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LISTENING TO THE CHILD WHO IS DYING

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LISTENING TO THE CHILD WHO IS DYING

By

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ABSTRACT

LISTENING TO THE CHILD WHO IS DYING

By

Emily Shamel Hacker

In this thesis I argue that adults, particularly parents and health care professionals, should listen to the child who is dying. Listening means not only a willingness to hear the stories of children, but also a willingness to consider honoring their wishes to discontinue life-sustaining treatment. First, I offer the claim that children are not fully listened to. Next, I introduce the idea of narrative practices in medicine in which children share their personal stories with adults and health care professionals in an attempt to achieve an understanding among them. Finally, I propose that listening to these stories may provide adults and health care professionals with an understanding of the dying child's position, and give them reason to honor her wishes to discontinue life-sustaining treatment.

For the campers at the Boggy Creek Gang Camp

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INTRODUCTION

I wake up every morning
I get up, take a shower,
Throw on some clothes
Tromp downstairs
And grab that everlasting cup of coffee,
Stare up at the nasty clock and give a nasty sigh,
It's time to go.
I jump in the car, pick up Stacey who lives out in the middle of nowhere,
But no one likes to drive to school alone.
I mope between the buses
And read that (after school soccer is cancelled today because the field is flooded)
What? It hasn't rained in three days.
The bell rings,
I kick my locker, as the rest slam one by one and the last of the students graze into class.
I arrived early to school but I'm still late to class
I go to classes I like, I sleep through classes I don't.
Was that you I bumped in the hallway?
I don't go along with the dress code,
And by the way, I have cancer.

-Tina Kenny, former camper

All too often, all that we, as adults and health care professionals, know of a pediatric patient is the nature of her illness. She is diagnosed at a young age with a disease that is most likely terminal. At that point we are concerned primarily with her physical condition and little with her personal interests and values; often we neglect to include her in conversation. The younger the patient, the less we engage her in even the most minor decisions concerning her health care. As children mature they are more likely able to engage themselves in conversations as they wish, though they are not necessarily assured significant involvement. Children, of all ages, have more to tell us about themselves than what their illness presents. They have a past, live a present, and acknowledge a future. They have much to teach us, to inform us of their lives so that we may understand. We cannot understand, though, if we are not willing to listen.

Therefore, I have written this thesis in order that we might realize the importance of listening to children who are dying. Listening means not only a willingness to hear their stories, but also a willingness to consider honoring their wishes to refuse life-sustaining treatment.[1]

It seems obvious that we should listen to children and value the stories they have to tell and I believe that in a general sense, we probably do. However, in the arena of health care, and more particularly health care decision-making, a child's voice is often too small to be considered. I have heard the stories children want to tell and I have learned so much from them. I have watched as a child begins to feel that what she has to say is significant and this is truly a remarkable thing. On the one hand it is remarkable in the sense that she is able to explain her feelings and justify her actions. On the other hand it is remarkable in the way that she informs her listeners of the unfamiliar, teaching them their duties and responsibilities. Children, like adults, deserve to be listened to. With so much good that can result from listening to and considering a child's personal story, why do adults and health care professionals exclude children from the dialogue that concerns them? In my attempt to persuade people that we should be listening to children who are dying, I ask this question. I briefly explore the psychological dynamics that may keep us from listening, while offering support from personal stories, clinical observation and published literature about what happens now.

In the second section of my thesis I make the claim that listening to stories of children who are dying has several invaluable benefits. The terms story and narrative are defined and used interchangeably throughout the thesis. I then present the purpose and usefulness of telling stories and listening to stories while emphasizing the importance of

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[1] Personal correspondence with Dr. Judith Andre, Michigan State University, 2002.

each. After exploring two stories, one case and one personal interaction, I anticipate and respond to possible objections to my claims.

The final section of my thesis presents a controversial issue within pediatric health care. The issue with which I am concerned considers decisions about continuing life-extending/sustaining treatment. I submit that after listening to stories of adolescents who are dying, parents and health care professionals may have reason to honor the young patient's wishes to discontinue treatment. I begin the moral argument by providing reasons, some grounded in the theories of Locke, Jeffrey Blustein and Lainie Friedman Ross, parents have duties or responsibilities toward their children. I discuss the rights parents have to assume authority over their children. Finally, decisions about continuing treatment sometimes fall outside of the boundaries of parental authority, and I believe that stories told by adolescents who are dying may convince us of this.

Throughout my thesis I use the words child, children, adolescent and young patient to refer to the population with which I am concerned. It is important to be aware that in the first two sections of my thesis, I am referring to children as those below the age of eighteen. The first two sections are applicable to children of all ages. The third section, however, refers only to adolescents. If the word children, or child is used in section three it refers to a young person under the care of her parents. The part of my thesis that suggests children are not listened to, but should be listened to is applicable to children of all ages. Children, in general, should be encouraged to speak freely and tell their personal stories. Listening to these stories may cause parents and health care professionals to allow the child some participation in general health care decisions. The final part of my thesis that suggests young patients may be determined competent to make decisions about continuing life-sustaining treatment is only applicable to adolescent patients, not young children.

Section 1

WHY ISN'T ANYBODY LISTENING?

Children are not supposed to die. Therefore it is not surprising that health care professionals find it especially difficult to discuss death with young patients and their families. Studies show that generally parents are dissatisfied with the way physicians handle these situations.[2] Parents wish for more open communication and support.[3] Learning about and coping with a child's terminal illness must be among the most tragic experiences for a parent. It is the physician's responsibility to learn to effectively communicate with these families while remaining sensitive to their reactions. It is not my intent to focus on the educational needs of physicians regarding their communication with terminally ill children and their families. Rather, I call attention to the fact that while communication between physicians and parents is not perfect, between physicians and children it is far from sufficient. Just as physicians have a difficult time talking to adults about their child's illness, it is even more difficult to talk with the child directly. In the following section I show that people do not talk to children about their illness situation as much as they should. I suggest some possible reasons why this discussion is not happening. Finally, I will argue that the most important aspect of communication with a child who is dying is listening to what she has to say. If physicians are not talking with children directly, the possibility of listening is non-existent. This possibility is one

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[2] M Harper, N Wisian, " Care of Bereaved Parents: A Study of Patient Satisfaction," J Reprod Med 39 (1994) : 80-86.

[3] Seema Khaneja, Barbara Milrod, "Educational Needs Among Pediatricians Regarding Caring for Terminally Ill Children," Arch Pediatr Adolesc Med 152 (1998) : 909.

with negative consequences if handled improperly, but if approached with sensitivity and thoughtfulness, can yield positive results.

The exclusion of pediatric patients from healthcare discussions

I have spent 20-30 hours observing interactions between healthcare professionals and families in the clinical setting. The majority of this time was spent following doctors in the pediatric oncology/hematology unit and rounding with the Medical Director of the Pediatric Intensive Care Unit. Though I have had limited clinical experience visiting with children and their families, my observations have been fairly consistent with what the scholarly literature says. Young patients, though questioned about their pain and symptoms, are not really listened to. As the level of conversation drops to a more serious tone, the young patients are often excluded. As treatment options are being discussed, or a poor prognosis is being made, the young patient always listens, though rarely is encouraged to participate in the discussion.[4] The patient may include himself in the discussion voluntarily, and receipt of this varies. However, encouragement to participate, or moreover direct discussion with the patient, is rare if the patient's parents are present. In fact, recent personal experience provides support for this. Twice in one week I visited my family physician, and on the second visit my mother accompanied me, while for the first I was alone. During the first visit I felt very comfortable communicating with my doctor as he displayed the x-rays he'd ordered. During the second visit, however, as a separate set of x-rays were displayed, the doctor turned his back to me, and spoke first to

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[4] Wanda K Mohr, Sheila Suess Kennedy, "The Conundrum of Children in the US Health Care System," Nursing Ethics 8 (2001) 196-210. JL Evans, "Are Children Competent to Make Decisions About their own Deaths?" Behav Sci Law 13 (1995) 27-41. NE Walker, CM Brooks, LS Wrightsman LS, Children's Right's in the United States (Thousand Oaks, CA: Sage, 1999).

my mother, explaining what he'd found from the films. So, even at 24 years of age, I was excluded by my family physician.

In contrast to my clinical observations are my camp observations. I have spent three complete summers at the Boggy Creek Gang Camp in Orlando, Florida. Each summer over one thousand kids age 6-17 attend camp. The kids that come to camp have a chronic or terminal illness ranging from asthma to cancer to various blood disorders. The summer is divided into eight one-week sessions, each designated by a different illness. My position at camp was camp counselor for the first two summers, and Unit Leader for the third. As a camp counselor I lived with and was responsible for 6-10 campers each week with help from 2-4 other counselors. As a Unit Leader I was responsible for all the campers and staff in the unit, which was composed of four cabins full of campers and counselors. While at camp, I spent all day and all night with my campers; we call them the shortest summers filled with the longest days. Besides being summer camp and not the hospital or clinic, the most prominent difference between the two settings is the absence of parents at camp. Kids of all ages rarely visit the hospital alone. Kids always attend camp alone. Camp is made for kids, not for parents and thus provides a unique perspective. I have had extensive experience with kids at camp. All of the kids at camp have a terminal or chronic illness and are considered to be very sick.

The "patch" at camp is the medical center, equipped to handle any chemotherapy treatment, transfusion, cut or bruise. Though we try to avoid the patch, it is expected most campers will spend some time there for various reasons. When I accompany a camper to the patch, I watch and listen as the doctor or nurse talks to her. I then watch and listen as the camper talks back to the doctor or nurse. A dialogue occurs between the health care professional and the young camper that focuses only on the camper and the reason for her visit. A 10-year-old camper of mine explained how different the patch was compared with her hospital – at the patch, "I get to talk." Her comment didn't mean much to me at that time. After spending time in the hospital, however, I am amazed at the difference. What I believed was normal practice, what I'd observed at the patch, turned out to be completely abnormal. My camper was right – the patch is a special place because the young patient is the focus and is encouraged to talk openly and freely about her condition. At camp she is asked to talk about how she is feeling, about her week at camp, and plans for the upcoming school year. She describes her condition with intricate detail, astonishing all of us with her knowledge of the disease. I'm afraid that in the hospital or clinic, these discussions are intermittent at best. It is difficult to talk with a child about her feelings when her feelings relate to her serious condition. It scares all of us who are expected to have these kinds of discussions, though these discussions are important. Why is it that we have such a difficult time talking about death? Why does this preclude us from directly addressing the child who is dying?

An exploration of why we do not discuss death

University of Florida pediatric residents claim that they do not feel confident in confronting families of the child who is dying largely due to their lack of formal training.[5] For physicians to feel comfortable talking about death with patients who are dying, extensive training is required. I'm not certain anyone will ever feel entirely comfortable addressing a dying child or a dying child's family. However, it must occur

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[5] M Behnke, E Setzer, P Mehta, "Death Counseling and Psychosocial Support by Physicians Concerning Dying Children," J Med Educ 59 (1984): 906-908.

and it is the role of the physician to convey the information and support the grieving patient and her family. Some physicians may feel directly responsible for the dying child's condition. This feeling of responsibility will surely make it more difficult to confront the patient and the family.

Our culture is one in which dying, especially among children, may be considered a failure. We live in a society that has trouble accepting death. Elisabeth Kubler-Ross highlights the need for practitioners to listen, to talk, to sit silently and to situate what the dying patient is saying against a backdrop of his life history.[6] These are all actions that can be learned in order to help the dying patient and his family. Kubler-Ross believes that physicians must first face their own fears of death before they are able to help others.[7] Perhaps this is a large part of the problem – that those of us in the position to confront dying patients have not dealt first with our own fears of death. Death is viewed as something that doctors should manage, not something to which they should succumb. If they are to first face their own fears of death, then they are acknowledging death as a possibility. In practice, particularly with pediatric intensivists, death is often considered not to be an option. If one invites the possibility of death to surface, he is not focusing all of his energy on life. Sack *et al* confirmed the extremely high expectations that physicians have of their duty to preserve life.[8]

It may never be understood exactly why we have such difficulty talking about death – we just do. And it is inevitable that health care professionals will continue to

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[6] Elisabeth Kubler-Ross, On Death and Dying (New York: Macmillan Publishing, 1969), 59-67.

[7] Kubler-Ross, 67.

[8] WH Sack, G Fritz, PG Krener, L Springer, "Death and the Pediatric House Officer Revisited," Pediatrics 73 (1984) : 676-681.

confront death among their patients. Therefore it is imperative that we learn how to discuss death with patients and families of all ages. Death should not be discussed with children in the same way it is discussed with adults. However, health care professionals should always be sensitively candid when discussing a terminal condition with patients and families. By sensitively candid I mean honest, yet appropriate and aware of the patient's position. This requires the physician to be in tune with the patient's and family's understanding of and willingness to accept the terminal diagnosis.

Encouraging and conducting appropriate conversations

Robert Buckman, MD provides a six-point protocol as a guide to presenting bad news to patients and their families.[9] The first step of the protocol is *getting started* in which Buckman emphasizes the importance of getting the physical setting right so that both the physician and the patient will feel more comfortable.[10] The second step focuses on assessing what the patient knows, while the third step is focused on how much the patient *wants* to know.[11] Step four considers the sharing of information with patients based on what the patient already knows, and what the patient wants to know.[12] The last two steps focus on the patient's reaction and plans for the future, though step five, responding to the patient's reaction, is the most important.[13] The patient's reactions and

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[9] Robert Buckman, How to Break Bad News: A Guide for Health Care Professionals (Baltimore: The Johns Hopkins University Press, 1992).

[10] Buckman, 68.

[11] Buckman, 71-78.

[12] Buckman, 79-90.

[13] Buckman, 90-97.

responses should guide the discussion between the patient and the physician. The physician must be sensitive to and aware of the patient's reactions, and continue the discussion accordingly. Guidelines such as these are useful when presenting a terminal diagnosis or poor prognosis with a patient. Members of the health care team should become comfortable with these types of guidelines, which will enable them to discuss difficult issues according to each patient's fears, concerns and wishes.

The importance of listening to pediatric patients

Within these discussions, the most important aspect is that health care professionals listen to their pediatric patients. Acquiring the skills necessary to feel confident in discussing death with patients and their families is of little use if the physician is unwilling to listen. Listening to the patient's concerns and expectations not only provides the patient with feelings of significance, but also serves as a guide for how to proceed. Often, the patient will lead the discussion if given a chance to express herself. Any member of the health care team that is having such a discussion with a young patient must be alert to the patient's reactions. If the young patient desires, she must be included in discussions involving her care. The young patient should decide the level of participation. The only way for the health care professional to elicit this information is by listening to the child who is dying.

Long before I was aware of any protocol or set of guidelines for these types of discussions, I found myself involved in a discussion with a seven-year-old camper. We were on paddleboat fishing when she asked if I knew she was sick. I did know that she was sick – all of the kids at camp are sick. I knew the severity of her condition and that both of her parents had died from the same disease. Fortunately, I also knew that she did not know her specific diagnosis, but knew she was at camp because "something was wrong with her blood." Most of the kids who come to camp know and understand their illness. There are a few, however, who have not been told. Had I not known that my young camper was unaware of her specific diagnosis, I may have assumed she did know, and proceeded with our conversation with that assumption. The significance of my story illustrates the importance of assessing what the patient already knows before disclosing any information that may be harmful or inappropriate. In this situation, I let my camper tell me what she knew about being sick; I let my camper lead the discussion.

I have described the contrast between my observations of discussion inside and out of the hospital setting. I have illustrated an ideal interaction between a younger patient and her physician as one that focuses on the young patient while encouraging her to speak freely. I have explained the difficult nature inherent in discussion involving death and dying with young patients and their families while exploring several reasons why this type of discussion is so difficult. As a transition into my next section I have introduced the good that can result from including and listening to young patients as they express concerns, fears and expectations about their illness. In the next section of my thesis I present the valuable concept of narrative as it pertains to ethical pediatric practices in medicine.

SECTION 2

ENCOURAGING THE TELLING OF STORIES SO THAT WE MIGHT LISTEN

"To make sense of ourselves and our world to ourselves and others, we tell tales – tales of truth, tall tales, tales of wisdom and woe – and listen to tales told by others. Stories, with their beginnings, middles, and ends, redeem life from contingency and make it something other than a meaningless succession of events...Stories disclose to us something about ourselves or about the human condition that we need to know, something that both figures in the light of our understanding of what life is generally like and throws light on the road we've traveled and the path ahead".[14]

Introduction

This section of my thesis introduces a branch of philosophy that considers narrative practices in medicine. I begin with a brief definition of narrative, an explanation of its usefulness and purpose and the importance of encouraging young patients to share their own personal narratives, or stories, while emphasizing the responsibility adults and health care professionals have to listen. For the purpose of this discussion, I will use the word story in a very general sense. Personal narrative and personal story will be used interchangeably; they share the same definition. A personal story, or a personal narrative is a relatively full expression of how one feels, why she feels this way, what she understands about her situation and what she wants to do. A full story does not necessarily contain all four of the above criteria. Stories may be told

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[14] Ronald A. Carson , "The Moral of the Story" in Stories and Their Limits: Narrative Approaches to Bioethics , ed. Hilde Lindemann Nelson (New York: Routledge , 1997) , 233.

through pictures, through poetry, or through language. However they are expressed, these stories are acts of communication that when heard will bring adults and healthcare professionals closer to understanding the patient's position, while enabling them to better determine her maturity and competence.

Some may deny the power of narrative, claiming it alone cannot deepen our understanding of moral issues. I believe, however, that the purpose and usefulness of narrative in medicine is significant.. When we share personal experiences, personal stories are likely to evolve. Patients sharing their stories with those caring for them not only explain and justify many of their feelings and emotions, but also provide some insight to the listening adults about their unique set of values. Narratives inform listeners. Often, a young patient's values are assumed to mimic her parent's values. By encouraging the patient to speak, and tell her story freely and at length, adults and health care professionals are able to get a firmer grasp on her unique set of values and beliefs. We become informed of a piece of the patient's moral life.[15]

Hilde Nelson provides two propositions that narrative ethics have been based upon. The first is that "moral principles are not lawlike, universal, and unyielding, but modifiable in light of the particulars of a given experience or situation. The second is that these particulars either naturally take a narrative form or must be given a narrative structure if they are to have moral meaning."[16] I base my discussion on the assumption that moral principles are not universal and unyielding. I will argue in favor of considering the particulars of a young patient's experience in order to ascribe moral

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[15] Nelson, viii.

[16] Nelson, vii-xx.

meaning to what may become her story. This is important if we are ultimately going to consider the adolescent's role in the decision-making process.

Furthermore, it is especially important that children are invited to share their stories not only because of the benefit it brings to the child, but also, and more importantly in this paper, because of the adult response. There is virtually no way for adults to assess the maturity and competence of the dying adolescent if she has not expressed herself fully. It is thus our responsibility to encourage her to share her story. Clearly, patients should be allowed to express their feelings freely. This is standard practice with adults. It is not standard practice with younger patients. Therefore, the question is not whether patients should be allowed to tell their story, but rather if younger patients are actually encouraged to do so.

In the following section I briefly explore the extent to which young patients are encouraged to tell their story, while emphasizing the responsibility adults have to listen to and consider the young patient's story. I hope to enunciate the power narrative activity can have in pediatric medicine as it helps adults and health care professionals to realize the existent gaps in their understanding of the patient as a person. Once these gaps are realized, I submit the possibility that open narrative might alleviate some of the conflict between the parent and the child. In the final section I address this issue of conflict and suggest reasons why parents may not always have total authority over the final decision of their child's health care.

What is narrative?

Expressing an opinion is just that – a mere expression. However, expressing an opinion should not be left at that. Instead, it should prompt a story. Behind all opinions lies a story waiting to unfold. I hope not to conflate these two concepts, story and statement, or expression. Rather I want to draw a useful connection between them, that a statement or expression has the potential to evolve into an important personal story or narrative. Again, a story or narrative is a relatively full expression of how one feels, why she feels this way, what she understands about her situation and what she wants to do. Stories emerge from simple statements or expressions. If these statements, or expressions are not fostered, however, they will remain just that, and little moral work can be done.

Something important happens as children convey their illness stories, or personal narratives. Exploration into what these personal stories are doing, to whom they are speaking, and why they are important is essential if adults and health care professionals are to fully understand the patient's moral perspective. I consider the claim that children's personal stories are practical in regard to the moral work that they can do in the medical setting. I will argue their significance and worth as crucial narratives from which emerge moral discoveries that deserve to be considered.

Purpose and usefulness of personal stories

Three general claims for stories are that they can enhance one's moral perception, that they can guide action and that they can justify action.[17] More particularly, though, are the claims offered from the teller's point of view, and those offered from the listener's point of view. We tell stories to justify actions or practices, discover our own duties and teach others their duties.[18] We listen to stories to be informed of things unfamiliar, to enhance our moral understanding of another person or situation and to justify our perspectives. Stories that are shared may validate the perspectives of the teller and the listener.

From my extensive observations of and involvement with terminally – ill children, I have witnessed the moral work that can be accomplished as children construct and tell their personal stories. Children telling stories about their illnesses reflect on their past experiences to create the story they are telling in the present. They take bits of relevant information from their narrative histories, and apply them to their current story in order to convey their message. This process allows children to tell their story to others on the one hand, but on the other hand, and perhaps more importantly, to better understand their own situation. "Illness narratives usually tell of the patient's personal experiences of the sick role and response to treatment, and often emphasize the patient's need to communicate to others the disorder and dislocation that often accompany serious illness."[19]

In order to tell their story, children must first construct their story. Sometimes this is done as the story is told, and other times the story is carefully constructed prior to it's telling. A child may construct her story to re-identify herself as worthy of respect. Once she feels worthy of respect, her moral agency is less inhibited. As she feels free to deliberate with others about how she is feeling, she will begin to tell her story. This is a process of healing not only herself, but also her moral community: her parents, her health

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[17] Nelson, vii-xx.

[18] Nelson, x-xii.

care providers and the community of children with whom she most closely identifies. During cancer week at camp, one of my campers told me her story. As she told me, I was driving her to the hospital for an emergency transfusion. We would be spending the night away from camp in an all too familiar setting for her. As we drove, I asked about her plans after camp. She was really looking forward to spending a relaxing week alone with her parents. Her brother was going to camp, and he was sometimes annoying. (I mentioned that I understood, I had two brothers, and they were sometimes annoying as well). She quickly replied that her brother was wonderful, and she admired his courage, but he had Tourettes Syndrome, and that he couldn't help it, and she knew that. She was "simply looking forward to some peace and quiet, quality time to catch up on some reading, you know." (About this time we passed an area of government housing) Amy observed the neighborhood as we passed, and asked me if it was a "ghetto." She looked at me smiling, exclaiming how lucky her family was that they didn't have to live that way. "Boy," she sighed, "I'm lucky." After a brief description of her house and her brother's "special" characteristics, I asked about her plans for the fall with her brother back at home. In the fall, she answered, she would spend a lot of time with her family and a few friends. She would do lots of reading, and write letters to her fellow campers; she loved to write letters. She said she would write to me, but I didn't have to write her back if I was too busy. But, she casually mentioned, it would be nice to stay in touch because she probably wouldn't be back at camp the following summer. I jokingly explained to her that I expected her to be my partner in crime for many summers to come. She answered, confidently, that she'd made the decision to refuse chemotherapy. She'd

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[19] Michele A. Carter, Sally S. Robinson, "A Narrative Approach to the Clinical Reasoning Process in Pediatric Intensive Care: The Story of Matthew," Journal of Medical Humanities 22 (2001) : 174.

relapsed a fourth time only a week before camp began and couldn't bear the thought of another round of chemo. "My body can't take it, and my heart, for sure, can't do it." I remember these words, and the knotted feeling I felt in my stomach. Always observant, Amy probably noticed my uneasiness, and announced that she wanted to do something really special at camp this summer, before she left – could I help her? All I could suggest in the midst of my jumbling emotions was that she sing a song the following night for the talent show. Very excited that I'd suggested singing, she began throwing out ideas from our camp songbook. Eventually she made a decision, Good Riddance by Green Day. I told her it was one of my favorites, and asked why she'd chosen it. She answered, "It reminds me of life since I got sick. Everything is unpredictable, and I just have to smile through it. If I don't, I'll die." I watched that night, as Amy stood alone on the giant stage, spotlight on her frail body, singing off key, and a smile was created on my face and in my heart. For a moment I understood her decision, her longing for peace.

Children encouraged to tell their stories learn about their own perceptions and refine the moral perceptions of others. They tell their stories to each other, and perhaps most significantly, to those of us *not* suffering from the illness. We may consider a young adolescent's decision to refuse treatment irrational and unacceptable. However, there is so much of one's life that we, as outsiders are unaware of that is crucial to understanding another's decision. Carl Elliott suggests "some actions are intelligible to us only within the context of some kind of narrative...When we place the action within such a narrative, what was previously baffling becomes intelligible."[20] This is often the case when one is trying to justify seemingly irrational actions.

Encouraging stories, while listening carefully

Only a small piece of her story, the above provides a taste of the moral meaning that can be derived from constructing and telling a story. Prior to my discussion with Amy, I would have thought her decision to refuse chemotherapy unreasonable and premature. After listening to her story, however, I felt differently. Amy's story as told above is not complete, and may not even be considered a story by many. It is, however, a segment of a life unfamiliar. Even if the above is not a story by definition, or seems to be choppy and incomplete, it is the prompt to a complete story; it is a preface. Statements such as Amy's should prompt families and health care professionals to foster more complete story telling. Like many children, Amy had a desire to speak and be heard. She had considered her situation, and constructed a story about it in order to justify her action of refusing another round of chemotherapy. I can report Amy's story, though my report does not do the same work as if Amy was freely telling her story to an open-minded listener. Amy's parents could have told the oncologist that Amy had refused the chemotherapy, though the explanation would have been void of personal moral significance. Only Amy could explain her feelings, and justify her convictions.

The stories of these children cannot do their moral work if there is no one to listen. Carl Elliott describes language as that which we use not to represent the world, but rather to interpret it, and in some ways, create it.[21] As young patients tell their stories, they are indeed creating a world not only for themselves, but for their listeners as well. We, as listeners, share a tremendous responsibility. Art Frank explains, "the ill

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[20] Carl Elliot, Bioethics, Culture and Identity: A Philosophical Disease (New York : Routledge, 1999), 132.

have already fulfilled their responsibility by being ill. The question is whether the rest of us can be responsible enough to see and hear what illness is, which ultimately means seeing and hearing what life is."[22] Ronald Carson suggests "narrative aims not at explanation but at an understanding. It moves us to ask: What happened then, and then what...? And what happens next will follow intelligibly, though not by entailment, from what occurred before as the story unfolds."[23] Sometimes children will provide only a statement, or a question that may lead us to infer something about their moral perspective. An inference, or an assumption, however is not sufficient. Statements or questions such as these should prompt us to ask what happened then, and then what, and why and so on. This is how stories are created and an understanding, between the teller and the listener, emerges. Stories must have an attentive listener in order to create such an understanding. Carson continues that this understanding between sender and receiver allows us to relate to each other.[24]

The good that may result

I have emphasized the responsibility we have to encourage the telling of stories. I have also expressed the importance of listening attentively to these stories. I will now clarify the good that can result from these narrative practices. First, competence is better assessed after hearing one's story than prior to hearing one's story. Voluntariness, provision of adequate information, understanding, competence, and making and

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[21] Elliot, 123.

[22] Arthur W. Frank, At the Will of the Body (Boston/New York : Houghton Mifflin Company , 1991) , 128.

[23] Nelson, 233.

expression of an actual decision are the five elements involved in making a legally valid medical decision according to Meisel, Roth and Linz.[25] Of the five, perhaps the most difficult to determine is competence. Competence is judged according to specific decisions. For example, one may be determined incompetent to drive a car, but competent to administer insulin injections to herself. For the purposes of this discussion, I submit the possibility that while one may be young and seemingly incompetent in many respects that young people usually are, she may be competent to participate in and assume some authority over her health care decisions.

Competence cannot be sufficiently determined, however, unless the patient is encouraged to tell her story, and we assume the position of the attentive listener. Only after hearing her story, questioning it, and analyzing it, is a fair judgment possible. I am not denying the possibility, or even the likelihood that the young adolescent will be determined incompetent to have full decision-making authority. In this case, the adolescent would not assume full authority, but rather a level of participation as deemed appropriate by those caring for her. Likewise, I do not deny the possibility that the adolescent will be determined competent to make such a decision. Competence, though difficult to determine, is more accurately evaluated after an adolescent has shared her story in an effort to provide those listening with a better understanding.

The determination of competence, however, should not be the only reason adolescents are encouraged to tell their story. In some situations, her level of competence

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[24] Nelson, 233.

[25] Stuart J. Younger, "Competence to Refuse Life-Sustaining Treatment" in End-of-Life Decisions: A Psychosocial Perspective, ed. Maurice D. Steinberg and Stuart J. Youngner (Washington, DC: American Psychiatric Press, Inc, 1998) , 22.

may be known prior to any narrative experience. In cases such as these, it is still useful to encourage the telling of personal stories.

In this situation, too, personal narrative is a matter of both telling and listening. By telling her story, the adolescent is better able to understand her own position as well as to increase the understanding of others. This aspect of narrative is particularly important within families. Families may often assume their loved one is experiencing similar feelings to their own. It is not uncommon, though, for patients to hide their true feelings from their families for fear of disappointing or upsetting them. Conflicts that arise from these misunderstandings can be critical to a family's relationship during difficult times. By sharing stories, each is better able to understand the other. Actions are justified and feelings are validated as information is disclosed.

Finally, this understanding that arises from story telling can help to lessen the conflicts existent between the child and his parents. Consider the following case:

> Peter was a 15-year-old male who developed an osteogenic sarcoma in his hip. After initial surgery he was started on chemotherapy and seemed to do well. However, after about 18 months he had a recurrence of his tumor and developed metastases to his lungs. A new form of chemotherapy was used, without success, and Peter became sicker. He informed his nurses that he did not want any more chemotherapy, and he was urged to tell his parents. Peter could not tell his parents, who in fact wanted chemotherapy to continue. Peter felt he had to do what his parents wanted because he did not want to hurt them. Since the nursing staff knew of Peter's wishes, they became angry at the parents and angry at the oncologist for continuing to administer chemotherapy. Some, in fact, refused to follow the orders that were written for Peter's chemotherapy. Peter remained reluctant to tell his parents until it was suggested that a meeting could be held in which staff would be there and would support him while he spoke to his parents. Such a meeting was organized, and Peter hesitantly told his parents that he wanted to stop chemotherapy so that he could live the remaining period of his life feeling as healthy as he

> could and out of the hospital. After much discussion, which included the parents stating that they wanted to feel that they had done all that could be done and Peter assuring them that he felt that all had been done, his parents were able to accept Peter's decision. Everyone was now able to accept the inevitable, without conflict, and join together in their sadness.[26]

It is cases such as this that have led to this paper. This is a clear example of the good that can result from telling and listening to stories. In this particular case, the nurses picked up on Peter's prompt that he did not want any more chemotherapy. Left as a statement, this does not constitute a story, even in the general sense to which I have been referring. It does serve, however, as a classic prompt to which health care professionals, parents and families should be alert. The nurses in this case, recognizing the prompt, encouraged Peter to talk to his parents. To make Peter more comfortable, the staff offered to facilitate a meeting during which Peter could freely tell his story. From the brief description of this case, it is not specified whether Peter actually told a full personal story. One might imagine, however, that that had to be the case in order for Peter and his parents to arrive at such a decision. The conflict that was present prior to the meeting was alleviated after Peter and his parents had the opportunity to tell their own stories freely and at length. Once Peter was able to express his wishes about chemotherapy, and tell the story accompanying those wishes, his parents were able to disclose their feelings about why they were so insistent on another round of chemotherapy. A peaceful resolution could not have arisen had Peter and his parents not had this opportunity to share their stories.

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[26] Julie R. Van der Feen, Michael S. Jellinek, "Consultation to End-of-Life Treatment Decisions in Children" in <u>End-of-Life Decisions: A Psychosocial Perspective</u>, ed. Maurice D. Steinberg and Stuart J. Youngner (Washington, DC : American Psychiatric Press, Inc., 1998) , 150.

Possible objections

It might be objected that narrative sessions such as the ones I've described above are too risky. There is the possibility that the narrative session will not result in conflict resolution. In Peter's case, for example, the parents could have reacted differently. It is possible that after Peter told his story, his parents would be disappointed and even more set on their conviction that Peter must undergo another round of chemotherapy. Such a situation could be devastating for both the parents and the child. The child may feel he has lost all defenses; he may feel even more disempowered as his interests were heard, and then refused. He was, after all, hesitant about disclosing his true feelings with his parents. He is likely to feel even more defeated in such a situation, which could lead to feelings of abandonment or depression. Moreover, he may begin to harbor his feelings about future issues, feeling that they are insignificant or simply wrong. The parents, though true to their original conviction, may suffer overwhelming feelings of guilt. These feelings could worsen if, after the treatment, the adolescent dies. These possible outcomes pose some risk to the idea of narrative practices that may complicate the possible benefits.

Response and conditions

Though I do not deny that there are risks, I believe that proper facilitation might prevent them. Facilitation is not required for young patients to tell their stories, or for parents and health care professionals to listen. It may be required, however, in cases such as Peter's in which a decision is pending on the narrative session. By proper facilitation I mean facilitation that occurs with both parties understanding that the conflict may not be resolved. In Peter's case, for example, the staff facilitators should have explained to Peter prior to the session that his parent's understanding was not guaranteed. Adolescents in similar situations must be told explicitly that the session may not result in their favor. It should be explained that if they tell their story, the chances that their parents will understand are improved, but by no means guaranteed. The decision to talk should then be left to the adolescent. Under these conditions, encouraging the adolescent to tell her story while insisting the parents listen can be beneficial in lessening the existing conflict.

Conclusion

When adolescents are faced with the decision of either continuing treatment, and possibly surviving, or refusing treatment, and dying a natural death there are many complicated issues to be considered. Conflicts of interest often arise between the health care providers, the family and the young patient. It is not within the scope of this paper to clearly define a method of resolving these conflicts, but rather to emphasize the importance of approaching such difficult medical decisions in a nurturing and humanistic way. This approach requires that the "narrative and phenomenological dimensions of the clinical reasoning process" be considered and understood.[27] In other words, all those involved should understand the whole illness experience as best as possible. The telling of the illness experience involves the family, the health care providers, and, most importantly, the young patient. The patient, through conveying her story, is able to add to her illness experience emotion and insight. Adolescents, like all patients, bring with them life stories laden with values, judgments, likes and dislikes, interests, and opinions. These are the components of one's life to which we owe our respect. If we are not willing to listen to these stories, we will not know what it is we are to respect. Decisions of this nature, whether or not to continue life-extending treatment, are accompanied by questions begging for "deeper analysis and interpretation of the broader human predicament of illness, loneliness, and the kind of life or death one might be trying to achieve."[28] The only way to begin to understand the broader human predicament is to first listen to the individual patient narrative. This is the critical first step to a fair, humanist approach to medical decision-making.

We have a responsibility to the narrative of human life. Some may feel that a child's voice is insignificant. I suggest, though, however small or feeble the voice may be, it is an essential voice within a larger social narrative that gives life its unity. Young patients with terminal illnesses have stories to tell of significant moral purpose. The work their personal narratives can do knows no limits. We, as listeners, have a responsibility to hear the messages they long to share. "We cannot understand a life, and what it might mean, without referring to the individual narrative and also to the social and cultural context in which it is lived."[29]

If adolescents are encouraged to tell their stories, and the moral purposes discussed above do result, then it is true that stories can enhance our moral perceptions and justify and explain our actions. By listening to these stories, we are able to

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[27] Carter and Robinson, 176.

[28] Carter and Robinson, 182.

sympathize with and better understand the decisions made by young adolescent patients. This understanding that results can play a significant role in lessening the difficult conflicts that arise between parents and their children.

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[29] Elliott, 133.

SECTION 3

NARRATIVE AS A MEANS FOR ALLEVIATING CONFLICT AND MAKING DECISIONS

Introduction and historical basis

There is considerable debate as to when, if ever, an adolescent should be able to make decisions regarding life-sustaining treatment. Most often, even if adolescents are involved in the decision-making process, their parents hold final authority. In the following discussion I explore the conflicts that arise when an adolescent decides to refuse further life-sustaining treatment and her parents disagree with this decision. Conflicts such as these complicate the already difficult issues of adolescent competence, autonomy and decision-making participation. Therefore, the reasons parents have authority over their child's health care decisions should be analyzed. Is there a moral obligation to parents to automatically accept their authority? If so, ought we also have a moral obligation to respect the decisions of competent, autonomous adolescents? I will address these questions and submit my proposal that adolescents suffering from terminal illnesses deserve not only to be listened to, but also to be respected as autonomous persons in their decision-making capacity. Listening to the adolescent's story might give health care professionals reason to honor her wishes while respectfully disengaging her parent's authority in this particular capacity.

On what grounds do parents have authority over their children's health care? Or, more generally speaking, what are the reasons parents have authority over their children at all? From a historical standpoint, it seems that parental authority has always existed.

The family, as an intimate network, has been responsible for the care of it's children. Hundreds of years ago, often the family could do for itself what everyone else could not; individuals had to rely on families for care. When a family member was ill it was often the immediate and extended family that provided medical care. Doctors were expensive and inaccessible so the adult members of the family were the source of care for the sick.[30] Those in the position to care for or look after the young or the ill assume an authoritative role. As those who are young or ill become older and healthier, they too will look after those succeeding them. Authority develops naturally as older family members must take responsibility for younger family members. As babies are born into families at different times, the age that one assumes responsibility varies. Familial, or more particularly parental authority is a practice that has developed over time because it works.

Parental duties, or responsibilities

The reasons parents have duties or responsibilities toward their children are many. Lockean theory grants that parents have a duty sanctioned by God to care for their children.[31] Locke's theory suggests that just as God has authority over His people, anything He sanctions must be followed. If He grants authority to parents, then they have a sacred duty to care for their children. In *Parents and Children: The Ethics of the Family,* Jeffrey Blustein describes the duties of parents as *duties of status, duties of need-fulfillment and duties of respect.*[32] Parents naturally acquire these duties of status as they

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[30] Hilde and James Lindemann Nelson, The Patient in the Family (New York: Routledge , 1995) , 6.

[31] Lainie Friedman Ross, Children, Families, and Health Care Decision Making (Oxford: Clarendon Press, 1998) , 20.

[32] Blustein, 115.

assume the relatively fixed position of being a parent, thus abiding by institutional rules.[33] In other words, when a parent becomes a parent, biologically or legally, he or she automatically assumes a position of responsibility. There are institutional norms to which parents should ascribe in order to sustain their position as parents. In addition to duties of status, Blustein defines the parental duties as duties of need-fulfillment.[34] In short, children have natural needs because of their cognitive and emotional deficiencies and parents have a moral obligation to satisfy the needs of their dependents.[35] A third set of parental duties is Blustien's duties of respect: "Duties of respect...are duties to respect a child's own desires and wants in matters that are not critical to protecting the child's basic interests, and where these desires and wants, if acted upon, are not likely to impede the child's development or harm others."[36] A different theory, offered by Lainie Friedman Ross suggests that family, as an important social institution, is the primary reason parental authority should be accepted.[37] Parents, according to Ross, should have ultimate authority over their children in order to give the children lifetime autonomy.[38] She suggests that parental responsibility includes helping "to define the child's well-being and conception of the good."[39] More generally, though, is Ross's belief that parents have authority because they are responsible for providing for all of their

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[33] Blustein, 115.

[34] Blustein, 116.

[35] Blustein, 116.

[36] Blustein, 117.

[37] Ross, 173.

[38] Ross, 173.

[39] Ross, 4.

children's basic needs.[40] These basic needs are essentially the same as Blustein's natural needs. Ross also assumes that all children are incompetent to make important health care decisions.[41] Thus, it appears Ross believes parents have authority over their children because children are incompetent and require a competent decision maker in their lives to promote lifetime autonomy, and competent parents are generally responsible for making such decisions.

There are numerous theories explaining the duties parents have toward their children, and it is not my purpose to address all of them. Common among the theories described above, and others I've not described is the consensus that parents should be responsible for their children because it is their inherent duty as parents to ensure their child's physical safety, emotional growth and moral growth. Locke, Blustein and Ross say basically the same thing insofar as children lack some level of competency and parents are therefore responsible for considering the children's best interests when making decisions for them. The justification behind different theories may vary, though the main idea is consistent. Generally, parents have more wisdom than their children. Wisdom develops over time as one confronts new and challenging experiences. It is a virtue that one must acquire. Often we think of the wise as those who are older, having experienced many years of hardship and reward. The wise have learned from mistakes and are able to make more responsible choices. Adults, generally considered wiser than children, are able to approach difficult decisions with caution; often they are able to

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[40] Ross, 5.

[41] Ross does state that although children are never fully competent to make these decisions, some have attained a "threshold level of competency" and should be at least considered in the decision-making process. Nevertheless, she believes "competency is a necessary, but not sufficient condition to justify respect for the child's autonomy." 7.

predict and avoid negative outcomes. Children, in their cognitive and emotional deficiencies may not be able to fully consider all of the aspects involved in making a difficult decision. Therefore, parents are held accountable for making wise decisions for their children insofar as the child's natural needs are being considered. However, it is important to understand that wisdom is something acquired, something learned as one experiences the unfamiliar. As a child matures, the boundaries in which the parent's authority is appropriate change. They are not rigid, but rather flexible and yielding to the development of the child.

Parental authority

Stemming from their duties as parents are their parental rights to have authority over their children. It is important to define the boundaries inside of which parents may appropriately use their authoritative right, their right to exercise power. Parents need to have authority in order to be accountable for their children, though they are accountable only insofar as they promote their children's best interests. Any use of authority that falls outside of these boundaries is unacceptable as it may cause the child harm. Parents that use their authority inappropriately may be forced to abandon their rights as parents. The boundaries within which parental authority is appropriate are difficult to determine. They vary with consideration of each situation and change as the child matures both cognitively and emotionally. Any use of authority that causes harm to the child will almost always fall outside of the boundaries. Within these boundaries, parents have the right to use their authority as they promote the child's well being, consider the child's emotional needs and encourage moral development.

There are many different matters over which parents have authoritative rights. Parents may acceptably prohibit their toddler from playing in the street to prevent the toddler from being hit by a car. I assume many would agree that this seems to be a reasonable use of authority. Where, then, does the use of authority become questionable? A widely accepted answer would be at the age of adulthood, or legal competency. However, levels of parental authority change as children mature. What if the parents prohibited their 15-year-old daughter from playing in the street in fear of her being hit by a car? Most would consider this unreasonable under normal circumstances. 15-year-old adolescents are generally competent enough to avoid playing in the street. At what point did the toddler develop enough competence to know not to play in the street? Was it at age 5, age 10 or not until age 15? The age one achieves competency is difficult to determine, especially as the circumstances become more complex.

Health care is the issue with which I am most concerned. Children are faced with decisions regarding their health everyday: decisions as simple as which band-aid to use and decisions as complex as which chemotherapy regimen to try. Few parents would deny their 5-year-old child the opportunity to choose her own band-aid. Few parents (if any), however, would not consider allowing a 5-year-old to choose which chemotherapy regimen to try. But what if the child were 15? Undoubtedly, the teen would be allowed to choose which band-aid he preferred. But would he be allowed the choice of which chemotherapy regimen to try? When children are under the age of 18, the boundaries within which parents retain the right to use authority are difficult to determine. If the patient were 18 or 20 he would have legal authority to make his own decision even if his parents disagreed. The boundaries within which parental authority is used should be flexible as different situations arise throughout a child's young life. As children grow and mature, they are able to make decisions that fall outside of the shrinking boundaries of their parent's authority.

Parental authority and decision-making

Ross states that even when children are determined to be competent decision-makers, parental authority is still appropriate. In other words, if there is a conflict between the competent child and the parent, and the parent is promoting a decision that will not harm the child, though is clearly against the child's wishes, the parent's decision should always be respected.[42] Though Ross acknowledges that a child may be determined competent to make a difficult decision, she denies the notion that that child might then assume decision-making authority. Blustein, however, attributes the duties of respect to parents with the child's personal interests in mind.

> It is rather that depriving another of freedom is morally wrong unless one has adequate justification for doing so, and it is not by itself an adequate justification to say that children lack the capacity for rational decision-making or that the choices they will make will not be fully autonomous. Even if this is true, children should have as much freedom as is compatible with their present needs, the long-range objectives of parenting, and the safety of others...children, as children, have a right to self-determination, a right to be themselves, quite apart from future beneficial consequences to themselves. At the same time, it is only when children's desires and wants are taken into account by those who rear them that they can start to grasp the idea of there being a reason for acting in one way rather than another and thus can engage in purposive behavior.[43]

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[42] Ross, 66.

[43] Blustein, 117-118.

Blustein not only acknowledges that children have a right to self-determination, but that they may also be capable of making important decisions as they develop their capacities for autonomous action. Blustein recognizes the flexibility of these boundaries: "...parents are not to have an unlimited right to determine for their children what their particular conception of the good shall be, or how they shall pursue it."[44] This aspect of Blustein's theory allows more freedom for the children within reasonable limits. Ross's theory defines a more rigid framework within which parents have authority over their children. Ross is concerned, primarily, with family dynamics and long-term, lifetime autonomy whereas Blustein focuses on the duties of and the duties toward individual children and their parents.

I agree with Ross that parents have a responsibility as authoritative figures to promote the moral development of their child. To encourage the moral development of children, children should be empowered, to a reasonable extent, to make choices. There are occasions that it may be in the child's best interest to make tough choices insofar as they are learning from the outcomes of those choices. Parents have a responsibility to instill values in their children while teaching them strategies to promote those values in the choices they make. Children cannot develop a unique set of values if they continue to mimic the values of their families and have decisions made for them accordingly. As children grow, parents have a responsibility to offer less demand and more guidance insofar as it promotes valuable experience. Making poor choices can promote valuable experience, as can making good choices. Ross believes that parents should always have the final authority over their children's decisions even if the child is deemed competent to make that decision. She states: "Sometimes the child's present identity and goals may

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[44] Blustein, 130.

conflict with those that the parents would like the child to develop. Parents may choose to not respect their child's present goals to promote alternative values and goals because it is their responsibility and privilege to do so."[45] I agree with Ross that parents have the authority to override their child's wishes, particularly when those wishes are potentially harmful to the child. Nevertheless, parents have a responsibility to listen to their child's story before dismissing it. This is their duty to promote the child's emotional and moral maturity. The point at which Ross and I might disagree is the extent to which under certain circumstances parents should renounce their authority and observe the child's competency to make that choice. I am not willing to say that parents should always have authority over their child's decisions even insofar as they are promoting the child's best interests and protecting her from harm. I believe that if an adolescent is fully competent to make such a difficult decision, then she fully understands her position, what it means, and what she wants to do about it. This is how I understand competency and therefore suggest that it may be not only a necessary, but also sufficient condition to allowing a particular adolescent decision-making authority.

Parents, according to Ross, are responsible for promoting their child's lifetime autonomy and for this reason should limit the child's short-term freedom when faced with difficult decisions.[46] Ross continues that the child's decisions are based on limited knowledge and experience and are thus not part of a "well-conceived life plan."[47] I agree with Ross that in many cases this is true. Parents generally do possess knowledge that their children do not. Furthermore, parents have the life-experience from which to draw

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[45] Ross, 47.

[46] Ross, 61.

when faced with difficult choices. However, I believe that children, who have been living with a serious illness for most of their young lives, have lived experiences and gained wisdom beyond what is expected from a healthy child. Under special circumstances such as these, I do not find Ross's lifetime autonomy argument convincing. I discuss the reasons why in the following section.

Decisions that fall outside of the boundaries

Often parents will agree with their child about a course of treatment. Sometimes, however, parents will disagree. Decisions about continuing life-sustaining treatment sometimes fall outside of the parental authority boundaries I've discussed. There may be times when it is appropriate to honor the wishes of the adolescent. I will offer three reasons why decisions such as these may fall outside of the boundaries.

Consistent among many of the reasons parents have duties toward and authority over their children is the belief that children lack the wisdom possessed by their parents. I have defined wisdom as a virtue that one acquires over time. It is my observation of and experience with children suffering from terminal illnesses that they are remarkably wise. Children that have been afflicted with a serious illness for much of their young lives share experiences that many adults do not. They have been forced to think about illness and its effects on their bodies and their lives. They have suffered through many painful treatments and embarrassment among their peers from hair loss, visible scars or significant weight fluctuation. Children suffering from terminal illnesses over a long period of time have extraordinary insight into their lives. It is quite possible that in cases such as these, children possess a unique, but considerable amount of wisdom that may

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[47] Ross, 61.

qualify them to make meaningful decisions about life-extending treatment. The kind of wisdom to which I am referring is unique to a child who is terminally ill. Parents, caretakers, friends and family cannot fully share the wisdom, nor are they able to develop it over time. As children are diagnosed with a terminal illness they are forced to begin thinking about their future autonomy whether or not they are aware of it. No longer are they able to focus only on their short-term freedom and everyday interests; they inevitably consider the future. Therefore, I believe that adolescents who have lived most of their lives with a terminal illness have developed the wisdom and insight necessary to see beyond their short-term interests to the possibility of future interests.

The parents of a child who is terminally ill, though completely involved with the child and the child's care, are often unable to distinguish between their needs as parents, the family's interests, and the child's best interests. The inability to disconnect everyone's separate interests could be problematic when making such critical decisions. Though the decision to continue or discontinue life-sustaining treatment affects the whole family, the child's individual interests must be considered separately. If parents are unable to disconnect their personal interests from the conflicting interests of the adolescent, the decision to discontinue treatment may then be one that necessarily falls outside the boundaries of parental authority. If the parent's authority was upheld under these circumstances, and the adolescent was required to continue treatment against his wishes, feelings of guilt among them might result.

Finally, decisions about continuing the treatment must fall outside the boundaries of parental authority if parents are promoting a treatment that will extend the adolescent's life, but will cause him prolonged suffering. Basically, if the young patient wishes to discontinue treatment in this type of situation, and there is a question about accepting or rejecting the conflicting wishes of his parents, the burdens and benefits approach should be considered. If, as in the example above, the treatment that the parents are promoting will extend life but only with prolonged suffering, then it would be a safe assumption that the burdens of treatment would outweigh the benefits and the adolescent would be allowed to discontinue treatment, against his parent's wishes. However, the burdens and benefits are not always clear. Conflict arises when the burdens and benefits are viewed from different perspectives; what a parent may see as a benefit, the adolescent may feel is a burden. Thus, the burdens and benefits approach is not always the most appropriate when considering these situations. Nevertheless, if parents promote a treatment for their adolescent that is clearly not in his best interest, the decision to discontinue life-extending treatment does fall outside the limits of their rights to use authority and must be considered by others, if not by the young patient himself.

The use of stories

Stories are a way in which we can be convinced that a treatment decision does fall outside these boundaries. When parents disagree with their child's goals, it is essential that they attempt to understand the child's personal story. By giving thoughtful consideration to the child's expressed interests, parents not only promote the general welfare of the child, but should also feel valuable as parents as they are able to grant some autonomy to their child. The moral development of the child is enhanced as he feels respect from his parents as they express a sincere interest in his unique set of values and his personhood. Often, this individuality is unknown unless prompted to emerge through the personal narrative. Parental authority is necessary for a quality narrative to develop. Parents also have the responsibility to encourage individuality within the child's personal narrative, and prompt it's emergence. My objective is to acknowledge the possibility that once the child has had the opportunity to share his personal narrative with his parents, they may feel justified to grant the child decision-making authority over his health care regimen.

What might the child possess that would give her leverage in having at least partial control in making decisions about life-sustaining treatment? Of what might a child's narrative consist that would allow him such authority? Adolescents who have been sick with a serious illness for an extensive period of time are more likely able to make educated decisions regarding their treatment. From my own observations of and conversations with seriously ill children, I have learned how much more the child understands her illness than most involved adults may realize. Children know what will happen if certain drugs are taken, or are not taken. They are aware of the consequences of their behavior. They know exactly how to give the injections so that they cause the least amount of pain. Children know their bodies, and they understand what is going on with them. I once accompanied a camper of mine to the patch (medical center) after swimming. She had a mechanical pump that allowed medicine to flow continuously into her heart. She was aware that any disruption of flow could be fatal. As we entered the patch, she began to unwrap the yards of plastic wrap used to waterproof the device. I noticed a lot of water dripping from her contraption at about the time she calmly mentioned that her "pump didn't seem to be working." Immediately there was a code called, and an army of doctors and nurses came to my smiling campers aid. Flustered, they retrieved the back-up pump from the freezer and nervously attempted to reconnect her. Lying on the table, lips a light shade of blue, my camper sighed heavily and told everyone to just calm down and let her do it. Within seconds she had connected the new line to her heart, and activated the new pump. "Please tell me you weren't as nervous as they were," she said to me as we left. My camper was eight years old. For eight years she had watched as other people poked at her chest with needles. For eight years she'd heard her mother warn caregivers about the consequences of a broken pump. And then, with a calm ease she took control of the situation and proved to understand her illness and her body better than all of us seemingly competent adults. This is what can happen when children are forced to live with a life-threatening illness. The question remains, then, is the terminally ill adolescent competent to make the decision to refuse life-sustaining treatment?

If after telling her story the adolescent is determined competent, or believed to fully understand her situation, she may be allowed to make the final decision about her treatment. However, health care professionals must be sure of her understanding; it must be clear that she is aware of her position and the likelihood of death if she chooses to forego treatment. If this is not clear, the adolescent should not be able to make the final decision. She is likely able to participate in the decision-making process, but should understand that she will not be allowed to have final authority. There are two main reasons why this is so important. First, the issue being considered concerns the life or death of a young person. Second, parents deserve and must have firm boundaries within which to act as parents. I feel that only if the adolescent is fully competent, and mature in her understanding of her personal situation, should it be considered that she assume decision-making authority over her health care.

According to Ross, parental authority to override the child's decision is legitimate not because it disempowers the child or dismisses his present-day autonomy but because it prolongs his lifetime autonomy.[48] She claims that the child's decisions are based on "limited knowledge and experience."[49] I agree with Ross that in some cases the child does have limited knowledge and experience. However, I firmly believe that in other cases a child may have more knowledge and experience useful to making an informed decision. These children possess a kind of wisdom that is uncommon, though powerful. It is a wisdom that can be realized by allowing children to tell their stories, and justify their unique position.

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[48] Ross, 173.

[49] Ross, 173.

CONCLUSION

Children who have been sick for the majority of their lives share a special kind of personal narrative. It is one whose characters are doctors and nurses, whose bad days are spent near the toilet and whose good days are considered normal by other, healthy kids. Children living with illness have illness narratives. The values and goals that surface through an illness narrative are reflective of the child's life with that illness. I have spent countless hours prompting and listening to personal stories. I have learned about specific diseases, what it's like to live with that disease and the joy of discovering the disease is in remission. I have also begun to learn, from children much younger than me, what it's like to know you're going to die. I've learned about the nightmares involved when approaching yet another painful treatment. I've learned about the fear of failing your parents: a fear of disappointment. I've learned all of these things from narrative as children shared their stories while fishing in the middle of the lake or passing a candle late at night for a cabin chat. I've learned that children who have lived with a terminal illness for most of their short lives have a story to tell that is based on knowledge and experience and dreams and reality. I grant that there may be an occasion where these young adolescents know what to do. I believe that if this is true, decision-making authority should be shared, if not granted.

If adolescents are able to understand the benefits and burdens of treatment, and are able to think clearly about their illness, decisions regarding the treatment should not exclude them. The adolescent knows and understands what life is like with the illness. She has decided to either accept or reject life with the illness. She knows that it won't go away. She understands that by refusing treatment she might die. Does she understand the finality of death? Perhaps. But I wonder does anyone really understand the finality of death? Is it not enough to understand the constant pain and suffering one experiences? Legally, the young adolescent is not competent to make the final decision to refuse treatment. Functionally, I believe it is possible that she is. Competence, after all, is not an objective term. It is one influenced by judgment and experience. The difficult question remains, then, of who determines competency and I believe that narrative is a possible means by which it can be assessed.

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