

Extreme Caregiving: An Ethical Analysis of Narratives by Parents

A THESIS
SUBMITTED TO THE FACULTY OF
UNIVERSITY OF MINNESOTA
BY

Lisa C. Freitag, M.D.

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
MASTER OF ARTS BIOETHICS

Adviser:
Joan Liaschenko, PhD, RN, FAAN

December 25, 2013

Copyright Lisa C. Freitag, 2013

ACKNOWLEDGEMENTS

This paper has been a long time in the making, and I owe thanks to many people who made a place for me to work out my somewhat odd ideas and helped me turn them into a thesis. My biggest thanks are owed to Joan Liaschenko whose endless support and hours of brilliant conversation helped me to organize my incoherent and emotional thoughts, gently correcting my false impressions and herding me into some semblance of academia. She guided me to narrative ethics, and to feminist and care ethics, and ultimately introduced me to the work of Joan Tronto. I also owe thanks to Joan Tronto for providing a theory of care ethics that works for me, and helping me to stretch it into a practical framework for considering a problem of caregiving. Both Joans showed an exceptional amount of kindness, wisdom and tolerance.

I would also like to thank Mary Faith Marshall for her guidance through the early stages of this project, when I thought it was going to be about limiting neonatal resuscitation. And to John Song who came in at the last minute, had to read hundreds of pages to catch up, and still found things we missed.

I must also thank the staff and fellow students at the University of Minnesota Center for Bioethics who welcomed a disgruntled pediatrician into a wonderful community. I particularly have to thank Margie O'Neill, without whose diligence and concern none of this would have happened.

DEDICATION

For the extreme caregivers who showed me what to look for: Elizabeth, Sandy, Annette, and Linda, though I suspect you won't have time to read it, and that it would have been more help to you to do the dishes and put in another load of laundry.

ABSTRACT

Home medical care for medically complex and intellectually disabled children is frequently prescribed by providers, but the consequences for the family of such care are rarely considered in full. It is recognized that at times the care required might become physically demanding and emotionally burdensome. However, I believe that this sort of caregiving often reaches extreme levels, making our continued reliance on family caregiving ethically problematic.

This paper analyzes several novel-length narratives by parents of intellectually disabled children to look deeper into the lives effected by this complex form of home care. Building on the care ethics framework developed by Joan Tronto, I examine particularly the ways in which the parents perceive their caregiving duties and demonstrate Tronto's caregiving virtues of attentiveness, responsibility, competence and responsiveness. This work begins to theorize caregiving in a new way, revealing previously unrecognized ethical concerns raised by this sort of extreme caregiving.

TABLE OF CONTENTS

Chapter One: Introduction	01
Chapter Two: Background	06
Defining Extreme Caregiving	07
Extent of the Problem	12
Obscuring the Problem	15
An Example of a Misunderstanding	25
Chapter Three: Methods: Narrative Ethics	28
Ways of doing narrative ethics	29
Types of illness narratives	38
Descriptions of the narratives	43
Limitations of this work	50
A word about making lemonade	53
Chapter Four: The Virtues of Care	56
The Phases of Care	57
Responsiveness	66
Chapter Five: Burden of care	73
Physical burden of care	76
Multiple parental responsibility for care	79
Financial burden	82
Social isolation	85
Emotional burden	88
Lack of choice	90
Ambivalence	93
Attentiveness and Responsibility	97
Chapter Six: Competence	100
The Quest for Knowledge	103
Framing competence	115
Goals of care	124

Summary and Implications	126
Chapter Seven: Responsiveness	129
The Child as Disease	133
The Unreliability of Interpreting needs	137
The Child as Teacher	144
Implications	148
Chapter Eight: Conclusions	150
Attentiveness and Responsibility	153
Competence	155
Responsiveness	157
Future Work	159
References	162

CHAPTER ONE INTRODUCTION

Until recently, no one . . . was willing to admit that a child could be loved and still be too difficult to be cared for by his or her parents. Because until twenty years ago, children this medically complex didn't exist. They didn't survive. High-tech medicine has created a new strain of human beings who require superhuman care. Society has yet to acknowledge this reality, especially at a practical level (Brown, 2011, p. 95-96).

This quote is from a memoir called *The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son*. The author, Ian Brown, is the father of one of those medically complex children whose survival is made possible only by recent advances in medicine. As medical providers, or consumers, of the benefits of modern medicine, it is too easy to stop with this extraordinary survival, and congratulate ourselves on our collective scientific prowess. We usually don't acknowledge that, for many of these children, survival does not guarantee normal health and development. We forget that, sometimes, continued life is maintained on a day to day basis, by constant vigilance and complex home care. The families of the children who represent that "new strain of human beings," often pay a high price for that survival. Brown is all too aware of the amount of care required, having provided it for his son for thirteen years of physically intense days and sleepless nights. It is indeed a superhuman undertaking.

I first became aware of the problem posed by this extraordinary caregiving as a child, watching my parents' efforts to raise my mentally retarded brother Paul at home. In the early sixties, the complex medical care needed by Ian Brown's son was not available. There were no gastrostomy feedings, which Brown describes in the first chapter of his book, so my mother spent eight hours a day during Paul's first two years feeding him a few drops at a time. Nor were there such things as appropriate classes in the schools, or therapy techniques to help delayed motor skills. My mother invented her own version of physical therapy to stretch his tight muscles, with my father building devices to help him crawl and, much later, walk. She did her best to help him learn to talk, and use the bathroom, and dress himself, with slow progress over years. Meanwhile, she and my father became activists for the disability movement, which quietly paralleled the civil rights movement, championing special education, founding a

local chapter of the Association for Retarded Children, and forcing closure of inhumane institutions.

Their work never really ended. When it became obvious that Paul would never be able to hold a job, my father founded the sheltered workshop where he still works today. And as they began to age, with my brother still unable to live independently, they returned to activism to find him placement in a group home. He was 47 years old when he moved out. Until that time, my siblings and I went about our lives aware that we might need to take on his care ourselves at any time.

When I chose to go to medical school, I was not really hoping to find a cure for my brother, though I did want, and eventually found, an explanation for his problems; birth anoxia with brain injury and mild cerebral palsy. But perhaps because of my family experiences, I began to connect with the families of medically complex and intellectually delayed children who arrived in my practice. Though much of their complex medical management by necessity falls to pediatric sub-specialists, it is not uncommon to see them in a general pediatric practice. Their arrival in the office even for a routine check-up or minor illness is usually enough to put my schedule behind for the rest of the day. Nothing about these kids is routine. But even expanding the usual ten minute visit to 20 minutes or an hour or even two hours cannot begin to address all the problems that need to be raised.

It is easy for medical providers to forget, when these children are being cared for at home and effectively out of sight, just how much care they need. It is rare to stop to think about the parents who administer all the medications that might be prescribed, arrange for recommended visits to therapists and specialists, and live with those problems around the clock. But over my years of pediatric practice, three “special needs” families let our relationships change from doctor/patient to friendship. I saw that my family, growing with Paul, was neither alone nor in a uniquely difficult caregiving situation. And I began to suspect that the consequences of this care were potentially deeper and more problematic than realized.

The parents of these children, like my parents, often become vocal advocates for their children, but they rarely stop to pay attention to their own needs. They are too busy with the endless round of caregiving to think about the superhuman work they are doing. Their own lives are often put aside by the urgent necessity of meeting their child’s needs. They rarely have time to think about, let alone tell, their own stories. Yet, over the

past few decades, a very few parents have dared to expose their feelings in published books. Their stories need to be heard.

The goal of this paper is, first of all, to describe the lives of these parents and the extra burdens that fall to them in raising these children with complex medical needs or intellectual disabilities. I will draw from personal experience, both with my own family and the lives of the families I encountered in pediatric practice, and those narratives by parents that are available. The providers of medical care need to be aware of the burdens imposed by the care they are prescribing, and aware that there is sometimes a high price being paid, out of their sight, for the miracle cures of which we are understandably proud. To highlight the problems, I have begun calling what they are doing for their children “extreme caregiving.”

A second goal in outlining the difficulties encountered in caring for these complex children, is to elucidate the consequences of caregiving for the parent/caregivers, as well as their often permanently dependent child. I believe that the difficulty and complexity of the tasks that have fallen to them raise ethical concerns that are not currently being addressed. I argue that the unique ethical problems arising from extreme caregiving, may impact relationships between parents and health care providers. I believe that understanding these parents’ attitudes and difficulties is essential when making medical decisions, particularly decisions around discharge planning or end of life discussions.

In order to penetrate the lives of these parents and their children, however, I have found that it is necessary to understand more about the act of caregiving itself. Many of the ethical consequences of the extraordinary duties that fall to these parents are best understood as caregiving problems. In order to understand them, we must advance our understanding of an ethic of care. So, as a final goal, I hope that an exploration of this complex form of caregiving will provide a conceptual framework that can be extended to other care situations, and used to elucidate the nature of caregiving itself.

I will begin by defining “extreme caregiving,” how I derived the term and how we might be able to recognize it. I will not attempt an exact definition, as arguing about who is and is not doing extreme caregiving is pointless, but I will explain how the children requiring extreme caregiving have been overlooked, and attempt to quantify their numbers. In the second chapter, I will also review past research that has been done on specific groups of children, some of whom undoubtedly require extreme caregiving.

Because those studies have generally concentrated on things other than meeting a child's needs, they do not form a complete picture of the necessary caregiving.

It is in narrative where I believe an accurate descriptions of the hidden emotional consequences of the extreme caregiving relationship can be found. Since I intend to attempt to uncover ethical concerns by analysis of narratives written by parents about raising these children, in Chapter Three I will provide a description of narrative ethics and its uses, concentrating on its use to analyze stories written as witness to sickness. In these narratives, the parent is witness to illness in their children's bodies, and not physically sick himself, but the relevance and importance of the stories are similar. I will then describe the various narratives and defend my choice of a few of them for deeper reading.

Next, we need a way to understand care, not as an emotion which all parents have for their children, but as an act to fulfill a need. In Chapter Four I will expand on theories of care proposed by political scientist Joan Tronto (1993). She has broken the act of caring into four phases, each of which move an actor closer to participating in the work of the meeting of needs. For each phase, she has proposed a virtue which can be used to ethically evaluate the action at that phase. I will expand upon her theories, perhaps in way their author never intended, by using the virtues as a framework from which to spotlight the many activities, both physical and emotional, in which these parents must engage in order to meet the complex needs of their children. The remainder of the chapters are based on Tronto's phases of care and their associated virtues.

In Chapter Five, I will concentrate on the first two phases, "caring about" and "taking care of." Their associated virtues are attentiveness and responsibility, and looking at the many duties to which parent extreme caregivers are called upon to be attentive to and responsible for will serve to accentuate the enormity of the task they are performing. In this chapter I will also list specific concerns which have already been raised in the ethics literature, about some types of pediatric home health care, and correlate them with quotes from the parents' narratives. In this way I hope to insure that the parent narrators are not considered to be exaggerating or unique in the claims they make about their lives.

Caregiving, or the actual hands-on meeting of needs, is the next of Tronto's phases of care, and these parents do one of the most complex forms of it. Chapter Six

discusses the virtue of this phase, competence, relying now almost completely on narratives. It is in this phase where I think extreme caregiving moves beyond merely requiring a lot more of an action, and toward requiring a new sort of action. These parents must become something that most parents are not: competent medical caregivers. This chapter uncovers the reasons the parent narrators seek competence, how they achieve that competence, and how they think about the abilities they acquire.

The final phase of care, care-receiving, with its associated virtue of responsiveness is the subject of Chapter Seven. This phase insures that the cared-for is an integral part of the care given, by asking the caregiver to elicit a response to care, and the care-receiver to provide it. However, the narrators of these stories are all parents of children who are either unreliable in their verbal responses, or unable to speak at all. That the narrators spend many pages looking for and interpreting their children's limited responses, attests to the importance of this phase. However the inability to elicit an accurate response raises ethical concerns, as it becomes apparent that the parents are not only the provider of their child's needs but often the sole interpreter of them. In these stories of sickness, the parent is the only storyteller for the child's life, and we shall see the uncertainty that this creates.

These parents are at the forefront of the ongoing revolution in home care, doing the most difficult of caregiving work, invisibly and without recognition. If the medical system continues to promote ever-more-difficult levels of pediatric home care, we must understand the lives these parents lead. We must understand the physical and emotional burden imposed by complex and prolonged caregiving. We must understand why families agree to take on the new burden of care, and how they arrange their lives around it. But mostly we must understand the intense relationship that forms between a parent who is also the provider of medical care and a child who is the recipient of such superhuman, extreme caregiving.

CHAPTER TWO BACKGROUND

Beginning in the late fifties, an increasing number of parents of children with “mental retardation” and other disabilities refused the suggestion that their children be institutionalized, and instead chose to care for them at home. At about the same time, advances in pediatric medicine began to result in astonishing increases in survival for dozens of congenital syndromes and pediatric disabling conditions. In addition, there have been recent advances in home health care, such as home ventilators and home gastrostomy feedings, which allow ever more medically complex children to be moved from the hospital into the home. Of course there have been huge benefits from these advances, as children are surviving and sometimes thriving with diseases, many of which had previously been considered fatal. But one of the unexpected complications of all of these changes is that an uncounted number of children with long-term disabilities and complex medical problems are now being cared for by their families at home.

While some children with these problems will need only the usual amount of parental involvement, many will require a much higher level of care. At the most severe end of a multitude of pediatric conditions, are children whose care is complex and often burdensome. Because these children fall across a large number of chronic diseases, syndromes, and diagnoses, and their medical needs and types of disability vary so widely, those who do require high levels of care have not yet been identified as a separate group. In fact, they are not all even technically children, as many who are severely developmentally delayed or at the most compromised end of the autistic spectrum have now grown to adulthood but still require a level of care usually encountered only in infants or small children. Yet despite these differences in age, diagnosis, and disability, they all have in common an ongoing need for care that is intense, complicated, and prolonged. Their parents must provide an often complex form of medical home care, combined with the usual duties of parenting, which are often extended by the child’s problems. Essentially, these children all require what I call an extreme level of caregiving.

Like other care work, the caregiving that the parents and families of these children provide for them is largely unrecognized. These children are visible in schools and communities, but the work that is done at home is not always apparent. Even the

physicians and hospitals who provide medical care often do not realize the extent or the practical consequences of the care they prescribe. This is a problem that can be expected to grow worse as medical care becomes more fractionated by specialty, and as continuing medical advances at the borders of survival insure an increasing number of effected children.

DEFINING EXTREME CAREGIVING

Eva Feder Kittay, in her analysis of caregiving presented in *Love's Labor* (1999), stresses that all of us will at some point in our lives require care; we all required care during childhood and many will require it again in old age. Early theories of care balance out the vulnerability and dependency incurred during those times, by the ability to provide care to others during times in which one is less dependent. However, Kittay notes that there are some people, including Kittay's daughter Sesha, whose need for care persists outside those expected periods, in whom the dependent state of infancy or childhood can last sometimes for an entire lifetime. Sesha's development never progressed beyond infancy, and she remains dependent on others for almost every aspect of her daily living. Sesha and others like her, are not then able to return the care they have received, or equalize their dependent status by performing care work for others. Kittay calls this extended state of vulnerability and dependency, "extreme dependency" (Kittay, 1999, p. xiii). People in this state require a good deal of care (or dependency work) throughout their lives. Kittay uses the situation of extreme dependency to analyze its consequences on vulnerability and autonomy, but I would like to turn it around and use it to analyze caregiving itself. If there are people who exhibit extreme dependency, it follows that they must require a similarly extreme level of caregiving. They require, then, "extreme caregiving."

Lynne Ray, in a 2002 paper based on interviews with thirty families of children with a variety of special needs, including medical fragility and technology dependence, identified a similar level of exceptional caregiving (Ray, 2002). The parents she interviewed were performing complex medical care, of the sort usually done only by specially trained hospital personnel. Like Kittay, Ray recognized that many of the children had severe delays in development and would, essentially, never outgrow their need for care. She called parenting these children, where stages of infancy and childhood can persist over an entire lifetime, "parenting plus." The care was actually

more difficult than parenting a typical infant or toddler, however. Ray found that these parents were also on the front line of their child's health care, responsible for "accurately diagnosing, and managing worrisome symptoms, complications, or emergencies" (Ray, 2002, p. 427). This "parenting plus" was being done without respite and in constant fear for their children's lives. She describes an intense, time-consuming, and emotionally difficult form of caregiving, for which there was often no anticipated endpoint. The prolongation of infancy or childhood, possibly throughout an entire life, is another aspect of extreme caregiving.

Though much of the work of pediatric medical caregiving, the often messy, unrecognized dirty work of care, is done by professionals, I do not believe that professional caregiving often becomes extreme. Hospital health care workers are trained to maintain IVs and give medications, to maintain ventilators, watch monitors, and plug in OG feeding tubes. Dressings must be replaced, and blood must be drawn, and fluids must be measured. There are some ordinary tasks as well; there are diapers to be changed and various secretions to be cleaned up, there are baths to be given and beds to be changed. Much of this work has no time limit, no schedule that can be relied upon. This is intense, and often stressful, but it is not extreme. The need is 24/7, but health care workers, of course, have shifts. No matter how busy, at some point the work of caring can be passed on to someone else.

It is when we shift to the home environment to provide this same level of care that I believe caregiving becomes extreme. The parents, essentially called upon to do all of the above, are placed in a new and uniquely difficult situation. They must do all of the work of nursing, while also continuing to maintain the home environment. They must be both parents and medical caregivers, round the clock and with no endpoint in sight.

There is another aspect that I believe is unique to extreme caregiving, and that is the intimate relationship that already exists between parent and child. While relationships do develop between professional caregivers and patients, the care is usually being provided to someone who at least starts out as a stranger, with whom there are no past emotional ties or conflicts. Professional caregivers sometimes are called on to meet emotional needs as well as the physical needs of the child, but with parents that support is expected. Many parents report difficulty balancing the dual role of parent and caregiver for this reason. Even if there is a professional health care worker in the home, because of emotional ties, the parent's responsibilities cannot easily be left

behind (Kirk, 1998). This emotional burden may be the most distinctive part of extreme caregiving, at once its most difficult and, possibly, most desirable aspect. Much of this paper will center around an attempt to understand the impact and evaluate the consequences of this emotional component.

Extreme caregiving, then, has four major components. One is its difficulty; complicated either by medical complexity or multiple time-consuming tasks. Second is the prolongation of difficult stages of childhood, causing parental caregiving to extend far beyond the expected time frame, sometimes for an entire lifetime. Third is its relentlessness; it is a burden that is taken on round-the-clock, with little possibility of relief. Fourth, and most important, extreme caregiving is performed for a person with whom the caregiver has an intense and personal relationship.

Parenting and Extreme Caregiving

Within an ethic of care, caregiving is understood as necessary work, done to fulfill a need. Caregiving in a broader definition can include the meeting of any need, from feeding the hungry to cleaning the environment, but it is most often thought of as an individual meeting the needs of another. It can be done by either professionals or non-professionals. Parenting is certainly a form of non-professional caregiving, and has its own unique problems and rewards. Typical parenting has fairly well-defined parameters and expectations. Parents are expected to, at a bare minimum, keep the child fed and healthy, and safe from physical harm. But most agree that parenting also involves fostering independence, allowing the child to grow into a happy, free, and productive adult (Malek, 2009). There are certainly times when this is not an easy task, however there are numerous sources of advice and support, and, when the child reaches adulthood, for better or worse, the dependency eventually ends.

Extreme caregiving includes these expectations of ordinary parenting, but the parameters need to be reinterpreted for a child who will never be without disease, or on whom the parent must sometimes perform painful medical procedures such as suctioning or physical therapy. It is also complicated by the vast (and usually unexpected) increase in a child's level of dependency. I have already stressed the possibility of prolonged dependency. As with Eva Kittay's daughter and Lynne Ray's families, difficult stages of childhood might be prolonged because of intellectual

disabilities or illness. Many such children remain permanently dependent, never able to reach a stage of self-sufficiency.

I have also mentioned the increase in difficulty and complexity of care. Of course, care of an infant or toddler is more time consuming than for an older child. However, care is also increased in complexity due to multiple medical needs. This is not the brief increase in care needed to deal with ordinary childhood illnesses, but complicated and ongoing care due to severe illness or disability. The children in Lynne Ray's study had medical home health care needs on a level that sometimes rivaled hospital or even pediatric ICU care (Ray, 2002). I will outline the multiplicity of those tasks in more detail in the chapter on the burden of care. Many children, of course, fall into both categories, having simultaneously prolonged dependency and complex medical needs.

Not surprisingly, just as this combination of parenting and medical caregiving extends the parameters of parenting, it does not fall easily into understood forms of medical caregiving. In a 2006 book promoting an ethic of medical care that is expanded to include palliation, Joseph J. Fins provides a list of the goals of medical care. His four goals are 1) cure, 2) restoring function, 3) prolonging life, and 4) comfort care/palliation (Fins, 2006, p. 226). The sort of care that these parents are providing, while it might be informed by expectations promoted by these goals, is not really included in any of them. For most of these children, there is no cure. There is no loss of function to restore, though there is a pursuit of incremental improvement in abilities. While life is preserved and prolonged, because these children are felt to be at the beginning of their lives, the concept of end of life care is not very useful. Likewise, while pain management is sometimes a factor, this is rarely thought of as palliative comfort care to ease dying.

Extreme caregiving then confuses the expectations and goals of both typical parenting and medical caregiving, and so is rarely recognized by those who study either. It exists across a spectrum of pediatric diseases and specialties, at the most severe end of hundreds of syndromes. While many of these children are studied as representatives of their various diseases, their common need for increased care is not often addressed. The children are not thought of as a group united by their need, and again, extreme caregiving falls unrecognized between the cracks. I suspect that only the parents who are doing it know what is involved.

I am aware that extreme caregiving can, and often does, occur at points in life other than childhood. Spouses caring for their partner through serious prolonged illness

will possibly be called upon to provide extreme caregiving, as will adults whose parents are at the end of their lives. Extreme caregiving by parents for their multiply impaired children, I believe, is more complex, in several important ways. The first is that the illness and possible death of a child is unexpected and often carries a larger emotional burden. The second is that the task of parenting a medically complex child is ongoing in a way that caring for a dying or sick person is not. These parents begin to realize that their children might live in a state of extreme dependency, as has Kittay's daughter, for decades. Behind the physical work and sleeplessness and worry is the persistent knowledge that the caregiving task might be unending, and that the child's need might extend beyond the death of the caregiver.

The third reason is more subtle and to me most interesting. Children are of course not yet fully developed as persons. It is one of the tasks of parenting to guide that development, keeping open for them as much potential for their future personhood as possible (Feinberg, 1980). Until that future, however, the parents are the holders of their child's identity as a person. They will inevitably create a life story for the child who is not yet able to do it for himself. However, many of the children I have defined as requiring extreme care do not have the intellectual capability to ever reach the independence required for fully autonomous adulthood. Their inability to express anything beyond the most basic of needs has been much discussed in the context of medical decision making, however this is not the only consequence of their limitation. A far more significant problem is that they do not have a life story that they can tell and shape for themselves. That story is constructed, and their personhood defined, by their parent/caregiver.

Extreme caregiving falls randomly on families, when severe illness devastates a well child or, more often, when congenital problems (from prematurity to birth injury to genetic syndromes) result in a fragile or disabled infant. Extreme caregiving happens when a premie is finally sent home from the NICU with a feeding tube, tracheostomy, cardiac monitor, seizure precautions, and fifteen different medications. It happens when a medically fragile 8-year-old with Cornelia DeLange Syndrome remains developmentally in the active but clueless 18-month stage, and has to be watched every second for years so he doesn't injure himself. It happens when an 14 year old, 160 pound autistic child has not yet learned to use a toilet or sit at a table, and whose behavior outbursts, backed by increasing strength, are becoming destructive. The worrisome addition to these situations is that in ten years, or twenty, the level of care

may be unchanged. Extreme caregiving also happens when a 50 year old, developmentally delayed man who is still functionally a five year old, remains in the care of his 70 year old mother whose own health is failing.

EXTENT OF THE PROBLEM

Statistics for the number of children requiring complex care at home are hard to come by. Most statistics available for medically complex children are done on fairly narrow parameters. They might estimate, for example, the number of children with one specific diagnosis, or evaluate the extent of the need for certain types of care, or monitor dependence on certain types of technology. Statistics for the number of children suffering from a single illness, for example, will include a range of severity, with no way to pinpoint the number of the sickest children whose care would be expected to be the most intense. Nor do they usually include an evaluation of the extent of home care required.

There are some statistics on the number of children who are dependent specifically on use of medical technology in the home. Technology dependence is, I believe, a fairly good marker for a high level of home care, though again the range of illnesses and severity is enormous. Kirk, writing in 1998 on technology dependent children in Britain, reported that the number of technology-dependent children in the USA ten years earlier, in 1988, was estimated to be around 100,000, and increasing at a rapid pace. The types of technology available included mechanical ventilation, home oxygen, home IV therapy, peritoneal dialysis and tube feedings (Kirk, 1998). Of course, statistics for children using a certain technology at home will not find the number of children whose lack of need for advanced equipment in no way lowers their need for care.

Another source of data, though still over ten years out of date, is a 1998 study done by the Minnesota Department of Health, Division of Family Health (MDHDFH) on Minnesota's TEFRA program. TEFRA is Minnesota's program for financial assistance to families with disabled children who require excess expensive medical care. (The acronym stands for Tax Equity Fairness and Responsibility Act, the law which established the criteria for the program. No one uses the full name, and the word TEFRA is commonly used to refer to every part of the implementation of the Act, from the forms filled out to the payments received.) To qualify for this assistance, children

must be “disabled with a physical or mental impairment that is comparable in severity to one that would prevent an adult from working and that is expected to last at least 12 months, or results in death.” An additional eligibility requirement is that the children must need “the level of care provided in a hospital, nursing home or Intermediate Care Facility for Persons with Mental Retardation” (Chan, Jahnke, Thorson, & Vanderberg (MDHDFH), 1998, p. 13).

Chan, et al. at the MDHDFH studied the make-up of the children and families benefitting from TEFRA in 1995, and released the results publicly in 1998. Questionnaires were sent to half of the families of the 3770 children enrolled in 1995, and 959 of them responded. Interestingly, part of the reason the survey was done was to document that the families receiving assistance were truly in need of the enormous level of financial outlay incurred by the program. Diagnoses ranged from spina bifida to autism, from cancer to mental retardation, with many children carrying multiple diagnoses (Chan et al., 1998, p. 24). The type of care these children required depended of course on their specific problem, and was often very different, though its time-consuming nature was not directly measured. Sixty seven percent of the children were on medications, with a mean number of 3 prescriptions, 25% had been hospitalized in the preceding year, and 35% required “durable medical equipment” in the home. Level of care could not be fully assessed, but parents reported that 82% of their children required constant or frequent supervision, and that “about one-fifth” were “totally dependent in all activities of daily living” (Chan et al., 1998, p. 2). That is, 20% of those 3770 children required assistance with every aspect of their daily lives.

It is not unreasonable to assume that most of the families on TEFRA are providing extreme caregiving for their child. If we assume that there were about 4000 children requiring extreme care in Minnesota, and that Minnesota is an average-sized state, we can presume that there were 200,000 children nationwide. This is likely a underestimation, since not every child who requires extreme care in Minnesota is on TEFRA, which is given mostly to families on medical assistance or with limited insurance, and is provided on a financial need basis. Nor does TEFRA extend out of childhood, which, as we have seen, is not a limitation on extreme caregiving. It is also based on a figure from 1995, which has almost certainly increased since then. I would guess the number by now has at least doubled.

The most recent estimate of numbers of children requiring extreme caregiving comes from Andrew Solomon's 2012 book, *Far From the Tree*. The seventh chapter is about parents coping with children with multiple severe disability, or MSD. He defines MSD as considerable impairment in several areas of sensory ability or cognition, and states that it refers to people with an "overwhelming number of challenges," many of which will never resolve enough to permit independent living. He reports that "Although the vagueness of the criteria for MSD makes it much harder to collate the relevant statistics than it is for single, clearly defined conditions, about twenty thousand children with MSD are born in the United States each year" (Solomon, 2011, p. 357). He also states that it has only been in the last 20 years that parents have been expected to bring home and care for such children. This estimate would indicate that there are somewhere around 400,000 families doing extreme caregiving, and would include only MSD children below 20 years old.

This number does not include another source of extreme caregiving, which is autism. The total number of people living with autism has not been reliably estimated, nor has the percentage of autistic children who require extreme caregiving. The results of a study done in 2008 by the Center for Disease Control and Prevention (CDC), which reported that one in every 88 children has been identified with autism spectrum disorder (ASD), have been highly publicized, as has the data that ASD diagnosis has been rapidly climbing in incidence (CDC, 2008). This says very little about the severity of problems over the entire spectrum of the disease. However I think it is safe to assume that tens of thousands of families, at least, are providing care for children at the most severe end of the spectrum.

Another unknown is the number of elderly parents still caring for dependent adult sons and daughters. I have only one, rather personal and imprecise estimate, which comes from suburban Philadelphia. In the late 1990s, my parents, then in their early seventies, were unable to find a home for my then 40 year old brother. They'd had some experience in political activism, helping found the Montgomery County Association for Retarded Children when my brother was a child. They found a state senator who expressed interest in the problem of placement, and was willing to attend a meeting. My parents relied on nothing but word of mouth (without the internet) and had a little over a month to inform their fellow caregivers. There were almost 300 people at that meeting, all living in one small suburban area.

An estimate of about 500,000 children under the age of 20 living at home with some combination of multiple severe disability, severe autism, or technology dependence would not be unrealistic. This does not of course include the unnumbered adults with similar disabilities who have not been able to leave home. I believe the actual number is much higher.

OBSCURING THE PROBLEM

To evaluate extreme caregiving, I will have to rely on a variety of different sources. Most of the recent information on caregiving from medical and ethics journals comes from studies on families caring for technology dependent children at home. Some of these children could be identified as multiply and severely disabled, but not all of them. As a pediatrician I have met numerous children with a variety of problems in the office or hospital. I have also had personal contact with several families of special needs children, as well as severely autistic children, and have seen first hand some of the problems. Looking for narrative accounts from families dealing with this sort of caregiving, I found that most of the memoirs available are by parents of severely autistic children. So I will include discussion of parents of children falling into all three areas-- technology dependence, multiple severe disability, and severe autism--in my investigation of extreme caregiving.

Gaining an understanding of the lives of impaired children from the medical literature is difficult. With the exception of the 1998 MDHDFH survey on TEFRA, I found very few studies which estimated the type of care required or how many hours that care might consume for caregiver(s). Many pediatric outcome studies report the possibility of developmental delay, stating that independent living may never be achieved, but they rarely discuss the implications of that outcome. And the meaning of phrases such as "moderately delayed," even when well-defined by numerical evaluations, do not give a very good window into the lives of those families.

The pediatric and neonatal literature abounds with studies of disabled, intellectually delayed, and chronically ill children, however, very few look at the caregiving consequences of their problems. I looked at several types of studies which seemed likely to yield information about caregiving, but found few satisfactory sources. This included searching NICU outcome studies, quality of life studies for survivors of various childhood conditions, studies of the effects of childhood chronic diseases on

parents and siblings, and studies involved in determining the effectiveness of discharge planning for technology dependent children. I will discuss each of them individually below.

NICU Outcome Studies

One source of data on caring for impaired children might be expected to come from the vast neonatology literature on survivors of premature birth requiring NICU treatment. Many of the most impaired children living at home are NICU survivors, though of course that is not the only source of disability. But premature babies are a relatively homogeneous group, and NICU survivors are often followed at a single center for long periods of time after discharge. They provide an easily accessible and frequently used cohort for study. The group most likely to have a poor outcome, and therefore require parental caregiving, are the extremely premature babies, born under 28 weeks gestation. The group born between 22 to 25 weeks is the most controversial and very likely to have a poor outcome. There are dozens of papers providing survival and outcome statistics, at all levels of gestational age at birth, but very few that give any kind of picture of the lives of their subjects.

A paper from 2005 from the UK is typical. Marlow et. al. did extensive developmental assessments at six years of age, on the survivors of delivery before 26 weeks (Marlow, Wolke, Bracewell, & Samara, 2005). The paper is rife with statistical analyses based on complicated cognitive, neuromotor, and sensory evaluations, but provides very little description of the actual level of functioning or the amount of care required by their 241 subjects. They found a very high level of disability, with only 20% of their subjects described as having no disability. This is a somewhat higher level of impairment than reported in other studies. The authors point out that one of the problems comparing their results to earlier studies is a lack of a consistent definition of severe disability. They feel that their study is an improvement, because of their precise definitions and measurements. Yet, the level of care required is not measured, nor does there seem to be any recognition of the consequences of the disability to child or family.

Marlow's group defined a disability as severe if "it was considered likely to make the child highly dependent on caregivers and if it included nonambulant cerebral palsy, an IQ score more than 3 SD below the mean, profound sensorineural hearing loss, or blindness" (Marlow et al., 2005, p. 10). Overall, 22% were identified as severe. "A

disability was defined as moderate if reasonable independence was likely to be reached and if it included ambulant cerebral palsy, an IQ score 2 to 3 SD below the mean, sensorineural hearing loss that was corrected with a hearing aid, and impaired vision without blindness.” They did not define “reasonable independence” (Marlow et al., 2005, p. 11). This level was present in 24% of the survivors. The largest group, 34%, was considered to be mildly disabled. “Mild disability included neurologic signs with minimal functional consequences or other impairments such as squints or refractive errors” (Marlow et al., 2005, p. 11). This group included those children with IQ scores from 1 to 2 SD below the mean, who will presumably eventually reach full independence, but I would suspect will need quite a lot of assistance to achieve it.

They also included a control group of non-premature students from the same age group. Even with several mildly cognitively disabled children in the control group, the differences are remarkable, with the non-premature students clustering above the mean IQ of 100, and the ex-micro premies averaging at best 70 to 80. The authors are concerned with the differences between the two groups, and with the frequency of “adverse cognitive sequelae” in the ex-premies. They recommend follow up to determine whether these sequelae create future academic and psychological difficulties. They do not consider the implications for current or future caregiving needs. Advancement in the care of the micro premie is expected to provide better outcomes for future infants.

A review of the effectiveness of perinatal care of the 23 to 25 week premie, published in 1995 by the American Academy of Pediatrics (AAP) in cooperation with the American College of Obstetrics and Gynecology (ACOG), reports similar poor outcomes. The survival rate is only 15 to 54%, depending on a variety of factors, and 72% are still on ventilators at one month. There is a 30% rate of severe (level III and IV) hemorrhages in the brain. They state, “Recent experience suggests that almost half of the surviving children who weigh less than 750 grams at birth experience moderate or severe disability, including blindness and cerebral palsy, and require special education. Many infants have more than one disability” (AAP/ACOG, 1995, p. 974). Yet the advice parents expecting an extremely premature delivery are to be given continues: “Families should be counseled that, despite the high rate of overall disability, many of these children are educable and can function within their family unit” (AAP/ACOG, 1995, p. 974).

I find the brevity and hubris behind that statement appalling. There is no consideration for the level of care, or length of that care, expected. Parents given this recommended counseling are receiving no useful information and are, quite possibly, being terribly misled. I suspect that physicians are likewise placated by this lack of information, and not often led to think beyond the rosy picture they paint. It is perhaps not surprising that health care providers are not fully aware of the problems faced by families raising an impaired child at home.

Quality of Life Studies

This is a more recent type of follow-up study, which, like outcome studies, has been used to follow up on the survivors of prematurity, and purports to be more specific about the effects of disability on the lives of children. Quality of life studies are conducted by ratings questionnaires, with several different verified scales now available. Subjects are asked to rate either their satisfaction with their lives or to rate the desirability of living in scaled states of disability which are similar to their own.

Quality of life studies have recently yielded some rather unexpected results when applied to cohorts of NICU survivors. An example is a 2007 study from Northern England, in which the researchers analyzed health related quality of life surveys in teenagers who had survived premature birth. Gray et al. sent questionnaires to every teen in the region who had been born before 28 weeks gestation in 1983 and 1984. They mailed 218 surveys, and received back 175, then compared them to 108 age-matched peers from the same schools. Interestingly, 28 surveys could not be included because those children were in special schools, where there were no control children. This effectively excluded the most impaired children in the cohort. Surprisingly, despite the known fact that ex-premies are at far more risk for health problems than children born at term, the “self-reported health status and health-related quality of life” of ex-premies in mainstream schools was not significantly different from their peers (Gray, Petrou, Hockley, & Gardner, 2007).

The authors give several interesting reasons why the ex-premies rate their health related quality of life as equivalent to their peers. In the conclusion they postulate that “it is possible that teenagers’ perceptions of their health status and health-related quality of life may be different from that of their families, caregivers or health professionals” (Gray et al., 2007, p. e91). But this statement from the introduction may be more accurate,

“[E]ach child has a unique perspective on and valuation of his or her health status and may also learn to conceal his or her true emotions from parents and caregivers” (Gray et al., 2007, p. e87).

This echoes a controversy following an earlier series of studies of quality of life in survivors of extreme prematurity, led by Saroj Saigal at McMaster University in Toronto. The group has been following a cohort of survivors of extremely low birth weight (ELBW) delivery over several decades. They have reported diminished cognitive abilities and school performance at age 8 (Saigal, Satzman, Rosenbaum, Campbell, & King, 1991), a much higher level of “neurosensory impairment” than their peers with normal birth weight at 12 to 15 years (Saigal et al., 1994), and ongoing health problems with “substantial morbidity” in adolescence (Saigal, Stoskopf, Streiner, & Burrows, 2001).

Saigal’s group has also been monitoring quality of life in this same cohort, initially by asking doctors and parents to rate the children’s lives. In 1996, they were for the first time able to obtain quality of life data directly from the children, as they were now in their teens. (Nine of the 141 surviving teens were too impaired to do the interview, so their parents acted as proxy.) They reported that the ELBW children, while they reported a significantly lower quality of life in terms of morbidity (increased problems with such things as cognition, sensation, mobility and pain), on satisfaction scales they “view[ed] their quality of life as quite satisfactory and [w]ere difficult to distinguish from controls” (Saigal et al., 1996, p. 453).

Several years later, they performed a similar interview survey, comparing the ELBW teens’ impressions of quality of life with those of NICU doctors and nurses. All groups were asked in interviews to rate the desirability of living in five hypothetical health states which were comparable to the health states of the ELBW teens. Saigal found that the teenagers and their parents rated living in impaired states much higher (more desirable) than did doctors and nurses (Saigal, et al., 1999). Both studies have been used to support the ongoing resuscitation of extremely premature infants, though the 2001 outcome study by the same group continued to show poor health outcomes (Saigal et al., 2001).

I am not an expert on the conducting of quality of life assessments, but on close reading of Saigal’s methods, believe that the only thing actually proved is that teenagers, both impaired and non-disabled, for the most part prefer to be alive. While the level of

impairments described implies an increased need for care, neither the level of this care nor the person performing this are part of Saigal's calculations.

Helen Harrison, an author and parent of a 26 week premie, published a protest of these and other studies in *The Journal of Clinical Ethics* in 2001. She points out various inconsistencies in Saigal's results, and postulates that the parents and teenagers involved in the studies might have been motivated to exaggerate their quality of life to meet the expectations of their doctors. She casts doubt on all quality of life studies, and suggests that the doctors' and nurses' assessments of quality of life might actually be more accurate than those of patients or parents. She believes that the unquestioning reliance on surveys that show satisfaction with poor outcomes is misleading other parents in their decisions surrounding resuscitation of extremely premature infants (Harrison, 2001).

I will return to this subject later, in the narrative methods section. For now, I will merely point out that these studies are not only contentious, but unlikely to reveal the reality of living with a multiply disabled child. The controversy demonstrates how very difficult it would be to evaluate the lives of these children or their caregivers based on quality of life studies.

Studying the Families of Medically Complex Children

Gaining an understanding of the lives of the families of disabled children is perhaps even more difficult. While there have been numerous studies of the effects on various family members of an impaired or chronically ill child, very few go beyond psychological profiles. I have by no means made an exhaustive study of this literature, but will summarize briefly several more recent studies. A few of the more recent ones do begin to consider caregiving.

Seltzer et al, in 2001 reported on "mid-life well-being" of the parents of disabled or mentally ill children. They state that earlier studies reported decreased ability to cope, increased levels of stress, and financial and marital strain in this group. However some of these results are inconsistent. They separated out self-reported parents of "mentally ill" and "disabled" children from a large population cohort followed over decades in Wisconsin. They screened those parents for multiple factors, including employment rate, family size and marital status, finding only minor differences from parents who did not report a mentally ill or disabled child. They found that those parents had decreased

social participation (meaning involvement in social organizations, and number of visits to friends), but were equal with the general population in their “psychological well-being,” which was screened by questionnaires about physical health, depression, and alcohol use (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).

Since then, a variety of similar parameters have been used to study the parents of children with a variety of disabilities. Mothers of developmentally delayed children have been found to be at elevated risk for depression, compared to mothers of typical children (Singer, 2006). Parents of children with developmental disabilities have been noted to have an increased level of caregiver stress if their child’s disability included behavior problems (Plant & Sanders, 2007). Aging parents of disabled children were noted to have higher levels of negative affect, poorer psychological well-being, and increased somatic symptoms (Ha, Hong, Seltzer, & Greenberg, 2008). Families of children with Down Syndrome in Australia were reported to have poorer family functioning, particularly if their child also displayed symptoms of autism (Povee, Roberts, Bourke, & Leonard, 2012). None of this comes as much of a surprise. Most of the recommendations for improvement center around family support such as counseling.

Another study which seems fairly typical, but does begin to look at aspects of care, was done at the University of Amsterdam in 2009. This group has been developing a scale for Health Related Quality of Life (HRQoL), and used it to evaluate the impact that various factors in caregiving can have on the parents of chronically ill children (Hatzman, Mauriec-Stam, Heymans, & Grootenhuis, 2009). Some of these parents were not extreme caregivers, but the group did include parents of Down Syndrome and multiply disabled children. They found that parents who had fewer days on holiday, illness of their own, and less emotional support, had lower HRQoL scores. But the most important factor they found affecting parents’ HRQoL was the care dependency of the child. Parents whose children needed more help had significant lowering of their HRQoL. The researchers recommended that these parents go out more and be given more emotional support, though, except for providing more respite care, they do not suggest ways in which this might be accomplished. They also state that they cannot verify that any of these things will actually improve the parents’ HRQoL.

To evaluate level of care, they evaluated eight domains in which the child might require help: physical, mobility, eating and drinking, medication use, coping with devices, entertaining, contact with other children, and education. This yielded an eight point scale

which would they used to determine the difficulty of caregiving. This is a good start, but would, I think give only a very rough idea of the amount of care needed by an individual child.

A final paper, from Texas A & M University, provides a much more extensive scale to examine caregiving, though the actual intent of this paper was to analyze factors influencing parents' requests for medicare payments for "formal care" (professional caregiving) for their children with intellectual disabilities (Fournier et al., 2012). For evaluation purposes, Fournier's group used a 20-page form developed by the state of Texas, and available on line, (Texas Personal Care Assessment Form (PCAF) 4-20, from Texas A&M University). This was originally intended for use in the elderly to determine medicaid eligibility for personal care assistance (PCA) at home, but is now being used by the State of Texas to determine aid for children as well. It has detailed questions about medical diagnoses, medications, and use of durable medical equipment. It also assesses ability to communicate, hearing, vision, memory, continence, and behavior problems. There is a separate section listing all the activities of daily living (ADL)--including mobility, feeding, hygiene, and housework--with which a person may require help. There is also a section in which the caregiver can report their own status, particularly employment or other commitments which might cause them to require more help. It is far from a perfect assessment, in my opinion, but does demonstrate well the complexity and individuality of home caregiving.

However Fournier et al, (2010) were actually interested, not in actual caregiving need, but in the number of hours of assistance parents of children with intellectual disabilities were requesting from the state. About a fourth of the Texas form is taken up with the parent's request for a specific number of hours and types of caregiving assistance. The study group referred to this consistently as parents' "perceived need" for personal care services (PCS). They did a very complicated analysis of the variables in the enormous amount of data provided by these forms, and were not able to satisfactorily make a model that would predict the number of hours parents requested. They end by concluding that, "Medical diagnoses, health conditions, communication problems, and incontinence have no direct effect on the number of hours caregivers believe they need. Instead, all these factors affect a child's functional status, which in turn translates those effects into the perceived hours needed for PCS" (Fournier et al., 2010, p. 220). So they were unable to predict how much assistance parents would

request based on the child's medical need. Instead, the hours requested seemed to be based on the child's "functional status," or level of disability. This was a seemingly disappointing and unexpected result, though it makes sense to me that parents would request more help if their child's disability interferes with more activities of daily living. I am also not sure why the researchers did not consider that parents of children with intellectual disability perceive a need for help because they actually do need help. It would have been far more informative, to evaluate the number of hours that actually might be consumed in the care that these parents provide, and look for ways in which to assist them.

Studies of Hospital Discharge Planning

Another way that home caregiving for children has been studied is to evaluate the ways in which parents are prepared to take care of their medically complex children following discharge from the hospital. This mostly involves the parents of children who need to use medical technology in the home. It has been noticed that some of these children are not so much being discharged from the hospital, as being given a little hospital to take home with them or, rather, "home is reconstructed as caregiving space" (Dyck, Konton, Angus, & McKeever, 2005). Wang states that "the traditional meaning of home is altered by the intrusion of medical machinery" (Wang & Bernard, 2004, p. 40). Yet, in my experience, the image both medical staff and parents have on discharge is of a family happily home again in a normal home environment.

There are numerous papers studying hospital discharge planning for medically complex children. Some examine its effectiveness at providing adequate medical care, more do cost analyses comparing it to hospital care, and many more evaluate various improvements in the efficiency with which parental training is carried out. According to Wang and Bernard, in a 2004 review of technology dependent children, the assumption is often that home is the best place for the child (Wang & Bernard, 2004, p. 38). It is also usually assumed that home care is the most cost effective way to care for the child, though some are questioning that assumption. Wang and Bernard mention that cost analyses are biased toward expensive hospital charges, and do not take into account the financial cost to the family of caregiving (Wang & Bernard, 2004, p. 41).

A review of the ethics of pediatric home health care, done in Chicago in 1992, questions both the presumed psychological benefits and cost reduction of complex

home health care, pointing out the ways in which home care can strain the parent-child as well as the doctor-patient relationships. Lantos and Kohrman recommends that the benefits of home care for the child must ethically be balanced against the burden of care for the family (Lantos & Kohrman, 1992). This is not ordinarily a part of discharge planning, as it is generally assumed that the family both desires to, and is able to, take care of their child at home.

Noddings, speaking about home health care for adults, has also noted the lack of preparation and support for the caregiver. She reports that family members are being trained, often unexpectedly, to use technology only recently available outside of the hospital setting. This is not work which they have chosen as a career, but have taken on out of need. "It is often assumed that almost anyone can be prepared to administer high-tech home care. Much attention is given to the quality of training, not much attention is given to the emotional needs of the caregiver" (Noddings, 1994, p. 3).

A recent American Academy of Pediatrics review on caring for children with complex medical needs or technology dependence states as the goal of home care "to ensure that each child remains healthy, thrives, and obtains optimal medical home and developmental supports that promote ongoing care at home and minimize recurrent hospitalizations" (Elias and Murphy (AAP), 2012, p. 996). These goals, like Joseph J. Fins' stated goals of medical care, are directed toward cure and rehabilitation. They do not attempt to redefine "health" and "thriving" for a child with a lifelong disability. They fail to acknowledge the complexity and length of the home caregiving task. In fact, the single most important goal seems to be to keep the child at home, and away from the hospital.

According to the AAP guidelines, before the child is discharged to home care, parents must be trained in the use of any necessary medical equipment, learn to do CPR, and understand when and how to call for help. They stress that discharge planning should include arranging medical followup, scheduling ongoing developmental evaluation, obtaining proper home equipment, and assuring insurance coverage. They also mention that family members may be stressed or otherwise affected by the ill child, and psych referral may be considered. They recommend that, prior to discharge, the parent spend one or two nights in the hospital with the child, during which time the parent provides all necessary care under nursing supervision (Elias and Murphy (AAP), 2012). One of two nights seems to me minimal preparation for a complex sometimes

lifelong task, and demonstrates lack of recognition of the difficulties likely to be encountered.

According to a study done by Ray (2002), parents agree that the preparation they receive is inadequate. The parents of technology dependent children whom she interviewed, said that it took them a long time to become comfortable with their caregiving tasks. Ray states that, "Parents estimated that it took 6 months before the technical aspects of care became the most taken-for-granted part of their child's care. This time frame seemed to apply regardless of the complexity of the care" (p. 426). As stated above, the AAP recommends that parents be given one or two nights in the hospital to learn the special care on which their child's life depends.

Neither the AAP guidelines for discharge planning, nor the numerous studies evaluating parental preparation for home care seem to me helpful in evaluating extreme caregiving. A relentless drive to accentuate the positive seems to be informing health care workers' and researchers' opinions and reports, making their analyses of caregiving for medically complex children rather suspect. Often it seems that the determination to keep the child at home serves to obscure the true complexity of caregiving required from the professionals that are ordering and monitoring it. Including an understanding of the lives, not of just of those children but of their families as well, in any medical decision-making, seems paramount to the task of providing ethical care for them.

AN EXAMPLE OF A MISUNDERSTANDING

John Lantos opens *The Lazarus Case*, his 2001 book about a semi-hypothetical neonatal case gone wrong, with this statement. "A baby who should have died did not die. Somebody was to blame. Clearly, somebody would have to take responsibility. Certain parties would pay a lot to find out why the baby had survived. They would figure out who was answerable. The culprit would roast" (Lantos, 2001, p. 1).

It is an interesting first paragraph, full of anger and, presumably, a large dose of irony. The case that follows is not a medical history but a court case, involving a lawsuit brought by the parents of a nameless baby, who had miraculously survived an extremely premature birth, against the doctors who had saved the baby's life. This was not, as I expected when I opened the book, a case of "wrongful life." The baby had not been resuscitated against the parents' objections. Rather the baby had been briefly resuscitated at birth, thought to be unsalvageable, and medical rescue had been

stopped. Efforts had been resumed some time later, when the baby failed to die as expected. The parents' lawsuit revolved around the fact that the baby had survived in a severely impaired condition. They blamed this poor outcome on the delay of treatment, though everyone should have been aware from the beginning that extreme prematurity alone frequently results in high levels of disability.

Lantos does not give much information about the baby's impairments. He reports medications for heart and lung problems, and for seizures. He mentions delayed development requiring early intervention programs, as well as weekly physical therapy, speech, and occupational therapy. The developmental delay requiring all this is described as "moderate," but a neurologist has admitted that the "ultimate neurologic prognosis, though not good, was still uncertain" (Lantos, 2001, p. 10). As an afterthought, Lantos mentions that the child, now three years old, is being fed by gastrostomy tube. The parents are suing for thirty-five million dollars.

Lantos seems somewhat bemused by the parents' actions. Their relationship with their doctors had always been amiable. They still bring the child to those doctors for follow-up care. He does not understand where their sudden anger has come from. While analyzing the doctors' decisions, his own difficulty in explaining why their actions were all justifiable, and the current state of the ethics of neonatal care, he never examines the lives of the parents. He does not imagine their side of the story.

But, based on those few statements above, some conclusions are possible. The parents are giving feedings by gastrostomy tube, which means that, at three years old, the baby still hasn't figured out how to suck and swallow, something which a normal newborn learns in a few hours. Along with the presence of seizures, this seems a very bad sign. The neurologist might be unwilling to convey the dismal prognosis, but it seems likely that the baby is and will always be significantly mentally impaired. The other medications, six in all, mean ongoing respiratory and cardiac problems, so the baby's general health is quite fragile. Frequent hospitalizations, for things as simple as colds, would be expected. The parents--charged with giving at least six medications (probably 12 to 15 separate doses each day, at least one as a fifteen minute breathing treatment), setting up and monitoring the gastrostomy feedings and equipment, maintaining that fragile health, and coordinating all those appointments for therapy--are spending most of the day (and likely the night too) caring for a child who may not ever learn to suck from a bottle. Likely one of them has already had to quit their job to become a more-than-full-

time caregiver and care coordinator. Likely they are financially strapped. Possibly they have figured out that they are in this new and unexpected care task for the rest of their lives. Thirty-five million might be too much to ask, but they probably feel they have no other reasonable option.

Lantos' Lazarus Case is hypothetical, a composite of real cases in which he has been involved. My estimation of the baby's and parents' lives is likewise hypothetical, based on cases from my own practice, from the pediatric literature, and from written accounts by parents, including the Ian Brown book (2011) quoted at the beginning of this chapter.

As Brown states, modern medicine has created a new situation by rescuing children who would not have previously survived and who now require an extraordinary amount of care. Lantos hints in his opening paragraph that the down side of these medical miracles is indeed an unknown number of children who perhaps shouldn't have survived, but whose continued existence is undeniable. Together with the medical advances that make this dubious survival possible, the burden of care has been increased by the move to care for those children at home rather than in institutions or hospitals. Lantos's book (2001) is a coherent and complete account of the doctor's side of the story. It is time now to understand the parent's side; not the choices they did or did not make, but the lives they must now build around the undeniable existence of the child. To do that, we must understand caregiving.

CHAPTER THREE METHODS: NARRATIVE ETHICS

Use of narrative or story in ethical thinking is a somewhat new concept, and has not received universal recognition in an ethical system looking for one-size-fits-all answers. However, narrative seems to many an appropriate way to consider ethical dilemmas, particularly those that are situational or relational and, therefore, do not fit comfortably in the universalist and strictly autonomous system of principle ethics.

The situation of extreme caregiving, often unrecognized and rarely studied, is intensely personal and isolated in the home environment. Analyzing the emotional consequences of this relationship would be difficult, using the usual methods of interview-based or medical outcome studies. Narrative is perhaps the only way to begin an ethical analysis of this intimate, hidden caregiving relationship. This chapter covers narrative ethics, its uses and potential pitfalls, and summarizes the parent caregiver narratives I will be using.

Narrative ethics has its beginning in stories told by physicians about the practice of medicine, but perhaps becomes more useful with the addition of stories of sickness told by their patients. It has now broadened to include the use of literature to teach medical humanities, and the use of case reports as stories to aid ethical decision making.

There are recognized problems with using stories as a basis for ethical decision making. Even the proponents of narrative ethics realize that stories contain untruths, or at least distortions of the truth. These can be deliberate, as the author purposely slants the story to make himself look better or changes facts to make a more engaging story. Or they can be subconscious if the author has unrecognized biases or prejudices. There is also no consistent basis upon which even the most truthfully told narrative can be identified as morally exemplary.

However, stories do have potential. In this section I will discuss some of the theories and uses of narrative, as well as some of the pitfalls of using them to do ethics. I will also describe the narratives I encountered during this project, and the admittedly biased reasons I have for choosing some of them for closer reading.

The narratives I have selected, I believe, have important messages both for pediatric medicine and for the field of bioethics, particularly the developing ethic of care. Even if some of the details about their lives and the lives of their children that these authors have provided are entirely fabricated, their books still point toward an injustice. Their stories are a demonstration that the 'good' of saving the lives of children with complex and previously-fatal syndromes, often assumed to be universal, has led to an immense and unrecognized burden placed on their families. In addition, the difficulty of the ongoing caregiving these narrators describe, even if exaggerated and self-serving, still exceeds the levels expected of professional caregivers. We may not have to decide from these stories whether these parents are 'good' or even 'moral' caregivers in order to learn from them something of the nature of caregiving at its most extreme level.

WAYS OF DOING NARRATIVE ETHICS

According to Howard Brody, the telling of stories is crucial to medicine, and the lack of ability to tell them can be devastating. Brody believes that, in order to provide guidance through an illness for a patient, a physician must be able to use narrative in both personal and relational ways. He suggests that physician burnout is in part due to "having no one to whom to tell one's stories of practice, and little opportunity of coming to understand for oneself the meaning of these stories" (Brody, 2003, p. 11). He also states that, in order to alleviate suffering, the physician must provide for the patient an explanation for the illness and a prognostication of the course of the illness. Both explanation and prognostication are a form of story. "Suffering is produced and alleviated by the meaning that one attaches to one's experience. The primary human mechanism for attaching meaning to particular experiences is to tell stories about them" (Brody, 2003, p. 13). An effective and ethical physician must then be a good storyteller, both in the stories he tells himself and the awareness of the stories he is relating to his patients.

Perhaps more important than understanding the physician's story is understanding the patient's story. This is important both for treating illness effectively and for making ethical decisions. An illness, again according to Brody, should be seen as a part of a life story, sending the arc of that story off on a new and often unexpected trajectory. Understanding the experience of illness from the patient's perspective is necessary in order to provide ethical care. "Patients come to physicians with broken stories as much as with broken bones and bodies," he says, and it is part of the

physician's job to understand and guide the healing of both (Brody, 2003, p.13). Arthur Frank also a proponent for the importance of narrative ethics, has gone even farther, saying that a serious illness is a "call for stories;" that the sick person must revise their life goals and create a new understanding of themselves by creating new stories (Frank, 1995, p. 53). If physicians distance themselves or fail to understand this task that their patient must be performing, they will miss much of the practice of medicine.

Frank has pointed out that clinicians and patients are, essentially, characters in each other's stories. The medical history and physical, as recorded on the medical chart, is only one way to tell that story, and, at least from the patient's perspective, possibly not the most accurate version (Frank, 2002). I agree with him that the medical record is a limiting, and in some ways destructive, way to tell a story of illness. Despite exhortations to treat the whole patient, practitioners are ever more finely focused on single parts of the patient's body. And despite the proliferation of patient support groups and informative pamphlets, illness still comes as a disruption in life through which the institution of medicine is not much of a navigator. The stories told by practitioners and heard by patients, and the stories told by patients and heard by their physicians, are quite different. It is not just the storytelling abilities of both parties that is inadequate, however, the fundamental stories we tell about illness and its meaning are sometimes broken. Our focus on cure and insistence on optimism creates a dissonance when a story does not have an ending in a complete and happy cure.

In my experience as a pediatrician, this deviation is most apparent in the care of medically complex and severely developmentally delayed children. Medical advances in pediatrics have created a new sort of story, one that alters the life trajectory not just for a patient but for an entire family, and for which we seem to be entirely unprepared. The debilitating illness happens to a child at the beginning of a life, and its consequences for both child and family often do not become immediately clear. If there is to be optimism, it must be created from very small amounts of progress. The families living this story have been telling it to each other through parent support groups and blogs for years, but their concerns have barely penetrated to public awareness. Meanwhile the medical system churns along, seemingly unaware of the problems it has created. This paper is a first attempt at listening to those stories.

I am a bit less certain about the use of story to prove the correctness of a moral conclusion. I agree that, as a form of ethics, hearing the patient's story is a valid way of

bringing the patient's interests to the forefront, possibly more effective than citing the principle of autonomy. In this way the patient's own story can provide a more personal and authentic account of illness than that provided in the medical chart. However, I agree with the sentiment expressed by John Arras in *Stories and Their Limits*; "[T]he connection between narrative and moral justification remains maddeningly obscure" (Arras, 1997, p. 67).

However, Hilde Lindemann Nelson has summarized the four ways in which narratives can be used in moral analysis (Lindemann Nelson, 2004). She has also helpfully outlined the ways in which narrative can be both used and abused by those methods. The reading that I am doing does not fall easily into any one of her categories, but I will try to summarize her ways of 'doing ethics' with narrative, and to describe the ways in which my readings might conform to those categories.

Cultural Understanding, or the stories we invoke

The first way to use narrative is to provide a cultural moral standard derived from cultural tradition. This type of ethics relies on stories that have emerged from long tradition and are so ingrained in a culture that they have become a signpost for a cultural priorities and moral understandings. Stories that are known and accepted as truth by most of the members of a society can be used as a form of moral justification which can uphold the morality of newer stories.

The pitfall with this, of course, is that not everyone, even within the same culture, will find themselves represented in the stories that form an overriding truth for most. These outsiders have had no part in the creation of the story, and have often been disenfranchised by the truths thought to be inherent in the culture. The story, at least from their point of view, cannot be a basis for moral judgement.

One way these outsiders can become recognized is by providing a counter-story, one in which their concerns and way of being are explained and legitimized. The telling of these different stories is not only a personal venture, but a way of creating a new community within a culture, collecting others who understand or recognize the story as representative of their own. Frank puts it like this, "The claim to speak in one's own voice and tell one's own story is not, however, a claim that this story is exclusively one's own. On the contrary, what is claimed is membership in a community of those who share one's story" (Frank, 1997, p. 36).

The stories I will be reporting on form a quiet voice standing against the more well-known and popular stories which tell us what being a parent is supposed to be all about. Yet I believe that the experiences related in these narratives are not unique; I have met through my pediatric practice others who are living similar stories but are silent. These books become, then, attempts to describe an unrecognized community of parents who are living with the same problems.

This recognition of shared experience has been an essential part of the disability movement from its outset. In many of the narratives, the discovery of other families dealing with similar problems is important enough to fill several chapters. The disability movement is in part created by and continued by the telling of these stories. However, it becomes clear that there are some parts of this story that even those who share it are unwilling to recount. The reshaping of stories in order to meet the expectations of this community are in themselves an interesting part of their story. The most interesting of the narratives, I think, are the ones that dare to question the authority of the story they think they should be telling, and compare it to their actual experiences.

Moral Education, or the stories we read

The second way in which narrative has been used is in moral education. This is one of the most popular use of stories in medicine. There is a widely-held idea that teaching the humanities to physicians or medical students will provide moral education, or will impart to doctors some previously absent empathy or understanding (Lindemann Nelson, 1997). It is generally thought that a certain type of critical reading of a certain type of great literature is needed to accomplish this. "Narrative competence may be defined, first as the ability to choose good literature, and second, as the ability to read good literature with care, skill, and critical judgement" (Lindemann Nelson, 2004, p. 171). Even Lindemann questions the usefulness of this approach, pointing out that such finely honed understanding is hard to come by, and hard to use as any kind of moral standard.

None of the books that I have read approach literary greatness. One of them, *A Child Called Noah*, by Josh Greenfeld became a popular read in its day, and the Greenfelds enjoyed a sometimes uncomfortable kind of notoriety for several years in the early 70s (Greenfeld, K.T., 2009). However I believe it has now sunk into obscurity. Another, *The Spirit Catches You and You Fall Down*, remains widely read among medical personnel but the understanding of the story is almost entirely focused on

cultural sensitivity (Kleinman & Benson, 2006). The story of Lia Lee's mother and the care which she provided for thirty years is barely noticed in our attempt to translate the priorities of American medicine for other cultures.

I believe that *The Boy in the Moon*, by Ian Brown (2011) should be required reading for all pediatricians, but I do not think that the reading of it is likely to confer any special moral sensibility. It is a much easier book to read than others which have been proposed as educational, however. The first chapter can be read in less than fifteen minutes, and the images it leaves behind of the relentless, tiresome tasks involved in caring for a medically complex child, should not quickly be forgotten. It will not change anyone's moral fiber, or bring about any dramatic reduction in suffering, but it may not be too much to expect that perhaps some pediatrician, after reading it, will take the extra time to simplify a child's medication regimen.

Building on Ethics Case Studies, or the stories we compare

This is actually the fourth of Lindemann's approaches, but it is an approach that I will not be using much, or will be using only in a sort of sideways manner. Her third approach, using the stories we tell about sickness, is much more useful to me, and will require a much longer discussion, which I will leave for last.

If the medical history is, as Frank (2002) suggests, the composing of a certain type of story, it is clear that the ethics consult or presentation of an ethics case history is also a way to construct a story. Just as with medical diagnosis, those ethics cases can be compared to each other, and used to build a larger understanding. So the similarities between an established ethics case where the moral meaning is clear, or at least agreed upon, and a newer or more complex ethics case story can be examined. This comparison will perhaps lead to justification for an ethical decision, based upon previous understanding of a similar situation. This casuistical approach is already familiar, as it is the way in which much of US common law has been reasoned.

The problem, of course, is coming up with a starting point, that paradigm case upon which there is ethical certainty. And even if a perfect case can be agreed upon, it would take only a small misunderstanding for the whole construct built upon it to topple. As has already been pointed out, our understanding of each others' stories, particularly between provider and patient, is inadequate.

With this approach, however, used with full awareness of its drawbacks, the ethicist by necessity will take care in hearing and eliciting the stories of those involved. Comparison with other stories and the outcomes of earlier cases is almost unavoidable. Uncertainty will lead, ideally, to more stories told and compared. This seems to me to be the only way to arrive at a solution that maximizes everyone's interests, while remaining within the constraints of the larger reality of the way in which medicine is perceived by most Americans. One can hope that enough stories heard and told together might also lead to a revision of that larger and somewhat misleading cultural understanding, where life is always good and death always failure, and states in between, such as disability, are invisible. Overall, however, I think telling and comparing stories is a valid way to 'do' ethics, and more likely to ultimately lead to a fair solution of an ethical dilemma than the reliance on a few principles.

In this, I seem to be in agreement with John Arras (1997), who concludes his critique of narrative ethics in "Nice Story. So What?" with the recognition that understanding narrative is an essential part of ethical analysis, but is not by itself a basis for moral statements. He outlines three approaches to the use of narrative, each relying more heavily on narrative. He dismisses the second two, the use of stories as a source of moral truth (ethical justification by historical narrative) and the use of the narrator as a source of authentic truth (the post modern approach), saying that they are both undermined by the essential unreliability of stories and storytellers. However he recommends the first approach, in which narrative is used in conjunction with established principles. He says, "I have come to the provisional conclusion that the first approach, which conceived of narrative as an essential element in any and all ethical analyses, constitutes a powerful and necessary correction to the narrowness and abstractness of some widespread versions of principle and theory-based ethics" (Arras, 1997, p. 84).

Stories of Sickness, or the stories we tell

The last of Lindemann's narrative approaches is the stories we tell or, more specifically, stories of illness told by patients. I have already mentioned the works of Brody and Frank which stress the importance of the patient's story in treating illness. Brody states that in order to provide good care, a physician and patient must develop a therapeutic relationship, which includes both doctor and patient understanding the

meaning of the illness in the patient's life. Frank adds that telling a story of the illness that is not reduced to the dispassion of the medical chart is essential for the patient to combat the loss of self that illness brings about. For both, narrative is an integral part of the clinical relationship.

The value of this for the practice of medicine is clear, though neither Frank nor Brody provide guidelines for exactly how a physician might go about aiding a patient in reclaiming his story and self from the narrative wreckage that illness has made of his life. While listening to the patient might be on the curriculum in medical school, narrative repair is not. I suspect that the best we can hope for now is not further wrecking the life narrative by insisting on intrusive or inappropriate narratives.

For the practice of ethics, listening closely to the patient is also not a new idea; it is presumably necessary to carry out the principle of autonomy. Narrative ethics gives moral weight to both the telling and the hearing of the patient's story. According to Lindemann, "The moral value of the story, then, lies in its ability to reveal both to the patient and to those in her storytelling community who the patient is and should be seen to be" (Lindemann Nelson, 2004, p. 173). Considering the patient's interests as a narrated story that is part of their bigger life story would provide the insights necessary to upholding autonomy.

But narrative ethics assumes further, that the story itself has a moral message beyond the value of evaluating the storyteller. Frank states, "People who tell stories of illness are witnesses, turning illness into a moral responsibility" (Frank, 1995, p. 137). In his assertion that illness stories are a form of testimony or witness, Frank implies that another moral use for stories of sickness is to impart understanding gained by living with pain or illness. The stories offer guidance for people who are also ill, or may become ill some day. They perhaps also offer a different and deeper view of what is important in life. The ill storyteller, by this testimony, becomes a sort of living proof of another way of being, one that those of us who are not ill can experience only second-hand.

The narrative then not only serves to reconstitute a self wrecked by illness, but also creates a community of listeners who share the experience. The story then can be of benefit to both teller and listener. The listeners may benefit from this either because they themselves have had similar experiences with the interruption of illness, or because they have heard the story and understand something of its message. In this way, sick people who are willing to share their story are like travelers to a foreign country which we

are expecting ourselves to visit some day. The report they bring back should be a guidebook for that unexplored territory.

The narratives that I have read are not exactly stories of sickness. The narrator is not the sick person, his own body a testimony to the changes in his life and in himself brought about by illness. He is instead the parent of a sick child. The stories are about the effects an illness can have on a life, but the person telling the story is observing the illness of another.

The illness certainly sends the child's life onto an unexpected trajectory. The child has barely begun a life story, but his parent nonetheless has certain expectations of that life. We will not hear from the child; in all these stories the child is unable--and probably will never be able--to speak for himself. We will not hear how the illness has changed the child's life except by comparing it to what the parent expected from it before the illness. In addition, the child's life is not the only life to have been sent on a new trajectory. The stories of both parent and child are inexorably altered. The parent has been sent into a new and difficult role, that of extreme caregiver. The parents who are willing to tell this story are, I think, writing from a different unexplored land, one where many lives are sent on an unexpected new trajectory by the illness of another. That new trajectory is partly defined by caregiving.

Though the illness resides in another's body, these parents are also witnesses to illness, and to ways of being taught through illness. All of the parents claim at some point that their child is their teacher from whom they have learned many important lessons about how to 'be.' This idea is expressed frequently, both in narratives by, and in interviews conducted with, parents of sick children.

Frank provides a way to understand this. Speaking of an adult chronic pain patient named Gail, he says, "Gail claims different knowledges, but what would her answer be if she were called to account for such knowledge? . . . Gail could certainly say this and that about delivery of health care, but her true witness, the witness that 'really matters' to use her phrase, is not what she could say but what she is" (Frank, 1995, p. 141). Her embodied, pain-ridden self is a message apart from what she communicates verbally. These parents, with the daily intimate contact of caregiving, do not have quite as close a contact with pain, but nonetheless must unavoidably experience the testimony of their children's bodies. Part of their story is a desperate attempt to understand this message, and to communicate with the reader what they have learned.

Their own journeys to cope with the changes the child's illnesses have made in their own lives, revolve around their attempts to discover the meaning of this message. They have to make do with the few clues they are given, and ultimately become the interpreter of their child's illness.

This message from their children, as a second-hand account, may be less reliable than similar messages sent in first person narratives from sick patients. However, I believe that the child's story is only a small part of the story that must be understood. The parents are also on an unexpected journey, perhaps not as common as the adult journey through illness and death, but it is not unusual, and may well have similarities with other forms of family caregiving. They have to reach beyond the usual concerns of parenting, in order to navigate the unknown territory of medical caregiving, often giving up their own plans and expectations in the process. How they find their way through the task of caregiving, indeed what they discover themselves becoming in order to perform the task, I think holds important clues to the process of caregiving itself.

And I maintain that, for medicine, understanding the journey made by these parents is essential. This is only in part because the parent becomes the voice of the child, and as such becomes the acknowledged custodian of the child's best interests. It is also important to understand the parent's story. That story is so entwined with the child's that any medical decision made must take both stories into account. Understanding of the parent's experience of the child's illness is just as important for clinicians as understanding of the first-person narrative of the sick patient.

John Hardwig, in *Autobiography, Biography, and Narrative Ethics* (1997) makes a similar statement about the importance of paying attention to other voices surrounding the ill patient. He notes that our current form of patient-centered ethics requires that we consider only the patient's interests. This reliance on one person's story, he says, is a form of oppression that "effectively silences all other members of her family." He adds, "Decisions are made every day that promote the patient's interests at truly staggering costs to the lives of other members of the patient's family. These decisions are routinely made as if families were no more than patient support systems or as if the interests of other members of the family were somehow morally irrelevant" (Hardwig, 1997, p. 59).

Parents taking care of medically complex children at home have been asked to sacrifice much to the best interests of their children. That they seemingly do so willingly does not make their sacrifice any less imposing. That their assessment of their child's

best interest might differ from that of their providers should be of no surprise to anyone. Yet their story is rarely listened to and, in fact, rarely even told. To ignore these parents' stories silences the voice of the people who are most significant in the disabled child's life, who must receive the medical care plan and turn it into action, and who must live intimately with the consequences of any decisions.

TYPES OF ILLNESS NARRATIVE

In my search for parent narratives of caring for sick children, I found myself drawn to certain types of narratives. I have been a medical provider for a variety of complex children in my pediatric practice, and became aware of both the number of parents living with multiply disabled children and the difficulty of the caregiving task they are doing. It was possible to piece together their stories, from details on the medical record and from quietly asked questions, but their stories were clearly incomplete.

Initially I looked on the internet, at parent support groups, caring bridge sites, and blogs. These were even less satisfactory. The stories are told in brief, emotional paragraphs, with little connection or follow-up. The narrators do not have to even identify themselves. It seemed a particularly unreliable way to tell a story, giving no idea whether a comment made on one day was immediately regretted by the next. There is no way to tell if a statement is a true feeling shining suddenly through or a work of fiction.

An example is a web site called "PostSecret". The site claims to be a repository for awful things that people think but would never dare to tell even a close friend. People supposedly mail their secrets on post cards and send them to a post office box, from which a mysterious person, or group of people, post them on line. New cards arrive frequently and older entries are archived. The anonymous web masters describe PostSecret as an "online community art project" (www.postsecret.com). There are some interesting and appalling secrets, many of which ring true.

One of the "secrets," posted on an unknown date from an anonymous person, shows a graphic of a child's brain with arrows pointing to areas of hypoxic ischemic encephalopathy damage. There is a second illustration of a brain, in bright red and yellow, torn in two. The message reads, "Part of me wants my severely disabled child to die so this nightmare can end . . . & I can just be me again." The back of the card adds,

“I’m terrified of what the future holds . . . and I’m so very tired”

(Postsecretcollection.com). This is an astonishing thing to say, but may well be representative of a parent of a special needs child. However, looking at some of the other “secrets,” it becomes apparent the secret-tellers all have very similar (and rather impressive) abilities in graphic design. There is no way to tell if a secret is truly representative or concocted by the designers.

It seemed best to rely, then, on narratives published in print, preferably in a longer form. While this does give a chance for the author to craft a story, perhaps altering it for purposes of his own, at least there is a reflective process required in the months it takes to put that many words on paper. Rather than rely on fiction, which would be filtered through another person, I looked for first person narratives written by parents of multiply disabled children. There are also narratives by siblings, and by people who grew up with disabilities themselves. Siblings, in particular, can and do participate in the caregiving process. They are also likely to have stories to tell about extreme caregiving, but at this early stage I think it best to focus on the parents.

My search for narratives was somewhat haphazard, relying on word of mouth, internet listings of books recommended by various disability web sites, and searches of the shelves of libraries and book stores. There are not many parents who have so far shared their stories of living with the sort of disability that makes a parent into an extreme caregiver. And many of the stories that I did find, did not seem to me to reflect the reality of raising such children that I had witnessed in my clinical practice. I found myself looking not just for parent narratives, but for a certain kind of narrative.

In *The Wounded Storyteller* Frank (1995) identifies three kinds of narratives about sickness, three different ways of approaching the story of sickness. Brody, in *Stories of Sickness* (2003), reiterates and refines those categories. Both divided narratives into three types, which they called restitution narratives, chaos narratives, and quest narratives. The narratives that seemed genuine to me fall into only one of those categories, the quest narrative. This section will provide a short description of all three types of sickness narratives, and support my selection of only one type.

Restitution Narratives

This is the most common and most popular narrative form. The restitution narrative follows a simple plot, in which illness interrupts a life but is overcome, restoring

the person to his former state of full health. It is a reassuring story, that illness can and will be cured, and is the preferred story told by the medical system and those that support it. Fortunately, it is also often true.

Brody indicates that the restitution narrative sometimes is helpful because the narrator will gain some wisdom from his illness experience that he will then impart in the narrative. Frank, however, states that a narrative in which some self-realization or change occurs, is no longer a restitution story. He sees the restitution story, not as a story about a person dealing with illness, but as a documentation of a method of cure. He says, that “restitution stories bear witness not to the struggles of the self but to the expertise of others; their competence and their caring that effect the cure” (Frank, 1995, p. 92). Restitution narratives reflect the optimistic and heroic narratives that are dominant in medicine and in the larger culture.

As a dominant narrative about medicine, the restitution narrative can be particularly destructive. It makes the body into a thing that has broken down and needs to be repaired by others. This commodification is encouraged by a medical system that celebrates its ability to sell restitution. Lost in the overwhelming story of success is the fact that not all illnesses are amenable to cure. Time and resources are often wasted in a vain attempt to make the story come out the way it is supposed to. “But eventually the reality and responsibility of mortality, and its mystery, have to be faced. Doing so requires a story outside the restitution narrative” (Frank, 1995, p. 84).

Chronic illness also falls outside the restitution narrative. “The problem arises when the ill person does not find restitution, or when someone who can only tell restitution stories encounters another whose health will not be restored” (Frank, 1995, p. 92). Since restitution stories are the only kind of stories that many people can tell, and the most likely to be published, there are restitution stories about chronic illnesses. According to Brody, since chronic illness by definition does not resolve, these restitution stories are “ultimately false” (Brody, 2003, p. 85).

There are restitution narratives by parents of children with chronic diseases, diseases that are known to be incurable and unremitting. They can usually be identified from their cover copy, in which their child’s unexpected miraculous cure is announced. They also take a format where the parent realizes that there is in fact nothing really wrong with their child, despite the fact that the child still has the disorder. They do seem

to be fairly common, and I encountered several, two of which I will review below. Like Brody, I find them deeply suspect.

One of the things I will be looking for in narrative accounts of extreme caregiving, is a description of the ongoing and intense relationship that forms between parent and child when they are also medical caregiver and patient. I found that in the restitution narratives, the optimism necessary to find restitution in a child's long-term, incurable disabilities essentially makes the child disappear. These narratives describe who the parents wish their child to be, rather than accepting what their child is actually like. In analyzing the difficulties and consequences of extreme caregiving, a reliable picture of both caregiver and cared-for is necessary. If the child's need for care, and the ongoing nature of the caregiving relationship, are lost in the parent's triumphant restitution, the narrative is difficult to interpret.

Chaos Narratives

The chaos narrative, according to Frank (1995), is not really a narrative, since it really has no plot, consisting instead as a series of interruptions. A chaos narrative can really only be lived, not told. "The person living a chaos story has no distance from her life and no reflective grasp on it. Lived chaos makes reflection, and consequently storytelling, impossible" (p. 98). The person living them does not have a presence or a voice in the story, and can only relate the random interruptions, without any organized past or future. The chaos narrative does not exactly describe the narrator or the chaos, but can supply enough of the edges of it that the real story can be partially reconstructed. According to Frank, the moral responsibility brought on by the chaos story is to listen to it, for only in the telling can the narrator find a way out of the chaos. However they are difficult to listen to, uncomfortable to hear, and a horror to live.

It seems likely that this type of story will rarely be encountered in published narrative form, but that many people, particularly the poor and disenfranchised, are living it. "The worst thing medical staff can do to someone in the chaos story is rush him to move on. Moving on is desirable; chaos is the pit of narrative wreckage. But attempting to push the person out of this wreckage only denies what is being experienced and compounds the chaos" (Frank, 1995, p. 110).

A chaos narrative is a bad place from which to raise a child. It is tempting (and sometimes necessary), when there is no possibility of rushing the parent out of chaos, to

at least remove the child from it. But most parents of special needs kids live barely controlled chaos lives, with most of the chaotic interruptions happening around and because of the child. They counter the chaos narrative, on a lived basis, by complicated systems of keeping track of their responsibilities. For some, this works well as a counter-narrative; and they are in control most of the time. For others, the schedule is all-consuming, both of time and self, and is in itself frequently comprised by interruptions.

Those extreme caregivers who are living chaos narratives, by definition, will not be able to provide much information on caregiving. Nor are they likely to write published narratives. However, chaos hovers at the edge of all of these parents' stories. They have often lived through it and, even when able to frame a more organized narrative, remain close enough to that edge that at any time they could again be consumed by chaos.

Quest Narratives

Since both restitution and quest narratives do not coherently depict the caregiving relationship, the narratives I have found most useful are quest narratives. The illness story told as a quest narrative becomes the description of a journey, which is often modeled after mythological quests, or the hero's journey. As in mythology, the journey can be divided into three parts. The first is "departure" from ordinary or prior existence, the often unexpected call to become a different person or follow a new path. In illness, of course, this call is heralded by symptoms and sealed by a diagnosis. The second stage is "initiation," in which the hero undergoes trials, comprised of physical, emotional, and/or social suffering. This may lead to transformation, or the idea that "the teller has been given something by the experience, usually some insight that must be passed on to others" (Frank, 1995, p. 118). The final stage of the journey is the "return," in which the hero reports on that experience or insight. It does not have to be a return to health. Brody notes that the point of the journey is to accomplish a specific goal, and that recovery is not necessary to achieve that goal. He states that, "Part of the transformation may be that one comes to change one's goal" (Brody, 2003, p. 87).

Both Brody and Frank agree that the quest narrative is the most useful type of illness narrative, benefiting both the storyteller and the listener. The narrator uses the story to work through the changes in his life that illness has brought about. The listener, or reader, or witness, "both affirms that change, which is one sort of moral duty, and gains a model for his own change, another moral duty" (Frank, 1995, page 128). A

written illness quest narrative becomes a moral effort, as both writer and reader work to become transformed by the events related.

The parent narratives that I found most revealing do take the form of quest narratives, though chaos is never far away. The illness is lived by the child, but the journey is undertaken by the parent. In fact, two of the three most useful narratives have the word 'journey' in their titles: Ian Brown's (2011) book, *The Boy in the Moon* is subtitled *A Father's Journey to Understand his Extraordinary Son*. Josh Greenfeld's (1970) book is titled *A Child Called Noah: A Family Journey*. They are very much illness quest narratives, with the quest undertaken by the parent in order to comprehend both the child and his illness. In some cases the journeys are literal, as diagnoses and treatments are searched out and available only at far away hospitals. And, unlike in the restitution narratives, one of the things that is sought is an understanding of the child's experience. Once they have accepted that there is no cure or easy solution--itself an arduous journey--they seek to know the child, and who he is within the context of his disability.

The stages of departure and initiation are not always sequential, as new diagnoses and new therapies for the illness often supplant old ones. While the child bears the illness and is the one on whom tests and treatments are performed, it is clear that the trials of the initiation are not limited to the sick child. They encompass the lives of the authors and their families as well, and all are changed by the illness. The return is both the act of and a result of the writing of the books. They are all reports from a land that few others have inhabited, or are even aware of.

The question to be asked, then, is What can we, as providers, parents, caregivers and witnesses, learn from this unexplored territory?

THE NARRATIVES

While I will use statements made by parents in my own practice, the majority of my information is taken from three autobiographies, spanning four decades. Noah Greenfeld, the subject of *A Child Called Noah* was born in 1966. The book was published in 1970, using excerpts from diaries kept during Noah's early years (Greenfeld, 1970). Ted Hart from *Without Reason* was born in 1970, but the book was written in 1989 (Hart, 1989). *The Boy in the Moon*, Walker Brown, was born in 1996, with the book published in Canada in 2011 and the USA in 2012 (Brown, 2012).

Interestingly, the author of all of these books is the child's father, not the mother, despite the fact that Greenfeld's wife was also a writer, and Brown's wife is, like him, a journalist. I cannot speculate why it is the fathers who had the successful books, except to point out that all three men admit somewhat guiltily that their wives did the majority of the care. (According to Noah's brother Karl Greenfeld, who wrote his own memoir about his life with Noah in 2009, his mother did write about Noah. In the late eighties, after Noah had been moved into assisted living, Fumiko Kometani wrote articles and several books in her native language, which were published in Japan (Greenfeld, K.T., 2009).)

None of the children were particularly medically complex, nor did they require complicated technology in the home, except for Walker Brown who was tube fed. However all did require extreme caregiving. Their care was complex, involving a variety of therapies, mostly for development delay, done both at home and at multiple visits to professionals. Their care was time-consuming, largely because of their behavior problems which often required round-the-clock attention. And eventually their caregivers were additionally burdened by the realization that there would be no effective treatments leading to cure, so that the need for care would be life long.

Quest Narratives

A Child Called Noah: A Family Journey, Josh Greenfeld, 1970

Greenfeld was a professional writer, the author of several novels and screenplays, when his second son Noah was born in 1966. He kept a diary during Noah's childhood, and published this book as the first of three volumes in which he collected his experiences dealing with Noah's problems. This book comprises Noah's first five years, when it first became apparent that there was something wrong, and during which a variety of medical encounters led eventually to the identification of autism. This is one of the earliest books about raising an autistic child, and was for a time quite famous. It was followed by two other books, numerous articles, and interviews, also about raising Noah. This first book is to me the most important, since the resulting publicity had not yet touched the author's life.

The journey undertaken was initially a search for a diagnosis which would confirm that Noah did indeed have problems. This led through several diagnoses, since at the time autism was even less well understood than it is now. The journey became literal when the family moved to New York and then California, looking for an effective

treatment program. The book ends on a hopeful note, with a diagnosis of autism and some promising improvements in speech and behavior with operant conditioning therapy.

Without Reason: A Family Copes with Two Generations of Autism, Charles Hart, 1989.

Hart's son Ted was born in 1974 and, like Noah Greenfeld, developed problems that were not immediately identifiable. Hart's journey, like Greenfeld's, was to identify and find treatment for Ted's unusual behavior. The diagnosis of autism was finally arrived at, by Hart himself, when Ted was ten years old. Surrounding this search for diagnosis and cure, and eventually becoming more important, is Hart's search to understand the way his son sees the world. Ted can read and talk and memorize things, but his ability to use the facts he can recite remains elusive. He never becomes toilet trained and he does not sleep at night. Obvious frustration and misunderstanding often lead to increasingly violent behavioral melt-downs. Hart wants to know who his son is, how he thinks, and how to help him eventually find a place in society.

Interestingly, Hart's much older brother Sumner (born in 1929) is also severely autistic, though his diagnosis is not established until Hart recognizes the similarities between his brother and his son. By that time, Sumner is over 50, and has been living in isolation with his mother since birth. Hart has to unlearn some of the lessons on the shame of disability that he learned from his mother's example. Hart also chronicles the problems that Sumner has after their mother's death, and makes parallels with Ted's emerging life.

Sumner is placed in an institution after his mother's death and, even though he is slightly verbal, the experience is at first nightmarish. By age 14, Ted's unpredictable behavior makes him impossible to handle at home. He has a much better time adapting to his new group home, though it is of course quite difficult for his father. The journey concludes with the opening of a new relationship made possible by Ted's new home.

The Boy in the Moon: A Father's Journey to Understand his Extraordinary Son, Ian Brown, 2011

Brown's son Walker was born in 1996, and by 8 months his very astute pediatrician had diagnosed his particular set of dysmorphic features, medical fragility, and developmental delay as a rare syndrome called CFC (Cardiofaciocutaneous

Syndrome). The book opens with a vivid description of caring for Walker at age eight years, which I think should be required reading for all who work in a pediatric hospital. Walker is the sickest of the children in these narratives, the only one requiring home medical equipment. He needed tube feedings, which is probably the least complex of the medical technology available for home use. His father's description of a night feeding in the opening chapter speaks volumes about the cost of this simplest of procedures.

Brown then backtracks to fill in details of his life with Walker, centering around his quest to understand who he is, why he is the way he is, what he might be thinking about, and how to communicate with him. There is no search for a diagnosis, just a prolonged and guilt-ridden search to understand the nature of this exceedingly rare problem. Brown is a journalist, and uses his skills to ferret out information, traveling widely to visit everything from genetics labs to the homes of fellow CFC parents. There is also no possibility of cure for this genetic defect, just a multitude of mostly failed attempts to modify behavior.

There is no question that Walker requires extreme caregiving. He remains non-verbal, unable to feed himself or toilet train, sleepless, and must often be restrained to prevent self-injurious behavior. Brown's descriptions of his life with Walker are vivid, deeply felt, and brutally honest. There is a rich description of the interactions between the two, as Brown carefully observes and describes Walker's behavior, and speculates on what he thinks Walker may be trying to express. But in spite of this, Walker remains as inscrutable and distant as the man in the moon.

In the final chapters, Walker becomes too much to handle at home, and has to be placed at age 13 in a group home. Like Hart, Brown's relationship with Walker changes and deepens when he is no longer a primary caregiver. This is an interesting subject for further work, and possibly offers a way out of some of the ethical dilemmas posed by extreme caregiving, but is beyond the scope of this paper. Brown uses his new freedom to visit a variety of institutions for the mentally disabled, including an exemplary one in France. His message upon return from his quest is to begin to outline for us the value that people like Walker offer to the world.

The Still Point of the Turning World, Emily Rapp, 2013.

This memoir is not exactly a record of extreme caregiving, but it does contain a journey of discovery, or at least speculation, about the meaning of a severe illness in a

child. It was written during and after the death of the writer's son from Tay Sachs Disease, a rare and lethal mutation which causes progressive neurologic destruction. Hers is a different sort of journey from the others' however, as Rapp learns of the diagnosis on the first few pages, and immediately accepts the fact that the disease will lead to death in the first few years of life. She does research the disease, but never with any expectation of discovering a cure. She also does not document the caregiving which she must have done. Though she decided to forgo life extending treatments such as tube feedings and home ventilation, she still would have had a formidable amount of medical care to administer, including multiple medications, seizure precautions, physical therapy, and comfort care.

The intent of the memoir is to describe her grieving process, a journey which began on the day of the diagnosis. However a large part of the grief is due to the realization that her son, who never advanced developmentally beyond age 6 months, would never be able to create a life story of his own. She takes on the task of creating a narrative for him, to imagine and describe the limited life he led to the best of her abilities. She examines him minutely, gauging both what he can and can't do, with an eye toward how her love and care for him are reflected in his limited responses. She has much to say therefor about the emotional component of the virtue of caregiver responsiveness.

Restitution Narratives

There are many books available whose cover descriptions or titles make it obvious that, even though they deal with chronic illnesses, the illness will be cured by the end. Some books, like *Changed by a Child*, a 1997 book by Barbara Gill about raising a child with Down Syndrome, whose cover states that it offers "comfort, solace, and resonance on every page," comprise a series of short essays offering uplifting advice. Other books declare themselves by their titles, such as *Miracle Birth Stories of Very Premature Babies: Little Thumbs Up!* written by the father of a micro-premie. The cover reads like an advertisement for a neonatal intensive care unit, claiming "miracle babies" and saying that the book is "an uplifting testament to hope" (Smith, 1999).

However I did find two useful restitution narratives. These were both written by mothers:

The Anti-Romantic Child: A Story of Unexpected Joy, Priscilla Gilman, 2011.

When her son, Benjamin is born in 1997, Gilman has specific expectations of a certain, rather old-fashioned, childhood. She thinks her hopes are dashed when he begins to have developmental issues. She does embark on a quest for a diagnosis and eventually arrives at Aspergers Syndrome. However she prefers to refer to this as hyperlexia with sensory integration dysfunction, and never uses either Aspergers or autism to refer to her son.

Benjamin does not actually require extreme caregiving, though he is not the easy romantic child Gilman was expecting. Perhaps because her child is less severely effected, her narrative brims with enthusiasm and hope and, to my thinking, quite a bit of denial. The book becomes a restitution narrative, with the author ultimately denying that there is, or has ever been, anything wrong. She can tell by Benj's poetry, which is included in the book, that the problem was never with him, but with herself being unable to recognize his romanticism.

However Gilman's search for knowledge and use of that knowledge is interesting, and in many ways similar to that of the three male quest narrators. She also does a great deal of research and acquires extensive medical knowledge, which will be discussed in the section on competence.

Finding Jesse: A Mother's Story of Grief, Grace, and Everyday Bliss, Marianne Leone, 2010

Despite the title, Finding Jesse, the severely impaired Jesse is nowhere described in the book. Jesse was effected by prolonged lack of oxygen at birth and had as a result severe cerebral palsy, minimal motor control, and inability to communicate. Nevertheless, his mother is absolutely sure that Jesse was, not merely mentally intact, but incredibly intelligent. Leone describes no interactions with Jesse that would help the reader confirm this. Jesse was mostly non-verbal, and communicated via an "eye gaze computer", to which he was introduced at age seven. On this, he did calculus and Latin homework, as well as writing poetry. Examples are included, but the process by which this communication was discovered and takes place is barely discussed.

Given the nature of the impairments his mother admits to, Jesse must have been on multiple medications, tube feedings, and monitors, therefor requiring a level of

extreme of caregiving beyond any of the children in the other narratives. However his mother rarely mentions this, and never describes it.

The book is mostly about his mother's efforts, against all odds, to assert this intelligence to the rest of the world, particularly to unfeeling doctors, teachers, and home care aides. Those who do recognize Jesse's intelligence are lavishly praised. It is also about her efforts to recover from his sudden death at age seventeen; a journey back from depression aided by her husband, actor Chris Cooper, the family dog, the writing of the book, and a tattoo that says 'Jesse.' Her love for Jesse is enormous, but the person she loved was not apparent to me from her book.

Other Narratives

i wish i were engulfed in flames: my insane life raising two boys with autism, Jeni Decker, 2011

This book is comprised of a series of humorous essays centering around the author's difficulties raising two autistic sons. She concentrates on the ways in which her sons' inappropriate behaviors and need for care constantly interrupt her life. There are honest depictions of her son's toileting (or rather lack of toileting) behaviors and masturbation in public. There are also numerous complaints about the effect of these interruptions on the author's sex life.

The book is, seemingly, a fairly successful chaos narrative. However its concentration on the embarrassing social situations caused by autism, rather than on the effort required for caregiving, makes it less useful as a story of illness, or a depiction of extreme caregiving.

The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures, Anne Fadiman, 1997

This book is famous not as a parenting memoir, but rather as a journalistic documentation of the wrongs visited on a Hmong girl named Lia Lee, by her American doctors. It is meant to depict the Hmong experience in America, and how it has been misunderstood. However, Lia's care, even before the sepsis that left her in a vegetative state, is the most difficult I have seen documented in print. Fadiman's portrait of the caregiving relationship between Lia and her mother, though neither in first person nor the

intent of the book, still provides interesting insight into both the nature of caregiving and the way in which it is often overlooked.

Boy Alone: A Brother's Memoir, Karl Taro Greenfeld, 2009

Josh Greenfeld's book, *A Child Called Noah*, is one of the three major memoirs about extreme caregiving. This memoir was written recently by Greenfeld's son, Noah's brother, Karl. It is not so much about Noah, who grew up to be much more severely autistic than was obvious from his father's early memoir, as it is about the effects Noah's problems had on the family. It is a much darker book than Josh Greenfeld's, filled with cynicism, guilt, and anger. Noah never did learn to speak, and his behavior deteriorated in adolescence. He began a series of disastrous placements in institutions at age 14. I have included it because it provides a further history of Noah, as well as some perceptive observations about the relationship between Noah and his father.

The Lazarus Case: Life and Death Issues in Neonatal Intensive Care, John Lantos, 2001.

The Lazarus case is a fictional court case of suspected neonatal malpractice constructed by Lantos, a pediatrician and ethicist, from his own experiences testifying in similar cases. It is a careful and nuanced study of medical thinking, progressing through a variety of important neonatal issues, as the author encounters the need to explain them. The impaired infant, whose parents have initiated the malpractice suit, is never seen, perhaps because Lantos' testimony is being taped before a group of lawyers as expert witness, not in a court room. It is therefore very much a doctor's story, and not a narrative about either sickness or caregiving.

LIMITATIONS OF THIS WORK

Many of the pitfalls of narrative ethics have been discussed above, making them a difficult source for moral underpinnings, though of course stories can be, and are, used in moral evaluation. Stories are crafted from a cultural ethos that may itself not be moral, or may tell the story of only the dominant part of the culture. There is no set standard for the stories we read, and even literary acclaim does not guarantee morality. Stories as case histories can be faulted for being intensely personal, situational, or anecdotal. Even

when compared with similar stories there is no agreed upon foundation story to use to cross check moral conclusions.

In addition, particularly in the modern accounts that I have found, stories are crafted from other stories and, particularly in the medical arena, much of the information authors use as a basis for their story is unreliable. There are for example widespread beliefs in what medicine can and cannot do that are based on repeated hearing of inaccurate stories, particularly the heroic and sanitized portrayal of emergency medicine in television and other media. These stories are not acknowledged as a source of information; they just seem to be things that everyone knows. A parent writing about his or her child's illness will already have preconceived ideas about the causes and meanings of that illness. I chose longer narratives in part to see how those attitudes toward medicine and illness might become more informed over time.

I also chose crafted narratives, novel-length biographies about living with a disabled child, to avoid the spur-of-the-moment blurt of emotion that is blogging. Of course the longer form also gives the narrator a chance to tidy up his feelings. One of the criticisms of narrative ethics is that the narrator usually has a stake in the telling of the story, and is never completely factual. This is true even in autobiography. It is possible to verify the authenticity of the facts about the author's life, but not to insure his reliability. However, I believe that the story told is in itself important, and its usefulness in moral analysis is not dependent on complete objectivity.

Narrative ethicist Rebecca Garden (2010) uses the example of Lucy Grealy's *Autobiography of a Face*, to show the ways in which even a personal narrative of illness can be subverted. According to Garden, Grealy gave her book a happy ending in order to get it published. She became well-known, and many then used the narrative to shed a positive light on disability, and hold Grealy up as an example of triumph over adversity. However Grealy's death from heroin overdose, together with a less happy retelling of her story by author Ann Patchett, has, according to Garden, been used to question the authenticity of that restitution story. Garden suggests that the possibility of subversion might cast doubt on the use of stories of sickness in ethical analysis. As Garden puts it, "the author is a concept produced by the text itself and through culture, a figment of cultural imagining to which readers ultimately do not have access" (Garden, 2010, p. 126). However, she ends by suggesting that both versions of Grealy's story are valid and useful in ethical analysis. The ambiguity itself, essentially, is instructive.

I agree that, even in an autobiography, the narrator may not always stick to factual truth. He may be fabricating events, or altering them consciously or subconsciously in order to make himself look better, or worse. Or he may have a hidden agenda, which he can mold his story to support, including agendas which are imposed or even coerced by the publication industry. Perhaps we can't completely trust him, but this does not decrease the value of the story. Narrative ethics, I believe, must accept the possibility that the narrator of any story might be suspect, and include that suspicion as a part of the narrative.

Johanna Shapiro agrees that narrators may in some ways be unreliable, but feels that patient stories are still of utmost importance. She acknowledges that the personal motivation of the author will introduce biases into a story, but feels also that "patients tell the story they need to tell" (Shapiro, 2011, p. 68). The unreliability and possible inauthenticity of the narrator therefore does not negate the usefulness of his story. She recommends that we "approach all stories from a context of narrative humility," paying attention not only the story being related but to the context in which the story is being told and the narrator's intent in the telling (Shapiro, 2011, p. 70). This I have tried to do.

Probably the biggest problem with this thesis is the choice of narratives. I admit to a somewhat random selection process, depending on chance and cover copy to select narratives. I by no means made an exhaustive search for every book written by the parent of an ill or disabled child. I have no doubt that there are books which I overlooked, and books which I perhaps should not have excluded.

I also chose a specific type of narrative. I believe that my avoidance of restitution narratives, would be supported by Frank, Brody, Shapiro, and Garden. However my selection of stories that reveal a specific context of anger, guilt, sorrow, or regret may be less supportable. I have no idea if these are more 'true' than the number of restitution stories available. They do reflect feelings that I have seen in my family and practice, but I cannot guarantee that they hold true for all parents of special needs children. I could be criticized for making a deliberate selection of stories which reinforced personal experiences.

Another limitation is in the types of narratives available. I found several books by the parents of autistic children, and those inform the majority of my thinking. Of the numerous disabling genetic conditions, I found accounts by parents of only two: the rare disease called CFC (Cardiofaciocutaneous Syndrome) and Tay Sachs. However there

are numerous other disorders which require extreme caregiving, and which are likely to have at least a few differences in consequence. There must be differences as well in the parenting of children with intellectual disabilities other than autism, children with chronic diseases that cause physical dependence without intellectual delay, and children with progressive medical problems who are not expected to live past adolescence. I encountered no narratives dealing with these types of illnesses.

However, I am using these narrative in hopes of amplifying unheard voices, to make visible some of the undocumented and invisible consequences of care. The narrative voices I did find serve to express at least some of the enormous consequences of extreme caregiving. I hope to reveal ethical issues that are barely on the radar of clinical ethics, by telling stories that, even if somewhat ambiguous, need to be heard. I am hoping that the willingness to put something, particularly something negative, into print under one's own name must count for something. Even the ways in which these parents might be misguided is important, as are the stories they might need to tell.

MAKING LEMONADE: A WORD ABOUT OPTIMISM

There is a particular limitation to parent's telling of illness stories for their children, which has been alluded to above but not discussed in full. It colors, I believe, the entire experience of having a disabled child, and is so culturally ingrained that it effects everything from individual parenting stories, to doctor patient interactions, to the construction of parent support groups. I am referring to an emphasis on positive thinking, which produces a near requirement or duty to always look on the bright side.

This phenomenon has been described recently in the literature by Helen Harrison, as "making lemonade" (Harrison, 2001). She feels that parents of disabled children are expected to have a positive attitude. She reports that both parents and children who express negative feelings about their experiences or disabilities have been forced out of support groups and off of internet lists. Most parents feel the need to appear strong for other parents, their doctors, and even themselves. Those who do not can be seen as complainers, bad parents, or politically incorrect in their attitudes toward disability.

Harrison believes that this attitude permeates and calls into question the results of quality of life studies, particularly those done by Saigal's group in Toronto (Saigal et

al., 1996, 1999). In a paper questioning the reliability of these influential studies of the quality of life of teenagers who survived extremely premature births, she points out several inconsistencies between actual and reported abilities. In these studies, severely impaired teenagers rated their quality of life higher than control teenagers on several scales, some of which, such as educational success, were clearly exaggerated. Other studies have likewise found and questioned the fact that teenage survivors of premature birth who clearly are in poor health, rate their health-related quality of life as equal to or even better than their unaffected peers (Gray et al., 2006).

Harrison proposes that the parents and children involved with these studies felt that they had to give a positive report, knowing that it was their doctors and hospital that were conducting the study. She feels that this inaccurately high assessment of the quality of life reflects, among other things, a coping mechanism for dealing with severe disability, a social mandate to be seen bearing up well under adversity, the need to maintain a politically correct attitude towards disability, and an unwillingness to disappoint the medical caregivers still actively involved with the child's care (Harrison, 2001).

This expectation is evident in the nature of the books published about special needs parenting, which seem to require at the very least a sunny acceptance and an insistence that everything has been all for the best by the end. It is apparent in on line parent groups, where tips for parenting--which brands of diapers fit best, where to find special formula, what gadget works best at capping a feeding tube--are mixed with cheeriness, as though these parents feel they must convince each other how wonderful their children and their lives are.

It is also not a new problem. My father once came home furious from a parent support meeting of the newly formed ARC (Montgomery County Association for Retarded Children), for which he was a founder and activist. The circle of parents had all been sharing how wonderful it was, and how blessed they were, to have the gift of a retarded child. My father found this attitude unbelievable. He was at a loss for words at their misunderstanding, but had finally managed to blurt out, "It is not a gift. Mental retardation is Hell." His remark had not been appreciated, which he found a shocking betrayal by people he thought he knew and trusted.

The parent authors of caregiving narratives have also commented on the expectation of positivity. Charles Hart, author of *Without Reason*, founded and attended

an early autism parent support group, in which he states outright that a positive attitude was desirable. “We tried to make the workshops a positive experience. Those parents needed more hope in their lives. They needed to feel positive about their handicapped children and to feel good about them selves as they struggled against social attitudes that tend to devalue people with disabilities and their parents” (Hart, 1999, p. 182). No doubt many in Hart’s group benefitted from the hope and positivity, though my father’s experiences in the same decade demonstrate that not everyone was able to feel that way.

Ian Brown also takes exception to this view of disability, calling parents who live their lives eagerly treating and championing and thereby denying their children’s limitations “disability masochists” (Brown, 2011, p. 75). He and his wife abandoned support groups. Though he understands the importance of such reassurance, he objects particularly to the religious overtones expected by such groups. “Walker had given my life shape, possibly even meaning. But Walker had also made our lives hell. On the hellish days the mawkish sermonizing about angels and specialness felt like rank self-delusion” (p. 135). And, “It was hard to think of Walker as a gift from God, unless God was a sadist who bore a little boy a grudge” (p. 136).

Helen Harrison, in the beginning of her paper on making lemonade states, “Upon becoming parents of a disabled or “high-risk” child, one of the first things we learn to do is lie--to our friends and family, to the doctors, to our child, and to ourselves. We quickly learn that others do not want an honest answer . . . and we oblige by giving the positive and politically correct answer” (Harrison, 2001, p. 239).

It is against this backdrop that I am trying to find narratives that relate the realities of caregiving for a medically complex or multiply disabled child. I am looking specifically for narrators who are willing to express the anger my father had, the sorrow that these parents live with day to day, and the ambiguity of their child’s existence. Josh Greenfeld, father of autistic Noah, says, “I’ve leafed through three books, chronicles by parents of severely disturbed or brain damaged children. None of them palpitated with truth for me. The parents didn’t burn with enough anger; they were all too damned heroic for me” (Greenfeld, 1970, p. 126). Like him, I am searching for truths that, for all of the reasons given above, many people are unwilling to say.

CHAPTER FOUR THE VIRTUES OF CARE

Having found several narratives by parent caregivers who are doing extreme caregiving, the question is, then, how to analyze them. I believe that the existence of children requiring extreme caregiving must be recognized, and that elucidating and evaluating the problems encountered by their caregivers is morally imperative. The analysis must not merely contain a description and definition of the lives of extreme caregivers, but also involve an ethical component. Yet, just as these children challenge the defined boundaries of medical care and of parenting, they also call for an expansion of our understanding of ethics. In this chapter I will build on theories of care proposed by Joan Tronto (1993) in order to work out a system by which components of the physical and emotional work of caregiving can be separated and discussed.

Under an ethic of principles, there are fairly clear guidelines, balancing parental duties, by setting a standard of beneficence and defining a level of harm at which society must intervene. However, harm to the parent is rarely considered as a possibility. The rules defining parental duties were not formulated to take into account the enormous physical and emotional burden that comes with extreme caregiving. The assumption that the caregiving must and should always fall on the parents has contributed to the invisibility of the work, and the harm, that is being done.

Likewise, the rules balancing parental autonomy with the child's emerging selfhood and autonomy, are not helpful. There is no allowance for the possibility that the child will not ever become self-sufficient. We shall see also that the burden of care is often accepted unknowingly, a choice made on insufficient information. Once accepted, the care becomes inescapable, leading to a great deal of guilt and ambiguity.

The undeniable existence of these children then poses a complex moral dilemma, but I believe that the existing rules are inadequate. We need to do better than trying to balance our understanding of parental duties and setting limits on unacceptable parental care. We need more than a desire to preserve the autonomy of both parent and child. Under an ethic of principle, the care these children require is invisible. Within the limitations of principle ethics, these children present, at best, an insolvable problem.

To better understand extreme caregiving, we need methods which examine the act of caring itself. To evaluate a state of extreme dependency requires an ethic which

acknowledges and accepts the existence of dependency, and seeks to understand the relationship that is caregiving. Thus, an ethic of care, which revolves around the recognition and meeting of needs, is more likely to provide the insight into the nature and depth of the caregiving relationship than an ethic of principles.

AN ETHIC OF CARE

In a departure from principle ethics, which Margaret Urban Walker has described as following a “theoretical-judicial” model of morality, some ethicists are working out a different method for making moral judgements. This method, based on relationships and emotions considered unimportant, or even undesirable, in principle ethics has been called both feminist ethics and care ethics. Both follow what Urban Walker called an “expressive-collaborative” model. This model departs from statements about individual rights and autonomy, concentrating instead on community and interdependence, and the possibility of caring for each other (Walker, 1992).

In the field of medicine, where the entire focus is on providing care, an ethic based on care and caring seems an ideal match. Particularly when analyzing caregiving, as I intend to do, an ethic based on the caring relationship seems more appropriate than an ethic based on prescribed universal rights and duties. However care ethics has been criticized for relying too much on unreliable and unmeasurable emotions such as caring, compassion, pity (Boyd, 2004), or empathy (Slote, 2007).

In her book *Moral Boundaries: A Political Argument for an Ethic of Care* Joan Tronto (1993) has proposed, among other things, a care ethic based on the ability to recognize and meet needs. Unlike theories based on emotion, the recognition of needs and the moral meeting of those needs can become measurable and actionable. Within that system, she has proposed four phases of care, each of which holds a unique moral property or virtue on which to base action. These phases serve to separate the action of caring from the emotion called caring (or empathy, or pity). The focus on the identification and meeting of needs has the potential to turn the discussion of an ethic of care away from a somewhat vague and controversial analysis of the emotion of caring, and toward an ethic where care becomes a politically actionable concept. Thus caring goes beyond an emotional interest in something to include reaching out to another and taking some action. “. . . [T]o care implies more than simply a passing interest or fancy but instead the acceptance of some form of burden” (Tronto, 1993, p. 103).

“Caring” is a complex process, involving emotional components that muddy the moral waters. For this reason, I have chosen the framework provided by Joan Tronto’s phases of care in order to break down the complex and intense act of extreme caregiving into specific components, each of which can then be evaluated on both an emotional and morally actionable level.

THE PHASES OF CARE

Since I will be relying on concepts developed from these four phases to provide a framework to analyze caregiving narratives, it is necessary to review this part of Tronto’s theories.

Tronto’s four phases of caring are: 1) Caring about. This is the closest to the emotion of caring, as it involves the usually empathic awareness that someone is in trouble. However within Tronto’s definition, there is an additional requirement of being open to the world, paying attention and being willing to notice unmet needs. 2) Taking care of. This involves taking on some of the burden of care, agreeing to help meet a need, but in an indirect manner. Things like making a contribution to a disaster relief fund, working for a day at Feed My Starving Children, or becoming an activist for the disabled are all ways to indirectly take care of a need. 3) Caregiving or caring for. The caregiver is the heart of caring, doing the often unrecognized dirty work of care. Caregiving is direct action: cleaning the muck out of flooded houses, preparing and delivering meals, or actually helping to build necessary wheelchair ramps. In health care, it is the changing of bedpans, the holding of hands, the coming in response to a distress call. This is the direct, hands-on work of care. Thus care is a practice, an action, not an emotion or a principle (Tronto, 1993, p. 105-108).

The last phase, number 4) is receiving care. This is an interesting and somewhat different phase. Including it in the set of phases acknowledges that all of us are interdependent and rely on others for some sort of care, though not all care is recognized as such. “Once again, care is not universal with regard to any specific needs, but all humans have needs that must be met” (Tronto, 1993, p. 110). It also acknowledges that, at some point, any of us could find our need for care increasing, and become the care-receiver of a different or more intense level of care. But since the other phases all seem to require some action, the inclusion of care-receiving suggests that the recipient of care is not to be a passive slate on which care is written. Tronto states that,

as part of the cycle of care, the recipient is in the best position to determine if needs are being met. But I would argue that the inclusion of care-receiving as a separate phase implies that the receiving of care is in itself a skill that might be mastered. It also implies that an inability to provide an adequate response to care might impede the caregiving process. I will return to this concept at length later.

Tronto has assigned to each phase of care an associated virtue, a way to begin to guide us in how to act in each of those degrees of closeness to care. The virtue associated with caring about is attentiveness. A person who demonstrates this will stay open to the recognition of needs of others, and likely will find many. They may feel sympathy or pity, but it is not a necessity. The virtue needed for the second phase, caring for, is responsibility, and is a call not merely to notice needs but to be ready to take some personal stake in the meeting of them. For the third phase, the caregiver must be able to perform care that actually meets the needs that are present, so the virtue that caregiving requires is competence in the provision of care. Tronto has also assigned a virtue to the process of care-receiving, that of responsiveness, in keeping with the tasks of the recipient to report on the effectiveness of the care and of the caregiver to be able to elicit that response.

The virtues that Tronto has assigned to the phases of care are modeled after Aristotalian virtues, where moral behavior is understood to be a mean between two extremes. Tronto does not specify the sort of extremes to be avoided for each virtue, however. In Aristotalian virtue ethics, a virtue is a sort of middle ground for behavior, surrounded by less desirable actions or attitudes of the same sort. By the technique of identifying the extremes of undesirable (or less moral) behavior, Aristotle approaches a definition of a certain moral virtue. In this way, as a sort of thought experiment, he is able to zero in on the true meaning of virtues by assessing the dangers of their extremes.

In much of the work in health care or nursing that follows Tronto's phases, including in some of her own work, all four phases of care are assigned to the individual nurse caregiver. Thus a nurse is called upon to care about and to take care of; to be attentive and responsible. She of course must be competent in her caregiving duties. In addition, the care-receiver is often not in a position to provide feedback, so that being responsive to her patient's needs becomes another duty of the nurse caregiver.

Edwards has criticized Tronto's work, saying that it does not provide an approach to moral problems in health care that is distinctive from approaches, such as virtue ethics, that have already been tried. He believes, correctly, that telling nurses to be attentive and responsive and competent is nothing new, and can be done with virtue ethics or principle ethics (Edwards, 2009).

Edwards has also stated that impartiality is an "essential element" of any ethical system. An ethic of care based solely on emotional caring can indeed be criticized for risking becoming too personal, too likely to result in unfair advantages to those in range of our vision. I'm not sure I agree that complete fairness is essential (or attainable), but it is important if an ethical system is to be useful. I disagree that principle ethics is likely to be applied with more justice and impartiality than an ethic of care, despite its attempts at universality. But Edwards agrees that Tronto's phases of care somewhat overcome the problem of impartiality (Edwards, 2009, p. 233). Attentiveness can be expressed in a way that makes caring into a set of actions that can be applied with justice in mind, not merely an emotion that will only be aroused unreliably.

Based on Tronto's levels, the number of things involved in caring is extensive, and the virtuous caregiver will have her hands full. But I don't believe that the caregiver should have to shoulder all of the aspects of care, all of the time. The four phases are quite versatile, and can be applied to an entire cultural or political system, as well as to the work of a single nurse. The phases, used in this way, are not then merely stages which a single actor or potential caregiver goes through as she approaches the need for care; from recognition of a need through to accomplishing the hard work of meeting it. They are degrees to which any agent or agency is involved in the caring process. In particular, attentiveness and responsibility enacted by others, both toward the care receiver and the caregiver, would likely improve the final result, which is the recognition and the meeting of needs.

I believe that when we examine the work of parent extreme caregivers, using Tronto's phases to pinpoint all aspects of the task, we will be able to break down this complex task into comprehensible components. We will be able to determine where extreme caregiving differs from typical parenting merely by the level of difficulty, and where its intense nature becomes morally problematic. I hope to learn something about the nature of caregiving itself. Discovering others who should be involved in some of the phases of care is not a primary goal of this thesis, however once the complexity and

consequences of the task become clear, I hope that the need for others in the medical system to take action will be obvious.

Caring About

Caring About is the first and least involved phase of caring. We are all capable of caring about those who are close to us. Caring about strangers is more difficult, but certainly possible, though we often require that their need be waved in our faces before we recognize it. And so the virtue associated with caring about is attentiveness, a quality that implies a certain way to look at the world; one that notices the needs of others, and recognizes both the possibility of fulfilling them and those who are already doing that work.

Peta Bowden (1998) has written a summary of feminist philosophers' thinking on the subject of ethical attentiveness, using the works of Simone Weil, Iris Murdoch, and Martha Nussbaum. What emerges is an ideal of attention as an act of looking clearly at another with a sort of patient expectancy, waiting to understand who they are and what their needs might be. One's own ego and selfishness should be put aside in the process, according to Weil, in an "energetic 'gymnastics' aimed at erasing all those attachments to persons and objects that we form for our own sakes rather than from any sense of those persons' and those objects' own intrinsic worth" (Bowden, 1998, p. 61). According to Bowden, Murdoch also sees attentiveness toward others as an emotional and possibly ecstatic engrossment in the other.

Bowden goes on to say that there is some controversy over whether such total putting aside of one's own self and desires is necessary. Weil's mental gymnastics seem to require a self abrogation that could ultimately be undesirable. However Bowden points out that this self-erasure is all too close to the disenfranchising self-denial that women as default caregivers are now starting to overcome. Applied to an ethic of care, this could lead caregivers to define their selves and desires almost entirely in terms of the interests of others.

However there is agreement that proper attentiveness to another will ultimately lead to a broader self-understanding. Attentiveness can become a continuous work building a world view that notices and values others, and cycles back toward self enrichment. It requires intelligence, imagination, and possibly education about the world inhabited by the other. "[N]ot only does attentiveness directed to others reflect back on

oneself in enriched possibilities for self-knowledge, but that correspondingly, ethical attentiveness to oneself, one's limits and prejudices, facilitates revised and augmented possibilities for attention to others" (Bowden, 1998, p. 72). Thus proper attention builds personhood in both the subject of the attention as well as in the attentive person.

Though Bowden is not specifically talking about child care, this sort of attentiveness applied to the parenting of either sick or well children is not inappropriate, and may well define excellent parenting. In my experience, the arrival of a child seems to provide an instant and possibly unavoidable closeness, an almost mandatory caring about. There is certainly a possibility of attentiveness that both engrosses and enriches, without loss of selfhood for either parent or child.

If attentiveness is considered as a virtue around a mean, too little attentiveness will express itself in self-interest, a scattered and unreliable recognition of the need for care. It is more difficult to imagine a situation in which there is too much attentiveness, but attention focused narrowly on a single area might lead to a sort of paternalism, where needs that don't actually exist are identified. It also could potentially lead to the loss of selfhood in the caregiver, if the caregiver becomes so focused on the needs of another that her own desires and life goals are put aside. Certainly both extremes exist in parenting, with children effected by neglectful or suffocating parents, and parents submerging both too little and too much of themselves in their children. In these statements, though, I have gone beyond attentiveness, and into considering the results of actions taken because of this attention.

It is not my intent here to provide a manual for attentive ethical parenting, but to analyze parent caregiving in its most difficult form. For this purpose, I must assume that parents of both typical and special needs children will be attentive in very similar ways. While parents of medically complex children do indeed have more needs to notice and pay attention to, their ability to recognize those needs is not in question. The action in this phase--attentiveness--while differing in the number of needs to be recognized, does not seem to me likely to reveal any unique aspects of caregiving.

Taking Care Of

The next question for an ethic of care is how to direct that hard-won moral attention. The mere knowledge of need is only a small step toward meeting that need. This second of Tronto's phases of care is agreeing to take care of a need, or being

willing to take some action to meet a need. She has assigned to it the virtue of responsibility. In order to respond to this, we need to know the extent to which the recognition of a need obliges a response to that need. We need an ethic of taking on responsibility.

John Caputo, in an essay called 'Against Ethics,' recognizes a form of ethical attentiveness which comes with the realization that needs, when noticed, will sometimes evoke a response. That response, which he identifies as obligation, is a realization that present needs call forth a sympathetic desire to help. He defines obligation as "the feeling that comes over us when others need our help, when they call out for help, or support, or freedom, or whatever they need, a feeling that grows in strength directly in proportion to the desperateness of the situation of the other" (Caputo, 1993, p. 5). However the form that response should take is not clear.

Principle ethics, which claims to be a guidebook for moral action and a secure foundation for good, does not help Caputo identify the proper response to this obligation. Instead, he says, it gives us the illusion of safety from responsibility, since there is no rule that requires action. But obligation comes anyway, often unexpectedly and chaotically, and we are not safe from it. Caputo puts it like this; "Still, I would say, obligation happens, the obligation of me to you and of both of us to others. It is all around us, on every side, constantly tugging at our sleeves, calling upon us for a response" (Caputo, 1993, p. 6). Principle ethics does not provide an answer to the question of which needs, when noticed, call forth an obligation or a requirement to act.

It seems to me that responsibility as a virtuous act might be the deliberate acknowledgment or acceptance of Caputo's obligation. Recognizing a need, we act, not from some assigned duty or in response to the rights of the vulnerable, but because we agree to take responsibility for some part of the necessary care. In doing so I believe we often must willingly sacrifice some degree of our own independence in order to attend to the needs of others.

Accepting responsibility for the raising of a child is a clear obligation of parenthood. Parents are judged on their ability to take on a variety of responsibilities, and parenting books are filled with advice on how to meet them. Most parents understand that this is a part of the parenting process. The parents of medically complex children do not differ from the parents of well children in this acceptance, except that the complexity and number of their responsibilities increases vastly. They inevitably learn to

take on this a new set of responsibilities, most of which were not expected. As we shall see, these responsibilities are numerous, time-consuming, and for some, endless. There is no ethic to dictate which of these responsibilities they might be allowed to put aside.

Like the virtue of attentiveness, responsibility is meant to be a mean between extremes. It is certainly possible to ignore needs which should be your responsibility, as well as take on more problems than one can handle. But it is not clear to me exactly how those extremes might be avoided, particularly by parents who have taken on the responsibility for raising a child, and find that the job more difficult than they expected. If there is no process by which responsibilities that have been taken on, but can't be met, can be passed on to another person, it is inevitable that some people will end up too burdened. It seems to me then that an ethic of responsibility might be impossible within a society that is not focused on recognizing and meeting each other's needs.

In Chapter Five, which discusses the burden imposed by extreme caregiving, I will outline the number and difficulty of the responsibilities that parents of multiply disabled and intellectually delayed children are obliged to take on. As with attentiveness, those responsibilities are not ethically different from those encountered by parents of typical children. There are just many more of them. If there are any new ethical implications, they will not be found by analyzing the way parents take on their unexpected responsibility. Instead, I believe that the existence of these children and the difficulties encountered by their caregiver/parents, once made visible, should call forth an obligation from us.

Framed within an ethic of care, these children have a level of need that is too vast to be the sole responsibility of their families. The parents of these children, we will see, are themselves in need of care. If we as medical providers wish to claim that we are taking responsibility for caring for medically complex children, we might find that we need to think about redirecting some of the responsibilities that currently fall on their extreme caregiver parents.

Caregiving

This is the most interesting phase to me, the heart of caring, an action both under-recognized and absolutely necessary. The emotion of caring or empathy is not required for the action of caregiving, though it may be necessary for doing it well. Tronto has assigned the virtue of competence to the hands-on caregiver (Tronto, 1993). This

one virtue I will take exception too. I don't think it embodies the entirety of the act of caregiving.

Competence as a virtue is most understandable when considering the physical act of caregiving. For the work of caring, in medicine as in other fields, you want people who do it well. For a sick patient in the hospital, you want people who know how to change bed linens without causing pain, how to work the suction equipment, how to start an IV. You want people who know what lab tests to order, are good at obtaining them, and know what they mean. You want nurses and doctors who have passed their boards, who aren't working while impaired, who are competent. You also want nurses and doctors to do only what is necessary, not ordering excessive tests or doing unnecessary procedures. Following a technological imperative to do things because they are available, or are reimbursed well, or will make a great research paper, is not desirable. All of this can be done, and done well, without any emotional attachment.

Defining competence as a virtue between extremes is not terribly difficult. A performance within certain standards of care is expected and in many circumstances has already been defined. We already have measurements of competence to apply to the practices of medicine and nursing. Incompetence is measurable with final exams. Over-competence is somewhat harder to spot, but would result in care that is either excessive or unnecessary. Because this is often carried out by the most admired, "cutting-edge" form of medicine, only constant vigilance regarding the actual best interest of patients can recognize it. This is the first hint that something other than competence in science is required for care.

Others agree that competence is not enough. Berit Lindahl, for example, states, "Competence without compassion can be brutal and inhuman, and the reverse, compassion without competence, is meaningless or, at worst, dangerous" (Lindahl, Sandman, & Rasmussen, 2006, p. 897). I agree, but requiring compassion from the caregiver puts us back to relying on the presence and strength of an emotion in order to evaluate care. However Tronto has not overlooked the need for caregiving to be moderated, but relies instead on feedback from the care receiver. I will return to this later.

There are no standard requirements for competence in the caregiving task that is parenting, but the task is fairly well defined, and its success can be measure somewhat by the growth of the child. Likewise, there are no recognized standards for competence

in caring for a medically complex child at home; there are merely a minimal set of expectations to be met prior to discharge from the hospital (Elias & Murphy (AAP), 2012). As I have said, many feel that these are inadequate, and parents report feeling unprepared and uncomfortable with caregiving for months following discharge (Ray, 2002). In Chapter Six, I will discuss the variety of tasks at which extreme caregivers must become competent, and the ways in which they acquire and frame that competence.

It is in this phase that I believe an analysis of extreme caregiving will begin to reveal significant, morally problematic differences from typical parenting. There is no precedent for requiring, acquiring, or maintaining the level of expertise these parents must achieve. The implication in guidelines, such as those provided by the AAP, is that competence can be gained easily by any parent, yet the full extent of the caregiving these parents are expected to carry out is rarely recognized. The only people completely aware of the level and types of competence needed to carry out extreme caregiving, I believe, are the parents who are doing it. Examining the way in which they expect themselves to be competent, think about their own competence, and eventually become competent, is a starting place for understanding what is required to be a caregiver. This might reveal valuable information, not just useful to prepare non-professionals to care for their medically complex children at home, but to understand the important task of caregiving for everyone who performs it.

RESPONSIVENESS

In the four phases of care, Tronto assigned the virtue of responsiveness to the fourth phase, care-receiving (Tronto, 1993). Yet while that responsiveness is certainly an aspect of care receiving, to best be demonstrated by the person requiring care, it often falls upon the caregiver to initiate it. I think it would be clearer to assign responsiveness right up front as an additional virtue required for caregiving, as well as for care receiving.

Caregiving in medicine does not seem to me to be merely the competent maintenance of a patient's physical health. Caregiving for a whole patient, as doctors and nurses have recently been asked to do, requires making a connection with another person. At its fullest, the caregiver interacts on a personal level with someone in need, responding to their emotional as well as physical needs. I suppose it is possible to identify responsiveness to emotional needs as a skill which the a moral caregiver must

learn to perform with competence. But interpreting a patient's emotional needs as a part of treating them as a whole person, is quite a different process, and will require a very different sort of competence.

I am basing my inclusion of the virtue of responsiveness as a second facet of caregiving on three initial examples, which will serve to demonstrate how subtle and complex responsiveness can be. The first is Hilde Lindemann's essay on "holding well" (Lindemann, 2009). Lindemann wrote about caring for patients (and family members) with dementia, and how a good caregiver will become a bridge to the past, a repository of memory of who the person used to be. Holding well "holds on to the demented person's identity for him or her" (p. 416), bestowing or recognizing humanity by remembering the life story already lived. This is a type of responsiveness.

When their children are young, parents must also carry out a form of "holding well," but they are holding a future for their child rather than remembering the past. The presence of a disability will unavoidably alter the anticipated future. Edward Verhagen, in a talk at ASBH last year, reported that advances in prenatal screening in the Netherlands have now made it possible to screen all infants for the presence of spina bifida prior to birth. Parents with advance warning of this disability are able either to have an early abortion or proceed with full knowledge of the consequences of spina bifida. Verhagen called the decision to go ahead with the pregnancy, "accepting the child" (Verhagen, 2012). All parents, by expecting and preparing for their child's future, are bringing forth and in some way creating their child as a human being. The parents who are able to accept a disabled child have been able to construct a different future for their child, a future which includes the disability.

The third example is from Francine Wynn (2002), who believes that one of the aspects of nursing is to give testimony to the life in the nurse's care. The caregiver is witness to any suffering or injustice, and responds emotionally with her own distress. This act can maintain a patient's humanity in the face of suffering. In Wynn's example, a nurse holds a dying infant who has been abandoned as non-viable by doctors and parents. By witnessing the child's death, she gives the life a story, however short, and confers it with humanity. However she also makes it possible to notice that a person has died, something which other caregivers were trying to deny. This is perhaps the ultimate in responsiveness, the bringing forth of a person (life?) by an act of caregiving (Wynn, 2002, p. 128-129).

Wynn also discusses the work of Agamben, a philosopher who studied the Holocaust. He proposed a duality to consider human life; zoe and bios. Zoe, or mere life, is the biological process of life; a heartbeat, the physiologic maintenance of the body. This is the daily work of medicine. But there is also bios (as in biography, not biology), the idea that persons are writing themselves a life story, in which encounters with the medical system are chapters and the providers of medicine are merely characters. Bios is where humanity and personhood are found. The maintenance of zoe, mere life, can be accomplished with competence. But to provide care for the whole patient, a bios, requires responsiveness.

But what is responsiveness but empathy and caring-as-emotion? Are we now back where we started, at an ethics of care requiring a virtue based in emotion to carry it out? This is the sort of ethic that has been dismissed in the past as inadequate, for some compelling reasons.

Boyd has spoken against the reliance on compassion (and its resulting emotion of pity) alone in order to fill the needs of the vulnerable in a democratic state. He believes that pity “rests inexorably on a sense of difference, is fueled by an aversion to suffering, and is more likely to yield a world of ‘reluctant spectators’ than one of simple souls eagerly rushing to the aid of others” (Boyd, 2004, p. 519). His understanding of caring through the emotion he calls pity would strand us all in a state of voyeuristic and helpless attention.

Even the proponents of virtue ethics recognize its lack of perfection. Slote, in a 2007 book encouraging the use of empathy as a virtue to measure ethical behavior in medicine, indicates that one of the problems with virtue ethics (an ethic of empathy) is that, like other abilities, empathy is not bestowed equally. Slote gives the example of setting empathic laws regarding hate speech. A law could be proposed wherein hate speech was defined as speech which emotionally harms another, which would then not be permitted as free speech. But any law administered which requires the determination of emotional harm is subject to the conclusions of the judge, who might not have the same priorities as were intended by the framers of the law. So laws requiring empathy-based judgements rely heavily on a similarly empathic judge. Use of empathy as a rule could easily backfire, as different judges have different levels of empathy. Use of the emotion of caring to set moral standards could likewise backfire (Slote, 2007).

Noddings (1984) believes that caring can be taught, and possibly that is so. However the field of medicine is a long way from teaching empathy or caring as a part of the profession. Too often, in my experience, considering the “whole patient” is a shorthand for taking a social history, usually a minimal inquiry into things like marital status, risk-taking behaviors such as smoking, and drug use. Professional training in empathy usually involves training in the communication of information to patients, and its effectiveness is measured in patient compliance with instructions (Frank, 2002, p. 20). An example is a brief letter to *Lancet* promoting empathy in physicians, which argues that during primary care visits physicians miss opportunities to convey information because they do not recognize verbal cues from the patient called “potential empathic opportunity continuers” (Neuwirth, 1997, p. 606). The writer admits that there is no established way to train physicians to recognize and respond to these moments. He is quite convinced however that, if used properly, the patient will “feel understood,” and be less likely to be non-compliant.

Adding to this lack of empathy is the ideal of clinical detachment. Those who step beyond the social history and attempt to feel what the patient is feeling or imagine themselves in the patient’s situation, are felt to be in danger of losing an objectivity necessary to the effective practice of medicine. A recent essay in the *Lancet* warns of this “dangerous practice of empathy,” saying that “full experience of mutuality or understanding is not possible” in the clinical setting (Macnaughton, 2009, p. 1940). Physicians who try to employ empathy and claim to feel what the patient is feeling, have no grounds on which to base that claim. They are in danger of a self-delusional misunderstanding of the very person they are attempting to relate to.

In the same essay, Macnaughton states that physicians could have a “momentary mirroring of that patient’s feelings” which is a form of sympathy, not empathy. She concludes, “Doctors do not need to feel the distress of their patients themselves to do something about it. We may have a momentary mirroring of that patient’s feeling within us, but what we maintain is sympathy (feeling for not with the patient) and the need to respond” (Macnaughton, 2009, p. 1941). I agree that, if the physician or caregiver maintains that sympathy, along with a need to respond, complete empathy is unnecessary for good caregiving. If that sympathy becomes a form of openness or ethical attentiveness to the needs of the patient/care receiver, the response made is more likely to be appropriate. If the relationship between caregiver and care

receiver sustains that cycle of responsiveness, evolving over time, perhaps moral caregiving is being accomplished.

But the phases of caring are not merely based on holding a proper emotional state, whether it is called empathy or compassion or pity. The attribute of responsiveness is based on emotion but also requires action. The results that it might engender in the cared-for could be observed, though our current ability to evaluate this is lacking. Certainly the scales that measure understanding of directions, or patient satisfaction, or patient compliance, are inadequate. Responsiveness is a cycle of perceiving need, responding to that need, then resetting the perceived need in response to that response. It is a feedback loop, always in the process of being perfected.

As a caregiving virtue, responsiveness must also be a mean between two extremes. It is once again not too difficult to define one extreme. Too little responsiveness will result in a sort of hard-heartedness, where patients are treated as interchangeable bodies harboring interesting diseases. (This can be done quite competently, I might add.) Too much responsiveness is more difficult to imagine, but it must be possible to be paralyzed in caregiving by too much emotional involvement. For medical providers, there likely is a level of emotional investment that would interfere with the ability to provide competent medical care. For parents and other family caregivers, this level of emotional attachment could take the form of complete engrossment in the other. This is not only potentially damaging to the self of the caregiver, who becomes lost in the other's needs, but may have consequences for the care receiver as well.

Extreme caregivers whose children are, and will always remain, minimally responsive must by necessity uphold both sides of the responsiveness feedback loop. These parents are called on, essentially, to provide the responses to care that their child cannot. Over a lifetime, they might find it particularly difficult, to "hold well" the life story of their child. It may be possible for the caregiving relationship to create and maintain a person who does not exist, or who no longer exists. This is precarious territory, and I will return to it in Chapter Seven.

So the way now to further an ethics of care is to determine how best to express the virtue of responsiveness and how that might translate into good (and moral) caregiving. It will, like the other virtues, be a mean between extremes that have yet to be determined. I propose to do that through an analysis of the most extreme form of caregiving, the parenting of a multiply impaired child. These parents, whose lives are

lived almost totally as a response to their child's disabilities, likely have much to teach us about the difficulties and consequences of responsiveness.

A Word About Care-receiving

Since I have moved the virtue of responsiveness to the realm of the caregiver, perhaps we need a new virtue for those receiving care. Assigning the virtue of responsiveness to the care-receiver was meant as a way to insure that care is offered rather than imposed, and to in some part reduce the vulnerability of the care-receiver to the caregiver. Care ethicists recognize, as does Tronto, that, "To be in a situation where one needs care is to be in a position of some vulnerability" (Tronto, 1993, p. 134). "The vulnerable care-receivers face "dangers . . . at the hands of their care givers and other champions, who may come to assume that they can define the needs of the vulnerable" (Tronto, 1993, p. 135). Responsiveness is meant to equalize that vulnerability.

In situations where the care-receiver will not or is reluctant to be responsive, then, it is up to the care-giver to try to elicit a response. "The moral precept of responsiveness requires that we remain alert to the possibilities for abuse that arise with vulnerability" (Tronto, 1993, p. 135). However, there are care situations in which the care-receiver is unable to respond. It is easy to imagine a position so vulnerable that there is no ability to protest inadequate or unwanted care. Those protests will be heard only if the caregiver is willing to listen to them. It is clear that responsiveness as a virtue must be shared with, or not completely shouldered by, the caregiver.

However, assigning any virtue to the care-receiver implies that there are some moral responsibilities to receiving care. A state of vulnerability cannot negate the ability, or completely forgive the necessity, to act morally. Certainly there are ways in which the care-receiver can undermine and make unpleasant the caregivers' tasks, thus complicating their own need for care. These infractions could constitute a moral wrong that cannot be excused by the vulnerability that is part of the need for care.

I think the best virtue to assign to care-receiving is acceptance, a mean between denial of the need for care and demanding too much care. However, evaluating this must be outside the scope of this thesis. The children who are the care receivers in the situation of extreme caregiving are, for the most part, even less capable of moral decision making than other children of the same age. Many of them are unresponsive or

minimally responsive. Their ability to accept care cannot readily be evaluated or questioned.

CHAPTER FIVE

THE BURDEN OF CARE: THE INVISIBLE WORK OF CARE

Joan Tronto (1993), in establishing the four phases of care, assigned to each a virtue or actionable ethical component. So from the four phases of care--caring about, taking care of, caregiving, and care receiving--come the "four ethical elements of care: attentiveness, responsibility, competence, and responsiveness" (Tronto, 1993, p. 127). These virtues are both ways of further defining just what is involved at each phase, as well as ways to explore how best to carry them out. Thinking about extreme caregiving by breaking it down into the four phases of care and their associated virtues will, I hope, begin to elucidate the nature as well as the moral consequences of this most difficult type of caring.

This chapter begins to evaluate extreme caregiving in the first two of Tronto's phases, the least intimate levels. Since much of the work being done in these two phases is common with typical parenting, some of the territory will be familiar. These are also the two phases which are easiest to observe, so there is relevant information from several interview-based studies which uncover ethical concerns in pediatric home health care. Those studies have already enumerated several categories for concern, and I will use them also in my analysis.

The virtues associated with the first two phases are attentiveness and responsibility. Both of these are assumed to be present in the raising of typical children, and I believe they can be assumed equally to be present in the parents of special needs children. The main difference in these two phases is in the number of things the extreme caregiver must be attentive to and take responsibility for. The burden of care is larger, both in the amount of physical work required and in its emotional and psychological consequences. There is also a difference in the length of time this caregiving will be required.

The best information about the nature of the parent/caregiver's responsibilities from the medical and ethical literature comes largely from the families of children who are dependent on technology in the home. Most of the papers in this field are concerned with discharge planning, providing tools for training the parents or analyses of the most cost-effective techniques. However a few papers, mostly from the nursing or ethics literature do provide insight into the burdens that this care imposes on families.

I chose three papers that review family experiences with technology dependence, spanning two decades, one from 1998 (Kirk, 1998), one from 2002 (Wang & Bernard, 2002), and one from 2012 (Cockett, 2012). The issues described, while sometimes given different labels, are remarkably similar. I also chose several more recent papers presenting data based on interviews with families of technology-dependent children. The children from these are mostly ventilator dependent, but cross a variety of syndromes and diagnoses. I have no doubt that all of the families interviewed were engaging in extreme caregiving.

Lynne Ray, in Alberta, Canada, interviewed 30 families of children with chronic health problems, who required a variety of durable medical equipment, from mobility aides to ventilators, specifically asking about the work required to give care to these children. Her study was published in the nursing literature (Ray, 2002). Also in the nursing literature, from 2005, is a study by Susan Kirk, in Manchester, UK. She interviewed the parents of 24 technology dependent children, again asking about their experiences performing this complex care. The children required one or more of the following technologies: home IVs, home dialysis, tracheostomy care, or home ventilation (Kirk, Glendinning, & Callery, 2005). This builds on an earlier review of the US and British literature about technology dependent families (Kirk, 1998). The only paper from the pediatric literature, though again carried out by nurses, is from 2008 by a group in Quebec, Canada, led by Franco Carnevale. His group interviewed 11 families of ventilator dependent children, concentrating on the families' moral experiences with care (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). The most recent paper, this one from the nursing ethics literature, was done by Dybwik et al., in Norway. This group used the content of earlier evaluations from focus groups and interviews involving families of ventilator dependent children, analyzing them for ethical issues (Dybwik, Nielsen, & Brinchmann, 2011). This is the only paper which found that the parents' concerns matched neatly the four principles of bioethics. The concerns thus raised were centered only around the decision to provide home ventilation, and did not include the difficulties in actually carrying it out. I include the paper largely because they consider whether or not the parents truly choose to take on the burden of such care.

It has been noted that, since caring is traditionally women's work, the largest burden of care often falls upon women and, as such, is relatively undervalued and underpaid (Noddings, 1994). This was not a theme of any of the research on technology

dependent children, where both fathers and mothers were interviewed (though there were more mothers than fathers), and there was no attempt to do separate analysis by gender. A review of the literature does mention that mothers were more likely than fathers to give up their jobs (Cockett, 2012), and there is an underlying assumption that mothers are doing most of the caregiving. However, I did not pursue more information on the gendered nature of extreme caregiving, nor try to explore the reasons why the narratives I found were largely written by men.

From the concerns raised by these papers, I chose a set of themes, which seemed to be the most common concerns of parents doing caregiving for a medically complex child. Most obvious is the physical burden of care, including the enormous amount of work required, multiple parental responsibilities, and the financial burden. Emotional concerns include ongoing grief, guilt and fear for the child's health, as well as more subtle concerns: a lack of choice at taking on the care, social isolation, and ambiguity in the relationship with the child.

It is interesting that most of the concerns raised by the families interviewed for these papers were reflected in the autobiographies written by fathers doing extreme caregiving. This chapter will correlate common themes from research interviews with quotes from the narratives. I will also add anecdotal information gathered from patients in my pediatric practice, including an unpublished essay by Annette Jennings, the parent of a special needs child. (Jennings, 1995) This will serve both to illuminate the problems encountered in raising such children that have been identified thus far, and show that the narratives I have chosen are not fiction. While the autobiographers were free as narrators to exaggerate or understate their problems, none of what they express is outside the range of feelings or experiences reported by research on the families of technology dependent children. Those similarities exist also despite the fact that the researchers interviewed only families of technology dependent children and the narrators experienced children with different medical problems who were not, for the most part, dependent on any technology.

THE PHYSICAL BURDEN OF CARE

The first, and what should be most obvious, factor in extreme caregiving is the sheer amount of work required to care for children with complex medical problems, technology dependence, or intellectual disability. Researchers interviewing families of

technology dependent children described “physical overburden” causing parental burnout and exhaustion (Wang & Bernard, 2004), as well as a high amount of sleeplessness and sleep deprivation (Wang & Bernard, 2004; Kirk, 1998). In an earlier review of the literature about families taking care of technology dependent children at home, Kirk reports that, “sleep deprivation due to anxiety about the child’s condition, false monitor alarms or the need to remain vigilant over their child during the night” is a consistent theme (Kirk, 1998, p. 106). Lynne Ray describes ‘parenting plus’ where the normal work of infancy--feedings, dealing with night-time crying, and diaper changes--extends years past the usual need. Her parents reported that they “were so busy doing things for their child that they didn’t have time to think about it” (Ray, 2002, p. 432).

Carnevale’s group, in researching the effects on the family of caring for technology dependent children, was able to recruit only twelve families, in part because the families contacted had difficulty scheduling time for the home interview required (Carnevale et al., 2006). This study concerned only children who received ventilator assistance at home. At the time, 38 families were registered with Quebec’s Program for Home Ventilatory Assistance, however only 15 families met the study criteria. Three had to be excluded due to “significant psychosocial issues in the home” (Carnevale et al., 2006, p. e51). Another family refused to participate. Eleven families were able to schedule the initial interview, upon which the study was based, but only three of them had time to schedule a longer, in-depth interview. Those families reported that, “Virtually every aspect of their lives was highly complicated and frequently overwhelming” (Carnevale et al., 2006, p. e53).

Carnevale et al. also noted that families with less ill children, those who did not require full time ventilation, or were able to receive support via face-mask rather than tracheostomy, were not significantly different or less distressed than those families whose children required full time ventilatory support via tracheostomy (Carnivale et al., 2006, p. e53). This is a very small sample, and may not be relevant for other types of home health care, but it lends support to the idea that all families caring for medically complex children at home encounter similar significant problems.

The sheer burden of work and sleeplessness involved in extreme caregiving is probably best described in the opening chapter of *The Boy in the Moon*, by Ian Brown (2011), whose son Walker, eight years old at the time, has a rare syndrome called CFC (Cardiofaciocutaneous Syndrome) .

For the first eight years of Walker's life, every night is the same. The same routing of tiny details, connected in precise order, each mundane, each crucial. . .

Tonight I wake up in the dark to a steady, motorized noise. . . Nnngah. Pause. Nnngah. Nnngah. . . It's my boy, Walker, grunting as he punches himself in the head, again and again. . . .

I count the grunts as I pad my way into his room: one a second. To get him to stop hitting himself, I have to lure him back to sleep, which means taking him downstairs and making him a bottle and bringing him back into bed with me.

That sounds simple enough, doesn't it? But with Walker, everything is complicated. Because of his syndrome, he can't eat solid food by mouth or swallow easily. Because he can't eat, he takes in formula through the night via a feeding system. The formula runs along a line from a feedbag and a pump on a metal IV stand, through a hole in Walker's sleeper and into a clever-looking permanent valve in his belly, sometimes known as a G-tube, or mickey. To take him out of bed and down into the kitchen to prepare the bottle that will ease him back to sleep, I have to disconnect the line from the mickey. To do this, I first have to turn off the pump (in the dark, so he doesn't wake up completely) and close the feed line. If I don't clamp the line, the sticky formula pours out onto the bed or the floor (the carpet in Walker's room is pale blue: there are patches that feel like the Gobi Desert under my feet, from all the times I have forgotten). To crimp the tube, I thumb a tiny red plastic roller down a slide. (It's my favourite part of the routine--one thing, at least, is easy, under my control.) I unzip his one-piece sleeper, reach inside to unlock the line from the mickey, pull the line out through the hole in his sleeper and hang it on the IV rack that holds the pump and feedbag. Close the mickey, rezip the sleeper. Then I reach in and lift all 45 pounds of Walker from the depths of the crib. He still sleeps in a crib. It's the only way we can keep him in bed at night. He can do a lot of damage on his own (Brown, 2011, pp. 1-2).

This is only a small part of the night time ritual, which takes another several pages. Brown and his wife have been doing it every night, taking turns, neither of them ever really getting a full night's sleep, for eight years. The individual caregiving tasks that must be done, like the disconnection of the gastrostomy tube, are simple, but they are not always done in ideal conditions. The frequent need to perform each task, together with the need to deal with the consequences of any mishaps, add up to an enormous amount of caregiving work. And, of the various home technologies available, Walker's gastrostomy tube is probably the least complicated.

It does not require home medical technology to cause care to be time consuming and exhausting, however. Another child with CFC, Savannah, uses her GT tube only for medications and fluid supplementation during the day. At age 19 however, she is not toilet trained and frequently wakes at night. Her father rocks her to sleep every night at about eight, and wakes when she does at four AM, bouncing her in his arms continuously to keep her happy and quiet. Her mother stays up until about midnight catching up on housework, in order to change Savannah's diaper (and often bedding) before she becomes uncomfortable enough to wake up. Both parents are up again at six, to get Savannah ready for her day program at school. They are doing the type of caregiving that Lynne Ray called parenting plus (Ray, 2002). After nineteen years of it, they are both exhausted.

Another example of the work of caring for a special needs child comes from Ann Fadiman's book about the cultural clash between American doctors and Hmong parents, caring for a child named Lia Lee, *The Spirit Catches You and You Fall Down* (Fadiman, 1997). Though Lia Lee lived in a persistent vegetative state from age four through to her death in 2012 at age 30, her mother Foua rejected all technology. Lia was not tube fed, though any other child in the same state would be. At first Lia's mother "squeezed formula into her mouth with a baby bottle" (Fadiman, 1997, p. 212). Later her mother pre-chewed food for Lia, or ground it up with a mortar and pestle, before putting it in her mouth.

Every day Foua boiled quantities of a spinach-like vegetable called zaub, which she grew specially for Lia in the parking lot, and fed her the broth. Lia usually straddled Foua's lap, her long legs sticking out on either side, while Foua, after putting her lips to the food to make sure it wasn't too hot, coaxed tiny bites into her mouth. She always wiped Lia's drool with her hand rather than with a napkin or a towel. "It takes a long time to eat," she told me [Fadiman] once, as she fed Lia rice. "You have to open Lia's mouth to look inside, because if there is already rice in there and you put some more in, she might vomit it back out. You have to hold your hand in back of her neck all the time or she can't swallow." Then she laughed and kissed Lia's ricey mouth (Fadiman, 1997, p. 217).

Foua would not even use the expensive wheelchair provided, preferring to carry Lia everywhere in a "nyias," a Hmong baby carrier, which she made herself. "It was perhaps the biggest nyias in Hmong history, since Lia was more than three feet tall and weighed thirty-six pounds," says Fadiman (1997, p. 210). Lia slept with Foua instead of

in the hospital bed acquired with some difficulty by a social worker. “ ‘Lia always sleeps with us,’ Foua told me. ‘She is the only child who sleeps in our bed. I hold her during the night and we pat her feet all night long because we love her so much. If you don’t pat Lia on her foot or her knee, she cries a lot.’ ” (Fadiman, 1997, pp. 212-213). Lia’s mother, whose birth date in a hut in the mountains of Laos is unrecorded, was somewhere around fifty when Fadiman’s book was published, and seventy when Lia died.

Not only is extreme caregiving for these children an enormous task, but it looms as a lifelong burden. For many children, as with Lia Lee, the need for care does not diminish with time. For developmentally delayed or neurologically impaired children, increasing body weight poses an increasing burden, and daily chores such as diapering and bathing become more difficult. Carnivale says, “Several families expressed concerns about how their children’s needs would be met as they grew older, when the parents would eventually become less physically capable of caring for them” (Carnevale et al., 2006, p. e54).

In 1986, my parents, who had become activists for the mentally retarded in the sixties, and who had always cared for my mentally retarded brother at home, returned briefly to politics. They found a state senator who seemed interested in the plight of aging parents of disabled children. (“Aren’t there group homes?” he asked. “Yes,” my mother reportedly replied. “And the only way I can get my son into one is by dying.”) With only word of mouth contact, within a few weeks they were able to compile for the senator a list of 300 “children” (as my mother called them; they were all at least 40) still living at home, all with parents over age 65, and all in the same small county on the edge of Philadelphia. Caregiving, particularly ‘parenting plus,’ does not come with retirement benefits.

MULTIPLE PARENTAL RESPONSIBILITY FOR CARE

The caregiving burden carried by the parents of an intellectually disabled or medically complex child is actually more complicated than that described above. The work of feeding and diapering and maintaining technology are essentially nursing tasks, though done often under less than ideal conditions. Almost all of the researchers on the parents of technology dependent children reported that these parents carry on a number of other caregiving tasks that are less obvious. They become not only caregivers, but also care coordinators, case managers, advocates for their child’s specific medical and

educational needs, activists for the provision of special services, and secretaries in the complicated and time consuming game of paperwork required by insurances and social services. They must translate the care prescribed by medical providers into the reality of their lives. Carnivale et al. (2006) says, "Parents had to integrate the multiple, often contradictory, complex roles of caregiver, advocate, activist, educator, and case manager. . . . Parents were often faced with the challenge of complying with prescribed care while adapting its application to a more livable plan for the home context" (p. e53).

They also are parents. The dual role of parent and caregiver is for many, particularly the parents of ventilator dependent children, one of the most difficult to fulfill. Susan Kirk reported on the specific difficulties encountered by these parents. The ventilator equipment is particularly intrusive, transforming the home into a medical space that operates round the clock. Home health care nurses or aides are often required, with the home becoming a public space often open to strangers. But perhaps the biggest factor distressing these parents was their nursing duties. Parents were required to do procedures such as suctioning which were clearly causing their child discomfort, conflicting with their parental role of protection (Kirk, 2005).

Those parent who do require help in the home find themselves learning another new skill set, care coordinator. Ray (2002) reports that some of the parents she interviewed were responsible essentially for the finding, hiring, and training of their home health care staff. They were "keeping time sheets, coordinating schedules, and essentially maintaining a pool of staff" (Ray, 2002, p. 429). In addition, particularly for medically complex children, parents must seek out and make appointments for the multiple doctors and therapists usually involved. It is not unusual for a child to regularly visit several specialists--one for each separate medical problem--as well as a variety of therapists. As a pediatrician, I once worked with a hospitalized child who had an unidentified syndrome that effected almost every bodily system. When I listed on her chart all of the specialists the child needed to visit, I had no problem coming up with fifteen different doctors. None of them were available in her tiny home town. In fact, they were spread between three different cities, all at least 100 miles away.

Of course, all of those visits demand another responsibility, care management, as the availability of services must be discovered and paid for. Every visit comes with attendant insurance paperwork. Minnesota's TEFRA program to provide supplemental insurance to disabled children requires a yearly update to assure the state once again

the child has not outgrown their permanent medical diagnosis, and is still in need of assistance. It takes 15 to 60 minutes of physician time, and far more than that for parents.

Advocacy is another responsibility that parents often find necessary to carry out. It is not unusual, in the rapidly changing field of medicine, for parents to learn about improved services or treatments that are not yet available for their child. The only way to achieve the best possible outcome for their child is to raise awareness, or raise money, or to start the service themselves. Charles Hart, author of *Without Reason* (1989), finding no community services after his son was finally diagnosed with autism in 1984, ultimately established his own parent support groups and parent workshops. A decade earlier, my father helped found a local chapter of the Association for Retarded Children, and later acted as president of a non-profit organization which established the sheltered workshop in which my brother still works. Both of my parents spent an enormous amount of time fighting for appropriate education, an effort which led to the Equal Opportunities Education Act passed in 1974.

And that Act has made possible the last of the multiple unexpected parental responsibilities, to become an educator. A mandate for appropriate education for all children does not mean that schools are automatically adopting every new service, nor that they make it easy for parents to obtain the services they believe will best benefit their child. The required Individual Educational Plans (IEPs) are produced at the cost of long hours of meetings, and are constantly in need of revision. It is not unusual for parents to have to visit the schoolroom regularly both to monitor the child's comfort in a new environment, and to assist the teachers with complicated care.

Ray (2002) reports that all of the parents she interviewed "found that they had no choice but to become an advocate for their child" (p. 429), constantly intervening with health care professionals, home health care services, and educational services in order to obtain what they needed to meet their child's needs. In addition, they often sought an understanding of their child's illness. "Collectively, parents spent an extraordinary amount of time searching for information, people, and services." (Ray, 2002, p. 429) Several parents reported that this activity took up as much as half of their caregiving time.

Caregiving it seems, is not a full time job. It is three full time jobs. At least.

FINANCIAL BURDEN

It is widely accepted, and would not be surprising to find, that families raising special needs children often encounter financial difficulties. This is mentioned in several of the papers on technology dependent children (Wang & Bernard, 2004; Kirk, 1998; Cockett, 2012), but is only reported as a broad generalization. And since those reports come from other countries--Canada, England, Australia--where universal health care is established, the difficulties encountered by the parents in their studies might be different from those encountered in the US. Though even in countries with universal health care, the additional expenses incurred by these families were felt to be significant (Cockett, 2012).

Information directly about families living in the USA is scant. Kirk (1998), writing from England, reported that in the US studies have shown as many as 40% of families experiencing financial difficulties (p. 108). This is corroborated by a survey done in Minnesota in 1998, on families receiving TEFRA, Minnesota's supplementary health coverage for disabled children (Chan et al. (MDHDFH), 1998). The average annual medical cost for a child on TEFRA in 1998 was \$35,000, of which only 77% was covered by various insurances. Families on TEFRA were spending about 11% of their income on medical care for their disabled children. (The average spent by families without a disabled child was 5.5%.) The expense of medical bills, home equipment, therapy, and home health care nurses will of course vary wildly depending on insurance coverage and diagnosis. But it can be assumed that this increased expenditure takes its financial toll on most, if not all, families doing extreme caregiving.

In addition, these numbers take into account only direct medical expenses; the indirect costs were not measured. For example, sixty four percent of the parents on TEFRA responded that their employment was affected in some way - with the most frequent response being "accepted a lower paying job with more flexibility or fewer demands" (Chan et al. (MDHDFH), 1998, p. 3). Cockett (2012) also mentions the frequent need for one parent of a technology dependent child to have to quit working, (p. 34), and Kirk (1998) adds that this is usually the mother (p.108).

But there are other, more deeply hidden expenses. Doctor and hospital visits are usually covered by insurance, but the travel expenses and the time taken off from work to get to them are not. Perhaps the large-sized diapers and the special formulas are covered, but not always. Special equipment is covered, though often with a waiting

period, but the simple things--safety locks needed well past the typical toddler years, gates that will keep a toddler in a seven year-old size body safe, toys that might interest an unreachable autistic child--are not. Wang & Bernard (2004) report, "equipment, pharmaceutical, electricity, telephone and transport expenses are potential financial burdens that are hidden within families" (p. 41)

These hidden costs have brought into question the overriding assumption that caring for these children at home is the most cost-effective way to provide care. To the medical system that enables the survival of technology dependent children, the expense incurred by these families is as invisible as the care the children require. Kirk (1998) states that home care of technology dependent children is in part motivated by evidence that suggests that home care reduces costs. She questions that evidence, however, suggesting that the financial, social, and emotional costs to families are not taken into account. She believes that most of the savings to insurance companies comes from "the substitution of parental for professional nursing care," which comes at a high cost in terms of stress to parents" (Kirk, 1998, p. 104)

Carnevale et al. (2006) do not question the assumption that home care is less expensive, but the group is also well aware of the costs to families. They recommend that a sustainable home care program "should require significant family supports in the way of salary support, provision of part-time assistance within the home, and the development of suitable respite services" (Carnevale et al., 2006, p. e59). Ray (2002) noted that, when these families are offered "support," it often comes in the form of counseling or therapy, which for many families just adds another appointment to their already full schedule. She also recommends providing health care coordinators, informative internet databases, and measuring the actual hands-on work required (Ray, 2002, pp. 435-6)

In my personal experience, this financial burden has been a major factor. The two families with special needs children that I know well have both been in difficult financial straits for years. Both of the mothers had to quit their jobs shortly after their children were discharged from the hospital after prolonged and rocky neonatal courses. And both families have at some point been forced to declare bankruptcy, in part due to medical and home health care expenses. They also have experienced difficulty in acknowledging that they need financial help. Years before declaring bankruptcy, one of the mothers wrote this advice for other parents of special needs children:

Aside from the difficulty of locating resources appropriate to your situation, difficulty may also be experienced in actually accepting assistance. As many of us like to think of ourselves as self-sufficient people who are in control of our lives, the realization that financial assistance from government programs for the disabled is necessary in order to meet the medical needs of our children can be devastating (Jennings, 1995).

Financial difficulties were not a large part of the parenting narratives that I encountered, however. It is not clear whether they had no problems, or simply did not include them as part of their stories. Certainly the caregiving they were doing curtailed the careers of many of the parents, particularly the mothers. Josh Greenfeld laments “[t]he books I will not write, the paintings Foumi [his wife] will never paint . . .” (Greenfeld, 1970, p. 169) because of caring for autistic Noah. Greenfeld’s wife, Foumi Kometani, worked on her writing at home, while doing the majority of the caregiving; Josh Greenfeld meanwhile found an office away from home. Charles Hart (1989) and his wife Sarah were both college professors when their autistic son Ted was born. She apparently continued with her job, but Charles Hart resigned from his job when Ted was eight “to become the primary homemaker, chauffeur, and resident child development specialist” (Hart, 1989, p.158). By the end of the book, he was working with state grant money to advocate for autism programs and research. He does not discuss the financial consequences of this.

Ian Brown and his wife had already hired a nanny named Olga to help with Walker’s older sister, while both he and his wife continued their writing careers. When Walker was born with CFC, they were fortunate that Olga was willing to stay, at least during the day, to help with him as well. Brown and his wife were on their own for their alternating sleepless nights (Brown, 2011). Philosopher Eva Kittay had a long-term caregiver Peggy, who took care of her mentally disabled daughter Sesha while she continued her career. After Peggy retired, Sesha was placed in a group home (Kittay, 1999, pp. 147-161). I do not know where either Ian Brown or Eva Kittay found the money to pay their wonderfully dedicated caregivers. Neither philosophy books nor parenting biographies seem to me a reliable source of piles of money.

Greenfeld (1970), the father of autistic Noah, makes this cynical observation, “Indeed, the more I read about such children, the more I’m convinced, unfortunately, that

only money can solve most of the problems of having a child like Noah. That's the damned truth of it. The more money I have, the less of a problem Noah becomes--I can hire out the problem to others. Have a crazy kid and get to understand the gut meaning of society" (p. 126). Ironically, Josh Greenfeld became quite famous for his books about Noah, in part paying for Noah's treatments and care by writing about his problems.

SOCIAL ISOLATION

Almost all of the papers on caring for technology dependent children mention social isolation as a concern reported by parents, and cite a number of different reasons why this is so. Ray (2002) mentions that families of chronically ill children become isolated as friends and even family members tend to drift away after initially offering support (p. 431). Wang and Bernard (2004) see social isolation as a failure of social services to provide adequate support (pp. 40-41). Kirk (1998) describes many families essentially becoming house-bound due to factors including parental exhaustion, difficulty finding respite care, and parent's fear of leaving their child with complex problems to someone else's care. She also mentions the intimidating nature of the changed home environment, taken over by medical equipment and home health care nurses (Kirk, 1998, p. 105). Carnevale et al. (2006) mention an additional factor; the distance between friends and family can increase when other's children grow up and move on to new things, while the disabled child remains behind, unchanged (p. e56). All these themes are echoed in the parenting biographies.

Loneliness and feeling trapped in the home was a common finding in a 1999 study of Finnish families caring for severely impaired children, who were not all technology dependent. Brinchmann (1999) conducted long interviews in the homes of seven families who had faced ethical decisions in the NICU and were experiencing life with a severely disabled child, though two of the children had since died. The families of the surviving impaired children expressed ambivalence toward their past decisions, and had extremely stressful lives. Brinchmann described their predicament as "The home can seem like a prison, from which it is impossible to escape" (Brinchmann, 1999, p. 137).

Interestingly, one of the parent autobiographies also used the term prison, to describe his mother's life with his autistic brother. Charles Hart (1989) is both brother to an autistic man, Sumner, and father of an autistic son, Ted. Sumner was born in 1929 at

a time when most parents chose to institutionalize their impaired children, but Sumner's mother refused to do this. She lived her whole life for Sumner, rarely going outside, in order to shelter him from condescending eyes, and herself from the shame of bearing him. However, it was in part advancing arthritis and the consequences of lack of care for herself that made her home a prison, as her activities in her old age became restricted by illness. (Hart, 1989, pp. 123-124). She continued to watch over Sumner, both of them trapped in her home, until her death.

Hart's mother's difficulties with Sumner demonstrate an additional, more subtle aspect to the social isolation experienced by these parents. Even in these more enlightened times, parents feel the need to protect their children and themselves from the disapproving eyes of strangers. In Carnevale's study in 2006, parents still reported feeling isolation from their families due to disapproval of their decision to keep their child at home. Another family with two impaired children reported avoiding public places like the mall because of their discomfort with the stares from strangers (Carnevale et al., 2006, p. e56).

Other parents describe the necessity to maintain appearances of normality, and thus establish their child's presence in the world, by being very conscious of appearance and dress. Nearly every morning, my mother would send my "mentally retarded" (the politically correct term at the time) brother Paul back up to the bathroom to shave areas that he had missed on the first, or sometimes, second attempt. It was terribly frustrating for him, and mystifying to me. The spots he missed were essentially invisible next to his unsteady gait and slack mouth. But my mother insisted that his cleanliness reflected the adequacy of the care she was providing. She interpreted the stares of strangers as disapproval of both herself and her son.

McKeever and Miller (2004), in a review of three studies on body image in children with disabilities, noted that mothers reported investing a lot of time and effort into keeping their children not only meticulously clean but also fashionably and brightly dressed. They understand this as a way for parents to increase their child's social worth by visual cues despite the obvious disability. (McKeever & Miller, 2004) It could also be seen as a way of bearing up under the stares, maintaining a personal wall against the guilt and embarrassment unavoidably engendered.

The stares of strangers are not without consequence. They can be reminders of the things that are put aside in order to get through the day. In many of the narratives,

there is a moment where watching normal children causes sadness and perhaps a bit of jealousy. Greenfeld (1970) describes a visit to friends with children the same ages as autistic Noah and his older brother Karl. He says,

It's getting painful to watch children grow past Noah. This afternoon we dined with some friends whose two-year-old son joined--or followed after--Karl and his older brother in play, while Noah just sat on the couch or in the corner, addressing his fingers and grinding his teeth. The same thing happened Thanksgiving Day. Other friends were over with their three kids. Their baby girl, a little thing, now talks, while Noah remains a baby (Greenfeld, 1970, p. 126).

There is another aspect to the reluctance to appear in public. Those stares remind the parent of the disability, essentially breaking down the private world in which the child's problems become the norm. Greenfeld (1970) describes an experience he has while touring special schools for Noah. This was in the early seventies, before the mandate to supply appropriate level education for all children. He finds a school for "retardates" of all ages, which has been established by a private community and arrives during a birthday party for an adult attendee. "Of course, they were all like children, those close-eyed, sweetly vacuous heads. I almost cried. I refused to imagine that Noah, my son, belonged in such a place, with such a group" (Greenfeld, 1970, p. 74) He was not ready to include Noah with these similarly impaired people. Perhaps he also wasn't ready to include himself in the company of parents of impaired children.

Ten years later, in the beginning of the book *Without Reason*, Charles Hart (1989) reports spending a lot of time apologizing or attempting to control embarrassing or inappropriate behaviors from his brother and, later, son. This was done both at home through behavior modification training and in public by rapidly withdrawing from potentially embarrassing situations. But neither Sumner nor Ted was equipped to notice public shame. They never saw or responded to the emotions of others. It is part of autism to be socially unaware. It is only late in the book that Hart realizes that he is doing this, not to protect them from humiliation, but to protect himself. "Protect Ted? Protect Sumner? Slowly I had to recognize that a sense of family shame made me want to hide them, protecting me from public judgment as surely as I tried to conceal them from their imaginary persecutors" (Hart, 1989, p. 264). That there is no need for such

shame, does not make the feeling any less real for him, or the isolating consequences any less difficult.

Interestingly, in the most recent of the parenting autobiographies, *The Boy in the Moon*, written in 2008, the author Brown claims not to be ashamed of his son in public. “The opinion of other people matters less and less the more you walk down the street with a boy whose lumpy looks attract attention, stares and smiles alike” (Brown, 2011, p. 36). Brown’s isolation is more a reordering of priorities, a life suddenly different from what he had expected. He says, “The boy recalibrates the world. The crisis of so-and-so’s unhappiness about her job or his inability to meet a woman who will pay him what he considers to be a sufficient degree of attention pales next to the crisis of how to stop Walker from beating his own brains out” (Brown, 2011, p. 36)

Yet Brown is still isolated. Walker is too much work, too complicated, to leave with a babysitter. There is no nearby family, and he does not dare to ask the few friends who persist in offering help to spend a second night. And though he does not hide Walker from people, he is not entirely comfortable either. Walker is an intrusive child, ranging from person to person intruding but not exactly paying attention to them. “He was a steady reminder not just of his presence, but of the existence of all children like him, the children we so often try to forget. For this reason we tended to select our dinner guests carefully” (Brown, 2011, p. 71). I suspect that the need for careful selection of friends and even family, is the most isolating aspect of raising any special needs child.

EMOTIONAL BURDEN

In addition to the physical burden, it is almost universally understood that caregiving for any disabled or chronically ill child carries a heavy emotional toll. The parents of technology dependent children live in a state of constant vigilance, listening for alarms from equipment and monitoring for signs of serious illness. For the sickest children, fear of death or of finding their child dead is ever present (Kirk, 1998; Ray, 2002; Wang & Bernard, 2004; Carnevale et al., 2006; Cockett, 2012) For those who are not quite so fragile, parents worry about what the future will bring, particularly if the child will be dependent on their care long-term (Carnevale et al., 2006). These fears and worries contribute to chronic anxiety, sorrow, sleeplessness, high levels of stress, and depression (Wang & Bernard, 2004). Also present are frustration, anger, and guilt. (Kirk, 1998)

All of these emotions are evident throughout the parent narratives (Greenfeld, 1970; Hart, 1989; Brown, 2011), often running together in a tangled mix. Though the children were not technology dependent, so there was no need to listen for alarms or live in constant fear of death, there was no less need for vigilance. Ted Hart and Noah Greenfeld needed to be watched for behavior outbursts, and Walker Brown for self-injury. Only Walker was medically fragile, but all of the parents felt worry, fear, and anxiety, both while they were going through the difficult process of diagnosis and once their fears were confirmed. There was a good deal of frustration and anger in this process as well; directed at the medical establishment's inability to provide an explanation or a cure, and at themselves for their own inability to save their children. All of them worried frequently about what their child's future would hold.

But the most present and unexpected emotion was guilt, and it is here that the parents narratives hold understanding that the research does not. Their guilt was in part over imagined inadequacy in caregiving. Josh Greenfeld (1970), for example, found that he was somehow unable to perform much of the caregiving for Noah. He alternately reported guilt, feeling a failure at fatherhood, resentment toward his wife and Noah, and admiration for his wife's caregiving abilities. Brown (2011) and his wife, though they shared some duties, also frequently argued about how much responsibility each was taking. Brown (2011), Greenfeld (1970), and Hart (1989) each had a second, typical child, and also expressed guilt about the time they spent on caregiving being taken away from the well sibling.

They also expressed guilt about the nature of their child's disability. This was particularly true for Greenfeld (1970) and Hart (1989), since their children were diagnosed during a period of time when autism was felt to be an emotional disturbance brought about by bad experiences or poor parenting. As they progressed through a series of understandings about the diagnosis and cause of their sons' problems, they alternately accepted and rejected blame. For example, a popular theory of autism at the time Noah Greenfeld was diagnosed, was that the problems were caused by maternal emotional detachment. The Greenfelds both felt guilty because they had not really wanted the pregnancy. But at other times, Greenfeld and his wife adopt other things to blame; vitamin deficiency, a mild head injury, and even genetics, arguing about whose genes are responsible for Noah's problems. (Greenfeld, 1970, p. 51-52)

Brown (2011) is the most articulate about his feelings of guilt, even as he knows he did nothing to cause his son's CFC syndrome. He speaks about the sadness, envy and guilt he feels when he inevitably compares his son to other CFC children, particularly if their children are less effected than Walker. Perhaps that other child's parents were better somehow; perhaps they were luckier, or more committed, or discovered some rare treatment that Brown did not, or implemented a new treatment in some earlier or more effective fashion. He reports that, "Every parent of a compromised child knows this secret envy, mines its thick seam of guilt" (Brown, 2011, p. 125). He also expresses a surprising amount of guilt that stands against all of the scientific evidence he collects about Walker's condition. He says, "Even a firm diagnosis cannot clear away the ancient sense of culpability that has been attributed to these random genetic events for literally thousands of years--the lingering swamp notion that there is always a reason such a disability occurs, that it is a punishment, and thus deserved" (Brown, 2011, pp. 122-3). I doubt that he is alone in that lingering, archaic feeling, irrational though it might be.

LACK OF CHOICE

In a 1992 paper on the ethics of pediatric home care, John Lantos reaffirms the central ethical principle of autonomy, however in pediatrics it is the autonomy of the child that is conserved, not that of the parent. He states the well-known and common position that, "[T]he central ethical principle which guides decision making in pediatrics is that decisions should reflect the best interest of the child" (Lantos, 1992, p. 922). It is therefore paramount that any decision to discharge a child to home care be clearly in the child's best interest, and any ethical qualms center around establishing the home as the best place for the child. "On one hand, if home care is both cheaper and more beneficial for the child than long-term hospitalization or institutional care, it would seem to be ethically imperative. However, the benefits of home care are uniquely sensitive to the voluntariness of parental participation." (Lantos, 1992, p. 922) The families must then understand what they are getting into, meet established competence standards, and agree on the goals of home care. However, while Lantos does state that the child's needs must be balanced against the family's needs and that parents should not be judged unacceptable if they are unable or unwilling to carry out home care, he does not explore the nature of the "voluntariness" of the parental decision.

Not all ethicists agree that the interests of the child (or the patient) always must always be paramount. Speaking about both pediatric and adult patients requiring home technology, Arras (1994) argues that the interests of other family members should also be taken into account. He says, “the systematic exclusion of the interests of family and friends who provide care at home is untenable and unjust” (Arras, 1994, p. s24). He feels that parents, when asked to provide home care, are not really allowed to refuse, lest they be seen as uncaring or bad parents. “When asked by trusted pediatrician whether they would like to have their child go home, parents have no choice but to accept the burden of home care” (Arras, 1994, p. s22). Parents also see that there are no viable alternatives to home care; few options for long-term hospitalization or long-term care facilities. Arras states, “Unless families have access to such alternatives, their initial acceptance of the home care plan becomes a trap from which there is no practical escape” (Arras, 1994, page s25).

The ethical dilemma has not been resolved in the years since then. In a 2011 study of the ethical challenges of home mechanical ventilation, much of the debate was still found to rotate around the decision to discharge the child from the hospital to home care (Dwybik et al., 2011). Major concerns included who should make the decision to provide home mechanical ventilation (HMV), the appropriate medical indications for HMV, the cost effectiveness of HMV, and whether HMV was in both the patient’s and families’ best interests. There was a particular concern raised by the families of pediatric patients, as some of the families interviewed in the study were not sure they had made the right decision to have a child on HMV at home. The parents “asked themselves whether they made the right decision, but in reality, they did not have other choices if the alternative was to let their child die” (Dwybik, 2011, page 240). It is possible that the children included in this study, most of whom had a progressive neurological disease, were being offered HMV as a life-extending therapy in the face of death. Therefore home care would have other ethical aspects not relevant to other disabled children.

However, in other studies where the children did not necessarily have terminal illnesses, parents have expressed similar sentiments. Several of the parents in Carnevale’s (2006) study of the families of technology dependent children also expressed that they felt they’d really had no choice but to take on the burden of care. “Many parents described the strangeness that they experienced with regard to ‘making a decision,’ as if there were really a choice when faced with life support decisions. Most

parents believed that when the alternative is to let your child die, 'free choice' is really a virtual choice and not a true choice" (Carnevale et al., 2006, page e53). Here, too, it seems that, at least in the parents' perceptions, the decision was between home care and death.

Once the child is at home, and the true nature and amount of care required is finally realized, the parents do not have an opportunity to reverse their decision. With the absence of alternative placement and respite care, parents are on their own. Many of the parents in Ray's (2002) study of the parents of chronically ill children reported that they were "so busy doing things for their child that they didn't have time to think about" what they were doing (Ray, 2002, p. 432). They became accustomed to the demanding work load. Any choice was framed as between "falling apart" or "getting on with the show" (Ray, 2002, p. 433). They just kept going, because there was no alternative. Parents in Brinchmann's (1999) study of severely impaired NICU survivors came to a similar conclusion. All of them at some point had been offered a chance to stop treatment while in the NICU. Several reported that they now regretted their decision, but as Brinchmann puts it "One cannot decide against something one already has" (Brinchmann, 1999, p. 141).

The children of the narrators of parenting biographies are not technology dependent, not as critically ill, and (with the exception of Walker Brown) not as disabled as the children of the families studied by Dwybik et al. (2011), Carnevale et al. (2006), or Brinchmann (1999). Caregiving is not at any point a life or death decision for them. Nonetheless, the caregiving that they take on is not fully voluntary. Josh Greenfeld (1979), for example, on several occasions associated with events that had been particularly trying, considers putting Noah in an institution. At the time this would have been understood as putting him into a precarious care situation, both out of sight and out of mind. So, after a day of no progress, and some regression in toilet training, he says, starkly, "Perhaps we ought to get rid of Noah. No, that would no solve anything. There are always demanding madnesses in one's life. No, that's a madness too: to make of Noah a metaphor. But as Noah gets old . . ." (Greenfeld, 1970, p. 107). He does not consider institutionalization a reasonable choice, and so sees no way out of doing the caregiving that will become more difficult as Noah gets older.

Ian Brown (2011) has a similar realization, and a better metaphor. Early in the book, when Walker is still an infant, fussy and not eating properly, but not yet diagnosed

with CFC, his father takes him to see his pediatrician. Unknown to Brown, the pediatrician is aware that Walker has a major syndrome, but has not yet identified it. He says to Brown, “We do want this child to live, don’t we?” Brown’s answer, recounting the experience in the writing of the book, is:

I decided it was a rhetorical question. . . Even if he had asked it outright, I can’t imagine my answer would have been anything but yes. All the ethical theorizing in the world can’t change the pressures of the moment: the squalling baby on the examining table, his distended stomach, the doctor’s obvious concern, his father standing gormlessly by. The call of the physical child and his need. . .

Criminal thoughts, or at least outlandish ones: what if we don’t take extraordinary measures? What if he gets sick and we don’t work so hard to get him better? Not murder, just nature. But even as I considered these grave plans, I knew I could never enact them. I’m not bragging; my hesitation wasn’t ethical or moral. It was a more medieval urge, instinctual and physical; fear of a particular mode of failure, fear of retribution if I ignored the dull call of his flesh and his body and his need.

In any event I felt like an ox slipping into its yoke. I could feel the heavy tragic years coming on ahead of me, as certain as bad weather (Brown, 2011, p. 26).

Brown likely speaks for all of the parents here. Extreme caregiving is not really a choice, but a necessity springing from a sort of instinctual parental duty. It is a combination of an ancient response of a parent to a child’s need, and a modern expectation of how parents should behave. Though he might be tired and sad, he is mostly willing to take up the burden demanded of him, because the care of this particular child has fallen to him and no one else is available to respond to the many needs.

AMBIVALENCE

The same uncertainty expressed above as a lack of choice in taking on the burden of care is also found in parents’ ambivalent feelings toward their disabled child. Several of the papers on caring for medically complex children at home contain brief summaries of the ambiguity of the emotions that parents sometimes reported.

Brinchmann (1999) described the impossible situation she found in families living with a severely disabled child, and believed that ambivalence in the parent’s relationships to their children was a major theme in the interviews she conducted. She stated, “The children are utterly dependent upon their parents, who both love and hate

their children. . . The parents lack relief from the situation. . . This and their total dependence create strong bonds between them, including an experience of love and adoration. Every day is full of contrasts, full of both sorrow and sadness, but also of love and happiness” (Brinchmann, 1999, p. 141).

Some of that ambivalence was expressed as regret, but that too was inconsistent. “Even though several of these parents maintained that they would have had an abortion or terminated the treatment for their child if they had known how serious the handicap was going to be, they still expressed that their lives with these children had given them something positive, something precious, which they would not have experienced otherwise” (Brinchmann, 1999, p. 141). Despite the feeling of being trapped in the home as in a prison, one mother reported, “losing her would be so much more emotionally painful than the burden of having her” (Brinchmann, 1999, p. 141)

Carnevale et al. (2006) found this same ambivalence in the families of children on home ventilators. The title of the paper is, “daily living with distress and enrichment,” highlighting the impression that the parents were balancing a complex tension between the two emotions. The sources of distress--the worry, fear, isolation, and burden of work--have been discussed above. But the parents also reported “deep enrichments and rewarding experiences that they could not imagine living without” (Carnevale, et al., 2006, p. e53) They might regret the life that they find themselves living, but they cannot alter it. And that life does hold rewarding moments and love for the child. “Some parents said that they sometimes asked themselves whether they made the right decision, but this was commonly resolved by realizing that life without their child would be unthinkable” (Carnevale et al., 2006, p. e53)

It should not be surprising to find that parents who find themselves trapped in a lifetime of care are at times experiencing conflicting emotions. During the brief times that they surface from the daily round of care work, they can realize that there is seemingly no end to the burden they have taken on. In the absence of adequate respite care and a dire shortage of long term care facilities, the parents of a child who might never become independent will realize that the only way out of their burdens is death, either the child’s or their own. Both are unthinkable.

But they are not un-thought. My father had a fantasy, that he confessed to me on several occasions over about twenty years, of a way to solve the problem of my mentally retarded brother’s care. He and my mother were finding it increasingly difficult to care for

Paul, and they did not want to have to burden anyone else with it. His fantasy was that he would go for a drive with Paul and, at a place where it was likely to be fatal, just drive off the road. They both would be killed in the fiery wreck. Problem solved! He was quite serious, and I was never entirely sure he wouldn't do it. But as much as he might have wanted to release us all from the burden, and himself from the guilt, he never took that final drastic solution.

Charles Hart in *Without Reason* (1989), has a similar plan when he first learns that his child Ted is "brain damaged." (The diagnosis of autism does not become clear until years later.) Hart knows of the life of "humiliation, grief, and frustration" (Hart, 1989, p. 44) that can be expected, because his experiences with his own brother, Sumner, who likewise suffered from this yet unidentified problem. He says, "Our child had ceased to be a source of hope and pride. Instead he had become a source of pain, a burden that would grow greater with time. I immediately foresaw the worst, Ted growing unmanageable and unkempt, disfigured and rejected by society" (Hart, 1989, p. 44). But Hart, like my own father, had a solution. "A plan formed in my mind. We could take a ride on one of our state ferries. When the ship cruised into the deep waters of Puget Sound I would hold my son close to me and jump overboard. Our suffering wouldn't last long . . ." (Hart, 1989, p. 46). Yet Hart's love for his son is undeniably present throughout his book.

Josh Greenfeld, the father of autistic Noah, does not express a murder/suicide fantasy in *A Child Called Noah* (1970), but he does admit, "There's simply no way out. I must confess something: sometimes I hope Noah gets sick and dies painlessly" (Greenfeld, 1970, p. 139). However, Noah's brother Karl has recently written his own memoir about growing up with Noah. In *Boy Alone*, Karl Taro Greenfeld (2009) reports that his father, in both conversations and interviews, did talk about killing Noah. According to Karl, Josh Greenfeld's scenarios did not include suicide, and mostly involved allowing Noah to fall overboard from a boat. Later, as Noah became older and more difficult to control, Josh Greenfeld publicly advocated euthanasia for severely autistic people. But, Karl points out, "But you see, my mother and father love Noah as any parents love their son" (K. Greenfeld, 2009, p. 219). Karl adds later, "My father used to tell me that he talked and wrote about killing Noah because that meant he could never do it, that the confession and motive were already there, on tape, in his books, so he could never get away with the crime" (K. Greenfeld, 2009, p. 338).

Ian Brown (2011) is even more inventive than either Hart or Greenfeld, and seemingly willing to confess about almost anything. He has several pages of fantasies about a way out for Walker and himself.

On especially difficult nights, or if it rained hard, or most of all after the terrible arguments my wife and I sometimes had, strained by sleeplessness and ashamed of our failure with this strange boy, I asked myself if it might not be braver to take my life, and to take Walker with me. Suicide is not my default setting. But the hopelessness of life ahead, caring for Walker, could raise the spectre in me. There was chloral hydrate; there were pills. There was the car, there were places to drive the car off of, there were lakes to walk into (Brown, 2011, p. 223).

One of my secret death fantasies was to pack Walker into a baby backpack I owned, a kind of Snuggli, and take him high up into the mountains of western Canada in the winter, one of my favourite places on earth, and lie down in a snowbank, and end it there, quietly hypothermically. I imagined the venture in complete detail, how I would pick a moment when Johanna [his wife] was at a movie and Hayley [his daughter] was at school, how I would get him out of the house and to the airport, with all his gear and all the ski equipment. Unfortunately that alone derailed my death fantasy: if I could get through that fucking nightmare, the airport with Walker and skis, I could survive anything, and there was no need to kill myself (Brown, 2011, p. 224).

The second plan is worrisome in its precision and detail, but, of course, Brown does not carry out any of it. I think it is interesting that even his fantasy suicide pact falls apart because he is just too tired from the daily round of caregiving. Not only would carrying out the plan be too much work, but the ability to carry it out would prove that the caregiving can be done after all. Instead, he resigns himself, not just to keep going, but to keep trying to make for himself a life outside of Walker's needs.

Yet he finds joy in Walker also. On one of those dark nights, exhausted, he falls down the steps while carrying Walker. Walker thinks it's hilarious. Brown says, "He laughed. Loved it. And so, I did too. He took me into darkness but he was often the way out as well" (Brown, 2011, p. 226.) His love for Walker is palpable, and wrenching. Early in the book, just after the nightmarish night wakening quoted at the beginning of this chapter, Walker falls asleep in Brown's arms. Brown says, "I long for the moment when he lets his crazy, formless body fall asleep against me. . . Sometimes I think this is his

gift to me--parceled out, to show me how rare and valuable it is. Walker, my teacher, my sweet, sweet, lost and broken boy” (Brown, 2011, p. 7).

That is the ambivalence of daily living with distress and enrichment.

ATTENTIVENESS AND RESPONSIBILITY

I have said that, in Tronto’s (1993) theories of care, the first two phases of care, caring about and taking care of, are associated with the virtues of attentiveness and responsibility. We have seen that parents who are extreme caregivers, while likely no more attentive or responsible than parents of typical children, do have many more things that they must be attentive to and take responsibility for.

Having undertaken the task of extreme caregiving, it becomes an expected, if not fully accepted, part of life. The many things that require attention become part of the daily routine. The responsibility has been, perhaps unknowingly, accepted. Ian Brown (2011), in another passage from *The Boy in the Moon*, talks about the way in which Walker’s care has become integrated into his life.

Gradually, as the endless routine of caring for him and watching him and stopping him and stimulating him became familiar, my fear subsided, and my grief was transformed into an unusual loneliness. Life with him and life without him: both were unthinkable. As much as I tried to consider alternatives, I couldn’t imagine not caring for him every day: couldn’t imagine a day without the morning wake-up, the cleanup, the dressing, the school, the return home, the tired wailing, the sudden change and the bursts of sunny happiness, the feeding, the pointless teaching, the hilarity, the hospitals and doctors, the steady worry, the night rambles, all repeated every day until it ended, however that happened (Brown, 2011, p. 68).

Parents everywhere find themselves making similar adaptations to the presence and needs of their children. However the parents who are extreme caregivers have so many more needs to adapt to. Notice also that Brown has realized, not only that there is no good way out of the daily grind of caregiving, but that the task is essentially unending. Walker’s death or banishment to an institution are both unthinkable, as is continuing the enormous task of caring for him on a daily basis. In the last sentence, he shies away from thinking about the future. It is clear that Walker’s needs will not go away, and that Brown will not be able to fill them forever, but the conditions upon which the caregiving might stop are not imaginable.

Josh Greenfeld (1970) has a similar recognition of both the difficulty and endlessness of the caregiving. He also shoulders the burden and the unknowable future together, out of his enduring love for his son. "July 19, 1969: We will do what we have to do. We will take care of him [Noah] as best we can until we can no longer take care of him. We will have him in our home and find ways to live in joy with him. And when we cannot enjoy him as much as I would like to, I will love him even more." (Greenfeld, 1970, p. 60) Taking on the endless burden of care is not really a choice when love or duty permits no other course of action.

The lack of choice in taking on the additional burden of extreme caregiving raises a moral question that within principle ethics would be considered by balancing parental autonomy and choice, against the civic duty of a parent to protect the vulnerable child. These parents are in many ways being forced into caregiving which they neither expected nor chose to do. But the existence of the child is undeniable, and the vulnerability of his need seems to supersede the desires of the parent. In this model, the parents truly are, as the parent/narrators often express, condemned as guilty for the child's problems. It is their fault the child exists, and so they must deal with the consequences.

The question can be considered in a different way with virtue ethics. If, as Tronto (1993) has proposed, attentiveness and taking responsibility are virtues associated with the first two phases of caring, they can be considered as Aristotelean virtues. These qualities, then, can be achieved by aiming for a balance between two extremes. Perhaps attentiveness can be balanced between inattentiveness and over-indulgence; responsibility between irresponsibility and over-commitment. Clearly these parents are taking both virtues to the maximum extreme. They are spending their lives monitoring their children's needs, attentive to too many things. And they have taken responsibility for far more than they can accomplish. They have subsumed their own lives and concerns in the needs of their children, put aside too many of their own needs and desires.

Yet their children have needs, many and complex, and no one else will meet them. The ethical fault here lies, I think, not with the parents, but with the medical system that creates and then ignores all but a few of these children's needs, and with a society that does not value or recognize care. This paper is in part an attempt to, as Lynne Ray puts it in the title of her 2002 paper, "make visible the invisible work" of caring for these

children. Once the work is made visible, it is apparent that these parent caregivers themselves need support and care.

Within Tronto's (1993) phases of care, there is no necessity for all of the phases to be carried out by a single individual caregiver, be it nurse or physician or parent. There is no reason to make the parents of special needs children compromise themselves in order to carry out every part of the task of caring for their children. This is not, then, a failure on the parent/caregiver's part; it is a societal failure of attentiveness. Likewise, these parents are not failing in their responsibility; we as a medical system have not taken on the responsibilities that we have created. We are not paying sufficient attention to the needs of either the child or the caregiver, nor taking sufficient responsibility for the care of the children whose existence is made possible by modern medicine.

CHAPTER SIX COMPETENCE

In the previous chapter, I reviewed the ways in which parenting a child who requires extreme caregiving differs from typical parenting, considering mostly the first two phases of care: 'caring about' and 'taking care of.' The virtues associated with these two phases--attentiveness and responsibility--are similar to what is expected from all parents, though the level of attentiveness and number of responsibilities is certainly greater. I have already begun to explore the third phase, caregiving, by discussing both the overwhelming burden of the caregiving work that must be done and its involuntary nature.

However I have not considered the implications of the virtue assigned to the third phase; competence. Of course, all parents are expected to competently care for their children, and the parameters of that competence are fairly well defined. There are certainly parents of typical children who do not provide competent care, and the moral problems raised by this are much discussed in both pediatric and ethics literature. The parents of disabled and medically complex children, however, must be competent beyond the realm of typical parenting. They must acquire a new set of skills, crossing into areas usually reserved for professionals.

Within Tronto's (1993) theory of care, competence becomes a moral action that can be evaluated by its effectiveness at meeting needs. If the actions of caregiving are done incompetently, the care provided is inadequate. "Intending to provide care, even accepting responsibility for it, but then failing to provide good care, means that in the end the need for care is not met" (Tronto, 1993, p. 133). Competence from a professional caregiver is, at least in some degree, trainable and measurable. Medical schools and nursing programs are all about establishing competence, though they concentrate on certain areas over others. The skills and knowledge taught are centered on the science of medicine; the tracking and measuring of physical and biological properties, the workings of anatomy and physiology, the understanding of biochemistry and pharmacology, and the physical skills to perform medical and nursing procedures. These things are easily measured by exams and licensing boards, and are the basis upon which the practice of medicine, nursing and other medical professions are established.

Tronto (1993) goes on to say that “good care becomes impossible” (p. 133) if the care is assigned to incompetent caregivers, and places fault for the poor care on both the inept caregiver and the organization that assigned the unqualified person to do the care. If those organizational ‘carers for’ deliberately assign an inadequate caregiver, they have deserted their virtue of taking responsibility.

But how are we to measure of competence in the parent caregiver? And who is to take responsibility for the appropriate carrying out of their work? There is of course no formal training or preparation even for typical parenting. The majority of parents are not trained in medicine or nursing, nor do they need to be. The burden of extreme caregiving falls on some parents at random, through accidents of genetics or disease or injury. We cannot expect to hold these parents to the same standards as we do trained medical providers, and yet we have seen the variety of skills that they are routinely called on to perform. They take on these new tasks--handling complicated medical equipment, advocacy, educational planning, tracking appointments and medications, and sheer persistence in handling persistent physical and behavioral needs--out of necessity, because there is no one else to do it.

Our expectation that anybody should be able to do this raises questions within Tronto’s (1993) phases of care about how we should consider competence as a moral issue. In my experience, parents who are for any reason unable to perform complex care are treated as inadequate, their failures sometimes taken as evidence for lack of caring (if not child abuse). An example is the experience of Lia Lee’s mother, Foua Yang, in *The Spirit Catches You and You Fall Down* (Fadiman, 1997). For Lia’s first few years, doctors saw Foua’s initial reluctance to give Lia seizure medications as a sign of lack of education and incompetence. When Lia continued having seizures, it was assumed that the mother has once again failed in her ability or willingness to administer the medications. This assumption caused her doctors to miss other possibilities, ultimately with disastrous results. The author of the book, Anne Fadiman (1997), poses this as a cultural clash but, while there are indeed cultural barriers, this sort of misunderstanding between doctor and patient is not unique to Hmong parents. Unwillingness or inability to comply with doctor’s orders, for any reason, is often assumed to be a sign of parental incompetence.

In his review of the parents of technology dependent children, Kirk (1998) found that there were often misunderstandings and disagreements between parents and

physicians. Kirk reported that, “. . . parents experience contradictory expectations as they are asked to become sophisticated health care experts and have responsibility for their child’s care but at the same time they are still expected to defer to, and comply with, the advice they receive from professionals” (Kirk, 1998, p. 111). She reported also that, as parents gained knowledge and experience, they became more assertive, and professionals often began to either avoid them or try to pressure them into compliance with advice. In my experience such disagreement is likely to center on a parental misunderstanding of medical science, and non-compliance is often framed as parental incompetence.

Parental ability is likewise often overlooked. Again, Lia Lee’s mother (Fadiman, 1997) provides an example, by the way in which her caregiving abilities are ignored. Foua took Lia home from the hospital after a complicated course of seizures and overwhelming sepsis, still febrile and with medical experts expecting her to die within a few days. But under her mother’s care, no longer dictated by experts, Lia’s condition stabilized. (Unfortunately neither her modern pediatric specialists nor her Hmong spirit doctors had a treatment for the resulting persistent vegetative state.) Later, her doctors spoke of Lia in the past tense, as though she were dead (Fadiman, 1997, p. 256) and no longer asked her mother adhere to any medical regimen. Foua quietly and desperately went on providing care as both she and Lia aged. No one, not even Fadiman, takes the mother’s ability to keep Lia alive as evidence of the enormous competence of Foua’s caregiving.

In news media articles about Lia’s death in August of 2012, after living for 26 years in the total dependence of a vegetative state, Foua Yang’s care is briefly acknowledged. An article in the Washington Post, quotes Anne Fadiman as saying, “It’s extraordinary she [Lia] survived so long in a vegetative state. It’s a testimony to the exceptional loving care her family gave her” (Magagnini, 2012). An article in the New York Times reports Lia as “redefining care,” however the intent of the article is to praise Lia and Fadiman for the book that caused many medical programs to reassess their training in cultural awareness. It does mention that the usual life span of a person in a persistent vegetative state is only a few years, but it does not directly attribute that survival to her mother’s caregiving (Fox, 2012). None of these articles questions that Lia’s prolonged survival is to be celebrated as a positive outcome, nor considers what that loving care might have cost Foua Yang or her other children.

Prior to discharge from the hospital, parents of technology dependent children receive instructions in the more technical parts of the care, in the use of medical equipment, the performance of CPR, and the administration of medications. We have seen that this training is brief and likely to be inadequate, and that it encompasses only a small portion of the expertise that parents must acquire. Parents have to discover for themselves how to carry out much of the rest of their caregiving duties. They must piece together their competence from any source they can find; from special education teachers, home health care nurses, psychologists, speech and occupational therapists, developmental specialists, other parents, and of course a multitude of physicians (Elias & Murphy [AAP], 2012). Neither the ways in which they accomplish this task, nor the ways in which they think about newfound abilities, have been studied.

We cannot begin to understand, let alone measure, parental competence in home health care until we understand the tasks they are performing. We do not know whether Foua's caregiving was exemplary in its competence or just an example of blind persistence, though I suspect it was remarkable in its excellence. We don't know whether other extreme caregivers feel they are performing well in a necessary and honorable task, or if they are merely getting by with a combination of servitude and lack of other options. We can measure caregiver ability to use complex equipment and, to some extent, the effect of the caregiving on the family, but there are no answers to such questions in the literature. Yet, now that we understand the weight of the burden of caregiving, we need to understand the moral implications of the competence that must be acquired.

NARRATIVE AND COMPETENCE: THE QUEST FOR KNOWLEDGE

If competence is to be a moral value desired in parental caregivers, the best place to start might be to determine how the parents themselves frame their competence. Again, I believe that published narratives by parents of children who require extreme caregiving may be a reliable source of information. The preceding chapter, showing that many of the concerns expressed by those caregiver narratives I have chosen correlate with current research on the subject, helps to defend their validity as sources of information on extreme caregiving. In this chapter, again, I will be focusing primarily on three narratives; *A Child Called Noah* by Josh Greenfeld (1970); *Without Reason* by Charles Hart (1989); and *The Boy in the Moon* by Ian Brown (2011).

One of the first things that becomes apparent in the narratives by these three extreme caregiver fathers, is how little space is devoted to the act of caregiving itself. In *The Boy in the Moon* (2011), Brown spends the first chapter describing the difficulties encountered in a night as primary caregiver for his son Walker, but then rarely mentions it again. The endless round of sleepless nights, messy feedings and diaper changes thereafter becomes a background thread acknowledged only by infrequent reminders of fatigue. Neither Greenfeld in *A Child Called Noah* (1970) nor Hart in *Without Reason* (1989) ever mention this aspect of care at all, though both of their sons, Noah Greenfeld and Ted Hart, surely must have had feeding and diapering issues. Whether this is because their wives were doing the majority of this sort of care, or whether this earlier generation did not talk about such things, is unclear.

Instead, the narratives focus on a search for knowledge about their child. None of the authors is precisely sure what it is they are searching for, and their ideas change over time. The search can be seen as the way in which parents are training themselves, after the fact and out of necessity, to be competent caregivers for their child. Unlike professional caregivers, they begin their “training” only after the need for it has arrived. There is no decision to undertake caregiving as a career, and no prior experience. There is also no test at the end, nor, in fact, any defined standard of success or endpoint to the learning process. The stakes for success or failure however are high, no less than the lives of their children.

The authors do indeed go on a journey of sorts, a quest in search of understanding of a life (or really multiple lives) effected by major disability. In fact, two of them use the word “journey” in the subtitles of their books: Greenfeld’s book is *A Child Called Noah: A Family Journey* (1970), and Brown’s full title is *The Boy in the Moon: A Father’s Journey to Understand His Extraordinary Son* (2011). These books are, like Brody’s stories of sickness, narratives centered around a quest to find a way through an illness (Brody, 2003), though the sick person is the narrator’s child, not the narrator himself. Large portions of these illness narratives are centered around this quest for knowledge, with the search done specifically to help the child/patient. Any information obtained is immediately and directly applied to helping the child. The search for knowledge then can be understood as an important part of the caregiving process. The ways in which they approach that search, think about their part in the search, and use

the information they acquire, can become windows into understanding the moral nature of competence in caregiving itself.

That search starts within the science of medicine, with a dawning recognition that the child is not developing normally, leading to a need for medical knowledge. The desire to find a medical answer for the problem, in the early stages, is balanced by a hope that there really isn't anything wrong. The acquisition of any diagnosis, even a wrong one, at once dashes hopes of normalcy and provides a new avenue for research. Once any diagnosis is proposed, it becomes a specific focus for knowledge centered around an understanding of that disease and a search for medical treatments or therapy. This voyage of discovery is an integral part of the narratives, taking up a good deal of the pages and becoming the main narrative arc of the stories.

Both *A Child Called Noah* (Greenfeld, 1970) and *Without Reason* (Hart, 1989) deal with autism, which was much more of a mystery in 1966 and 1970 (respectively, the years Noah Greenfeld and Ted Hart were born) than it is now. Some of the information sought so eagerly by Greenfeld and Hart is now readily available, and their two boys certainly wouldn't today have to go through so many wrong diagnoses. However advances in medical knowledge, while they have been significant, have still not arrived at final answers. Nor have those advances resulted in any more definitive treatments. The journey undertaken by the parents of a child diagnosed with autism today might involve different concepts and medical jargon; for example, the words "sensory integration disorder," "hypersensitivity to stimuli," or "behavior meltdowns," have replaced phrases like "emotionally disturbed" and "childhood psychosis." This reflects subtle but real differences in the way the illness is perceived, but the journey to discover what autism means for a modern family will in many ways be similar to that of Greenfeld and Hart.

The Boy in the Moon, written just a few years ago (2011), deals with a rare genetic disease called CFC (Cardiofaciocutaneous Syndrome). Like autism in the sixties and seventies, CFC is still going through a phase of research to define the characteristics of the disease and determine who, precisely, has CFC, rather than some other rarely seen syndrome. The details of this disease and its diagnosis are complex, and are not necessary for our understanding here. Though the number of identified patients is rising, there will never be the numbers now seen with autism. (There are only a few hundred cases of CFC now, whereas autism, according to a widely publicized

study done in 2008, effects 1 in 88 children (CDC, 2008)). In this sense of standing alone at an unexplored frontier, Brown's search for information mirrors the earlier searches by Greenfeld and Hart.

Two of the authors mentioned so far are journalists by profession, and had resources not available to every parent. The Greenfelds (1970) used their connections to move to California for an extended time in order to bring Noah to an operant conditioning program at UCLA, then on the cutting edge of behavioral research into autism. And Ian Brown (2011) used his journalistic abilities to gain interviews with researchers in San Francisco who had recently identified three genes associated with CFC. But both are also primarily the father of a sick child, and their journalistic observations are very much filtered through their own personal need for information. Brown also was able to travel throughout the US and Canada, meeting other children with CFC and interviewing their parents. They are not structured interviews, nor reported in full, but they contribute to Brown's understanding of himself and Walker. They can also add to our understanding of the extreme caregiver.

I will first explore the journey itself, both how and why it is conducted. We will see that the journey is begun out of need, and guided almost exclusively by a desire to help their own child, with no mention of an expectation to advance medical science or even to apply their knowledge to other children. Everything learned is immediately applied specifically to their own situation, and often requires a change in family life centered around caregiving. Several things become apparent when examining these parents' quests for knowledge. The first is that the extent of scientific knowledge attained is unexpectedly large. The second, and more interesting, is that, despite this, none of the narrators think of themselves as experts.

Reason for the Search

The search begins, as I have said, with the need to establish a diagnosis; to find out what, if anything, is wrong with their child. This is a surprisingly gradual process, often requiring visits to ever-more-specialized physicians over a period of months or years. The fastest diagnosis in any of the narratives was Walker Brown's diagnosis of CFC, made at eight months of age; which still meant many months of uncertainty, frequent illnesses, and weekly doctor visits (Brown, 2011). The longest was Ted Hart, who did not receive the appropriate diagnosis of autism until age eight (Hart, 1989).

Noah Greenfeld had received autism as a diagnosis at about age three but, because it was still relatively unknown in the 1970s, his parents did not find it very helpful and later denied it as a diagnosis (Greenfeld, 1970; K. Greenfeld, 2009).

The arrival of any diagnosis, even a wrong one, provides an avenue both for further specialist involvement and for individual research. Following the diagnosis, Walker Brown was immediately referred to a genetics clinic; Ted Hart and Noah Greenfeld were referred to a variety of child psychiatrists. The parents also begin their own research--reading the latest papers, searching the internet (when available), seeking out different specialists, and joining with other parents--hoping to understand the illness that has effected their child.

However the parents quickly learn that a diagnosis only gives a name to the problem; it does not solve it. Nor does it entirely define the extent of the problem. Both CFC and autism are chronic conditions, with a large amount of individual variability and no known cure. The parent's search branches out into discovering and exploring the options for therapy. This ranges from reading up on the latest genetic theories to finding toys which might be beneficial. They must look for the best schools, and choose the right doctors. And they must select forms of intervention, often identifying physical and behavioral therapy that is intensive and largely carried out at home.

The authors' search for knowledge about their child's condition is to them an essential task for caregiving. Everything they learn effects their lives deeply, as new therapies become part of the daily routine of care. Even once they realize that there is no cure, they expect that any knowledge they attain can be used to better the child's life. They are hoping to provide the best outcome, the most promising future available for their child.

However, though the main reason for undertaking the search for knowledge is always expressed in the possibility of benefit for their child, the parents are looking not just a for an effective treatment, but to understand the child. They wish to know the child by understanding his condition, what it means and why it has chosen their child (and them). Ian Brown describes his journey into medicine:

I was always looking for a context in which to make sense of Walker, in which his disorganized life (and my unavoidable devotion to it) might make take on more meaning and purpose. . . . What I had yet to find out was why he was the way he was. And so I turned to science, to see if the laboratory could explain my boy Walker (Brown, 2011, p. 157).

In a sense, Brown's journey does not start until Walker has left home, finally placed in a group home at age eleven. Brown begins traveling extensively in search of information. Though he is physically getting further away from Walker, he calls his driving across the country "work[ing] my way closer to Walker" (Brown, 2011, p. 112).

Hart (1989) gives a different though related explanation for his search. He needs to understand his son Ted in order to integrate him with the rest of the world, find him a place and value in society, a place that was never obtained by his autistic older brother. He studies autism diligently and urgently, knowing that the disease is not well understood and that there are no guaranteed treatments, but that Ted would need every benefit in order to thrive.

The mysteries behind autism had fascinated writers and curious professionals for over forty years. But the uncertainties of the disorder took on a special urgency for us. More than that, it became an unwanted mission for Sara and me. We had to understand our child in order to make a place for him in the world (Hart, 1989, p. 198).

Ultimately the fathers find that, even though their understanding of them is incomplete, their love for their sons is undeniable. Brown (2011) tells a story about his mother's (Walker's grandmother) reaction when she learned the likely extent of Walker's disability. According to Brown, she matter-of-factly says, "Well, we'll just have to love him as he is then." Brown recognizes the triteness of this expression, but also its essential truth. He continues, "Its not much of an answer: We'll just have to love him as he is. But it is the only answer that is always there, waiting. My mother has a talent for striking the flinty bottom of the truth" (Brown, 2011, p. 93).

A diary entry from Greenfeld (1970), made when Noah was almost four, summarizes not only this aspect of undeniable love but also reveals that even at this early stage, he is beginning to realize the difficult task ahead of him. At the time, Noah's diagnosis is mental retardation, a diagnosis which Greenfeld questions, but feels he must come to terms with. There is by then clearly something wrong, and some degree of retardation is the explanation he is given. He writes, "No matter how severe Noah's retardation, I refuse to view his condition as a life-searing tragedy. We will do what we have to do. We will take care of him as best we can until we can no longer take care of

him. We will have him in our home and find ways to live in joy with him. And when we cannot enjoy him as much as I would like to, I will love him even more” (Greenfeld, 1970, p. 60).

Level of Knowledge Attained

All of the narrators do extensive research into their child’s illness, launching from the most recent professional opinion or diagnosis or therapy. This includes the reading of professional journals and books on any topic even seemingly related, finding and then arranging visits with a variety of professionals, and obtaining advice from teachers, therapists, and even other parents. The quest for knowledge runs as a thread through the narratives, as promising new diagnoses or therapies are discovered, attempted and, often, discarded.

Greenfeld’s (1970) son Noah, born in 1966 with autism, goes through a variety of diagnoses during his childhood: mental retardation, “atonic diplegia,” emotionally disturbed, and childhood schizophrenia. Greenfeld reads books on brain damage, emotional disturbances and retardation. He also reads about new forms of treatments being proposed: megavitamin therapy, patterning, operant conditioning. He is possibly the least informed of the three fathers, but Noah is only three years old when the book ends.

Ted Hart, born in 1974 with autism, is also initially diagnosed with mental retardation, followed by a variety of other diagnoses, and his father Charles Hart (1989) is initially willing to rely on professional knowledge. However, when Ted is eight years old, Hart makes the diagnosis of autism himself, after being invited by one of Ted’s teachers to a conference on autism. He recognizes not only his son, but also his own brother Sumner, in an Autism Behavior Checklist available at the conference. The possibility of autism, that “unspeakable condition, the leprosy of mental handicaps” (Hart, 1989, p. 70) is horrifying, but “offered the first clue toward understanding” (Hart, 1989, p. 71) Embracing the diagnosis, the Harts immediately read everything they can find about autism, and join the Autism Society. He quickly becomes a volunteer for the autism society, often teaching parents of newly diagnosed autistic children.

Ian Brown’s (2011) son, Walker, born in 1996, received his diagnosis of CFC (Cardiofaciocutaneous Syndrome) at age eight months, an extraordinarily early age. The Browns had the advantage of a pediatrician at a major pediatric center in Toronto, who

had an interest in unusual syndromes. CFC was first described in 1979, and there were still only about 100 reported cases worldwide at the time of Walker's diagnosis in 1997, according to Brown. A genetic test for CFC was not released until 2007. Walker was tested for those genes, plus a few others that had been identified at other labs, a few years later. He was negative, but his diagnosis remains CFC, as it is the best fit with his symptoms and appearance so far available. Brown (2011) says, "The medical profession--at least the handful of doctors who studied cardiofaciocutaneous syndrome, or knew what it was--was learning about the syndrome as we did" (p. 8).

Brown, like Hart and Greenfeld, researches the syndrome extensively, by reading in medical journals about genetics and neurology, by finding and consulting with a wide variety of neurology, education and genetics specialists. His descriptions of the advances in genetics and behavioral neurology are precisely written and full of up to date information, some of which is on a frontier of medicine of which I, as a pediatrician, am only vaguely aware.

Based on Brown's (2011) intricate description of CFC, I made contact with the mother of Savannah, who had been my patient for a few years before moving out of state. Despite seeing numerous specialists at our university hospital after her birth in 2004, Savannah's illness had remained a mystery. It seemed to me that CFC might be our long-sought diagnosis. Her mother was way ahead of me. Savannah is now eighteen, and has a working diagnosis of CFC established through geneticists at her current university hospital, though she, like Walker, did not test positive for any of the genetic markers so far identified.

Brown had another resource, not available to Greenfeld and Hart; the internet. He eventually finds internet sites dedicated to CFC and some related syndromes, where parents swap information on the latest discoveries, along with parenting advice and sympathy. He considers many of these parents experts in the field. Of this CFC network, he says, "Some mothers. . . knew more than any doctor, and were widely consulted for medical and technical help" (Brown, 2011, p. 135).

After Walker is placed in a group home at age 11, Brown (2011) begins traveling to meet other children with CFC and speak with their parents. He meets some of the people who are active in the on-line CFC network, and reports their stories. Most of those parents were not as lucky in early diagnosis as Walker was, and went through numerous doctors and specialists in the search. Two of the mothers reported being

instrumental in their child's CFC diagnosis, bringing journal articles and photographs to their pediatricians, an act that was not always appreciated. Both of these had received an earlier diagnosis of a different obscure syndrome but felt, based on their own research, that this syndrome didn't quite fit their child. They discovered the existence of CFC on their own, and had it confirmed through sheer persistence. Both of those children are confirmed as CFC by genetic testing. Brown (2011) concludes, after interviewing them and a number of other CFC parents, "Most parents of CFC children know more about the affliction than their pediatricians" (p. 9). I think he is correct in this assessment.

Depictions of Self Knowledge

Despite the vast amount of research done and the extensive knowledge obtained, these fathers do not claim any real expertise for themselves. Though they have become something like experts on their child's individual illnesses, often surpassing the knowledge of general doctors, they don't ever claim this as a valuable skill, or an acquiring of competence. For all three, the words they use to describe their own search for an acquisition of knowledge and search are often quite disparaging.

Greenfeld (1970), after reading books about brain damage and mental retardation, emotional disturbances, and patterning, admits that his "diagnosis of the day" for Noah is based on whatever book he just read, and calls his knowledge "my amateur diagnostic attempts" (Greenfeld, 1970, p. 69). I suspect by this point he actually knew as much or more than any of the doctors who saw Noah. He also uses the word amateur again later to describe an attempt at giving Noah Vitamin C, which his wife had read was a possible cure for schizophrenia, Noah's current (and still incorrect) professional diagnosis (Greenfeld, 1970, p. 85).

Hart (1989) does not initially trust his own understanding of the professional information he receives. After one session during which he has been given expert advice about Ted's problems, he says, "I experienced shock resembling amnesia, periods when it was impossible to recall specifics of the doctor's language. I had to ask Sara [his wife], 'Did he say significantly retarded or seriously retarded?' It was enough to make us question our sanity" (Hart, 1989, p. 52). Mental retardation was not even the correct diagnosis. Interestingly, after he has correctly diagnosed his son's and brother's autism from a behavior checklist that had been available since 1943, Hart blames himself for

the oversight. “[H]ow could I, with my education and community contacts, have remained ignorant for so long, never knowing that my brother’s and son’s problems could be explained by a disorder others had named and studied?” (Hart, 1989, p 71).

Eventually, Hart resigns from his job “as training administrator for two local hospitals to become the primary homemaker, chauffeur, and resident child development specialist” (Hart, 1989, p. 158). He calls himself a “house husband,” which does not seem to be something he is proud of. He attends conferences on autism and at one point accepts a grant to study programs for autistic children across the country. But in the midst of all this newly acquired expertise, He hears on the news about a person who must be autistic, and calls his assessment an “amateur diagnosis of autism” (Hart, 1989, p. 229).

As the only author whose child is technology dependent, Brown (2011) does not seem to recognize any special skill in his management of his son’s feeding tube. In the first chapter, where he describes a grueling night-time feeding, his description mostly centers on his own feelings of incompetence at the task. The technology is just there, and using it is a complicated but necessary ingredient in the goal of getting through the night. Brown also belittles his extensive research into CFC saying, “I worked at home on the dining room table, plowing my way through incomprehensible papers on genetics or neurology” (Brown, 2011, p. 51). He then provides a brief but precise description of one of the papers he’s been reading, a complicated theory about the connection between nerve myelination and out-of-control behavior. Brown continues throughout the book to provide summaries of the ongoing research into CFC; theories of possible treatments, accurate descriptions used for diagnosis, and finally the theory behind the genetic mutations now thought to cause the syndrome, all accurate and well written. Yet, while he describes other parents as experts, he never claims this for himself.

None of the authors ever claim their considerable knowledge as any kind of professional expertise or clinical competence. Those things they do learn, they immediately apply to their own child, often making huge changes in their own lives to accommodate those lessons. Anything they learn that might help their child becomes a part of their day-to-day existence, a necessity for just getting by. Probably the strongest praise any of them gives their own abilities is from Greenfeld (1970), after returning from California where he went to pursue therapy for Noah; “ And, most important, we now

have more confidence in our ability to cope with him--something we must never again let anybody or any ideology take away from us" (p.173).

Depictions of Professional Competence

The words all three authors use to describe doctors' and other professionals' knowledge are quite different from the way they describe their own. All of the families, of course, have frequent encounters with doctors, starting with their pediatricians and progressing on through neurologists, geneticists, psychiatrists, and researchers. The words they use to describe these people, while not always complimentary, retain a certain degree of admiration and reverence. They reveal an ambivalence, a combination of hope placed in science and awe toward the doctors who seem to have expertise in that science, tempered by disappointment as it becomes clear that none of them can cure their child.

Greenfeld (1970) is particularly disparaging of doctors at times. He says things like, "Parents will find themselves getting little in the way of help and much in the way of confusion from the medical profession" (Greenfeld, 1970, p. 5) and, "we never should have gotten involved with neurologists" (Greenfeld, 1970, p. 84). After he makes an appointment for Noah with "an analyst friend's analyst friend," he muses that the appointment is not likely to be very helpful. "I mean," he says, "they don't seem to know what to do with Noah after they've played their little note taking games, anyway" (Greenfeld, 1970, p. 86).

But he contacts new professionals with such hope and respect. There is a "Viennese child psychoanalyst" (Greenfeld, 1970, p. 80), and an "analyst-type psychiatrist" who "specializes in children" (Greenfeld, 1970, pp. 86-7). Of a psychiatrist that he hears about who specializes in megavitamin therapy, he says, "More and more I like the idea of a psychiatrist who is a man of science with an understanding and respect for the workings of biochemistry. Wasn't it Freud himself who said the cures for mental illness will most likely be uncovered in the field of biochemistry" (Greenfeld, 1970, p. 89). The Greenfelds also take Noah to an "operant conditioning program developed at UCLA by Dr. Ivar Lovass" (Greenfeld, 1970, p. 92). Greenfeld describes Dr Lovass as "a virtuoso therapist," who can "'play the patient' with the skill of a classically trained musician hip to all the joys of jazz improvisation" (Greenfeld, 1970, p. 145).

Hart (1989) does not make any judgements about doctors as a group, and though he has his misgivings about specific doctors and their recommendations, he does not criticize them. He is haunted by the fact that his similarly effected older brother never received any treatment for his condition, and expresses his urgency in seeking out professional opinions; "Fifty years of hope had failed my mother and Sumner. I didn't want to see the mistakes of the past repeated" (Hart, 1989, p. 53). So he and his wife "accepted the recommendations of the clinic and threw ourselves into a frantic search for help" (Hart, 1989, p. 54). One evaluation, performed at a pediatric specialty center, is particularly impressive; "For two days physicians and therapists measured, weighed, tested, analyzed, and discussed our child." (Hart, 1989, p. 59) The diagnosis arrived at is equally impressive, pervasive developmental disorder with an emphasis on communication problems. This opens up a new realm of professional activity, specialty physicians, and a "special kindergarden designed as a communication classroom" (Hart, 1989, p. 59).

Brown's (2011) descriptions of his interactions with doctors are particularly descriptive. Where Brown himself "plows his way through incomprehensible papers" (p. 51), Walker's pediatrician, who "had a long-standing interest in rare afflictions and their human consequences" (p. 29), was "leafing through the medical literature on rare afflictions" (p. 30) trying to find a syndrome that matched Walker's problems. He was, as Brown puts it, "trying to find a particular plant in a vast garden of exotic flowers, each one more bizarre than the next." (p. 30)

His descriptions of the researchers he later meets alternate between bemusement and awe. His initial impression on meeting the researchers in a lab that has identified some CFC genes is less than complimentary; "The geneticists themselves bore the slightly startled air of soldiers who had just emerged from the deep jungle, only to be told that the war they had been fighting had been over for twenty years" (Brown, 2011, p. 161). Yet he describes one particular researcher glowingly: "Her area of expertise was the effects of genetic mutation on cognition--an explorer at the far edge of not one but two frontiers of medical research, the barely known genes and the still unknown brain" (Brown, 2011, p. 175). A different researcher, a geneticist, admits to Hart that she has only ever seen one child with CFC, the disease she has been studying in her lab. She had been horrified by its severity, evidence for Hart that she is out of touch with the reality of CFC. However he goes on to praise her abilities; "She saw the entire

[research] process from a scientific height, as evidence of the elegance of human biology” (Brown, 2011, p. 161).

It seems that these parents deny their own competence and knowledge while, for the most part, raising up the abilities and knowledge of doctors and researchers. They consider themselves incompetent or barely competent amateurs, while praising professional knowledge. Even professionals whom they suspect to be somewhat deficient are given, at the very least, respectful attention.

As we shall see, however, professional contributions to parents’ knowledge are often disappointing, in that they do not ultimately provide the answer parents are looking for. Even a firm, correct diagnosis does not lead to the understanding that parents desire. In addition, the recommendations of specialists rarely provide a benefit for their children, and never lead to a cure. There are hints of the ambiguity this causes in these parents’ relationships with doctors, which I will go into later. First, I’d like to look at what the narratives indicate are the causes of the differences between professional and parent knowledge.

FRAMING COMPETENCE

In a care ethic that defines good caregiving in terms of competence, it is disturbing that such expertise is discounted by the person acquiring it as a part of caregiving. There are three reasons supported by the narratives why caregivers might think negatively of their own abilities. The first is that they receive very little encouragement in it from some of the professionals they meet. The second is that their expertise is solely applied to their own child; they do not have the broad scientific background or experience to claim professional expertise. This is demonstrated in the texts mostly by the authors’ discomfort with the language of science and medicine.

The third, and I think most significant, reason is that, simply, they are not able to cure their child. Their complex journey, which is undertaken specifically to help their child, fails to end in a cure, or even a reliable long-term benefit, for their sons’ problems. Even the secondary goal, of understanding the disease in order to understand the child, fails when they remain unable to communicate with him.

Yet, I do not believe that any of these authors can be considered incompetent. They seem to me to be ideal extreme caregivers. If competence is to be used as a moral virtue on which to base the adequacy of caregiving, this suggests that we must find a

different expectation or definition of competence for the parent caregiver (and quite possibly for any family caregiver). It also suggests that we are sorely lacking a proper definition of what constitutes success in this extreme caregiving situation.

I will review first relate what the extreme caregiving narrators, Greenfeld (1970), Hart (1989), and Brown (2011), have to say about each of the factors above. Then I will review the ways in which current goals of parenting, medical care, and pediatric home health care might be contributing to these parent's feeling of failure.

Lack of Professional Support

While the professional world does not actively encourage these three authors in their search for understanding, there were relatively few examples of actual discouragement from professionals. In fact, the access all three were offered to professional expertise was quite remarkable. The two journalists, Greenfeld (1970) and Brown (2011), enjoyed a particularly high amount of personal attention from a variety of professionals, however they perhaps also enjoyed a high level of privilege. It is likely, for example, that a genetics laboratory that has just announced the discovery of genetic markers for an obscure disease would welcome a visit from a journalist such as Brown. That same welcome might not be extended to every parent of a child with the disease.

Only one parent, Hart (1989), encountered any trouble with his son's doctors. When Ted was five, the Harts approached their primary physician with a request for a second opinion, on the advice of one of Ted's preschool teachers, who didn't feel comfortable with his current diagnosis of mental retardation. Hart tells the story, "Our pediatrician scoffed at getting a second opinion. He implied that we were emotionally immature for failing to accept the first opinion and threatened that he would no longer see Ted as a patient if we continued to discuss his condition with 'people on the street'" (Hart, 1989, p. 58). The physician's disparagement, not just of Hart, but of all non-physician expertise is plain. Hart switched doctors, though not without some anxiety and uncertainty.

Later Harts had to petition their school district for proper therapy for Ted. At the hearing, the district representatives listened only to the experts who had come to plead Ted's case. Hart, reasonably, was not surprised by this, but was disappointed to find that his knowledge of Ted's needs was not seen as even a little bit important. He blamed himself for not speaking out well enough for his son (Hart, 1989).

Brown (2011), who had the benefit over Hart of some advances in doctor-patient relationships, did not encounter any problems personally, though he does at times express impatience with physicians. He did report an experience similar to Hart's which was told to him by another CFC parent. This parent was convinced that her son's diagnosis of Costello syndrome, based on information she had found on the internet, was incorrect. She discovered a description of CFC in a magazine, and took it to her pediatrician to get his opinion. Her pediatrician, she told Brown, "couldn't have cared less" (Brown, 2011, p. 153). She had the same reaction as Hart. She also switched doctors.

Further discussion of the complexities of the doctor patient relationship, and how a professional should walk the line between permissiveness and paternalism in patient's requests for verification of information, are not in the scope of this paper. Neither are ramblings about the relative number of times information acquired by patients is actually useful. My point is only that perhaps one of the reasons why these authors discounted their own knowledge is that their abilities were not recognized or encouraged by professionals. However I believe this to be a relatively small contributor.

The Distance Created by Language

There is another aspect of professional expertise that is commented on by several of the authors; the words used by professionals to describe medical conditions. With their seeming importance and almost deliberate incomprehensibility, these words inspire confidence in the scientific ability and professionalism of the person who can use them easily. However they also serve, by emphasizing a basis of knowledge not ordinarily accessible, to humble the lay person and point out how little he knows.

Hart (1989), for example, seemed impressed and comforted by some of the labels eventually attached to his son Ted. Part of Ted's strangeness was a tendency to repeat things he'd heard, without seeming to be aware of their meanings. After seeing an expert in communication disorders, Hart says, "The doctor never seemed surprised by Ted's strange speech patterns. He taught us the technical terms for the senseless language we heard so often: echolalia for the repeated phrases of other's speech and idioglossia, meaning language of idiots, for Ted's original but nonsensical phrases" (Hart, 1989, p. 66). Even though Hart realizes that the Latin word is merely descriptive of the

problem, and not terribly complimentary to Ted, the use of the word idioglossia made it into an identifiable symptom, and therefore somehow more impressive and accurate.

Brown (2011) is a bit more skeptical about the usefulness of the words, but is still sometimes overwhelmed by them. To him, they embody a science fictional attitude that is at once impressive and unrealistic. He says, of the names of Walker's medications, after casually listing thirteen of them, "They sounded like the names of ambassadors to an intergalactic conference of aliens" (Brown, 2011, p. 45), and of the words used in genetics research, "The genes and their complicated acronyms (most of which related to their chemical composition) sounded like newly discovered planets to me, as baffling and rarefied as genetics itself" (Brown, 2011, p. 166). He is also impressed by the exactitude they imply, but ultimately disappointed in them. Talking about an early visit to his pediatrician, he notices the multitude of unfamiliar words used on his son's chart. They are mostly Latin descriptions of Walker's facial features, as he finds out later, but the doctor's knowledge of them is both comforting and daunting. He says, of his pediatrician, "[He] always used the scientific terms on the boy's chart--it made for more accurate communication with other doctors. They were serious words, embodying a professional standard of exactitude. But Walker Brown was a hard boy to be exact about" (Brown, 2011, p. 28). Even as he is praising them, Brown is beginning to realize that they are not terribly helpful.

The words used as diagnostic labels are particularly difficult, as they create both hope and anxiety in the parents. A diagnosis means that a problem has been identified and pinpointed, which leads to possibility of a cure. But it also means that a problem exists. During the phase where Noah's diagnosis is still uncertain, Greenfeld (1970) expresses his reluctance at times to visit specialists; "I'm afraid to go to a doctor because I know that we'll then find out whatever the specialist knows. Expertise discovers itself in its subjects" (p. 51). As long as Noah remains without an exact diagnosis, Greenfeld can hope that he will just outgrow his problems.

Brown (2011) echoes this sentiment with his feelings about his first referral to a genetics specialist; "Any parent of a child with a syndrome remembers the day he or she is told to see the genetics department. It is the second circle of diagnostic hell. What has been, to that point, a matter of health, something you could fix, is suddenly a matter of science, carved in genetic stone" (p. 31). The diagnosis can nail down the problem, and make it true and real, in a way that physical descriptions, even in Latin, do not.

The words of a diagnosis sound very scientific and precise, and can confer a certainty that sometimes is not actually present. Those words also can be used both to recognize and obscure problems. An example of this is Ted Hart's diagnosis of pervasive developmental disorder, which he was given at age five. Reading this as a pediatrician and knowing that this was the current way of describing autism, I thought that the doctors had finally (at last!) arrived at the correct diagnosis, which was clear to me from Hart's descriptions of Ted's problems. But Hart did not know this. He learned the true meaning of those words two years later, when he recognized his son's and brother's symptoms on an autism checklist. When confronted with this, Hart's doctor admitted to using the new term deliberately to obscure the more well-known, and therefore more horrifying, diagnosis of autism (Hart, 1989, pp. 75-76).

Another author of a narrative about a special needs child, Priscilla Gilman, in *The Anti-Romantic Child* (2011), uses the language of medicine to disguise her child's diagnosis from both the reader and herself. She is repelled by it, saying, "There is nothing less romantic, literary, or lyrical than the language of pathology, diagnosis, symptom checklists" (p. 100). Her son Benjamin's diagnosis, she reports, is hyperlexia with sensory integration dysfunction. This is a modern description of autism, much like Ted Hart's diagnosis of pervasive developmental disorder, though Benjamin is not as severely effected as Ted. His mother prefers this lyrical collection of words over the simpler diagnosis of autism, in part because it clouds the extent of her son's problems. Toward the end of the book, she does admit to sometimes using the term Asperger's Syndrome to simplify explanations, but she does not accept even that milder form of autism as Benjamin's true diagnosis.

So the medical words inspire both confidence and humility, and a parent who has been through the diagnostic process learns to both hope for and distrust them. Ian Brown (2011), summarizes the complexity of this in his own beautifully complex language. He has listed, in italics and without defining, some thirty medical terms that have been applied to Walker in association with his diagnosis of CFC. He goes on to say;

The language of Walker's strangeness held me captive. New words had been invented for a new creation, infused with the pretend exactitude of scientific nomenclature, as if all the labels said something helpful and useful, which of course in any comparative sense they did. The alluring

multisyllabic complexity necessary to describe a simpleton, to use the old, once-scientific word for such a boy (Brown, 2011, p. 158).

He is held captive by the brilliant words, but at the same time recognizes their essential meaninglessness. Years of high-sounding scientific progress is relegated to nothing except different words to describe a child whose problems can't be solved. And yet perhaps there is still a tiny hope that, in a comparative sense, some progress has been, and yet will be, made.

The language of medicine creates a distance between parent and professional, and emphasizes to the lay person that they are not trained in all the intricacies of science, that their knowledge is limited. But it does not seem to me to be the major source of these authors' sense of failure. The disappointment expressed in these examples is directed mostly at the broken promise of science, but it seems to me that their feelings of incompetence are directed toward themselves, as a form of personal failure. All three eventually learn enough to become at least suspicious of professional expertise, yet they never stop pursuing it, as though they continue to believe that there is something outside of their knowledge that will eventually help their sons, if they can only find it.

Inability to Help their Child

The most significant reason why these parents consider their knowledge and competence insufficient, I believe, is that it is very specifically obtained and applied, with only their own child in mind. The parents do not have the foundations of science, or a general interest in medicine, on which to develop a broader expertise. They want to help their own child. But they eventually discover that, no matter how much they have learned, they have not been able to solve their child's problems.

Their goal, which is at all stages, to find help for their child and to know their child, is never reached. First they seek a diagnosis that is expected to lead to a cure. When that fails they seek to understand the disease, both in order to obtain the best form of therapy and to understand why their child has been targeted. They search to understand their son by understanding his condition.

In all of the narratives, the parents are frustrated by their inability to understand their child. Noah Greenfeld and Walker Brown are unable to communicate verbally, and Ted Hart's speech is inconsistent and often doesn't make sense. The authors' quests for

competence are often expressed as an attempt to find their child, to connect with him despite the limited communication. But their sons remain unable to communicate despite multiple therapies. In part, the narrators don't claim expertise, and with it competence, because they feel they have failed in this quest for understanding.

Charles Hart (1989), after spending the bulk of his book musing about and trying to comprehend and respond appropriately to what he thinks is his autistic son's desperate attempts at communication, expresses this failure directly. He says, "We also felt a sense of failure. In spite of the years of family counseling and our growing expertise in autism, we felt incompetent that we couldn't apply this knowledge more effectively. Understanding Ted's disability didn't enable us to direct his behavior a positive way" (p. 215). He has sought understanding of the science of autism through conferences and diagnostic centers, but Ted has remained beyond his reach. All this knowledge, this medical competence, while it was helpful at times, was never sufficient to meet this goal of helping his son.

When Brown (2011) finds out that three genes associated with CFC have been found, the feelings he reports reveal his growing conflict with medical discoveries. He worries that the discovery will change Walker for him, change the private and odd relationship they have developed. But in spite of the fact that he has already experienced the disappointment of the inability of a genetic diagnoses to provide a cure, he is excited by the discovery. He says, "Not to say there wasn't huge hope in the discovery. If I knew what genetic misstep had caused Walker's troubles, I would have a hook to hang those troubles on. I might even have a cure for them. There would be a firm and unassailable cause, something to blame and something to fix . . ." (Brown, page 160).

Yet reality sets in eventually. It takes over a year for the test to become available, and for the Canadian medical system to agree to do it. By the time the test is done, Brown is aware that it will change nothing for him or for Walker, that in fact the test itself might be an intrusion:

To test, or not to test: that is the question. Whether 'tis calmer in the mind to ignore the touts and dreams of genetic research, or to scan each cracked gene known to man, and by testing think we have an answer. To test and test and test some more, and by this test pretend it ends the heartache and the thousand natural shocks his small flesh is heir to. 'Tis a consummation devoutly to be wished (Brown, 2011, p. 169).

The disappointment in themselves and their abilities expressed by all three writers extends, unavoidably, to the science of medicine on which they had pinned (and often continue to pin) so many of their hopes. Their frustration with doctors and hospitals and researchers is a strong thread through their narratives, yet the failure of medicine does not seem to negate any of their own failure. Instead it seems to wind together, reinforcing a feeling that something that could have been done at some point might have been overlooked.

The hope and broken promise of all this expertise is related best, I think, in an extended description by Brown (2011) of Walker's toys. The Browns have amassed quite a collection of special toys that were supposed to stimulate Walker's development, brought in over the years by a variety of developmental experts. Many of them were lent or rented from now forgotten sources, left behind in the hope that Walker might learn something from them, though it is never clear exactly what that lesson might have been. They are bright with hope, stamped with mysterious instructions that hint at success, and Walker never responded to any of them. They lie in abandoned heaps around his house, a reminder of all the expertise that has been invested in Walker. But at the same time, they are just toys, ridiculous objects to expect so much from.

Yet, even while he is making fun of their essential silliness and inexplicable purpose, Brown seems to accept that it was his own inabilities--not understanding the toys, or not using them often enough, or not forcing them on Walker--that caused Walker's lack of response. He also takes their continued presence in his home as a sign of a different sort of incompetence. Most of them were supposedly loans, to be returned some day to the company or program that provided them. That he has never had the time or energy to accomplish this clearly bothers Brown, as does the fact that he has now forgotten where most of them came from. He will never be able to return them and, since they are not his, he will never be able to throw them out. So they persist as a reminder of both failures, the incompetence of disorganization and the larger failure to reach his son (Brown, 2011, pp. 18-23).

All three authors express their frustration and disappointment with medicine, but it is not consistent throughout the narrative. It does not form an arc leading in a progression from hope to disillusionment. Instead there are periods of criticism, often still

mixed with hope, as new therapies are discovered and tried. It is as though, while they can express bitterness at times, they can never quite abandon the institution that has failed them. In part this is because they must continue to rely on the medicines and therapies they have been doing, and because they require intervention for illnesses. But it is also because to do so, to finally admit that medicine has failed them, is to give up hope entirely.

Greenfeld (1970) expresses his disappointment near the beginning of the book, as a way to inform us of the complexity of the journey he is about to relate to the reader. He writes,

What's the matter with Noah? For the longest time it seemed to depend upon what diagnosis we were willing to shop around for. . . . But we finally discovered that the diagnosis didn't seem to matter, it was all so sadly academic. The medical profession was merely playing Aristotelian nomenclature and classification games at our expense. For though we live in one of the richest states in the nation, there was no single viable treatment immediately available for Noah, no matter what category he could eventually be assigned to (Greenfeld,1970, p. 4-5).

Yet even at the end of the narrative, he continues to seek medical answers, writing about his efforts in two more books about Noah.

Brown (2011) likewise scatters his disillusionment in between an ongoing search for help for Walker. He sums up his many visits to the children's hospital, each one holding hope and frustration and despair, in this way:

All those stuffed animals in the hospital store in the lobby of the brilliant children's hospital in the middle of the downtown of the brilliant genius city. And yet the place was filled with doctors who couldn't help my boy. I developed a degree of skepticism toward the medical profession that tended to show itself after the fourth doctor in a row told me something I already knew. Sometimes they saw my skepticism and agreed with it, quietly admitting their own helplessness, which made me like them again. Sometimes they spotted my frustration, and stayed away. . . I learned an almost geological patience (Brown, 2011, p. 63).

Later, after a visit to a series of therapists who are unable to stop Walker from hitting himself, or even add to his understanding of why Walker is doing this, he says, simply, "That's when I thought, boy, they don't know anything. I see now: no one's been helping us, because no one can" (Brown, 2011, p. 95). He learns this lesson, over and

over, but never quite convinces himself of its essential truth. No one holds a key to Walker; there is no cure, no effective treatment. No one understands Walker better than he himself does, and he has not been able to reach him. Despite the inability of medical science to provide answers, or even much help, Brown always takes the weight of that failure back on himself.

THE GOALS OF CARE

I have suggested that the reason these very competent experts--in both medical understanding and providing care--do not recognize their own competence is because they lack a realistic definition for success. None of the understood goals of medical care, even those set specifically for pediatric home care, really apply to the situation of extreme caregiving. None of the goals of medical care--cure, restoring function, prolonging life, or palliation--provide a reachable definition for success. The parents have failed to find a cure or even a treatment with a reliable long-term benefits. While their children do make some slow developmental progress, functioning at the level expected at any age is not achieved. Success is measured instead sometimes only by getting through the day.

Yet these narrators are not failures. They merely have not lived up to their own expectation, or perhaps hope, that they would be able to cure their son's illness. They have not been able to restore their son to a normal life, or even to communicate effectively with him. The standard of competence that they have set for themselves is too high, their goals are unachievable.

The goals of pediatric home care are more helpful in defining successful caregiving, but do not take into account all of the problems. In the recent AAP paper outlining the goals of home care for children, the stated overall goal is "to ensure that each child remains healthy, thrives, and obtains optimal medical home and developmental supports that promote ongoing care at home and minimize recurrent hospitalizations" (Elias & Murphy [AAP], 2012, p. 996). These goals are all in the realm of science, measurable by need for medical encounters, vital signs, and developmental assessments. The parents' abilities to recognize illnesses before they become severe, keep the child clean and well fed, and use medical equipment and medications properly can be demonstrated. By these standards, Greenfeld (1970), Hart (1989), and Brown (2011), have succeeded admirably. There were no deaths, no accusations of neglect, no

chains of unnecessary hospitalizations, no unexplained illnesses. The parent/narrators have reached a level of ability, grounded in their own child's physical needs, yet do not seem to be satisfied with it.

But these goals take into account only the child's survival. By their dissatisfaction with their abilities, the narrators imply that caregiving means more than meeting bodily needs. There is one clue to this in the AAP guidelines above: the word 'thrives.' In the context of the paper, this translates to 'grows,' measured by the plotting of height and weight on an appropriate growth chart. However the word does have another meaning that is more in line with what I believe our parent/caregivers would consider important. They want their sons to thrive in more than bodily health and size. They want their sons to grow into persons who can make their desires and personalities clear. They want to know who their sons are; and who they might become. It is in their inability to do this, in their inability to communicate with their sons, that they consider themselves incompetent.

The goals for pediatric home health care also miss another important factor; they set no time limit on care. Successful parents are supposed to not only keep their child healthy, but also help him grow to independence, at which point their job is more or less done. However, none of these children ever reached a point where they could live independently. Thus the caregiving task could never be completed or discontinued.

This endlessness is another contributor to parental feelings of incompetence. None of the narrators were ultimately able to continue their home care. Their children stayed out of the hospital when younger, but all three eventually became too much to handle at home and were placed in group homes. Both Brown and Hart discuss this decision in detail as part of their narratives. Greenfeld included the search for a home for Noah in a subsequent book. This decision is a complex subject, not in the scope of this paper, except to say that there is a great deal of guilt and rationalization in the choice. Though they are able to defend their decisions, and are able to conclude that it benefited their sons as well as themselves, both Hart and Brown clearly continue to consider their need for placement as another failure.

I spoke in the beginning of this chapter about the relative ease of recognizing competence in medical providers, using standards that have already been established. Those standards may, at least for some professions, be rigorous, but they are attainable and measurable. They are also grounded completely in a knowledge of science, and

tested for effectiveness largely in the impersonal data retrieved from the patient's body. Extreme caregivers have no such measure for success. Medical knowledge is not their primary goal, nor is the continued survival or lack of acute illnesses for the child. There is no gauge to measure the developmental progress that is made, one difficult day at a time, nor will there be, since there is no way to predict each child's developmental potential in advance. So these parents have no choice but to keep learning, working with their child, and completing the daily round of caregiving, for as long as they can. It is certainly possible that the task they have been set is so vast that no one can possibly succeed at it. They have undertaken a heavy burden of care, alone, and the only endpoint to their care is either in giving up the child to the care of others or in the ultimate failure of death.

SUMMARY AND IMPLICATIONS

As part of the caregiving process, many parents launch themselves into a search for knowledge pertaining to their child's condition. The knowledge they acquire is sometimes extensive, with some becoming near experts on that condition. This is not something they would have considered undertaking or, indeed, even known about, if their children had not been affected. The knowledge attained is not supported, or often even recognized, by professionals. Nor is it likely to be claimed by themselves. Yet the search for knowledge is integral in the process; it is the basis for their illness quest narrative.

These parents do not randomly choose to become experts on some rare disease; they do so in order to provide the best care possible for their child. The reason for the search is solely to help their child, and involves finding a way to understand or reach their child. In time, the search for knowledge becomes oriented toward the future, as parents learn that the child's condition will persist and that the burden of care will be permanent. The relationship with medicine and science thus begins full of promise, with the ideal that a cure exists and help will be found, but ends with a good deal of disillusionment. This ambiguity runs through all three narratives, and leads to a difficult relationship between the parent, who is presumed to be a non-expert, and professional experts.

The caregiving narrators did not recognize their expertise in part because it was ultimately inadequate for reaching the goals they set for themselves in caring for their

children. Both cure and effective therapy eluded them. More importantly, they did not learn, in their search for knowledge, what was for them the most important thing; who their children were or how to communicate with them. They performed the difficult and thankless task of physical caregiving well and, I think, realized that the lack of a cure is not ultimately their fault. But clearly the professional goal of keeping the child as physically well as possible is not enough for them. They feel that they have failed at the larger goal of helping sons to reach their potential as human beings in the world.

Within an ethic of care, this search for knowledge can be considered as an attempt to become a competent caregiver. If we assign competence as a moral virtue required for the act of caregiving, as Tronto (1993) has done, the acquisition of competence becomes a moral act that can be judged as part of a range of possible actions. Incompetent caregiving leads to the incomplete or inadequate meeting of needs. I believe that the three narrators, Greenfeld (1970), Hart (1989), and Brown (2011), are in fact exemplary caregivers, and not in any way incompetent. We cannot know for sure, but I doubt anyone could have done a better job raising their sons to their maximal potential. That they continued to consider themselves incompetent, despite attaining extensive medical knowledge and success in keeping their sons healthy, implies that the goals of caregiving set by medical providers are inadequate. However, the goals these parents set for themselves--curing their child, reaching their child, or being able to care for the child forever--are impossibly stringent.

Having claimed competence as a moral virtue, we must start at the beginning and learn from them what is truly involved in competently performing the job which has fallen upon them. The importance of understanding the way in which these parent caregivers acquire competence and think about their own abilities becomes clear. In this way we can begin to set a standard for competent caregiving behavior.

The first thing we must recognize is that competence in parent caregiving cannot be defined by medical knowledge. A search for this degree of competence is admirable, but cannot be a mandatory requirement for either parents of a disabled child or family caregivers. Very few parents have the resources available to these authors; access to medical journals and the ability to understand them even minimally, access to professionals gained by a career in journalism, ability to travel across the country for new programs or information. However, we do need to encourage this scientific competence, promote it, and recognize it when it happens. With the internet available to

almost everyone, parents are likely to attempt this search to the best of their abilities. In my experience this is very common, and can often lead to the exceptional understanding demonstrated by Greenfeld, Hart, and Brown.

The second thing we must recognize is that success in caregiving cannot be defined as an expectation that the child will remain in the home forever. Extreme caregiving is an enormous task, and there is very little support available. There is really no way to fully prepare a family for the task, and most of them acquire the competence needed along the way and amidst a great deal of insecurity. Being unable at any point to care for the child at home cannot be labeled as failure.

The last, and most important, thing is that professionals and parents have very different goals of care. Medicine may concentrate on physical and bodily needs, but families expect their children to thrive in other ways. They want them not just to grow, but grow up; to learn, to become the best person they can be, and to claim the future that is theirs. Promoting this form of growth is arguably the biggest task of parenting, and fulfilling this need may be the most complex aspect of caregiving for the medically complex or disabled child. The increased level of dependency and delay in expected developmental stages makes this a different, unexpected path for each individual child.

The communication barriers make each child's unique needs and desires difficult to determine. The reading of needs required in order to meet them falls within the last phase of caregiving; responsiveness.

CHAPTER SEVEN RESPONSIVENESS

ON RESPONSIVENESS

Joan Tronto (1993) has identified responsiveness as the most important characteristic or necessary virtue of her fourth phase of care. This phase is care-receiving, and it seems to be the care-receiver, not the caregiver, from whom responsiveness is desired. In giving this task to the care receiver, Tronto insures that care does not become unwanted or unnecessary. This completes a cycle of care, beginning with paying attention to needs, proceeding to taking a responsibility for meeting them, and finally leading to the performance of the hands-on tasks of caregiving. In this final phase, the recipient is encouraged and expected to report back on both the quality and desirability of the care given, making it possible to alter the first three phases so that care does not become paternalistic.

The assignment of a potential virtue to dependency suggests that receiving care is itself an action that can be done morally; that being cared for might carry its own responsibilities and duties. A recent essay by Park McArthur (2012), a young woman with a degenerative neurologic disease who requires “significant physical help” in all activities of daily living, speaks to this directly. She recognizes a form of trust between herself and her caregivers which requires input from both parties. She says, “As a dependent adult who can communicate with her caregivers, I possess a particular authority: I am able to articulate how I want and need to be cared for” (McArthur, 2012, p. 167). She also tries to be part of her caregivers’ lives, paying attention to their needs as well as her own. She calls this responsiveness, “a continual process of learning how to ask for, and how to receive, help” (McArthur, 2012, p. 167). This suggests that being responsive to care is a skill, the possession of which might ease the burden of care for both caregiver and care receiver. This effectively creates a feedback loop between caregiver and care receiver, with the act of care becoming a cooperative effort between them. Perhaps the most advanced level of caregiving might occur when the caregiver receives care in some form back from the care receiver, as Park is able to provide for her own caregivers. I will return to this later.

However, in wider practice, demanding virtuous behavior from the most vulnerable participant in the caring cycle is problematic. Not everyone who needs care will be able to immediately identify their exact needs. Nor will everyone be aware that a response is desirable or even possible. It might take time for a care-receiver to develop the skill or virtue of responsiveness to care, or that ability might not always emerge. In such cases, the caregiver must then assume some of the burden of responsiveness, in order to interpret needs as they are expressed and alter care as indicated. It would then be up to the caregiver to teach and encourage responsiveness. This produces a new requirement for the caregiver, a new virtue in addition to competence.

Tronto, in defining responsiveness, notes its similarity to the earlier concept of reciprocity. Reciprocity as a concept was developed as a part of the acquisition of moral skills. Kohlberg, in his six stages of moral development, defined it as “the ability of [moral] reasoners to put themselves in the place of the other person in the dilemma” (Tronto, 1993, p. 67). Responsiveness in caregiving, according to Tronto, goes beyond that, asking the responsive caregiver not merely to imagine the care-receiver’s feelings but to actually inquire about them. “Responsiveness suggests a different way to understand the needs of others rather than to put ourselves into their position. Instead, it suggests that we consider the other’s position as that other expresses it.” (Tronto, 1993, p. 136) The expressed needs revealed would in turn create a new level of awareness, and the ability to return to the first phase of care, with a deeper level of attentiveness.

An example of competent caregiving that is lacking in responsiveness comes from the memoir *Bed Number Ten* by Sue Baier and Mary Zimmeth Schomaker (1995). In it, the narrator is temporarily rendered almost completely unresponsive by a rare paralytic illness called Guillain Barre Syndrome. She is intubated, tube fed, and unable to move anything except her eyelids. She is also uncomfortably warm. Her husband, during one of the short visits he is permitted, through a laborious (and responsive) process of ‘yes/no’ blinks, manages to understand this, and removes her blankets. For a short time, she is comfortable. However, after her husband leaves, her nurse, competently noticing the missing blankets and reciprocally assuming that she must be cold without them, promptly replaces them.

The crucial involvement of the caregiver in the responsiveness cycle, suggests to me that caregiving as a moral act requires two parallel virtues, competence and

responsiveness. Competence can be acquired and understood (and measured) in terms of caring for physical needs. Responsiveness implies a different sort of connection, one that will be much harder to train and quantify. Responsiveness, if it is to be different from reciprocity, requires not merely an imagining of how the caregiver would feel in the care-receiver's position, but an actual assessment of the care-receiver's emotional state, and a real understanding of the situation of his needs within his life.

This addition of responsiveness as well as competence to the caregiver's virtues, adds a new dimension to caregiving. Francine Wynn (2002), in a paper enlarging the role of nurses, brings in the concepts, advanced initially by Agamben, of *zoe* and *bios*. *Zoe* is "mere life" or "bare life;" the physical and biological life of the body. The maintenance of bodily health is the clear object of medicine and nursing, a goal toward which most of the science is aimed. *Bios* has the same root as biography, the story of a life lived. This is the life particular to an individual, his past history and hopes for the future. Perhaps it is the source of the personhood which is so important in bioethics and philosophy. If *zoe* is bodily life, *bios* is the narrative of a life. Competence is a virtue for *zoe*, considering the needs of the physical body. Responsiveness requires the discovery or understanding or telling of a story.

For the caregiver, being responsive requires maintaining a *bios*, and that requires a proficiency at narration. Maintaining a *bios* might require keeping a patient's story intact when memory fails, as in Hilde Lindemann's (2009) concept of "holding well" the elderly demented person. Perhaps a contrast between our images of poor nursing home care, where bodies are fed and cleaned and maintained, can be contrasted with a home that provides "memory care," where part of the daily routine is to review and remember stories of the elderly person's life. Additionally, maintaining a *bios* might require being a witness to the suffering written on the body of the ill patient, as suggested by Frank's Wounded Storyteller, or helping an ill person write a new life story changed by the unexpected presence of illness, as in Brody's (2003) *Stories of Sickness*.

In the cases above, the care-receiver is the author and protagonist of their own story, and the virtuous caregiver must (merely) elicit and promote it. A responsive caregiver for an adult can, in most situations, elicit a response to care and/or relate to a story already at least partly told. But this is not the case for infants and children for whom there is no life story to act upon. Maintaining a *bios* for an infant might require, as it did for the nurses Wynn (2002) studied, who held dying infants who others had abandoned,

providing testimony to the presence of a life, however brief. For those dying infants, the nurse was the only teller of the short story that she has called into existence. But for most infants, even very sick ones, their bios is longer and more complicated. They are stories that are constantly developing, though, as Wynn states, “All infants, even at the beginning, hold within themselves the possibility of bios” (Wynn, 2002, p. 124). The infant’s story is perhaps only a potential story, but it is no less important.

A careful parent will guard that story along with guarding the child’s future, so that the story eventually told is the child’s own authentic story. However, in many of the children requiring extreme caregiving, that story is delayed along with the child’s development. In some, there is never a coherent or reliable response. The parent extreme caregiver must then become responsible for both parts of the responsiveness cycle, as the parent is called upon to both interpret and meet the unresponsive (or unreliably responsive) child’s needs. In order to meet physical and medical needs, the parent must learn to read the child’s body for clues to discomfort or illness. In order to be responsive to the child’s bios, the parent might have to become the only coherent narrator of the child’s life.

Emily Rapp (2013), whose son Ronan had a fatal neurodegenerative disease called Tay Sachs, writes in her memoir that she considered finding her son’s story one of her main tasks of caregiving. The disease causes progressive neurological destruction, so Ronan barely reaches a development level of 6 months before regressing into unresponsiveness. She says, “My other task beyond physical care, I began to realize, was to find Ronan’s quiet, gap-ridden myth, his idiosyncratic narrative--to interpret it, share it, and learn from it” (Rapp, 2013, p. 48.) She spends a book in trying to make sense of his limited world, looking to poetry, myth, and philosophy, to try to discover Ronan’s place in the world and understand his experience of life. She knows that the story she tells for him will be the only one he will ever have.

The authors of three of the extreme caregiving narratives (Greenfeld, 1970; Hart, 1989; Brown, 2011) have as a goal to understand their son’s stories, understand who their sons are. They often speak directly about the lack of responsiveness from their non-communicative sons. Ted Hart and Noah Greenfeld, both with autism, were very delayed in language acquisition, and never became able to clearly express themselves verbally. Walker Brown, with the more severe CFC Syndrome never developed an ability to communicate verbally at all. All three had unusual behaviors which their fathers

assumed to have meaning, and often interpreted as a frustrated attempt to express their needs or desires. All three narratives contain a struggle to understand the meaning behind their sons' attempts at communication, and thus are stories about attempts to establish responsiveness with an unreliably responsive care receiver.

The purpose of this chapter is to examine the ways in which these three caregivers meet the challenge of responsiveness. It is clearly of paramount importance to them; as mentioned in the previous chapter, the main purpose of their narrative quests is a search for their child, seeking to know and understand who their child is. This chapter will analyze the ways in which they look for a response, the ways in which they frame the child's needs despite adequate response, and the ways in which they acknowledge the incompleteness of their understanding.

THE CHILD AS DISEASE

The first place these three parent/narrators look for understanding is in the child's body; they attempt to find the child through understanding their disease. Of course this is also an attempt to help their child, hoping that medical knowledge will provide, or at least facilitate, a treatment. This activity is not abandoned even once it becomes clear that there is no easy cure available, and continues despite the resulting disillusionment with medicine. As we have seen in Chapter Five, parents acquire a good amount of medical knowledge in this pursuit, becoming unacknowledged experts in the diagnosis and treatment of their sons' disorders.

Seeking to understand the child by learning as much as possible about the bodily consequences of their disability, is not unreasonable. For the sons of the three narrators, as with many special needs children, it is inevitable that their illness or disability becomes some part of the definition of who they are. Its presence has unavoidably rewritten the narrative of their lives. I once asked the mother of a child with a different syndrome, Cornelia DeLange Syndrome (CDLS), if she ever wished that Samuel had been born without all of the problems that disease has brought him. Samuel is developmentally delayed, still a toddler at age nine years, and has a variety of medical problems that make his long-term life expectancy uncertain. Her answer surprised me. She said that she could have no regrets, because Samuel has CDLS, and a child without CDLS would be a different child. The child that she has, and loves, is Samuel.

Samuel's story is inextricable from CDLS; to have a different body would mean being a different child.

Emily Rapp (2013), author of a memoir about the death of her son from Tay Sachs, a relentless, incurable neuro-degenerative disease, agrees with Samuel's mother somewhat. Remembering the experience of an ordinary day with Ronan, she says, "I rolled through the grocery store with my floppy, beautiful boy and some days I wouldn't have had it any other way because to wish otherwise would be to wish for another baby, which I did not" (p. 184). She is a bit more ambivalent, however, going on to state that at other times she "railed against [the] fact" (p. 184) of his illness and impending death, wishing for the ability to cure him. Yet she knows that this is impossible, both because there is no cure and because a different body would make him a different child.

Eva Kittay (2011) makes a similar point, though not quite the same, in a paper discussing the procedure that has become known as the Ashley Treatment, a surgical intervention to stop growth and sexual development in severely delayed pre-pubertal girls by removing breast buds, ovaries, and uterus. Where some see this treatment as a way to keep Ashley physically small enough to remain in a care situation where she is seemingly happy, Kittay sees this as a violation of her bodily integrity, done for the convenience of her caregivers. I can see her point, though I do not entirely agree, as I believe that it is essential to take into account the caregiver's point of view. However Kittay's reasoning supports an argument that the child's body is part of the child's bios. Ashley's story certainly has been changed by the surgical alterations of her body which will prevent her from reaching physical maturity as a woman. It was also irrevocably changed by the disability with which she was born, and which caused her intellectual delay. Like Samuel and Ronan, Ashley cannot escape the confines defined for her by her body.

However, the story witnessed in their bodies cannot be the whole story for these children. Samuel is a unique individual whose bios, like that of any toddler, is filled with wonder at the strange things that happen around him and joy in small (sometimes very small) triumphs. Ashley's story, though she may be largely unaware of it, now includes ethicists such as Kittay (2011), who are guarding and reinforcing what individuality she has. The sons of the three narrators also have stories outside that told by their bodies and, as their father search for knowledge about their bodies, they become more interested in discovering those unique stories.

For Greenfeld (1970) and Hart (1989), whose sons Noah and Ted are autistic, the quest for medical knowledge overlaps with and becomes a quest for connection with their sons. In part this is because their early search is frustrated by wrong diagnoses, leading to a continuous reassessment of their son's potential. But when they arrive at the diagnosis of autism they find a misunderstood disorder that primarily effects communication. Many of the treatments which have evolved under the science of medicine are aimed toward improvement of speech and communication. The goal of understanding who their sons are as unique individuals requires a pursuit of medical treatments that will break through the communication barrier. Understanding the disease becomes a literal attempt to understand the child, the only way to discover who their child is.

Ian Brown (2011) has a harder task, because Walker's CFC is a much more complicated syndrome, involving genetic defects, medical fragility, and multiple disability in addition to communication problems. When Brown goes on his "journey to understand his extraordinary son" (from the subtitle), he has avenues of exploration, such as genetic DNA sequencing, that are not available to (and not needed by) Greenfeld and Hart. But he also ultimately wants knowledge not just of his son's body, but of who he is.

The search for medical information undertaken by all three narrators, is not a search for medical expertise. They seek only to know their own child. And while all three eventually find a diagnosis, they do not find the child's identity there. At some point, they learn instead to fight this medical identity, to avoid seeing their child as a disease. They all develop a resentment toward the clinical aspects of medicine and those practitioners who see only the disability and not the child. I am reminded of a phrase frequently used during my pediatric training: "The child is not the disease." This is a reminder aimed at professional caregivers to pay attention to more than the child's medical chart, to see the child as a whole person beyond the illness or disability, and to consider the needs of the child situated within a family.

Though Ian Brown (2011) studies CFC in detail, he comes to resent the picture of Walker as merely a genetic defect. He realizes that Walker's body might be part of the bios, but it is not his whole story. Even describing his body, as he does near the beginning of *The Boy in the Moon*, it is evident that Brown knows this. He describes his son's body in unusual and poetic terms: "His shoulder blades and the bones of his back are oddly soft, plastic, bendable, as if covered by some miracle upholstery. The skin of

his arms and thighs feels almost manufactured too, too much matte and not enough flow, the cells rampaging, overbuilding, one of the more direct results of the genetic miscues that made him this way” (p. 12). Despite the use of mechanical and clinical words, something individual and beautiful shines through. He calls Walker “my sweet, sweet, lost and broken boy” (p. 7).

Not all parents are as accepting of the child’s disabilities as part of their true selves, however. Ian Brown’s wife Johanna does not think of Walker’s CFC as being a part of him. Brown (2011) quotes her as saying:

I hear parents of other handicapped kids saying all the time, “I wouldn’t change my child,” Johanna said one night as we were lying in bed, talking as we fell asleep. “They say, ‘I wouldn’t trade him for anything.’ But I would. I would trade Walker, if I could push a button, for the most ordinary kid who got C’s in school. I would trade him in an instant. I wouldn’t trade him for my sake, for our sake. But I would trade for his sake. I think Walker has a very, very hard life.” (Brown, 2011, p. 80)

She is also not interested in meeting other children with CFC, an experience which for her husband is part of understanding Walker. She wants to see Walker only as himself, and is afraid that the knowledge of others will make him into “a kid with a syndrome” (p. 113). But for Brown, the experience of meeting other children with CFC is monumental. He says, “Even the briefest meeting with another CFC child felt like the discovery of a new element” (p. 120).

Walker is more than his disease, more even than his genetic makeup, and those medical professionals whose job it is to elucidate Walker’s problems are often not able to hear his whole story. In this quote from *The Boy in the Moon*, Brown (2011) describes both the realization that Walker’s disease is not his whole identity, and the disconnect that often occurs between parent and professional. It also is a testimony to the sorrow that results from the “broken” body that sets Walker apart from other children. Brown says,

[T]o a laboratory geneticist who studied CFC as a genetic disorder, the syndrome was always only that: a disorder, an unfixable spelling mistake in the grammar of humanness. I understood that stance, and also hated it. Seeing Walker only as a genetic disorder was a guaranteed way for me to remember that there is such a thing as genetic order, that for each Walker, there are millions of genetically complete children. In a genetics

lab, Walker would always be a deleterious effect of nature and evolution, and little more. (Brown, 2011, p.177).

To Brown, Walker must be more than the genetic mutation that produced his syndrome. Brown must become the one who recognizes the “more” that Walker is, and the one on whom the burden of discovering what that “more” might be falls. He must find and nurture Walker’s true self, his story, his bios.

THE UNRELIABILITY OF INTERPRETING NEEDS

Even in the parenting of typical infants, as most parents could attest, the determination of physical needs is not always easy. One of the most frustrating medical problems in the neonate, for parent and pediatrician alike, is colic. This is marked by inconsolable and unexplainable crying, and occurs in infants from age two weeks to about four months. The parent of course has a mental list of things that might cause a baby to cry so much; hunger, cold, dirty diapers, pain, heat, constipation. One by one, those possibilities are checked, and remedied if possible, and the baby’s crying continues. Some babies respond to being held close, some to being left alone. Many seem to like noise, or motion. They will finally fall asleep during a long car ride, only to resume crying again as they are carefully being carried back inside. The parent cannot help but imagine some horrible pain, with terrible consequences if its source is overlooked. But the baby can’t describe what, if anything, is hurting. The pediatrician also has a long mental list of possibilities, most of which can be discarded as diagnoses because of a lack of corroborating symptoms or lab abnormalities. There are formulas to try, advice to be given. But the pediatrician knows no more than the parent. The baby can’t tell anyone what is wrong.

Infants “outgrow” this problem eventually, of course. And sooner or later, when something does hurt, children become able to at least point to the “owie.” But many special needs children are not able to reliably report on their needs until much later, if at all. This leaves the parent/caregiver in much the same situation as the parent of a colicky infant; if the child seems distressed, they often have to guess not just about what the problem might be, but whether or not there is actually a problem. Yet most pediatricians learn to pay attention to those parents’ concerns. If the mother of a multiply impaired, medically fragile child says that she thinks her child is becoming very sick and

should be in the hospital, I have found it best to hospitalize that child, because she is very likely to be right. She is not always right, of course, but often enough.

In their studies of mothers of children with severe chronic illness or disabilities, McKeever and Miller (2004) report briefly on this ability of parents to interpret needs. They do not have statistics for how often mothers are correct about their child's needs, but they do report on the bond that forms between maternal caregiver and the child cared for in the home. They provide several narratives from parents whose concerns were ignored, some resulting in inadequate care. They state that the mothers learned to "accurately determine, respond to, and compensate for children's physical needs and multiple vulnerabilities," and as a result, "their need for vigilant attention to subtle physiological, behavioural and emotional cues led to extremely close relationships. Mothers 'knew' the children in a way few others did and were uniquely attuned to them" (McKeever and Miller, 2004, p. 1182).

But the virtue of responsiveness, I have already indicated, requires more than a maintenance of physical needs, no matter how difficult they are to establish. For many of the special needs parents in McKeever and Miller's (2004) study, the task of mothering such children involved seeking social value (or "cultural capital") for their children. By this McKeever means that the mothers reported taking many actions that could be interpreted as placing their child in a position where others were able to value their children as much as the mothers themselves did. This included everything from insisting on proper medical care, to pushing for services that otherwise would have been denied, to dressing the child in fashionable clothes. McKeever did not study the ways mothers valued their children, nor the ways the relationship with the child were established. However, it would not be unreasonable to assume that the "vigilant attention" to the child's care carries with it a form of responsiveness that attempts to interpret the child as a person as well as a body with certain medical needs.

This interpretation is sometimes fairly uncomplicated. For example, autistic Ted, the subject of Charles Hart's (1989) book *Without Reason*, responds differently in different environments. In one scene in the book, Hart is told by a teacher at a day program that they are working hard to teach Ted to tie his shoes. But Ted has already learned to do this at home. His parents realize that they must intervene and become the primary interpreter of their son's limited communications. "[Ted] still needed us to interpret the rest of the world and we had to translate his behaviors to others. If we didn't

have the conferences with teachers or explain his abilities to others at the YMCA, they would expect too little and allow him to underachieve” (Hart, 1989, p. 165). His parents take on the role of interpreting and explaining Ted’s needs and abilities to outsiders.

However, the possibility of underachieving is not even on the horizon for some parents whose children cannot speak for themselves at all. Care ethicist Eva Kittay is also the mother of a severely disabled “child” (she is a dependent adult now). Kittay describes her daughter, Sesha, in an essay in *Love’s Labors*, titled “Not My Way, Sesha. Your Way. Slowly.” Sesha “has no measurable IQ” and Kittay states that “many capacities she will not develop at all” (Kittay, 1999, p. 151). Yet to Kittay, and apparently also to Peggy, her paid caregiver for over two decades (and who provided the quote which became the title of the essay), Sesha is a unique individual full of boundless joy and love and a certain amount of stubbornness. In a later paper, Kittay describes her as having “her own personality, her own mature beauty,” and as becoming “increasingly mature emotionally” (Kittay, 2011, p. 614). Yet Sesha does not talk, or walk, or even eat. Kittay admits that her understanding of her daughter is incomplete, but so is our understanding of others who can communicate fully:

I have come to grow increasingly more humble in what I think I know about my daughter . . . The quality of containment, of mystery that we each present to each other, regardless of ability, is increasingly clear to me. We always see each other through a glass darkly, but when viewing a child with cognitive disabilities, the glass is darker still (Kittay, 2011, p. 614).

Kittay and Peggy, while likely Sesha’s best and only interpreters, have very little information to work from. Their responsiveness in caregiving must include a large amount of uncertainty.

In *Loves’ Labors*, Kittay (1999) describes a happy day for Sesha, in which she gives her caregiver, Peggy, a kiss. Sesha’s kisses are “legendary” and “distinctive.” Kittay describes them, “mouth open, top teeth lightly (and sometimes not so lightly) pressing on your cheek, her breath full of excitement and happiness, her arms around your neck (if you’re lucky; if not, arms up, hands on hair, which caveman-like, she uses to pull your face to her mouth)” (Kittay, 1999, pp. 150-151). This could describe other things, as Sesha tangles her fingers in someone’s hair and pulls them into her bared

teeth, but Kittay says it is a kiss. Kittay and apparently also Peggy interpret this as an expression of Sesha's boundless love and joy. They are probably right.

Noah Greenfeld, at age three, has a perhaps similar kiss, described by Greenfeld (1970). His wife, Foumi, he says, "claims that [Noah] sometimes comes over to her and presses his lips against hers. And at times he does the same thing to me. But I'm convinced he's considering more a bite than a kiss on those occasions--and sometimes I have the tooth nibble marks to prove it" (p. 183). Noah's two primary caregivers, witnessing the same action, disagree on its meaning. There is no way to determine which of them is correct.

Another example of a potential misunderstanding comes from Charles Hart (1989), and involved his autistic brother Sumner. Unlike Sesha or Noah, Sumner can speak, but he does not always understand the meaning of his words. Their father had been absent for much of their lives, and had been abusive at times. After his death, Sumner says to his mother, "Daddy went to heaven." Their mother puts several meanings on this. The first is that Sumner understands that his father is dead. The second is that Sumner loved his father enough to assume that he would go to heaven. However later Hart overhears Sumner saying to himself, "I'm going to beat up Daddy. Daddy went to Hell" (Hart, 1989, p. 18). No one ever tells this to his mother. Neither Hart nor his mother could truly interpret the meaning of those two statements, but in their caring for him, they cannot help but try.

Looking for the true self of the non-communicative or unreliably communicative child is not easy. These parents may be searching diligently and honestly to discover who their child is, but there are very few clues to go on. This is the source of the title of Ian Brown's (2011) book, the *Boy in the Moon*. Walker is able to give Brown very few clues about himself. "Sometimes," Brown says, "watching Walker is like looking at the moon: you see the face of the man in the moon, yet you know there's actually no man there" (p. 3).

The *Boy in the Moon* (2011) is full of attempts to put meaning or understanding on Walker's unusual behaviors, and Brown is fully aware of the limitations of his interpretations. For example, Walker likes to play with plastic bags full of pop can tabs or, rather, this specific "toy" focuses Walker's attention repeatedly. Brown fills several paragraphs with musings as to what Walker might be enjoying about the sensation of kneading a bag of pop can tabs, if indeed he can enjoy anything. The section becomes a

flight of fantasy as to what this means to his son, or what anything might mean to his son. He says at the end, "Or maybe I am reaching. He gives me no choice but to reach this way. He and I invent our world together every moment I am with him" (Brown, 2011, p. 15).

At age three Walker begins hurting himself, hitting himself and banging his head hard enough to cause injury. Unsurprisingly, the source of this self-injurious behavior is a mystery that requires an urgent answer. However Brown (2011) never finds one. He says,

Sometimes Walker was in agony as he smacked himself and screamed with pain. At other times he seemed to do it more expressively, as a way to clear his head, or to let us know he would be saying something if he could talk. Sometimes--and this was unbearably sad--he laughed immediately afterwards. He couldn't tell us anything and we had to imagine everything (p. 77).

Walker sometimes laughs in response to self injury, when he must be in pain. Yet at other points in the book, Brown delights in his son's laughter, assuming that it means he is happy. He has, really, no choice but to do so. If Brown is to be a responsive caregiver, caring for his son's bios as well as his body, he must construct a story from the few facts he is given, inconsistent though they may be.

I have observed the attempts of another child with CFC, Savannah, to communicate. Savannah at age 19 has no words, but she does use some sign language. Over the years, she has had many caregivers, and each one has received their own name sign, a specific area of the body to which Savvy points. Her mother's days are filled with responding to a ceaseless, and to me seemingly random, pointing. At each gesture, her mother says the caregiver's name, and gives an often detailed report about where they might be and what they might be doing at the moment. Savannah sometimes laughs, or nods, or cries, and then immediately points somewhere else. Her mother takes this as evidence that Savvy is very loving, and cares deeply for all the people she knows. I am often convinced that the real point for Savvy is to draw her mother's attention back to herself, and away from any distractions. Both of us could be wrong.

Angie Lydicksen, mother of Luke, another child with CFC, who was interviewed by Ian Brown (2011), told him:

I think Luke, for the most part, he's happy. When he does cry, he usually cries for a reason. I think his quality of life is good, for the most part--I think he's happy in his own little world. And for the most part I'm happy that he's happy. Sometimes it breaks your heart, because he's stuck in his own little world. But sometimes I wonder if it's not better there. Sometimes--because he goes to bed with a smile and wakes up with a smile--I like to think he's happy all the time. I like to think he is (p. 155).

She thinks he is happy. But she does not know, and will never know, for sure. So she monitors his body for signs of pain or illness, and monitors his moods as best she can, and hopes that he is happy when nothing seems to be wrong.

Emily Rapp (2013), who knows that her son Ronan with Tay Sachs Disease will never advance developmentally past 6 to 8 months of age and then will regress into a vegetative state and death, also wonders about his happiness, but is less convinced.

Was Ronan unhappy? No. He had no label for that.

Are we any happier when we know (or think we know) the difference between unhappy and happy? I doubt it. Life is really lived within those parentheses, in what we don't know or expect, in what has already disappeared, in what is already gone. When Ronan's sensory faculties disappeared, did that mean that his narrative went with it, or did he simply exist in that gap, a place we could not access without relinquishing the desire to understand its parameters, to make sense of it? (Rapp, 2013, p. 46)

She finds his story by living in the brief moments of joy and connectedness she has with him, but simultaneously unable to forget the dismal future ahead. Ronan's story is in those moments, described in glorious detail. His bios, while informed by death, is not a story about dying. The inevitable death looms, but is never described in the book.

All of these parents, Emily Rapp, Ian Brown, Savannah's mother, and Angie Lydicksen are creating stories from their children's limited actions. They are at least partly aware that there is very little evidence for their interpretations. Perhaps it is unavoidable that they make stories in which they, themselves find comfort. Through their constant caregiving they become uniquely attuned, not only to their child's bodily needs, but to their child's bios. And if there is no obvious story, they must perhaps invent one.

They also realize their limitations, at least some of the time. Hart (1989) admits that sometime he could not always "trust trust our own judgment when it came to making

decisions about Ted's future. . . We had lost a sense of proportion and couldn't gauge whether our efforts were enough, too much, or too little" (p. 183). And Brown (2011) asks, "I often wondered if we were imagining Walker's progress, inventing the connections we thought he was making. . . He made people feel things. But did he feel anything?" (p. 38) This uncertainty is probably best expressed by Brown in this statement:

To hear him speak his own name? . . . To hear him say, Ma, I love you? My heart is banging at the thought. Fuck you, Dada! would be the Gettysburg Address. . . I don't need to Walker to say I love you to know he does. But if he spoke a word, it would be proof that he had something to say and that he wanted to say it, that there was a point to his saying it (Brown, 2011, pp. 124-125).

He knows Walker's limitations, that Walker cannot speak. He also acknowledges his own limitations, that any words he attributes to Walker must be created by himself. Yet says that he knows that Walker loves him, a reflection perhaps of his own love for Walker. And he knows that this is a bit of a fantasy, adding, "In my mind, we [Walker and Brown] chat nonstop. But in actual life, my son can't speak" (Brown, 2011, p. 125).

As extreme caregivers, these parents become the primary interpreters of their children to the outside world, particularly to the medical system, which expects and requires from them an accurate assessment of bodily needs.. They must translate and communicate the physical signs of possible illness, and often simultaneously promote their child as a person of value to the world. As responsive caregivers, they become the best, and often only, interpreter of the child's needs. And it seems that they either expect themselves as morally responsive caregivers to create a bios for their child, or that they become storytellers as an inevitable part of the act of caregiving.

The question raised here is, Whose story is this? Is it Walker's or his father's? Ronan's or his mother's? Since neither cannot be cheated of his own story any more thoroughly than he has already been cheated of life by his disease, perhaps it does not matter? Yet Brown and Rapp remain the uncontested storytellers, and Walker's and Ronan's inner lives remain a mystery. I think that Walker and Brown share their story, and that Ronan's story and his mother's are one and the same. Their lives, looped through the responsiveness needed for interpretation of needs, become a tangled thread, their stories inseparable.

THE CHILD AS TEACHER

There is a common narrative within the stories of severely ill or dying children, that the child has been a teacher to everyone with whom they have had close contact. It is not unusual to hear that the child has taught parents and other adults lessons, often ones requiring a mature and complex wisdom. Very young children, and even infants, have been credited with teaching such uplifting things as dealing with adversity, bearing up under pain, or even the relating the meaning of life. I understand that the parent has really learned these things by being a witness to the child's illness, but that experience is related as a lesson, with the child placed in the position of teacher. I believe this is another example of a possibly misplaced sense of responsiveness, giving to the child a story which is at least partly created by the parent.

There is some precedent for considering the person in need of care as a teacher. Arthur Frank (1995) discusses something he calls the "pedagogy of suffering," an idea that "one who suffers has something to teach" (p. 150). The caregiver, as witness to the suffering, learns important lessons from the wounded body. This can be perceived, as Frank does, as a benefit received in return for the work of caregiving, thus equalizing the dependency of the relationship. Frank sees this return in part as an assuaging of loneliness and the opportunity for communion with others provided by the caregiving relationship. I agree that this could be true in some circumstances, but it is hard for me to see the life lessons learned by the endless unpleasant chore that is much of caregiving as an opportunity for community. It is harder for me to imagine this coming from an incommunicative or unresponsive child.

However, Christine Montross (2007) reports in a book of meditations on the anatomy lab encountered in her first year of medical school, that a sort of learning relationship can be formed with even a dead body. She reports in her book *Body of Work* that, in some Thai Buddhist medical schools, the body to be dissected is given the title of "great teacher," held in high esteem, and honored in several ceremonies (pp. 78-80). This is of course not standard practice in American medical schools, where measures are taken to distance the student from the humanity of the body. Certainly, however, there is a fair amount of emotional work which must be done by the student of anatomy in order to reconcile the knowledge received from this source with previously held notions

of life and personhood. It may matter very much to the student whether the body in question is seen as a passive provider of cells and parts or an active teacher of life lessons. But the inert body obviously cannot actively participate in this.

The narrators of extreme caregiving stories are no exception to the idea that lessons learned can be taught by the most incommunicative of teachers. From Charles Hart (1989), it is reported that:

They [autistic people] have taught me to ask what it means to be human, what it means to live in this baffling world of sights and sounds and messages. Although their misunderstandings appear more obvious than my own, they have taught me never to underestimate the capacity of my fellow human beings to misunderstand or fail in communication. Most of all they have taught me that I can't assume that any two people think alike or that words will mean the same to the reader that they meant to the writer (Hart, 1989, p. 258).

He goes on to profusely thank both his autistic brother and son for this teaching. Clearly however, any learning had to have been derived from himself, and his own careful observations. Such ideas could never have been communicated by his either his brother or son. These two supposed teachers, because of their autism, are not equipped to ever reach such an understanding themselves, let alone communicate it.

Shelly Greenhaw, mother of another child with CFC, Kinley, reports in an interview with Ian Brown (2011):

Right now, I think Kinley has--oh boy--without trying, taught me how to live with joy, despite tough circumstances. And to use my time wisely. Not to worry about tomorrow too much, but to enjoy today. She's taught me to laugh at the little things. She's helped me with my vision of life. Boy, she's helped me see that each person has something to contribute, and to learn from as many people as we can. . . I think I've learned, too, that we're very interdependent (Brown, 2011, pp. 144-145).

Kinley is no more able to communicate than is Brown's son, Walker. And even Brown, the most cynical and clear-eyed of the parent narrators, frequently refers to Walker as his teacher. "Sometimes I think this is his gift to me--parceled out, to show me how rare and valuable it is. Walker, my teacher, my sweet, sweet, lost and broken boy" (Brown, 2011, p. 7).

The doctors in the genetics lab learn a somewhat different lesson from children with CFC, worth mentioning because the recipient of this sort of teaching is not a close family member who would find gratification in imagining the child as more abled. One of the geneticists studying CFC who was interviewed by Brown (2011) make the claim that, “We are going to learn so much from these kids” (p. 165). The lessons learned involve a complicated connection between certain genetic defects in CFC which overlap with genes being studied as markers for cancer. These lessons will of course be learned from observations of the child’s body; blood and bone marrow and DNA, and not from the child himself. However the child is given credit. “We are going to learn how to treat them better from knowing their genes. . . . We are going to learn so much about cancer treatment from these children . . .” (Brown, 2011, p. 165). In fact, identification of genes associated with CFC has not led to a cure for cancer. It does not even lead to a genetic test that confirms Walker’s diagnosis, since after testing it is demonstrated that Walker does not carry any of the identified genes. (This is true for many other CFC children as well.) The connection is, however, an effective way to receive funding for research in this very rare syndrome.

The lesson more often taught by these children is deeper even than a cancer cure however. It is no less that a demonstration of the meaning of life. They provide lessons in personal growth, as in this statement by Gilman (2011), whose son is mildly autistic, “But the blessings of being his mother far outweigh the worry and stress and fatigue. Truly he has made me an infinitely stronger, more patient and compassionate person” (pp. 196-197). They provide lessons in compassion and understanding of disability, as in this statement from Ian Brown (2011), “The disabled are a challenge to everyone’s established sense of order: they frighten us, if not with their faces, then with their obvious need. They call us to be more than we ever thought we would have to be. . . . We all wanted to free ourselves from having to face the darker truth that each disability is personal, unique, and possibly unsolvable” (p.150). Or they can provide a recognition that something once thought important for life is not so critical after all, such as this statement from Kittay (1999): “We didn’t yet realize how much she would teach us, but we already knew that we had learned something. That which we believed we valued, what we--I--thought was at the center of humanity, the capacity for thought, for reason, was not it, not it at all” (p. 150).

But perhaps the most important lesson taught (or demonstrated or learned) is in how, simply, to just “be,” or “to live in the moment.” Ian Brown (2011) reports that a developmental pediatrician, who had just diagnosed significant delays in his son Walker, told him this: “The Buddhists say the way to enlightenment, to pure being, is by getting your mind out of the way. I’m not trying to be trite, but Walker already knows how to do that He is pure being. He may be developmentally delayed, or moderately retarded, but in that way, he’s already miles ahead of most of us” (p. 68). Presumably this specialist had knowledge of many children with delays. Possibly he had told many parents this in the past. Brown, whose responses to trite platitudes is usually edged with cynicism, accepts this completely, saying only, “That was the first time someone suggested Walker had a gift the rest of us didn’t” (p. 68).

Brown (2011) expounds on this “gift” later in the book; “[O]n his good days, Walker is proof of what the imperfect and the fragile have to offer; a reminder that there are many ways to be human; a concentrator of joy; an insistent nudge to pay attention to every passing mote of daily life that otherwise slips by uncounted” (p. 180). But his wife disagrees with him, resenting the well-worn concept that his disability might supply others with some special understanding. She is quite bitter about it, saying, “I’m not sure that I agree that his lasting value is to have touched people. That his whole life has to be this fucking Gandhi thing, making people feel better about themselves” (p. 182).

Emily Rapp (2013) stands with Brown’s wife. She is not only the mother of a dying child, she has a congenital disability herself, and is the author of an earlier book called *Poster Child: A Memoir*. She too has heard the platitudes that the disabled have lessons to teach us all, and clearly disagrees with them.

The meaning of Ronan’s life was not to teach me; we often say this about people who defy our notions of normal and I find it pathetic, patronizing, and a way of distancing ourselves from our own fragile bodies and tenuous lives. I don’t believe that disabled people exist to teach people life stories--that is not their purpose; it isn’t anyone’s purpose. We are not “the disabled,” some shapeless, teeming mass of nonnormative bodies designed for teaching purposes, like some kind of specially designed pedagogical barbarian horde (Rapp, 2013, p. 114).

I support Emily Rapp’s and Joanna Walker’s position. If there are lessons to be learned from stories of sickness, we must learn them for ourselves, and not expect the disabled and ill to provide them. With careful observation we can bear witness and perhaps add

something to our own stories. But, though we might learn something from Walker and Ronan and Ted and Sumner, they are not, and should not be expected to be, our teachers.

IMPLICATIONS

I have maintained that moral caregiving requires responsiveness to care, provided by the care-receiver but elicited and supported by the caregiver. This responsiveness, at its best, is a form of mutual storytelling, in which feedback between caregiver and cared-for creates a relationship between them. This allows the care-receiver dignity and personhood despite dependency, and the caregiver a sense of connection and, possibly, self worth. This is not, however, without problems. The caregiving feedback loop breaks down when the care-receiver is unable to provide a reliable response. This occurs largely in multiply impaired, intellectually challenged or autistic children, where communication is limited or non-existent. This leaves the caregiver, usually the parent, in a position of uncertainty.

I have shown that extreme caregivers spend a good deal of emotional effort in attempting to read the child's limited response. They become finely tuned to the messages of discomfort or wellness read sometimes only from their children's bodies. Indeed, they are expected by the medical system to do this as an adjunct to providing competent home care. But they also interpret their children's moods as well as their physical bodily needs. They attempt to create larger meaning from their child's responses. And they transfer some of their own longing for a response to the child, by envisioning him as the active teacher of the life lessons they have learned from the experience of caregiving. The result is the creation of a story of a life that might be at least partly imaginary.

I do not know if this is a reaction to the tragedy of illness or disability, an attempt to create hope from meaninglessness, or a necessary buffer against the endless tedium of providing bodily care. It does seem to arise, however, from the responsiveness that I believe is required for moral caregiving. I believe that it is an unavoidable element of good caregiving, and is therefore commendable and desirable. It should be encouraged and nurtured. However, someone must remain aware that the narrative created is not entirely based on reality. The caregiver, who is the creator of the story, likely cannot be expected to maintain objectivity.

For the most part, however, I think the story created is mutually beneficial, creating a bond between caregiver and cared-for that acknowledges both of them as persons of importance in the world, despite inadequate levels of responsiveness. Ian Brown (2011), for example, speaks to his son by clicking his tongue. Or, rather, when Brown clicks at Walker, sometimes Walker clicks back. It is their only verbal communication;

My relationship with Walker, after all, had been personal, and private; we operated by our own standards, by what worked between us. I 'spoke' to him and he 'spoke' to me, clicking our tongues back and forth to one another to let each other know that we were paying attention, that we knew the other was there, and listening (Brown, 2011, p. 159).

It seems a good standard to set for responsiveness; to know that someone is paying attention; that someone else is there, and listening.

In most situations, the creation of a bios by the caregiver fills this function. It is a form of being there and paying attention, even if the story told cannot be proven to be true. The minimally responsive child will likely not be harmed by it, or even aware of it, and the resulting caregiving is excellent. But there might be circumstances where the caregiver's insistence on a fulfilling or uplifting story can be detrimental or at least problematic. The possibility exists that the story can become a somewhat selfish form of disillusionment, provided only for the benefit of the parent. And the inseparability of their stories may result in lack of objectivity that could interfere with the parent's ability to determine the best interests of the child.

CHAPTER EIGHT CONCLUSIONS

I have estimated that there are at least a half a million children with long-term, complex medical problems or moderate to severe intellectual delays, who are being cared for by their parents at home. Some of them require medical technology; others will remain stuck in difficult developmental stages requiring round the clock attention for years. All of them require a variety of medical interventions, therapies, and monitoring. Many of those children, particularly those with severe developmental delay or autism, will require this care for their entire lives.

In a 2001 book exploring new topics in bioethics and public policy, Carol Levine reports that family caregiving is an emerging problem with numerous unexplored ethical aspects. She estimates that as many as 27 million caregivers are providing long term home health care. Much of the burden of caregiving falls to family members, who traditionally are called upon to take responsibility for the care of their loved ones when they are in need. Medicine, by its success in staving off death, has extended the time period over which care must be provided, and thus has increased the burden of care, sometimes placing it on families for whom there is very little support. Levine speaks of an enormous burden of care placed on “wives or husbands, sisters or brothers, daughters or sons, lovers or companions” (Levine, 2011, p. 175). Parents, and the existence of medically complex children requiring long term care, are not considered. Yet the existence of these children is undeniable.

On a spectrum of caregiving difficulty, caring for these children seems to me to be one of the most burdensome and emotionally charged of caregiving tasks. I have therefor called the care these parents are providing “extreme caregiving.” Extreme caregiving involves fulfilling complex medical needs, often in the absence of expected cure or even significant long-term improvement. It involves “parenting plus,” the long-term necessity to meet needs that are usually confined to the first few months or years of life (Ray, 2002). It is a round the clock duty, usually with no relief in sight, as it cannot be easily passed to someone else. And it is complicated by the intimate relationship between the child and the parents who are also medical caregivers.

This group has not been recognized in part because the survival of such complex children is a recent phenomenon. These children also cross borders of diagnostic

categories and pediatric sub-specialties. Children requiring extreme care are found at the most severe end of multiple pediatric diagnoses and syndromes. Their medical care is usually provided by several specialists, each of whom is dealing with only a small part of the child's problems. It is only when they are hospitalized, an event everyone wishes to avoid, that the full extent of their needs might become apparent. Like other types of home caregiving, extreme caregiving is largely invisible, even to those who prescribe and monitor it. Just as with home care for adults, the number of people requiring care and providing that care can be expected to increase as advances in medicine make more home care possible and necessary.

It is critical, therefore, to understand how these children are being cared for; why parents take on complex caregiving, how they become competent at it, and what they must do emotionally to endure the task. We need to know more than occasional statistics about, for example, the percentage increase in maternal depression or sibling behavior problems. We need instead to fully evaluate the burden, both physical and emotional, that such care imposes on parents and families. In our evaluations of the cost of home health care, we must include more than the savings from keeping a child out of the hospital. We need to understand the full cost to the family of becoming competent caregivers for a medically complex child. Asking families to take this on without true understanding of the consequences is, I believe, ethically unsupportable.

Yet our understanding of care itself is rudimentary. Proponents of an ethic of care have pointed repeatedly to the invisibility of the work being done, and the lack of respect shown to those who do it. To further complicate analysis, the lines between the emotion of caring and the work of caregiving are not often made clear. Part of our understanding must include an analysis of the sort of work that is being done.

I have therefore chosen to use the phases of care proposed by Joan Tronto (1993), which break "caring" down into actionable concepts, which can be ethically evaluated by the virtues she has assigned to them. These phases are, again: 1) caring about, with its virtue of attentiveness, 2) caring for, with its virtue of (taking) responsibility, 3) the hands on work of caregiving, which must be done competently, and 4) care-receiving, whose virtue of responsiveness forms a bond between caregiver and cared-for which strengthens the necessity and appropriateness of the care that is given.

Because there are so few studies which look deeply into the lives of these families, I believe the only way to evaluate them is by hearing their stories. Those stories

are not often told, however. The people who most need to be heard are spending their days and nights doing the care they have been assigned. Often, the only stories that are told are the ones we want to hear, the ones about miracle babies and blessings. We need to hear also the uncomfortable stories. We need to understand that at least some of the parents who take on this care feel that they were given no choice, doubt their capability to perform their tasks, and can recognize the endlessness of their burden.

For this reason I chose narratives that do not always accentuate the positive. These parent/narrators are honest, occasionally brutally so, about the ambivalence they feel toward their children, the uncertainty they feel about their own abilities, and the complex relationship formed when a parent is also a medical caregiver. The three main narratives span several decades, but have much in common. All of the children are intellectually disabled; one with severe autism (Greenfeld, 1970), one with moderate autism (Hart, 1989), and one with a syndrome called CFC which has components of medical fragility, severe intellectual disability, and autism (Brown 2011). Though these children are not, for the most part, dependent on medical technology, the issues the parent/narrators raise are similar to those reported by ethicists studying the families of technology dependent children. They also share concerns that I have witnessed both in pediatric practice and in my own personal life, growing up with an intellectually disabled brother.

I evaluated these, and several other, narratives within the framework suggested by Tronto's (1993) phases of care. I looked for the ways in which extreme caregiving differs from typical parenting in levels of attentiveness and responsibility. I looked for clues about parental formation of competence in the physical tasks involved with caregiving, including the level of medical knowledge acquired and the parent's conceptualization of that knowledge. And I paid particular attention to descriptions of the ways in which parents who must also become medical caregivers construct their understanding of their children's needs, since none of these children were ever able to be more than minimally responsive. By evaluating this particularly difficult form of caregiving using Tronto's phases of care, I hope also to expand on current theories of care, particularly in my analysis of the relationship that forms between a caregiver and a minimally responsive or unresponsive care-receiver.

ATTENTIVENESS AND RESPONSIBILITY

Attentiveness and responsibility of course are the virtues associated with Tronto's first two phases of care; caring about and caring for. In these two phases, it seems likely that typical parents and parents who are doing extreme caregiving have a similar sort of caring activity. Both types of parents are to the same degree caring about their children by being attentive to their needs, and caring for their children by taking on the responsibilities that come with having a child. What differs is the amount of needs that must be met for medically complex and intellectually disabled children.

A parent with a special needs child must be attentive to and take responsibility for more things than the parents of a typical child. The often overwhelming burden of care associated with infancy, such as feeding, diapering, attending round the clock to crying, can be extended over decades. Several academic studies of parents of technology dependent children confirm the sheer physical burden of work that special needs parenting requires. The narratives I have found support this also.

The number of new responsibilities that parents doing extreme caregiving must take on, is also clear. Parents all report numerous and varied unexpected duties such as learning to maintain home medical equipment, responding to alarms, and dealing with frequent illnesses. They must become advocates for their child's care, coordinate visits to multiple specialists, administer medications and therapies, and keep track of enormous amounts of information for insurance purposes. In addition, when their child reaches school age, they must become adept at seeking out and often coordinating an appropriate education.

The financial burden is also clear. Insurance and insurance supplements cover much of the hospital care, but many of the simple things required for home health care are not covered by insurance. In addition, the time required for caregiving usually prevents at least one parent from working outside the home. Families find that things like the cost of diapers, the cost of special formulas or food, and the cost of travel add up to large numbers over time. Even the narrators, all of whom seemed to be highly successful journalists, mentioned the financial burdens at times. My experience from my pediatric practice is more telling; with several families needing to declare bankruptcy to deal with the increased costs and decreased income.

The emotional burden is also recognized in numerous studies documenting parental, particularly maternal, psychological problems such as depression and stress

levels. Often referral for therapy is recommended, though the reasons for these difficulties are rarely explored. Studying the families of technology dependent children, as well as the narratives by extreme caregivers, the source of these problems becomes clear. Constant work and sleeplessness, together with the fear and anxiety of dealing with a sick child, will understandably cause the most stable of parents to feel stress. The many varieties of guilt available--for bringing the child into the world, causing or being unable to heal the child's problems, for doing too much, or too little, for providing the genes that created a child with so many problems--only add to the problem. It should be no surprise that marriages falter and mental health deteriorates under such circumstances. These parents need help, physical assistance, not another appointment for therapy.

Carnevale et al. (2006) have interestingly described the lives of the parents of technology dependent children as "daily living with distress and enrichment." Interviewing the parents of ventilator dependent children, they did indeed uncover a good deal of ambivalence. However it is in the parents' narratives where the level of ambivalence becomes clear. These parents obviously love their children, and state often that their child's death would be unthinkable. At the same time, several narrators confess to sometimes elaborate murder or murder/suicide fantasies as a way of dealing with the awful present and uncertain future. It is true that all of the confessors of such feelings are men; I found no circumstances where mothers expressed such feelings.

Ethically problematic also is the lack of choice these parents feel in taking on the burden of care. They have chosen to be parents, of course, but the level of involvement required for extreme caregiving multiplies the expected burden. They are attentive and responsible people who find themselves swamped by their unexpected duties. They give up sleep, promising careers, and financial security, one small step at a time, and by the time they realize the enormity of the task it is too late to give it up. Friends and relatives disappear. Respite care is hard to find, and the presence of a home health care nurse or aid carries its own difficulties in lack of privacy, scheduling problems, and financial outlay. They end up at home and isolated, with the growing certainty that their child's needs will outlive their energy, if not themselves. Death is both the worst thing that could happen, and the only way out.

If attentiveness and responsibility are considered as moral virtues, where the proper level of each is balanced between too little and too much, it becomes apparent

that these parents are providing an amount of both virtues that exceeds the usual expectations. They are investing so much in their caregiving that they have put their own desires and selves aside. However, they have few other options. Someone must care for the child, and the child happens to, as Ian Brown (2011) puts it, “require superhuman care” (p. 96). The providers of the medical technology that creates these children are, I believe, largely unaware of this hidden cost of home care. By failing to recognize the existence of such difficult care, they are essentially abandoning both the parents who are carrying out their directions, and the children who are their patients.

COMPETENCE

It is in the third phase of caring, caregiving, where the differences between extreme caregiving and typical parenting become wide. While typical parents do need to acquire some forms of competence in order to do a good job of raising their children, extreme caregivers must learn a whole new type of competencies. With very little training or guidance, they must become medical caregivers. Their goal of becoming good parents suddenly and unexpectedly requires the taking on of, essentially, a new career, one that was neither desired nor anticipated, and that does not have any possibility of financial benefit. While many parents rise to the task admirably, they do so at a high cost. Very little consideration is given to their ability to provide such care; it is just assumed that they will do it.

I believe that this expectation that anyone--parent or spouse or sibling--can and should take on the duties of caregiver for an ailing family member, is common to many home caregiving situations. The idea that everyone is able, and should be willing, to provide home health care, has become a driving force behind the movement of ever more complex health care into the home. Our insistence that the patient's desire to stay at home takes precedence over any other concern, also contributes to a growing number of overworked and unprepared caregivers. In the case of extreme caregiving, it is evident that parents never truly become comfortable with their caregiving abilities. And while they are willing to do anything for their child, and want their child to live at home, they find themselves terribly unprepared for the reality.

In the caregiving narratives and in my pediatric experience, many parents become exceedingly knowledgeable about their child's disease. It is not unusual for a parent to be more up to date on the current research than their pediatrician. This was

demonstrated by detailed descriptions of medical advances cited by all of the narrators. These parents took on a personal search for any information they could find that might lead to a treatment or cure. Yet they are never acknowledged as experts, even by themselves. Lack of professional support and the distance created by the language of medicine both lead them to doubt their competence.

In addition, all their knowledge seems to lead to a sense of disappointment and failure. Parents come to blame themselves and their inabilities for their child's ongoing problems. There is a certain amount of resentment toward and disappointment in the medical system as well. But, in narratives about extreme caregiving, the sense of failure is evident.

I have speculated that the reason for this feeling of failure is that the goals of care as currently expressed do not account for long-term disability. The usual goals of medical care (Fins, 2006), curing illness or restoring function, do not really apply to a child who will spend years in a state of infantile dependence, or whose developmental progress is measured in tiny steps that each require months or years of intensive therapy to accomplish. No more relevant are Fins' (2006) recently added goals of medical care; prolonging life or palliation to ease death. The majority of these children do not have a life limiting problem. While some of the most effected children do have illnesses that in the past were expected to be fatal, that is not likely to be acknowledged. The child's survival is framed as a miracle that can be extended indefinitely. There is an expectation that the child will always improve and grow, and that death is unexpected and possibly another sign of failure. And so, extreme parenting requires far more than prolonging life.

Nor are the goals of pediatric home health care, established recently by the AAP (Elias & Murphy [AAP], 2012), particularly helpful. The intent to ensure that a child remains healthy and thrives, is difficult to carry out when, in fact, the child will never reach a "normal" state of health. And the hope that the child will remain at home and out of the hospital merely insures that the extent of need for medical and developmental home support remains invisible. The expectation of progress to normalcy, I believe, leads parents to feel that their caregiving is lacking. They take on themselves the fault for our inability to cure or find effective treatment for their children.

The expectation that the child will remain in the home indefinitely also contributes to the sense of failure. Children are expected to grow up and have their own lives, not

forever remain dependent. All of the parents realize, with growing despair, that they will not be able to meet their child's needs forever. Since they know that their home is the best, if not the only, place where there is adequate caregiving, they feel acutely their failure at being unable to provide it forever.

RESPONSIVENESS

It is in the fourth phase of caring, care-receiving, with its associated virtue of responsiveness, that extreme caregiving begins to raise ethical issues that center around the care-receiver rather than the caregiver. The earlier phases are all to be carried out by the caregiver, and any ethical issues raised by the virtues of attentiveness, responsibility, and competence can be analyzed by considering the actions of the caregiver. Responsiveness, however, requires cooperation. The caregiver is charged to elicit a response, spending whatever time and effort is needed to insure that it is genuine. Ethical problems arise when the care receiver is unresponsive or unable to provide a consistent response. This is not an unusual circumstance in extreme caregiving.

I have theorized responsiveness as a narrative process that occurs between caregiver and care-receiver, an active process of refining care to match the needs present. In order for this to work effectively, it must become a sort of feedback loop, as care is given by the caregiver, responded to by the cared-for, and then altered in response. In an ideal situation, both participants must be able to connect on an intimate level, changing the narrative of their lives to accept and meet the needs of the cared-for. In reality, I believe it often falls to the caregiver to both elicit and interpret the response from the care-receiver. A virtuously responsive caregiver, therefore, will become an interpreter and promoter of her charge's life story.

For parents doing extreme caregiving, this often means becoming a sometimes lifelong interpreter, not only of the child's physical needs, but of who the child is. They find themselves attempting to imbue meaning to their children's lives, with very little to go on. Typical parents do this work as well, forming an idea of who their child is from their expectations, and attempting to mold the child productively. As a child gets older, he will inevitably inform the parents of all the ways in which they have erred in their impressions. The unreliably communicative child does not have an opportunity to do this, and remains forever the product of his parent's interpretations.

I have demonstrated that several narrators of extreme caregiving are desperately trying to be responsive to their children. Greenfeld (1970) and Hart (1989) journey to find out everything they can about autism in hopes of discovering who their sons are. Brown (2011) tries to connect with his son by learning everything he can about his syndrome, and even traveling to meet other children similarly affected. Rapp (2013) feels the need to provide a life narrative for a son who will never develop beyond age six months, and will gradually lose all awareness of his own existence. All four are clearly aware that their attempts are inadequate; that they will never be able to truly hear their son's voices. Brown and Rapp are additionally aware that the only voice that their child has, is the story that they have constructed for him, and may not in fact be authentic.

Yet I believe that constructing and maintaining a life story is a part of moral caregiving. Responsiveness as a virtue is an act of mutual creation of narrative. For the elderly demented patient, this can mean maintaining as much as possible the memory of a life lived, as recommended by Hilde Lindemann (2009). For a sick patient, this can mean working together on piecing together a new meaning for a life disrupted by illness, as suggested by Frank Brody (2003). For the parents of chronically disabled children, as reported by Park McArthur (2012), who depends on her parent's care for advancing muscular dystrophy, responsiveness means participating in the caregiving process in such a way as to engender trust, acknowledge independence, and maintain dignity. But for children with intellectual disability, the narrative remains the creation of the parent. The child's life story is unverifiable, and may exist only in the mind of the caregiver.

This could have several unrecognized consequences, apart from the obvious possibility of infringement on the child's autonomy and authenticity. For example, most children have more than one caregiver; there are two parents, and often an array of home health care workers, teachers, and therapists. Problems can arise when caregivers disagree on how much care the child needs, how to handle behavior problems, or how aggressively to pursue medical treatment. Perhaps the source of these disagreements is rooted in each caregiver telling themselves a different story for the child. Perhaps divorce, family stress, and other problems are partly caused by dissonance in their narratives. This is unknown territory.

Another example is in end of life discussions, when the miracle cures for a no-longer-fatal syndrome are no longer effective. Medical providers and parents are almost certainly telling themselves different stories about who these gravely ill children are.

Where a nurse or physician may see a nearly completely unresponsive child body suffering at every new procedure, the parents may have imbued that child with an inner life that is not visible to an outsider. A parent's insistence that "everything" must be done for their child might be driven by guilt. Or it might be that the parent is fighting to maintain a life whose inner richness only they can see. Or it might be that the parent has become so involved in caregiving and the construction of the child's life that they see the child's death as a loss of part of themselves. Again, this is unknown.

Arthur Frank (2002) has stated that patients and doctors must understand each others' stories in order to truly communicate. Each patient, and each doctor, arrives at an encounter with preconceived ideas about themselves, and the place that an illness might have in their lives. Certainly, there is almost no way to conduct a dialog about withdrawal of care as long as each side is unaware of the other's stories. Yet we have very little understanding still of the stories of parents who are extreme caregivers.

FUTURE WORK

Perhaps the most difficult part of extreme parenting is its seeming endlessness. The parents are trapped in a responsibility that far exceeds what is expected of parents. The need for respite care comes up reasonably often in discussions of home caregiving, but there is almost no recognition of the fact that, for children, this sort of care can extend for decades. It has been suggested recently that there are limits to family responsibility for caregiving (Levine, 2001). However, none of the studies on home health care and family caregiving that I am aware of, mention the existence of the prolonged child caregiving that these parents perform.

Judging from the frequent comments in these narratives, and from personal experiences and communications, the realization that there will never be relief from caregiving is one of the hardest things to deal with in extreme caregiving. In part this is because it requires an acknowledgement of failure; the child will never be cured, or grow into full independence. But it is mostly a practical realization, that, no matter how hard the parent might work, the work will never be done.

The final stage in typical parenting is the launching of the grown child into an independent life. For many of these children, this expectation is impossible to fulfill; the child's ongoing level of dependence will never allow it. Adolescence for these children involves a growing realization that the need for caregiving might continue past the point

where the parent is physically able to do it. This leads to ambiguous feelings as the parents come to simultaneously hope and fear, that the child will outlive the parent. It is likely that the caregiving task might be less of a burden if there were some endpoint other than death.

It is less clear, but possible, that the child might also benefit from a different care situation. Even an intellectually impaired child might benefit from a new environment, possibly growing up in new ways by moving away from home. If the parents are constructing a life story for the child, as I believe they are, that story might become fuller or more authentic if other caregivers are able to contribute to it in potentially new ways. This is suggested in the final chapters of both Ian Brown's (2011) *The Boy in the Moon* and by Charles Hart's (1989) *Without Reason*. I have also observed this benefit in my brother after placement at age 47 in an excellent group home. The possibility that increased authenticity and fuller personhood can be attained in a new care situation should be more fully explored.

If this is so; if even intellectually impaired people can benefit from moving out of parental home care, this might add to a mandate for increasing long-term care opportunities outside the home. The injustice of the long-term burden of work placed on these parents also provides an ethical mandate. At this point, parents continue extreme caregiving well past what should be asked of them, simply because there is no one else who will do it, or perhaps no one else who will do it as well as they can. It seems that alternate care situations outside the home are needed to benefit both parent/caregiver and grown child.

I have estimated that there are at least five hundred thousand children living at home with long-term complex needs, which means that 500,000 new places for grown-ups who cannot live independently need to be made for them. Yet our current system has barely begun to offer adequate places for those dependent adults who already exist. We need to expand the number of group homes and other care facilities enormously. We also must develop innovative ways to care for people; ways that provide attentive, responsible, competent and responsive care. This too is a relatively unexplored area. While it is possible to find competent care outside the home, very few of the existing models of care are actually capable of taking the place of family or expanding their clients' worlds. I suspect that the most important aspect of any form of alternative care will be the responsiveness of the new caregivers.

Extreme caregiving is, I believe, a new form of caregiving, characterized by its difficult, prolonged, and intimate nature. While theories of home care are emerging, there is little understanding of this combination of medical caregiving and parenting. The goals of both are confused and rendered inadequate. Conceptualizing extreme caregiving by analyzing it via Tronto's (1993) phases of care has, I hope, provided a start in evaluating the ethical consequences of this form of caregiving, as well as broadened our understanding of what care is.

REFERENCES:

American Academy of Pediatrics (AAP) Committee on Fetus and Newborn and American College of Obstetrics and Gynecology (ACOG) Committee on Obstetric Practice. (1995). Perinatal care at the threshold of viability. *Pediatrics*, 96(5), 974-976.

Arras, John. (1997). Nice story but so what? Narrative and justification in ethics. In H. Lindemann-Nelson (Ed.), *Stories and Their Limits: Narrative approaches to bioethics* (pp. 65-88). New York, NY: Routledge.

Aristotle. *The Ethics of Aristotle: The Nicomachean ethics*. (J.A.K. Thomson, Trans. 1956, H. Tredennick, Rev. 1976). New York, NY: Penguin Books, Penguin Classic paperback edition.

Baier, S. & Schomaker, M.Z. (1995). *Bed number ten*. Boca Raton, FL: CRC Press.

Bowden, P. (1998). Ethical attention: Accumulating understandings. *European Journal of Philosophy*, 6(1), 59-77.

Boyd, R. (2004). Pity's pathologies portrayed: Rousseau and the limits of democratic compassion. *Political Theory*, 32, 519-546.

Brinchmann, B.S. (1999). When the home becomes a prison: Living with a severely disabled child. *Nursing Ethics*, 6(2): 137-143.

Brody, H. (1997). Who gets to tell the story: Narrative in postmodern bioethics. In H. Lindemann Nelson (Ed.), *Stories and Their Limits: Narrative approaches to bioethics* (pp. 18-30). New York, NY: Routledge.

Brody, Howard. (2003). *Stories of sickness* (2nd ed.). New York, NY: Oxford University Press.

Brown, Ian. (2011). *The boy in the moon: A father's journey to understand his extraordinary son*. New York, NY: St Martin's Press.

Caputo, John D. (1993). *Against ethics: Contributions to a poetics of obligation with constant reference to deconstruction*. Bloomington, IN: Indiana University Press.

Carnevale, F.A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, 117(1), e48-e60.

Centers for Disease Control and Prevention (CDC). (2008). *Prevalence of autism spectrum disorders (ASD's): Autism and developmental disabilities monitoring network, 14 Sites, United States, 2008*. Retrieved September 10, 2013, from <http://www.cdc.gov/ncbddd/autism/data.html>.

Chan, B., Jahnke, L., Thorson, S., & Vanderburg, N. Minnesota Department of Health Division of Family Health (MDHDFH). (1998, August). *Caring for our children: A study of*

TEFRA in Minnesota, Research by Minnesota Children with Special Health Needs.
Retrieved July 18, 2013, from
<http://www.mnddc.org/past/pdf/90s/98/98-DOH-TEFRA.pdf>.

Cockett, A. (2012). Technology dependence and children: A review of the evidence. *Nursing Children and Young People*, 24(1), 32-35.

Decker, Jeni. (2011). *I wish I were engulfed in flames: my insane life raising two boys with autism.* (Advance Reading Copy.) New York, NY: Skyhorse Publishing.

Dybwik, K., Nielsen, E.W., & Brinchmann, B.S. (2011). Ethical challenges in home mechanical ventilation: A secondary analysis. *Nursing Ethics*, 19(2), 233-244.

Dyck, I., Konton, P., Angus, J., & McKeever, P. (2005). The home as a site for long-term care: Meanings and management of bodies and spaces. *Health and Place*, 11, 173-185.

Edwards, S.D. (2009). Three versions of an ethics of care. *Nursing Philosophy*, 10, 231-240.

Elias, E.R., & Murphy, N.A. (2012). Home care of children and youth with complex health care needs and technology dependencies, A clinical report from the American Academy of Pediatrics (AAP). *Pediatrics*, 129(5), 996-1005.

Fadiman, Anne, (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures.* New York, NY: Farrar, Straus and Giroux.

Feinberg, J. (1980) The child's right to an open future. In W. Aiken, W. & H. LaFollette, (Eds.) *Whose child? Children's rights, parental authority, and state power*, Totowa, NJ: Rowman and Littlefield.

Fins, J. J. (2006). *A palliative ethic of care: Clinical wisdom at life's end.* Boston, MA: Jones and Bartlett Publishers

Fournier, C.J., Davis, M.S., Patnaik, A., Elliott, T.R., Dyer, J.A., Jasek, E.E., & Phillips, C.D., (2010). Modeling caregivers' perceptions of children's need for formal care: Physical function, intellectual disability, and behavior. *Disability and Health Journal*, 3, 213-221.

Fox, M. (2012, September 14). Lia Lee dies: Life went on around her, redefining care. *The New York Times*. Retrieved from www.nytimes.com/2012/09/15/us/life-went-on-around-her-redefining-care.

Frank, Arthur. (1995). *The Wounded Storyteller: Body, Illness, and Ethics.* Chicago, IL: University of Chicago Press.

Frank, Arthur. (1997). Enacting illness stories: When, what, and why. In H. Lindemann Nelson (Ed.), *Stories and Their Limits: Narrative approaches to bioethics* (pp. 31-49). New York, NY: Routledge.

Frank, A.W. (2002). "How can they act like that?" Clinicians and patients as characters in each other's stories. *Hastings Center Report*, 32(6), 14-22.

Garden, Rebecca. (2010). Telling stories about illness and disability. *Perspectives in Biology and Medicine*, 52(1), 121-135.

Gill, Barbara. (1997). *Changed by a child*. New York, NY: Doubleday.

Gilman, Priscilla. (2011). *The anti-romantic child: A story of unexpected joy*. New York, NY: Harper Collins.

Gray, R., Petrou, S., Hockley, C., & Gardner, F. (2007). Self-reported health status and health-related quality of life of teenagers who were born before 29 weeks' gestational age. *Pediatrics*, 120(1), e86-e93.

Greenfeld, Josh. (1970). *A child called Noah: A family journey*. New York, NY: Harcourt Brace Jovanivich Publishers.

Greenfeld, Karl Taro. (2009). *Boy alone: A brother's memoir*. New York, NY: Harper Collins Publishers, 2009.

Ha, J.H., Hong, J., Seltzer, M.M., & Greenberg, J.S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a national study. *Journal of Health and Social Behavior*, 49(3), 301-16.

Hardwig, J. (1997). Autobiography, biography, and narrative ethics. In H. Lindemann Nelson (Ed.), *Stories and Their Limits: Narrative approaches to bioethics* (pp. 50-64). New York, NY: Routledge.

Harrison, H. (2001). Making lemonade: A parent's view of "Quality of Life" studies. *The Journal of Clinical Ethics*, 12(3), 239-250.

Hart, Charles. (1989). *Without reason: A family copes with two generations of autism*. New York, NY: Harper and Rowe.

Hatzmann, J., Mauriec-Stam, H., Heymans, H., & Grootenhuis, M. (2009). A predictive model of health related quality of life of parents of chronically ill children: The importance of care-dependency of their child and their support system. *Health and Quality of Life Outcomes*, 7(72), 1-9.

Jennings, Annette. (1995). *My heart child: A portrait of Savannah: Life lessons learned from an infant with chronic illness*. Unpublished.

Kirk, S. (1998). Families' experiences of caring at home for a technology-dependent child: a review of the literature. *Child: Care, Health and Development*, 24(2), 101-114.

Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing*, 51(5), 456-464.

Kittay, Eva Feder. (1999). *Love's labor: Essays on women, equality, and dependency*. New York, NY: Routledge.

Kittay, Eva. (2011). Forever small: The strange case of Ashley X. *Hypatia*, 26(3), 610-631.

Kleinman, A., & Benson, P. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it. *PLoS Medicine*, 3(10), 1673-1677.

Lantos, J.D., & Kohrman, A.F. (1992), Ethical aspects of pediatric home care. *Pediatrics*, 80(5), 920-924.

Lantos, John D. (2001) *The Lazarus case: Life and death issues in neonatal intensive care*. Baltimore, MD: The Johns Hopkins University Press.

Leone, Marianne. (2010). *Knowing Jesse: A mother's story of grief, grace, and everyday bliss*. New York, NY: Simon and Schuster.

Levine, C. (2001). Home Sweet Hospital: The Nature and Limits of Family Responsibilities for Home Health Care. In A.W. Galston & E.G. Shurr (Eds.) *New Dimensions in Bioethics: Science, Ethics and the Formulation of Public Policy*. Norwell, MA: Kluwer Academic Publishers.

Lindahl, B., Sandman, P., & Rasmussen, B.H. (2006). On being dependent on home mechanical ventilation: Depictions of patients' experiences over time. *Qualitative Health Research*, 17(7), 881-901.

Lindemann Nelson, H. (1997). Introduction. In H. Lindemann Nelson (Ed.), *Stories and Their Limits: Narrative approaches to bioethics* (pp. vii-xx). New York, NY: Routledge.

Lindemann Nelson, H. (2004) Four Narrative Approaches to Bioethics. In G. Khushf (Ed.), *Handbook of Bioethics: Taking stock of the field from a philosophical perspective*. Springer Science and Business Media, EBSCO Publishing.

Lindemann, H. (2009). Holding one another (well, wrongly, clumsily) in a time of dementia. *Metaphilosophy*, 40(3-4), 416-424.

Macnaughton, J. (2009). The dangerous practice of empathy. *The Lancet*, 373(June 6), 1940-41.

Magagnini, S. (2012, September 16). Lia Lee dies; daughter of Hmong refugees changed American views of medicine. *The Washington Post*. Retrieved from www.washingtonpost.com/national/health-science/lia-lee-dies-daughter-of-hmong-refugees.

Malek, J. (2009). What really is in a child's best interest? Toward a more precise picture of the interests of children. *The Journal of Clinical Ethics*, 20(2), 175-182.

Marlow, N., Wolke, D., Bracewell, M.A., & Samara, M., (2005). Neurologic and developmental disability at six years of age after extremely preterm birth. *New England Journal of Medicine*, 352(1), 9-19.

McArthur, Park. (2012). Carried and held: Getting good at being helped. *The International Journal of Feminist Approaches to Bioethics*, 5(2), 162- 169.

McKeever, P. and Miller, K-L. (2004). Mothering children who have disabilities: a Bourdieusian interpretation of maternal practices. *Social Science and Medicine*, 59, 1177-1191.

Montross, C. (2007). *Body of work: Meditations on mortality from the human anatomy lab*. New York, NY: The Penguin Press.

Neuwirth, Z.E. (1997). Physician empathy--should we care? *The Lancet*, 350 (Aug 30), 606.

Noddings, N. (1984) *Caring: A feminine approach to ethics and moral education*. Berkeley, CA: University of California Press.

Noddings, N. (1994) Moral obligation or moral support for high-tech home care? *Hastings Center Report*, 24(5, special supplement), S6-S10.

Plant, K.M., & Sanders, M.R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disabilities Resources*, 51(pt 2), 109-124.

Postsecret, retrieved on September 10, 2013 from www.postsecret.com.

Postsecretcollection archived card, retrieved on September 10, 2013 from <http://postsecretcollection.com/PostCards/8dab0aa0e43245ccb426ab7b0f1d36d6/>.

Povee, K., Roberts, L., Bourke, J., & Leonard, H. (2012). Family functioning in families with a child with Down Syndrome: A mixed methods approach. *Journal of Intellectual Disabilities Resources*, 56(10), 961-73.

Rapp, Emily. (2013). *The still point of the turning world*. New York, NY: The Penguin Press.

Ray, L.D. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing*, 17(6), 424-438.

Saigal, S., Szatman, P., Rosenbaum, P., Campbell, D., & King, S. (1991). Cognitive abilities and school performance of extremely low birth weight children and matched term control children at age 8 years: a regional study. *The Journal of Pediatrics*, 118(5), 751-60.

Saigal, S., Rosenbaum, P., Stoskopf, B., Hoult, L., Furlong, W., Feeny, D., Burrows, E., & Torrance, G. (1994). Comprehensive assessment of the health status of extremely low birth weight children at eight years of age: Comparison with a reference group. *The Journal of Pediatrics*, 125(3), 411-417.

Saigal, S., Feeny, D., Rosenbaum, P., Furlong, W., Burrows, E., & Stoskopf, B. (1996). Self-perceived health status and health-related quality of life of extremely low-birth-weight infants at adolescence. *Journal of the American Medical Association*, 276(6), 453-459.

Saigal, S., Stoskopf, B.I., Feeny, D., Furlong, W., Burrows, E., Rosenbaum, P.I., & Hoult, L. (1999). Differences in preferences for neonatal outcomes among health professionals, parents, and adolescents. *Journal of the American Medical Association*, 281(21), 1991-1997.

Saigal, S., Stoskopf, B.I., Streiner, D.I., & Burrows, E. (2001). Physical growth and current health status of infants who were of extremely low birth weight and controls at adolescence. *Pediatrics*, 108(2), 407-415.

Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Pettee, Y., & Hong, J. (2002). Life course impacts of parenting a child with a disability. *American Journal of Mental Retardation*, 106(3), 265-286.

Shapiro, Johanna. (2011). Illness narratives: reliability, authenticity and the empathic witness. *Medical Humanities*, 37(2), 68-72.

Singer, G.H. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation*, May; 111(3), 155-169.

Slote, M. (2007). *The ethics of care and empathy*. New York, NY: Routledge.

Smith, Timothy. (1999). *Miracle birth stories of very premature babies: Little thumbs up!* Westport, CT: Bergin and Garvey.

Solomon, Andrew. (2011). *Far from the tree: Parents, children, and the search for identity*. New York, NY: Scribner.

Texas A&M Health Science Center, Texas Personal Care Assessment Form (PCAF) 4-20 for Children Ages 4-20. Retrieved July 18, 2013, from pcaf.tamu.edu/pdf/pcaf_420_for_website.pdf

Tronto, Joan. (1993). *Moral boundaries: A political argument for an ethic of care*. New York, NY: Routledge.

Verhagen, E. (2012). The Groningen Protocol: Which way does the slippery slope tilt? presented at the 2012 American Society for Bioethics and the Humanities conference.

Walker, Margaret Urban. (1992). *Feminism, ethics, and the question of theory*. *Hypatia*, 7(3), 23-38.

Wang, K.W.K., & Bernard, A. (2004). Technology-dependent children and their families: A review. *Journal of Advanced Nursing*, 45(1): 36-46.

Wynn, F. (2002). Nursing and the concept of life: towards an ethics of testimony. *Nursing Philosophy*, 3, 120-132.