. His mother continued to glare at her son.

Two Strikes

Arthur has been told twice that he has cancer. He relapsed after his initial diagnosis. That time the cancer was found in his spine. His physician called his mother on a Friday afternoon.

"Dr. Rose called me . . . on Friday to let me know that something was wrong," Iris recalled. Then he called her back because he said he knew she would not be able to continue with the weekend, so he told her by phone. "'I want to tell you by phone, but I want to see you on Monday.' And he told me: 'Arthur got leukemia again on his spine.' The spinal tap is where they saw the little traces of leukemia," Iris explained. "So he told me, it's just a little."

“I told the doctor, ‘OK, but don’t tell Arthur.’ I didn’t want to tell anyone, because I didn’t want to,” his mom explained. Arthur recalled: “I came in first this time, and they came [the medical team members]. They wanted to talk to my parents first. I waited in the room, and I was watching TV, and they called me, ‘Hey, come in here.’ The doctor was sitting down, and dad, my mom [and the nurses whom he called by name]. My nurse, Laura, was there, and she was like, kind of crying. Well, like, tears in her eyes. And I was like, ‘Oh, shit. Straight up,’” Arthur told them.

Arthur’s physician said to him: “‘Arthur, you have cancer again. We found some in your spine, and it’s going to your head. You have cancer again,’” Arthur recalled. Arthur said that Dr. Rose was visibly upset when he delivered the news. “Oh, yeah. He was kind of like, watery eyes, and my dad was watery eyes, and he said, ‘The only thing we can do is just do a bone marrow transplant. I don’t want you to think that everything we have been doing with the chemotherapy is just a total waste of time. It didn’t work, but if you want to do this [the transplant] so you can live . . . ,’ and I said, ‘Well, yeah. Do it. I want to live. Do this,’” Arthur mandated.

Brotherish

Arthur’s big brother was his bone marrow donor. “My brother and me, well, I love him to death because he’s my big brother, and he always takes care of me,” Arthur explained.

At one point Arthur's older brother told him: "You know, I'm always there for you and thank God that you and I have the same blood for you to be alive." Arthur calls such conversations *brotherish*.

Dad

Not only is Arthur extremely close to his brother, he speaks very fondly of his father. Trading places with his son is something Arthur's dad wishes he could do, according to the 16-year-old.

"Sometimes with my dad, he's just quiet about it. He doesn't want to show how he feels, but I know how he feels," Arthur explained. "He doesn't want me suffering. He would rather want him [to suffer], than to see me suffer. It hurts to see me in pain," he added.

The 'D' Word

All of the family members think about the possibility of cancer killing Arthur. The reality that in the last 2 years cancer has been found in his blood, spine, and brain is especially discouraging. "Yeah, everyone thinks about death," Arthur stated. Yet he is philosophical and seemingly resolved in his words: "If the day comes, there is no stopping it," he stated matter-of-factly.

In the meantime, Arthur is optimistic. "I've always thought about going on [continuing to live]. . . . 'Oh, I have cancer again'" he said, simulating a

conversation in reference to his last relapse. “It’s not going to stop me. I’ll keep on going forever.”

He continued with a question that he answered himself: “Why don’t I give up? I want to live, all to the fullest in this life, before I go to the next,” he added.

A Mom’s Faith and Philosophy

For Iris, things seemed to be not quite as simple or straightforward. Perhaps she talks and interrupts her son a lot to sort things out in her own mind, or to make things better for her son. Whatever the reason, Iris readily admits she is scared about the possibility of losing Arthur.

“I’m scared about him dying for sure. I always thought that I’m not going to make it if he dies. I don’t know what I’m going to do. But God has given me strength to focus. . . . My faith is that he is going to survive, because God already made a miracle on his life. I know it for sure, and when God makes a miracle, He doesn’t take it away. He gives you the miracle and that’s it,” she explained.

“And I know that I have 2 sons only, and through my oldest son he gave me the life of this one [looking at her son sitting in the wheelchair], because of his blood that he gave to him. So I try not to think of that. But when I was thinking, one time he was very sick, like 2 or 3 times he was very sick here in the hospital, so I was crying too much, because I don’t want for him to be dead. I don’t want to,” she stated.

She continued, “And I know that my husband is not going to tolerate that [her constant crying]—nobody is going to tolerate that, but I just keep on praying and praying and praying every day. I’m happy now. I’m happier than before because I know that he is doing good, even though he is not walking this moment, but he’s here, and he’s going to walk, this is not forever. This is just for his bones to get better. So I’m trying not to think that something bad is going to happen to him because I know that he’s OK,” she added.

Gratitude

Regardless of what may or may not be in store for him in the future, Arthur continues to understand that others are in similar and often worse medical situations. When he first saw young children who had lost legs to cancer, the 14-year-old told Iris: “Oh, Mom, you see, I should be happy. I’m happy at least I have all my [legs and arms]—at least I have only leukemia. At least I don’t have cancer in my legs, Mom, because look, it’s better than them. I have leukemia [and I am better] than them that have cancer in their legs because they don’t have legs. At least me, I can walk,” Arthur stated.

Yet his mother sees things differently than her son, including when her son said he was glad he did not have bone cancer. “I said [to herself, although she is now saying this in front of her son], *It’s worse for you, mijito, because you have cancer in your whole blood. Imagine that.* But I’m not going to take away that illusion that it’s better to have leukemia than cancer of the legs. But I’m not going

to take away what you were thinking. To you, it was doing you good,” she said to her son. “Because if I said, ‘It’s worse, *mijito*, because of. . . .’” Her voice trails off. She does not finish her sentence.

Faith and Family

What sustains Iris is her love for her family and her faith. If she were talking to a parent of a child newly diagnosed with cancer, she would tell him or her: “‘It doesn’t matter what the doctor tells you, you have to believe in what Jesus says. That God says that if you believe in Him, you have to walk by faith, not what you see around. If the doctor says he has cancer, it’s not the end of the world. You just have to focus your life, everything on the word of Jesus, and with Jesus. Or you believe that in God, you are going to make it.’ Because there is only so much that you can do. ‘Yes, it’s going to be difficult because you are not accustomed to your routine, and what you do in everyday life. It’s going to change everything,’” she continued. “‘It’s going to change too many things. You are going to have to be with him all the time in the hospital, and you have to worry about the temperatures coming up and down. Because if you see a hike in temperature, and you don’t take care of that, then he can die,’” she added.

In the last 2 years, Iris has spent most of her life taking care of her youngest son in addition to her work, her older son, her husband, and her extended family. She talks like a rock star’s road manager in saying she does “all

the booking” for her son’s medical appointments, which she never misses attending in person for any reason.

She is also Arthur’s driver, making the 6-hour round-trip visit to and from the cancer hospital at least 3 times a week. During one particularly bad episode for her son, Iris made the 6-hour drive twice in one day. Regardless of the distance, she is eternally grateful for the hospital and its personnel who are helping her son.

Only Stupid People

Because of Arthur’s consistent usage of curse words despite repeated chastisements from his mother, I asked him toward the end of the interview if he were angry about his situation. “I guess, in a way. I wish I [were] OK. Everyone has problems, even if they are not medical problems—people have problems with their marriage or child abuse. Of course, I’m angry, a little bit, but I have to deal with it,” he replied stoically.

One of the ways Arthur deals with his anger is by talking to his friends. Some understand; many do not. Some of his friends simply say to Arthur: ‘Oh, well, that sucks.’ “And some of them try to give me advice but they don’t even make sense. It’s like, *What the hell are you talking about, are you stoned?*”

One of the stupidest things people say to Arthur, including one of his female friends with whom he goes to school, is that “things happen for a reason,” he commented. “People who don’t really think, say that. Someone who thinks that

quote is good . . .” At that time, Arthur’s mother interrupts and says to her son: “Sometimes I say that quote.” He immediately replies: “No, that’s stupid!” She retorts: “Well, sometimes I say it.” He again asks his mother: “[You say] ‘everything happens for a reason’?” She responds: “Well, please, sometimes I say that.” The exchange between the two ends, and the room falls silent.

After a few minutes, Arthur is again philosophical: “People have their own beliefs. It just happens, OK, it just happens. But I didn’t want to hear that. I wanted to hear, you know, that ‘You can always talk to us about it’ or ‘I’m always here for you, whenever you need a friend, I’m here,’ something like that. Not in those exact words, but something. I was supposed to hear some comforting words, not some stupid stuff,” he argued. “Yeah, it was like she [his school friend] didn’t even care. There are some people who understand and then some people who don’t. That’s what kind of makes me angry. She said the wrong thing, so OK, whatever,” he stated.

Arthur wonders if people distance themselves from people like him who are ill, especially young people, because they do not know what to say, or they may say something wrong or stupid. “Yeah, some people don’t know what to say. I think it’s because it scares them, or they don’t hang out with me as much as they used to, or they don’t want to see their friend like that. But you have to see somebody like that. It’s better that they are like that, and they are your friends. You can talk to them,” he stated.

He continued: “it’s like, cancer is not contagious, don’t let them think that, I’m like, *Read a book. You have the Internet? Well, use it,*” he added.

Not Anymore

Arthur began to do more wheelies about the room, as he did periodically throughout the interview. There is a sense he and his mother will continue their own banter throughout their 3-hour drive home.

When asked what he might say to a newly diagnosed cancer patient, Arthur quickly responded: “I would just tell him, I hope everything works out the best for you, and it’s not easy. You have some hard times, you are going to feel like you want to die because of all the pain you feel. It hurts you so much, your soul, it really feels like too much,” he stated.

He continued: “You just want to say, ‘Forget it. I want to die.’ But don’t feel like that. Find other ways to make yourself feel better. Like, listen to music or talk to people about it. Stay occupied. Even when you feel bad, when you feel like, when you feel real bad, like something inside of me is biting me, or something, use your imagination. Pretend you are at the beach with girls all around you or something—something—escape from that. Hopefully you would be OK,” he offered.

On this Good News day, Arthur continued his ‘straight talk’ philosophy as he did another wheelie: “Some people are worse,” he commented. “I have cancer—but not anymore,” he said with a smile and a turn.

L. Quiet Considerations

Fran²⁶ looks like a stunningly beautiful model for hair shampoo in a women's magazine that guarantees to improve your life by turning your long, dry, lifeless hair into a cascade of fine silk running down your back. Whatever she is doing to her hair, the product is working for her: Fran is simply exquisite from head to toe as she enters a coffee shop next to a busy bookstore. She is 17 years old.

People watch her walk through the coffee shop. She does not seem to notice. She is a cross between Jackie Kennedy and Audrey Hepburn in blue jeans, a T-shirt, and jacket. Her eyelashes are long and beautiful, and they frame dark, expressive eyes highlighted by sparkly shadow. You can almost picture her on a Saturday afternoon at the shopping mall with a group of her teenage girlfriends, each trying to decide what color of shiny eye shadow to buy.

In sum, Fran is drop-dead (excuse the pun) gorgeous. She carries a quiet and unassuming countenance with her beauty, which makes her even more attractive.

Neither Fran nor I thought to tell each other what we looked like when we set up the interview on the phone. She has arrived at the coffee shop well after our appointed time late one afternoon. Prior to that moment, I was convinced she was

²⁶ In this story, I have changed the name of the person I call "Fran."

going to be a no-show, although she knew I was driving several hours specifically to interview her.

Although I was the only female sitting alone in the place, and my tape recorder and notebook were in front of me on a table I had strategically selected in a corner area, she did not scan the room upon arrival, nor even glance over my way to make any type of eye contact. Instead, she immediately walked directly to the middle of the room.

She sat down, and ordered nothing. She just sat with one elbow propped up on the table, her head resting on that elbow. Her body language suggested she was tired, bored, or mad—maybe all of the above.

For a few minutes I continued to sit at my own table in the corner, wondering if this was indeed Fran. Although I knew Fran was 17 years old, this young woman looked much older. And her captivating beauty, independence, and mobility were not things I had counted on since most of the interview respondents to date had noticeable signs of medical problems like oxygen tanks and wheelchairs.

For a few minutes, we both just sat at our respective tables. Then I took the initiative and walked over to her. She immediately looked up and smiled when I asked, “Are you Fran?” She shook my hand loosely, and apologized for being late because she could not wake up from an afternoon nap after school ended. I thanked her for agreeing to the interview. She repeatedly replied, “No problem.”

After a few moments of idle chatter between the two of us, I moved my notebook and tape recorder over to where she was sitting. She was alone at the coffee shop because her father dropped her off to meet me for the conversation. Interestingly enough, she has viewed much of her life as being alone or at least different.

Save for the intermittent buzz of a noisy and aggravating coffee grinder and a young man periodically shouting “Tall, mocha latte light” or some semblance thereof, Fran began to tell me about her exceptional young life. It started 17 years ago as a healthy baby born on New Year’s Day.

Problems Galore

From across the table, Fran appeared to be in picture-perfect health. She smiled a great deal; her teeth were shiny and white; and she seemed to feel relatively well. She looked like any other average, albeit extra-beautiful, teenager. When you begin to talk with her, however, you cannot help but notice her beautifully expressive eyes periodically roll way back up into her head. The abnormality is significantly noticeable.

However, eye rolling is among the least of her problems although it is one of the many offshoots of a lifetime of healthcare issues. When Fran was 4, she was diagnosed with Chronic Myeloid Leukemia (CML), a slowly progressing

cancer that affects the body's white blood cells.²⁷ CML is considered rare in that it affects only about 6,000 new individuals every year. Fran's brother, 6 years her senior, was her bone marrow transplant donor in 1990.

Fran has been in remission from the leukemia for 13 years. However, other problems have arisen, creating significant long-term healthcare issues for her.

One of her problems is that she has Stevens-Johnson Syndrome (SJS) - an illness causing severe swelling and destruction of the skin and mucous membranes. It usually begins in the form of a body rash.²⁸ Given that the mucous membranes eventually become involved with the rash, ulcerations can form on the eyelids and within the mouth. Over time the rash progresses and develops blisters that are sometimes severe enough to be categorized as third-degree burns. Many children with severe SJS are treated in hospital burn units.

SJS is extremely rare. In the United States, the incidence of SJS is estimated to be between 2.6 and 7.1 cases per 1 million persons per year.²⁹ Most scientists say SJS stems from an allergic-type reaction to medications, although

²⁷ CMLHelp.org. (2004, n.d.). *CML Background*. Retrieved Jan. 14, 2004, from <http://www.cmlhelp.org/cml/events1.htm>.

²⁸ iVillage (2001, April 23). *Health: Stevens-Johnson Syndrome (SJS)*. Retrieved Jan. 14, 2004, from http://www.parentsplace.com/health/illnesses/qas/0,,239266_101322,00.html.

²⁹ eMedicine (2001, July 10). *Stevens-Johnson Syndrome (SJS)*. Retrieved Jan. 14, 2004, from <http://www.emedicine.com/oph/topic268.htm>.

the exact cause is still being debated. Besides eye problems, SJS also causes a variety of skin lesions inside and outside the body. Symptoms from SJS have left Fran with significant scarring on her intestines. As a result, she has undergone an intestinal triple bypass.

The bypass surgery triggered Reactive Airway Disease (RAD). RAD is also frequently referred to as pediatric asthma. Symptoms include recurrent wheezing, recurrent coughing, fever, and altered mental states.³⁰ Pediatric asthma, or RAD, is a leading cause of hospitalization, chronic disease, and school absenteeism.³¹ In severe cases of RAD, damage to the lungs can accumulate over time to such a degree that the airways can become permanently narrowed.

Fran's life seems almost like a strong onion that is being peeled back, layer by layer. At each step of the way, there is strong emotional and physical reaction. At this point in the interview, I noticed that Fran is smiling. She says she is smiling because her list of maladies seems almost comical to her when she thinks about her whole life as a young person.

She continued to add to the list. "Then later I got epilepsy. And that's about it," she stated matter-of-factly with a smile.

³⁰ eMedicine (2003, Nov. 18). *Pediatrics, Reactive Airway Disease*. Retrieved Jan. 14, 2004, from <http://www.emedicine.com/emerg/topic363.htm>.

³¹ University of Maryland Medicine (2002, Sept. 13). *Pediatric asthma*. Retrieved Jan. 14, 2004, from <http://www.umm.edu>.

From a Distance

Fran continues to battle epileptic seizures and breathing problems on a routine basis. She sleeps with oxygen at night, which makes her feel different.

“At first, when I began to understand all this, I was just a little upset. I felt really like different from everyone else, but now I am beginning to accept that it’s in the past. Even though it has affected me now, I am just going to have to accept it, and try to be a normal person,” she explained.

While she works hard to accept her illness, she senses that others run away from it, and thus from her. “I think they [people] keep their distance, because my mom is like that. She is afraid to tell me stuff sometimes, because she is afraid of saying the wrong things, or she knows she can’t do anything about it, except take me to the doctors and try to get medicine,” she mentioned.

She continued, “My dad has relied more on faith. He’ll just pray to God, and I tell him that I don’t really have that faith right now. And he says to keep doing it. I really don’t like to communicate with my father about that,” she added.

Cover

Fran was only 4 when she encountered leukemia. She remembers first being diagnosed in April. Her parents were upset because it was around Easter. She vaguely remembers some of her many early days spent in the hospital,

including the nurses and other healthcare professionals who went out of their way to be funny so she would have more good than bad days.

Despite their best intentions, physicians frightened Fran—more so than the nurses. “The nurses explained a lot to me. I guess I got to be better friends with the nurses, since they were there longer than the doctors,” Fran explained. She also said the physicians seemed to know before anyone else that something bad was going to happen.

“Doctors? I know I didn’t really like them coming, so I kind of got under my covers and stuff when they came. I was kind of scared,” she recalled.

Words

Remission is a good word for cancer patients like Fran. Yet there are many more bad words. For Fran, the bad-word dictionary includes words and phrases like *surgery*, *come back*, *seizures*, *found something there*, and *new medication*.

Fran does not specifically remember being told she was sick. “I do remember some stuff in the hospital. But I don’t really remember pain or anything,” she commented. “I know my mother told me that I told her, “Mommy, I know I’m sick.”

Sacrificial Reminders

As with many ill children and young people, there is much conversation with Fran about sibling interaction and support. In Fran’s case, she is very close to

her younger sister, age 16, and her 23-year-old brother from whom she received her bone marrow. Yet their relationships are not without sibling relational challenges.

One of the benefits Fran derives from talking with her mature, younger sister is that her sister will keep things to herself. “I feel weird [when more people know about her illness]. I guess I’m kind of in the center of stuff, and I don’t like to be because I’m very shy,” she explained.

Yet things are not always good between the sisters. “My sister feels like she’s being deprived of attention. She tells me sometimes, and I can see how she feels too, and I feel bad. I’m not trying to be [at the center of attention], [but] I’m usually the one they ask about,” she added.

Fran is also embarrassed when her younger sister has to take care of her, like when they go out together. “I just feel like, weird. If me and my sister go out, and I’m having seizures, they want my sister to watch over me, and I feel really different because I’m the older one supposed to be watching over her,” she explained.

She is grateful for her brother’s bone marrow that has kept her in remission for many years. Nonetheless, the issue is not without tension. “He’s going to college and stuff, and even though we fight a lot, a couple of times he has brought it up” [the bone marrow he gave Fran] by saying things like ‘Well, I gave you your bone marrow type thing.’ I don’t know, it’s just kind of sad

because he can bring that against me and stuff,” she stated. “And my parents have, too. Like if I get mad at my brother, they will tell me that ‘he gave you your bone marrow, so. . . .’ I don’t know, it’s just really weird,” she added.

Straight-Forward

At times Fran thinks talking about her illness “makes it worse” because “soon everyone will know,” she commented. Nonetheless, one of the persons with whom she must talk about her illness is her primary pulmonary specialist.

Fran thinks her physician is a “good doctor. She’s kind of straight-forward.” Yet at times, hearing straightforward talk is hard. “She said if I had gotten pneumonia in December, if I had gotten one [referring to a lung transplant], then I would be all right, maybe. And if I didn’t [get a new lung], then I was just going to die. I don’t know, sometimes it just kind of hurts,” she mentioned.

“I come out of the office crying a lot,” she said. “I think about it [death and dying] —that I will be gone,” she said. Fran suggested a better approach on the part of physicians and others might seem to be a “little more informative, and don’t like, say it straightforward, just tell them what can happen if you do or don’t . . . just use a little bit more sensitive words than *die* or *pass on*,” she replied.

La Malita

La malita is the Spanish phrase meaning “the sick one.” That term and its connotation is why Fran does not like talking about her illness with her family. Yet that is how she is consistently identified.

“It feels weird, kind of, being known like that. That’s a little embarrassing. That’s a bad thing when a lot of people know,” she commented. Fran explained that her mother consistently has to remind family members she is the mother of other children when they only ask about Fran because she is ill.

Aloneness

One might think someone as beautiful and kind-hearted as Fran would be as popular in high school as the homecoming queen. Yet she suggested such is not the case. “I don’t have a lot of friends, just because I feel like I’m shy, and I feel a lot different than them, so I don’t feel like I should be with them.” When asked specifically how she feels different, she replied: “just the way I am—the way my past was and stuff.”

Fran is especially close, however, to two individual friends she has known a long time. “He [referring to one of her friends] just tells me how strong I am, and he would have given up, and stuff like that,” she commented. Fran said talk like that makes her feel better because it makes her “know, I guess, that I’m doing the right thing,” she replied.

Fran spends a lot of her time wondering if she is doing the right thing. She also spends a lot of her time telling her two friends and sister that she “likes to take care of myself most of the time,” so that they will not continually remain behind with her as she struggles to physically keep up.

‘I Prayed and Prayed’ . . .

Fran is no longer interested in spiritual talk, because “God is not listening,” she said. “I’m Catholic. I used to be really in to that, but lately I really don’t have any faith anymore. I’m starting to give up on stuff like that, because I have prayed and prayed that I hope I get better soon,” she explained. “Then it just seems like every year, something else goes wrong. I feel like He’s not listening or something,” she stated.

She continued: “I’m starting to really give up on faith now. And I guess my father is like, really religious, and he wants me to stay a Catholic, and wants me to get back my faith, but I don’t know, I guess he’s not really helping me with getting back my faith. We go to Mass, and to me it’s kind of boring. I just want to go to a church that’s out-going, kind of, that will get you in the spirit. He doesn’t want to do that. He said that we have to go to where he wants to go until we are 18, and out of the house. He doesn’t let us explore new stuff like that. I wish he would,” she added.

This is an area of tension between Fran and her dad, and to a lesser extent, her mother. “She’s more easy-going about that, and she is willing to take us to

some churches. But both of them want us to believe in God. I just want to explore different churches and different religions to see where I fit in,” she said.

Fran added that soon she hopes to get a car for her 18th birthday, possibly at Christmas. Some of the first places she plans on driving to will be new churches in the area.

Withholding

In order to be perceived the same as everyone else, Fran withholds medical information from her parents. “Yeah, I have done that a lot of the time [not told her parents she was feeling badly],” she commented.

She continued, “Sometimes, I guess, when I tell them it seems like they get mad at me, but they say they are mad at the illness. That’s why they get upset. But I don’t know. I know when I’m about to have a seizure, they want me to tell, but a lot of times I don’t. I just go along with it,” she added.

Costs

Fran wonders at times about the hardships her illness has placed on those around her. “I think that it [her parents’ relationship] would be better, because a lot of times I feel like I’m just a waste-of-money-type thing. They have just spent a lot of money on me because of health stuff,” she commented.

“Maybe if I had never gotten sick, they would still have that money and stuff. I don’t know. I’m not sure. That’s just something I think, because when we

get bills, it's usually because of my doctors and stuff, and I just think that," she replied. She added: "Yeah, maybe they [her parents] would have been better off, like had a better relationship there [the place where they lived before they moved because of Fran's illness]."

Stories, Strangers, and Satanism

Despite her shyness, Fran has a story to tell, and she wants to tell it. In meeting a new person who had cancer, she said she would first share with her or him her own personal experiences. "First I would tell them about my story, and I guess, just tell them that I will be there if they ever need me to talk to, just to help out along the way," she commented. "I know they have family, but sometimes a stranger or a friend can help make things better in some ways. I don't know, I would just be there for them and everything," she said. Stories are important in Fran's life because "I like to read. It just helps to know there are other people out there going through the same thing and stuff."

Some day Fran would like to write her own story in the form of a book. She mentioned she likes true stories, like *Jay's Journal* and *Go Ask Alice*. *Jay's Journal* is a story about a young boy's addiction to drugs and Satanism before his suicide at age 16. *Go Ask Alice* is a chronicle of information designed specifically for young people concerned with physical, sexual, and emotional health.

Fran battled depression when she was in the 6th grade. She continues to struggle with finding her own way as a shy and somewhat alone individual.

“That’s what *Jay’s Journal* is about [depression and searching]. He [Jay] believes in God at first, and he started exploring, and kind of went the wrong path, and stuff like that. I thought of that [Satanism], but after I read the book I knew it wasn’t a good idea,” she said.

Two Roads Converged . . .

Regardless of any spiritual path she may or may not take, Fran’s short-term goals are to get her driver’s license and graduate with her class from high school. She hopes to be able to go to college. She also would like to volunteer her time with the Big Brothers, Big Sisters program once she turns 18. She definitely likes working with children and young people, like in her mother’s daycare. Eventually she hopes to have her own family and children.

In the meantime, she will continue to think about her life, and the choices she needs to make in terms of which roads to travel.

Research Weights

When this interview was conducted, Fran was not only concerned about shopping at the bookstore next door for a Christmas present for her sister, she was also worried about bigger issues, like whether or not to undergo a lung transplant. In her spare time from schoolwork, she does research on the pros and cons of lung transplantation given her particular types of medical problems.

Her physicians want Fran to move forward with the transplant. “Yeah, they are wanting to [do a transplant], so I’ll research that,” she explained. “And they are thinking of also doing another brain surgery [for her epilepsy]. I still have to get tested for that. I do research for that, because they say if they do it [the surgery], there is a chance that I will have weakness in my left arm, or that I might be paralyzed, so I’m trying to do a lot of research,” she commented.

An Update

After the first of the 2004 New Year, I contacted Fran via e-mail to see if she had made any decision on whether to seek a transplant. I also wanted to see in general how she was doing. She responded:

I’m doing all right. My breathing had gotten bad last week, but it’s doing better. How are you? I didn’t get a car for Christmas, and was kinda sad but I did get a picture phone, so that was OK. For my birthday on January 1st, I had a BBQ with family and friends. Then on January 2nd, I had a little get-together with some of my friends, and finally on Jan. 3rd, I went to my first club that was Hardbodies. Hehe. It was fun and that was the end of my B-Day celebration. . . . How was your Christmas and New Year’s Eve? I still haven’t made the decision on whether or not I want a lung transplant, but I’m leaning more towards yes. Well, thanks for the e-mail.

Quiet Considerations

Life’s handouts have put more on the plate of this painfully shy and gorgeous Jackie Onassis–look-alike in 17 brief years than most people experience

in entire lifetimes. As our interview on that day before Christmas drew to a close and the java man announced the readiness of a *grande cappuccino decaf*, I was acutely aware then, and remain so now, of the remarkableness of this beautiful 17-year-old young woman, inside and out. Her future stakes and decisions are considerable.

M. Enough

When I walked in to the small hospital room, 18-year-old Ryan³² was talking to his young-looking mother. His mother said to me with a smile: “I’m going to leave you two alone—he’ll talk more if I’m not around.” With that, she left the room.

Turning to Ryan I said “Hello” to a striking, congenial-looking, fair-haired young man. He was dressed in street clothes and propped up on pillows, lying under a white hospital blanket. A worn baseball cap covered his head.

Although he did not smile often during the interview, when we first met his long, angular face broke into a tight smile. Ryan had a quiet and strong countenance.

Nothing about Ryan’s physical being suggested anything out of the ordinary except the reality he was lying in a hospital bed in street clothes. He told

³² In this story, I have changed the names of the people I call “Ryan,” “Dee,” and “Ralf.”

me he was hoping to go home that day. A laptop computer was positioned on top of the blanket. He had been surfing the Internet.

Ryan and I chatted briefly about what he was doing on his computer, and I thanked him for agreeing to the interview. He shrugged and said “No problem.” On the surface, one would think Ryan had not a care in the world beyond that of any normal teenage male.

As I sat down and looked around the room for a plug for the tape recorder, I noticed an interesting item laying on top of a small hospital table to the right of his bed. During prior interviews I had observed a host of medical equipment like intravenous fluid bags, hangers, oxygen units, beepers and so on—almost to the point that such items had become routine to me over time. But today this particular item was something I had never seen before in any of my interviews. It was something I had never really thought about before until that precise moment: an artificial leg.

Mobility

Certainly I have seen quite a few people walking with artificial legs, but I have never looked at one up close or apart from its master. This particular leg was positioned sideways on the table, almost like an old bathrobe lying on a bed. Nothing was around it. It was just there in plain view, or out of sight, depending on one’s field of vision.

The leg seemed somewhat strange to me at first in that the shiny long metal rod that screamed *high tech* slid down into an old, worn lone canvas tennis shoe. This contrasting of the old and the new, and the shiny metal next to the tattered cloth seemed peculiarly sweet yet melancholy, for want of a better description.

Ryan noticed me looking at the leg. He asked: “Ever seen a \$40,000 leg?” “Can’t say that I have,” was my reply. He told me the leg was his. I asked him if the leg had a name, and he said no.

Having become increasingly sensitive to the high emotional and economic costs of being sick, and since Ryan had brought up the cost, I asked him if he and his family had to pay for the leg out of their own pockets. He quickly replied “No,” thanks to the extensive efforts of his physician in lobbying the insurance company. His parents told me the same thing later on when I talked with them outside Ryan’s room. The expression of relief on each of their faces was universal and huge.

Ryan watched me set up my tape recorder. He said nothing. During those few moments I thought about this 18-year-old young man who was wearing a worn baseball cap and who now had one long angular leg and a stump and a metal rod for his other limb. He began by telling me about his life, and how he came to have an artificial leg.

A Sprained Ankle . . .

Sandy-haired Ryan is an athlete who loves sports. He has played baseball, lifted weights, and participated in other athletic adventures. In fact, his initial wake-up call to physical problems came when he was playing baseball.

“I sprained my ankle playing baseball, and then I had X-rays for that. Then a month after that I started getting pains a little bit below my knee, and then I had an X-ray for that, and it showed up as a tumor,” he stated in a direct, matter-of-fact way. The word *tumor* immediately signaled to Ryan and his parents that he had cancer, even though at first the doctor never indicated whether the tumor was benign or malignant.

“It was just a regular doctor’s office, and they said . . . they saw the X-ray, and they said it was a tumor,” he commented. “So we pretty much . . . you could make the assumption that a tumor is cancerous,” he added. “We went to the one bone specialist, and they weren’t sure, so they had to go all the way in there and test it and make sure and everything. So yeah, it was cancerous,” he said.

Ryan’s bone doctor said to him, “Oh you got this, there.” “Yeah, basically he tells it how it is, I guess. That’s one way to do it. He doesn’t feel sympathy for anybody,” he explained. Ryan went on to say that his physician “just has to do his job . . . to help you.”

A \$40,000 Leg

Eighteen-year-old Ryan suffers from Osteogenic Sarcoma, also known as Osteosarcoma, which is how Ryan and his family identify the disease.

Osteosarcoma accounts for approximately 5 percent of all childhood cancers.

Most cases are caused by non-inheritable DNA errors in the bone.³³ Although the disease itself is relatively rare, Osteosarcoma is the most frequent form of bone cancer, found most commonly in young people ages 15 to 25.³⁴ More than 90 percent of the tumors are formed in the growing ends of the bones. More than 80 percent of Osteosarcoma sites are found around the knees. Osteosarcoma can spread throughout the body.

“It’s called Osteosarcoma. It’s a bone cancer. It was found in 2001 in my tibia in my leg,” Ryan explained. “They took out half my tibia, and then I had chemo for 6 months after that. And then about 6 months after finishing chemo, it reoccurred in my lungs. I had 3 lesions. Two of them were cancerous. They removed those,” he stated. “Another 6 months of chemo. And then 6 months after that, it showed up in my tibia again. So this time it was amputation,” he added.

He goes on to explain: “I haven’t had any chemo yet or anything like that [this time around]. They can’t give me anymore,” he said. “So they are going to

³³ Wright (2004, n.d.). *Oncology: Osteosarcoma*. Retrieved Jan. 24, 2004, from <http://www.wmt.com/patients/oncology/osteosarcoma.asp>.

³⁴ Children’s Cancer Web (2003, July 20). *Osteosarcoma*. Retrieved Jan. 24, 2004, from <http://www.cancerindex.org/ccw/guide2o.htm>.

have to find some other treatment to give me that will hopefully kill it,” Ryan explained.

Spreading

Ryan continued to talk about the progression of his disease. “They have already found a few more lesions on my lungs. They are not sure what they are yet. They are pretty sure they might be cancer. But they are not sure yet,” he said perfunctorily.

When asked when he will know for sure, he explained, “Not until I have a biopsy or until they see them start growing. I have already had 3 chest X-rays, 3 chest CAT scans, and they have all stayed the same size. They haven’t grown yet, so they will have the possibility of them not being there,” he added.

No Whining

What is life like for an 18-year-old who has already lost a leg to bone cancer and may be facing lung cancer for a second time without the option of chemotherapy? “I don’t know. You can’t do anything about it anyway, so you just make do,” he added. “I just let them do what they have to do. That’s it,” he stated. Ryan tells me his parents worry more about his illness than he does.

This or That

Ryan answered many of my questions with short, terse answers. My sense is that while he voluntarily consented to an interview at the request of his physician, he gets easily frustrated when the answers to life's questions are not easy. In fact, he expressed that frustration with me. When I asked him in what ways he thought other people might describe him, he replied: "I've been asked that before, and I still don't know. I don't like questions like that because they make me think. . . . I don't like questions where, it's not exact. It's like math where the answer is this or this. I hate that," he said. "It's got to be one answer," he added.

Pretty Bummed

When I asked Ryan why he consented to an interview, he shrugged and replied: "I didn't have anything better to do, how about that?" On this particular day he is back in the hospital because of an ailment similar to a collapsed lung. It is the second time he has had this problem in the past 2 months. "I don't know what causes it. It happens to a lot of people who are my build, tall and skinny. I had it before last month. It could be from like a jolt, like getting hit in the side or something. Numerous things can cause it," he explained.

When this happened the last time, Ryan had a chest tube inserted to alleviate the problem. This time they are simply monitoring him to make sure it

does not get worse. “You can feel it. It hurts when you breathe in. Like yesterday, I started breathing in, and it just started hurting. And I felt it, and I knew it felt like from before,” he commented. When I asked him if he becomes aggravated over having the same medical problems once again, he replied: “Nah. You can’t stop it. There is nothing you can do about it.”

The other piece of Ryan’s medical equation will be unfolding soon when the test results show whether or not the new lung lesions are cancerous. He seemed unfazed to the point of being nonchalant about the possibility. “Yes—have/had. Oh, I guess I still have it,” he stated.

The only time Ryan remembered being truly upset about having cancer was upon his initial diagnosis. His parents later reaffirmed how hard receiving the news was for everyone. “I got an upset stomach, like that, but I couldn’t do anything about it anyway. You just have to deal with it,” he stated. Later his father told me that Ryan vomited upon hearing the news. His father wept openly.

Ryan continued: “Maybe sometimes [I worry], but it’s nothing big. I guess most of the time when I worry it’s about when I have to get the scans to find out if it actually is *it* again. It’s good to know, but if it is [cancer again], I’m pretty bummed,” he said. “But you can’t do anything about it anyway,” he said again.

Day by Day

While Ryan, his parents, and his younger brother wait on the latest test results, Ryan takes things a step at a time. “I just go on,” he stated. He does not think about the future in a long-term way, but rather he said he goes “day by day.”

As the interview progressed, I became acutely aware of the generosity of Ryan’s willingness to talk with me in the first place for whatever the real reasons. He is not a young man who cares to talk at all, including about his illness. “I mean you’ve already heard the worst that’s already going to happen, so why bring it up again? I mean, it’s not going to help or anything. I mean it might help some people, but not me,” he added with a shrug. He does not talk about his illness with his friends. “We’re not really that close—we just hang out and do stuff. They wouldn’t care if I . . .” he said as his voice trailed off without completing the sentence.

Strike Three

Of all the adversities that have come his way, I asked Ryan which is the worst thus far. He replied: “I guess all 3 times were the worst. He [the leg physician] just tells it like it is. He just comes in there and tells you what you have, and what they are going to do, and that’s it. Like this time, he showed me, ‘Yeah, you have a tumor, and we are going to amputate,’ and that’s it,” Ryan recalled. That is when Ryan became pretty bummed, and his stomach turned sour.

Humor

Ryan said sometimes he jokes about his illness, depending on those around him. He does not joke with his parents because they worry a lot. At one point in the interview he stated that he worries more than his parents—then he immediately corrected himself and said they worry more than him. I did not press him on the issue. “You just have to deal with it,” he stated.

“I make jokes about having a stump now because it’s funnier to joke about it than to whine about it,” he said.

Woo Hoo

Before Ryan’s leg was amputated, he was in his freshmen year in college studying computer science. Because he was surfing the Internet before I arrived, I asked Ryan if he used the web to gather research about his illness or talk with other young people with the same disease, as other cancer patients had expressed previously to me. “I don’t ever talk to anybody in here or anything. My parents go to the little web sites where you can talk to other people who have it—the same illness as you. Why? I mean—they have it. Woo hoo. They have it. I have it too. That’s how I see it, I don’t know,” he commented.

For the time being, Ryan will continue to await more information on the new lesions on his lungs. He has not been going to school because “I can’t really walk around the hills out there. Plus, I’m having the physical therapy, to learn

how to walk good before I go back. So that's basically it. I'll go home, and everyone else will go to school or work, and I'll stay home and watch TV, surf the net, play video games," he stated.

Self-Sufficiency

One of the strongest components of Ryan's constitution is his intense desire to be self-sufficient. At one point in our conversation I noticed his lips quivering slightly, and I asked if he ever cried about having cancer. He replied succinctly: "No." When I probed further simply by repeating his answer in an interrogatory fashion, he added: "I don't think there's a reason to—nothing to cry about." He also commented that he did not think there was anything he had done in his life that "I'm proud of."

As we closed the interview, I asked Ryan about his younger brother in terms of something he might find to be proud of in his life. Specifically I asked Ryan if the tables were turned and something were to happen to his brother, would he care for him?" Ryan replied: "He's self-sufficient, too."

OK

Perhaps in my own desire to end each interview on a more positive than negative note, and especially so since this particular interview was my last in the data set, I asked Ryan what he would want people to think or say about him right

now at age 18, a young man with an expensive artificial leg. He thought for a long time and then replied: “That he’s OK to be around, I guess.”

Did He Talk?

As I walked out of Ryan’s room and headed for the elevator to leave the hospital, Ryan’s mother was waiting in the colorful sitting area down the hall. A gentleman sat near her two chairs over. I had seen the gentleman a few times before that day walking the halls. His slumped shoulders and burrowed face exuded sadness and worry as he paced the halls.

Ryan’s mom, Dee, introduced me to her husband and Ryan’s father, Ralf. Together they seemed verbally and visually anxious for information about their son that I was constrained by confidentiality rules not to share. Yet their primary interest was bottom-line basic, for they immediately asked almost in unison: “Did he talk?”

Ryan’s Parents

For the next hour, I had the unplanned privilege of sitting with Dee and Ralf as they shared their own perspectives in dealing with their oldest son’s illness. I had not specifically requested the opportunity to interview them, given Ryan’s age of 18. However, parental perspectives are critically important in understanding the holistic and familial systemic nature of communication during this unique time in peoples’ lives. Thus I asked if I could record our conversation.

They willingly agreed. They were hungry to talk—almost to the opposite extreme from their son, who was verbally contained, albeit polite.

Starting Young

Dee and Ralf seemed incredibly young to have a son Ryan's age. They explained to me that they married very young when Dee was only 16. They had been married 24 years.

Dee and Ralf cried throughout most of the interview. At the risk of exposing troublesome researcher bias, I must admit I cried with them, as I had been able to keep myself from doing in all but a couple of the previous interviews. I cried with them at times because they were hurting so badly, watching their first-born experience cancer for possibly the third time with treatment doors shutting all around them.

I also cried because they individually and collectively seemed like such genuinely nice people. Self-described as opposites, Dee told me she was a teacher, and Ralf a rancher, thus his weathered skin and blue jeans. He struck me as a rough and tough rancher who would prefer not to have people see him cry—but those days were long gone. Today he was sitting in front of a total stranger crying like a weary baby.

Filling in the Blanks: The Strong Man

One of the most interesting perspectives in talking with Ryan's parents is that without betraying confidences, they were able to help fill in some of the missing blanks in my interview with their son. After talking with them, I was reminded that stories are simply snapshots of what people say or do at that moment, without the benefit of the immediate screen before or after.

Ralf and Dee told me that when he was first diagnosed, Ryan used the Internet to meet others who had cancer, including a young female friend whom he went to visit, thanks to the financial goodwill of family friends. They also explained to me that Ryan had always been an aficionado of computer games, and that somehow his gaming friends on the Internet became aware of his illness, and they posted a notice to all those who like to play similar games. Ryan then received over 600 "best wishes" e-mails from total strangers across the world, including Japan, Australia, Switzerland, and others. Ryan, Mr. I'd-Rather-Not-Talk-About-It, took the time to personally answer most of them. Ryan never mentioned any of this in our conversation.

Dee expressed some level of frustration at Ryan's willingness to talk with cyberspace strangers about his illness, as opposed to his parents or his brother. Nonetheless, she seemed grateful that he was talking at all. "I think he keeps everything . . . , not that he keeps everything in, he just takes everything in stride," she commented.

That said, Ralf and Dee both marvel at their son's emotional and physical strength. They recalled a time when the family went to Disneyland for Ryan's Make-a-Wish trip right after Ryan had been playing paintball with one of his cancer nurses. During the paintball game, Ryan fractured his leg prior to the amputation. He said nothing about hurting his leg until much later when he was walking around the theme park and his knee began swelling. "His knee starting swelling up a little bit, and he was saying that it was hurting him. And we were like, *Oh my gosh*, we were all scared to death," his mother commented. "And come to find out, he had fractured it playing paintball, and by the time that he got in [to see the physician], it had healed over. They said that was good though, because the calcification made it stronger. So when he broke [it], the crack in there [the calcification] really helped strengthen that. It [the cancer] came back there, yeah, unfortunately," she added.

Brevity

From talking with Ryan's parents, a perspective became clear as to why their son might be terse in his own communication. Despite talking a great deal and crying even more, Ryan's dad does not mince words. "Basically, it sucks because what choice do you have?" Ralf said through his tears, specifically commenting on the amputation.

He continued: "That's the way he [Ryan] deals with it. He's always joked about stuff. And as far as talking—" Now Dee interjects: "He's never talked about

it,” she finished the sentence for her husband. Ryan’s dad continued: “I always wondered if he [Ryan] knew what was going on. I asked him one time. And I got the answer. ‘Yes, I’m not stupid,’” his father says Ryan told him. “I said ‘That’s fine.’ I smiled and let it go. You know, I’m not. . . . It’s just hard,” he added as he wiped his eyes.

Reading Faces

Scholars point to the importance of nonverbal and verbal cues in understanding communication interactions. Both Ryan’s parents say wonderful things about the medical personnel. In fact, the staff has become extended members of the family. Reading their faces has become an important and telling ritual.

“You can see in their faces that it hurts them [to repeatedly have to deliver bad news to Ryan and his family],” Dee commented. Dee tells me that “Yes,” the staff sometimes cries in front of Ryan when they know his cancer has returned. Ralf tells me “No,” they do not cry. Together they explain.

“No, not in front of Ryan—with us,” Dee clarified. Ralf added: “They know. They know. You can see them, you know, the doctor, it hurts.” Dee added: “It’s scary.” Ralf and Dee also said they try not to cry too much in front of Ryan. “We try to be strong for him, that’s true,” Dee stated. “We try not to [cry]. We try to hide it,” Ralf added.

Both parents added that despite their intentions, Ryan has seen them cry repeatedly in the last 3 years of their medical journey. “He knows we are worried about it,” Ralf said. Both parents also tell me their younger son is concerned about the situation. “He’s [at age 15] had to grow up the last 3 years, really. Because see, we live out in the country, and we have cattle and stuff like that. He’s concerned about his brother. He’s worried, but he’s doing good,” Ralf added. “You know that he’s getting the raw end,” Dee said. “You know, he’s seen that we favor him [Ryan] a little bit more. You know, he’s seen us. I’ve talked to him. He knows,” Ralf added.

Teenager Perspectives

Ralf and Dee have similar yet different perspectives on Ryan’s thinking at this point in the disease process. Dee believes her first-born is stubborn, and that out of the stubbornness and strength come his ability to always take everything in stride, including cancer. Both parents believe that some of their son’s strong and terse constitution is nothing more than the typical defiance of any 18 year old—ill or not.

One of the most important components for Ryan in terms of his illness, according to his parents, relates to his wanting to be just like everyone else. He hates being looked upon as different. “You know the one thing too, the chemo stuff, when he lost his hair, the principal, I went to see her,” Ryan’s mother commented. “She said he [Ryan] can wear his cap to school. All he has to do is

carry a little note. I told him and he said, ‘No, it won’t bother me.’ He still says, ‘I’m not handicapped,’ Dee stated. She continued: “You know, he hates to use the handicapped sign. He did use it, when he was going to college. . . . It was hard. That was before they removed the leg. It was hurting real bad to walk and stuff. And you know we would be in the car together. We will use it [the handicapped symbol sign] so he doesn’t have to walk so far, because he’s getting used to the leg. He doesn’t like it. He says: ‘We don’t need to park here—park down there. I’m not handicapped.’”

Ryan’s dad also commented: “And then you get tired of asking, ‘Are you OK?’ He gets frustrated with us—every 5 minutes us asking him that—sometimes—yeah, sometimes [he gets angry]. He’s been like that since he was itty bitty,” Ralf commented.

Enough

Once again I find myself amazed at the determination, vulnerability, and honesty of 2 kind individuals. Their willingness to share their story and gut-wrenching hurt with a total stranger is amazing. As I closed the interview, I asked both Dee and Ralf about their future. They are hopeful that now that Ryan is aging into adulthood he will become eligible for new medical clinical trials and thus receive different kinds of treatment that could stop his cancer from occurring again.

In the meantime, they talk at length about their mutual desire not to see their 18-year-old son hurt anymore. They are worried about the future, and cry openly. Their son amazes them in terms of his resolve, strength, and determination for whatever the reasons. They intend to hold tight to one another and Ryan and his young brother—each in their own respective ways. “There’s no reason for this to break a family,” Ryan’s father said steadfastly.

Talking helps sometimes—especially for Ryan’s mother. Crying is inevitable for both of them. “Don’t put off anything you plan to do. Don’t take anything for granted,” Ralf told me. He also added: “When I’m around him [Ryan], I’m better.” Dee echoed the same sentiment. They come every day to the hospital and sit and wait.

Ryan’s mom commented: “It’s hard. I just can’t imagine that we are going through all of this. Once, OK—twice, maybe. Three times, boy, it’s like, *OK, that’s enough*. You know, so we just think that we aren’t going to get through it,” she confided.

The youthful looking mother continued with her sorrowful lamentation as if she was saying her prayer out loud to anyone who would listen: “You know, just let him go on with his life. Let him live his life. He’s only 18. He’s just starting out college, you know, trying. He’s doing great with that leg. That’s not bothering him,” she cried.

Dee looked over at her husband who is crying openly. She said to me: “I pray all the time. I say to keep him cancer free, give it to me. You know, he [Ryan] has never disliked it. And that’s one thing that he has never said: ‘It’s not fair, why me?’—not one time. I’ve said it enough for. . . .” Dee cannot finish the sentence because of her tears. I respond for her, “. . . all of you.” She and Ryan’s dad both looked down and nodded yes. They had had enough.

CHAPTER 3:

THEIR STORIES: OUR LESSONS

The preceding 13 stories represent conversations and interviews held over a 6-month period. They were conducted with approximately 30 individuals directly involved in personal healthcare situations. They represent glimpses of individuals and families in the best of trying times considering the somber context, such as when Arthur and his mom received good news for the day in the midst of a relapse (-Source: “Good News, Mijito! What the Hell!”). They depict snapshots of weary and lonely souls in the worst of times, like Corazon who sits alone in the butterfly room watching her son waste away (-Source: “Waiting”).

They represent children and young people who have a lot to say and who want people to listen, like “Unfiltered Harry.” They depict children and adolescents whose voices have been lost or shut out between struggling parents, as depicted in “Blistered.” Many of the stories present images of seriously ill yet strong-willed young people who are running their own shows.

Many of the stories represent parents who are struggling in far greater degrees than their children. At a minimum, they represent parents who would give anything to be able to trade places with their offspring.

The stories represent ordinary people who are living in extraordinary situations described by most as the worst times in their lives. Yet the majority of those interviewed are moving forward with strong conviction and brave hearts.

Some of the stories represent missed or lost voices. They are *missed* in that interviews could not be arranged before the young people died, or *lost* in that they have died since the interviews took place.

Words come to mind in writing and thinking about these stories and the lessons they offer. Those words are presented below in random order:

hope	anger	determination
aloneness	weariness	fear
relations	talk	individuality
patience	love	uncertainty
resolve	God	gratitude
worry	stupidity	cynicism
certainty	connection	spirituality
humor	lamentation	weird
euphemism	intelligence	sadness

. . . and many more

Amidst the expansive uniqueness of the stories and the personal characteristics and philosophies of the respondents, there are similarities. There are themes found

in the richness of the data. There are stories on top of stories. There are surprise findings and absent expectations.

Like life, there are many loose ends and uncertainties worthy of additional research. Everyone dies. Regardless of how hard we avoid thinking or talking about the issue, the inevitable will come to each of us personally and to everyone around us, most of whom we will not want to let go.

If everyone is going to die eventually, why not talk about it more now? If we cannot cast a veil of protective sanctuary around our children, why not learn from them? If “out of the mouths of babes” comes great wisdom, why not talk to and with our children about the unthinkable they may be facing? If our children and young people have stories to tell, why not listen?

The overarching aim of this dissertation is to directly hear the personal stories of those youthful voices distinctly absent from extant literature. The stories are theirs to tell. The lessons are ours to consider.

In keeping with my methodology for this dissertation, thematic findings from the interviews are offered in narrative style. Themes are generally presented in random order with qualifying commentary.

Glaser and Strauss (1967, p. 251) suggest the root of all significant theorizing is the “sensitive insights of the observer himself.” The themes offered are a few of the major conceptualizations heard throughout the interviews. They are among many general and more specific notions surfacing from the data. Using

Glaser and Strauss's cue, I offer these themes, based on my own insights from personally conducting each interview, hearing all of the stories firsthand, analyzing the data, reviewing extant literature, and reviewing background information in keeping with the previously discussed research methodology. Themes discussed in order are: (1) acceptance and determination; (2) communication and 'straight talk'; (3) unnecessary and undesired external sense-making; (4) isolation; (5) spiritual talk; (6) client control; (7) natural alliances; and (8) individuality.

Acceptance and Determination

Although the presentation of themes is offered in random order, the theme of *acceptance and determination* comes to the forefront, given its dominance throughout the data from those who conceivably have the most to lose: the ill children and adolescents themselves. For whatever their reasons or the historical cognitive processes that brought them to their individual ways of thinking, collectively the young people with whom I spoke are universally accepting of their particular lots in life. As well, they are determined to make the best of whatever time they have left on this earth.

Kubler-Ross (1969) identifies *acceptance* as one of the 5 key stages of grief beginning with *denial and isolation* (a period of shock that functions as a buffer against the overwhelming reality of the situation), *anger*, *bargaining*

(making pleas to others such as God or other forms of a higher being to try and forestall or avoid the loss), *depression*, and ultimately *acceptance*. Kubler-Ross suggests individuals move in and out of the various stages. Going in to data collection, I had expected to see evidences of all of the stages of grief at different times from both the young people and their parents. Such was the case.

However, what I did not expect to find was the universality and degree of *acceptance* from the children themselves, even more so than the parents, regarding the distinct possibilities they could or would die soon. Without equivocation, the young people whom I interviewed were collectively very accepting of their particular situations. Such evidences from the transcripts are contained below.

Moreover, not only were the children and young people *accepting*, they were *determined* to make the best of the bad situations they were being forced to accept. The notion of determination is offered from a definitional perspective: a firm intention or a firmness of purpose.³⁵ Determination followed acceptance in every interview on the part of the children. In fact, not one of the respondents said to me, “I am going to beat this disease.” Instead, they talked mostly in very perfunctory ways as to how they were determined to live out their lives in the

³⁵ Webster’s *New World Dictionary of the American Language: The 100,000th Edition* (1971). New York, NY: The World Publishing Company: Times Mirror.

ways *they* wanted, spending whatever time they had left doing things with those they loved the most.

This is not to say the respondents were ready to give up or admit their fights were over—far from it. Many of the young people were still receiving chemotherapy, considering lung transplants, or awaiting new test results with hope. Only in 1 situation had the young person, age 15, determined on his own to no longer receive treatments, against the wishes of his parents (-Source: “Blistered”).

Determination is presented here in a conceptual framework based on a variety of fronts. First is the notion of *real time*. This is to say that for the time being, the individuals were by and large accepting of what they had experienced, what they were experiencing, and to whatever outcomes were headed their way, good or bad. In sum, being ill had become a known and accepted way of living, and one that no longer required an emotionally or conversationally *upbeat* form of language or behavior, regardless of how relatively bright or bleak their predicaments.

Secondly, a comment is made regarding time in relation to how long these individuals had been battling their illnesses. Some of the young people had been sick for 16 or more years with advanced illnesses, some for only 1 or 2 years. My initial thinking was that perhaps I would have heard many more expressions of *anger talk* and less *acceptance and determination* across the interviews had I

targeted children and young people only recently diagnosed. The argument could be made that such individuals may not have had time to become accustomed to their situations, thus I would have heard less resolve.

On the other hand, one might argue that for those children and young people who had been sick for almost their whole lifetimes, weariness and frustration could have given way less to acceptance and more toward anger and bitterness. Nonetheless, despite the wide sample of children and young people with advanced illnesses in terms of lengths of illness, the two sides of the *acceptance and determination* coin were heard in every single interview in a variety of ways.

Below are a few of the many examples pointing to the notions of acceptance and determination in response to the general question of “What is living like with a life-threatening illness?”

If I go through my life thinking I am going to die, then obviously no matter how strong willed you are - you're going to. It's going to affect you. So I just try to [stay strong], until they tell me otherwise.

. . . And if God takes me young, then I enjoyed what I had. That's just the way it is.

—Source: “Unfiltered Harry”; excerpt 1
(Harry, 20-years-old, has 50-50 odds, down from 70-30,
for remaining in remission from leukemia,
despite having had it twice)

I wish I [were] OK. Everyone has their problems, even if they are not medical problems—people have their problems with their marriage or child abuse. Of course, I’m angry, a little bit, but I have to deal with it.

—Source: “Good News, Mijito! What the Hell!”; excerpt 2
(Arthur, 16-years-old, is currently in remission from leukemia, having had it twice)

I think Patrick [ill son] is given a special grace because I have seen him respond more negatively emotionally to algebra before and since cancer, than he did the whole time [the cancer journey]. I’m not kidding you. I think he was really given a special grace.

—Source: “Praising Life: The Last Chapter”; excerpt 3
(Parent of Patrick, 12-years-old, who is currently ending his first full year of remission, having undergone bone marrow transplantation)

I don’t ask questions anymore like *Why?* Everything happens for a reason. . . . Deep down inside they [other people] might see that I might die. And they don’t want to bring it up, which is perfectly fine with me. I don’t really want to talk about it. I’m real to the fact that I may die. We’ve all got to die.

—Source: “Authenticity”; excerpt 4
(Eduardo, 18-years-old, has relapsed with leukemia)

Me, it’s like, *OK, it’s Monday. I’m going to the doctor.* [I] just get up, and go about my business, like you would get up and go to school or work. That’s how I get up and go to the doctor. Not like every day, but basically, pretty close to it. And if I wasn’t in the hospital for chemo, I was in there for pneumonia or low blood counts, or what’s the word I’m looking for, Neutropenia, when you have an unexplained fever and your blood counts are low. . . . Just like it was my daily routine. As far as now, even if I do die, I still

have time. I would at least probably say a year or 2—worse case scenario, you know, I’m open.

—Source: “Unfiltered Harry”; excerpt 5³⁶

It’s called Osteosarcoma. It’s a bone cancer. It was found in 2001 in my tibia in my leg. They had to . . . take out half of my tibia. Then I had chemo for 6 months after that. And then about 6 months after finishing chemo, it reoccurred in my lungs. I had 3 lesions. Two of them were cancerous. They removed those. Another 6 months of chemo. And then 6 months after that, it showed up in my tibia again. So this time it was an amputation. I haven’t had chemo yet or anything like that. They can’t give me anymore through my whole body or whatever. No more chemo at all. They have already found a few more lesions on my lungs, and they are not sure what they are yet. They are pretty sure they might be cancer. . . . You can’t do anything about it, so you just make do. . . . You can’t stop it. There is nothing you can do. I just say ‘oh well, I can’t do anything about it.’ I just go on.

—Source: “Enough”; excerpt 6
(Ryan, 20-years-old, has had this rare form of bone cancer twice in the leg that was amputated, once in the lungs, and is currently awaiting tests to determine if new lesions found in the lungs are also cancer)

In sum, I was surprised by the notion of acceptance and determination from all of the ill respondents who were of the age to know what was happening to their bodies, and the seriousness of their medical prognoses. I was surprised by the absence of *despair talk* about their situations and long-term futures in general.

³⁶ Note: Explanatory parenthetical references are provided only once per person quoted.

This is not to be confused by the periodic presence of what I define as *frustration talk*, e.g. not wanting to be viewed as being different from healthy people who do not need oxygen, who move faster, who do not need medical assistance, or who do not have to make so many visits to the hospital.

Frustrated? Yes. Despairing? No. Determined? Definitely.

The theme of *acceptance and determination* as significantly found in this study brings forward some primary, basic questions stemming from extant literature. As previously mentioned, Sprang and McNeil (1995) identify death as one of the most avoided topics in societal conversation. Thus the question surfaces: Why? Why are we as a society so afraid to even *talk* about death when we are physically healthy, when younger people who are critically ill have accepted their situations and are willing to talk about them in direct and almost matter-of-fact ways?

One of my underlying assumptions here relates back to the many individuals who expressed disdain as to why I would ever be interested in this research in the first place. Several persons commented specifically that they would be afraid to tackle such research because some of the young people might not realize they were possibly going to die. This research suggests, however, that such is not the case. In all instances of my interviews, the young people were fully aware that their lives might indeed be shortened because of the progression of their diseases. As such, as a result of this study I suggest that if the very people

who are living the unthinkable, the children, have already accepted the possibilities of their own deaths and at very young ages already made significant determinations as to how they want to live the rest of their lives, should we not at least begin to talk about death in greater frequency?

One of the research questions from this study asks: “What can we learn from hearing the stories of children and young people who are seriously ill?” One of the fundamental answers should be that we should learn to take our cue from those individuals at very young ages with the greatest potential for loss. This would mean all of us would begin talking honestly about death as an inevitable part of living, including with those who are presently dying—no matter their ages.

While listening to the young people share their stories, frequently a visual image came to my mind of children skiing. Seldom have I encountered a tentative child skier who has been on the slopes for more than a few minutes. Instead, they take a brief lesson, and then seemingly become experts who race down the slopes like daredevils, sans poles or fear, leaving adults long behind.

The analogy of skiing children to children with life-threatening illnesses is not one of time, but of conviction. So many of the stories I heard were told with the same resolute determination of a child skier. In answering all of the questions, the general response seemed to say: “This is just what I have to do to get to the bottom of the hill, or to live my life despite having a life-threatening illness for as long as I can go.”

Fear is an important and relevant conceptualization in thinking about the child skier who zooms down the hill. Is he or she afraid? One would suggest *not* given the speed and determination with which the hill is tackled by many young skiers whom I've witnessed. They seem to know no fear.

Yet extant literature suggests a “universal acceptance” of denial of impending death by adolescents that evolves over time (Freyer, 2004, p. 396). This notion is contrary to the findings of this study.

While fear may indeed be a part of the equation, the stories I heard suggest that fear exists less on the part of the children than in those around them, e.g., their parents or other adults who may be afraid of making the situation worse, or recognizing that the situation even exists in the first place.

The content and tenor of all the stories I heard suggest there is no need for the voices of seriously ill or dying children to be silent. We need not be afraid to talk with these individuals, or shelter them from their medical realities. In fact, if and when we try to do so, we are not fooling them, only ourselves. Not only do they know the score, they seem to accept it, and are determined to chart the remaining course of their lives, leaving the rest of us far behind wringing our hands with worry over what to do or say.

In fact, those very individuals who are chronologically the youngest and physically the frailest, and with the most to lose, seem to be the most aware and open. They are extremely cognizant as to the nature of their illnesses, their future

likelihood of relapsing, the emotional well-being of their parents, their future in terms of how they want to spend their time, and the like. They are also willing to be open in graphic detail about their anger, fears, dark moments, and disappointments.

All but 2 of the young people who were asked to give interviews consented. Most of the respondents were vocal, and willing to talk in detail, although some were recognizably more reticent in providing elaborate and lengthy responses. At a minimum we should learn from their individual stories, and take their verbal cues of acceptance and determination as permission to enter the conversation with honesty and directness.

Communication / ‘Straight Talk’

Scholarship suggests that productive communication is critically important during this time in peoples’ lives. Effective communication is arguably the most important component of caring for the dying because it presupposes an attitude of respect, candor, and collaboration that should begin early in the course of any child or adolescent diagnosed with a potentially fatal or chronic illness (Freyer, 2004).

The notion of communication being critically important from the initial moments of a disease progression was reaffirmed repeatedly across the interviews without exception. In sum, patients and family members alike remember in

specific detail as to *what*, *when*, and *how* they were first told about the diagnoses of life-threatening illnesses. They remember if their physicians were terse in delivering the news of the illnesses, if the physicians told the parents first and then the children, if the information was conveyed in a sad or hopeful way, if the conversations were brief or lengthy with explanatory details, and so forth. Even the young people who were most reticent about providing particular details in response to certain questions about the future were more than willing to think back to the first time they heard they were sick, and what those messages conveyed to them.

All but 1 of the young people interviewed for this study preferred what they called *straight talk* in conversing about their illnesses regardless of their audience. The only respondent who expressed some form of hesitation on the theme of straight talk in general created a demarcation in the use of straightforward words, like *death* and *die*, as opposed to being straightforward in describing the situation at hand by using facts and detailed information.

One individual made fun of the notion of *sugar-coating* the situation in delivering medical news. Several respondents took great delight in conveying some of the many euphemisms used by those around them in place of the word *death*. They included *pushing up daisies*, *kicking the bucket*, *buying the farm*, *crossing the river*, and *taking a dirt nap*. More of the ill children and young people used the word *death* than did their healthy family members. One family

expressed a strong preference for *smart, detailed talk* as opposed to *simplistic talk*, e.g. a notion of a *thumbs up/thumbs down* response without benefit of additional detailed explanatory information.

Specific words are important and have negative and positive connotations. The word *remission* is the most favored. No one talks of a *cure*. Words like *quality of life, reoccurrence, came back, found something there, scans, new medications*, and *seizures* are difficult to hear. For the younger children (in this case ages 5 and 6), metaphoric words and phrases are important where stomach cancer becomes *little rocks in your stomach* and intravenous ports and their bandages are respectively called *choo-choo trains* and *train stations*.

Demarcations between past and present tense are of critical importance given the connotations they suggest. Some examples follow:

Actually Marcus [the ill child] doesn't have leukemia. He's in remission. Well, he's still on treatment, so it's kind of a personal choice on words—ones that we think are important, and we certainly emphasize with him. He probably went into remission on day seven of treatment, which most kids with leukemia do. But they still think that on a molecular level, he still might have leukemia, so they continue to treat him for about 3 years. But the clinical definition of remission most kids reach in a month."

—Source: "Intellectual Capital"; excerpt 7
(Parent of Marcus, 5-years-old, who is ending
his first full year of remission from leukemia
following a bone marrow transplantation)

Delivery is also critical. These young people are attuned to not only *what* is being said, but also *how* and *where*. *Pauses* and sentences or phrases that start with *uh* signify bad news. Parents being asked to step outside their child or young person's room signals the delivery of bad news. Telephone calls usually convey more routine information, unless the patient is being asked to come to the hospital right away.

Several of the young people spoke extensively about the value of *realistic talk* as opposed to *optimistic talk*, e.g., being practical in what may or may not happen, as opposed to creating a positive picture of the future. Regardless of the particular type of talk being discussed, everyone in the interview population, children, young people, parents, siblings, and healthcare providers alike, pointed to communication as a critical variable.

Below are a few evidences of the preferential for *straight talk*, generically defined based on the stories I heard as *calling things as they really are*:

You know how people are like, *Stay up*, saying that it is going to be all right? I always found it so corny. And now that I'm in the position [of being ill], it sounds even more corny. I don't like it when they [other people] tell me what they think, and they tell me what they think like they know what is going to happen.

—Source: "Authenticity"; excerpt 8
(Eduardo, 18-years-old, relapsed 2 months
before the interview and was in the hospital
because of spiking temperatures)

They [the medical staff] ask me first if I want them to tell me straight out. [He says that he does].

—Source: “Blistered”; excerpt 9
(Oscar, 15-years-old, has had leukemia
for the last 10 years and is now
facing brain cancer)

Well, now, I think there is no other way [than straightforward] to tell you that you have cancer because I mean, because you think at the time, *Oh gee, 12-years-old, real harsh, could you tell me in a nicer way?* How well or nice can it be told? ‘Gee, hee hee, you’ve got cancer?’ If you have it [cancer] there is nothing else they can do. Like, you’re paralyzed, what do you do, you go to the doctor, ‘Gee doc, I’m paralyzed, what do you got for me?’ ‘Why don’t you take this wheelchair and roll your ass around town?’ . . . I mean, what the hell? If you just got shit, shit, there is nothing else. There is nothing else you can do.

—Source: “Good News, Mijito! What the Hell!”; excerpt 10
(Arthur, 16-years-old, has been a leukemia patient
for 3 years, having had cancer in his blood,
spine, and brain, presently in remission)

The theme of *straight talk preferred* brings to mind important findings advanced by Miller and Knapp (1986) relating to various avoidance strategies used in lieu of talking with someone who is known to be dying. One of those strategies, as mentioned previously, relates to *being upbeat*.

Why? Why do we feel the need to consistently be upbeat if the very people who are ill prefer straight talk? Again I suggest we should take our cue from those who are at the heart of the matter, and proceed accordingly. If the

seriously ill children and young people have the wisdom and strength to talk about their own situations with resolve and candor, should we not at least question our own need to be *upbeat* as a way to dance around the topic of death?

With that said, one of the respondents distinguished straight talk from what might be perceived as *cruel* or *beaten* talk, suggesting that talk at this particular time in peoples' lives should be tailored to the recipients' preferences. This particular respondent preferred what might be called *informative talk* in lieu of straight talk:

She's kind of straightforward [referring to her physician]. She said if I had gotten pneumonia in December, if I can get one [referring to a lung transplant], then I would be OK, maybe. And if I didn't [get a new lung], then I was just going to die. I don't know, sometimes it kind of hurts. I come out of the office crying a lot. I think about it [death]—that I will be gone. Perhaps they [physicians] and others might seem to be a little more informative, and don't say like, say it straightforward, just tell them what can happen if you do or don't . . . just use a little bit more sensitive words than *die* or *pass on*.

(Source: "Quiet Considerations"; excerpt 11
(Fran, 17-years-old, a leukemia patient in remission who is now battling a series of secondary medical problems such as diminished lung capacity, asthma, and epilepsy, and is perhaps facing lung transplantation and brain surgery)

Regardless of whether the words are perceived as sensitive, straightforward, honest, euphemistic, or whatever, communicating is important to children and young people with advanced illnesses, and it varies by respondent, although

straight talk was significantly preferred. In sum, the young people interviewed for this study consistently expressed a desire to be told accurate and authentic information about their medical situations in a direct manner. In fact, they poked fun at what they perceived to be peoples' well-meaning yet stupid attempts to do otherwise.

Unnecessary and Undesired External Sense-making

Dervin (1989) points to the value of listening to members of an audience in an effort to better determine how individuals make sense of their everyday worlds and how they see their situations, past, present, and future. She also argues that sense-making rests on a premise of *discontinuity*, in which gaps naturally occur in all facets of our lives for which we create bridges to fill in the blanks, both cognitively, i.e., by constructing them in our heads, and physically, i.e., through coping with illness.

The theoretical conceptualizations of sense-making strategies and the constant need for filling in the gaps are important ones in the context of this study. First, one of the research questions upon which the study was initially predicated relates to how ill children and young people were making sense of their lives at this time.

The stories I heard suggest numerous different strategies both micro- and macro- in conceptualizations. These include *coping strategies*, such as developing

a new or maintaining an already-existent close relationship with God that includes prayer and meditation; *diversion strategies*, such as preoccupying your mind away from the situation at hand by playing computer games; and *intellectual strategies*, such as collecting and analyzing the most-recent data relative to the respective illness being experienced.

Numerous other general strategies existed such as being humorous or flippant about the disease, attending support group sessions, journaling, spending time on various charitable events relating to specific diseases, and reaching out to those involved in pastoral care.

Beyond listing out various coping strategies, there is no simple answer, however, to the question of how these children and young people who happen to be ill, and their family members, are assessing their own personal reality. Part of the answer relates back to the notion of being resolved to what is going on in their everyday lives. Most of the young people have told me in their own words that the journey of sense-making is circular and co-constructed: that *simply* by going through the motions of their everyday lives, they have been able to make sense of their everyday lives, as hard or big as the obstacles may have been.

Dervin (1989) also speaks to a sense-making triangle conceptualized as (1) how respondents see their situation; (2) what gaps respondents have to face or bridge; and (3) in what ways respondents see the bridges they have made as helpful for filling in those gaps. My purpose in mentioning the sense-making

triangle is to use it as a way of emphasizing the third theme found in the data: *unnecessary and undesired external sense-making*.

In short, while sense-making as a whole may be important to the ill children and young people regardless of how it is constructed, they are not at all interested in *other people doing it for them*. This theme is not to be confused with respondents' desire to obtain information from medical personnel on the status of their respective illnesses, as a form of physical bridging for coping purposes.

However, from a cognitive and emotional standpoint many of the young people expressed strong feelings of being personally and brutally offended by albeit well-intentioned outsiders who try and make sense of their situations by attempting to "sew up the loose ends" for them. In fact, in several interviews, the young people seemed angrier about this form of external sense-making than they did about being ill in the first place.

For example, one 16-year-old respondent and his mother had the following tense exchange during their interview:

Son:	And some of them [outsiders] try to give me advice but they don't even make sense. [They say]: "Oh well, that sucks." It's like, <i>What the hell are you talking about, are you stoned?</i>
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He goes on to explain that people often try and help him make sense of things by saying "things happen for a reason."

Son: People who don't really think, say that. Someone who thinks that quote is good . . .

His mother: *[interrupting him]* Sometimes I say that quote.

Son: No, that's stupid! *[His mother tells him again that sometimes she says that. He turns to her.]* Everything happens for a reason? *[The room then goes quiet between the mother and son.]*

—Source: “Good News, Mijito! What The Hell!”; excerpt 12

Additional evidences are found throughout the data as to this definite and intense desire not to have others make sense of the young peoples' situations for them:

I've gone through a lot of rough stuff in my life, the leukemia, a bunch of other stuff, you know, I've had a pretty rough life. And you know, everybody says that *Oh Heaven is the perfect place, it's paradise*, and this and that. That's probably true, but to me, it's not. I don't think that it's the perfect place. Just because of the fact that, it may be the perfect place in the end, but to me, even though I have been through so much, this is the perfect place for me. I love my family; I love my environment; I love the people around me. Who's to tell you what those people [the people who wrote the Bible] were on back then. They were on acid or something.

Yeah, there's this guy, he's in the sky, I've seen Him. . . . They can't let everybody in [to Heaven], so there's got to be some [in Hell]. Everybody always tells me, all you've got to do is ask for forgiveness for any bad things you've ever done, and you'll get right in. If it were that easy, Hell would go out of business. The devil would get out and become an angel again.

—Source: “Unfiltered Harry”; excerpt 13

I'm not real optimistic. I'm pessimistic. I focus on the negative. Yeah, I've always been like that. . . . You know how people tell you: “You are going to be all right. God has to know—you don't

really know what is going to happen to you. . . .” I don’t like it when they tell me what they think, and they tell me what they think like they know what is going to happen. And they tell you that you are going to be all right.

—Source: “Authenticity”; excerpt 14

Isolation

Kalish (1976) states a *social death* occurs in many instances long before an individual dies, during which time people isolate themselves from the person who is known to be ill or dying. Several of the young people confirmed this notion by talking about feeling alone or isolated as reflected in the stories. One respondent had the following to say:

I think they [outside people] keep their distance, because my mom is like that. She is afraid to tell me stuff sometimes, because she is afraid of saying the wrong things, or she knows she can’t do anything about it, except take me to the doctors to try to get medicine.

—Source: “Quiet Considerations”; excerpt 15

Silverman (2000) argues in favor of the development of a vocabulary for talking with each other and dying children given the shadow that hangs over everyone during such challenging times. In thinking about the notions of sense-making, social deaths, and the need for a better vocabulary to use during these times, again I suggest we listen to the children.

Specifically I believe the stories tell us 5 key things within the context of sense-making and isolation: (1) There is little reason to isolate ourselves from dying or seriously ill youngsters, given that many of their situations cannot get much worse. (2) Facing advanced illnesses or dying when you are young makes little if any sense in the first place. (3) The ill young people themselves will do the bulk of their own sense-making. (4) Healthy people are often offensive when they try and make sense of things for people who are ill or dying. (5) There needs to be a better vocabulary or way of communicating during this unique time to minimize occurrences of isolation and offensiveness.

Spiritual Talk

All but 1 of the collective interviews resulted in extensive spiritual talk, particularly about God or a higher being beyond that which is on this physical plane. Some of the young people were angry at or disappointed in God specifically because of the situations they were facing. From a completely different vantage point, 1 respondent saw himself as a Christian goodwill ambassador anointed by God specifically because of his intense desire to leave a legacy behind by ministering to others while on earth. In so doing, he, and his mother, had anointed himself *minister*.

Many of the young people questioned the existence of a God or a higher being of any kind. Such questions stemmed primarily from the reality that their

prayers for better health were not being recognized, or the repeated suggestion that a loving God would not allow young people to die. One respondent specifically questioned the reality that some people who are very kind are allowed to die, while others less worthy, like people who commit crimes, live.

Spiritual talk was also significant in a majority of parents, most especially in terms of asking for help and comfort in getting through the ordeals currently being experienced. Two of the family members talked with their children in terms of who would be waiting for them *on the other side* after they died. None of the parents expressed disdain or hate for anyone in particular, such as God or a spiritual force for the situation currently being experienced by their children.

None of the children and young people themselves expressed the notion that whenever they were to die, they would then be buried or cremated, and that nothing else would happen. Instead, while ill children and young people may be resolved to their literal situations at hand, all but 1 of them were thinking and wondering in a more spiritual way about what was going to happen to them next.

The young people and children in this study are frequently framing their spiritual talk in terms of thinking and talking about Heaven and to a lesser extent, Hell. The notion of a Heaven was comforting to many. The possibility of Hell was disconcerting to a few.

Several examples from the transcripts follow:

Yeah, even though I may look like I'm playing my [computer or video games] or I'm doing something else, I'm talking to God

actually. That's my time alone when I'm playing my games. I just talk to Him in the mornings when I'm just there. . . . Well, there's some stuff coming in the future. Next year I don't know the whole story. Only God knows what's in store for me next year. Yeah, there are quite a few things coming in the future—probably this month or the next. It will be quite a few weeks from now. I'm just praying about it.

—Source: “Minister Mike Foretells”; excerpt 16
(Mike, 12-years-old, is a long-time Spinal Muscular Atrophy patient who died several months after the interview)

Again, this is a great reminder that there are no guarantees regarding our future on this planet, and that applies to all of us. Although we know our ultimate destination, we do not know how or when we will be ushered from this life to the next, or how much pleasure we will enjoy or suffering we will endure until that time. We are grateful for today, and grateful for the guarantee of life eternal in Heaven.

—Source: “Praising Life: The Last Chapter”; excerpt 17
(background source³⁷)

Just be patient, and let it [life] play out. I don't want to rush it. Because it might not be what I want it to be.

—Source: “Leonzo's Lead”; excerpt 18
(Leonzo, 18-years-old, is a 2-year leukemia patient who had relapsed 2 months before the interview)

[I pray] just for health.

³⁷ Background source was quoted from the Patrick Ede family web site; www.caringbridge.org/tx/patricketede, used with permission.

—Source: “It Happens”; excerpt 19
(Trudy, 15-years-old, is a Cystic Fibrosis patient diagnosed
at 8 weeks old who has undergone a lung transplantation)

My dad has relied more on faith. He’ll just pray to God, and I tell him that I don’t really have that faith right now. And he says to keep doing it. . . . God is not listening. I’m Catholic. I used to be really in to that, but lately I don’t have any faith anymore. I’m starting to give up on stuff like that, because I have prayed and prayed that I hope I get better soon. Then it seems like every year, something else goes wrong. I feel like He’s not listening or something. I’m starting to really give up on faith now. I thought of that [Satanism], but after I read the book (*Jay’s Journal*),³⁸ I knew it wasn’t a good idea.

—Source: “Quiet Considerations”; excerpt 20

I told her [the chaplain], I don’t seem to understand. I was like, you hear on the news about people robbing banks and stuff. They get shot 3 or 4 times in the head, and they still live, and get out of jail a year later. . . . And you’ve got the sweetest little boy I’ve ever met in my whole life [a younger cancer patient]—a 5-year-old boy named Lucas—sweetest little boy you’ll ever meet in your life. He is so sweet. And he just dies. You know what I mean? I just don’t think it’s fair.

—Source: “Unfiltered Harry”; excerpt 21
(Harry, a 20-year-old cancer patient, talking about
his 5-year-old friend whom he met
in the cancer hospital and who later died)

A parent: *[to a child]* [I] pray for the people who are helping you.
Give them knowledge and wisdom. That God may, you

³⁸ *Jay’s Journal*, as mentioned in the actual story, is a book about a young boy’s addiction to drugs and Satanism before his suicide at age 16.

know, that the hands may be His hands as far as the healing and the care.

—Source: “Blistered”; excerpt 22

A parent: *[to God]* I say my prayers: why does he have to keep going through this?

—Source: “Enough”; excerpt 23
(Parent of Ryan, 18-years-old, who has a rare bone cancer that metastasized in the lungs. Initially the leg was amputated and extensive chemotherapy was given; the family is now awaiting results on additional scans to indicate whether or not new lesions found in the lungs are cancerous. There is the possibility of the young person participating in new research clinical trials when he becomes an adult.)

[When I was] a lot more immature, I had that kind of attitude of, *God did it so I'm mad at Him*. It's like when you're little, you know, and your parents don't let you get something. Well, telling them something, getting rude with them is not going to help you any. You know what I mean? So you might as well be nice. Now I've gotten more into praying instead of being mad. Usually I'm not a selfish person at all, like if you knew me, you would know that. So the [usual] way I pray is like, to let me be healthy and to keep me around. But if He doesn't, I know there's a reason that I probably don't know but that I will find out when I get up there, wherever I'm going. I'll probably find it out. But I just tell them that, you know, if He does end up taking me, just to make sure that my family is OK. . . . Yeah, show me [referring to Heaven]. Who can tell me, “Oh, I've been there, Heaven's the *coolest* place around, you know, it's *happening!*” Nobody can tell you that.

—Source: “Unfiltered Harry”; excerpt 24

[Parental report on behalf of a young child with stomach cancer who was too ill to be interviewed. The child used to say:] Do you

think He's [God] in my stomach? I think He drank my punch because I'm thirsty again. Well, he's probably thirsty. He could take a drink in my stomach, that's OK. . . . All these kids have cancer; are all of them going to die? What happens if the devil wins, mommy? [*Referring to coming back from Heaven to play a joke on a cousin*]: I'm going to go take out the cables when you are watching *Kim Possible*. Yeah, I'm going to take them all out, and you're not going to be able to see it. . . . Well, I don't want to go to Heaven right now. Maybe tomorrow.

—Source: "Waiting"; excerpt 25
(Mother of Marcelo, 6-years-old.
Marcelo died a month after the interview)

Client Control

Scholars suggest through the telling of stories we begin to gain personal and political power through our own individual and collective voices (Geist-Martin, Ray, & Sharf, 2003). Whether or not the respondents in this study gained individual power through the telling of their stories remains untested. However, a strong theme found in the data served as an extension of the notion of determination, and related specifically to individualized power through *control*.

With significant conviction, a majority of the ill young people expressed strong desire for greater control over their lives. They talked of control in terms of who made their healthcare decisions, what treatments were and were not performed on their bodies, and others.

They talked of wanting to control where they celebrated their birthdays and what goals they had for the future in terms of college, provided they were going to live that long. They especially talked of wanting to control how others saw them in terms of being perceived as *normal* individuals, not sick people who were forced to wear oxygen or transport in wheelchairs.

The ill respondents expressed dual frustration over wanting more control, and in losing what they already had. A few of the older respondents, e.g., age 18 and above, repeatedly talked of feeling sorry for the younger cancer babies and patients who were bound by parental control as opposed to individualized decision making.

In several cases respondents described instances in which they controlled the amount of information they released about their medical conditions in order to (1) protect their parents, and (2) better control the environments around them. At times the control issue created tension between the ill child or young person and his or her parents.

Some illustrative quotations follow:

You know what? This is my body. You are going to do things to *my* body. . . . So you speak to me!

—Source: “Minister Mike Foretells”; excerpt 27
(Mike, speaking at 11-years-old)

The disease needs me to start tonight on chemo? Well, the disease can wait until tomorrow. That doesn’t meet up with my schedule. I

don't feel like starting tonight. I'm not going to live my life depending on what I need to do to beat that disease. It's not going to work. Either the disease is going to work my way, or it is just not going to work, and that's not the way it was meant to be. I told him [the physician] that I wanted to go home and think about it. I was like, I don't even know if I want to go through this again.

—Source: “Unfiltered Harry”; excerpt 28
(Harry went home that night to count his blessings, spend time with family, and make a decision about starting treatment again given his relapse. He partied that night with friends and then started treatment again the next day.)

Yeah, I have done that a lot of the times [not told her parents she was feeling badly or about to have a seizure]. Sometimes, I guess, when I tell them it seems like they get mad at me, but they say they are mad at the illness. That's why they get upset. But I don't know. I know when I'm about to have a seizure. They want me to tell, but a lot of times I don't. I just go along with it.

—Source: “Quiet Considerations”; excerpt 29

You know, all the fun stuff that we take for granted, he never got a chance to do [referring to a young cancer patient who died at 5 years of age]. He never got a chance to just, make his own decisions. You know? You wake up on your day off or something and you are like, where am I going to go today, what am I going to do? Nobody's telling you what to do because you are not 5 years old. You just go about your day, wherever you want to go, you go. If you want to get in your car right now and drive to Canada, you'll do it, just because you want to. And he never got to drive a car. Have a girlfriend. Go to high school. Actually have a group of friends that he went out and had fun with. He never got to do nothing.

—Source: “Unfiltered Harry”; excerpt 30

Much of extant literature on end-of-life issues relates to who is in control when tough decisions have to be made in any healthcare situation, especially when the client is a child or young person. Bluebond-Langner (2003) and her colleagues at Rutgers University are presently undertaking a study titled *Decision Making for Children with Cancer When Cure Is Not Likely: Scope of the Problem and Recommendations for Clinical Practice*. Bluebond-Langner suggests that to date there have been no studies on how healthcare decisions are made for children with life-threatening or life-shortening illnesses from a social perspective that involves all participants.

Stories from my study showed young people wanting to maintain control of their lives through the good and bad times. They are smart in knowing the power of information to help them get where they want to be. They want to hear from and deal directly with their physicians and healthcare professionals. They are frustrated when they lose control, and often manipulate information and behavior to help them regain the situation.

Natural Alliances

Years ago Burton (1975) found that parents often feel compelled to evade their older children who ask questions about end-of-life issues. Based on evidence obtained in this study, things have changed over time to a large extent.

Many of the ill young people talk openly and freely with their parents about their illnesses. In some families the communication lines were clear and open. Many of the ill young people looked to family members for guidance, direction, and support. In other families, communication was severely strained, to the point of breaking down at times during the interviews.

Some parents actually looked to their children for support. One father and mother told me they were emotionally stronger when near their ill son because their son made them stronger (-Source: “Enough”). Parents shared experiences about talking to healthy siblings about the possibility of losing a brother or sister.

Figure 3.1 depicts the traditional circle of compassion and conversation for the ill children and young people in the sample set. In this figure the term “physicians” is used to refer to other members of the medical team as well.

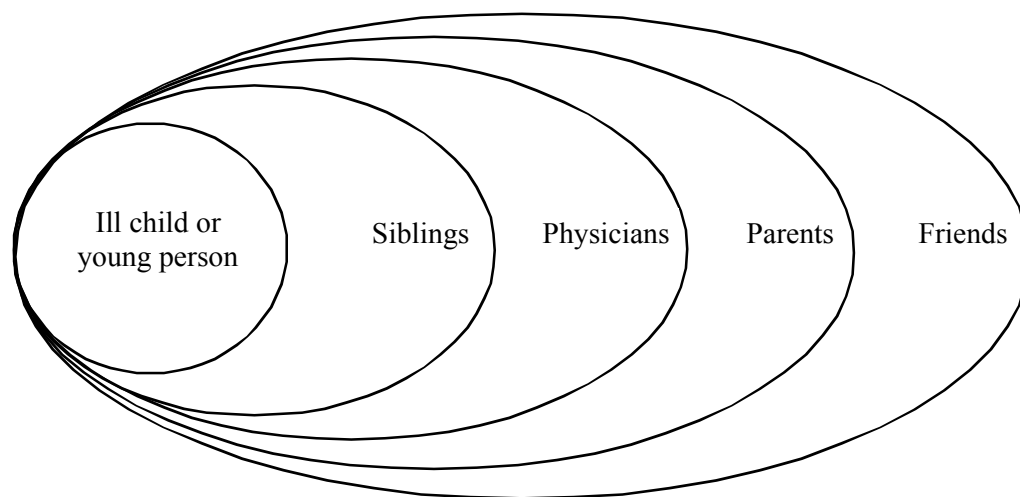


Figure 3.1. Conversational Flow from Dying/Ill Young People.

Kane, Hellsten, and Coldsmith (in press) argue healthcare providers must understand the multiple dimensions of children with cancer who suffer and the complex set of relationships within their natural, e.g., family and friends, and the clinical, e.g., paid medical, healthcare, and social, networks. Kane and colleagues affirm studies that assess perceptions of support in an effort to diminish the significant suffering experienced by children living with and dying from advanced cancer.

Relationships are critical. Based on this study, children with advanced or terminal illnesses were talking to their siblings and physicians first and foremost, then their parents, and then their friends. In one particular study, the respondent talked about being close to her sister because she was one of the few people who could maintain confidences, and who would take care of her when she became ill while out with friends. This scenario was mentioned despite what the ill sister said was an ongoing perception on the part of the healthy sister that she was being *deprived of attention* (-Source: “Quiet Considerations”).

In many cases, the healthy siblings became emotional confidants as well as physical saviors for the ill children and young people, having donated bone marrow to their ill siblings. Such scenarios frequently strengthened the communication bonds. One family told of the situation in which the only Christmas present the healthy brother wanted was to be selected as the bone marrow donor for his brother who had leukemia. “It’s Me! It’s Me! It’s Me!” the

healthy brother shouted over and over again while running through the house. When the bone marrow transplantation was over, the first thing the healthy brother asked when he awoke right before becoming ill was: “(Did) I help my brother? (-Source: “Praising Life: The Final Chapter”).

Secondary throughout all of the interviews are expressions of gratitude from the ill children and young people for their healthcare providers, especially physicians and nurses. Although at times they may wish the news being delivered by their medical staff were different in content or delivery style, ill young people are very close to those physicians and nurses and others who care for them. An example from the transcripts is offered:

I’ve been going there so long, I trust them. If Dr. Carter tells me there is nothing wrong, then there’s nothing wrong. If Ted [oncology nurse] tells me he thinks that I’m going to get cured, then that’s what I’m going to believe. They’ve just built up trust with me. You know, everybody down there [the cancer hospital] has. They’ve made it to where, as far as I know, they’ve never just lied to my face. They’ve sugar-coated stuff in the past like I said, but, that’s their job, they’re supposed to do that.

—Source: “Unfiltered Harry”; excerpt 31

The conceptualization of natural alliances within this context is two-fold. First, developing natural alliances with young people who are dying is a critical component for understanding and meeting the special needs of children who are seriously or critically ill. My argument is that we must align ourselves with children and young people if their voices are ever to be heard. Secondly, if

children's voices are ever to come to the forefront, we must not only hear directly from them through their stories, we must also understand with whom they are talking within their own natural alliances.

From this study, I suggest the most important core group of individuals surrounding ill children falls within a context of natural alliances as opposed to external therapists. What this means in sum is that children in this research sample who had advanced illnesses first talked with members of their own family about their illnesses, most specifically their siblings. Beyond siblings they interfaced most extensively with their physicians, parents, and friends in that order. Understanding this communication network will allow for the implementation of improved communication strategies to help lessen the distance between society and this important segment of the population during difficult times of transitions. An additional expansion as to the implications of the theme of natural alliances and its importance will be discussed in the final chapter.

Individuality

Riessman (1993) reminds us that neither nature nor the world tells stories, individuals do. The concluding theme offered here is to state an obvious finding from letting the stories speak for themselves: they are all different.

Some of the respondents themselves recognize the individuality of their situations. They are often hesitant to give advice or place judgment on how things

should be for others, in parallel fashion to the reality that they do not want external sense-making imposed on them or their lives. A case in point:

Question: Is there anything you would say to other children or young people with cancer or their parents?

Response: Me personally? No. Because you are going to feel the way you feel about it. And nobody can make you feel anything. . . . You don't know how other people feel. I mean, they can tell you, but at the end of the day you are still going to feel what you feel. So it doesn't really matter what anybody says.

—Source: “Authenticity”; excerpt 32
(Eduardo, 18-years-old, leukemia patient
who recently relapsed)

Each of the ill children and young people with whom I had the privilege of conversing, and their parents and healthcare providers, are just the same as everyone else in that they are all individually different in their stories. They see themselves as so individualized sometimes they do not want their story to be used to try and make sense of other peoples' lives.

Devers and Morton Robinson (2002, p. 245) point to the sensitivity of working with individuals specifically on the subject of death given that the “qualitative researcher must be exquisitely sensitive to the emotional responses of the participants.” From a researcher standpoint, I hope I have captured the individuality of each respondent's story while providing the thematic findings. The simple fact that these individuals were willing to give me some of their most

valuable time and talk so freely about the uncertain and rough parts of their lives
will always amaze me.

The stories are theirs to tell. The lessons are ours to ponder.

CHAPTER 4:

ENVISIONING AN APPLIED PERSPECTIVE

Within the hearts and minds of these unique stories from ill young people lives a host of applied communication strategies. Individually, the stories themselves represent the experiences of many brave hearts in terms of their own sense-making. Collectively, they offer a unique and first-hand glimpse into how we can better reach out to individuals who are seriously ill. They also represent significant opportunities to expand upon extant scholarship in the death and dying genre from an applied societal communicative perspective.

As I stated in the introductory chapter, this research was not designed to suggest a right or wrong way to die. Everyone does it differently. As an arguable extension, perhaps there is no right or wrong way to communicate with someone who is dying. Certainly there seems to be no cookie-cutter approach that works for all.

However, from this study's data come *preferred* ways for communicating with persons who are dying or seriously ill, including children and young people. In fact, if we will just listen closely to their stories, the youngsters themselves will tell us how to do it.

This final chapter offers several key applied strategies for improving communication with children and young people who are seriously or terminally ill. The strategies are gleaned from the stories themselves and the themes of the stories as discussed in the previous chapter. They are distinguished between individual interpersonal strategies and organizational strategies.

Interpersonal Strategies

One of the primary ways of thinking about preferred ways of communicating and interacting with children and adolescents who are critically ill begins with one-on-one relationships. Several interpersonal strategies are suggested within this context.

Show Up and Be Present

Most of the young people in the data sample told of experiences of being distanced by many others, including members of their immediate families. For many of the young people, their external hospital and hospice care team members had assumed the roles of surrogate family members. Healthcare professionals were often mentioned by the respondents in a context of friendship, such as being attendees at birthday events and playing sports games together. In one particular situation involving an older child, the person going with her to talk with a

physician about a lung transplant was not a parent or family member, but rather a member of the hospice care team.

By no means am I suggesting this type of social support is a bad phenomenon. Rather, it points to an interesting societal and familial reticence that may occur at times in staying close to those who are slipping away.

Distancing was not always external. During several of the interviews, I sensed the young people themselves were doing their own distancing from within their situations for a host of reasons. Extant literature suggests this is relatively common with individuals who are in serious healthcare situations or who may be dying.

The phenomenon of self-imposed isolation and withdrawal, which is also referred to as *social death*, has been observed in persons dying from AIDS (Barrett, 1995). Within the specific world of children ages 6 to 10, Spinetta, Rigler, and Karon (1973) found higher levels of anxiety in children with fatal illnesses (leukemia), including a perceived psychological distancing from those around them that was preferred by the children themselves.

However, a majority of the young people in general expressed an overarching perspective in the narratives that they wanted to be surrounded by those who love them. They wanted to communicate, as evidenced by their willingness to sit with a total stranger to tell their stories.

By and large the respondents were willing to give an extensive amounts of their time toward the interviews. In one particular case, an ill child and his mother were facing a 3-hour drive home and the evening was late; yet they continued to talk extensively about their own experiences. Very little prompting was required in most of the interviews. In fact, in many instances involving group interviews, all parties seemed anxious to talk, which often resulted in individuals interrupting or talking over one another.

In sum, the individuals I interviewed wanted me to listen to their stories in a parallel fashion to how they suggested people should go about being a part of their lives: by simply nodding and listening and *being there* for them. They expressed a consistent desire to simply want to go to their favorite movies or to restaurants with friends beyond their medical caregivers who clinically understood their situations. They said they wanted to interact with individuals beyond hospice care team members.³⁹

Within the worlds of these children and young people, there are times when things cannot get much worse, short of unbearable human suffering or death. That is what the young people said to me. Thus, there is no need for us as a

³⁹ Note: In no way am I advocating in favor of minimizing the need for healthcare intervention medically, psychologically, and spiritually. In fact, in many instances the young people spoke with deep affinity and love for their healthcare workers. My point is that while such professionals are delivering care on a variety of perspectives, they are also frequently assuming the roles of surrogate family members given the periodic distancing of actual friends and family.

society to distance ourselves because we are afraid we will say or do the wrong thing. Recognizing that adults can and sometimes do make things worse by being controlling, dogmatic, paternalistic, or the like, the stories suggest a reality in which the worst of the worst has already been experienced.

Listen and Hear

During data collection I spent a great deal of time simply listening to the ill children. Generally I would begin each interview with a broad, open-ended question along the lines of “Tell me about your life.” In many cases, the young people would still be talking on their own volition for quite some time into the interview. Thus I assumed the role of listener rather than interviewer in many of the dialogues.

This was not always the case, however. In several of the interviews, there was greater hesitation on the part of the young people in responding, especially when the parent(s) remained in the room—despite my indicating a preference for doing separate interviews. Nonetheless, even in these *reticence interviews* there were rich data to be gained, especially when I continued to assume the role of a *listener*, as opposed to a *talker* trying to fill awkward pauses (and there were many) with idle conversation.

Goldman-Eisler (1968) suggests pauses occur in a variety of forms, and are unevenly distributed throughout the flow of conversation. Knapp and Hall

(1997) identify pauses as a form of nonverbal behavior frequently used to regulate verbal behavior.

Prior to this study, I did not have a full appreciation for such insights into the value of what is *not* said just as much as what is said through listening and not talking. As uncomfortable as long pauses may be from my own personal vantage point, this study provided me with a new perspective on how much data and insight can be gained by simply being quiet.

The same holds true for communication in general beyond a research perspective. Nearly all of the young people simply wanted to tell their stories, and to have someone listen. Some may have seemed hesitant at first, but many of them completely took charge of the interview in mid-stream. Others who talked much less gave great insight into their situations and perspectives as a result of pauses in the conversation. From an applied perspective, the stories themselves point to the value in not only *showing up*—but also to the strategy of *listening more* and talking less.

Accept a Premise of Uncertainty

Seeking to reduce the unknown through increased communication has always been an important theoretical framework in the communication field. The goal is one that should be ever-present in peoples' minds.

With that said, however, the children and young people reminded me repeatedly through the telling of their stories that uncertainties abound in their

worlds amidst known and structured medical routines. They know to get up in the mornings and head to clinics for more chemotherapy, depending on the progression of their disease. Some of the teenagers and young adults drive themselves, and have done so for extended periods of time. Some of the parents talked of infants who were dropped off at the cancer hospital for more rounds of chemotherapy. Much of their days are known. What they obviously do not know is what those treatment therapies will do for them on a long-term basis.

For some of the young people, the uncertainties are logistical in nature, e.g., they were not certain as to when and where their disease would take them. For others, the questioning was more spiritual and corporeal in nature, e.g., is there a Heaven or a Hell or a God?

In deference to individuals' religious beliefs, there are no concrete and certain answers to such questions. No one has died and come back to tell us what it is like, near-death experiences aside. No one can say with personal and quantifiable, photographic proof that there is a Heaven or a Hell or a higher being. No one can tell a child or a young person that dying will or will not hurt. No one can honestly say from an experiential perspective there is no reason to be afraid.

The young people with whom I spoke were resolved to their situations largely because they recognized that most of their lives now center around a final unknown outcome that might be close at hand on any given day. Over time, these young people have become resolved to the certainty of uncertainty.

This is not to say they accepted everything—far from it. Questions were the order of the day. Yet finding final answers and reducing the uncertainty was not the expected outcome in the minds of those who were very ill. In my opinion the young people asked questions more to *talk through* issues than to gain final resolute answers that no one had to offer. Thus I believe the stories point to an important strategy for all of us who are healthy: accept a premise of foundational uncertainty that will not go away despite the best of intentions or the most perfect of interactions.

Leave the Sense-Making to the Young People

Upon reflection about the interviews and a re-reading of the transcripts, I have become personally convinced that while society was effectively distancing itself from the world of dying children, they were busy figuring things out on their own. The resolve and conviction of these individuals who have experienced horrible illnesses at such young ages will forever amaze me in terms of their personal abilities and strength to make sense and order out of their own lives with minimal help from others.

In fact, one of the key ways we may be able to communicate better with and hear more from young people who are critically ill is to *let them tell us* what they think about their lives and what may happen to them, as opposed to us telling them how to make sense of situations we have never experienced ourselves. There is a sense from listening to the stories that the uncertainty inherent in this type of

situation is much more tolerable to the ill young people than society, e.g., healthy adults.

By and large, the young people talked specifically about periodically being *frustrated* with their same-age friends for being insensitive and curt in response to the medical situation, e.g., “That sucks,” or “It happens.” Beyond that, however, what seems to infuriate the ill young people even more are the sweeping futuristic comments they hear from healthy adults who try to make sense of everything for them. This strategy gives rise to perspectives for the use of language and phraseology boundaries.

Consider Specific Language

Talking with people who are seriously ill or dying is important as the literature and common sense suggests. We cannot always listen; nor do the ill young people want us to remain consistently silent while they talk. In actuality, they seem genuinely hungry for the give and take of dialogue on a variety of fronts.

With that said, many of the interviewees told me of specific language phrases that are troublesome and offensive to them. They serve only to make bad situations worse, as I was told repeatedly. While well-intentioned individuals may have a genuine desire to make things better by imposing their own sense-making on those who are ill, the young people themselves want to make sense of their own situations.

In the world of hospice and palliative care for dying individuals, the usual and customarily stated operational goal is to adequately meet the *physical, psychological, social, and spiritual needs* of a patient. Where does communication fit into that goal?

Obviously we must try and communicate if we are to accomplish that objective. Yet should not communication be a stand-alone area of emphasis in serving those whose lives may be shortened because of illnesses?

My suggested strategy here is that detailed consideration be given on how *best* to talk with those who are living with advanced and terminal illnesses. In the Committee on Palliative and End-of-Life Care report titled *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families* (2003), consideration is given to the physical, emotional and psychological, spiritual, and practical dimensions of care. Perhaps consideration should also be given to the development of a *language of rhetorical care*. In so doing we should ask those who are the most ill to help us formulate such a language.

Several of the young people whom I interviewed began that process by naming specific phrases or words that are offensive. Those words and phrases are listed in Table 4.1 along with some alternative, more-preferred considerations based on phrases heard during the interviews and those I have created and added to the list.

In thinking about this conceptualization of a language of rhetorical care for those with advanced illness, important emphasis should be given to the notion of context. Bateson (1978) suggests context gives meaning to words and actions. Granted, some young people might not agree with the offensiveness of phrases such as those offered here given their upbringings, surroundings, parental involvement, age, particular medical situation, degree of religiosity, and so on. For some, these phrases may be neutral if not comforting.

Yet the point here is two-fold: (1) specific language matters to the young people whom I interviewed; and (2) language should carefully be considered when the situation warrants more than listening during this critical time in young peoples' lives.

Persons who want to communicate more effectively with persons who are seriously ill need to consider what words and phrases they use in specific regard to the needs of their audience at the time as opposed to their own personal beliefs. If the phrases contained in Table 4.1 offend a majority of the ill young people in this study, then why would we want to use those phrases in talking with them, even if we believe them to be true from our own personal perspectives?

With that said, however, one significant qualification is advanced: like any rhetorical strategy, a good one must be adapted to the audience. In some cases, a particular language phrase or strategy labeled below as offensive may actually become humorous and acceptable, if not comforting, depending on the person

who delivers the phrase and the relationship and history he or she has with the young person who is ill. As well, prescriptive language may at times be appropriate, and at other times, inappropriate, depending on context. In sum, shared personal experiences between those who are intimately involved in the communication interactions are the backdrop around which the language of rhetorical care is offered. The experiences inevitably create the contexts by which suggested strategies are adapted for specific audiences during this unique time in peoples' lives, children and adults alike.

Table 4.1. Language of Rhetorical Care—Suggested Phraseology

Language phrases found to be <i>offensive</i> when said by healthy individuals as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population	<i>Preferred</i> language phrases/behavioral strategies as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population
<p>“Everything happens for a reason.”</p>	<p>“I am very sorry this is happening.” —<i>or</i>— “You can always talk with me.” —<i>or</i>— “I’m always here whenever you need someone.”</p> <p><i>Note:</i> If you say this, mean it, and be there for the person. Follow whatever words you say with action, e.g., by staying close to the individual who is ill—otherwise do not say it.</p>

Table 4.1. Language of Rhetorical Care—Suggested Phraseology (cont.)

Language phrases found to be <i>offensive</i> when said by healthy individuals as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population	<i>Preferred</i> language phrases/behavioral strategies as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population
“‘You are going to be all right.’”	“‘I am here for you.’”
“‘This is God’s will.’”	“‘I’m sorry this happened.’” (Say nothing about <i>why</i> this happened.)
“‘Keep praying hard.’”	“‘Is there anything I can do for you?’”
“‘Heaven is the perfect place.’”	“‘What I know for certain is that I am here for you now.’” (Say nothing about where the ill person may or may not be going unless that person instigates the conversation. Instead just listen. Stay focused on the present, not the future.)
“‘One must not question things at this time.’”	“‘If I were in your shoes, I would have many questions too. I just wish I had all the answers for you. What I know for certain is that I am here to listen.’”

Table 4.1. Language of Rhetorical Care—Suggested Phraseology (cont.)

Language phrases found to be <i>offensive</i> when said by healthy individuals as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population	<i>Preferred</i> language phrases/behavioral strategies as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population
<p>“I know how you feel. When I was sick. . . .”</p>	<p>“I can only imagine how hard this must be, or how you must feel right now. Just know that I am here for you, and I will stay and listen or just be here for you if you do not want to talk right now.”</p> <p>(Avoid comparisons with your own personal past experiences.)</p>
<p>“Don’t worry.”</p>	<p>“If you are worried right now or concerned about things, I think that is absolutely understandable. Just know that you don’t have to worry alone. I am here for you.”</p>
<p>“Don’t dwell on things. Be happy. Let’s talk about something else.”</p>	<p>“Whatever you want to talk about or do today is exactly what I want to do as well.”</p>
<p>“You’ll feel better tomorrow. Right now, try and think of something else. Seen any good movies lately?”</p>	<p>“I’m here to listen and be supportive in whatever way that I can. However you feel right now is fine with me.”</p>
<p>“The books I’ve read say we should be. . . .”</p> <p>(e.g., focusing on the positive right now)</p>	<p>“To be perfectly honest, sometimes I’m not sure what to say, so please tell me if I say the wrong thing because I simply want to be here for you.”</p>

Table 4.1. Language of Rhetorical Care—Suggested Phraseology (cont.)

Language phrases found to be <i>offensive</i> when said by healthy individuals as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population	<i>Preferred</i> language phrases/behavioral strategies as based on responses from a majority of young persons with terminal/advanced illnesses in the sample population
“Are you OK? How’s it going?”	“Tell me, if you would like, what kind of a day you are having today. I would like to know.”
“Does it hurt?”	“Are you feeling uncomfortable? — <i>or</i> — “Is there something I can get you?”

Another word of clarification is offered as to the importance of who is doing the talking in terms of what language may or may not be offensive. For example, several of the ill pediatric respondents themselves used the phrases above that they also identified as *offensive language*. The overriding distinguishing factor in the determination of what was and was not offensive related to who was doing the talking.

For example, a couple of the respondents personally gained comfort and made better sense about their own situations from believing their illnesses were the result of God’s will. On the other hand, they were also offended by hearing that very sentiment as an assessment commentary about them from others who were not ill.

A second caveat is advanced relative to the notion of *being there*, given its predominance in the suggested phraseology. The conceptualization offered here is that the person who says he or she will be there for the ill person is referring to self-action as opposed to any spiritual action, e.g., that God will be there.

The strategy of language consideration can be extended into the organizational realm in terms of additional training in the area of death and dying and serious illness communication. Several additional strategies are offered from an organizational perspective.

Organizational Strategies

Organizational strategies are offered in response to many of the systemic, programmatic suggestions heard during the interviews on the part of the young persons, family members, and their healthcare providers. The strategies were all suggested as ways to better respond to the needs of critically ill adolescents and their families.

Increase Physician Training in Communication

Several of the physician and healthcare respondents whom I interviewed talked extensively about needing additional training on end-of-life communication. The stories themselves repeatedly reinforced this need.

Extant literature speaks in great measure on the difficulty of delivering bad news, especially when children and young people are involved. As well, a few physicians spoke specifically of the need for additional qualitative training along the lines of narratives and stories as ways to understand the alliances and relationships upon which ill children rely during tough times.

One of the most telling observations from the stories related to the vivid memories from each of the ill adolescents and their family members as to the first time they were told of their diagnoses. As stated prior, respondents remember exactly where they were, who told them, what date they were told, what day of the week it was, and how they responded even though in some cases many years may have passed. Often the young people remembered very terse deliveries of initial diagnoses of malignancies. Thus, the initial communication on the part of the physicians remains critically important from listening to these individuals' stories.

Yet physicians are among the first to express hesitation in their skills sets relating to the communicative end of delivering care—especially in terminal situations. As the head of one pediatric clinic said to me, “There is no concerted effort to teach this [how to communicate effectively].” Another oncologist talked

about “missing the boat” in terms of looking only at quantitative data as opposed to relationships and communicative interactions, including storytelling.⁴⁰

Throughout the stories, the young people described numerous instances in which they have become very close to their physicians and especially their nurses, despite some of the terse ways in which bad news may have been delivered initially. They rely heavily on what the healthcare workers tell them, and in some cases, do not tell them. Additional training is warranted from a strategic perspective relating specifically to communication for physicians and their colleagues in the healthcare fields.

One way of thinking about this matter from an applied perspective is to argue that since protocols exist for diagnosing patients, filling out patient paperwork, making insurance claims, visiting patients during certain hours, and so on, should we not think extensively about how we talk with and hear from seriously ill children and young people? From an organizational standpoint, the data support a definite need for increased physician and healthcare provider sensitivity training in this area. Developing a rhetorical language of care as outlined above is warranted.

⁴⁰ Individual physicians making these exact comments are left unnamed, largely out of requests from the physicians themselves.

Create New Communicative Training Models

This study showed the seriously ill or dying young people talked mostly with their siblings. Thus, one of the key strategies from an organizational perspective is to reach out to brothers and sisters in a targeted effort to learn more about what is being said, how communication is being delivered, in what ways the relationships work together, what communication constraints exist, and other facets of research that will improve communication.

As with all research studies, there are new facts and data for additional research that immediately come to mind. In this case, additional intervention is warranted, starting with the siblings of seriously ill children to ascertain more about such relationships during these unique and changing periods of time. Other research areas deserve further study as outlined in the following section.

Future Considerations

Rubin and Rubin (1995) suggest research projects are successful if they generate a lot of new questions and possible answers not initially deemed important prior to data collection. Browning (1978) claims one rationale for using qualitative methods in grounded theory is the generous nature of the methodology

itself in allowing for new research areas not specifically considered prior to data collection.⁴¹

This study began with the following research questions:

- RQ1:** What can scholars and society alike learn from hearing the personal stories and narratives of dying children or children facing life-threatening illnesses?
- RQ2:** What meaning and sense-making are these individuals constructing during this time in their lives, and toward what ends?

True to form, responses to these inquiries point to other areas deserving of additional examination. One overarching area relates to meaning through self-emergence stemming from social interaction. Or in the context of this study: how dying or seriously ill young people perceive themselves, how others perceive them, and connections between the two that help form meaning. Two specific theoretical frameworks are advanced: (1) symbolic interactionism (SI); and (2) identity.

SI theory is a product of an intellectual movement known as symbolic interactionism. Mead (1934) and Blumer (1969) led the movement as based on

⁴¹ As extant scholarship affirms, qualitative research offers a generous methodological nature. However, within the confines of this particular research study, I recognize there could be limitations stemming from possible effects caused by the nature of the sample population. In essence, I was “talking to the talkers,” e.g. individuals who voluntarily consented to interviews without compensation, and who usually talked freely in response to questions. As well, although I am aware of only two young people who directly declined to be interviewed, additional consideration should be given as to the possibility of

the premise that the self emerges out of an individual's interaction with significant others. Within SI theory, communication plays a direct and key role in that it serves as the foundation upon which social interaction is based. In essence, the self emerges through social interaction stemming from communication.

Blumer (1969, p. 2) specifically conceptualized symbolic interactionism as 3 fundamental principles: “(1) people act toward things, including each other, on the basis of meanings they have for them; (2) these meanings are derived through social interaction with others; and (3) these meanings are managed and transformed through an interpretive process people use to make sense of and handle the objects that constitute their social worlds.” Symbolic interactionism, based on the teachings of Mead and Blumer as inspired by the writings of William James, John Dewey, and Charles Horton Cooley, combines with functionalism and conflict theory as the 3 key prongs of most sociology textbooks (Fine, 1993).

One of the more significant domains of symbolic interactionism is the creation of the self (Fine, 1993). Turner (1976, 1978) argues self identification and creation stem directly from cultural and social trends. Denzin (1987) says the self is generated through rhetoric and story telling by oneself. Tajfel (1981) advances the theoretical frame of social identity in which the self is defined by *identity badges*, such as nationality, gender, personality, religion, occupation, education, and others. These identity badges allow individuals to project their

unintentional and unknown selection bias on the part of physicians who referred

own inner selves within certain social and personal categories while enabling others to do the same as an ongoing form of classification.

Within the context of this particular study, I presented an applied language phraseology built on a notion of rhetorical care designed specifically for ill children assuming a caveat of audience adaptation. Based on the findings of this study, certain phrases and words can be used in ways to more effectively communicate with critically ill adolescents.

However, the situation justifies more than words and phrases. On a more theoretical foundation, future research should examine how critically ill young people come to define themselves and make meaning of their lives based on those definitions.

As well, consideration should be given as to how the self-identities of those closest to the ill young people are being shaped by such interactions. In essence, SI and social identity theory offer ways to think about self emergence on the part of children and young people who are ill, and how that emergence has come about as a result of social interactions with peers, healthcare professionals, parents who may be in crises, and society in general. Again we return to the stories for validation, beginning with an initial observation.

What made me think initially about symbolic interactionism and identity formation was a brief conversation I had with one of the referring physicians in

patients to me.

Texas with whom I worked extensively on the project. Our conversation concerned the St. Jude Children's Research Hospital in Tennessee and its non-interest in this particular research study.

Despite having a reputation as the premier children's healthcare research institution in the country, St. Jude Children's Research Hospital representatives denied my request to interview any of their patients or family members. The request was denied despite my (1) being a personal donor to the institution; (2) being referred to the institution by a family member of a child who was still receiving services there; (3) willingness to complete whatever paperwork was mandated, including a third IRB proposal if necessary; and (4) ability to travel to and from Tennessee on my own time and expense at their convenience. No explanation was offered for the denial.⁴²

When I asked the Texas physicians with whom I ultimately worked on the study why they thought the premier children's research institution might not be interested, one person responded: "They sell hope there. They aren't interested in talking about the reality of children dying."⁴³

In no way am I trying to slight or question the long-standing solid reputation of St. Jude Hospital as a premier research healthcare facility. Yet the

⁴² Author's note: The specific justification offered here is not designed to castigate this particular healthcare institution, but rather give background evidence as to why the research request warranted approval, based on the author's bias.

⁴³ Name withheld by request.

notion of “selling hope” has stayed with me throughout the study. It raises a series of deeper theoretical issues beyond words and phrases in terms of how ill children’s identities might change as situational variables change such as where they receive their care, and the ways in which they interact socially with family members and healthcare providers from other facilities with different organizational cultures.

The stories themselves also spoke directly to a theoretical framework of symbolic interactionism and identity emergence in terms of how the children saw themselves, and wanted others to see them as well. Time and time again the young interviewees spoke of their intense desires to have their social interactions with those around them be a certain way.

They were adamant in wanting interactions to be based on straightforward and honest communication. They wanted to be treated the same as other healthy individuals their own age. They wanted to be talked *with*, instead of *down to*. They wanted to be treated as “people, not animals (-Source: “Minister Mike Foretells”). The notion here worthy of additional examination is a perceived disconnect in how the children see themselves, as compared with how others see them. In sum, the ill children and adolescents in this study did not define themselves in terms of their diseases, but instead through their social connections and relationships, spirituality, dependence, outlook, and the like. This is

contrasted with others who seemed to define them more in terms of their diseases and lifelong struggles.

The young people also spoke quite forcibly and in great detail about how they **did not** want their social interactions to be. They did not want to be kept at arm's length from those they loved simply because they were sick. They did not want to be patronized or shut out from key decision-making involving major healthcare issues or even routine activities of daily living. They did not want their diseases to drive the ways in which they connected with others.

Specific questions like the following deserve consideration:

Ill Children Looking At Themselves:

- what identity badges do children with incurable illnesses wear in our society?
- where do the badges come from?
- how are the badges created?
- do the badges change with age?
- do the badges change over time as the diseases progress?
- in what way do the badges help ill children define themselves?

Ill Children Looking At Others:

- in what way do the badges of ill children affect their social interactions with others?

- do ill children see themselves as marginalized in comparison to healthy children and, if so, in what way?
- in what way are the identities of ill children similar or different from others around them?
- to what extent, if any, is being sick a constant part of ill children's identities?

Others Looking At Ill Children:

- do healthy adults and children always think of ill children in relation to their illnesses?
- from a societal perspective can ill children ever be considered the same as healthy children as they repeatedly wished for throughout the stories?
- how do the self-identity badges of those closest to ill children define social transactions with them?
- are children with life-threatening illnesses always considered in terms of certain emotional contexts, e.g. as being sad to the point of being in complete denial of or immobilized by their illnesses?

Others Looking At Themselves In The Context Of Ill Children:

- to what extent does society project its own collective identities regarding death and dying onto ill children?

- do identity badges change within a family structure when a child becomes ill, and if so, in what way?
- in what way has society short-changed its understanding of pediatric death and dying by not listening closely to the voices of ill children?

Questions like these point to the need for expanded theoretical consideration involving SI, self-emergence, and identity within a frame of pediatric death and dying. Prospective research questions might include:

- RQ 3:** Following the identification of a life-threatening problem in young people, to what extent can the resulting communication patterns be anticipated and defined by symbolic interaction theory?
- RQ 4:** In what ways do seriously ill young people construct their self-identifies throughout the progression of their diseases?

One final area for future consideration needs to be mentioned. It relates specifically to public policy problems stemming from the myriad of complex issues surrounding healthcare in general, and more specifically death and dying.

The Committee on Palliative and End-of-Life Care (2003, p. 85) identified numerous struggles that should be addressed, including “trying to coordinate care that frequently takes place at multiple sites (e.g., specialized referral center, outpatient clinic, community hospital, home), a large and frequently changing array of healthcare professionals (e.g., generalist and specialist pediatricians,

nurses, social workers, child-life specialists, case managers), and differing criteria for insurance coverage of different services (e.g., in-patient care, home health services, hospice, psychosocial services, respite care, out-patient drugs and equipment).”

The stories included in this research project identified specific problems relating to financial issues, e.g. how families are able to pay the healthcare bills they constantly incur, understanding the regulatory requirements in order to receive Medicaid and other governmental assistance, the lack of outside organizations to share in the costs, the ease in obtaining accurate and understandable information on diseases, language barriers, the need for additional training, and the like. On a more global and public policy frame, several of the respondents, adolescents and healthcare providers alike called for additional policy intervention by national, state and local policy leaders relating to both programmatic and monetary issues associated with end-of-life care.

Conclusion

Carverhill (2002) suggests becoming a participant observer of people and their dying is a narrative all its own. Bartholome (1993, p. 31) offers the following in specifically defining respect for dying children. The commentary captures a good but limited starting point for further research in this area:

Respect for dying children involves a series of challenges for their parents and their healthcare providers. It means a willingness to acknowledge our limited capacity to rescue them or protect them from death. It demands that the healthcare providers accept the responsibility for identifying terminally ill children. It means a willingness to respond to their experiences and to be truthful and to assist them in developing their own understanding of the reality they face. It demands that we respect their capacity for autonomy by allowing them to participate actively in making decisions about appropriate care. And it means supporting them and their coping strategies as they attempt to maintain control over their lives to the end. It means, above all, a willingness and ability to trust that they can manage their own dying at least as well as *big people*.

In order for us to fully appreciate the infinite wisdom that comes from the mouths of babes, we must put them center stage at the best and worst times of their lives. We must acknowledge that respect and compassion for dying adolescents involves a series of challenges not only for their parents and healthcare providers, *but also* and *most especially* for the children and young people themselves who are rising to the occasion in their own individualized ways.

Many of the young people whom I interviewed were coping better than their parents. Their voices, and the voices of those they represent, deserve to be heard in conversations about life and death, as hard as that may be for all of us. From the youngest among us comes sage wisdom about unthinkable life events.

Kaufman (2000) suggests medical practice does not allow for a transition, a process, or a passage between life and death. Yet everyone dies. Perhaps now is the time to truly begin listening to what children and young people who are dying

or experiencing advanced illness have to say about an inescapable time in all our lives.

APPENDICES

APPENDIX A: AGENCY/ENTITY CONTACT LISTING

Following is a list of agencies and entities I contacted in my search for respondents for this study. The list is in alphabetical order; it is not exhaustive.

- Abbott
- Alzheimer's Association Coalition of Texas
- American Cancer Society
- Any Baby Can, Austin and San Antonio
- Austin Community College
- Baptist Life General Commission
- Brian's House, Dallas
- Cancer Together
- Candlelighters (Childhood Cancer Foundation)
- CASA (Court Appointed Special Advocates)
- Center for Attitudinal Healing
- Chemo Angels
- Childhood Hematology Oncology Associates, Denver
- Children's Hospital and Medical Center, Dallas
- Children's Hospital of Austin
- Christopher House, Austin

- Christus Santa Rosa Hospital, Department of Pediatric Palliative Care Center
- Coalition of Nurses in Advanced Practice
- Community Hospice of Texas
- Curing Kids
- Dr. Christine Eiser, Professor, University of Sheffield, author of *Children with Cancer: The Quality of Life*
- Dr. Martha Morse, Pediatric Pulmonary Specialist, San Antonio
- Family Voices, New Mexico and Louisiana
- First Descents, Vail
- First United Methodist Church, New Braunfels
- Galveston Safety Net
- Greater San Antonio Hospice Council
- Healing Alliance
- Heart of the Valley, San Benito
- Hope Hospice, New Braunfels
- Hospice Austin
- Hospice Brazos Valley
- Hospice of Guadalupe Valley Hospital, Seguin
- Hospice Victoria
- Houston Hospice
- Houston, Marek and Griffin, Victoria
- Jackson and Walker, Austin
- Johnson & Johnson
- Leukemia and Lymphoma Society
- Make-a-Wish
- Mariner Health Care, Inc.
- Medical City, Dallas
- Memorial Hermann Hospital, Houston
- Mental Health Association, Texas

- Methodist Hospital, San Antonio
- National Alliance for the Mentally Ill, Texas
- National Association of Social Workers, Texas Chapter
- National Institutes of Health
- Office of the Attorney General
- Omega Hospital, Brownsville
- Our Children's House at Baylor, Baylor Healthcare System
- Pfizer, Inc.
- Planet Cancer
- PPD, Austin
- Provident Hospice/St. Paul Hospice
- Sammy's House, Austin
- San Antonio Pediatric Pulmonary
- Scott and White Pediatric Hospital, Temple
- Seton Healthcare, Austin
- Skilled Healthcare, Inc.
- Specially for Children, Austin
- St. Jude Children's Research Hospital, Memphis
- Texans Care for Children
- Texas Association of Homes and Services for the Aging
- Texas Children's Hospital, Houston
- Texas Health Care Association
- Texas Institute for Health Policy Research
- Texas Non-Profit Hospice Alliance
- Texas Nurse Practitioners
- Texas Partnership for End-of-Life Care (presentation at November 14, 2003, Annual Membership Meeting, Houston)
- Texas Renal Coalition
- Texas Silver Haired Congress

- Texas Silver Haired Legislature
- Texas State University, San Marcos
- The Butterfly Program, Houston
- The George Mark House, Oakland
- The University of Texas at Austin, School of Nursing
- The University of Texas Health Science Center at San Antonio
- The University of Texas MD Anderson Cancer Center, Houston
- The Warm Place, Fort Worth
- Transplants for Children
- Trevor Romain, Author/Lecturer
- United Way of San Antonio
- United Way of the Brazos Valley
- United Way of the Texas Gulf Coast
- United Ways of Texas
- Various pediatricians throughout Texas
- Willford Hall Military Hospital, San Antonio
- Wonders and Worries

Appendix B: Newsletter Solicitation Copy

The following copy was inserted into statewide healthcare newsletters such as for the Texas Nurse Practitioners and the National Association of Social Workers – Texas Chapter.

Do you know of children and young persons ages 6-21 with life-threatening illnesses, and their parents, who might be willing to be interviewed in person by a student working on her dissertation from The University of Texas at Austin, Department of Communication Studies? If so, please contact Melody Chatelle, doctoral student, at 512/502-9545 (office); 512/502-9501 (home); or mchatell@onr.com. Collect calls welcomed. I am a certified *Hospice Austin* volunteer, and will be sensitive to the issues associated with categorizing these children. UT-Austin and the Institutional Review Board have approved the study. Participants' names will not be publicized. Will travel for interviews.

Appendix C: Data Collection Letter

Melody Chatelle, Doctoral Student
The University of Texas at Austin

512/502-9545 (office) 512/502-9501 (home)
512/922-4622 (cell) mchatell@onr.com (e-mail)

Fall 2003

Dear Parent(s):

Thank you for taking time out of your busy schedule to read this letter. I am conducting a study relating to the perspectives of children who are seriously ill. As such, I would like to hear the personal stories of children and young people and their parents concerning the situations they are experiencing.

In order to expand the body of knowledge about seriously ill children and thus be of help to other parents and children in the future, this research will be based on interviews with children, ages 6-21. These interviews will take place at convenient times and locations for individuals like you who might be willing to talk with me. Interviews:

- will last approximately one hour in length;
- will be tape recorded, but actual names will *not* be used in the final paper;
- will include initial interviews with children and parents together, and then separate interviews;
- will involve a few questions that I can show you in advance if you'd like; and
- can be stopped at any time during the process.

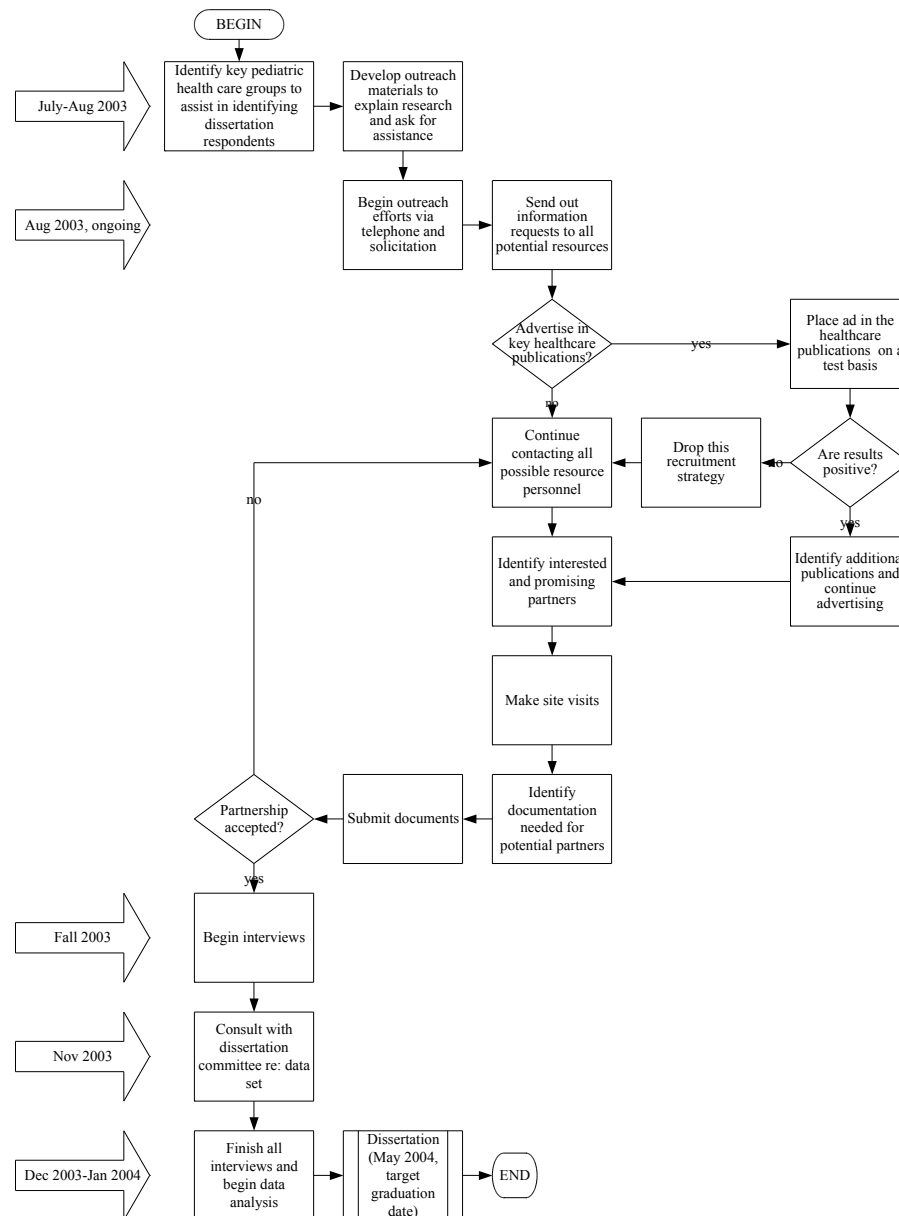
This study is for a doctoral dissertation at the University of Texas. Healthcare representatives have been kind enough to help me in my search for children and parents to interview by sharing this letter with you. Might I talk with you at your convenience with the hopes of possibly scheduling an initial interview?

At the top of this letter is my contact information. I would be very grateful for an opportunity to talk with you in person, via E-mail, or on the phone to answer any questions you may have about the possibility of my interviewing you and your child. Please feel free to call collect, if necessary. Many thanks in advance, and my sincerest best wishes to you and your family!

Yours very truly,
Melody Chatelle, student

Appendix D: Interview Decision Tree

Figure D.1. Interview Decision Tree.



Appendix E: Interview Protocol

Table E.1. Interview Protocol

<p>An initial conversation will be started on the part of the researcher to establish rapport and ease of conversation with the child and/or parent. Background information will be provided by the interviewer to the extent appropriate as to the overall purpose of the study, as well as the general interests of the researcher. Reaffirmation will be made regarding the confidential nature of the names of respondents in keeping with the requirements outlined by the Institutional Review Board (IRB), and constituted by Protected Health Information (PHI) subject to the Health Insurance Portability and Accountability Act (HIPAA) privacy rule.</p>	
Questions to Children/Young People:	Questions to Parents/Responsible Parties:
<ul style="list-style-type: none"> • Tell me about yourself and your life. • If you were a student who was interested in children and serious illnesses, what questions would you ask? • Is talking about your situation with others helpful or difficult or destructive? How do you talk about your illness, if you do? What words do you use? • With whom do you talk most about your illness? • Do you think about your future, and if so, when and in what ways? • Do you express your emotions during this time of your life, and if so, in what ways? 	<ul style="list-style-type: none"> • Would you tell me your personal story about living with your child's serious illness? • How do you talk with your child about his or her illness, if at all? • Are there special ways in which you talk about your child's illness or do you try to avoid talking about the illness? • How has the communication changed, if at all, within your family unit as a result of your child's illness? • What is happening within your family right now from a communicative perspective? How are your other children involved (if applicable)?

<p>Questions to Children/Young People:</p>	<p>Questions to Parents/Responsible Parties:</p>
<ul style="list-style-type: none"> • Do people try to help and support you, and if so, in what ways? Do their efforts matter or work? • Do you talk about your illness, or are you quiet about it? In what ways do you talk about your illness, if you do? • Can you tell me about or recount that conversation? Follow-up: What words did you use? 	<ul style="list-style-type: none"> • How is your child's doctor(s) or nurse(s) or hospice worker(s) involved in the communication surrounding your child's illness? • How does the communication surrounding the needs of your ill child flow? Is that flow different than before your child became ill? • How is information conveyed when there is an acute episode involving your child? • Are there certain words or behaviors used to describe your child's situation that are not usually a part of the adult world? • How do you regard the future for your child, and how do you talk about or convey that future with your child?

Appendix F: Respondent Profile

Table F.1 provides a profile of the children/young people interviewed for this study.

Table F.1 Respondent Profile.

Child's Name ⁴⁴ /Story Reference	Age	Ethnicity /Gender	Illness	Length of illness (at time of interview)	Treatment status	Illness notes	Family notes	Interview notes
Mike (Story: <i>Minister Mike Foretells</i>)	12	Hispanic male	Spinal Muscular Atrophy (SMA)	12 years	Died 6 months after the interview – March 2004	Confined to a wheelchair – at risk from infections – ongoing lung problems	Lived with his mother – older brother died from the same disease at age 4	At-home interview with both son and mother separately and together – total interview lasted approximately 2 hours
Richard (Story: <i>The Hooters Guy</i>)	16	Hispanic male	Ataxia- Telangiec- tasia (A-T)	16 years	Died 1 month after the interview – November 2003	N/A	Lived with his mother and young healthy brother	At-home interview with both mother and son separately and together – total interview lasted approximately 2 hours

⁴⁴ All names reflect the names used within the story narratives.

Marcus (Story: <i>Intellectual Capital</i>)	5	Anglo male	Leukemia	3 years	Ongoing treatments for prevention	Currently in remission	Lives with parents and older sister	At-home interview with entire family together – total interview lasted approximately 2 hours
Patrick (Story: <i>Praising Life: The Last Chapter</i>)	12	Anglo male	Acute Myeloid Leukemia (AML)	1 year	Ongoing treatments for prevention	Currently in remission	Lives with parents and young brother and sister – brother was bone marrow donor	In-home interview at Patrick's grandmother's home – interviewed the family together excluding his younger sister - interview lasted over 2 hours
Leonzo (Story: <i>Leonzo's Lead</i>)	13	Hispanic male	Acute Lymphocytic Leukemia (ALL)	7 years	Treatments continuing such as antibiotics for periodic fevers	Leukemia progressing despite bone marrow transplant	Lives with mother – has numerous siblings	In-hospital room interview for approximately 1 hour – spoke only to Leonzo although his mother was in the room – she only speaks Spanish
Eduardo (Story: <i>Authenticity</i>)	18	Hispanic male	Acute Lymphocytic Leukemia (ALL)	2 years	Treatments ongoing	Relapsed 2 months before the interview	An only child – close to his aunt	In-hospital room interview for approximately 45 minutes – Eduardo only

Harry (Story: <i>Unfiltered Harry</i>)	20	Anglo male	Acute Lymphocytic Leukemia (ALL)	6 years	Treatments ongoing	Presently in remission – 3 rd time with cancer – odds are 50-50 for long term survival	Close to parents and girlfriend and girlfriend's children	At-home interview for approximately 2.5 hours – Harry only
Corazon (mother speaking for her 6-year-old son who was dying) (Story: <i>Waiting</i>)	Mother: 29 Son: 6	Hispanic male (ill)	Neuroblastoma (stomach cancer)	2 years	Deceased – died 1 month after the interview in December 2003	N/A	Mother very close to her ill son and her younger son who is autistic	In-hospital room (<i>butterfly room</i>) interview for approximately 55 minutes – mother (Corazon) only
Trudy (Story: <i>It Happens</i>)	15	Anglo Female	Cystic Fibrosis (CF)	15 years	Ongoing treatments – prior lung transplant	New lungs expected to last 5 years – can be replaced – difficulty with ongoing breathing issues	Recently moved back to mother's home	Restaurant interview with both Trudy and her mother – joint interview lasted approximately 1 hour
Oscar (Story: <i>Blistered</i>)	15	Hispanic male	Acute Lymphocytic Leukemia (ALL), brain cancer	10 years	Died – early part of 2004 (February)	Medical personnel have indicated treatments have since been discontinued	Difficult communication issues in the family were evidenced during the interview	In-hospital interview with Oscar and his parents together – joint interview lasted approximately 1.5 hours

Arthur (Story: <i>Good News, Mijito! What the Hell!</i>)	16	Hispanic male	Leukemia	1 year	In remission – has had leukemia twice	Ongoing checkups/ treatments being received as warranted	Close to parents and brother – brother was his bone marrow donor	In-hospital interview with Arthur and his mother – joint interview lasted approximately 1.5 hours
Fran (Story: <i>Quiet Considerations</i>)	17	Anglo female	Chronic Myeloid Leukemia (CML), epilepsy, Stevens-Johnson Syndrome (SJS), and pediatric asthma	13 years with CML	In remission from CML – considering brain surgery for epilepsy and possible lung transplant	Ongoing checkups/ treatments	Close to sister who helps care for her – brother was her bone marrow donor	Coffee shop interview – lasted approximately 1.25 hours
Ryan (Story: <i>Enough</i>)	8	Anglo male	Osteosarcoma (bone cancer)	2 years	Has had cancer 3 times; 1 leg amputated, cannot receive anymore chemotherapy – possible lung cancer	Awaiting tests on lung lesions	Close to parents	In-room hospital interview held with Ryan for approximately 35 minutes – interviewed both his mother and father together for approximately 1 hour

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