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OPEN RELATIONSHIPS/HONEST ANSWERS: A DYING CHILD'S UNDERSTANDING OF TERMINAL ILLNESS AND THE VALUE IN MAKING THE TRUTH AVAILABLE

By

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ABSTRACT

OPEN RELATIONSHIPS/HONEST ANSWERS: A DYING CHILD'S UNDERSTANDING OF TERMINAL ILLNESS AND THE VALUE IN MAKING THE TRUTH AVAILABLE

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This thesis argues that dying children have a moral claim to an open relationship with their practitioner. First, I explain that an open relationship allows honest communication between the patient and the practitioner. Such a relationship cannot exist without sharing, autonomy, benevolence, compassion, courage, prudence, phronesis, and justice. Next, I argue that such a relationship is morally ideal; then, that contemporary theories of cognitive development do not rule out the possibility that children are capable of such a relationship; finally, that some children's literature may be a beneficial tool for helping children communicate about and understand difficult issues.

To all my friends and family who constantly remind me of the power of faith, hope and love. To my two furry angels, who always know when I need them most. To those who are forever gone from this earth, you are always with me and give me the strength to get up when I fall. And, mostly to all the children who have touched my life and help me open my eyes to the miracles all around- you are the true miracles.

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I owe many of my thoughts and my ability to think in an interdisciplinary way to the IPHH department and all the professors that conduct their courses in a way that opens the minds of students and helps us to draw parallels among ideas that at first glance seem to have no connections. A special thanks to Dr. Tom Tomlinson for expanding my mind and to all my colleagues that kept me thinking of good arguments to all I believe.

Finally, I would like to thank my mom for reading more prospective and thesis drafts than one person should have to. You always told me pursue those things that caught my heart and made me happy. That has to be the best advice that a parent could ever give. Hopefully one day I will be able to give to others as much as you have always given to me.

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INTRODUCTION

> No one knows with regard to death whether it is not really the greatest blessing that can happen to a man; but people dread it as though they were certain that it is the greatest evil. This is ignorance, which thinks that it knows what it does not, must surely be ignorance most culpable.
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> -Plato, *The Apology*

Death is one of the most difficult subjects to talk about because it reminds us that we have little control over the world; this is never clearer than when we look at children and realize that they too, die. I began this thesis trying to understand what it is like to be a child with a terminal illness, yet there was no real way for me to understand that without projecting my own feelings on the children that I so desperately wanted to help.

I figured that children needed hope, but only hope that was valid and true. I believed that children needed and wanted to know the truth in all its nuances. Then, it struck me that I was no better than the people before me. And I had to rethink my plan of attack. If I really wanted to help children and make dying an easier process, then I had to look at what the dying child really wants to know. So, I have changed my focus, knowing full well that children are capable of much more than we adults sometimes suspect. I began to think not about what children should be told, but rather what they want to know. I cannot say that I fully understand what is going on in the dying child's mind, but my aim in this thesis is to explore how a dying child might see death and the dying process, what type of relationship might make the dying process easier and finally whether there are tools available to aid in the dying child's understanding of death. I feel much passion about this subject. Much of me thinks that it is unfair that a child has to die and most of me wishes that we never had to wade through such painful subjects. And yet I feel fortunate that I can bring a new look to this age old problem.

In this thesis I am looking at children living with terminal illness, age seven to ten, who have reached the terminal phase of their illness. I have chosen this age group because it comes between the times when a child still does not fully understand the notion of personhood and when the child desperately wants to be an adult. I have also chosen to look at children who are in settings where death is all around and presumed to affect their minds, as well as their bodies. In addition, these children will have been primarily raised in health care settings. Therefore, they have spent a considerable amount of time in the hospital. [1] This may also mean that some of the children were first diagnosed with chronic illnesses and have since become terminal.

I have learned, through conversation with Dr. Linda Spence,[2] that children are given different information about their diagnosis and prognosis in different care settings. In today's health care system, children are usually cared for at the clinic or the hospital, although sometimes children are cared for at home or in hospice type settings. Because children may receive different information depending on the setting in which they receive their care, it is important, throughout this thesis, to keep in mind that the children I will be focusing on have been cared for in the hospital and may not be able to benefit from insight that the caring team in the clinic may have.

Finally, my focus in this study will only be on the white, middle class culture with which I am familiar. Given more time, this study would be complemented by a

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[1] "Considerable," meaning that they have been hospitalized at least once a month since diagnosis.

[2] Dr. Linda Spence, RN teaches in the Nursing department at Michigan State University and has done considerable clinic and hospital work with dying children throughout her career.

look at other cultures and how they might view children and terminal illness differently.

In this thesis, I will be exploring how children living with terminal illness might come to understand and question death and dying. I will look at the value an honest open relationship might have for children and at their ability to ask questions about their health and receive honest answers. In addition, I will discuss studies relevant to children's ability to understand death. Finally, I will review some of the tools that might aid in the child's understanding of such an abstract concept. [3] Throughout this thesis, I will focus on what we need to do for dying children. I will pay particular attention to the ways relationships between the caring team and the child affect that child's understanding of death and dying and their ability to receive honest answers to their questions. I will also look at the value of personal engagement between the child and the caring team. Finally, I will look at literature as a promising tool in the dying child's understanding of death and loss. However, I will not be looking at the social world that is created for the dying child or the emotional help children might need to get through this process.[4]

On a final note, I will look at the child as separate from the unit of family. I am doing this for the reason that dying children are facing a trauma that has already caused them to disengage from their family. They are in the hospital and by this very fact have experienced separation from the family unit and isolation from other children. [5] In this thesis, I will focus my attention on the child's development and

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[3] I will primarily be looking at literature as an aid in this understanding process.

[4] Both of these are interesting questions, but there is not enough time to explore them in this thesis. For more information on these topics refer to work done by Myra Bluebond-Langer in her dissertation and several of her books.

[5] Bauer, David. "What of the Dying Child?" In *Death in the Life of Children*, ed. Kaoru Yamamoto (Arizona: Kappa Delta Pi, 1978) 83.

their understanding. This understanding certainly does not occur in a vacuum. The child is exposed to what other people think and understand, but I have chosen not to look at the family context for several reasons. The most important reason is that much work has been done on the family and how they, as a unit, deal with the crisis of death and dying.

Clare Mulholland once said that there is nothing worse than not knowing what you already knew. [6] Let us not sentence our children to this fate that may be worse than death.

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[6] Clare Mulholland, 1973.

Chapter 1

REVIEW OF SCHOLARLY LITERATURE

My review of the scholarly literature is based on four disciplines. These are: child development, philosophy, nursing and children's literature about death and dying. I have taken this interdisciplinary approach to this thesis because I think that it is important to keep in mind that children, even those that are facing death, are trying to make sense of a world that is complex and muti-faceted. While there have been few studies and little written about communication between a child and their provider, it is fairly plausible that some of the issues I am looking at may have been explored in other disciplines. A more complete study of dying children and the benefits of open relationships would certainly include a review of scholarly literature in anthropology and sociology. However, those disciplines, along with others, are beyond the scope of this thesis.

Research about children's ability to understand death

We have for centuries been thinking and writing about death and dying, but these discussions have mostly concerned adults. Studies that have adult subjects may seem irrelevant to this discussion of children dying from terminal illness, but it has been noticed by Kenneth Doka that studies done on adults may show us something about children. Ideally we would focus our attention on studies done on dying children, but very few of these studies exist and it is likely that they never will. [7] Despite these impediments, we can make sense of some of these data as they apply to

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[7] I suggest this because it is almost impossible to be allowed to study children, especially those dying from terminal illness. Organizations that are designed to protect research subjects are not likely to allow studies on children, especially if those studies are dealing with issues of death and dying.

children when we realize that "as a general rule, a child's struggle with life-threatening illness is both similar to and different from that of an adult." [8] It is hard to see how it is possible for the child to have experiences similar to an adult; after all children are not just small adults. However, Doka noticed that a child's death experience is similar to that of adults in the ways of coping with the physical and social aspects. Doka noted that children were well aware of and able to experience loss of the physical, in similar ways to adults. This means that dying children and adults coped with body function loss in similar enough ways that it is possible to use studies conducted on adults to explore children.

Although there were those similarities, Doka noted that adults and children were different in the ways of available communication and development issues. Children, especially those who are young, have fewer words to draw from for active communication. On the other hand, adults are able to communicate more clearly because they have more words available. Also, children are still developing in a number of ways. Children are physically growing, gaining motor skills and strength and are experiencing much mental growth. Adults, while they may be experiencing some minor mental growth, are fully matured beings. Because of these differences, it was an important time for children and those people interested in their development, when studies involving children began.

However, it was not until the 1930s that this really happened. Even then there were few studies, but beginning in the 1970s intense interest began in the study of

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[8] Doka, Kenneth. "The Cruel Paradox: Children Who Are Living with Life-Threatening Illnesses." In *Handbook of Childhood Death and Bereavement*, ed. Charles Corr and Donna Corr, (New York: Springer Publishing Co., 1996) 94.

children and how they might come to understand death.[9] Yet, despite the number of studies in the 70s and 80s, there has been little progress in this area of child development. There are several reasons for this lack of progress, though most have something to do with the fact that results of these studies are confusing and the models of the studies usually begin with assumptions that may not be accurate. For example, in the majority of these studies, "it has been generally assumed that children's concepts of death develop in accordance with Piaget's general theory of cognitive development."[10] This may be an accurate assumption for well children and some sick children, but many people call the development stages, which Piaget's claims occur in all persons, into question.

Several experts in the field of child development, who have done studies of this sort, including Flanel and Gelman and Baillargeon, believe that the "process of concept development in general is more complex, extends over a longer period of the life span and results in more varied and individualized outcomes."[11] So, at this point we are left with little understanding on how the child actually understands death and dying. This becomes more clear when we look at how the ill child, especially the terminally ill child, understands these concepts.

There have been few studies done on the understanding a child who is sick or terminally ill may have about death. Yet, in these studies and others (those on children that are well) we can notice one relationship that helps us to understand how the child dying from a terminal illness may develop an understanding of death that is far more

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[9] Speece, Mark and Sandor Brent. "The Development of Children's Understanding of Death." In *Handbook of Childhood Death and Bereavement*, ed. Charles Corr and Donna Corr (New York: Springer Publishing Co.,1996) 29.

[10] Speece, "The Development of Children's Understanding of Death" 43.

[11] Flanel 1985 and Gelman and Baillargeon 1983.

mature than the understanding the average child may have. This relationship shows that more experienced children, those that see and think about death more, were more likely to have mature concepts of death. The first clinician to really suggest this about ill children was Myra Bluebond-Langer who stated that children who had experience and exposure to life threatening illness may have a more mature concept of death than held by healthy children of relatively the same age.[12] Since the time of her study, in 1978, six major studies have been done, but the results are equivocal. Studies done in 1984 by Fetch and in 1990 by Groolman found a significant relationship between a mature concept of death and life experience, but the other four studies showed mixed results or no relationship. [13] Further studies have done little to show how the child with terminal illness understands death, but have indicated that children with life threatening illnesses are aware of what is going on in their bodies, even when parents and caregivers try to conceal or withhold that information. [14]

At this point, even with the studies that have been conducted on well children, dying children from other cultures, and dying adults we are left without a definite answer to how the child with illness or terminal illness may develop an understanding of death. However, on the studies that have been conducted, it is plausible that children who are terminally ill do have a more advanced notion and understanding of death. I suggest this, because it seems plausible that children who are constantly exposed to death and dying would be better able to grasp these concepts because they are no longer abstract concepts to them. These children have spent much of their time in an

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[12] Bluebond-Langer, Myra. "Awareness and Communication In Terminally Ill Children: Pattern, Process, and Pretense," (Diss. University of Illinois, 1975).

[13] Fetch 1984 and Groolman 1990. as described by Speece, "The Development of Children's Understanding of Death" 49.

[14] Doka 97.

institution. They make their friends on the hospital ward and their friends die there. These children hear about and witness death and are certainly affected by that. My intention is to shed light on the child living with terminal illness in an institution so that it is clear that their experiences do affect their understanding. With the help of the studies conducted in the past and careful consideration of how those studies may relate to the dying child, I plan to examine the following questions: should we, health care professionals, acknowledge that death is approaching for the child? Do children sense that they are dying, even without our explicit words? Do we rob children of their right to come to a finis (end) after having possessed an end (telos), if we do not tell them what they ask to know? Are children not able to make end of life decisions without accurate information? These questions seem to be of utmost importance, if we really want to help dying children. We must look at these questions, despite the confusion we have seen in the outcomes of various studies. And, we must decide what children need from us, so that they can reach their end. In the body of this thesis, I will suggest that honest relationships, that involve personal engagement, will provide the child an appropriate platform from which they can ask questions and receive honest answers.

Work on Honesty in Health Care

In order to talk about honest relationships we must take a look at Sissela Bok's book, *Lying: Moral Choice in Public and Private Life.* [15] From this look at truthfulness, trust and the consequences of lying, we can come to some conclusions about the value of honest relationships. The next step will be to see if this relationship is possible in the medical setting. To establish this, we must turn our focus to philosophy and truth-telling in the medical setting.

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[15] Bok, Sissela. *Lying: Moral Choice in Public and Private Life,* (New York: Pantheon Books, 1978).

In the world where doctors control the information and patients are only able to possess that information if the doctor chooses to disclose it to them, it is important to see if doctors do in fact disclose crucial information [16] and if they do not what are their reasons for not doing so. Until the 1960s the pattern was that doctors did not disclose information (88% of physicians followed this policy of nondisclosure) because they feared that patients rich with the knowledge about their terminal condition would "commit suicide, not cooperate with treatment or become depressed."[17] Interestingly enough at the same time a study, by Samp and Currei, that surveyed cancer patients and their families, showed that 87% believed that patients should be told their diagnosis and prognosis.[18] It was not until the end of the 1970s that physicians started to change their beliefs about disclosure practices. At this point in time, 98% of physicians reported that their usual policy was to tell patients their diagnosis.[19] This is obviously quite a dramatic change from the 12% that had the usual policy of disclosure in the 1960s. Unfortunately this dramatic change in disclosure practices only occurred if the patient was an adult. It turned out that physicians clearly had a different policy when it came to disclosure with a child patient. Novack, et al. found that 18% of a sample of

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[16] I suggest that crucial information is that about diagnosis and prognosis, but also any other information that the patient might request.

[17] Beauchamp, Tom and Robert Veatch. *Ethical Issues in Death and Dying*. 2nd ed, (New Jersey: Prentice Hall, 1996) 64.

[18] Samp, Robert and Anthony R. Currei. "A Questionnaire Survey on Public Cancer Education Obtained from Cancer Patients and their Families." *Cancer* 10 (1957): 382.

[19] Novack, Dennis, Robin Plumer, Raymond Smith, Herbert Ochitill, Gary Marrow and John Bennett. " Changes in Physicians' Attitudes Toward Telling the Cancer Patient." *Journal of the AMA* 241 (March 1979): 898.

219 physicians were less likely to tell children their diagnosis.[20] It seems that the reasons for this discrepancy in disclosure practices between adults and children had much to do with age, intelligence, and emotional stability of the patient.[21] These results are not surprising and are easy to understand, though it is not clear how physicians, in these studies, were able to gauge the intelligence or the emotional stability of patients. However much we look at the changes in the practice of disclosure it is clear that the children are left out of this movement. This may be due to the very protective nature we all seem to have toward children or may be just plain unfair to the young patient.

Philosophers and lay persons stand on both sides of this issue about telling the available truth (for the standard reasons; see chapter 2). However, we notice again that we must look at this issue first from outside the realm of the child dying from a terminal illness. It is unfortunate that we must do that, but the reality is that, "although references to children sometimes occur in the context of discussions of particular topics, those who have proposed ethical theory have, by and large, ignored children."[22] After a look at honest relationships and truth-telling in the medical setting, we will turn our attention to children and how they develop the skills to understand abstract concepts and how an honest and supportive relationship might benefit them. There is unfortunately a lack of literature available to begin this type of discussion. Therefore, I will spend much of this chapter laying out the important parts of cognitive development for all children and using some of the more salient ideas given to us by the nursing field.

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[20] Novack, et al. 899.

[21] Novack, et al. 900.

[22] "Children and Ethical Theory." *Encyclopedia of Ethics.* 1992 ed., 137.

Work on the use of Literature in Communicating with Children

Currently there is a lack of available information and studies that attempt to show the positive effect that literature may have on the dying child's understanding of death and dying. Therefore, this section of the thesis will draw from information on the use of literature in aiding the moral imagination of adults and the new biobliotherapy movement.

Bioliotherapy is a tool to help people solve problems and show them that they are not the first to encounter such a problem, together with Martha Nussbaum's proposal that the literary imagination has some value in aiding our thinking about concepts that are abstract to us, points us to the notion that literature may have some value for the dying child. However, there is little literature designed to teach a child about their own death. It is clear that, despite the fact that some people have looked at the merits of literature, we are left with questions about the value literature has for the dying child. Along with looking at honest relationships, the possibility of such a relationship in the medical setting, cognitive development in children, and the value of children's literature, I will constantly be making it clear that the most important aspect of relationships with dying children may be the personal engagement that allows for honest answers to sometimes difficult questions.

Chapter 2

WHAT'S SO GREAT ABOUT THE TRUTH?

> What tormented Iván Ilych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he need keep quiet and undergo a treatment and then something very good would result. He however knew that nothing would come of it, only still more agonizing suffering and death. This deception tortured him- their not wishing to admit what they all knew and what he knew, but wanting to lie to him concerning his terrible condition, and wishing and forcing him to participate in that lie. Those lies- lies enacted over him on the eve of his death and destined to degrade this awful solemn act to the level of their visitings, their curtains, their sturgeon for dinner- were a terrible agony for Iván Ilych.
>
> -Leo Tolstoy, *The Death of Iván Ilych.*

In this chapter we are going to take a look at the basic philosophical arguments for and against truth telling. This chapter will lay out the ground work for the next three chapters. Chapter 3 will deal with the nature and value of open relationships. Chapter 4 will look at the cognitive development of the dying child and make the claim that dying children may need the personal engagement set up in honest relationships. Finally, in chapter 5, the focus will turn to an appropriate tool that might aid in a dying child's understanding of death and dying. Now, we turn to truth. Recall that we must first look at truth without any discussion of children. Later, we will have to ask if any of the reasons for telling or not telling the truth can be used to deal with dying children.

To Tell the Truth

On one side of the issue about the importance of truth-telling and its value, are those people who believe that it is simply wrong to lie. They claim that honesty is an inherent duty of morality and is not dependent on whether telling the lie or the truth does any harm. [23] This is an absolutist position which says that telling the truth is always more important than the consequences of that truth. These people make the claim that to tell the truth is a duty. This means that in any relationship or practice the truth must be told or the practice fails. This way of looking at truth and its value may work in the world that has little to do with children and even less to do with illness and dying. It goes too far for my purposes, but cannot be easily dismissed. We cannot dismiss this because in many situations a veracious person would be an ideal participant. Just imagine a situation where it was impossible to count on another person's word or action, and you can easily see how a person who is able to be honest, truthful and accurate would be ideal, at least in that respect.

On the Other Side

On the other extreme is the thought that people are entirely unable to handle any of the truth, but this view does not seem to be held by anyone who has a reasonable idea about the value of truth or the nature of human beings. Instead, people who disagree with the idea that the truth should be told no matter what the costs, tend to be very concerned about the possible negative consequences that disclosure might have. Most people who hold varying philosophical beliefs fit on the spectrum between telling the whole truth and complete nondisclosure. Here I will be discussing consequentialist ideas about truth telling, though there are also non-consequentialist ideas for this same type of limited disclosure.

Sidgwick claims that the truth may cause harm and we must take that into consideration, but we must also "weigh the gain of any deception against the

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[23] This is like the views expressed by Immanuel Kant.

imperilment of mutual confidence involved in all violation of truth." [24] He justifies such a statement on consequentialist grounds, and states that in order to act in the right way, we must compare the consequences of lying to those of not lying in each particular case. Others agree with Sidgwick when they claim that generally "harms done by lying and failing to speak truthfully are greater than the expected gains."[25] W.D. Ross agrees with Sidgwick's proposal that both duty and consequences matter.[26] These philosophers and many more seem to all be saying something similar. They are stating a need for truth, but hold that truth need not be complete and is open to interpretation. Sissela Bok states that "the whole truth is out of reach. But this fact has very little to do with our choices about whether to lie or to speak honestly, about what we say and what we hold back." [27] I agree completely: Complete information about illness and the processes the body would go through during that illness would be impossible information to give. However, giving known information in a completely truthful way is not absurd unless the patient cannot handle that information or does not want it. Additionally, if patients want and can handle the truth, then there must be some practical or operational reasons for telling the truth. These reasons have something to do with gaining patient cooperation and giving patients some kind of control of their lives. There is also the possibility that when patients are misinformed or lied to they lose complete trust in their practitioners and become suspicious of all the care that is given to them.

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[24] Sidgwick, Henry. "The Classification of Duties of Veracity." *Methods of Ethics* (1907), 312.

[25] Cabot, Richard. "The Use of Truth and Falsehood in Medicine: An Experimental Study." *American Medicine* 5 (1903) 344.

[26] Ross, W.D. *The Right and the Good*, (Oxford: Oxford University Press, 1930) 28.

[27] Bok 4.

Another Important Question

Here we are faced with a completely new question. Do patients really want to know the truth? Experts stand on both sides of this issue as well. Some say that patients do in fact want the truth and the harm that might result from such disclosure is much less than physicians think.[28] Others say that falsehoods may be wrong, but full disclosure is not needed and that the physician has a right to withhold information from the patient for the good of that patient.[29] Along these lines, some experts note that even when the patient seeks the truth, this may be the last thing that they really want. [30] So far we are left with a dilemma. We still are not aware of what value truth telling might have for children and we still are unaware of what patients want. The statements and arguments on both sides of the issue are pretty convincing and none of them can be easily dismissed. Up until now we have been looking at adult patients, for which the increasing ethical consensus is that the truth should be made available. However, there remains disagreement about the degree of truth that should be given and the detail with which information should be supplies. Now we will turn our focus to the child dying from a terminal illness and decide which arguments and statements fit that situation best.

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[28] Bok 13.

[29] Worthington, Hooker. *Physician and Patient: Or, a Practical View of the Mutual Duties, Relations and Interests of the Medical Profession and Community,* (New York: Baker and Schribbner, 1849). 359. Recall that this was written well before the doctrine of informed consent.

[30] Meyer, Bernard. "Truth and the Physician." In *Ethical Issues in Medicine: The Role of the Physician in Today's Society,* ed. E. Fuller Torrey, (New York: Little Brown and Company, 1968) 167.

Do These Reasons Fit For Children?

Lantos makes it clear that we are now moving into practically uncharted territory with his statement, "as with most modern bioethics paradigms, all bets are off when it comes to pediatrics." [31] He is right about this, but then makes the claim that, "if it is a good thing to tell children the truth, it is not for the same practical or operational reasons we tell adults."[32] I disagree, however his thinking is in line with the idea that children are going through similar, but not the same, things as adults when they face death. However, if we come to the conclusion that it is our moral duty to tell adults at least some of the truth, then we must want to gain their cooperation or empower them and give them some control of their lives. I believe that these are at least three good reasons to tell the truth to adults and may be the same reasons for telling children the truth. It seems as if it is important that children, as well as adults, cooperate with their practitioners, continue to have some control over their lives, and have some sense of responsibility about their health care. Sissela Bok points out that "some level of truthfulness has always been seen as essential to human society." [33] I take this to mean that this truthfulness is essential to all members of human society. Our human society does include dying children who may have the same need to hear the truth that adults possess.

I am not advocating full disclosure. I am sure that in some cases the complete complex truth could have devastating effects. Imagine a scenario in which the child begins to ask questions about their illness, but not about death. In this situation, if they were told that they are about to die, then that might devastate the child and make them

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[31] Lantos, John. "Should we Always Tell Children the Truth?" In *Perspectives in Biology and Medicine (Autumn 1996)*, ed. Richard Landu, et al. (Illinois: University of Chicago Press, 1996) 84.

[32] Lantos 84.

[33] Bok 18.

less willing to cooperate with future medical procedures. I am also convinced that if we truly want a child to participate in their medical care then we must give them information. Doka writes, "if the child is going to have a sense of participation and control in the illness, he or she will need to know what is wrong and what is likely to occur." [34] We are practically convinced that adults need this control and have a right to make choices about their lives and their deaths. Why is that not the case for children? Aside from the fact that some people have come to believe that "generally minors below the ages of 11-13 do not possess many of the cognitive capacities one would associate with the psychological elements of intelligent consent." [35] My fear is that the only true reason we fail to disclose to children dying from a terminal illness is that it is really hard to be emotionally superficial when everyone is aware of the truth. It hardly seems clear that children have no need or want of the truth. What does seem clear is that, "adults own difficulties in dealing with the deaths of children probably underlies their inclination to withhold information from children."[36]

I believe that the only conclusions that we can draw from the studies done and the arguments laid out by experts in their field is that there are truly, "no established criteria as to how much to tell children."[37] Though I think, in light of the idea that children dying from a terminal illness may have knowledge about disease that surpasses the knowledge a well child may have (an idea expressed fully in chapter four) and keeping in mind that I am not advocating full disclosure, it is fairly possible to see a need for health care professionals to give "straight answers to straight

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[34] Doka 97.

[35] Doka 97. I will show in chapter four that this fact is highly debatable.

[36] Mohowald, Mary. *Women and Children in Health Care: An Unequal Majority* (Oxford: Oxford University Press, 1993) 196.

[37] Buckingham 70.

questions."[38] If practitioners make the choice to supply children with the information they are requesting, then children might cooperate with their care, be able to have some control over their lives, and make decisions about their own bodies and health. I am pretty sure that nobody really knows what each child wants to know, but we should understand the need some dying children may have for the truth. If that need is not met some children will be worse off due to our lies.

I am convinced, through my work with children, [39] that even if a child is not aware that her or she is dying, the child at least knows that something is wrong with them. The natural reaction to the realization that something is wrong is to ask questions. Children want to know why someone is taking their blood, why they have to stay in bed and even if they are going to die. I have seen how children react when they know lies are being told to them. I have seen them completely lose trust in the people that have lied to them. Sissela Bok makes it clear that, "those who learn that they have been lied to in an important matter are resentful, disappointed and suspicious." [40] We can easily avoid these negative reactions to being lied to by answering questions in the truest way possible. I can agree that children may have no need for the statistics of success and failure rates that we so readily supply to adults, but children do have needs for information. This information can be given to children in many ways and may need to given in several ways in order for the child to fully make sense of it in relation to what they already understand in the world. In the next three chapters, I will lay out a type of relationship in which it is possible for children to ask questions and receive honest answers, I will suggest that the dying child is capable of

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[38] Cabot 84.

[39] This work has been with both dying children and those who have experienced the death of a loved one.

[40] Bok 20.

understanding answers about death and dying that caregivers may give them, and I will talk about the importance of personal engagement in the relationship and in all tools that aid in the child's understanding of death and dying.

Chapter 3

AN ATMOSPHERE OF OPENNESS

Open Relationships

In order to see how open relationships might be important for dying children and might aid in their ability to ask questions about their health care, we must first look at what open relationships are. Relationships are talked about in a number of social and professional areas, but for the purpose of our discussion we will focus on the open relationship between the practitioner and patient. There are many potential problems with such a relationship that will be included in this discussion, but first I will turn my focus to establishment of an open practitioner/patient relationship. The goal in such a relationship is not only disclosure. A more important goal might be open communication that exists in a relationship between persons who choose to be truthful, benevolent, compassionate, caring and courageous. Participates of the relationship must also choose to act with prudence, exercise phronesis, believe in justice, and retain autonomy.

The relationship should place both the patient and the caring team on a level that allows both of them to put themselves in the other person's position. It must be a partnership that advocates communication and sharing. Active verbal communication and sharing will provide a platform for an open relationship. Both the patient and the practitioner should be able to verbally express their hopes and desires and be willing to share knowledge openly with one another. [41] Without such aspects, it seems impossible that most dying children would be comfortable enough to

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[41] Other types of communication, including nonverbal, may also be used in an open relationship. However, nonverbal communication should only be seen as an additional aspect in the interaction between the practitioner and the patient.

ask questions to the practitioner. The health practitioners' goal is the establishment of a relationship that affords the patient an opportunity to ask questions and receive honest answers. An additional goal of the relationship is to create an atmosphere where neither party feels as if information is being hidden. These are probably lofty goals in all types of relationships and are definitely hard to achieve in the medical setting.

Establishment of the Relationship

In the medical setting, the practitioner has a certain power over the patient. This power is grounded in medical education and the information dumping that I think is common in the medical discourse. Giving all the information, even when it is not requested, may be telling the truth, but is does not aid the patient in their understanding of their condition. However, information dumping does allow the practitioner to remain emotionally distanced from the patient. Education about the biology of illness, that is not shared, continues to allow the practitioner to distance themselves from their patient. Naturally the practitioner knows more about the biology of illness than the patient. If the team chooses to dump all the biological facts on a patient, without being asked for them, or fails to give information when requested, then that patient is left with no power over his or her own illness. Sissela Bok points out that, "lying to patients has,..., seemed an especially excusable act." [42] Additionally, the medical community seems to avoid the issue of truth entirely. In fact, the A. M. A. Principles of Ethics mention little about when or if to tell the truth. The only mention of truth-telling is embedded in discussions about informed consent.[43] The idea of

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[42] Bok 222.

[43] American Medical Association, *Code of Medical Ethics*, 8.08 Informed Consent, 1997.

veracity is absent from virtually all medical oaths and codes. The Hippocratic oath, which so many physicians use to explain their actions, makes no mention of truthfulness. [44] We have to question this lack of direction about when or if to tell the truth in medical care. The lack of direction makes it clear that, "a physician can decide to tell as much or as little as he wants the patient to know, so long as he breaks no laws."[45] The truth is that there are no legal statutes that mandate what a practitioner must tell a patient, but that does not mean that there are no principles that govern such an action.

There seem to be some fundamental principles in medicine. Two of these principles are discussed by Sissela Bok; these are the principles of beneficence and nonmaleficence. [46] To these principles, I add: autonomy, truthfulness, benevolence, compassion, courage, prudence, phronesis, and justice. The most important may be beneficence and truthfulness. Fundamental to the practice of medicine is doing good. Beneficence is basically preventing harm, removing harm and doing good even at some cost or risk to oneself. This idea allows the practitioner to see the patient as a complex being, with feelings and spirituality. The important aspect of beneficence for this discussion is that what is good for a patient is that which is defined as good by the patient. [47] The only way to understand what the patient believes is good is to communicate with that patient. For a dying person, it may be very important for them to decide what happens at the end of their life. They may want to make decisions about who should get their property, what kind of burial or casket they want, and may have the need to repair relationships. If we are beneficent and if we look at patients with

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[44] Bok 223.

[45] Bok 224.

[46] Bok 222.

[47] Pellegrino, Edmund D. and David C. Thomasman, *The Virtues in Medical Practice*, (New York: Oxford University Press, 1993) 64.

the knowledge that they are more than sick bodies, then we make sure that they are cared for emotionally as well as physiologically.

The other significantly important aspect of the relationship is truthfulness. We looked a bit at trust in the previous chapter. Here, we revisit it only to remind ourselves that truth must be delivered in such a way that patients can openly receive it in an understandable way. Many times practitioners deliver information with more medical jargon than the average person can understand. This is one way to deliver asked for information in such a way that practitioners can remain distanced from the patient and still feel as if they have answered questions. The practitioner is being honest with the patient, but is not doing anything to benefit that patient's understanding of his/her condition. This type of communication is ineffective in helping the patient to make sense of their world. If practitioners truly want to help some patients, then they usually have to communicate effectively with them. Additionally, practitioners must engage with patients in ways that are appropriate for each patient's level of understanding and ability to use the information sought. Practitioners must remember that some patients cannot handle some information. It would be harmful to give information to patients in ways in which they could not make sense of the information. Harm also comes to the patient when practitioners fail to be benevolent in their practice. Benevolence is the virtue that disposes the practitioner to be committed to the high ethical standards for which medicine is known. [48] The harm continues without compassion which suggests the ideas of cosuffering, of fellowship in the experience, of comprehension of "what it's like," and even of taking upon oneself something of another's pain and making it one's own. [49] In order to avoid harm, the participants in the relationship must also have courage and exercise prudence.

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[48] Drane, James F. *Becoming a Good Doctor: The Place of Virtue and Character in Medical Ethics*, (Kansas City: Sheed and Ward, 1988) 33.

[49] Pellegrino 79.

Courage and prudence are virtues of practice. It takes courage to overcome our presuppositions. More importantly, it takes courage to engage in an open relationship where one's feelings and thoughts are often exposed. It also takes prudence to engage in such a relationship. Prudence is the exercise of practical judgment.[50] It is stepping back and looking at the whole person and then making a judgment about what is best for that person. This virtue, along with the others, must be carried out with phronesis and justice. Justice is simply rendering what is due to others.[51] Phronesis, as captured by Aristotle, means practical wisdom.[52] It is the capacity for moral insight. Phronesis is one's ability to gain understanding about how to carry out the best wishes of another person. Each of these components to an open relationship is designed to help prevent harm. I believe that they do so, but to understand how we must turn our attention to what harm is and how we might be able to avoid it.

Harm

To avoid harm we must first figure out what it is. The Encyclopedia of Ethics tells us that, " a necessary element in all harming is that it have an adverse effect on someone's interests."[53] This means that in order to harm persons we must be doing something that keeps them from achieving their goals or receiving what is owed to them. Therefore, we must come to some conclusion about the goals that a patient might have in the relationship with their practitioner. Sissela Bok noted, in her discussion of people with terminal illness, that "for the great number of patients the goal must be disclosure, and the atmosphere of openness."[54] Notice that the goal is not only

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[50] As offered by Mark Hanson- Associate for Religion- The Hastings Center.

[51] Pellegrino 92.

[52] Pelligrino 84.

[53] Encyclopedia of Ethics 437.

[54] Bok 239.

disclosure. The goal is also the atmosphere of openness that may come from an honest relationship. Here Bok is not saying that patients should be told information about their illness that they may not want; she is addressing the need some patients might have for open communication. Certainly it would be a problem to give information to a patient that has made no request for such information. In fact giving information in this way might be harmful. Maybe sometimes it is better for some patients to live in denial for a while. Maybe the truth is more than some patients can handle. For those people, the news should not be given. People have the right to receive information when they request it and not receive information when they have not asked for it. Personal autonomy does not end when a person is diagnosed with a terminal illness. Patients with terminal illness still have the ability to make autonomous decisions about their bodies and their health care. I am convinced that patients have the same need for open communication as people outside of the hospital.

The argument against this notion is that even if ordinary people may understand what is spoken to them, this is not true for patients. [55] This may be true; some patients cannot understand some information, even when they ask for it. But, some patients can and do. Some patients recognize that there is something wrong with their bodies and recognize how practitioners care for them when death is imminent.

Personal Interaction

In much of the literature, it is noted that the primary goal of those who choose to work with patients is for those patients to get well.[56] Unfortunately, in the case where the caregiver is treating and caring for a person dying from a terminal illness,

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[55] Bok 227.

[56] Rothenberg, Michael. "Problems posed for staff who care for the child." In *Care of the Child Facing Death*, ed. Lindy Burton (London: Routledge and Kegan Paul Ltd.,1974) 39.

this goal cannot be reached. According to Michael Rothenberg, a natural impulse, that all of us experience when we are faced with the dilemma of not being able to reach our goals, is to withdraw from the situation.[57] If he is correct, then we are faced with a problem. The problem is that a relationship probably cannot survive when one of the participants is withdrawing from the other. Patients seem to have the ability to recognize that people are withdrawing from them; a phenomenon that occurs all too often in the medical setting. We can see in the literature that people write of death as "a battle lost." [58] We see that "death is to be fought with any means possible." [59] Through this struggle to keep patients alive, there is little room for the dying person to be cared for in such a way as to be able to deal with the facts of life and untimely death. This becomes an even bigger problem when we turn to children whom many of us assume cannot even begin to understand their diagnosis and prognosis and have been excluded from most literature about relationships in the medical setting. In the next chapter, I will focus my attention on this issue of what dying children may be capable of understanding. Here, I will try to make some sense of the value of honest relationships with dying children.

Practitioner/Child Patient Relationship

There seems to be some value in carefully listening to a child's questions and providing honest answers to those questions, but what is the value? Are some children, especially those who are dying, better off because they have open

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[57] Rothenberg 44.

[58] Gordon, Bianca. "An Interdisciplinary Approach to the Dying Child and his Family," In *Care of the Child Facing Death*, ed. Lindy Burton (London: Routledge and Kegan Paul Ltd., 1974) 143.

[59] Easson, William. *The Dying Child: The Management of the Child or Adolescent Who is Dying* (Illinois: Charles C. Thomas Publishers, 1970) 91.

relationships with their practitioners? These are tough questions that we have done a poor job of examining. In the current literature, authors spend a great deal of time talking about the doctor/patient relationship as it pertains to adults. What they fail to discuss is the more common relationship between the nurse and the patient and any sort of relationship between a dying child and their practitioner. So, here we must come to some conclusions about the value of an open relationship with dying children by recalling what we know about dying children, what we know about their worlds and what we have come to understand about communication and sharing. My belief is that an open relationship will allow each dying child to make sense of the world, not be alone as they go through this discovery, and retain some power over their lives.

Most practitioners and patients who engage in open relationships find that this engagement needs some degree of emotion, personal interest, individuality, and mutual knowledge. [60] The two or perhaps more parties of these relationships need some emotional connection so that they can share the burdens of illness; they need to have personal interest in one another so they can share their hopes and desires; they need to maintain individuality so that one party does not command too much from the other; and they need to share mutual knowledge so that they can help one another throughout the sometimes tragic experience of death. This entry in the Encyclopedia of Ethics is focusing on adult relationships, but I do not see why these same four aspects of open relationships would not be important to dying children. Dying children are trying to make sense of a world that is full of the horrors of needles, medicine that makes them feel sick, and the inevitability of death. It seems almost impossible to imagine how a child could make sense of such a world unaided. The aid that these children need might be found in an open relationship that involves emotional support, personal interest, and mutual knowledge. Earlier we talked about the power that comes

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[60] *Encyclopedia of Ethics*, "Personal Relationships," 956.

from knowledge: the power that comes from medical information that is not shared. Isn't it possible that children need some of this power so that they can make sense of their world? Sissela Bok noted that one nurse found that, "from personal experience...patients who aren't told about their terminal illness have so many verbal and emotional questions unanswered that many will begin to realize that their illness is more serious than they're being told.."[61] If patients are left with these unanswered questions, then are they not in some sense left to die alone? I think that they are left to die alone and, I believe, that this aloneness is more harmful than we know. I cannot think of anything that does this more than to take away a person's right to information about themselves. It may be difficult to gauge what a patient wants to know, particularly if that patient is a young child, but we can all but eliminate this problem if we provide a relationship that allows for open questioning and answering. This type of relationship, the same type of relationship that we believe is effective for adult patients, may prove to be effective for child patients as they make sense of their world. If practitioners truly want to help some children, then they probably have to communicate effectively with them. Additionally, practitioners must engage with children in ways that are appropriate for each child's level of understanding and ability to use the information they are asking for. Practitioners must remember that some patients cannot handle some information. This is particularly true for some children; I deal with this issue in the next chapter.

Potential Problems

The type of open relationship that I believe practitioners should try to have with their patients has potential problems. The main problem is that it is hard to judge what patients really are able to understand and what they really want to know. I

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[61] Bok 225.

believe that the solution to this problem comes from the relationship itself. An open relationship will most probably provide the opportunity for the practitioner to learn how the patient is dealing with the information already possessed and the patient's ability to deal with additional information. Here I am not saying that practitioners should withhold information just because they do not think that patients are ready to hear that information. Rather, I am pointing out the need for practitioners to supply asked for information in a way that patients can understand and accept it. This may mean that the practitioner may have to explain the facts of prognosis in various ways to the same patient. The time should be taken to do so. In my experience as a patient and in working with children, I have come to understand that people rarely ask for information that they are not ready to hear. I do some volunteer work with grieving children and have noticed, on numerous occasions, that they ask detailed questions about the death of their parents only when they are prepared to hear the answers. Health care practitioners must trust that children can gauge what information they are ready to hear and then supply that information when it is requested. An additional problem may be that some people assume that children, that are told the truth about their diagnosis and prognosis, will be robed of hope. I disagree, children that are given information that they request can still have hope. They may have a different type of hope, but it is hope none the less. Children that are given information when they request it have the true hope that comes from knowing you are not alone and you have some control over your life.

The argument that children are not among those people that can understand information about their conditions remains. I disagree and hope to show that dying children can understand honest answers to their questions. In order to look at this issue we must look at cognitive development in children and discover what children may be able to comprehend.

Chapter 4

COGNITIVE DEVELOPMENT: HOW A CHILD DYING FROM A TERMINAL ILLNESS UNDERSTANDS DEATH

> He was a truly remarkable young man, mature beyond his years. But, then critical illness has a way of maturing people.
>
> -Marilynne Sequin, RN.

Cognitive Development: What is it?

Cognitive development as defined is the "intellectual development over time of a child especially in skills such as thinking, perceiving, reasoning and judging." [62] Studying cognitive development is extremely difficult because it has many components. However, in this thesis, I will focus on only some of these components. I will be looking at learning and more importantly how one gains information about the world. Recall that I am focusing on children aged seven to ten who are dying from a terminal illness. These children are sure to be gaining information that is unlike the information gained by the average healthy child. This is, however, not clear in studies that have been done on the cognitive development of children, mostly because we have failed to do many studies on the child dying from a terminal illness. I will also attempt to show that, based on what we know about cognitive development, the child dying from a terminal illness might have a higher cognitive level about death and dying than a healthy child.

It has been noted that children learn what they live. This means that children are better able to grasp those concepts with which they are most familiar.[63] Based on

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[62] Leve, Robert. *Childhood: The Study of Development*, (New York: Random House, 1980) 219.

[63] Leve 187.

this notion, a child living in a world filled with illness and death probably grasps these concepts better than a child who has never seen or experienced illness and death. Childhood development specialists have also noticed a correlation between intelligence and one's experiences.[64] We have come to understand that children are able to acquire cognitive thinking processes at different rates and in different times of their development, yet all children seem to need to acquire at least the following three processes before they can make sense of their world. The processes are: first, the child needs to be faced with new information or the need to redefine previously held information, second, the child needs to be able to transform that information so that it can be used in new situations and third, the child must be able to evaluate the new learning to make sure that it fits accurately into their world view.[65] Once a child had gained these processes, then the child should be able to think about the world they experience in such a way that they can acquire and use information.

Much of what we know about cognitive development and the assumptions for many of the studies I have been referencing have come from the work done by the Swiss psychologist, Jean Piaget. Piaget, in his detailed look at cognitive development, attempts to answer the basic question of "how does the simple infant gradually develop into an adult who is capable of abstract reasoning?"[66] Piaget predicts that children, at least those that I am talking about, are in what he calls the concrete operations phase. In this phase the child begins to conceptualize in a concrete way. They think logically, can classify things and develop the use of elementary logic.[67] The child can now organize their world based on this logic and see

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[64] Leve 188.

[65] Leve 225.

[66] Leve 196.

[67] Leve 320.

where things fit. Piaget implies that a child of this age and developmental level is probably unable to view or understand the more abstract concepts in our world. This means that they, at the age of seven through the age of eleven, could probably not grasp the concept of death in a way that we do as adults. Piaget's claim is that one does not begin to have genuine conceptual operations until one is close to the age of puberty. [68] These ideas suggest that children dying from a terminal illness might be able to understand the concrete aspects of hospital care and procedure, but they would most likely be unable to grasp ideas about death and dying in the way that adults do.

From discussions with children and those people that care for them as well as some of the more salient aspects of studies done on children, it is obvious that children do think about and understand the more concrete aspects of being ill. Myra Bluebond-Langer found, through her research with dying children, that "the children knew that the disease was a series of relapses and remissions, of 'good times and bad times,' against a back drop of bone pain, headaches that did not go away with aspirin, hemorrhaging that never seemed to stop, constant weakness, anemia, and infections that required hospitalization."[69] These children were at least aware of the physical changes that they were experiencing, but were probably aware of much more. In Bluebond-Langer's study she noted that, "the leukemic child acquired a great deal of information about the hospital, staff, rules and procedures; about the disease, its treatment, process and prognosis, before he died." [70] The dying child was immersed in the routines of the

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[68] Kastenbaum, Robert. "The Child's Understanding of Death: How Does it Develop?" In *Explaining Death to Children*, ed. Earl Grollman (Boston: Beacon Press, 1967)97.

[69] Bluebond-Langer, Myra. "Awareness and Communication In Terminally Ill Children: Pattern, Process, and Pretense," (Diss. University of Illinois, 1975)210.

[70] Bluebond-Langer, Myra. "Awareness and Communication In Terminally Ill Children: Pattern, Process, and Pretense," 213.

hospital and picked up various kinds of information that could affect the child's understanding of the more abstract concepts of death and dying. Because these children are so immersed in the various aspects of life in the hospital, they might also become immersed in ideas of death in the hospital. If this is true, then these children might be able to reason about abstract concepts of death in more advanced ways then the average healthy child who is not exposed to death and dying.

Views that Cast Doubt on Piagetian Theory

Piaget's model helps us to understand that all children, despite their different life patterns, are at some point able to deal with the more concrete aspects of the world. However, because Piaget never looked at dying children it may be inappropriate to use his model to look at the dying child. I believe that the world of the dying child is different from that of the well children. Furthermore, researchers who have studied Piagetian theory and then tried to see how it fits dying children have seen that the theory is not always very accurate for some children.

Studies have shown that, "even the young child has begun to enjoy the 'world of ideas' on at least an entrance level." [71] Also, it is noted that, "from approximately the age of five, the child seems gradually to be accommodating himself to the proposition that death is final, inevitable, universal and personal."[72] These children are beginning to understand the implication of death. They are coming to leave behind the thought that death is like going to sleep. Some researchers even speculate "that thoughts of death are intertwined with the total pattern of personality development right from the beginning, influencing and being influenced by the child's experiences." [73] If these

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[71] Kastenbaum 97.

[72] Kastenbaum 101.

[73] Kastenbaum 106.

researchers' findings are accurate, then it is possible that the dying child age 7-10 is able not only to deal with the concept of death, but also able to understand what death is and how death and dying fit in to their view of the world. Furthermore, many researchers have come to the conclusions that, "if not aware at a conceptual level, children are at least aware that something is happening to their bodies." [74] If children are aware of what is going on in their bodies, as the research suggests, then I would argue that we have some duty to those children. That duty would be to open discussion with each child in such a way that they can ask questions and we can respond with the truth.

Robert Coles tells us that children are full of whys.[75] They are curious when they see petechiae [76] on their skin. They wonder why they are having trouble breathing or why some lab technician keeps coming into their room to take their blood. Coles tells us that he has learned a lesson through his work; he has found that "children very much need a sense of purpose and direction in life....." [77] Coles was not talking about the child dying from a terminal illness, but he speaks a truth of all children. Just because these children are dying, it doesn't make them any less children. They have the same need to understand the world. They just have a different world to understand. They have to understand a world full of death, pain and unfortunately silence. Myra Bluebond-Langer found, in her study, that most of the children were aware that they were dying. She noted that they expressed this

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[74] Judd, Dorothy. *Give Sorrow Words: Working with a Dying Child*, (London: Free Association Press, 1989) 29.

[75] Coles, Robert. *The Moral Imagination of Children*, (New York: Random House, 1997) 101.

[76] Condition in which minute hemorrhagic spots, of pinpoint to pinhead size, develop on the skin.

[77] Coles 177.

awareness in very different ways; some directly said they were going to die; others were less direct, but all knew something was wrong with them and the world they lived in.[78]

I have gone about this chapter trying to make sense of the world in which the dying child is placed and I have tried to show that they live in a world that is different from the world in which the healthy child lives. If children do learn what they live, then the dying child does learn about death. However, that dying child learns about death amidst a host of other development problems. My focus in this thesis is on the cognitive development of the dying child, but I would be foolhardy to believe that cognitive development is not effected by the other areas of development. So, now we turn to some other areas of child development. Unfortunately, here again we have almost no data on the dying child. Therefore, we will begin our look at the child living with a chronic illness. Recall that many of the children dying from a terminal illness were first diagnosed with a chronic illness.

Other Issues in Child Development

Clearly illness affects development, but what is that effect and does that effect carry to the area of cognitive development? Studies on children with chronic illness have conclusively shown that in most areas of development the child will be behind the rest of the children his/her age. [79] Over the life-span, from infancy through adolescence, the child may have trouble developing autonomy, learning social roles, mastering body control skills (especially motor skills), establishing

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[78] Bluebond-Langer, Myra. "Awareness and Communication In Terminally Ill Children: Pattern, Process, and Pretense,"213.

[79] Yoos, Lori. "Chronic Childhood Illness: Developmental Issues." *Pediatric Nursing* 13 (Jan.-Feb.) 26.

independence, and being comfortable with their body. [80] Though each of these may affect the cognitive development of the child, the profound cognitive effects of long term hospital care and illness seem to be related to establishing a full set of tools that help one to understand and use concrete operations. This is most likely due to the reality that much of the knowledge the child needs to acquire is acquired in the social setting of the classroom.[81] However, this study of children with chronic illness did not look at how these children were able to understand illness or death. More recent studies of children and illness have looked at healthy children and what they understand about illness and death. These studies tend to suggest that "children's concepts of illness do evolve in a systematic and predictable sequence consistent with Piaget's theory of cognitive development." [82] However, we must remain clear that most of these studies are done on healthy children and the data might not reflect a dying child's understanding. The few studies done on ill, dying, or hospitalized children seem to show different results than those done on healthy children. These studies, although not all of them, tend to show that there is a definite correlation between a child's cognitive development and their understanding of illness.[83] This suggests that children who have experienced illness or have been in the hospital are better able to understand illness causality and other illness concepts. This does not suggest that these children have an overall higher cognitive level than well children. These studies make the suggestion that ill children are better able to understand illness. Despite the

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[80] Yoos 26-7.

[81] Yoos 27.

[82] Burbauch, Daniel and Lizette Peterson. "Children's Concepts of Physical Illness: A Review and Critique of the Cognitive Development Literature," *Health Psychology* 5(3) (1986) 307. and Perrin, Ellen and Susan Gerrity. "There's a Demon in Your Belly: Children's Understanding of Illness," *Pediatrics* 67 (June 1981) 848.

[83] Burbauch 314.

reality that there are no published studies, in the area this thesis pertains to, done on dying children and there may never be any, I suggest that, based on research done on ill or hospitalized children, studies on dying children might show that these children have a more established and better understanding of death than do healthy children.

If I am right about what research might show in respect to the dying child's ability to understand death and we are able to establish a mutually honest and giving relationship between the practitioner and the child, then it is fairly possible that we will be able to aid the dying child in their search for meaning about life and death. Next, we turn to literature as a tool in supplying the information that dying children may request. This tool is one that will probably not work without personal engagement and a belief that dying children can understand death.

Chapter 5

CHILDREN'S LITERATURE: A TOOL FOR APPROPRIATE DISCLOSURE

> ...literature: it is held to be instrumental to the communication of truths that could in principle be adequately stated without literature....
>
> -Martha Nussbaum, *Love's Knowledge*

Literature's Value

It will take more than good literature to help a child understand death and dying. Literature cannot stand alone; it can only act as a complement to personal engagement. However, without it we may fail to help children understand death and dying. My beliefs in the strength of literature as a teaching tool to contribute to one's ability to grasp abstract concepts are not mine alone. Martha Nussbaum tells us that stories not only allow us the opportunity to "embrace the ordinary,"[84] but also to gain some understanding of those things that are outside of the world we readily experience. If literature does in fact afford us the opportunity to grasp the ordinary, then literature would be a positive tool in helping children dying from a terminal disease to grasp the concept of death. Eulalie Ross notes that as a child learns about life and death, "the experience of reading a book can contribute to the child's growth, and the better the book, the more vigorous the growth." [85] On the basis of this, we must come to some understanding of what makes a book good and what growth we are really trying to achieve.

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[84] Nussbaum, Martha. *Poetic Justice: The Literary Imagination and Public Life*, (Boston: Beacon Press, 1995) 9.

[85] Ross, Eulalie. "Children's Books Relating to Death: A Discussion in Explaining Death to Children." In *Explaining Death to Children*, ed. Earl Grollman (Boston: Becan Press, 1967) 249.

What Makes a Book Good?

If children really want to know about death and dying, then the best possible book is one that shows death in at least an honest way. In useful literature death would be "presented for the child to absorb and ponder over, strengthening as he does so the inner resources that will help him cope with death when it moves within his confines."[86] However, if children and the adults that care for them are more concerned about loss of function, the useful literature would discuss loss of function and the importance of that in relation to how the world now looks to the child. If the literature is good, then it will give an accurate depiction of death or loss and help the child to gain some "tolerance for the enigma."[87] Good literature, that which is useful, will also promote growth in the child's understanding of death.

Growing through the use of Literature

We cannot expect that all good literature about death or loss will have a profound effect on our child's understanding of these concepts, but we can expect that some good literature will have a positive effect on some children. This effect will be in the form of a complex realization about the world and how they fit into that world. They can gain much in the way of understanding about how death and loss really function in the world. Unfortunately, because children have not experienced as much of the world as some authors of children's literature, we must always be aware of the possibility that some literature about death and loss is not good literature.

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[86] Ross, Eulalie 271.

[87] Ross, Eulalie 257.

Trouble: Bad Literature

Literature that distorts the world by presenting historical or scientific facts falsely or misrepresents the importance of suffering or harm, is literature that does more harm than good. [88] Fantasy literature, that twists the historical and scientific facts of the world, has a place in aiding the growing imagination of the child. Yet, it fails the child when we are talking about something as serious and difficult as death and loss. Those books that give children a false idea about the world and how death really affects us, on the most personal level, are harmful. Therefore, we must always be aware of what good literature is and we must help our children to read critically.

The Tools

We must give all our children, especially those dying from a terminal illness, the skills "to recognize and then match behavior to the moral circumstances at hand."[89] We must recognize that children may not be able to learn about abstract concepts and how to react to those concepts when they become reality, if their discovery of the world is entirely unaided. [90] One such aid is good literature. Although literature may not be the only tool in the education of our dying children, it is certainly a tool we cannot overlook. It is a fact that many of us have a hard time talking to children about death and loss. Recall the story about Angela's parents from chapter one; here is another part of the story:

> She proceeded to tell me how she had been diagnosed with cancer more than two years ago and that she knew she would die. Angela was

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[88] Nussbaum 75.

[89] Churchland, Paul. "Neural Representations of the Social World" In *Mind and Morals: Essays on Ethics and Cognitive Science*, ed. Larry May, Marilyn Friedman and Andy Clark (Massachusetts: MIT Press, 1996) 105.

[90] Churchland 105.

> heartbroken that her mother and father could not talk with her about her death. She had tried to discuss it with her doctor, but he had rebuked her abruptly for such talk...[91]

If Angela's parents are not able to talk about death and her doctor rebukes her for the mere thought of it, then who is going to explain death and loss to her? Angela's case may be a special one. Maybe I am wrong. Maybe most parents are willing to talk about death and maybe most doctors and nurses want to have open dialogues with their patients; still what is the harm in the use of good literature as an aid in a child's understanding? There doesn't seem to be any harm. Surely some children will benefit from the use of good literature and none will be harmed. Some researchers say that a child conceives of death based on their age, other researchers say that this conception comes from maturity. Might it also come from what a child is taught? [92]

I turn next to a look at current children's literature. The books listed and talked about here are examples of good literature, but each of us must look at all books before we give them to any children and only use those that are appropriate for a particular child.

Examples of Good Literature

For the children in the age group to which this thesis is targeted, there are few books that really get at the heart of death and dying. Most literature about death and loss is written for the survivors. The literature is written for those people who have experienced the death of others, but are not about to die. This is a failure on the part of authors of children's literature that may have much to do with our fear of childhood death. Maybe when we begin to realize that death is natural and discover that dying

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[91] Seguin 74.

[92] Sylvia Anthony makes this idea clear in her book, *The Discovery of Death in Childhood and After*. This is also an idea held by most of the people that work with children and use literature as a tool in their work.

children really do need to gain some understanding of death so that they can go peacefully, there will be a multitude of books available for these children. Until then, we have to look critically at books that are available and make sure that they give children a realistic look at death and loss.

The books that I believe to be the most useful for children, between the ages of seven to ten, are books that look at death in a number of ways. Antoine de Saint-Exupéry, in *The Little Prince*,[93] gives the child a look at both life and death. He explains that there is nothing sad about leaving your old shell (body) behind. This book may confuse some children, but it is a wonderful book for adults to share with children who may believe that the spirit exists separately from the body. Eleanor Coerr, in *Sadako*,[94] gives the child a realistic look at dying from cancer and how death can be a very peaceful time. Carl Sandburg's poem, "Blue Silver", gives children a very beautiful look a child's funeral. The idea of being in a coffin may be extremely terrifying for children, but Sandburg's words,

> So they made a long silver box, just long enough to reach from her head to her feet. And they put on her a blue silver dress and a blue silver band around her forehead and blue silver shoes on her feet. There were soft blue silk and silver sleeves to cover her left arm and her right arm- the two arms crossed on her breast like the letter V.[95]

make the event easier to understand and not so scary. We can also see stories about death in *The Chronicles of Narnia*.[96] In this seven book series, four children travel on many adventures and face death in very real ways. These are adventure books, but

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[93] De Saint-Exupéry, Antonie. *The Little Prince*, (San Diego: Harcourt Brace & Company, 1943).

[94] Coerr, Eleanor. *Sadako*, (New York: G. P. Putnam's Sons, 1993).

[95] Sandburg, Carl. "Blue Silver." In *Rootabaga Stories*.

[96] Lewis, C. S. *The Chronicles of Narnia*, (New York: Macmillan Publishing Co., 1970).

in worlds where these children face death there is always a detailed exploration of how they feel about the loss of life. We can also get some idea about death from *Charlotte's Web* and *Little Women.* However, these books fail to talk about death as it really affects the child's person. Some of the best literature that is written for children is written by children and adults who had childhood illness. A child can learn much about body function loss by reading Lucy Grealy's, *Autobiography of A Face.*[97] This is a true story about a young child with a cancer that causes her to have some facial abnormalities. It is an autobiography, not about death, but about fear and feeling different. In this book, Lucy Grealy had a hard time feeling normal anywhere outside of the hospital. The hospital became her safe place where she was more like the other children. It is possible that many other children dying of a terminal illness feel this way. I think it would be very beneficial for them to know they are not alone. Other books that detail how children deal with terminal illness are: *The Kid's Book about Death and Dying,*[98] *Love, Mark,*[99] and many others.[100] These are compilations of stories and letters written by children facing terminal disease, some of whom are dying. One book that I believe should be shared with every child is *There Is a Rainbow Behind Every Dark Cloud*,[101] which is a picture and word book that allows children to see other children living with terminal illness. In this book, children living with and dying from

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[97] Grealy, Lucy. *Autobiography of a Face,* (Boston: Houghton Mifflin Company, 1994).

[98] Rofes, Eric. *The Kids' Book about Death and Dying,* (Boston: Little, Brown Publishers, 1985).

[99] Scivani, Mark. *Love, Mark,* (Syracuse: Hope for the Bereaved, 1980).

[100] For a very comprehensive look at the currently available literature on death and dying look at: Grollman, Earl. *Talking About Death: A Dialogue between Parent and Child,* (Boston: Beacon Press, 1990).

[101] Center for Attitudinal Healing, *There Is a Rainbow Behind Every Dark Cloud,* (California: Celestial Arts, 1979).

terminal illness detail their feelings about terminal illness in such a way that one cannot help being touched by their deep insight and understanding. Finally, for those children who may need or want more advanced literature *Shira: A Legacy of Courage*[102] is a great biography of a child who comes to terms with illness and dying. However, good literature can only be good for children if it is presented by someone who is willing to invest some time with children and provide for them healthy communication about death and loss.

Additionally, written words are not the not the only source of dialogue about death and dying. For instance, there are some great short films that do a wonderful job of introducing children to death and to other children dying from terminal illness. For example, *Nine-Year-Olds Talk About Death*, a film that shows healthy fourth-graders talking about death, introduces this concept in a light that is easily understood by all children. There are also some films that discuss specific aspects of death, such as funerals, cremation and burial, that might be helpful in a child's understanding of the more concrete aspects of the dying process. However, neither literature nor film will be successful as a learning tool without healthy communication and interaction between the child and the caregivers or parents supplying these tools.

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[102] Grollman, Sharon. *Shira: A Legacy of Courage*, (New York: Doubleday, 1988).

CONCLUSION

In this thesis the focus has been on the seven to ten year old child who is dying from a terminal illness. We have looked at some of the philosophies held by those people that choose to disclose the truth, seen the value in the an open relationship, looked at what information dying children are cognitively able to process and grasp, and finally explored a tool that may help children grasp the concept of death and see how it fits into their world. I have stated how dying children might need an open relationship with their practitioners so that they feel comfortable asking questions and receiving honest answers. And I have shown a need for each child to have some control over his or own body and death. It might be said that the reality of what I want for children, that they be supplied with the information they ask for, may rob them of hope. I believe that true hope only has one source. That source is knowing that you will receive the truth when you ask to hear it. I think that most people, even children, can and do deal with the reality of death. Maybe we, as caregivers, do not want to deal with death and can hardly handle it when a child dies, but I would argue that children tend to not ask for more than they really want to know.

I have argued that the dying child, in the last stages of illness, knows a great deal about medicine, loss and death. We hear it time and time again: children learn what they live. A dying child lives in a world where death is near. That child is bound to learn about death. Hopefully, we can all be able to deal with death enough that these children do not have to die alone. Yes, the child still dies and those of us left will mourn that loss, no matter what the child understands when he or she dies. But can we really allow the dying child, who knows they are dying, to live the end of their life alone?

Additionally, I would like to propose some changes in the ways in which we educate or children and the practitioners that care for them. Yet, I know that bringing about large scale educational change may take a lifetime. We might consider policy of death

education in schools, for all children. That way if they are ever faced with a terminal illness, they would know a little about being ill and what death is like. Certainly, just knowing something does not take away the impact of it actually happening, but it may soften the blow. I also propose that adult caregivers are exposed to better training about death, especially as it concerns children. Medical care is taught in such a way that cure is more important than care and death is always avoided. We must make room in education for death. Medicine is not a perfect enterprise; therefore patients will die. We must be prepared for that, so that we can help the patient in their last stages of life. We must also make room for open relationships in the medical setting. It certainly will take more time to establish a relationship than it takes to "dump" information. We must take that time. Our children are worth it. Lantos writes, " most children in the world who die don't get dialysis, TPIV, or the truth. Might not two out of three be enough?"[103] I say no, two out of these three will never be enough, not if we can do all three and we can.

On a final note, I am pleased to add that things are starting to change in this area. We are starting to talk about children and death. We are starting to realize that children and their beliefs and ideas are important. Recently, OPRR[104] , a federal agency to which most federally funded research most answer, has adopted a policy requiring the use of children in all research that involves human subjects, unless conditions are met that show why children must be excluded from the research. There has also been much discussions about dying children and their rights to make decisions

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[103] Lantos 91.

[104] OPRR- Office of Protection from Research Risk

about their own health care on nationally recognized television programming. [105] These are positive steps in treating children as important participants in decision making. May we continue to take such positive steps.

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[105] One story line on television's ER dealt with this issue as it pertained to a child with cancer deciding to have an experimental treatment.

BIBLIOGRAPHY

BIBLIOGRAPHY

American Medical Association, *Code of Medical Ethics.* 8.08 Informed Consent, 1997.

Anthony, Sylvia. *The Discovery of Death in Childhood and After.* New York: Harcourt Brace, 1940.

Bauer, David. " What of the Dying Child?" In *Death in the Life of Children*, ed. Kaoru Yamamoto. Arizona: Kappa Delta Pi, 1978.

Beauchamp, Tom and Robert Veatch. *Ethical Issues in Death and Dying.* 2nd ed. New Jersey: Prentice Hall, 1996.

Bluebond-Langer, Myra. *The Private Worlds of Dying Children.* New Jersey: Princeton University Press, 1978.

Bluebond-Langer, Myra. "Awareness and Communication In Terminally Ill Children: Pattern, Process, and Pretense." Diss. University of Illinois, 1975.

Bok, Sissela. *Lying: Moral; Choice in Public and Private Life.* New York: Panetheon Books, 1978.

Buckingham, Robert. *A Special Kind of Love: Care of the Dying Child.* New York: Continuum Publishing Co., 1983.

Burbach, Daniel J. and Lizette Peterson. "Children's Concepts of Physical Illness: A Review and Critique of the Cognitive- Development Literature." *Health Psychology* 1986, 5(3): 307-325.

Cabot, Richard. "The Use of Truth and Falsehood in Medicine: An Experimental Study." *American Medicine* 5(1903): 344-49.

Center for Attitudinal Healing. *There is a Rainbow Behind Every Dark Cloud.* California: Celestial Arts, 1979.

"Children and Ethical Theory." *Encyclopedia of Ethics.* 1992 ed.

Churchland, Paul. "Neural Representations of the Social World" In *Mind and Morals: Essays on Ethics and Cognitive Science*, ed. Larry May, Marilyn Friedman and Andy Clark. Massachusetts: MIT Press, 1996.

Coerr, Eleanor. *Sadako.* New York: G. P. Putnam's Sons, 1993.

Coles, Robert. *The Moral Intelligence of Children*. New York: Random House, 1997.

De Saint-Exupéry, Antonie. *The Little Prince*. San Diego: Harcourt Brace & Company, 1943.

Doka, Kenneth. "The Cruel Paradox: Children Who Are Living with Life- Threatening Illnesses." In *Handbook of Childhood Death and Bereavement*, ed. Charles Corr and Donna Corr. New York: Springer Publishing Co., 1996.

Drane, James F. *Becoming a Good Doctor: The Place of Virtue and Character in Medical Ethics*. Kansas City: Sheed and Ward, 1988.

Easson, William. *The Dying Child: The Management of the Child or Adolescent Who is Dying*. Illinois: Charles C. Thomas Publishers, 1970.

Encyclopedia of Ethics, 1992 ed.

Fry. " Images of Death in Children." In *Death in the Life of Children*, ed. Kaoru Yamamoto. Arizona: Kappa Delta Pi, 1978.

Gareth, Matthews. "Children's Concepts of Illness and Death." In *Children and Health Care: Moral and Social Issues*, ed. Loretta Kopelman and John C. Moskop. Boston: Kluwer Academic Publishers, 1989.

Grealy, Lucy. *Autobiography of a Face*. Boston: Houghton Mifflin Company, 1994.

Grissco, Thomas and Linda Vierling. "Minors' Consent to Treatment: A Developmental Perspective." *Professional Psychology* 9 (August 1978): 412-27.

Grollman, Sharon. *Shira: A Legacy of Courage*. New York: Doubleday,1988.

Goldman, Ann. *Care of the Dying Child*. Oxford: Oxford University Press, 1994.

Gordon, Audrey K. and Dennis Klass. *They Need to Know: How to Teach Children about Death*. New Jersey: Prentice Hall Inc., 1979.

Gordon, Bianca. "An Interdisciplinary Approach to the Dying Child and His Family" In *Care of the Child Facing Death*. Lindy Burton, ed. London: and Kegan Paul Ltd., 1974.

Grollman, Earl. *Talking About Death: A Dialogue between Parent and Child*. Boston: Beacon Press, 1990.

Jackson, Jennifer. "Telling the Truth." *Journal of Medical Ethics* 17(1991): 5-9.

Judd, Dorothy. *Give Sorrow Words: Working with a Dying Child*. London: Free Association Books, 1989.

Kastenbaum, Robert. " The Child's Understanding of Death: How Does it Develop?" In *Explaining Death to Children*, ed. Earl Grollman. Boston: Becan Press, 1967.

Lantos, John. "Should we Always Tell Children the Truth?" In *Perspectives in Biology and Medicine (Autumn 1996)*, ed. Richard Landu, et al. Illinois: University of Chicago Press, 1996.

Lewis, C. S. *The Chronicles of Narnia.* New York: Macmillen Publishing Co., 1970.

Leve, Robert. *Childhood: The Study of Development.* New York: Random House, 1980.

Lipkin, Mack. "On Lying to Patients." *Newsweek* (June 4, 1979): 13.

Marten, George and Alvin Mauer. " Psychosocial Interactions of the Dying Child, the Parents, and Health-Care Professionals." In *Children and Death: Perspectives from Birth through Adolescence*, ed. John Schowalter, et al. New York: Praeger Publishers, 1987.

Meyer, Bernard. "Truth and the Physician." In *Ethical Issues in Medicine: The Role of the Physician in Today's Society*, ed. E. Fuller Torrey. New York: Little Brown and Company, 1968.

Mohowald, Mary. *Women and Children in Health Care: An Unequal Majority.* Oxford: Oxford University Press, 1993.

Mulholland, Clare. 1973.

Novack, Dennis, Robin Plumer, Raymond Smith, Herbert Ochitill, Gary Marrow and John Bennett. " Changes in Physicians' Attitudes Toward Telling the Cancer Patient." *Journal of the AMA* 241 (March 1979): 897-900.

Nussbaum, Martha. *Poetic Justice: The Literary Imagination and Public Life.* Boston: Beacon Press, 1995.

Pekkanen, John. *MD..: Doctor's talk about themselves.* New York: Dell Publishing, 1988.

Pellegrino, Edmund D. and David C. Thomasman. *The Virtues in Medical Practice.* New York: Oxford University Press, 1993.

Perrin, Ellen C. and Susan Gerrity. " There's a Demon in Your Belly: Children's Understanding of Illness." *Pediatrics* 67 (November 1981): 841-849.

Rofes, Eric. *The Kids' Book about Death and Dying.* Boston: Little, Brown Publishers, 1985.

Ross, Eulalie. "Children's Books Relating to Death: A Discussion in Explaining Death to Children." In *Explaining Death to Children*, ed. Earl Grollman. Boston: Becan Press, 1967.

Ross, W. D. *The Right and the Good.* Oxford: Oxford University Press, 1930.

Rothenberg, Michael. "Problems posed for staff who care for the child." In *Care of the Child Facing Death.* Lindy Burton, ed. London: Routledge and Kegan Paul Ltd., 1974.

Sandburg, Carl. "Blue Silver." In *Rootabaga Stories.*

Samp, Robert and Anthony R. Currei. "A Questionnaire Survey on Public Cancer Education Obtained from Cancer Patients and their Families." *Cancer* 10 (1957): 382-384.

Scivani, Mark. *Love, Mark.* Syracuse: Hope for the Bereaved, 1980.

Seguin, Marilynne and Cheryl Smith. *A Gentle Death.* Canada: Key Porter Books, Ltd., 1994.

Sidgwick, Henry. "The Classification of Duties of Veracity." *Methods of Ethics* (1907):312.

Speece, Mark and Sandor Brent. "The Development of Children's Understanding of Death." In *Handbook of Childhood Death and Bereavement*, ed. Charles Corr and Donna Corr. New York: Springer Publishing Co., 1996.

Speece, Mark and Sandor Brent. "Irreversibility, Nonfunctionality and Universality: Children's Understanding of Three Components of a Death Concept." In *Children and Death: Perspectives from Birth through Adolescence*, ed. John Schowaiter, et al. New York: Praeger Publishers, 1987.

Weir, Robert and Charles Peters. "Affirming the Decisions Adolescents Make about Life and Death." *Hastings Center Report* 27 (November 1997): 29-40.

Worthington, Hooker. *Physician and Patient: Or, a Practical View of the Mutual Duties, Relations and Interests of the Medical Profession and Community.* New York: Baker and Schribbner, 1849.

Van Eys, Jan. " The Definition of Dying and the Personhood of the Child." In *Children and Death: Perspectives from Birth through Adolescence*, ed. John Schowaiter, et al. New York: Praeger Publishers, 1987.

Yoos, Lori. "Chronic Childhood Illness: Developmental Issues." *Pediatric Nursing* 13 (Jan.-Feb.) 25-28.