Personal Experiences at the Intersection of Illness and Family: A Critical Rhetorical Analysis from Autoethnographic and Comic Memoir Perspectives

A dissertation presented to
the faculty of
the Scripps College of Communication of Ohio University

In partial fulfillment
of the requirements for the degree
Doctor of Philosophy

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May 2019

This dissertation titled

Personal Experiences at the Intersection of Illness and Family: A Critical Rhetorical Analysis from Autoethnographic and Comic Memoir Perspectives

by

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has been approved for
the School of Communication Studies
and the Scripps College of Communication by

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ABSTRACT

BUTTON, ANDREA NOEL GUZIEC, Ph.D., May 2019, Communication Studies

Personal Experiences at the Intersection of Illness and Family: A Critical Rhetorical Analysis from Autoethnographic and Comic Memoir Perspectives

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Illness can strike a person and family at any time. Although American culture is beginning to shift in how we talk about illness, there is still a cloud over how we communicate about illness; specifically that of our ill/aging parent(s). This study explores how personal experiences intersect with illness and family combining autoethnographic accounts of caring for an ill/aging parent with the works of three comic memoir authors. Seeking to address and analyze the experiences surrounding caring for an ill and/or aging parent, a critical rhetorical framework guided by the works of Raymie E. McKerrow and Michel Foucault is applied to our sociocultural understandings of health, illness, and caregiving.

Findings explore both the experiences surrounding caring for an ill/aging parent as well as the systematic structures embedded in the caregiving experience. Chapter Two focuses on personal experiences from an 'other' and 'self" orientation through autoethnographic accounts, specifically the influential nature of Pastoral Care (Foucault) of the body. Chapter's Three and Four explore these same orientations 'other' and 'self' through a critical rhetorical analysis of three comic memoirs: *Can't We Talk About Something More Pleasant* by Roz Chast, *Mom's Cancer* by Brian Fies, *Aliceheimer's: Alzheimer's Through the Looking Glass* by Dana Walrath. The analysis identifies key similarities and differences between each authors' lived experiences. Chapter Five advances the central argument that each author is predispositioned to confirm to and operate within the power structures embedded in our sociocultural understandings of health. I conclude with a discussion of the two major discoveries connected to my central argument, and follow that following with the major contribution of the analysis, the significance of the stories told and used for the analysis, implications for future research, and lastly final reflections.

DEDICATION

To those that supported me.

For those that doubted me.

Most importantly, for my dad – who never gave up on me and who provided me the ultimate gift: Himself.

ACKNOWLEDGEMENTS

I wish to present my special thanks to Dr. Raymie E. McKerrow. No words will ever be enough for me to express my thoughts of being able to work with you and learn from you. You have had a lasting impact on me and my life for which I will be forever grateful. Your passion, your dedication, your patience – you. You give everything you have and a little of what you don't to make sure your advisee's succeed. Thank you for the hours, days, months, and years spent with me on this project and for never giving up on me – even when I wanted to.

I would like to show my gratitude to the following professors that not only inspired me but exemplified traits that I aspire to uphold and to possess.

Dr. Lynn Harter, your passion and love for teaching has been not only influential in what I aspire to become, but a ray of light along this journey. Your thirst for knowledge continues to inspire me and the internal strength you embody will forever be an attribute I strive to achieve in my own life.

Dr. Judith Lee, because of you I was introduced to the genre of comic memoirs. Thank you for your passion and your dedication to teaching the graphic/comic medium.

Dr. Adam Tyma, words cannot describe how thankful I am to have you in my life and for your dedication to see me to the end of this journey. Your faith in me, the compassion you've shown me, your bluntness when I needed it most, and your kind words when I needed a gentle nudge to not give up helped me to succeed.

I would like to thank my committee. You have remained steadfast in supporting me and my project. You did not question my timeline, nor my decision to come home

when I did to provide support and care for my dad. Instead, you stood by me and provided endless support. I thank you.

To my cohort members, Dr. Stevie Munz and Dr. Justin Rudnick. You both have been an instrumental part of my success. You have listened to me talk out ideas, you have supported me in my decisions, and you have provided much needed laughter along the way. Thank you for allowing me to be a part of your lives.

To my friends, Steve Buchanan, Gina DeMars, Jennifer DeRouchy, Kelly Klein, Jaci Kollars, Andrea Mullen, Andy Mullen, Peggy Pattavina, George Pearlbach, Shawn Palandri, Sarah Stone, and Tad Vollmar, and Graciela E. G. Zarazua. You supported me in the darkest of days when I wanted to give up. You provided words of encouragement, laughs, support, and most of all your friendship. Thank you.

To my cats – Frank, Dean, Stanley (12.15.17), and Frida (08.23.18). Your unwavering support, your unconditional love, and your constant presence in my life (and on my computer, my keyboard, my desk, my drafts, my books, my papers) got me through the most difficult of times. You were my true writing companions.

To Joseph, no matter our fate you have helped me become better. You have supported with words and also silence – knowing which was needed when. You have seen me through the most difficult times – even if at a distance. One of the greatest gifts we can give another is the gift of silence. For it is in the silence that we must embrace the self, reflect on who we are, and what we want to ultimately become; trusting in the Lord to guide our way. Thank you.

To my sister Terika, words on this page will never communicate to you how much of an influence you have had on me and my life. No matter what, you stand by my side – without judgment or criticism. I hope I have shown you and continue to show you the same dedication and love that you express to me.

To my mother, Theresa. Mom, I'm going to keep this simple. Thank you. I know you will understand all of the unsaid words this dedication cannot hold.

Lastly, I express gratitude to my father, Joseph. Dad, without you this dissertation would not be what it is. Thank you for trusting in me and thank you for willingly – without question or doubt – opening your life to me. It takes a strong person to open your life to another, knowing you are a key part of their work. You, without question or doubt said: "Whatever you need Annie." ~ *I love you more today, less than I will tomorrow.*

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FOREWORD

Since my early childhood, I have been connected to the notions of health and medicine through personal experience. Modern medicine and medical encounters and interactions with medical staff is something that I was exposed to early on in life and continue to be exposed to, despite my personal desire to be healthy and "well." As the years passed and my personal experiences with medical issues increased, it never occurred to me that I might one day be inspired to research and write on an aspect of the very discourses I tried so hard to not be a part of; the discourses of medicine and health. In my naivety, I failed to realize what I now see all too clearly: we are all part of this discourse. I believe that we are, in part, defined by it; that it, in part, defines us, and that one day, each individual (in one way or another), will be an active part *of* and *in* the discourses of health and medicine.

During my doctoral journey, I have been drawn to rhetorical constructions of health and the body, the narratives that develop these constructions, and the socio-cultural constructions of health and wellbeing. Yet I was unable to understand how my interests could be stitched together to form a larger project of both interest and worth to the discipline. Not only could I not see how my interests connected together in a larger scope, I felt I was an odd duckling with my methodology. I wanted to use critical rhetorical means to study narrative discursive constructions of health and wellbeing. Some traditional rhetoricians would argue, "Rhetoric can't do." Some qualitative scholars would suggest that narratives should be studied thematically, yet I was convinced that health narratives could be studied through critical rhetorical means. I was just unsure how.

I would argue that I was introduced to my dissertation topic by fate; but to be logical, I came across my topic through a special topics class covering the functions of technology in rhetoric, focusing on graphic novels. To be honest, this was my first exposure with the graphic medium via written form. Sure, I had seen movies that were based on Marvel Comic Books but I had never read a comic before in its entirety, and did not plan to start reading them anytime soon – that is, until I registered for the class. Our first day, we were assigned to read *99 Ways to Tell a Story: Exercises in Style*, by Matt Madden. After finishing the book, I knew my life, both academic and personal, would be forever changed. A whole new way of seeing the world and word, yes word, was introduced to me via this book. No longer was I confined to reading only words but I now had both the visual and linguistic avenues to learn from, make sense of, and process the relationship between word and world.

We were assigned seminal texts of the graphic novel genre as well as lesser-known novels but it was one specific novel, a graphic health memoir, that drew my attention to the possibility of incorporating/utilizing graphic novels into a larger research project. I came to realize that the graphic health narrative/memoir is a rhetorical construction of health and the body; it is a narrative that discursively develops these specific rhetorical constructions, and the graphic health narrative/memoir operates by and through socio-cultural understandings of health and well-being. Not only do graphic health narrative/memoirs use written language/discourse, but they also utilize the visual spectrum to communicate these ideas. As a communication scholar, I hit the research jackpot! I found a health text that could be analyzed.

The more graphic novels I read, the more I became interested in blending graphic with narrative and its connection to health communication. Questions that surfaced varied: Who is writing the novels? Is their narrative representative of others' experiences? What medical information, if any, is being transmitted and/or disseminated through the graphic novels/memoirs? Whose interests are being served through the publication of graphic health narratives? In what ways can graphic health narratives be used in doctor/patient communication and patient education? What are the implications of health narratives being communicated through the graphic medium?

Due to my increased interest, I began to search the web and the library database on the topics of graphic novels, graphic narrative/memoir, and medicine. I was directed to a website, graphicmedicine.org. I was excited to see other academics already working with some of my ideas and interests. Much of the website and work to date focuses on the use of comic strip-like designs to communicate various health messages, yet little work explored the use of full narratives as a communicative tool for health and illness related topics. Exploratory work with both the graphic medium and graphic novels is being completed at medical schools such as Penn State College of Medicine and Johns Hopkins University School of Medicine, among other various international institutions. These institutions are leading the way by integrating the use of comics in various ways into the curriculum for medical students as well as implementing the use of comics into patient education and care. Medical doctors and scholars from various fields gather together at the yearly Comics and Medicine International Conference allowing doctors, scholars, and various medical staff to share ideas in expanding this newer area of research. It is evident that the blending of comics and health related issues is a topic holding current and future value to the communication discipline; specifically from a rhetorical, narrative, health, and critical cultural perspective. Thus, it is apparent that analyzing how graphic novels and narrative co-operate through rhetorical means is a vital research area in need of exploration.

A major reason I see for this ‘need’ is that the graphic health memoir is gaining new momentum as a viable way personal health narratives can be and are being communicated. Over the past two decades, there has been an increase in the number of graphic health memoirs being published while the graphic medium has also seen an increase in mainstream interest. Along with popular recognition, graphic novels and memoirs have gained acclaim both in the graphic sector as well as mainstream popular press with numerous publishing awards while also finding increased interest in the academic world.

The emphasis on comics and the graphic novel within the academic sector has extended to the communication discipline. However, current communication research has placed more emphasis on comics in popular culture (e.g., Duncan, Smith and Levitz’s *The Power of Comics: History, Form, and Culture*). There has been less research in our discipline that looks at the graphic novel as a means to communicate narratives, specifically health narratives. My goal for this work is to contribute to existing literature in our field within the rhetorical, narrative, and health disciplines by incorporating arguments supporting the study of the graphic medium as a viable area of research.

A Note on Terminology

The terms graphic medium, graphic health memoir, and graphic novel were used in this foreword as these were the terms used and preferred when I was first introduced to this genre of literature. In Chapter One, I will explain this terminology in more depth, providing the history behind the terms and the cognizant choice to switch term use from graphic novel(s) and various other terms used to represent “the graphic” to comic(s), the comic medium, and comic memoirs.

CHAPTER ONE: INTRODUCTION

At what point do we realize we want to write down our stories? What drives us to do so, to commit to the story told, realizing it will forever be? I'm not sure I know the answer to these questions or if I will ever know the answers to these questions for I believe it is an internal voice – something you must do in order to be complete. Writing can be a creative outlet to some, therapeutic to others. Writing can be the chance you get to speak your voice without fear, or writing can be fear producing. The beauty and utter amazement surrounding writing is that it is unique, singular; yet writing can produce the idea that normalcy exists and can produce connection. Connection between people, connection to the individual, connection to a deep level of understanding, connection to self, and a connection to others.

Funny. I never considered myself a writer yet as I reflect back, I have always been writing. I have pages of poems, short stories, lyrics, blog entries, personal journal entries, guiding questions, even a Barbie soap opera (with the help of my sister). In moments of happiness, pain, sorrow, confusion, anger, creativity – I put pen to paper and write. I often select the pen/paper method as it is a more natural and fluid process – it is how I learned to write. As I moved forward in my educational journey, I was still writing, but in an academic format. I used my personal experiences to guide my research topics but it was not until first year of my Ph.D. program that I was encouraged to include my own voice – in the form of personal stories – within my academic writing. While the desire to include my own stories still remained inside me, this writing style fell away for much of my doctoral journey where I focused on critical rhetoric. It was not until I began the dissertation process that I once again began using my own voice, in the form of stories. This style was at first used to help "get me into" the writing process but quickly became my preferred writing style. I still identify as a critical rhetorical scholar but one that uses autoethnographic means to critically analyze social and cultural constructions of the world of which I am a part.

I share this as I feel it is an important aspect of my identity as a person and a scholar. As a writer, I found myself (and still do find myself) reading what others have written. I find reading just as important to me as writing as I do not feel complete without either. It makes sense to me now why I was drawn to the topic(s) selected for my dissertation and my research. I have a connection to each. I am invested in creative writing, in memoir, in the visual, in topics surrounding health, and our social and cultural understandings of life – as we live it and experience it. I use stories as a means to help me understand and process what is happening in my own life as well as the world around me.

Stories are powerful. Stories reflect the personal and also the social. In the article "Narrative Research in Communication: Key Principles and Issues" Daniel McDonald defines a story as "the sequence, or order, in which the events occur . . . consisting of those actors, events, space, and time described within a temporal sequence of events" (117). Stories can be, and often are, housed in narratives. Narratives can be about you or someone else but narratives, as Lynn Harter identifies, focus "attention on experience by interpreting the experience and creating a representation from that experience" (*Imagining New Normals* 14). Narratives can, for the sake of my argument, be included in memoirs. A memoir is defined as "a written account of an event that one has lived through or of the life or character of a person whom one knew" (*Oxford American Dictionary* 554).

This work is in part, a working memoir and in part an analysis of already existing memoirs. As explained in the forward, I came to a genre of memoir in the comic form while taking a doctoral seminar. Drawn to this form of memoir writing, I found myself more engaged than ever before in the written accounts told by each author. I was drawn to their writing, to their artistic renditions, and how those pictorial representations supported and extended the stories being told within their memoirs. I was fascinated with their experiences, often connecting myself to them. Each memoir I read was different yet had similar underpinnings. They followed certain social norms and ideologies, often having outcomes I had either personally experienced or knew someone who had. This caught my attention as a critical scholar as I wondered if these experiences are the norm? Were there other outcomes? Were there other options for other outcomes? Part of me questioned if these stories were being published to fuel our normalized discourses of health and illness in our country – but after much thought and deliberation, I realized I could never figure that out or make an argument for that statement. So, while my original design was to have an argument I was looking to support during my analysis through a Foucauldian framework, that argument slowly drifted to the recesses of my mind and was soon forgotten. Instead, I used the works of Michel Foucault to guide my analysis. In my analysis, I applied those Foucauldian terms/theories to each memoir, identifying moments where those terms/theories were present. Doing so allowed me to create a critical vocabulary for identifying commonalities across each text, including those that resonated with my own experience, thus assisting in my rhetorical critique.

The remainder of this chapter will focus on the contexts surrounding and framing my analysis. First, I will provide an explanation of the texts selected for the analysis; second, I will focus on the socio-cultural understanding of health; third, I will highlight the importance of health/illness narratives for this project; fourth, I will explain the theoretical and critical orientation selected for my analysis, focusing on the Praxis of Critical Rhetoric and key Foucauldian terms; finally, I will provide a short summary of this first chapter and conclude with description of how the remainder of the work will be organized.

Selected Texts

An Introduction

As previously explained, I came to learn of comic memoirs during a doctoral seminar in my final semester of my Ph.D. program. I knew of comics and the genre of comics but I was unaware that there existed a genre of comic memoirs. In our seminar, we studied various types of memoirs written in the comic form but one text stood out to me more than the others, and for good reason. *Can't We Talk About Something More Pleasant* by Roz Chast is a memoir focusing on her experiences in caring for her aging (and soon to become ill) parents. I immediately connected to her stories, her experiences, her fears, her worries. I wondered if other caregiving memoirs existed in this format, so I did like I always do and started researching. I found one text, *Special Exits* by Joyce Famer. I quickly purchased it; began reading it and had to stop. The story was too close to home. The penmanship was raw, digging up emotions in me I tried so hard to push down in order to get through my experiences caring for my dad. Still searching, I discovered the Comics in Medicine Conference.[1] While at the conference, I had the privilege of meeting other scholars and scanning the tables of books brought in by a variety of publishing companies. At first, I picked up a book titled *Mom's Cancer* by Brian Fies. I knew Mr. Fies was a keynote speaker and doing a special breakout session at the conference, so I added that book to my "to buy" stack. I then gravitated toward a text: *Aliceheimers: Alzheimer's Through the Looking Glass* by Dana Walrath. Seeing her artistic renditions were different than most comic memoirs I read, I added her book to my "to buy" stack. Most books that were on display had a connection to medicine (obviously) and to be honest, I was interested in them all but I ended up buying books that I gravitated toward topically.

Initially, for my dissertation, I had selected health memoirs that were all female authored and that spanned a variety of health topics, including: mental health, cancer, caring for aging parents, and weight loss. I could see myself in each text but as I began to dig in to the analysis, something happened. That something, was nothing. While I could analyze each text, I was struggling to see the connection between texts. I did what I do best: I freaked out. I emailed my advisor and after a conversation with him, I decided to go back and re-read the texts that focused on the experiences of being a caregiver. It was there, in the memoirs of Roz Chast, Brian Fies, and Dana Walrath, that I found my

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[1] See Foreword for background on how I came to learn, know, and be a part of the Comics in Medicine Conference.

dissertation focus or rather, I found me. I was able to see how my stories connected to the comic memoir form, how my stories connected to those experiences of Chast, Fies, and Walrath and how my stories added to this genre of memoir.

I will be honest, I cannot draw. Well, I can but it is quite elementary compared to the artistry and works of Chast, Fies, and Walrath. I do make sense through the visual and I have begun to dabble with the comic form. Yet for purposes of this work and since I am a novice, I chose to use personal photographs to capture visually what I was experiencing during certain moments of my caregiving journey. For me, photographs have the ability to communicate meaning of a story being told, just as a drawn rendition does. Is it the same, no. But for my purposes, focusing on the stories being told, the inclusion of photographs serve my purpose.

You might be asking yourself, but what does she mean when she says comic memoir? I will explore briefly the genre of comic memoir starting with the situation in which this genre sits: Graphic Narratives. Graphic Narratives are housed under the common term comics. The use of terms – which term is preferred - is highly debated in the field of comics, in certain academic circles, and is beginning to be present in mainstream conversations. For example, Will Eisner addresses terminology differences in his various instructional works, explaining the history behind each term along with the structural differences.[2] In a recent article titled "Comics and Graphic Narratives: A Global Cultural Commons" published by Dominic Davies for *Words without Borders: An*

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[2] For a full review of Eisner's writings on this topic, see: *Comics and Sequential Art: Principles and Practices from the Legendary Cartoonist* and *Graphic Storytelling and Visual Narrative*.

Online Magazine for International Literature, he provides a brief history surrounding the two terms—comics and graphic narratives—and makes an argument for why we must begin the shift back to comics from graphic narratives. He states:

> Though this history and terminology is a disputed one, I think it is important to reclaim the term "comics" for this proliferating body of work. If the pieces collected in this special issue of *Words without Borders* may not all be humorous—that is to say, they are not "comic" as such—they are still representative of the innovative developments in this remarkable medium. As readers, we should celebrate these developments, while not losing sight of the long tradition of co-mixing that came before them and to which they owe their existence. The small cross-section collected here demonstrates the ways in which the comics form melds different artistic and literary techniques to create new narrative modes that allow readers to view the world through a different frame of reference. Indeed, explicitly constructed through "framed" sequences, comics as a medium foregrounds its own self-referentiality, confessing the contingency of its own perspective. In so doing, comics offer a welcome antidote to what has been controversially called a "post-truth" world, where images circulate at lightning speed, are repeatedly taken out of context, and are often mobilized toward dubious political ends.

Davies makes a strong and succinct argument for why I prefer the term comic for the texts I am analyzing. I align with his views in that comics represent much more – incorporating both the artists views as well as the readers views. The term comics provides inclusion of the art, literature, artists voice, and readers reception through the medium. For this reason, I will be using the term comic and comic memoir to represent the texts selected (outside of my own writing) for this analysis.

Comics and Comic Memoirs

In America, we are familiar with the term comics. With the rise in popularity of the comic superhero movie (initially written in comic book form) popular culture and mainstream media have increased awareness to this, at once known as underground, movement. Comics, graphics, graphic narratives, comic memoirs all are names that represent the comic form; that being stories told with pictorial content. What term is used varies depending on what is being spoken of, who is speaking, the location, and what is being argued. This pictorial content is penned in a variety of styles (pen, pencil, computer assisted) yet has its roots in art and drawing.

The use of pictorial and graphic representations as a form of storytelling is not new. We see evidence of this form of storytelling as early as primal man, advancing with the Egyptian civilization and throughout time. Although graphic historians offer various timeframes of the introduction of the graphic and modern day comics[3] as we know them to be, it was not until the early 1900's that a novel without words was introduced (*Comics*

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[3] Modern day comics are described to be in the format of the comic strip, comic book, and comic satire. See further discussions by Will Eisner in his Instructional Books: *Comics and Sequential Art: Principles and Practices from the Legendary Cartoonist* and *Graphic Storytelling and Visual Narrative*, Mario Saraceni in *The Language of Comics*, and Douglas Wolk in *Reading Comics: How Graphic Novels Work and What They Mean*.

and Sequential Art 20). Comics have been part of American culture since the early 1900's, using the medium for political satire, medical communication, and storytelling. Will Eisner identifies the start of comics with the alteration in the definition of literacy during the latter half of the twentieth century (*Comics and Sequential Art* xv). He claims, "The proliferation of the use of images as a communicant was propelled by the growth of a technology that required less in text-reading skills. . . . Indeed, visual literacy has entered the panoply of skills required for communication. Comics are at the center of this phenomenon" (xv). Eisner continues to provide a background for the history of the graphic medium noting that although the graphic medium was used for various communicative tools in the early and mid-1900's, it was in the late 1960's and beyond that comics began reaching into the literary sphere.

Comics as a literary form saw an influx between 1967 and 1990. This wave began with underground movements and moved to more mainstream market shares with the increased availability of comics through the comic book store. Easier access created a "maturation of the medium. At last, comics sought to deal with subject matter . . . [from] autobiography, social protest, reality-based human relationships and history" (*Comics and Sequential Art* xvi). Adult subject matter was now available in the comic (graphic) form.

Although more comic (graphic) works were beginning to be published from the late 1960's on, it was not until 1978 that the pre-existing term "graphic novel" was popularized with publication of Will Eisner's *A Contract With God*. The first graphic novel to receive critical acclaim, winning the Pulitzer Prize in 1992, was Art

Spiegelman's *Maus: A Survivor's Tale.* Some critics view the award of the Pulitzer Prize as the turning point for the genre. From 1992 on, the graphic medium would see more personal narratives introduced into the graphic landscape, allowing for personal stories to now be represented with visual imagery. A few examples of these graphic memoirs are *American Splendor and More American Splendor: The Life and Times of Harvey Pekar* by Harvey Pekar; *One Hundred Demons* by Linda Barry; *Fun Home: A Family Tragicomic* by Alison Bechdel; *Asterios Polyp* by David Mazzucchelli; *Mom's Cancer* by Brian Fries. Although the books above are only a small selection representing various personal narratives, one form of narrative has gained popularity within the genre - the health/illness narrative.

While there is no compounded list of all health narratives told in the comic form, comic enthusiasts would argue that Justin Green's personal account of living with OCD as told in *Binky Brown Meets the Holy Virgin Mary* is the first full length graphic memoir focusing on health. While I do agree that Green's OCD narrative is the first full length comic (graphic) memoir with a health focus, my personal research has lead me to identify the start of the health/illness genre of comic (graphic) memoirs to be around the 1990's – a seminal work being Harvey Pekar and Joyce Brabner's *Our Cancer Year*.[4] From the 1990's on, more narrators and artists brought their own personal stories and experiences to the comic medium. Although a fair portion of the comic memoirs focusing on health and illness related topics are penned and illustrated by males, there are a substantial number of books authored by females. Recent academic work within literature and

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[4] Illustrated by Frank Stack.

women's studies has analyzed the works of Marisa Acocella Marchetto (*Cancer Vixen*) and Ellen Forney (*Marbles: Mania, Depression, Michelangelo, & Me*) looking specifically at embodiment, visual embodiment, and representations of health and health experiences through the comic medium,[5] yet, as noted earlier, little work is being published in the communication discipline covering personal narratives focusing on health related topics produced in a comic medium.[6] Due to the impact personal narratives have on our everyday understandings of health I have selected three texts that focus on the experiences surrounding caring for an ill and/or aging parent. These texts were selected due to the focus being placed on the reflective commentaries of the personal experiences surrounding caring for an ill and/or aging parent. The three texts are: *Can't We Talk about Something More Pleasant* by Roz Chast; *Mom's Cancer* by Brian Fies; and *Aliceheimer's: Alzheimer's Through the Looking Glass* by Dana Walrath. Each selected text focuses on the author's personal experiences in being a caregiver, highlighting (often unbeknownst to themselves) socio-cultural understandings of health.

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[5] See Courtney Donovan's "Representations of Health, Embodiment, and Experience in Graphic Memoir" and Martha Stoddard Holmes's "Cancer Comics: Narrative Cancer through Sequential Art".

[6] See Laurel Hourani, et al.'s *Graphic Novels: A New Stress Mitigation Tool for Military Training: Developing Content for Hard-to-Reach Audiences*, Melinda Krakow's *Graphic Narratives and Cancer Prevention: A Case Study of an American Cancer Society Comic Book*, Andy J. King's *Using Comics to Communicate About Health: An Introduction to the Symposium on Visual Narratives and Graphic Health*, and Sarah McNicol and Simon Weaver's *"Dude! You mean you've never eaten a peanut butter and jelly sandwich?!?" Nut Allergy as Stigma in Comic Books.*

Socio-Cultural Understanding of Health

I must be upfront in the fact that my dissertation is not studying caregiving as a standalone topic. I did not complete an in-depth analysis of caregiving literature for this work. I was aware of caregiving literature from a variety of courses focusing on health communication during my doctoral program but the communication of caregiving was not and is not the focus of this study. Rather, the topic of caregiving blossomed out of the critical analysis (as I will be describing later in this chapter) of the experiences surrounding caring for an ill and/or aging parent. To clarify, I started my writing process using my own stories. My stories focused on moments during caring for my dad. I was not focused on caregiving per se, rather I wrote about the experiences with him. It was not until much later that I noticed that each author, Chast, Fies, and Walrath, were providing reflective commentaries of their experiences surrounding caring for an ill and/or aging parent. These reflective commentaries emphasized a specific aspect of how we, as Americans, socially and culturally understand health. We must be honest with ourselves that we, as a culture, are obsessed with the topic and the idea of health. How that obsession manifests itself varies depending on what topic or what aspect of health is of interest.

We (as humans) recognize that we have bodies, but "it is often not until illness or pain is experienced that the body comes into conscious being" (Lupton *Medicine as Culture* 20). Sociologists have studied health and illness providing various theoretical perspectives[7] to aid in our understanding of illness. Communication scholars also provide

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[7] For an overview see Lupton's book *Medicine as Culture: Illness, Disease, and the Body.*

various avenues to understand the ways in which we view and communicate about health and illness[8] exploring health through various topics. A good portion of the literature in our field studies the topic of health from both a quantitative and qualitative perspective, looking at relational issues in health, uncertainty in health, interpersonal health communication, managing health information, as well as stress and coping, just to name a few. Communication research has also explored health narratives from an embodied approach.[9] If we critically evaluate how communication studies has approach the topic of health, we can see underlying influences both socially and culturally connecting to American ideology on this specific subject.

To help us further understand the social and cultural ideology of health, Deborah Lupton's work provides a concise and useful overview of literature and theory within the

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[8] See edited texts such as: *Emerging Perspectives in Health Communication: Meaning, Culture, and Power* by Heather M. Zoller and Mohan J. Dutta (Eds.), *Methodologies for the Rhetoric of Health Communication* by Lisa Meloncon and J. Blake Scott (Eds.), *Storied Health and Illness: Communicating Personal, Cultural, and Political Complexities* by Jill Yamasaki, Patricia Geist-Martin, and Barbara F. Sharf (Eds.), and *The Routledge Handbook of Health Communication* by Teresa L. Thompson and Roxanne Parrot (Eds.).

[9] In her book chapter, "Becoming the Story: Narratives as Collaborative, Social Enactments of Individual, Relational, and Public Identities," Christina S. Beck argues that personal narratives can be viewed in rhetorical constructions within the public setting. Beck's work pulls from various other authors including Charmaz, Kleinman, and Frank to explore ideas of how individuals enact and respond to illness. She also explores the idea as the health narrative as being relational, supporting this argument by using Goffman and Holstein and Gubrium, among others as well as arguing the health narrative is a public experience, citing Petronio's Communication Privacy Management Theory. See Beck's chapter for her full argument.

field of sociology. In her book, *Medicine as Culture: Illness, Disease and the Body,* Lupton provides a detailed overview of the sociology of health and illness. Specifically, she outlines three perspectives of the sociology of illness: the functionalist approach, the political economy perspective, and social constructionism. The functionalist approach views the relations that take place within the health-care setting to operate within defined roles. More specifically, it holds that harmony and social order are preserved by the fulfillment of the already specified roles. Important to the functionalist perspective is the "view of illness as a potential state of social 'deviance'; that is, a failure to conform to societal expectations and norms in some way. Illness is considered an unnatural state of the human body, causing both physical and social dysfunction, and therefore must be alleviated as soon as possible" (4). The political economy perspective argues that "the institution of medicine exists to attempt to ensure that the population remains healthy enough to contribute to the economic system as workers and consumers" (6). An important aspect of the political economy perspective is that medicine serves to "perpetuate social inequalities that divide between the privileged and the underprivileged, rather than ameliorate them" (6). The social constructionist approach views human subjects as a part of intricate histories that are established in and through social practices and discourses. This approach to health and illness emphasizes that states and experiences of illness and disease are "inevitably known and interpreted via social activity and therefore should be examined using cultural and social analysis" (9). Also found within the sociology of health and illness is the medical anthropology perspective which explores various cultural constructions of illness. As Merrill Singer identifies, the medical anthropology perspective includes, but is not limited to, "the social production of medical knowledge; the importance of consciousness and agency in health-related behaviors and beliefs; the relation of health and medical language to power; the identification and labeling of disease; and the meaning of the illness experience" (qtd. in Lupton *Medicine* 12).[10]

Out of these perspectives comes our ability to better understand how American culture has arrived at an understanding of our health, specifically the illness experience. While the above provides an understanding of how American culture has come to view the illness experience, for my purposes, I will place most emphasis on the social constructionist approach as well as the medical anthropology perspective. As understood, the social constructionist approach provides the ability to view and examine health through cultural and social means. Within this approach, emphasis is placed on health being a social experience and interpreted through social activity. This view aligns with my critical approach to the analysis of the selected comic memoirs. The medical anthropology perspective provides insight when critically evaluating medical knowledge as understood on both a social and personal level, how we come to understand our health

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[10] I understand there is an overreliance of Lupton's work, yet I argue that her perspectives connect areas of sociology, communication, and health from a critical, cultural, historical perspective. While other authors explore similar content from a critical perspective (see Richard Gwyn's work *Communicating Health and Illness*), Lupton's work bridges the cultural perspective along with the critical perspective providing a modern-day Foucauldian-style argument structure. While I could replicate her research lineage, I feel it is best to provide full recognition to Lupton and her development of key arguments that ground my theoretical arguments for my work.

behaviors and beliefs, and how power operates in the medical context; through the use of language, the medical structure, identification of disease and illness as well as the overall meaning of our individual/social illness experience. Having framed the context for this study with key terms and introducing the socio-cultural construction of health, the next section further narrows the discussion in introducing the "body" as the site of illness.

The Illness Experience and the Body

At the core of the illness experience is how we understand and view the body. "Bodies are regarded as not simply shaped by social relationships, but as entering into the construction of these relationships, both facilitated and limited by historical, cultural, and political factors" (Lupton *Medicine* 22).[11] How we choose to discern, maintain, and view our body resides in our ability to comprehend the meaning of our body within historical, cultural, and political constructions. In his article, "Bringing Bodies Back In: A Decade Review," Arthur Frank outlines four views of the body: the medicalized body; the sexual body; the disciplined body; and the talking body. The medicalized body concentrates on how disease is managed medically, whereas the talking body places emphasis on the interaction that takes place in the medical encounter. The sexual body seeks to understand how the body can be both sexual and exploited in the experiences of both healthy and ill, while the disciplined body focuses on the multiple ways the body can be disciplined. All views of the body are imperative in understanding how illness is experienced.

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[11] See also Gaylene Becker's book *Disrupted Lives: How People Create Meaning in a Chaotic World* and Elizabeth Grosz's book *Volatile Bodies: Toward a Corporeal Feminism*.

In her book *Medicine as Culture*, Deborah Lupton argues that an important contribution to the notions of the four views of the body is the idea of discourse surrounding the body. She claims that our cultural construction of the healthy body determines how illness is managed and spoken of. Socially and culturally we have an ideal image and understanding of what “being healthy” means. For Lupton, by placing the body into the larger socio-cultural discourse of promotion of and desire to achieve the idealized, healthy body, the body has now become a site of trouble needing to be fixed. The idea of the body as a site of trouble needing to be fixed is not new. Historically, with the introduction of the bio-medical model, “there was a shift away from a person-centered cosmology of illness to an object-centered cosmology” (84). The ill patient is often viewed as an object needing to be fixed. “The ill in modern western societies are expected to place themselves in the hands of the ‘science’ of medicine: being sick and being treated have become synonymous” (86). In his book *The Birth of the Clinic,* Michel Foucault argues that the body has become the site of surveillance, regulation, and political and ideological control. For Foucault, Lupton, and others, this control ultimately constructs our view and comprehension of what healthy means and how we achieve this constructed ideology of health. It makes sense then, from this theoretical perspective, that how we manage and speak of illness is interwoven with the various discourses of what we deem as healthy.

Popular health discourse in American culture includes ideas of what illness is, what disease is, what is ideal in terms of body weight and mass, and what is ideal regarding eating and dietary choices, among others. Connecting our health discourses is the idea of the body as a site (Lupton *Medicine* 20-50). When engaging the health discourses from this ideological standpoint, we begin to focus on how they impact our individual body. Not only do we place emphasis on how our body is situated within the larger socio-cultural construction of what we deem is healthy, but we also begin to define ourselves by how we achieve this idealized notion of the healthy body (McCracken n.p.) for ourselves and for others – specifically those whom we have a relationship with and/or an investment in. One way we define ourselves is through the art of self-reflection. Self-reflection can manifest itself into a story, a narrative, or a memoir. In the following section, I will briefly discuss the terms "story" and "narrative" and their connections to the selected texts for my analysis.

Storytelling and Narrative

The terms story and narrative are often interchanged yet they theoretically act in different ways. As Lynn Harter describes in her book *Imagining New Normals,* "Narrators focus attention on experience and interpret it, creating a representation from raw experience" (14). Out of this experience develops a personal representation and interpretation of that specific experience: a story. She continues, stating: "Storytelling is an aesthetic and knowledge producing experience insofar as it offers an enlarged sense of possibility, a greater depth of insight, fuller and richer interactions" (14). Viewing stories as knowledge producing experiences allows us to interpret stories at a deeper, more critical level. Harter even goes as far to argue, "As such, stories instruct us about what to notice, and how to judge actions and outcomes" (5). Harter's point regarding how narratives, engaged in the form of storytelling as knowledge producing, and the power behind and within stories offers a key lens with which to view the selected texts, mine included. By giving stories the authority to instruct the reader, to aid in the instruction of how to judge actions and outcomes, stories and storytelling can be viewed as powerful, and power producing tools. The story itself sits with a narrative. To review, narratives can be about you or someone else yet as Lynn Harter emphasizes, narratives focus "attention on experience by interpreting the experience and creating a representation from that experience" (*Imagining New Normals* 14). One way we often make sense of our own health or issues and/or concerns surrounding our health or another's health is through the act of telling a story. Those stories often are connected to and by interpretation of the storied experience. As true to the American way, we have a genre that focuses specifically on these types of stories: the health/illness narrative.

Health/Illness Narrative

I would feel safe to say that we have all been guilty of telling a story connected to our health at some point in our lives. It may be a short story or it may be a long story, but the fact remains that we have likely done so, describing the detail of our account. Theoretically speaking, health narratives focus on the overall condition of the body. Oftentimes, illness is a major focus of health narratives as illness tends to refer to feelings that come with having a disease (Ingram n.p.) How the illness experience is expressed can vary among individuals. One popular way individuals express or tell of their illness experience is through the sharing of stories and/or personal narratives. "The concept of narrative underpins examination of the ways in which people give meaning, sense and structure to the trajectory of their illness" (Lupton *Medicine* 86). Lupton continues to explain the meaning making process that takes place in the illness experience suggesting "giving meaning to the illness experience involves drawing on a range of dominant discourse and cultural resources from the lifeworld, including those from folk knowledge about the body and illness, as well as expert discourse originating from biomedicine and alternative medicine and those circulating in the mass media and the internet" (86). Another perspective in the meaning making process of the illness experience is that of the 'lay' account.

Richard Gwyn outlines the lay perspective and suggests that the 'lay' account or description not only takes into account personal experience with illness but also the social understanding and representation of illness and health (*Communicating Health* 34). One of Gwyn's arguments is that language is a driving force in the development and perpetuation of health related ideas and topics. Gwyn's work provides supportive reasoning for examining narratives of illness and health as rhetorical constructions.

Important within the discourses surrounding illness is the autobiographical story (also termed as memoir) as this specific form of story gives personal meaning and sense to the illness experience. In his article, "Bringing Bodies Back In: A Decade Review," Arthur Frank concludes that illness narratives can include those that story life-threatening illnesses to minor symptoms – any health issue that urges the suffering to seek answers and to find satisfactory enlightenment of their illness.

A dominant theoretical view for understanding illness narratives is Arthur Frank's book, *The Wounded Storyteller: Body, Illness, and Ethics*. Frank discusses three types of illness narratives: the restitution narrative, the chaos narrative, and the quest narrative.

Frank believes these three illness narrative types should act as listening devices (76), to aid the listener in following the story being told.[12] The restitution narrative is the preferred story of Western Cultures as it promotes a healthy outcome from illness. It suggests that if you are sick, you will be healthy again. The storyline focuses on treatments, tests, and possible outcomes of following varying treatment plans. The chaos narrative is the opposite of the restitution narrative as the plot never improves. Important to the quest narrative structure is the lack of narrative structure. The plot is event driven, based on the experiences of the storyteller. The quest narrative focuses on illness as a quest; "Illness is the occasion of a journey that becomes a quest" (115).[13] I argue that Frank's narrative types help to understand the ways in which individuals explain their illness experience.

Within the narrative capacity is the ability to construct individual identity, specifically of the illness experience. In her book *The Vulnerable Empowered Woman*, Tasha N. Dubriwny recognizes the importance of personal identity when communicating illness narratives by highlighting the significance of the meaning making capabilities as well as the ability to ground the human experience. Kenneth Burke (1973) argues that narratives are "equipment for living" as they help people make and act on meaning (93–304). Walter R. Fisher, in his article "The Narrative Paradigm: In the Beginning" extends

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[12] The notion of an illness story being a listening device is an important one. When applying this concept to reading comic memoirs, the reader can view the illness story as a means to listen to the narrative being told through both story and the visual.

[13] Frank notes that most published illness stories are quest narratives (115).

Burke's meaning-making in explaining the capacity for humans to be storytelling creatures. Fisher grounds this human ability by explaining how symbols are used to create a common identity of the human experience. Key to the illness narrative is the construction of personal identity – an identity often shared though the storytelling of an illness narrative. As Jaber F. Gubrium and James Holstein argue, "Stories in society deploy a distinctive narrative reality" (*Analyzing Narrative Reality* 15). I view the illness narrative as an integration of personal identity into the distinctive narrative reality Gubrium and Holstein describe because illness narratives are not only personal accounts of one's illness but they are also part of the society in which they reside. Our stories, whether they are illness focused or health focused are alive and active in our culture. They can be found in blog format, as self-published books, and in mainstream literature under the genre of the memoir.

Memoir

The genre of memoir is long standing and has been part of our culture since ancient times. Memoir developed out of autobiography "as stories about the lives of historical figures began to replace the tales of mythic heroes as a way of coming to terms with existence through narrative (Freeman and Brockmeier 79) (qtd. in Duncan, Smith, and Levitz 231). While the memoir has moved through time since its first form in ancient Greece and Rome, the now popular form of the memoir is attributed to the rise of Christianity (Duncan, Smith, and Levitz 231).

In the book *The Power of Comics: History Form, and Culture Second Edition*, authors Randy Duncan, Matthew J. Smith, and Paul Levitz trace the history of the memoir and its inception in comic form. They summarize:

> The cornerstone of the memoir genre in western civilization is generally considered to be *Confessions* (398) by Aurelius Augustinus Hipponensis, better known as Saint Augustine. Augustine's Confessions has come to be regarded as the paradigm for writing about oneself (Freccero 17). Augustine developed "three autobiographical forms-historical self-reflection, philosophical self-exploration, and poetic self-expression-from which every subsequent autobiographer would select the one most appropriate to his own situation" (Spengemann 32). Almost 1,400 years later, Jean-Jacuqes Rousseau secularized memoir in his own Confessions (1782, 1789) by presenting not a spiritual journey but an exploration of the experiences that shaped his personal worldview. (231-232)

It was not until the 1930's that the memoir made its appearance in comics form, resulting in the blend of two major comic traditions: American comic strips and Japanese manga with the work of "Henry" Yoshitaka Kiyama (Duncan, Smith, and Levitz 232).

The comic memoir (in the form known today) developed out of the underground comix movement with the 1972 memoir by Justin Green, *Binky Brown Meets the Holy Virgin Mary* (Duncan, Smith, and Levitz 232; Eisner *Comics* 4). This subgenre of comics, the comic memoir, holds true to the historical form of the memoir as it tells of our experiences through autobiographical accounts.

As defined earlier in this chapter, memoir is “a written account of an event that one has lived through or of the life or character of a person whom one knew” (*Oxford American Dictionary* 554). In her conversation regarding the connection between autobiography and comic memoir, Elizabeth El Refaie suggests that “autobiography should thus be seen as a mode of reading rather than simply as a way of writing” (17). Understanding that the memoir, specifically the comic memoir, is autobiographical in nature we as readers can come to the memoir as a mode of writing, or we can read the memoir as a mode of reading as Refaie suggests. We as readers have the ability to read the selected text as initially designed, or we can place lenses over our eyes and mind and shift the perception of what we are reading. I would argue that we come to whatever we read with some level of preconceived notions or lenses – despite our desire to come with a clean slate. For me, it takes a conscious effort to clear my mind of preconceived ideas or personal experiences I may have that connect to what I am reading (and I do not believe I am able to do so completely). There are times I make the conscious effort to clear and there are other times where I allow my orientations to operate freely in my mind.

At the outset of my dissertation, I read each text as far removed from my personal orientations as I could. I read. I consumed their stories. After I was done I sat back. I meditated on their stories, on their artistic inclusions and renditions of certain moments in their journey. I could not help but wonder, why are my experiences so similar? I was also blinded by power. I could see elements of power at play within and throughout the stories of Chast, Fies, and Walrath (as well as my own). I had decided the framework for my analysis was going to be critical rhetoric, applying various works and theories by Michel Foucault using Raymie E. McKerrow's "Principles and Praxis" found in his seminal essay "Critical Rhetoric: Theory and Praxis," as a guiding framework within which the analysis might be considered. What I did not expect was the level of inclusion of my own stories. The next section will explore the following: First, I will provide a short reflection of my working knowledge of autoethnography, how I came to use this form of writing in my work, and how my own stories connect to the selected texts; Second, I will explain how McKerrow's "*Principles and Praxis*" were used as guiding principles for my analysis; Finally, I will provide a brief introduction to Michel Foucault, highlighting the major theories used for my analysis.

Theoretical and Critical Orientation Guiding the Analysis of the Comic Memoir

Autoethnography

Personal Connection to Autoethnography

"I am not an autoethnographic writer" – a declarative sentence once common in my description of self and of my writing. This statement has since changed although I am not certain I am bold enough to say that I am. Those that know me well may argue (and have believed for some time) that my writing style does fit within the tradition of autoethnographic writing but I was hesitant to identify as an autoethnographic writer and more hesitant to explore this style in my own work – although I was writing in the style all along. I will be upfront is stating that it was not my initial intention to include my own stories in my dissertation, rather my goal was to complete a critical rhetorical analysis of selected comic memoirs. The analysis was moving forward, I was able to analyze – take my notes in my style, but when it came time to transfer analysis to full sentence/paragraph structure I hit block after block. I was writing at a snails pace. I have no objection to snails and their pace, but that writing pace proved to get me off track, overwhelmed, and it ultimately hindered my production. It was then suggested that I start writing my own experiences to "get my head into the analysis" (since it was a well-known fact that I was managing my dad's care). Desperate for my blocks to be lifted, I began to write. I was already writing in my journal and taking notes about my own experiences, but this was the first time (outside from a seminar paper my first year of my doctoral program) I made a conscious effort to narrate my own experiences. I sat down and started writing. I continued to write. I expressed my thoughts, often suppressed or hidden away in journal pages only I would see and felt release; it was as though a weight had been lifted off me. A dam broke. My internal dam. A dam created from years of harsh words and belief my voice was not worth being heard (especially in written format for I was told I could not write) and upon that breach, a river of words started flowing . . .

Theoretical Understanding of Autoethnography

As explained earlier, I am not a trained autoethnographic writer. I was familiar with the qualitative style of inquiry due to theoretical training during my master's and my doctoral program but it is not my trained area of focus like critical rhetoric is. Much of what I learned about the form and the theory was done through self-teaching, a few amazing and thought provoking conversations with Tony Adams, and a lot of reading. I familiarized myself with seminal works in our discipline including the writings of Tony Adams, Jimmy Manning, Carolyn Ellis and Arthur P. Bochner, Stacy Holman Jones, and

Norman K. Denzin. I reviewed books and journal articles written on the subject of Autoethnography – seeking new information not found in the writings of those names listed above. I read book chapters on the topic seeking to develop a stronger understanding of autoethnography and see various writing styles included in this area of study. In essence, I was teaching myself about the method I so strongly connected to, yet denied connection to for years.

The background surrounding the term autoethnography is an important component to my method of inquiry as it provides grounding and foresight into my analysis chapters. In their encyclopedia entry "Autoethnography," Tony E. Adams, Carolyn Ellis, and Stacy Holman Jones situate the study of autoethnography in the communication discipline by providing a brief history of this specific method of inquiry, the process of the method, key purposes and practices, and finally personal insights from producing autoethnographic research. Simply explained, Adams, Ellis, and Holman Jones clarify that "autoethnography is a research method that uses personal experience ("auto") to describe and interpret ("graphy") cultural texts, experiences, beliefs, and practices ("ethno")" (1). As Arthur P. Bochner explains in his book *Coming to Narrative: A Personal History of Paradigm Change in the Human Sciences,* researchers were practicing the art of autoethnography since the 1980's, writing about the importance of storytelling and personal narrative but not using the term autoethnography. Adams, Ellis, and Holman Jones identify that "In the 1990's "autoethnography" became a method of voice for using personal experiences and reflexivity to examine cultural experiences, especially within communication" (2).

Although various types of autoethnography exist, I was specifically drawn to one: Personal narratives. In their article "Autoethnography: An Overview," authors Carolyn Ellis, Tony E. Adams, and Arthur P. Bochner describe personal narratives as:

> Stories about authors who view themselves as the phenomenon and write evocative narratives specifically focused on their academic, research, and personal lives (e.g., Berry 2007; Goodall, 2006; Poulos, 2008; Tillmann, 2009). These often are the most controversial forms of autoethnography for traditional social scientists, especially if they are not accompanied by more traditional analysis and/or connections to scholarly literature. Personal narratives propose to understand a self or some aspect of a life as it intersects with a cultural context, connect to other participants as co-researchers, and invite readers to enter the author's world and to use what they learn there to reflect on, understand, and cope with their own lives (Ellis, 2004, p. 46). (quoted in Ellis, Adams, and Bochner para: 24)

Ellis, Adams, and Bochner's definition summarizes my approach to my own narratives included in this work. Their definition also supports how I see my own narratives theoretically operating as well as how my writing fits into the larger body of autoethnographic work by communication scholars.

My Approach to Autoethnography - The Difference

My understanding and approach to autoethnography does fit into the description of personal narrative – a type of autoethnography, yet my approach does not live and breathe within the definition of personal narrative as stated in the prior paragraph. For me, the clarification provided by Adams, Ellis, and Holman Jones regarding the intersection of autobiography and ethnography is especially helpful when explaining my own approach to Autoethnography. They explain:

> Understanding autoethnography requires working at the intersection of *auto*biography and e*thnography*. When we do autobiography – or write about the self – we often call on memory and hindsight to reflect on past experiences; talk with others about the past; examine texts such as photographs, personal journals, and recording; . . . (e.g., Goodall, 2006). Then we write these experiences to assemble a text that uses tenets of storytelling devices, such as narrative voice, character development, and dramatic tension, to create evocative and specific representations of the culture/cultural experience and to give audiences a sense of how being there in the experience feels (e.g., Ellis, 2004).
>
> When we do ethnography, we observe, participate in, and write about a culture and/or a cultural experience . . . Typically, ethnographers approach cultural communities inductively, allowing observations to guide what they write, that is their "findings" . . .
>
> Taken together, the process, principles, and practices of autobiography and ethnography contribute to the way we write and practice autoethnography, as well as the goals and purposes we have for autoethnographic work. (2-3)

As stated in the previously cited article "Autoethnography," Adams, Ellis, and Holman Jones outline four major purposes and practices of autoethnography. These four purposes are: 1) to challenge and/or provide alternatives to dominant cultural ideologies; 2) to share knowledge from an inside perspective; 3) to provide description of moments within everyday experiences that traditional research cannot capture; 4) to reach a larger audience, often non-academic, by creating accessible research that can be understood by academics and non-academics (3-5).

My approach to my own written accounts (as will be seen in Chapter Two) blends components of autobiography and ethnography (as described above), yet with sharp edges. While I uphold the purpose and practices of autoethnography (as outlined above), I make the choice to use more traditional autobiographical and ethnographic writing styles in certain moments in my own writing. This decision was done for the following reasons: First, I wanted to provide a clear distinction to you, the reader, when personal reflection, written accounts – by way of journals, and photographs were being used and when observation was taking place; Second, I wanted certain personal experiences expressed without connection to research (connection to research being one of the primary purposes and practices of autoethnography as stated by Adams, Ellis, and Holman Jones); Finally, my stylistic approach to my written accounts express the internal struggle I felt (and still feel) regarding how I manage, identify, and process information within my role as daughter, caregiver, guardian, writer, academic, and critical scholar. While these various roles can operate in tandem, they can operate separately yet for me, they operate with very sharp edges within and between.

Additional to the selective choice of the inclusion of autobiographic and ethnographic written approaches, my own written accounts add an additional layer(s). I do use my own narrative, as Ellis, Adams, and Bochner state, to “understand a self or some aspect of life as it intersects with a cultural context" but I go a step beyond. I not only ground my narratives in critical theory, specifically the writings of Michel Foucault and Debora Lupton, but I also provide a connection to two specific cultural contexts - experiences surrounding caregiving and comic memoirs – in one medium: the comic memoir. My goal in approaching the autoethnographic personal narrative from this style is to rhetorically analyze my own experiences while also analyzing the experiences of the comic memoir authors – seeking to discover possible commonalities and differences in our lived experiences.

Ethics Statement

Research Protocol – Upholding Ethical Values When Writing About Family

"How does your dad feel, knowing you are writing about him?"

"Don't you worry what people are going to think about your dad, you, your family when then read this?"

"Is this a true representation of your dad, your experiences? Or your perception of these moments?"

"Did you get your dad's permission? Can your dad give you permission since he is technically under your 'protection' but is also still your dad?"

How will dad feel when he reads this passage? This story? What will he see when he looks at this picture?

How do I represent dad in a way that is true to my experiences and my perception of our moments together but that is respectful of him? His body? His being?

How do I represent my relationship with my dad in a way that will capture what we have experienced together?

How do I communicate to you, the reader, that my dad has never left my mind as I drafted each story, each experience? That my dad first gave me permission to write about his health in 2012 (in my first doctoral seminar). That my dad, in every conversation I have had with him and still have with him (to this day) asks me “Annie, how is the writing going?”

The first tiers of questions are ones that I often received when explaining to people what my dissertation research was about. These questions were asked by those within the academy and by those outside the academy; Friends, family members, peers, faculty members, my committee. Yes, I did put much thought and many hours of contemplation and introspective soul searching about my approach to the topic – my stories, my images, my detail – but I never once anticipated the complexities of writing about my dad. I am very aware of IRB protocol, protected classes, ensuring anonymity of those individuals in my experiences that did not want to be named and/or identified, yet I forged on not realizing the layered and possible problematic outcomes of writing about my dad while holding the title of legal guardian, in addition to being his daughter. Naysayers can argue that I took advantage of my father, knowing he is sick and knowing I hold “power” over him, for my own personal gain. My response to this concern is: I obtained permission from my father years before his medical diagnosis, years before being assigned as his legal guardian. Still, there can be pause for questioning regarding the power dynamics at play: how my dad is presented, how his team of doctors are presented, how family members and friends are presented. Recognizing that these questions and concerns exist is important: I believe addressing the possible ethical complications surrounding my unique situation will respond to most of these concerns.

The beauty of being close to my dad is that I was at most of his major medical appointments. I use the term major medical appointments to cover appointments that dealt with major tests, milestone checkups, and/or appointment made by myself or a family member in response to recognition of decline in my dad's health. In each appointment, I took notes. I identified to the medical team that I was taking notes and again restated my purpose of taking notes when the physician entered the room. In each meeting, I asked if I could use notes in my writing if I decided to write on said moment at a later time. Each time, I was provided a yes. In some appointments, this statement would spark further conversation about my research – especially with Dr. Sorell – in others it was more of a formality. Dr. Sorell, an internationally renowned researcher and scholar was always interested in supportive of me and my work. He would often conclude my dad's checkups with follow-up questions for me regarding my progress in my program, how I was moving on my pre-proposal, and finally my dissertation proposal. He retired prior to my dissertation proposal defense. At one of my first encounters with him, I explained I read a research article of his in a previous seminar and I asked if I could not use a pseudonym with him – as I wanted to reference him by name due to his research, his dedication to the Med Center and to my dad. He smiled and said, for you – yes. Dr. Sorell is the only physician I included in my stories that is represented by non-pseudonym name. All other physicians have pseudonym's created – or are referenced by type of doctor (i.e. his Psychiatrist). This was a purposeful move on my part as my writing about them was connected to my dad – rather than having the story be about them specifically.

In other stories, where family members or friends appear, I reference by first name. I selected this approach for the following reasons. First, if you look up my grandmother's obituary, you will find the names of all my family – making anonymity a falsified idea. Using a false name for a family member would shield the privacy of which family member it was, but again, in speaking to my aunt and other members of my family as well as close friends, they were in support of using non-pseudonym names. The one family member that I did not use first name for, rather used title for, is my spouse. I selected the term "Husband" to create distance and to also create separation. His name is also Joseph (Joe). In stories where Joe and Joe are together, it became confusing from a writing perspective – thus the introduction of the use of "Husband."

As you will learned, my family and I are close. My dad and I have a very special bond. I am the only person he says "he trusts to be his guardian" and I believe that. Together, we trust each other. He trusts that I will be honest with him, with my use of our experiences together, and most importantly with myself. He understands the sacrifices I made to obtain a Ph.D. and has always been in support of my decision(s). As a father, he only wants the best for me. When writing, I would often call him and go over what I was writing about, the frustrations I felt, the sadness, the grief, the internal battles, the anger I had because I cannot be everything to him nor give him everything I feel that he should have – but cannot have due to medical restrictions. I purposefully made him aware of all of this so he knew what I was going through during the writing process, what I was writing about, and how my stories were taking shape. He never once asked me to change anything, or think about it this way or that, rather he said “when you’re done, I can read it over for edits. I know you don’t think I’m a good writer, but I’m great at English.” While I decided to not have dad “edit” my draft(s), I did share with him what was in the stories being told – allowing him to partake in the writing process, since after all, most of the stoires are about him.

Like with all writing, nothing is prefect. I am sure there is a nurse I likely forgot, I know I did not go find the Walmart clerk to ask if it was okay to include his dialogue – yet these moments are moments in time that occurred, that had witnesses (outside myself and my dad), and in the case of Walmart – is likely on some random “people of Walmart website.” I make light of this only to highlight that not all moments can be signed off on. They are experienced in the moment. What is important for me to stress is that my writing is representative of how I experienced that moment, in that moment of time. In retrospect, I’m sure the narrative would be slightly different. What would not be different are the on-going conversations I have had with my dad during this entire process, the verbal consent my father gave my many years ago – providing me the go-ahead to write – about him, about us, about his life – and the constant battle I still feel when writing about the very personal. The voice of doubt, fear, shame, rejection is always present, but every now and again, one voice comes through – loud and clear – telling me to go ahead, to be true to myself and to “simplify Annie, simplify”; that voice belongs to my dad. Thus, to conclude, my ethical obligation throughout this retelling of our life together is to be true to my recollections and notes—to be true to my father's explicit faith in my ability to 'get the story right.'

Situating the Comic Memoir

In his forward to *Graphic Storytelling and Visual Narrative*, cartoonist Will Eisner states the following about comics:

> While words are a vital component [of comics], the major dependence of description and narration is on universally understood images, crafted with the intention of imitating or exaggerating reality. The result is often a preoccupation with graphic elements. Page layout, high-impact effects, startling rendering techniques and mind-blowing color can monopolize the creator's attention. The effect of this is that the writer and artist are deflected from the discipline of storytelling construction and become absorbed in a packaging effort . . . Despite the high visibility and attention that artwork compels, I hold that the story is the most critical component in a comic. Not only is it the intellectual frame on which all artwork rests, but it, more than anything else, helps the work endure. (xi-xii)

Eisner's approach and belief that the most critical component of comics is the story, is not a dominant stance in academic essays and books written on the subject. For example, there are essays that focus on the use of color in storytelling and sequential narrative as seen in Durwin S. Talon's essay. Mieke Bal places emphasis on visual essentialism and the object in visual culture. Silke Horstkotte and Nancy Pedri's essay covers Focalization in Graphic Narratives while Pascal Lefèvre's essay uses three components of the visual that are often cited as elements for analysis of the graphic: "drawing styles, temporal dimensions of individual panels, and the interpretation of sequences of panels" (14). Elizabeth Rosen's chapter "The Narrative Intersection of Image and Text: Teaching Panel Frames in Comics" in the edited volume *Teaching the Graphic Novel* walks the reader through panel construction and framing, while Joseph Witek's chapter "Comics Modes: Caricature and Illustration in the Crumb Family's Dirty *Laundry*"[14] provides an explanation of caricature and illustration.

The book *The Power of Comics: History, Form, and Culture Second Edition*, by authors Randy Duncan, Matthew J. Smith, and Paul Levitz provide a succinct background of the history, form, and culture surrounding comic books and the genres within. In the unit on form, the authors review prior literature written on comics placing emphasis on story creation, experiencing the story, as well as three major genres of comics: classifications of comics, superhero comics, and memoirs. In their chapters on story creation and experiencing the story, they argue the importance of both the visual and the textual, citing literary, linguistic, and cognitive science research along with seminal American comic author and theorist Will Eisner and Scott McCloud. There is substance to the arguments developed by Duncan, Smith, and Levitz for the importance and reliance on both the visual and textual to communicate a story yet for this work, I align myself with the stance of Will Eisner in the belief that "the story is the most critical component in a comic" (*Graphic Storytelling* xii). While previous analyses and books place emphasis on the visual artistry and how it informs the graphic, I approached my

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[14] Chapter can be found in *Critical Approaches to Comics: Theories and Methods*, edited by Matthew J. Smith and Randy Duncan.

analysis from the Eisner view just noted above. While I do bring in the graphic and artistic elements when they apply to a point I am making in my analysis, it serves to emphasize the story.

Theoretical and Critical Orientation – Critical Rhetorical Analysis

At the core of critical rhetoric is the notion of power. In his seminal essay, "Critical Rhetoric: Theory and Praxis," Raymie E. McKerrow states "The task of a critical rhetoric is to undermine and expose the discourse of power in order to thwart its effects in a social relation" (98). Completing a critical rhetorical analysis of comic memoirs focusing on caregiving allows the opportunity to identify the nature of power differentials (as power is ever present in some fashion w/in social relations, as is the potential for resistance). The analysis structure provides the opportunity to evaluate what type of power exists, to what extent power is present, and how power is managed. In what follows, I will first review the critical principles employed, and then discuss specific concepts that are from Foucault's work, specifically selected for my analysis.

Critical Orientation – Raymie E. McKerrow's Principles of Practice

To conduct a critical rhetorical analysis, I utilized McKerrow's "8 Principles of Praxis for Critical Rhetoric" found in his seminal essay. It is important to note that I did not use McKerrow's principles as a methodology but rather, as he articulates, as "an orientation" (100). Thus, you will not find me referencing "principle x" in the analysis—rather, they function in the same way a journalist's 'who-what-when….' function in building a story. McKerrow's principles were coupled with and informed a Foucauldian analysis of the selected texts. McKerrow's principles of critical rhetoric provided an overarching orientation for using Foucauldian concepts to analyze each memoir. As McKerrow notes in an essay on using this approach as a critical tool, "adopting a **critical stance** toward the world is precisely the orientation that animates the critical rhetoric project"[15] (sic). As Kent Ono suggests, "Taking a critical stance means addressing issues of power; taking such a perspective helps broaden the focus of critical scholarship and brings together varying critical traditions" (93).[16] For this reason, McKerrow argues that at a minimum, the critic must include the juridical and productive dimensions of power, claiming, "State power exists, [state] power is repressive, and is accessible to critique" ("Critical Rhetoric" 101). He goes on to say, "That power is not only repressive but potentially productive, that its effects are pervasive throughout the social world and that these effects are accessible to analyze" (101) is an equally important component in understanding power as something other than a possession. McKerrow's viewpoint on the inclusion of power dimensions in critical analysis was a guiding component for my work. By focusing on power's repressive and productive nature, I was able to decipher how power operates in and through each selected text.

Critical rhetoric as practice is the first guiding principle. Principle #1 states, "Ideologiekritik" is in fact not a method, but a practice" (McGee, 1984, p. 49)," (qtd. In McKerrow, "Critical Rhetoric" 102). At the core of Principle #1 is the idea that understanding cannot be separate from evaluation (102). In order to fully describe each text, the critic (myself) must fully understand each text to be able to describe what is

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[15] See Raymie E. McKerrow's, "Critical Rhetoric: An Orientation Toward Criticism."

[16] For the full discussion from Kent A. Ono, see his article: "Critical: A Finer Edge."

taking place within it. Furthermore, the critic must operate from an "orientation" or a "perspective."[17] It is important to note that I operate from the ontology that our reality is socially constructed. An important part of our social reality is our individual and societal understanding of cultural identities. I define cultural identity as a person's social identity including, but not limited to, gender, sexuality, race/ethnicity, age, and ability. To follow in McKerrow's language, my orientation is from a critical cultural perspective. By that I mean I sought to uncover how power is operating in and through our social reality.

"Principle #2. The discourse of power is material," argues, "Participants are not passive bystanders, simply absorbing the ideology and having no power to alter its force or its character. Ideology is a property of the social world, but agents have the capacity to interact in that world to modify the discourse" (102). McKerrow further argues, "They [participants] come to a system of discourse with an ideological grid already in place and participate in terms of that grid's determinative nature" (102). I view the comic memoir as a living example of Principle #2. Both the readers and authors are interacting with the world, yet they are interacting within the discourse of health that is already in place, just through a different medium.

Important to both critical rhetoric and the graphic form is the notion of participation. The reader of a graphic text is a participant – interpreting both narrative and

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[17] Both concepts of "orientation" and "perspective" come from the works of McKerrow and McGee. For further discussion of concepts, Raymie E. McKerrow's, "Critical Rhetoric: An Orientation Toward Criticism and Michael Calvin McGee's, "Another Philippic: Notes on the Ideological Turn in Criticism."

visual representations of the narrative, creating their interpretation of the story. Critical rhetoric:

> Links praxis, both as object of study and as style, to "a mode of transformative activity" (Benhabib, 1986, p. 67) in which the social relations in which people participate are perceived as "real" to them, even though they exist only as fictions in a rhetorically constituted universe of discourse. (103)

This transformative activity, participation as real yet existing only as fictions, is the essence of the comic memoir. The comic is a medium that asks for active participation from the reader by the design of the story through the graphic medium (Eisner *Comics* 1-6; Stoddard 151-160). Through panel design, artistry, and narrative, the author gives some creative leeway to the reader; to use the author's narrative to not only tell their story, but to also develop their own interpretation of the artistic representation of their narrative. The meaning of the narrative is co-created between author and reader; in this sense, there is no single 'right' meaning that can be discovered.

"Principle #3. Rhetoric constitutes doxastic rather than epistemic knowledge" (103) is grounded in the notion of truth. Expanding on Hariman's (1986) work on Doxa, McKerrow uses the knowledge from traditional rhetoric that Doxa includes "reputation" and "opinion," and "functions as much by concealment as by revelation" (104). The sense of "truth" that doxa calls for is not oriented towards certainty, but rather is concerned with what symbols "'do' in society as contrasted to what they 'are'" (104). As expressed earlier, the analysis focused, not on the "Truth" expressed in the stories told by authors, but on their sense of 'truths' as they have experienced illness in their lives.

Viewing comic memoirs through doxastic knowledge allowed for the ability to include how reputation and opinion shape our ways of knowing. Furthermore, doxastic knowledge not only engages ways of knowing to allow for an understanding of how symbols of health come to possess power but it also aids in interpreting the impact these symbols (representing various health ideas, topics, knowledges) have on people's interpretations of shared reality (104).

Principle #4. "Naming is the central symbolic act of a nominalist rhetoric" argues for the power of language, but takes it one step further (105). The aspect of naming has been inclusive to rhetoric from Burke's notion of "naming as an interpretive act" to McGee's "ideographs."[18] What McKerrow identifies as missing in this process of naming is the idea of "rhetoric as nominalist" (105). In other words, nominalist rhetoric does not assume abstract names exist as real; rather it argues for "a sense that terms are contingently based – the reasons for their emergence are not premised on fixed, determinative models of inquiry" (106).

"Influence is not causality," Principle #5, suggests, in terms of this study, that comic memoirs do not serve as causal agents in making people change their approach to health issues. That said, it is the case that things we hear, read, or have conversations over may function as implicit influences in making up our mind about health options or strategies to pursue. The "power" comic memoirs possess is inherent within the narratives (including visual themes as 'narrative tools') being expressed. Should one take

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[18] For a more detailed discussion, see McKerrow's essay for full lineage.

this treatment over another? Any single memoir may not ‘make the difference’ in a causal sense, but taken with other influences, may be a factor in decisions being made.

In order to fully understand what is taking place in the selected memoirs, identification of what is absent as well as what is present is necessary, which is the driving force of “Principle #6. Absence is as important as presence in understanding and evaluating symbolic action” (107). McKerrow suggests, “Terms are not ‘unconnected’”; in the formation of a text, out of fragments of what is said, the resulting “picture” needs to be checked against “what is absent” as well as what is present” (107). The absence of information may be as important, or more important, than what is being communicated in each memoir. To grasp the most complete “picture” in evaluating symbolic action within the graphic, identifying the ‘said’ and ‘unsaid’ in both text and visual senses is necessary.

“Principle #7. Fragments contain the potential for polysemic rather than monosemic interpretation” (107) directly relates to the analysis of comic health memoirs. “A polysemic critique is one which uncovers a subordinate or secondary reading which contains the seeds of subversion or rejection of authority, at the same time that the primary reading appears to confirm the power of the dominant cultural norms” (108). At the core of the comic movement is the idea of supporting diversity and difference. Also driving the comic movement is the idea that comics are a form of resistance to the dominant discourse.[19] Utilizing principle #7 aids in uncovering possible subordinate or

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[19] The idea of comics as a form of resistance to the dominant discourse came out of Jared Gardner’s Keynote address to the 2015 Comics and Medicine Conference held in Riverside California. Jared Gardner

counter narratives of various health experiences while under the semblance of confirming to the dominant cultural norms.

The final principle, “Principle #8. Criticism is a performance” (108), asks the critic to come to the process of analysis from an active stance. “In the sense of a critical rhetoric, it places the focus on the activity as a statement; the critic as inventor becomes arguer or advocate for an interpretation of the collected fragments” (108). The comic form invites participation and investment from the reader. In the case of comic memoirs, the memoirs are working with the notion of invisible versus visible illness. More specifically, the comic moves beyond metaphor to communicate the non-visible. It is important to note that comics are individual performances; the comic memoir is also viewed as an individual performance. In the case of the comic memoir, I actively interpreted the narrative, frames, graphic representations, and what is between the gutters (that information that is missing and/or purposefully left out) to critically evaluate the stories being told in the selected texts in the manner explained above.

Application of Raymie E. McKerrow’s critical orientation—Principles of practice.

You might wonder how I applied a structure that is guiding in nature to aid in my analysis. The truth is, it just happened. Is that theoretically or methodology sound? Most likely no, not to most. McKerrow’s Critical Orientation is just that, an orientation. By definition, an orientation exists to position in relation to something else *(Oxford American Dictionary*). McKerrow’s principles provided me an orientation to help

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position myself, critically, in relation to the content I was analyzing. I carefully selected the word content rather than texts as my analysis focused more on just the texts. As a critical scholar, my position is grounded in social and cultural understandings of the world around me focusing on aspects of power. Using McKerrow's Critical Orientation aided in not only how I approached the analysis but what I focused on. Orienting myself with McKerrow's "8 Principles" provided a solid foundation, although not structured, for how I engaged in the reading of each text, how I approached the identification of commonalities across texts, and which Foucauldian theories/terms best fit the arguments being set forth in my analysis and discussions.

Theoretical Orientation – Michel Foucault

The best way for me to begin to highlight the extensive work of Foucault is to provide a brief background of the man himself and provide an overview of the Foucauldian concepts guiding this analysis. I will also provide an exemplar of how I see the concept linking to and working within the comic memoirs selected for my analysis. For purposes of this section, I feel it is important to note that I may link Foucauldian concepts together for purposes of my own analysis structure that may or may not be talked about in tandem within his writings.

Foucault – a brief introduction.

Michael Foucault was a French born theorist and author. According to Chris Horrocks and Zoran Jevtic, in their book *Introducing Foucault: A Graphic Guide*, instead of the term author, Foucault would be more apt to use the term "transdiscursive man" as he viewed himself as an author of theory, tradition, and discipline. Foucault is known for his historical approach to social and cultural topics. For example, in his text *Discipline and Punish*, Foucault approached the study of the modern-day penitentiary system through a historical framework. Foucault started this groundbreaking text with historical research dating back to the 1400's to help the reader understand the changes in the penitentiary system and current methods of legal punishment and reformation.

Foucault chose to write on current social topics of importance to either him or society of that time. Some of those topics include the histories of our health system, our penitentiary system, sexuality, social power, individual power, governmental structures and power. Although some may view his selection of topics as limiting to the time in which they were written, I argue that Foucault's work can be applied to many current social and cultural events/topics – as I illustrate in structuring the analysis in succeeding chapters. Foucault's concentration in detailing the historical foundations of these topics listed above, among others, provides a grounded stance when using his work as a theoretical and analytical framework. How you might ask? Since much, if not all, of Foucault's work is historically rooted, it provides the evidence and reasoning needed to make grounded claims. As I have approached my analysis from a socio-cultural perspective, having evidence that is historical aids in the soundness of my arguments – showing how certain ideas and or constructions of how we view and/or see the experiences surrounding caring for an ill and/or aging parent(s) is present both our social and cultural understandings. While I could write an entire work on the life of Michel Foucault, my focus here is to provide a brief overview of his writings and how he approaches the subjects on which he devoted his life to write about. For purposes of this work, I will now place emphasis on certain Foucauldian concepts and ideas that were used to begin my analysis. It is important to note that this overview of Foucauldian concepts is not exhaustive with respect to what was used in my analysis. The terms and theories selected at the outset of my analysis were selected based on extensive reading of Foucault's work and were theories I, as a critical scholar, wanted to emphasize. I explain the central concepts/terms in what follows.

Power: In relation to discourse, truth, and pastorship –.

Foucault's main reason for discussing discourse is to assist in providing explanation of the rules of right being "implemented by the relations of power in the production of discourses of truth" (*Power/Knowledge* 93). Foucault articulates very clearly in his essay, "Two Lectures. Lecture One: 7 January 1976,"[20] that you cannot define discourse without considering both power and truth. He continues saying:

> There are manifold relations of power which permeate, characterize and constitute the social body, and these relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and the functioning of a discourse. There can be no possible exercise of power without a certain economy of discourses of truth which operates through and on the basis of this association. We are subjected to the production of truth through power and we cannot exercise power except through the production of truth. (93)

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[20] Foucault's essay can be found in the book: *Power/Knowledge: Selected Interviews and Other Writings 1972-1977.*

Foucault asserts “we are forced to produce the truth of power that our society demands, of which it has need, in order to function: we *must* [emphasis in original] speak the truth; we are constrained or condemned to confess or to discover the truth” (93). Notice, in Foucault’s description of discourse, truth is the focus. Discourse, in the political sense, achieves different outcomes for power over the body. Foucault states in his work *The Archaeology of Knowledge*, “We know perfectly well that we are not free to say just anything, that we cannot simply speak of anything, when we like or where we like; not just anyone, finally, may speak of just anything” (216). As articulated in Foucault’s explanation of the constraints on discourse, the political is operating as procedural. Discourse functions as a never-ending apparatus in which the power relations occur. Understanding that discourse is all around us, and that some discourses are more easily penetrable than others, it should make us think: who’s truth is being told? More specifically, is there a separation of our own personal truth surrounding our own health experiences from the larger social construction of truth’s surrounding health, specifically that of the caregiver experience? These questions were used as a starting point to guide my analysis when using the concept of discourse when analyzing the selected comic memoirs for this work.

Foucault’s notion of Pastoral Power is founded upon the Christian theme of pastorship. The pastoral relationship is unique. The relationship is based off an implied knowledge between pastor and sheep; it is an individualized knowledge.[21] As explained

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[21] Foucault’s lecture “Pastoral power and political reason (1979)” can be found in the book, *Religion and culture Michel Foucault,* edited by Jeremy R. Carrette. His full discussion can be found in *Security,*

in the book *Religion and culture Michel Foucault*, edited by Jeremy R. Carrette, "The shepherd must be informed as to the material needs of each member of the flock and provide for them when necessary" (142). First, while keeping watch, the shepherd works; "He puts himself out, for those he nourishes…second, he watches over them" (138). By watching over the flock, the shepherd "must also know each one's particular needs" (138). Third the shepherd's role is "to ensure the salvation of his flock" (137). "It's a matter of constant, individualised [sic] and final kindness. Constant kindness…" (138). This kindness can also be viewed as "devotedness…[or] keeping watch" (138). Unique to the pastoral theme is the understanding of how power operates within this unique relationship. The shepherd wields power over the flock with the primary purpose of the shepherd to guide and/or lead the flock. "Conversely, the shepherd has only to disappear for the flock to be scattered. In other words, the shepherd's immediate presence and direct action cause the flock to exist" (137). Foucault posits that power "only exists in action" (*Power/Knowledge* 98). Foucault raises the questions, "If power is exercised, what sort of exercise does it involve? In what does it consists? What is its mechanism?" (*Power/Knowledge* 89). Policing is also a part of the pastoral relationship. The ideas surrounding the duties of the police, as outlined in Foucault's selected essay *Pastoral Power and Political Reason (1979),* are such that the police see to everything that

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Territory, Population: Lectures at the College De France 1977-1978. Edited by Michael Senellart, Translated by Graham Burchell.

pertains to the happiness of men; including that of man's health.[22] Foucault argues, "Power is essentially that which represses. Power represses nature, the instincts, a class, individuals" (*Power/Knowledge* 89-90). Foucault sees power as a vehicle to repress the voice of the ill. I applied Foucault's notion of pastoral power to analyze the following: Who might be viewed as the role of pastor in the comic memoirs? What influence, if any, does this "pastor" hold in the narrative? What information, if any, is being disseminated within this specific relationship if evident in the stories told? In what ways, if any, is power a relational force within the identified pastoral relationship?

If we look at the role of the Pastor, as Foucault defines and describes, we can identify a connection to Foucault's concepts of discourse and truth. For example, if the role of the pastor is to ensure the happiness of man, including man's health, there would be power relations in place to manifest these desired outcomes. For Foucault, discourse is the cyclical process where power relations occur. In the context of health, one major way for power relations to occur through discourse, as well as Pastorship, is in the form of discipline.

A major argument in Foucault's work is that disciplining acts as a political vehicle for specific power relations over the body. Foucault brings to light a political apparatus regarding the body. He argues that during the classical age, the body became an object of investment. Foucault discovered that more attention was paid to the body from this point forward in history; specifically, focus was placed on training, shaping, and

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[22] Foucault's discussion of Delamare can be found in his essay "Pastoral Power and Political Reason (1979)" (149-151) in the edited book, *Religion and culture: Michel Foucault*.

manipulating the body. Once this cultural shift occurred, techniques were employed to carry out the political nature of disciplining the body: the scale of control; the object of control; finally, modality. For Foucault, "The historical moment of the disciplines was the moment when an art of the human body was born . . . the formation of a relation that in the mechanism itself makes it more obedient as it becomes more useful, and conversely" (*Discipline* 137-138). He continues by saying, "Thus discipline produces subjected and practised (sic) bodies, 'docile' bodies" (138). The notion of the docile body is best used to explain the disciplining of the body as a political force. "A body is docile that may be subjected, used, transformed and improved. . . . . Discipline increases the forces of the body (in economic terms of utility) and diminishes the same forces (in political terms of obedience)" (136-138). In short, the body becomes an investment for both political and social control. Foucault emphasizes, "Discipline is an art of rank, a technique for the transformation of arrangements. It individualizes bodies by a location that does not give them a fixed position, but distributes them and circulates them in a network of relations" (146). Foucault does go into more detail about the ways in which the body can be controlled, for example: through activity, space, movement/gesture, time, and exercise. Foucault summarizes succinctly the notion of discipline and the docile body; so, to use his own words:

> To sum up, it might be said that discipline creates out of the bodies it controls four types of individuality, or rather an individuality that is endowed with four characteristics: it is cellular (by the play of spatial distribution), it is organic (by the coding of activities), it is genetic (by the accumulation of time), it is

> combinatory (by the composition of forces). And, in doing so, it operates four great techniques: it draws up tables; it prescribes movements; it imposes exercises; lastly; in order to obtain the combination of forces, it arranges 'tactics'. Tactics, the art of constructing, with located bodies, coded activities and trained aptitudes, mechanisms in which the product of the various forces is increased by their calculated combination are no doubt the highest form of disciplinary practice. (*Discipline* 167)

Another aspect of disciplining Foucault references is that of self-discipline through the act of surveillance – both culturally and by way of the self. A major component of disciplinary power is a level of 'training.'[23] Through the act of training, "Discipline 'makes' individuals; it is the specific technique of a power that regards individuals both as objects and as instruments of its exercise" (*Discipline* 170). One way this exercise is implemented over others is through the act of observation. Foucault provides the examples of observational types found in society; school buildings, hospitals, and prisons. He suggests, "The perfect disciplinary apparatus would make it possible for a single gaze to see everything constantly" (173). Foucault argues that out of this idea stems the act of surveillance of other(s) and of the self by way of the gaze. For through the acts of surveillance the gaze becomes part of the larger system.

> Although surveillance rests on individuals, its functioning is that of a network of relations from top to bottom, but also to a certain extent from bottom to top and

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[23] For more detail regarding training as an aspect of disciplinary power, see Foucault's chapter, "The means of correct training," in *Discipline and Punish*.

> laterally; this network 'holds' the whole together and traverses it in its entirety with effects of power that derive from one another; supervisors, perpetually supervised. . . . Discipline makes possible the operation of a relational power that sustains itself by its own mechanism and which, for the spectacle of public events, substitutes the uninterrupted play of calculated gazes. . . . It is a power that seems all the less 'corporal' in that it is more subtly 'physical.' (*Discipline* 176-177)

In essence, we see the act of disciplining others, as well as the self, take on the public form as well as the private monitoring – both using aspects of surveillance.

Foucault views the act of examination central to discipline. "The examination combines the techniques of an observing hierarchy and those of a normalizing judgment. It is a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish" (*Discipline* 184). Foucault contextualizes the act of examination in a medical sense, yet it goes beyond the originally intended context. Foucault explains that the act of examining, through an individual being visible, creates a level of discipline. "In discipline, it is the subjects who have been seen. Their visibility assures the hold of the power that is exercised over them. It is the fact of being constantly seen, of being able to always be seen, that maintains the disciplined individual in his subjection" (*Discipline* 187). For Foucault, the act of examination creates objectification. The presence of examination, as Foucault argues, creates visibility of the self to the self and to others. The act of examining thus creates a form of discipline – both by the self and of others. "The individual is no doubt the fictitious atom of an 'ideological' representation of society; but he is also a reality fabricated by this specific technology of power that I have called 'discipline'" (*Discipline* 194).

As articulated earlier, "The gaze is alert and everywhere" (*Discipline* 194). For Foucault, the gaze (in the original context) was used in his discussion of Panopticism – the highest form of regulatory discipline. He defines Panopticism as a "laboratory of power" (204), "a generalizable model of functioning" (205), and "a type of location of bodies in space, of distribution of individuals in relation to one another, of hierarchical organization of disposition of centres (sic) and channels of power, of definition of the instruments and modes of intervention of power" (205). Foucault related this distribution in physical spaces like schools, prisons, and hospitals. Yet later, he clarified its "reach" in noting; "'Discipline' may be identified as neither with an institution nor with an apparatus; it is a type of power, a modality for its exercise, comprising a whole set of instruments, techniques, procedures, levels of application, targets; it is a 'physics' or an 'anatomy' of power, a technology" (215). The idea of Panopticism – discipline through constant monitoring by both hired personnel as well as other prisoners - is a successful form of discipline.

Although Foucault's work on discipline, surveillance, and the gaze is specifying a historical trajectory of societal structures – specifically schools, hospitals, and his well-known work on prisons – his theoretical ideas of how individuals and societies become disciplined is applicable for multiple conversations. When trying to comprehend how members of society, both culturally and individually, respond to and understand health related ideas and messages, it is pertinent to use Foucault's work on disciplining to aid in the analysis and discussion. Foucault has proven, historically, how the body has become a site of discipline. As briefly touched upon earlier, he provided a historical argument for the ways in which the body responds to and monitors both the self, and others, through various forms of ‘disciplinary measures;’ specifically, the “gaze,” “surveillance,” and “examination.” I applied Foucault’s work on disciplining to develop the following questions to aid in my analysis: How is the ill/aging body, as an object, a target of disciplinary power? How is the ill/aging body represented within the comic memoirs selected for analysis? What is the occasion (or need) that makes the body ‘docile’ in the caregiving context? In what ways is the gaze operating in the comic memoirs? How are social discipline and self-discipline represented through the comic memoirs?

The guiding questions presented in this section were used as a means to situate myself in relation to Foucault’s work and to the comic memoirs selected for the analysis. It was not my intention to have every question answered, although in most cases they were – in one way or another. Rather, the questions were developed with the intent to assist me in seeing how Foucault’s ideas and theories could be applied as constructs moving the analysis forward.

Summary

The goal of this chapter was to provide an argument for the importance of studying memoir, in comic form, that focus on the experiences surrounding caring for an ill and/or aging parent(s). To build my argument, I first provided an explanation of the texts selected for the analysis; second, I explained the role our socio-cultural understanding of health plays in our view of health and health related topics; third, I highlighted the importance storytelling and narrative to the project, situating both in a health frame; fourth, I discussed the theoretical and critical orientation used for my analysis, including my orientation toward autoethnography, situating the comic memoir, and focusing on the Praxis of Critical Rhetoric and key Foucauldian terms.

The remainder of the dissertation is structured as follows. Chapter Two focuses on the analysis of my own stories. Chapters Three and Four focus on the analysis of the comic memoirs of Chast, Fies, and Walrath, integrating connections to my own experiences where warranted. The following is the list of the analysis chapters:

Chapter Two – Pastoral Care of the Body – Personal Experiences Surrounding the Care of an Ill/Aging Parent

Chapter Three – Three Narratives Alike and Different - Lived Experiences Through Orientation(s) of the ‘Other’ Surrounding Caregiving

Chapter Four – Three Narratives Alike and Different – Lived Experiences Through Orientation(s) of the ‘Self’ Surrounding Caregiving

Chapter Five – Dominating Bodies and Restricting Freedom – reflects on the analysis offering major discoveries that developed out of the analysis, major contributions, key insights of the analysis including the role and significance of the work, implications for future research, and concluding remarks.

Conclusion

As I close this chapter and move into the thematic analysis of my own stories as well as the works of Chast, Fies, and Walrath, I am reminded of my own still vulnerable self as it reflects on the stories others. I am hyper aware of my own self, while also being mindful of the concerns and struggles that others face. I understand that I cannot remove myself from my work, my analysis, nor would I want to if I could.

My experiences, in all their realness and rawness, are just that, mine. I no longer shy away from who I have become as a person, a researcher/scholar, and writer. I understand this person is ever changing and growing. I embrace my critical ontology – in both life and academia, my belief that stories are purposeful (to what level and for whom is decided by the individual who is reading), and my personal stance that our own knowledge of health (as the all-encompassing term it is) can both hinder and help us see the reality presented to us in whatever format we are looking at.

These aspects of self, that I have learned to embrace and not shy away from, are ever present in my analysis. For I have learned that if I am not true to myself, in what I write (no matter the format) and in the arguments that I make, then I am silencing myself. This work is a testimony to what can be produced when you unlock fear, embrace self, honor solitude, fight off self-doubt, accept change, and enter the conversation saying "Fuck it . . . where's my sword?"

CHAPTER TWO: PASTORAL CARE OF THE BODY – PERSONAL EXPERIENCES SURROUNDING THE CARE OF AN ILL/AGING PARENT

"Memoir must be written because each of us must possess a created version of the past . . .. We must acquiesce to our experience and our gift to transform experience into meaning."

Patricia Hampl *I Could Tell You Stories* (32)[24]

In a conversation with Dr. Jimmy Manning, he suggested that I keep asking myself three questions during the writing process: What are the stories I want to tell? What is the importance of each story? What does each story accomplish? With these questions as a guide, I asked myself: How can I organize these stories to share my experiences in a meaningful way to you, the reader? My biggest challenge in this process is that I am actively experiencing my time as a caregiver in relation to my dad's illness. While I write from my personal journal notes, in examination rooms, or from notes taken on various articles and books (academic and non-academic) from personal research that I have conducted on the topic, I also have the privilege to be able to write about an experience that just took place or that is actively taking place. Instead of writing my stories after my father is gone, I am writing in the moment while also writing about past experiences I took notes on or journaled about. I kept thinking, how will I organize my stories so that they will make sense since some happened a few years ago and some happened yesterday? Then I realized that I'm trying too hard. I recognized that I don't think in an organized fashion and that I often must work backwards, in-between and

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[24] I will explore this idea more in the discussion section of this chapter.

around. While I have documented these moments in my personal journal, in note fashion, in scribbled thoughts on random pages, I am still having to recall these moments and build on them.

I have discovered that these first moments were the hardest for me to express. I believe this to be true, in part due to shock, anxiety, and stress surrounding these initial moments. I believe this to also be true as I was in my first year of my doctoral program, hence away from the direct, daily contact with these issues that I now experience in real time – meaning that my knowledge base in heath communication literature was sparse at the time. Engaging in the process of meta-analysis on my own journey, I have come to discover that as I moved through my program of study and began to experience more with my father, I used the academic literature to help me navigate difficult situations and various communicative interactions I have had over the course of this journey. My academic sense has provided me the skills to communicate with doctors, medical practitioners, as well as friends and family of my dad; but sadly, oftentimes my academic mind shuts off when communicating with my dad in certain situations. Emotion drives many conversations – sometimes for the good and other times for the bad.

This chapter focuses on the caregiver experience. To fully grasp the caregiver experience, I have provided short narratives. These narratives are divided into two parts. The first part focuses on an ‘other’ orientation of caregiving – using stories about my dad (including a brief family history and short medical history of my dad, and various stages of his diagnosis), while the second part focuses on a ‘self’ orientation of caregiving – sharing stories about me (including reflections, journal entries, and short stories). I have divided these moments by both memory and time. While my narratives do not cover every moment or every doctor visit, they do provide insight while also creating the ability for you, the reader, to become aware of the dual orientations, both ‘other’ and ‘self’ that surround the caregiving experience.

The stories in Part I reflect on an ‘other’ orientation of caregiving while Part II reflects on a ‘self’ orientation. What do I mean by ‘other’ and ‘self’ orientation? I hear my dad telling me to “Simplify Annie, simplify.” For me, the ‘other’ and ‘self’ orientations of caregiving help explain how I have given visible or tangible form to the idea, feeling, and quality of the role of the caregiver. My own journey as a caregiver has exemplified both – ‘other’ and ‘self’ orientations; ‘other’ being the lived experiences of caregiving that include the projected social expectations when in this role of caregiving, ‘self’ being my self-reflexive lived experiences surrounding being a caregiver (how I feel/felt as a caregiver; how I internalized this role). What is important to stress is oftentimes the orientation of ‘self’ is interwoven and interlaced with the orientation(s) of the ‘other’ for one cannot wholly separate self from how one operates in the role of caregiver. Yes, at times this muddies the waters but for purposes of this analysis, it was the most logical way to operationalize ‘other’ and ‘self’ orientations.

In the book *The Power of Comics: History, Form, and Culture*, authors Randy Duncan, Matthew J. Smith, and Paul Levitz define memoir as “a form of writing about one’s own life that often focuses on particular life-changing incidents and their consequences” (389). In Chapter One, I defined memoir as “a written account of an event that one has lived through or of the life or character of a person whom one knew”

(*Oxford American Dictionary* 554). By sharing my experiences of being a caregiver through the inclusion of narratives focusing on orientations of ‘other’ and ‘self’, grounding them with literature and outside knowledge when necessary, I can more easily express the connection between the theoretical arguments being made within this chapter as well as the connection between my own experiences and the selected comic memoirs that I explore in Chapter Three and Chapter Four.

The chapter is organized as follows: First, I provide my own narratives about caregiving;[25] Second, I provide reflections connecting my own experiences to published scholarship; Third, I provide a short summary and lead in to the second analysis chapter.

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[25] This first set of stories were the most difficult for me to write. The reason? I am not sure. I found there to be an internal struggle; making sure the timeframe was presented accurately. I also struggled on a mental and emotional level about the content of what was being shared. While these are stories about me and my dad, he is still my dad and a person going through a terminal illness. He is facing his own mortality. He is often doing it alone or with a very small group of people near. I know I can be a burden to him; that my overbearing nature can come into play if I don’t agree with his choices, yet I also know the comfort I bring him (often going unstated between us). These emotions factored in to my abilities to come back to this time, although well documented, and narrate in a meaningful way, being true to the experiences. This first section is chronological in order, interspersing moments of personal reflection.

Part I – ‘Other’ Orientation(s) of Caregiving Moments

A Brief Family History

My mom and dad met in Arizona.[26] As the story goes, my dad asked a friend to get him into a Hungarian club that was hosting a dance so he could meet women (as it was an untapped resource for available women). My mom was at the club for the dance as her and her mother were members of the Hungarian community. I’m not sure how they met or if that is even important. What I do know is that my mom was seeing someone else that night she met my dad. Did they dance? I don’t know. I do know they were engaged three months after the dance and married three months after that – they married August, 1969.

Five years after their marriage, my sister came along. She was born in June of 1974. Four years after, on a hot summer July day, I arrived. Four years from my arrival (1982), my parents were divorced. I don’t remember the divorce or the years that followed expect a few moments here and there. I do know that my mom was at every family meal my dad’s family had. These meals included religious celebrations like Christmas, Easter, and First Communions. She was also invited to Thanksgiving, as well as family birthday parties, weddings, etc. My dad and his family made sure my mom was

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[26] In her book, *Black Sheep and Kissing Cousins: How Our Family Stories Shape Us,* author Elizabeth Stone argues, “As folklorists have observed, the courtship story tends to be a staple in any family which tells stories at all . . .” (64). She goes on to say the courtship story “is the first collective memory of the new family, paradoxically shared even by children who were unborn at the time” (64). The observation by Stone is true of my parents’ courtship story as well.

invited and felt welcome in every instance. It wasn't until I was much older (around high school) that I realized that this was not the norm for other divorced families. Many times, friends would ask me if it was odd that Mom and Dad still talked and saw each other on a regular basis, that they were nice to each other. I responded, "No, why would it be?" Little did I know this was not the norm.

Being that my mom and dad are divorced yet still communicate regularly, our family is unique. We are also unique in regards to how we communicate with each other. My mom said, "Well, some would say we are codependent while others may say we just care. I like to think we care about each other." It is this level of care that is communicated through our actions and our communication patterns. My dad comes from a family where he spoke to his parents every day, if not multiple times a day. He tried to visit them every day and if that wasn't possible, he did see them at least once or twice a week. My mom has no living relatives that we know of. She lost her sister when she was nine, her mother in her early forty's. Why does this matter? It sets the tone for the type of communication that I have with my family and what type of communication expectations have been set for our family. What are those expectations? We call each other – sometimes daily. If that cannot be achieved, it's every other day. We see each other when we can. We let each other know what is going on in our lives. If we are sick, if we are well. This communication continued all throughout my childhood, into my young adult life, when my sister went away to college, when I was at college (although living at home), when I got married . . . you get the picture.

Ohio University - Fall 2012

Upon being accepted into the Doctoral program at Ohio University, I was required to move from Omaha, Nebraska to Athens, Ohio. In the Fall of 2012, my dad made the long journey with me from Omaha to Ohio. We packed the U-Haul trailer, drove the eight hundred-plus miles in two vehicles, unpacked the U-Haul, set up my apartment, and explored the tiny town of Athens. After I was settled, about a week or so, my dad returned home to Omaha. He called almost daily, as did my mom and sister. Even though I was in Ohio for my program, the expectation of regular calls to give updates didn't change. In fact, it probably increased. The Fall of 2012 came and went. I spoke to my parents and sister regularly. I came home for the winter break (thankful for the time off), took a vacation with Husband, and headed back to Ohio in early January.

The Call – Spring 2013

As phone calls were (and still are) a regular thing for our family, I didn't expect anything different with the type or the number of calls I would be receiving from my family now that I was back in Ohio for the spring semester of my first year. Little did I know, this would change.

The Call, Part I

The initial call happened in the Spring semester of 2013; February to be exact. Being away was already difficult for me as our family has always been close. If Mom or Dad were sick, I would always know of the ailment. If Mom or Dad needed something, I would always know about it and try to help. We were a family that talks about everything;[27] this is what I have learned to accept as normal in our family. So, while it was shocking to hear my phone ring at one-thirty a.m. it came as no surprise when I looked at the phone (wondering who is calling me at this hour) and saw my mom's name. I grudgingly, with sleepy eyes, picked up the phone. She was sick, in a panic, and didn't know who else to call.[28] Even though I was eight hundred-plus miles away, I told her I would help her as I could. I had two real options: call an ambulance (which she repeatedly told me she didn't want as she "just wanted to know which hospital to go to that would care for her") or call my dad to take her to the emergency room. I inquired with my mom once again about her status, if she could drive herself, her symptoms. I listened to how she was breathing, that she was slowly calming down. With all these factors in mind, I went with option B – to call Dad – as I did not think Mom was in danger of losing her life. I told my mom I would call Dad to see if he could take her in and that I would call her right back.

The Call, Part II

My dad answered, as he always does but sounded off. It could have been that it was close to two a.m. or it could be that he was up and down all night from his back pain.

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[27] Looking back to my dad's relationship with his parents, I can see how our communication has developed into what it is. Dad talked to Grandma and Grandpa every day, often seeing them every day as well. When my grandpa became sick, my dad and his sister (my aunt), would take shifts to be there with him and Grandma. They did not want them to bear the illness alone.

[28] To be fair, my mom has lived alone for over ten years. She has been divorced from my dad for thirty-five years and never re-married. She has had an increasingly difficult time with upper respiratory issues – chronic bronchitis – while never a smoker.

I didn’t think too much of it so I pressed on with the reason for my call. I informed him of Mom’s condition. Again, he was slower to respond than normal. He seemed really tired and groggy so I asked him if he was okay. There was hesitation in his response. After a long pause, he told me that he hadn’t been feeling well but that he would go pick her up and take her to the hospital. I paused for a moment. Do I inquire about how he’s doing? Or do I let it go for the moment and focus on Mom? I had to know so I asked, “Why have you not been feeling well?” Another long pause followed my question. “Tell your mom I’ll be there in about forty-five minutes. I need to take a shower before I go anywhere.” Something was not right. I pried, “Dad, what’s going on? Are you sick? I can call an ambulance for Mom; just stay in bed.” Another pause. I had to decide, do I let this go for the time being or do I keep prying? Without hesitation, I asked, “What’s going on with your health?” Dad replied, “Annie, I haven’t been out of bed in four days.” The sound of my nickname crushed my heart. He tried to divert my question back to Mom but I probed until he finally opened up. “I was in the hospital last week. I didn’t want to tell you over the phone. I wanted to wait until you were home for Spring Break . . .” I interrupted him, “Tell me what Dad?” “I (pause) I have cirrhosis of the liver.” In a matter of minutes, my life had changed. Two parents ill, one with a terminal disease.

After the Call

I couldn’t go back to sleep after talking to Dad. I made sure Mom made it to the hospital but in the back of my mind, all I could think about was his news. His diagnosis was stuck in my mind as I drifted in and out of sleep over the next few hours. I awoke unrested, wondering if it was a dream, quickly realizing I was in a new reality; one with a new illness. I called my sister and told her the news. Her response was like mine, one without shock, without surprise, but with somberness. I wondered if this reaction was normal. If somewhere, deep down inside I was prepared for news like this or if I was in shock. Over the next twenty-four hours, my sister and I were very methodical with our approach to the news. She inquired about how much research I had already started doing, knowing that the likelihood of me already doing research was high, and she told me that she would begin as well. She also said she would call Mike, her brother-in-law, who is a physician and continue researching online. I chose to continue researching the databases of medical journals and to also reach out to my good friend and retired family physician, George.[29] I was determined to be prepared when I could be home and go to my father's appointments with him. I wanted to be well versed in the disease and be able to interact intelligently with the attending physician and other medical personal on behalf of my father.[30]

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[29] Our family is blessed by having family members and/or close family friends who are physicians. I understand that not all people are afforded this blessing.

[30] At this point in my doctoral program, my area of study was not yet determined. I was going into this news exhausted from school, the news of my dad, trying to learn as much as I could about the disease. My knowledge of health communication literature at the time of learning of my dad's illness (late February, 2013) through Spring of 2015 was limited. During the Spring 2013 semester, I was enrolled in course titled Foucault and Health. How I came to take this class is a miracle in and of itself. I had a random conversation with Dr. McKerrow whom I spoke to only a few times during my first semester at Ohio, one being at the tail end of fall semester. He mentioned he and Dr. Harter were co-teaching a class in the spring bridging Foucault and Health Communication. While the Foucault part was of interest to me, the health

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Back Story – Dad's Preexisting Medical Conditions

Looking back, I can think of a few moments (almost in photograph quality) of where and when my dad was healthy. One moment was the time where we were in a pool at a motel and he was picking me up out of the water and throwing me across to land with a big splash. Another was when we were driving to Worlds of Fun in Kansas City (in the heat of the summer) and I asked for a glove because "my hands were cold" when I was really trying to find something to clean up spilled Dr. Pepper on the floor of his new Buick. Or there is the time I asked him why he had perma-creases down the front of his jeans (I later discovered that he had them sewn that way). Yes, these all happened and they are quite vivid in my mind. While these memories stand out, they are often replaced with the memories of Dad's back hurting, images of him struggling to move (but trying to hide it), Dad not coming to family holiday celebrations because he was not feeling up to

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communication side (at that time) wasn't at the top of my list. Dr. McKerrow encouraged me to take the class as he said he thought it would be of interest to me. He said that, even while it may not end up being an area of study for me, it might be cathartic due to my personal health struggles. I listened to him, I mean, who wouldn't listen to advice from Dr. McKerrow? While taking the Foucault and Health class, I was introduced to Debora Lupton, Elizabeth Grosz, Arthur Frank, and of course Michel Foucault. These authors were sinking in my mind all while learning of my dad's diagnosis, reading more on his illness, trying to navigate through other health communication literature so I could be as knowledgeable as I could be when going to appointments with my dad. No matter how much I read, I felt as though I was at a disadvantage. This feeling drove me to read more, study more, and ultimately lead me to my area of emphasis in my doctoral program.

it (either physically and/or emotionally), Dad sad, Dad mad, Dad manic, Dad being Dad. No matter what has happened, Dad is and always will be Dad. I will stand by him, I will get mad at him, I will wonder about him, I will question what he would be like if he didn't have the list of ailments he has lived with for most of his life, but no matter what, I will always love him.

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Re: J. G.G. III: The following interlude summarizes my dad's medical history

DOB: 08/30/1945

Back/Lower-Back Medical History

1976	First Laminectomy
1977	Second Laminectomy
1985	Third Laminectomy
1990	Fourth Laminectomy
1992	Fifth Laminectomy
2012	Rhizotomy/with Neck

Interspersed between back operations, twenty-five back epidurals were administered with Cortisone, Novocain, and/or Morphine. Morphine drips to his back were also administered as treatment during this time. His final epidural was administered in 1994.

Neck Medical History

2004-2012	Epidural treatments
2012	Rhizotomy/with Lower Back

Twenty-five neck epidural treatments were administered with Cortisone, Novocain, and/or Morphine. Neck epidurals have not been administered since late 2012.

Mental Health History

1980	Diagnosed with bipolar disorder – receives ongoing treatment.

Other diagnoses include arthritis, high blood pressure, and severe hearing loss. As if this was not enough for one person to manage, my dad now had yet another diagnosis to manage – cirrhosis.

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In conversations with my dad that happened shortly after I learned of his news, I asked him what he knew of his new diagnosis. His only response, "It's a terminal illness." I probed a little deeper to find he had no information to offer beyond his simplistic response.[31] I do acknowledge that when someone is given the news that they

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[31] I later learned that my dad had received this diagnosis in 2010 but did not tell anyone. I, along with my family, was responding to the news as though this was the first time he had heard of the diagnosis as this

have a terminal illness, it can cause shock, but this situation was different. My dad had been a product of the medical system for decades. His simplistic answer spoke volumes; the underlying messages of defeat and lack of control haunted his response to me. For the first time, I felt a shift occurring.

I visited my dad while home over Spring Break, shortly after his call. We discussed his disease, what his plan was (I figured out he really did not have one), and what he would do until I was home for the summer. Knowing his sister, also a retired nurse, lived a short distance from him eased my mind a little (not much by any means). Going back to school was very difficult. I knew my semester would be over sooner than I would realize but I wondered how I would manage the next three years. I had to compartmentalize, something I was never good at doing.

Summer 2013

Summer 2013 is quite a blur. We saw physicians, specialists, my dad's primary care physician (multiple times over the course of the summer) and I felt as though we got no real answers. Dad was hospitalized for confusion and other complications.[32] After he

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was the first time we had heard of this news. I am not sure if he was quiet due to not remembering this diagnosis or if he was silent as a response to the news he had received. As Debora Lupton suggests, "Receiving bad news about one's health and entering into 'deep illness' can lead to a profound state of shock, disorientation and the feeling that one's control over one's life has suddenly been called into question" (*Medicine* 85).

[32] This was the first hospitalization due to complications related to cirrhosis, yet we did not know it at the time.

was released from the hospital, we went to a follow-up visit with his primary care physician.

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Re: J. G. G. III

DOB: 08/30/1945

Subjective (History of present illness): Patient is a 67-year-old male who was recently hospitalized due to dizziness, distended stomach with fluid buildup, and loss of appetite. Patient is of sound mind inquiring about illness, loss of muscle, and changes in skin texture. He seems very concerned regarding the previously stated issues and keeps referring back to his previous body build prior to his muscle loss. Patient is interested in gaining back lost muscle mass and is inquiring about lifting routines and protein supplements as potential avenues to achieve desired goal.

Objective (Examination): Height: 5'10" Weight: 200 BP: 122/7

Patient is an older gentleman and is very matter of fact with his medical issues. Skin has aged considerably since last seen. Patient has lost most of his muscle mass. Stomach is distended and appears to be retaining fluid. Despite his diagnosis, patient makes light of his illness and his physical traits: loss of muscle, his skin texture, and his distended belly.

Assessment: Purpose of visit was to go over test results during his recent hospitalization. While hospitalized, a series of tests were run. It seems multiple tests were re-run. Hospital did not contact primary internal medicine physician or admitting physician while hospitalized. Hospital did not identify patient as having cirrhosis. Sent home from hospital on a mild diuretic for stomach distension. Discussed stages of cirrhosis with *patient, fielded questions from patient and patient's daughter. Spent over an hour and a half with patient and his daughter. Patient could not understand how he got this disease. Emphasis was placed on different ways patients can get cirrhosis, focusing on fatty liver and alcohol consumption. Patient identified as never being a big drinker. Informed patient, "It's just bad luck." Patient also inquired about a liver transplant, saying he did not wish to have one. Informed patient, "Even if he wanted a transplant, he didn't qualify as he is outside the age-range." Patient again stated that he did not wish for a transplant. Plan: Increase dose of diuretic and suggested patient see dietitian at clinic. Reminded patient of his appointment with the liver specialist next week.*

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There comes a time where you no longer see your father as the dad he once was. I can remember when he would jump in the swimming pool with me, or when he would scream all the way down every massive hill of a rollercoaster just to make me laugh, or when he would take me to the Aksarben (Nebraska spelled backwards) parking lot to teach me how to drive when I was fourteen, without Mom knowing. The memories are still there; the image of Dad in a white V-neck t-shirt, boot cut denim jeans with a crease up the front, cowboy boots, and his silver and turquoise cross around his neck which he never, to this day, leaves the house without. That is the dad I will always see in my mind. What I see now is a very different picture.

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The image of my father sitting on the examination table is one I will never forget. A sixty-seven year-old man, looking as though he was eighty, acting as though he was a young child. For the first time, I saw a mixture of fear and sadness in his eyes. He shifted nervously, the sound of his Nike exercise pants swishing as he moved. No longer did his legs fill in the pants as they once did just a few months prior. I could now see the outline of his thin legs, lacking any muscle they once had. He moved his watch from side to side as we waited for the doctor to come in. Small talk was not an option at this moment. Just being there is what he needed, nothing more. I had my list of questions prepared, my cell phone out to record the appointment, and I calmly waited with my father. Our roles have now started to change: I am now the caregiver, while he is now the child.

Over the course of the appointment, the doctor discussed my father's diagnosis of Cirrhosis, reviewed his test results from when he was recently hospitalized, identified he was diagnosed with this same disease (Cirrhosis) in 2010, and fielded questions about his "newfound" illness.[33] My father tried to make jokes along the way, being the strong man he is, but his jokes disappeared over the hour and half we met with the physician. Confusion was written all over his body. Although he kept asking repeatedly, "How? Why?" he did not put up a fight. My father continued to ask very basic questions focusing on changes in his body, what he could do to slow down the disease, and again,

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[33] It was at this point that I realized that my dad had been ill for a few years but did not tell anyone. I am not sure if he did not understand what that 2010 diagnosis meant, if he had forgotten about the diagnosis, or if he didn't want to acknowledge the disease. Either way, when we were at the doctor's the information being shared with him all seemed new to him, as though he had never heard of this diagnosis before.

what could have been the cause of the disease for him. The only answers the doctor could provide were, “It’s just bad luck” and “It is most likely caused by a fatty liver; which is both genetic and can also be due to diet.” “Neither of which,” she continued, “can be controlled.” He took in the information being shared with him from the physician, and did the only thing he could do. He accepted it.

Knowing his daily battles with pain and feeling his hopelessness fill the room, I decided to take over the discussion for my father. I pulled out my notes and the questions my sister and I constructed and began the long inquiry through conversation with the doctor. A few questions in, she asked if I was a medical student, saying that I seemed to know a lot about the disease. I informed her I was doctoral student studying communication. It appeared she was taken aback by my answer, but I quickly pressed on with more questions. I situated more questions between information that I wanted to verify with her and what she thought his timeframe of survival was. I spent most of the conversation focusing on, what seemed to be, the lack of communication between the hospital and the doctor’s office. I questioned her about the tests administered while my father was in the hospital and why the specialist was not called when he was admitted to the hospital, since his records document his diagnosis. I pressed further asking why there were no checkups completed from 2010 to 2013 regarding his illness. I kindly reminded the doctor that they see my father on a regular basis, at least once a month, so I was curious how he could not have been asked about this specific illness and if he had been in for his checkups. Out of frustration, I then asked, “How did he not know the seriousness of the illness?” “Wouldn't have that been something communicated to him?” My father just sat there on the examination table, legs dangling, looking at me in total shock and with a little bit of embarrassment. The physician sat there, speechless.[34]

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After the follow-up appointment with my dad's primary care physician, I knew I needed to find a different team of doctors to handle his diagnosis. His primary care physician was fine. I respect her and we get along fine, which we still do to this day. But I knew he needed a different care team for his Cirrhosis diagnosis. I went back to the internet and conducted searches, I got lost in the medical journal databases through the University library, I spoke to my friend George to see if he had any opinions. Being in Omaha, we are privileged to have two nationally recognized schools of medicine here. I knew between one of them, I would find the right team of doctors. I just had to look.

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It was a rainy summer afternoon and I had not yet gotten in my run. Due to the thunderstorm, I decided to run on the treadmill to avoided the lightning and rain. I headed down the basement stairs, then to the large closet where my treadmill is stored. As I got settled for my run, I saw a stack of papers from a previous Qualitative Research Methods class I took at University of Nebraska, Lincoln with Dr. Creswell. I paused on the

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[34] To this day, I can remember sitting in the doctor's office with my father. I remember being protective of him and his needs, as I still am to this day. I recall thinking, this is the first of most likely many appointments to come. Although I was well read, I was completely out of my element, I was alone with my father, and we were going through this experience together. I never knew these thoughts would haunt me then and continue to haunt me even now.

treadmill and stared at the stack of papers and journal articles. As if struck by lightning, I hopped off the treadmill and grabbed the stack of papers and ran up the stairs. I searched through the stack looking for a specific article we read in the class. It was about patients' experience with waiting for a liver transplant. I could see the article clear as day as I was searching the stack of papers. When I came to find the article I was searching for, there it was; the article along with the names and institutions of the doctors that conducted the study. Doctor Michael F. Sorrell, M.D., James H. Sorrell, M.D., University of Nebraska Medical Center. The next day I called my dad's current attending Gastrologist (not at the Med Center) and asked him to refer us to the Med Center.[35] It took six months to get an appointment, but he was finally seen.

Fall 2013

On November 12, 2013, my dad was re-diagnosed with Cirrhosis by the team of doctors at UNMC. I was not at this appointment. My Aunt Margie went with my dad for me. She called me after to inform me of how the appointment went and that she gave the doctor's my name as initial point of contact. I asked her who his physician would be. I held my breath knowing it was a longshot to be assigned Dr. Michael Sorrell. She responded, "Dr. Sorrell. We got lucky, honey. He is with the best." Luck? Miracle? Chance? I didn't know and I didn't care. He was in, with the best.

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[35] I asked for this referral for two reasons. First, my dad's current attending Gastrologist mentioned he may be moving out of state. Second, I wanted to be with the best team of doctors. Knowing the Med Center is one of the leading transplant hospitals in the nation for liver and kidney transplants, it was a no-brainer.

Shortly after his appointment in November of 2013 my dad was re-evaluated in January of 2014. On January 23, 2014, he was diagnosed with Ascites[36] and Chronic Kidney Disease (CKD) Stage 3.

Summer 2014

I can remember when I couldn't wait for summer to arrive. As a child, I longed for no school, being able to stay up later, watch for lightning bugs, go to the pool, just be. The summer of 2014 redefined summer for me. While I still enjoy the early sunrises, the bird chirps waking me up, the long summer days, I am not sure I will see summer with my rose-colored glasses on anymore. The summer of 2014 was a summer of firsts. It was the summer that I felt like I became an adult. I gained true responsibility for another person without having a child. As expressed earlier, I felt as though my dad was becoming my child. The big take-a-ways of Summer 2014? My dad starting paracentesis[37] and going through a forty-hour pre-transplant evaluation with my dad. The lazy summer days were slowly drifting away.

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[36] Ascites is the accumulation of fluid (usually serous fluid which is a pale yellow and clear fluid) that accumulates in the abdominal (peritoneal) cavity. The abdominal cavity is located below the chest cavity, separated from it by the diaphragm. Ascitic fluid can have many sources such as liver disease, cancers, congestive heart failure, or kidney failure. (Nabili "Ascities" medicinenet.com)

[37] Paracentesis is a procedure that removes fluid buildup that has collected between the muscles and abdominal wall. The fluid that builds up is called ascites. Ascites is often a symptom of cirrhosis, cancer, infection or other medical conditions. A needle is used to pull the unwanted fluid off the belly. For patients that go through paracentesis for liver issues, this procedure is used to remove fluid, to reduce pressure and

The Summer of Firsts

After being diagnosed with Liver Disease and then Kidney Disease shortly after, in all of my conversations with my dad, the word transplant was never in his vocabulary. The word “No” to the question of the possibility for transplant was. My dad repeatedly told physicians that he was not interested in a transplant. Now, I know that doctor’s must present patients with all their options for treatment but I was very aggravated how physicians kept pushing the issue when my dad clearly was not interested. His reasoning, he is in constant pain with his back; even with a new liver and kidney, this pain would not go away. So, my dad was adamant about his answer of no. He had lived his life. He was tired. He was tired of being in pain – these were my dad’s words. It wasn’t until he found out my older sister was pregnant and her first baby being due in October of 2014 that his mind started to shift about the possibly of a transplant. I still believe this was his motivating factor to go through the pre-transplant evaluation process. That and starting paracentesis.

The Removal of the Liquid – aka Paracentesis – Part I

On June 11, 2014, my dad went in for his first paracentesis.

Pre-transplant Evaluation.

Initially, my dad was against any idea about a transplant. Somewhere in time, this shifted and my dad decided to go through the pre-transplant evaluation. What is fascinating about the pre-transplant evaluation process is the idea of hope. Hope that you

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pain caused by the unwanted fluid buildup. The procedure itself is done when needed by the patient. For more information, see https://www.medicinenet.com/ascites/article.htm.

will pass, hope that you will be selected as a candidate, hope you get a call. Hope. The actuality of the process is that it is long, intrusive to the patient and their family, and open to untruthful answers. To be fair, this type of screening process must take place due to the sheer number of people that need organs. What plagued me was the ability to speak untruly because a person is faced with their own mortality.[38] In a span of two weeks, we spent forty hours in appointments, tests, psychiatric evaluations, classes, coaching, and deep conversations about becoming a transplant candidate, what happens when you become a transplant candidate, if you get a call for organs, and the wait. In all the talks, workups, and visits, nothing was said about what would happen if you were not chosen. Furthermore, nothing was spoken about what might happen if you were chosen as a

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[38] During the full evaluation process, I was honest about my dad and his behaviors. While he got very upset at me for speaking truthfully, I did not want to mislead the team of physicians and nurses. The process of organ donation is much more detailed than I provide here. When being evaluated for an organ transplant, you are possibly getting the gift of life from someone who has lost or is losing theirs. I do not take this responsibility lightly which is why I was forthcoming about my dad. This is also why family members are interviewed during the evaluation process. To ensure the patient's answers are honest. While I do believe the system can be cheated, during this entire process I thought a lot. I thought about my dad's answers. I wondered why he stated one thing but did another. Why he said he would change habit A when he had no intention of changing habit A (as he said after we left each day). I was faced with a harsh reality. Do I lie about my dad to give him a possible chance at becoming a transplant candidate? Or do I speak the truth to not let the idea of a possible chance at a second round at life fester? That summer, I cheated on my Dad. I spoke truthfully of his daily dietary habits, his not listening to doctor's suggestions and treatment plans. I felt I had a moral obligation to both my father and to the possible donor that was providing the means at a second chance for life.

candidate but never got a call. The appointments were built on hope. Hope you made the list, hope you got the call.

What was frightening during this time was learning about the transplant process. It was hammered into our heads (well my head, I'm not one-hundred percent sure if my dad truly realized the medical side to a transplant if selected and called). If you are selected, you have a very small window of time to make it to the hospital to ensure organ life. The recovery period from a transplant is six to eight weeks of hospital stay, then another six to twelve months of around the clock care by a family member (or nurse if you can afford an in-house nurse). During this twelve-month recovery period there are multiple checkups, medicines that must be administered and strict diets that must be followed. What can be missed is the fact that once you endure a transplant, you must take specific medicine to ensure your body does not reject that organ, for the reminder of your life. You are also required to get re-checked, re-evaluated, and must be monitored by doctors for the rest of your life as well. For a person gaining a life, that may not seem like much. For a family member listening to all the information, I was thinking to myself: *How do families make this happen? How do people without families make this happen?* While I was happy of the possibility of my dad having a second chance at his life, how was I going to make it happen if he did make the list and get the call? Instead of joy, fear and worry consumed me. His pre-transplant evaluation was completed on July 8, 2014.

Post-transplant Evaluation.

About a month after the full pre-transplant evaluation was complete, we were in a follow-up appointment with my dad's liver doctor (well, the team of doctors). Dad was told that he made the transplant list. I was thinking to myself: *How on earth did that happen?*[39] I was happy, shocked, and scared. The doctors informed us of the waiting process, reminded us again of the how a person is selected from the list, and reminded us that on average fifty to seventy percent of applicants are selected to be placed on the list and out of those fifty to seventy percent, less than ten percent get a call.[40] This can be due to suitable donors, matching donors to individuals waiting for a transplant, and advancement of the disease in the person waiting for a transplant. The only thing to do now was wait.

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We waited. And waited. August arrived and I had to head back to Ohio for year three of my program – Fall Semester. Dad's treatment plan went on. I went to doctor appointments when I could – trying to make his six-month check-up around school breaks. It was difficult but we managed. During this time, Dad was on the monthly paracentesis removal plan.

Fall/Winter 2014

During the fall, not much changed with Dad's treatment. I would call to see how he was doing and feeling. I would stay positive when he got down.

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[39] Yes, my pessimistic side was showing but I was truly dumbfounded how he made the list between all his pre-existing conditions, his poor dietary choices, his inability or unwillingness to follow strict doctor's orders; the list goes on and on.

[40] These statistics were based on the specific organ being needed, the center of which my dad was evaluated through, and the time of my dad's evaluation workup in 2014.

The Removal of the Liquid – aka Paracentesis – Part II

In December of 2014, my dad moved up to a semi-monthly fluid removal. When I came home for winter break, I could see a small level of decline in my dad. I picked up on this as I did not see him every day as others did. I took him to his paracentesis appointments during the time I was home. I sat in on the procedures with him, I witnessed the toll it took on his body. I started questioning how long he would be able to live on his own. As all breaks are, my time at home was short.

Spring Semester 2015

January 2015 arrived and once again I had to go to Ohio for the Spring Semester of my third year of course work. Not that leaving was ever easy, but this time it was more difficult for me. I could see his decline. I anticipated what was around the corner. I knew I had difficult discussions coming up. While at school for my spring semester, my dad went in two times a month to get his fluid removed. With each passing month, I questioned what would happen in three months or six months from now. I had the chance to come home for Spring Break in March and again, I saw more decline in my dad's physical and mental health. He didn't seem the same, even from a few months back. After arriving back at school to finish out my semester I wondered, could I do this for another year? Would Dad be able to do this alone for another year? What happens if he has a rapid decline? I had to decide if I inform my program of my dad's declining state or if I push through and finish out the program. After much deliberation, many calls and conversations with my dad's doctors, conversations with my advisor, the choice was clear. I needed to be home. After the conclusion of the spring semester, I packed up my apartment, rented a U-Haul with a tow-behind flat bed for my car, and drove the 860-ish miles to home - alone. Home to be with my dad, home to be with Husband, home to be by family, home to write my dissertation; I was home.

At the end of May, 2015, my dad graduated to weekly paracentesis appointments; just one year after the initial start of these appointments.[41] I couldn't predict the future, but I knew permanently coming home when I did was the right thing to do.[42]

Summer 2015

Summer 2015 was uneventful as uneventful goes for a terminally ill person. I made it a point to do activities with my dad. Husband and I took him to a College World Series game, we had him over for movie night, we took him to the restaurant of his choice for his birthday: Red Lobster.

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[41] Currently, my dad is on the weekly removal plan. On average, he gets six-nine liters of liquid removed. To put that into perspective, that is three to five 2-liter soda bottles of liquid they take off his stomach weekly. The fluid averages to be between twelve-twenty pounds. Every week, he gains twelve-twenty pounds of fluid and has that same weight taken off in a span of two-four hours (the average appointment time).

[42] Going off intuition, I could foresee the complications that could possibly take place in the near future. Not knowing the severity of the situation at the time, I concluded that I needed to be home. My intuition was correct; I became my father's legal guardian (under emergency order) in December of 2015. I will narrate this transition in detail in Chapter Three.

Figure. 1. Andrea Iaccheri,[43] personal photographs, 2015.

I tried to keep his activities normal, despite him not feeling the best. I would monitor his physical and emotional health, understanding the days he would want to be alone and the days where he would call numerous times because he was feeling lonely. I began to become attuned to the subtle changes. I understood that his health was declining.

Fall 2015

Witnessing Decline

From the day of his diagnosis, my dad has been declining. At first it was slow, often unnoticed to the untrained eye. The more I learned of the illness, the more aware I became of the signs. There were small changes in his physical and mental decline over

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[43] Personal photographs reference my previous name, Andrea Iaccheri.

the course of his illness as well as significant moments of decline.[44] The first significant moment of decline happened in October of 2015.

October 3, 2015.

Everything seemed normal.[45] Dad seemed in good spirits and in good health (in the context of his daily struggles). I drove Dad down to have a joint birthday celebration for him and Mom (Dad's birthday was August 30, Mom's October 3). Dad ate a bit, laughed a bit, smiled.

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[44] In his book *Being Mortal*, Atual Gawande address the changes in the pattern of decline. He argues that for chronic illness, "Instead of just delaying the moment of the downward drop, our treatments can stretch the descent out until it ends up looking less like a cliff and more like a hilly road down the mountain" (27).

[45] I use the term normal in relation to the normalcies of helping Dad manage his illness and diagnosis of kidney and liver disease; taking him to appointments, ensuring he is taking his medications, etc.

Figure 2. Andrea Iaccheri, personal photograph, 2015.

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The first major moment of significant decline occurred with the realization that Dad could no longer take care of his house, nor make rational decisions regarding certain aspects of his living situation. It had been a few weeks since I had physically been in his house. I had picked him up and dropped him off for various errands/appointments but I hadn't been inside and throughout his property since October 3, the day of the birthday celebration.

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October 22, 2015.

My sister and I went to pick up some paperwork from his house to help him organize; we were greeted by disaster.[46] We opened the front door and were hit with a mess. I walked into the living room and could not believe what I was seeing.

The Livingroom:

Figure 3. Andrea Iaccheri, personal photograph, 2015.

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[46] While conducting his research, Atual Gawande discovered that the very old do not fear death as much as ". . . what happens sort of death" (*Mortal* 55). In his chapter titled Dependence, Gawande captures the struggles that our elders face. ". . . the losses accumulate to the point where life's daily requirements become more than we can physically or mentally mange on our own . . . most of us are unprepared for it. We rarely pay more than a glancing attention to how we will live when we need help until it's too late to do much about it" (55). This is the exact issue our family was faced with.

I then made my way to the kitchen. Another mess.

The Kitchen:

Figure 4. Andrea Iaccheri, personal photograph, 2015.

We then traveled upstairs to his bedroom. I remember thinking, it can’t get worse.

The Master Bedroom:

Figure 5. Andrea Iaccheri, personal photograph, 2015.

As we moved through the bedroom, we found obvious reasons he was having issues living in a large two-story house.

Figure 6. Andrea Iaccheri, personal photograph, 2015.

And more reasons as we moved through other bedrooms on the second floor.[47]

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[47] This photo is of a catch urinal – with human waste in it. These were found through the house.

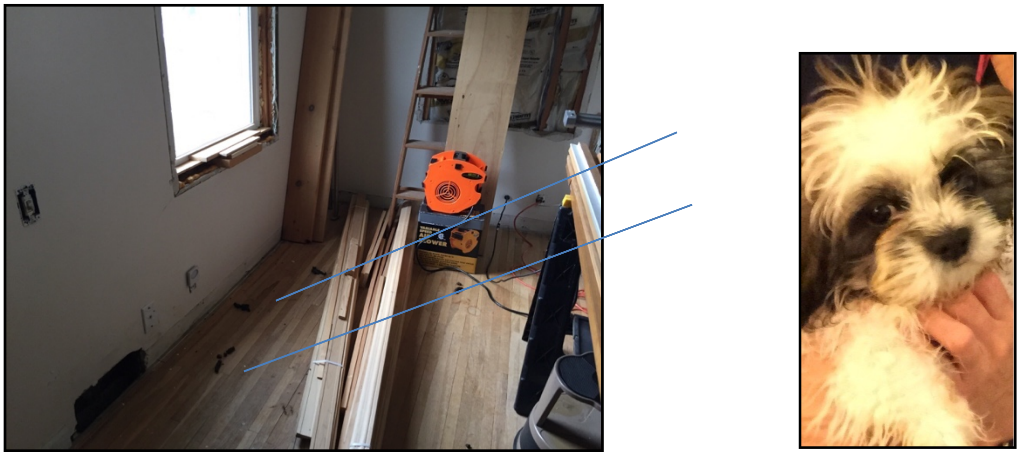

Figure 7. Andrea Iaccheri, personal photographs, 2015.[48]

While my sister moved about the main floor, I decided to go check the basement. What I found broke me. My first and only mini breakdown over my dad.[49]

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[48] In the photo on the left is dog feces. This was found all around the room. The photo on the right is the culprit, Muffin. My dad bought Muffin without discussing her with any family member prior to adding her to his family.

[49] To this day, I have not had a breakdown since this one back in October of 2015. I have barely cried, shown little emotion to others nor have I allowed myself to express emotion. I get angry, yes. I get sad, yes. But I rarely allow myself to get caught up in the emotion. *Noted May 29, 2017.*

Figure 8. Andrea Iaccheri, personal photograph, 2015.

Out of respect for my father, I will not go into grave detail. What I will disclose is this: He had been without plumbing for a week.[50] It was on the bed in bedroom next to the bathroom with the buckets that I lost it.

Figure 9. Andrea Iaccheri, personal photograph, 2015.

I can remember the smell drifting into the bedroom as I sat alone and cried. I couldn't even process what was happening, I could only smell. The stench filled the room around me, the clothes I was sitting on. I sat and I shook. I remember hearing a faint voice in the distance saying, "Andrea? Is everything okay?" I couldn't respond.
All I could do was shake and cry.

I heard footsteps approach rapidly down the stairs and then I heard my name again, "Andrea? What's wrong?"

All I could do was point towards the bathroom and watch my sister's shoulders slump as she took in the view.

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[50] Let your imagination go as to what the buckets were used for and what I found in the toilet.

I knew, we both knew, that my dad's life would forever change after this day. The evidence was clear that he could no longer care for such a big space, or for himself.[51]

Due to what was found, I thought it would be best to call his acting psychiatrist. I was asked to come to his office and show him photos of the house. After his physician reviewed all the photos, asked us questions, asked me questions (since I am the one who sees my father on a regular basis), it was recommended that my dad go under supervised care and get his medications evened out. The following is a timeline of the events:

10.22.17 late a.m.	Went to Dad's house to gather paperwork, took photos of living condition, went to see psych Dr. After a long meeting, were told he must be under supervised care.
10.22.15 early p.m.	Summons filed.
10.22.15 late p.m.	Firefighters called to home due to dad poring a mix of random house cleaners down drain to clean out human waste that was gathered; Dad taken to care unit by me, after police explained summons.
10.23.15	Back to Dad's. Find more human waste; called Hazmat to clean.

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[51] After witnessing this moment, I was heartbroken. I took much of the blame that his house ended up in the disrepair that it was in. He mentioned he needed help fixing a pipe in his upstairs bathroom once, but never said anything about it after that. I was told that I could not blame myself. That my dad is an adult and should know when he is living in unsanitary conditions. Yet, I was unable to remove myself from the blame of his current situation or from what transpired after this discovery. I am not sure I have truly forgiven myself to this day for the events that transpired after this day in October of 2015.

10.24.15	Saturday. I stayed home, hid, exhausted from the last few days' events.
10.25.15	Sunday. Visited Dad at the hospital. Very difficult. Dad was rehashing "scenario." Expressed anger and sadness.
10.26.15	Teaching day for me. Took calls from various people; dad's psychiatrist, my sister. Dad transferred to another facility. Had a family meeting.
10.27.15	Visited Dad. Felt like lockdown.
10.28.15	Visited Dad again. Remember there being therapy dogs. Dad fearful of not going home.
10.29.15	Exhaustion.
10.30.15	Power of Attorney Granted. Filed for Emergency Guardianship.[52]

Dad didn't go home to his house after this incident. I had to make a choice, under the guidance of his physicians that it would be best to place him in a home that had some level of care and security. Finding a place that would take someone with a mental health history was difficult. I worked non-stop to find a suitable place for him. While he was

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[52] I could have signed my dad out and had him come live with me and Husband. Dad asked. I asked his acting psychiatrist. His psychiatrist suggested we stay until I found him a place. He said my dad would possibly take advantage of me and that I was not emotionally equipped to handle his "persuasive abilities." Husband agreed. Said it was in my dad's best interest to stay until he had a place of his own that was safe. This killed me. Having to leave dad, knowing he was unhappy, hurt me. A little of my heart died that day. I couldn't help my dad.

still under controlled care, I arranged to pack and move basic furniture, clothing, personal items, kitchen items (ones that were not dirty).

11.14.2015 We (meaning my mom - my dad's ex-wife, my sister, and I) moved and unpacked his belongings to his new space. He was brought home from the hospital to his new residence. It was small. He hated it. But most importantly, it was clean, had working plumbing, and was a mile away from my house.[53]

My dad's psych doctor encouraged us to keep my dad away from his house for a short time after he was released. I understood his directive and I believe this was the best decision for him. I know my dad did not listen to me or his doctor and found ways to get back to his old house.

On December 9, 2015, I legally became my dad's guardian. Little did I know what this would entail.[54]

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[53] Gawande argues, "Your changes of avoiding the nursing home are directly related to the number of children you have, and per what little research has been done, having at least one daughter seems to be crucial to the amount of help you will receive" *(Mortal* 79).

[54] I found out the details of my role as acting Guardian of my father during the state mandated course that I took on February 16, 2016, after the Guardianship was instated. I was now in charge of all major decisions, my dad's financials, and his medical decisions. There were fifty other people in the class with me. All in shock of what was now expected of them, many of whom were in situations like me; guardianship instated, class after. You would think it would be class first, instate after (to make sure those being instated can handle the requirements. No further comment on that).

The year of 2016.

The 2016 year was not without Emergency Room visits and routine doctor visits, but for the most part, Dad stayed stable in his health. In May of 2016, Dad was officially out of his house. In August, I found him a different apartment (with more space and a full kitchen) at a senior community and after speaking to all of his physicians (Psychiatric, Kidney, Liver, and General Practitioner), I made the decision to move him. Dad was very grateful for this move. All in all, 2016 was . . . manageable.

Dad's health was stabilized. He was in good spirits. We were managing. Then 2017 arrived.

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January 4, 2017.

Dad's behavior had changed. He was getting lethargic. I recorded his current pain medications by photographing the bottles. Looking at the type and the dose. I was trying to make connections on my own while also contacting his physicians.

January 25, 2017.

I picked Dad up from his weekly parenthesis appointment. What greeted me, I've never experienced before; The Oxy-coma. It took myself and two nurses over an hour to get Dad from his wheelchair into my car. Upon success, Dad was in a coma-like state for the drive back to his apartment.

Figure 10. Andrea Iaccheri, personal photograph, 2017.

I had to delay his return to home as he was immobile, mumbling, and I had no one to help me. This was the beginning of the second major decline.

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I saw no improvements in his behavior after that day. Due to the lethargic behaver, I took him in to see his general practitioner for a check-up a few days later.

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January 27, 2017.

As we waited for the physician, my dad just sat in the examination room, awake but not present.

Figure 11. Andrea Iaccheri, personal photograph, 2017.

The doctor told me this was normal behavior for someone dealing with emphatic encephalopathy. As she was talking to my dad, I thought to myself ***I do not agree at all*** *with this diagnosis*, but I kept my mouth shut. I did express after she was done with her examination that I believed this was something more; that I’ve witnessed my dad be confused from the encephalopathy caused by liver disease, and that this was different. The Doctor told me to watch his behavior and if there is no improvement, to call her office early next week.

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Upon leaving his appointment, I called his Psych doctor and informed them of his behavior. The nurse that returned my call told me that they would either have his doctor or an attending physician call me later that night.

At nine-thirty p.m., one of the physicians called from the psychiatric office. They went through what I was seeing, gave me suggestions, and said to take him to the E.R. if his symptoms did not improve or if they got worse.

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January 29, 2017.

Sunday afternoon. My dad’s symptoms were not getting better, he was hallucinating, I was scared. We were back in the E.R.[55]

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After six hours of being in the E.R., Dad was admitted due to toxic levels of Lithium buildup in his system. I stayed with him as they moved him from E.R. to the main hospital. He was a little more aware of what was taking place by the time he was settled into his room in the hospital. It was one-thirty a.m.

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[55] As stated earlier in the chapter, 2016 was not without numerous visits to the E.R. along with our regular doctors’ appointments.

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Dad was admitted to the hospital on Sunday, January 29, 2017. He was kept until his Lithium levels were in a normal range. This took a few weeks to obtain. During his stay at the hospital, he had a few falls, incurred a few bruises from the heartrate monitor, and ate a lot of "good food" (as he described it). He also loved the view from his room as it looked out to one of his favorite places to eat: McDonalds.

He was in good spirits having been in the hospital for over two weeks but I could see a noticeable difference in his body. His skin seemed to change, his body was weaker overall, his appetite never really returned to what it was (despite the good food that was available to eat). Dad was improving, but not back to the level he was at before early January. I couldn't help my mind from going to the question: *What does this all mean?*

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February 8, 2017.

"It's like my memory is gone. I can't think of the word. It's just gone." *Dad.*

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I asked for assistance again today with Dad as I was not able to get down to the hospital to visit due to a nasty cold I contracted. Yet another day where the person helping me look after Dad "couldn't make it." This seems to be a reoccurring theme. I would rather have people not offer than offer and back out at the last minute. People suggest I "hire" help and I think to myself, "Where will that money come from?" How quick people are to want to remove "responsibility" to make life easier on them, yet those *that are legally bound to their responsibilities must push through, find a way, sacrifice self.*

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February 14, 2017.

There is a scarlet letter for those with mental illness. Shocks me, yet doesn't.

I feel more sadness.

~personal journal entry

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Dad was transferred today from the Med Center to a short-term rehab facility. I have been trying, along with the placement staff, to find a suitable fit for him. Finding this spot took a week. First, we had to overcome the fact that many facilities will not take a patient with a history of mental illness. Then, we had to find a place with an open bed (out of the few places that did work with mental health patients) that was also qualified to handle someone with liver and kidney disease. The next hurdle was reputation. Not many facilities get a three-star rating (out of five), fewer get four-stars, and only one had a five-star. It took a week to find a suitable fit.

My favorite moment during the week of placement hell was when the hospital wanted to place my dad in a facility that just got quarantined the previous day due to an influenza outbreak. They said he could come but we had to prove he had his flu shot. I informed the placement director for the home that he was set, but that I did not get immunized. It was like I had the plague. I was told I would not be allowed to visit and that I was required to get the shot, let it take effect, and then I could go see him. I thought for a moment before I responded. I said to the person, “So, you want me to send my dad to a facility quarantined by the health authority, not have access to any family member (since none of us get the flu vaccination), and you think that is okay? That this is something that I should do? (pause, no response). You’re out of your mind. No thank you!” (I hung up). The hospital placement director was not happy with me, as that was the only open bed at the time. I told them, “Well, he will just stay here another day then as I’m not sending my dad to a place that has an outbreak of any kind.”

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February 22, 2017.

Can never really do enough, say enough. Lead the right life. I’m expected to do more, be more. Sacrifice more.

~ personal journal entry

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Dad was sent home today after a stay in short term rehab. He was there a total of eight days. I got sick when he was in Douglas County Health. I was not able to go visit him every day like he expected or would have liked. I know my lack of visits disappointed him but I also felt burnout and found it more and more difficult to be everywhere he wants me to be and be present all the time.[56]

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[56] I still feel this way to this day. Finding a balance is the hardest thing for me; to understand I can’t do everything and to accept that. I feel the weight of disappointment – my own and that of my dad. I feel guilt for not being there and guilt for taking time for me. Driving him home that day I knew he was sad; Sad I didn’t do more, wasn’t there more for him.

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February 25, 2017.

Dad went to the hair salon with me. I think he may have taken a pain pill a short time before I picked him up. He repeated the same few sentences, “That will be fine” and “I’m sorry.” I don’t think he realized it. He was out of it yet responding with those same two sentences. It is hard seeing him like this. When we got to the salon, he was even worse. Lethargic, unresponsive. Sadness overwhelmed me.

I got him into the salon where he proceeded to “nap” with his eyes open, slumped in the chair. He wanted a haircut. I tried to tell him we could re-schedule, he shook his head no. The stylist was compassionate, knowing of my father’s illness, yet the others in the salon didn’t know what he was dealing with. Questioning looks probed me. Looks of disgust, looks of sadness. As I sat there I tried to go on with the day, push past the anxiety building within me.

After a while, Dad started to wake up from his Oxy-coma. He started joking and being his dashing self. By the end of the trip, I was able to get a photo of us with our new haircuts. He, being the forever goofball, me with a goofy, child-like grin. I cherish this photo. It is one where we are both smiling amidst chaos and decline.

Figure 12. Andrea Iaccheri, personal photograph, 2017.

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Sad eyes

Sad eyes, tired eyes, worn out eyes.
Eyes deep in search of something I yet not know.
Eyes filled with sorrow.
Long days and sleepless nights,
Not yet sure of what's to come.
Sad eyes, tired eyes, worn out eyes.
I see what is to come.

Andrea Iaccheri, 2017

I wrote this poem shortly after my dad's most recent trip to his kidney specialists. We have been going to Dr. Berry[57] for about three years. This most recent visit taking place on March 10, 2017, was the shortest yet. I call it the Three Minute Visit, because that is what it was. Three minutes with Dr. Berry. In reality, the entire visit took more like an hour and a half with the waiting, the collection of vitals before going back, and the list of questions by the nurse once in the examination room, but the actual face time with Dr. Berry, three minutes. I am choosing to write about this specific visit for a few reasons. First, in the rooms at the medical center there are chairs on two opposite walls. One chair by the door and two chairs next to the station that holds the computer in the room. I normally take the lone chair by the door while Dad sits in the chair next to the computer. This time, we switched places. I was in the "patient chair." I sat and answered all the questions about medications, how he was feeling, updates between last visit and now and Dad sat across from me. He looked not at me, nor at the nurse but out – somewhere not in the room we were currently in. His eyes were sad, tired. His eyes were hollow.

As the nurse was rambling on, I decided that I would pull up his most recent lab results (blood draw) from his medical records that can be accessed through the patient portal online. I wanted to see for myself what the results of his blood work were, prior to the doctor coming in.[58] After the nurse left, I checked in with Dad to see how he was;

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[57] The name has been changed to protect the physician's identity.

[58] I made this decision for a few reasons. First, from our past experiences, over half the time my dad was not told to go in for blood work prior to his appointment. In these instances, we had the visit with the

there was no response. He still sat with his arm on the countertop, staring into the vast space of the exam room.

Figure 13. Andrea Iaccheri, personal photograph, 2017.

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specialist without having "results" to discuss. Second, when Dad did get lab work done prior to his specialist appointment, Dr. Berry often did not speak about the actual results to my dad, rather he spoke in generalities. Due to these outcomes, I started to pull and read Dad's lab results early on in this process, researching each category, each level and what they all represented.

As he sat, I checked his lab results: GFR 25, Creatinine 2.54.[59] Dad had hit Stage 4 – Severe loss of kidney function. I sat there, silent looking across at my dad wondering: *What is next? What do I say?*

As if on cue, the door started to open. My dad straightened himself when he saw Dr. Berry walk in. The doctor said hello to my dad and said hello to me and shook my hand. He sat on his stool next to the computer and logged in. He asked my dad how he was doing. My dad chuckled a bit and said, “Well I’m here, aren’t I?” Dr. Berry said, “Yes. But that means you’re still managing everything okay.” My dad just sat there. Dr. Berry informed us that he got the lab results back, that his GFR was a 25 and his Creatinine was a 2.54. Dr. Berry continued saying “So, his GFR went down and his Creatinine is up. At this point, we would start dialysis but since you’re not going with that treatment option, there is really nothing much more for me to do. Since you go to your weekly parenthesis and will be doing weekly lab work there, I will ask the doctor handling those procedures to contact me if they see anything change drastically and you can call me if you notice change yourself. We won’t schedule a six-month follow up, we

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[59] According to The National Kidney Foundation, there are 5 stages for kidney disease. The GFR (Glomerular Filtration Rate) is deemed as the best test for measuring kidney function to determine stage of kidney disease with the Creatinine level measuring your overall kidney function. Stage 1 has a GFR of 90 or above; Stage 2, 89 to 60; Stage 3a, 59 to 44; Stage 3b 44 to 30; Stage 4, 29 to 15; Stage 5, less than 15. The description of the stages are as follows: “Stage 1 – kidney damage with normal kidney function; Stage 2 – kidney damage with mild loss of kidney function; Stage 3a – mild to moderate loss of kidney function; 3b – moderate to severe loss of kidney function; Stage 4 – severe loss of kidney function (when people go on dialysis); Stage 5 – kidney failure” (“A to Z Health Guide: Glomerular Filtration Rate (GFR)”).

will just do a visit as needed. Any questions?" I sat there quiet. My dad was even more quiet. I asked Dr. Berry what we could expect next. He said that the body will keep trying to process and that his levels will slowly or rapidly decline. That unfortunately, there is no set process the body goes through because each individual is different. He told us to "Take care" and "Call his office if something changes." He shook my hand, shook my dad's hand and he was gone. Poof! The Three Minute Visit.

Recap of visit: My dad found out his kidney function went from moderate to severe loss of kidney function. People normally with severe loss of kidney function go on dialysis. My dad had already decided in his previous appointments that dialysis was not in his treatment plan. Now that my dad was at the stage where dialysis would normally be performed and he has chosen not to pursue that treatment plan, there was nothing the medical community could do and so my dad was now moved to the "call if something drastically changes" stage: i.e. call when your kidney function decreases to the level of kidney failure. In the meantime, go to your weekly parenthesis appointments and keep doing what you are doing.

Translation/What I make of this interaction: We know you are actively dying. You have selected the "I will not prolong my life further by going on Dialysis" option. There is nothing else we can do for you medically. Keep in touch so we don't feel totally heartless and we know when your kidneys are starting to shut down so you can go into hospice.

What did not take place in this doctor appointment, nor was it EVER offered to my father or our family, was a conversation of what severe loss of kidney function looks/acts like. What will happen to the body? What signs can I and others that are with my dad regularly watch for? What types of bodily changes will he go through? What physical changes to the body will we be privy to witnessing? Nothing. Not even the option for my dad to talk to someone about the dying process or what my dad might be feeling with facing his death. Nothing. We can talk treatments and treatment plans and possible outcomes of treatment all day but once a person decides to not move forward with the option of treatment or if treatment no longer works, the outcome for that person will be death. Not to sound morbid here but that is the reality. In my father's case, his death may happen through sleep but those chances are slim. What will most likely be the case is death by organ or multiple organ failure; not a pretty way to go. Time and time again, both myself and my aunt (my dad's sister who is a registered nurse) would ask these questions for the benefit of my father. We wanted to be open with the conversation of death and dying to ensure my father was comfortable of the outcome of his illness. Never once was our initiation of that topic selected by physicians or medical staff. Those conversations were left up to us - the family.[60] Knowing what I was up against, the fact

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[60] Foucault discuss the changes in how we (society) come to understand medicine and the practice of medicine in our modern culture. Foucault provides historical contexts for these changes, starting in the 18th century. He speaks of changes that include monitoring, recording, and the formation of a systematic system. Within his writings, he identifies that by monitoring body via medicine, the body can be controlled. While his work does mention the concept of death, it is approached from a medicalized view, with emphasis on what happens to the dead body *(Power*). In her book *Medicine as Culture: Illness, Disease and the Body,* Lupton extends Foucault's work on the dead body by exploring the rituals associated with

that the doctors and medical staff did not want to talk about death and dying, I continued to talk to my dad about what was to come.[61] We have had these conversations before, these conversations were nothing new. Instead of skimming the surface, I began to have more meaningful and (to be honest) scary conversations about death and dying.

In light of the recent office visit and lab results, I am glad I took the initiative and spoke of death and end of life decisions on multiple occasions prior to his Three Minute Visit with Dr. Berry.

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death and what happens to the dead body within the medical context. Neither Foucault nor Lupton explore the expert or lay conversations surrounding the topic of death and dying.

[61] In order to be prepared for these conversations, I went back to the book *Being Mortal: Medicine and What Matters in the End* by Atul Gawande. After reading, I went to the bookstore and found a newer book written on the subject titled *Modern Death: How Medicine Changed the End of Life,* by Haider Warraich. Standing in the isle of the bookstore, I read the jacket cover for Warraich's book. I realized his book was an extension to Gawande's book *Being Mortal.* Gawande's book was written to extend Sherwin B. Neuland's book *How We Die: Reflections on Life's Final Chapter*. To fully understand the arguments made by Gawande and Warraich, I knew I needed to start from the beginning. So, I bought Neuland's book as well. I read the books in chronological order to comprehend the overarching argument the authors are making about how we, as American's, understand and come to terms with our own mortality. I used all three authors to assist me in my conversations with my dad about death and dying.

"The" Conversation(s).[62]

Let me preface this story by identifying that my dad is and always will be prepared for the eventuality of death. He has had a will since I can remember and has not been shy about his wishes. The first time I can recall being the initiator of "The" Conversation was when I was running errands with my dad. I had to make a quick detour and drop off an item to Husband while he was at his office. Right before the office building sits a large mortuary. As if on cue, my dad asked where we were going just as I had turned off the main road we were traveling on. I slowed down in front of the mortuary, looked over at my dad and said, "Well, since you're sick and all, I thought I would have you pick out your casket." He just looked at me. I looked at him, I looked the way to the Mortuary and looked back at my dad and started laughing saying "I *got* you!" My dad started laughing and said, "Boy you sure did." I started the car forward again and he said, "Where are we *really* going?" "To drop off something at Husband's office." Dad responded, "You sure got me there. Pick out my casket..."

This joke happened a few summers after my dad was diagnosed with liver and kidney disease. I knew I could joke with my dad about this topic because I was aware of

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[62] "The" Conversation deals with all aspects of death including end of life decisions, planning, personal wishes. After my father lost his brother to suicide, he took the initiative to write out his will and his end of life wishes. From time to time, long before he found out he was terminally ill, he would remind me of where he kept the document, who needed to know about his wishes, and what his wishes were. I have not asked if his preparation and open communication was initiated by the sudden loss of his brother or not. I did not know the importance of such decision making until being faced with my father's illness.

his end of life wishes.[63] Since being diagnosed with his disease (now diseases), he has been very vocal about his end of life choices. But these choices were not new. He decided on his end of life decisions well before his illness. He wrote his choices out by hand and had them notarized, he made copies and kept them in multiple places, he made his decisions far in advance – away from his sickness; before this illness ever plagued his body. In a society that reveres youth and agelessness, a society that promotes life over death, my father chose to be prepared. He chose to know what he wanted in terms of end of life care and how he wanted to die.[64]

While we, we meaning society, try to immortalize the human body, doing every procedure known to us to ensure another breath of life is taken, often final breaths are taken without their final wishes being heard. Final breaths of life are taken and end of life decisions go unspoken. An individual that does not want to be revived has their heart jump-started back to life because their end of life plan went unspoken or undocumented. Why do we choose not to talk about the end of our own life or the life of another? What makes us keep our end of life decisions silent, unspoken? How do we who are caregivers ensure "the conversation" takes place when the individual facing death is still in a mental state to make sound decisions? What makes us want to prolong our life – past our natural

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[63] One wish being that he does not want a formal burial.

[64] While my dad has communicated his wishes for his funeral, his choice of cremation, and what he desires our family to do with his ashes, there are still many unknowns. We don't know how he will pass or when he will pass. We are unsure of whether he will be in pain, if it will be short or if it will be quick.

expiration? These questions lead us to the larger statement proposed by Atul Gawande: "How to die" (*Mortal* 158).[65]

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March 31, 2017.

"The Good Life"

Back to the E.R. once again. This specific trip developed out of concern that Dad's lithium level was increasing although he had not taken his lithium the past 3 nights. After I got the results from the attending nurse at the psych office, I had to call Dad to inform him, once again, that he was going to need to go to the ER. His response when I called was, "Again?! But why? I was just there?" I told him that his doctor was concerned with the fact his lithium went up even though he didn't take his dose the past few nights. I asked if his Lady Friend was still with him and he was reluctant to answer the question. I was hoping she was there so she could drop Dad off at my work so I could then take him in to the E.R. Luckily, for me, she was still there.

Dad arrived at my office about an hour after I called. He looked disheveled. His pants were bunched up around his ankles, his white socks showing in stark contrast to his grey sweat pants. He stumbled carrying his packed bag – just in case he had to stay overnight (always thinking ahead).

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[65] Gawande argues, "In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality and created a new difficulty for mankind: how to die" (158).

As I got my dad in my car, I inform him that I need to stop for gas (or we may not make it to the E.R.). He didn't object. This may have been selfish of me, but I decided to go into the convenience store to pick up a drink with caffeine, some gum, and a snack; I also grabbed a Coke for Dad. I know the trips to the E.R. are long. I got back to the car and handed Dad his Coke. I let him know to drink what he could now as they would probably hold fluids from him until they figure out what is wrong. He looked over at me, eyes cast down and said "Thank you."

The drive to the E.R. was lacking any real conversation. Every pickup, every transfer seems to be void of any meaningful conversations, rather, the topics are more true to updates on how he feels, what needs to be taken care of in way of bills (if he's admitted), concern for lack of communication with family members. The same conversations every time he is in my vehicle. As I drive down Center street passing Arby's I realize I fall into these patterns and yet, I still partake in the pattern. I'm annoyed with myself but also wonder what I would talk to him about? What would I bring up? I chastise myself as I turn onto Saddle Creek Road wondering how I got to this point in life, not being able to talk to my dad about non-health matters? Either his or my own? When did our relationship turn so mechanical? Devoid of meaningful and lasting memories?

Almost in a blur we arrived at the E.R. Dad was able to walk in on his own as I parked the car. We were quickly admitted and placed in a room. Following an unstated norm, my dad and I fell into our roles. He looked at me from his bed, wanting me to answer the questions the various medical staff members would ask. He would lie back.

As if we were in the movie Groundhog's Day (yes, I'm dating myself here), the same questions from the staff were asked and the same responses from both me and my dad were given. The same condition brings us to the E.R., the same responses are produced, we walk through the motions yet we are trapped in the colorless four walls of the tiny patient room in the emergency department.

Figure 14. Andrea Iaccheri, personal photograph, 2017.

Time passes.

Medical staff come in and out of the room.

More time passes.

I am anxious, exhausted from the week, further exhaustion setting in due to the additional stress of being back in the E.R. with Dad. Selfish thoughts fill my mind. All I wanted to do was go for a run after work and go home to sit with my cats. Instead, another Friday night in the E.R. Dad is sleeping. I read to pass the time, sitting in the uncomfortable chair. I reach out to a close friend letting him know that the hospitals should put in treadmills for family/friends of patients. It's was a poor excuse to bring some humor into the situation but also allowed me to express my frustration of having another night of personal goals put aside to care for Dad.[66]

I'm drawn from my own thoughts when I see Dad stir. Through groggy eyes, he tells me he needs to use the restroom. I step out of the room trying to find a medical aid or nurse to assist. I've been down this road a time or two and know Dad still needs to hold on to some level of personal pride. I walk the halls and find no one. I return to the room, his need evident.

"Well," I say, "it looks like I get to help this time." He looks up at me.

"Annie, help me get this stuff off." (He was referring to the heart rate monitor on his finger.) As I pulled the monitor off his left forefinger, the beeps started. Ah, the sound

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[66] I know this sounds selfish to many and I'm somewhat ashamed to think this way, but I also know the importance of recognizing feelings when they are present.

of the machine notifying us that Dad is no longer hooked up. Knowing I can't win the battle with the beeping machine, I place the monitor on my own finger, while I try and help him up to a standing position. I handed him a catch bottle and moved to pull the privacy curtain. As the seconds' pass, I know there is no gain. I grab my phone and suggest I put on a little mood music (thank you Spotify). I see a Tony Bennett playlist and hit the first song, not paying attention to the title. I place the phone on the bed and the sound of violins fill the silent room. Then Tony's voice comes on singing:

O*h the good life, full of fun seems to be the ideal.*
Mm, the good life lets you hide all the sadness you feel
You won't really fall in love for you can't take the chance
So please be honest with yourself, don't try to fake romance

Dad says, almost to himself, "Ah the good life," as Tony Bennett continues …

It's the good life to be free and explore the unknown

(I look over my shoulder to see my dad is done)

Like the heartaches when you learn you must face them alone

I turned around and shut off the music on my way to help my Dad re-situate himself. I took the catch container and placed it on the floor so I could assist him more easily. As I helped him sit down, I moved the heartrate monitor from my finger to his.[67] I quickly moved to the far wall holding various sizes of rubber gloves and grab two, moving my

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[67] When I selected the Spotify playlist, I had no control over what song came on. I was more worried about getting Dad up to use the bathroom. When moving the heartrate monitor from my finger to his, I couldn't help but think about the words Tony Bennett was singing in *The Good Life*.

way back to Dad. I helped him sit down, I grabbed his legs and gently lifted them onto the bed. I pulled the blanket up over his shoulders, tucking under his chin, and moved the bed back a bit to make him move comfortable. As I moved to put on the gloves to handle the catch container I realized what I just saw; what I just experienced. After I put the catch container on the counter, I went in search for a nurse in case they needed a urine sample. I returned with no luck of notifying anyone. I moved to my designated spot, the uncomfortable chair by the door and found an article I brought. Flipping the document over, I started to write out my feelings in this moment:

> *Not sure how I feel about seeing my father's rear end due to the fact the nurses wouldn't come in to assist as he struggled to stand to use the bathroom in the hospital room, leaning one hand on the wall to help support his body.*[68]

Dad is sleeping yet again but winces, obviously in pain. The medical staff comes in and out and people don't seem to care. They are non-observant. They seem not to care about his pain.

Time just ticks away.

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[68] When we initially arrived and my dad was checked in/placed in a room, they were very specific in his instructions. Do not get up without medical assistance, let us know if you need anything, etc. When I went in search of a nurse/medical aid to help my dad get up to use the bathroom, I found no help. I used the nurse button, still no response. Due to my dad's weakness and his need to use the bathroom, I had to help. The struggle he had, the image of him being weak, the obvious shame he was experiencing by me helping him was difficult to witness. I also wondered why no one from the medical staff came to assist.

Dad starts to wake . . .

Trying to talk about anything but his health, I asked Dad to tell me about the time he had the kegger in a church in Arizona. He chuckled. I've heard of this moment, but never the details of how he actually pulled it off.

"So, did you break in? Bust a door? Break a window?" I probed.

Dad, with a hint of a smile on his face responded, "Oh no. Never did anything to harm the church. I had a small friend."

I needed clarification on that description. "Small friend? Like tiny person small?"

He looked at me like I didn't get it. "He was just tiny. We scouted out the church a few times and noticed a window. We hoisted the small guy up, he slipped through the window, opened the doors, and that was that."

"So, you just rolled Kegs into a church? And no one noticed or seemed to care?" I could not process how no one noticed.

Dad continued on explaining, "The church was on a busy street. People were not looking for a party. Although it became a big party. We had hundreds there. Until it got busted."

Now I was really curious. My dad the party promoter. "How did you promote this party?" I asked.

He smiled, "Word of mouth. (pause) And was it legendary. We never did any damage to the church but did we have fun." I could almost see him being transported back to that moment in time. He looked off, a hint of a smile on his face.

"And what music did you have playing."

He looked at me for a long time. "You know what? I don't even know if we had music. If we did, I don't remember it. All I know is, I really don't like beer. Never have. It's the taste. Really just . . ."

"Awful?" I finish his thought.

"Yeah," he said. "It just doesn't taste good."

At that moment, a nurse walked in. My dad didn't continue with the story, rather he tried to make small talk with the nurse. She did what she needed to do then hurried out the door. He looked out at me, shook his head in disappointment and rested it back. My window of non-medical talk with Dad was over.

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Our care system promotes compassion and empathy and yet people get out of the room as fast as they can. They don't want to connect or stay, it's a bed, a number, an assignment.

I look around the room, again feeling trapped between the system and in the system. I want to fight back, I want to not listen, I want to disengage and yet I find myself constantly in this situation, in this room, acting as a health disciplinarian and an extension of the system.

The window behind where I sit allows surveillance of the room from the outside hall. Monitor for what purpose? For the patient's good? Or for systematic control?[69] Why

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[69] In this moment, all I could think of was the writing of Michel Foucault; specifically, his work on the docile body and surveillance in the book *Discipline and Punish*. First, Foucault's writing on docile bodies

do we rush into the E.R. when the patient wants to die? What's the purpose? Do we let them fulfill their wishes or do we place our own desires for them to live a bit longer onto them? Why can't I let Dad pass? Why does the health system control me in such a way that I listen to the doctors' instructions over my father's desires for his own life?

When does my role as a caregiver need to be focused on my dad's own desires for his body rather than what the medical community wants or suggests? Or can it ever be that way due to our system?

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suggests there are three levels in operation: scale of control; object of control; modality (*Discipline* 137). Scale of control is concerned with power over the active body, object of control focuses on the economy and efficiency of the body, and modality is the idea of constant correction. The window in the E.R. brought all three ideas from theoretical to applied in an instant. I sat there – looking out the window realizing and in all reality accepting of the space I was in and that I was in fact acting as a docile body. Second, I actively witnessed surveillance in its purest form. Based on ideas from Bentham's *Panopticon,* Foucault connects Bentham's specific design to other structures such as schools and hospitals. Bentham's *Panopticon* is an architectural structure designed to provide surveillance from a central tower from within the building. We see this design in modern-day hospitals. As I was sitting in the hospital room, I knew the window was behind me. I knew what it's purpose was. Each room had a window, the nursing station located centrally to view into any window at any time. Foucault states, "The Panopticon functions as a kind of laboratory of power. Thanks to its mechanisms of observation, it gains in efficiency and in the ability to penetrate into men's behavior (sic) . . ." (*Discipline* 204). He continues by explaining, "The Panopticon, on the other hand, must be understood as a generalizable model of functioning; a way of defining power relations in terms of the everyday life of men" (205). Here I was, being controlled, yet allowing myself to be controlled.

May 8, 2017.

Nothing seems to be going right. More anxiety, less time, more stress, less support. Life stressors – never easy. I wonder what it will be like when I can't call Dad anymore.

~ personal journal entry

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May 23, 2017.

Dad was mumbling again, not making full thoughts. He was able to express that he waits for me, for my calls, for me to stop by.

I can't recall much from my childhood but I think I remember waiting for my dad to come by. These memories elude me as I have blocked out most of my childhood memories. What struck me today was the fact that he now waits for me; like I did for him so many years ago.

How is it that the roles can so easily reverse? How can we desire the same things at vastly different ages? I know I'm failing Dad by not seeing him more often, by not visiting every day like I should. I don't have the energy but I also don't want him to think he is dying alone.

We sit apart, alone. I write about the isolation I feel, the isolation he feels, and yet, we sit apart, alone.

~ personal journal entry

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During the writing process, I realized that my own narratives provided me a space to not only explore the lived experiences connected to being a caregiver and how I internalized my role as caregiver but also how I came to understand illness at a deeper level. Part I of this chapter explored orientations of the ‘other’ surrounding caregiving moments. Part II of this chapter focuses on a ‘self’ driven orientation of experiences surrounding caregiving. Part II is deeply personal and reflective using my own narratives where I explored some of my deepest thoughts about my experiences. Two major themes emerge from the vignettes included in Part II; that of isolation and anxiety.[70]

Part II – ‘Self’ Orientation(s) of Caregiving

Bathrobes and Cat Purrs

February 17, 2017

As I sit on the edge of my bed in my bathrobe with my journal in hand, my personal exhaustion has set in. I need to get soup from the store but I don't want to get changed. The thought of going to the store in my bathrobe has crossed my mind, more than once. It sounds comfy, warm, and appealing. As I ponder my dinner debacle, I feel the weight of Stanley (my cat) jump up on the bed and know he is near.

The bathrobe has become a symbol of security, comfort, warmth. As I sit deciding on what I will do, pondering my bathrobe, I feel the light pat, pat, pat of Stanley’s cat paw on my back. A cloak for strength? A cover for hiding? I’m not sure. I feel yet another pat, pat, pat of Stanley’s paw, now on my leg. The comfort of Stanley and

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[70] Some of the stories in Part II overlap in time with stories in Part I. There was no way to avoid this from a storytelling perspective. The dates are important for me to share as they reflect moments of struggle, pain, isolation, anxiety, and fear in my journey as caregiver. The dates are meant to assist in connecting moments between the orientations of ‘other’ and ‘self.’

knowing he wants to sit with me makes my decision easy. I lift my tired legs up on the bed and shift my body so I'm now laying. As if on cue, Stanley cuddles in and leans on my leg - the soft rhythm of his purr settling in.

Figure 15. Andrea Iaccheri, personal photograph, 2017.

Like Stanley's purr, the robe soothes me when chaos exists around me at every turn. The purr of the cat and the warmth of the robe heal the exhaustion brought on by responsibilities to others; not to myself.

The Walmart Reprimand – An All-Time Caregiver Low[71]

March 5, 2017

There are moments in time when you know you have hit a low. When stress, exhaustion, and life demands have pressed you to a limit you didn't think possible. Your body and mind react to push through the harsh demands, even though your limbs ache and all you want to do is crawl into bed and throw a blanket over your head. This low hit on my anniversary. To be fair, I most likely did this to myself – I created an undue stress as I spent my weekend working and did not take into full consideration my father's needs at the time. I didn't ignore him, but I also did not address the situation with first warning either.

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[71] I am not proud of this moment. I was originally not going to include it in my work as I felt embarrassed and ashamed how this trip for groceries turned out. I had written up a draft and then I stopped short of finishing. I was ashamed. I felt horrible as I relived the events. It was not until I was finished telling this story to a colleague of mine that the thought of including the story was pondered. I was asked my rationale for not including this story after I shared my experience with him. My answer: it is embarrassing; I didn't handle the situation like I should have; I know better . . . the list went on and on in my head. He told me to finish writing it and then make the decision. I finished it. I have made the decision to include this piece in with the other Caregiving Moments. It is honest. It expresses truths of caregiving moments some may experience. I'm practicing vulnerability – to open up and share my less than perfect moment with you. Life is full of imperfect moments. It is what we choose to do with those moments that makes a difference in our own lives and the lives of others. In her book *Daring Greatly*, author and shame researcher Brené Brown names this act as daring greatly. I am daring to share this vulnerable moment in my caretaking experience, so you are able to recognize the real, true, and often emotionally painful and/or sad moments caregivers experience.

As a caregiver, you get burned out. Caregiver burnout is very real. You put the needs of others before your own, you let areas in your own life go to serve the needs of the person you are caring for; the list goes on and on (see website…on caregiving burnout – know the signs).[72] In these instances, research tells you to ask for help, give yourself space, take time for yourself. Knowing my stress level was higher than normal, I listened to the advice of the experts and gave myself space, took time for myself and tried* to ask for help. I put an asterisk by the word try as I have not had much success in getting help from others for basic tasks with my father – tasks like grocery shopping. In normal instances, such as this, my dad's lady friend would go shopping with him for me. Due to a personal loss, her time to spend with my dad and help with basic tasks had been limited. The food shopping trip was on me. And I put it off . . .

Calls came in, repeated calls. I answered but informed my dad that I was not available to take him at that moment knowing this would be, at the very least, a two-hour trip. He did not want to provide me the list to go get the items and deliver to him (as I knew this would cut an hour off the trip) so I told him I would try for later that day. This day happened to be my anniversary. Husband was out of town, he arrived back at six

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[72] The following websites and articles were used while writing this piece. I referenced the various articles to identify if I was experiencing caregiver burnout and if I was, what I could do. These links were also sent by my mom and sister as they were worried about me. See: "Recognizing Caregiver Burnout?" found on www.webmd.com; "Caregiver Stress & Burnout: Tips for Regaining Your Energy, Optimism, and Hope" by Melinda Smith, found on www.helpguide.org; Burnout articles found on www.agingcare.com *Entire website is an excellent resource for the topic of caregiving.

p.m.; shortly after he got back, we decided to go to dinner near the house. We were about to leave when Dad called yet again. He asked again if I could take him to the store. I kindly asked him if I could call him right back. I looked over at Husband, informed him Dad was very low on food and drink and asked if we could take him for a quick food run after dinner. I'm thinking to myself, Dad has his list, I can help get the items, Husband can serve as backup, we should be okay on time. Disillusion had set in with me. I know my dad, I know his habits, but I was hopeful. I mean, my dad knew it was our anniversary and Husband just got back into town. I called Dad back and informed him we would be there after dinner. Looking back on this moment, I should have recognized the disaster waiting to happen but exhaustion had set in. I knew my dad needed staple food item, and, I didn't want to go alone; this was the perfect storm.

After dinner, we went to pick up Dad. I told Husband to stay in the car and I would run in and get him. Everything seemed normal at the time. Dad was pretty much ready to go when I got there, I aided him in getting his coat on and we were back out to the car within five to ten minutes. I helped Dad into the front seat so he and Husband could talk (this provided me another break in making conversation). I slid in the back and we pulled out of the apartment parking lot.

The drive to Walmart from my dad's is an easy one. Yet Maple Street is dark from his apartment until you hit 170 Street. I don't normally notice the darkness but tonight, it was more prevalent. There was a stillness although the winds were gusting up to twenty Miles per Hour. I embraced the stillness looking out at the dark farmland as we approached Walmart listening to the steady hum of the Jeep engine and the sound of male voices drift to the backseat. I felt alone and tired. I tried to mentally prepare myself for the trip ahead. I interrupted the conversation to ask Dad if he had his list. I wanted to make sure I had my arsenal to keep us on a schedule – get in and get out.

Arriving at Walmart, I helped Dad out of the car and we walked (well, I walked and he hobbled) through the sliding doors; the cold, industrial feeling hitting me in the face. I assisted Dad in getting his motorized shopping cart and getting settled. Now, on any other given day, I would normally take Dad to Walmart in running shoes, comfy pants and a comfy top (a.k.a. my workout gear). As it was my anniversary, I was in a nice top, jeans, my coat, and heels. You may be wondering, how does clothing choice even matter? Trust me, it does. As Dad fiddled with the handlebar of the motorized cart, the familiar sound of the beeping filled my ears as he tried to navigate the cart out of its designated space. With a lurch, he moved forward. I quickly tried to react but was slower to respond . . . due to my choice in apparel. I looked down at my feet and thought, “Shit, why did I wear heels?!?” I looked up and Dad was gone. I scanned the entrance of the store, looking down the main isle and then over to the produce section. I could see his gray quaff slightly blowing as his cart weaved through the produce stands – he was already halfway through the produce department. I scurried to catch up with him, the sound of my heels clicking as they hit the hard, cold, lifeless cement floor.

Dad seemed to speed up, if that is even possible in a motorized shopping cart, as if he knew I was trying to catch up with him. He moved the cart to the bread stands by the bakery area and then did a sharp turn to head to the meat section. Catching up to him, I put my hand on the cart portion asking him to slow down. He stopped the cart, looked up at me then pushed his wrist forward and the cart went jerking with him. Off he went down the aisle between the wall display and the center island meat holder. Once down the aisle, he turned the cart counter clock wise next to the island meat holder and went around a second time, and a third time. I followed him around the first go, and then I just stopped waiting for him to lap me yet again. Grabbing hold of the handle bar, I got him slowed to a stop.

“You can’t keep doing this Dad!” I said. I continued, “We have a list. We need to stick to the list!”

He looked like he had been caught breaking a rule. I was peeved. In my calmest voice I could use, I asked what type of meat he was looking for and if I could help him find it. He wanted thinly sliced pork chops. Now, to be honest, I rarely buy meat and I never buy meat at Walmart so that is two strikes against me finding this specific type in a short time. To my luck, an employee was walking out to the back with a rolling cart of meat. I quickly moved toward him and asked for his help. He kindly provided Dad with a few pre-packaged options, none quite to my dad’s liking. Taking charge of the situation, I made a selection and put the package in his cart. Once the meat was placed, Dad was on the move yet again. This time to inner aisles.

I was able to keep up with him down the bread isle. Weaving through people and side-swiping carts, I tried to apologize as we moved down from one end to the other. I could feel the eyes burning into my skin as we passed people by. Some eyes had sympathy, some were just plain pissed off. He made a quick turn and sped off. From that point on I felt like I was playing hide and seek with Dad. Once I would catch up to him, I would tell him how we needed to get the items on the list. He would look down or look away, then he would speed off. The time between the downward look or the look away varied; sometimes they were short, other times he would slump in the chair in such a way and shake his hands. People would walk by and stare. No one asked if he was okay. This happened repeatedly. Each time I would catch up to him, my ability to stay calm would reduce, until I had no calmness left. That's when it all "hit the fan."

Keep in mind that Husband was somewhere in Walmart. He went to a different area of the store in the first few moments of arriving once he could see how the trip was going to play out. I was texting him as the game of hide and seek with dad was taking place, getting more aggravated with Dad and honestly more aggravated with him as he was to be my backup – who too quickly disappeared. Texts were exchanged and I finally found out that he was waiting in the car. Explaining the situation I was experiencing via text to Husband in Walmart (yes, I was that person), while he sat in the car outside, he responded:

If I come in, it will not be good

Me being desperate, I wrote back as I was walking down the main isle between the food and the rest of the store . . .

I don't care…he won't listen to me and I keep losing him

By this this time, I was walking down the main stretch looking for Dad – seeing him down by the Ensure area. Feeling a vibration, I look down at the message coming across my screen:

Shit, what a way to spend our anniversary

Ignoring the sadness, anger, and overall shitty feeling that was overcoming me, I caught up with Dad. I put two boxes of Walmart brand Ensure in his cart and lead him back out to the main stretch. Another vibration:

Where are you??

Just as I was reading the text, I looked up. And then I saw him. His muscular frame seeming like it took up the whole aisle as he was quickly moving toward us. Seeping from his body was authority with a sprinkling of rage.

Husband: "What the **fuck** Joe? What are you doing? We need to go. We've been here long enough."

My dad looked up to me, then to Husband, “What am *I* doing??” he asked, his voice raising at the end of the question. He quickly followed with, “The question is more like what are *you* doing?”

There it was, in the middle of Walmart, for everyone to see.

Husband looked at me, “Get whatever else he needs and be done. I’ll be in the car.” Then turned and stormed back down the aisle he came from his body still moving with authority, this time in a Gaston-like manner.[73]

As he walked away, there I was with dad. I, looking down at him, him looking up at me. A wave of sadness overtook me. As we moved back down to the self-checkout stands I was moving as slow as the motor cart was. The same cart that was so fast just a little time before. We moved our way to the checkout stands. Seeing the lines of people, I headed

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[73] I feel it is important to identify that this shopping trip was a first for Husband. He has never had to deal with my Father in this manner. Husband has purposefully developed a friendship type relationship, rather than a father/son type of relationship to ensure that my dad knew he had someone in the family that he could talk to, be with, and not have his illness be the topic or focus of conversation. While this is good, it also hinders his ability to handle my father in various situations; this being one. I am not justifying his behavior; rather, I am explaining how individuals vary in their response to either new or stressful experiences. My father reverted to childlike behavior. When the elderly exhibit child-like behavior, individuals (caregivers, family members, etc.) take on behavior correcting communication patterns While this may not be the ideal choice given the specific situation that is being experienced, behavior correcting patterns are often used. Similar to a reprimanding a child, we reprimand our elders, as seen through this experience.

toward the self-checkout lanes. Just when I thought things couldn’t get worse, the self-checkout line happened.

As we are slowing emptying the contents of the cart in the horseshoe like self-checkout area, anyone in close proximity could hear us. It probably sounded something like this:

“Okay Dad, hand me the milk.”

“Dad, get me. . .”

“No Dad, that isn’t ringing up right. . .”

The dad references were every other word. I reached in the cart and pulled out a bottle of wine or champagne. I looked at him and thought at some point in this escapade, Dad found a way to get the bottle past me (probably when he lost me time number seven!). Not thinking anything of it, I reached out to scan the bottle. In comes the Walmart clerk.

Walmart: (Looking directly at my dad) “May I see your ID?”

My dad looked at him (I swear with fire in his eyes), then looks at me and says, “You’ve got to be kidding. Do I look fucking twenty-five?” (Ah yes, we are to that moment when the F word starts flying…)

Then the Walmart clerk looked at me: “May I see your ID?” he asked.

I respond: “I don’t have it on me. It’s in the car.”

Walmart: “Well, I’m sorry but you won’t be able to buy the alcohol.”

Dad: “Are you fucking kidding me? I’m the one buying it, she is my daughter. How old do you think she is? Knowing how old I am since you have my ID?”

Walmart: “It’s state policy.”

Dad: “The hell it is . . . the person buying the alcohol only needs to show the ID” (FYI – Dad was a liquor sales manager for over twenty-five years, he knows his laws regarding liquor sales).

Walmart: “It’s a store policy.”

Dad: “Fuck this! You can keep the fucking food and all of it. This is fucking crazy! I’m seventy-one and she’s thirty-**.”

Me: (trying to hide my face as I respond) “Dad, you need your food. Let’s just pay and leave.”

As I’m trying to finish out the transaction, Dad responds: “This is ridiculous (as he is throwing his bags into his motor cart). I’m never coming here again and you’re never taking me anywhere to get food again. This is just crazy.” More mumbling…

Me: (taking the receipt off the machine) “Come on Dad. Let’s get you home.”

All I heard was the sound of the cart and my heels clicking on the cold cement floor as we exited Walmart.

A little more of my heart died that day.

Alone and Trapped

March 11, 2017

It is a cold, overcast day. I was driving down 144 Street earlier this morning to find that the company that recently purchased land once owned by Boys Town had begun work on preparing land for development.[74] As I drove by, I saw perfectly healthy trees cut down, lying in heaps.

Figure 16. Andrea Iaccheri, personal photograph, 2017.

Trees that once stood are now cut down; the green of the pine trees facing towards the sky in a way they have never once been. This open space, lined by trees, housing an old barn, small out-houses and acres upon acres of farmland was a space of solitude for me; open space in the middle of a fast-growing city. This land, the acres of farm land and the

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[74] Boys Town is a registered national historic landmark located in Omaha, Nebraska. Father Flanagan purchased Overlook Farm in 1921 becoming the permanent site of Boys Town. The Boys Town organization aids at-risk children. The Boys Town Village is home to churches, homes, schools, a national research hospital and until recently Overlook Farm. Overlook Farm was recently sold to a development company. This sale is transforming the land and area surrounding Boys Town.

wilderness it housed, was isolated from the development of a city. It stood open and bare yet isolated in its square shape, surrounded by busy city streets, schools, and houses.

Figure 17. Andrea Iaccheri, personal photograph, 2017.

Its isolation from the development shows strength to some, weakness to others. Strength in that it lasted as bare farmland for so long in a city striving for growth and development; weakness in that it was isolated yet surrounded by the development the city so desperately wanted and needed. To me, this land (as it once was and no longer will be) represents how one can feel so isolated although surrounded by family, friends, acquaintances; how a person can feel and be strong while holding on to solitude and yet feel so alone and often trapped by their current state (feeling, mood, or other).[75]

Who Takes Care of the Caregiver?

April 4, 2017

As I sit on my kitchen counter trying to eat a bowl of soup, I silently ponder my abilities to meet my one hour of scheduled writing time I put on my calendar for tonight. I think back to my recent trip to Minneapolis for a regional conference, when I had the privilege of staying with my friend James. We were out and about and I had a flair up; one he has seen often during our friendship. I tried to laugh my way through it by self-identifying as "the healthiest sick person I know." He looked over at me and said, "You know, that is the best description you've given yourself yet!"[76] My self-description as the

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[75] The feeling of social isolation has set in. From where does this feeling manifest? Have I been socially isolated by people I know or have I socially isolated myself due to the stress and pressure of caring for my dad? I am not sure if this is a question that I will ever know or care to know the answer to. Unless you have been privy to watching someone slowly leave this world, watching someone come face to face with their own mortality – in a slow and often painful process due to the medical components, I am not sure one can truly understand the emotional energy and toll it takes on the psyche to witness and be a part of their realizations day in and day out.

[76] I share my personal health moments not for sympathy but for me to self-recognize how I push myself to extreme limits to stay healthy to care for another individual while I am barely holding on to the idea of caring for myself. It raises the question of who cares for the caregiver. More importantly, how does the caregiver self-monitor and discipline themselves in order to maintain the self for the person they are caring for? At what level does the idea of self-disappear to care for another?

healthiest sick person I know plagues my thoughts as I know the importance of meeting my writing goal for the day but also knowing my body well enough to identify when I will be productive at the computer and when I won't be.

Today fits the category of the unproductive day. My body is aching everywhere and my stomach is causing issues once again. Still trying to consume my soup that is now getting cold I realize that no matter what I try and do to keep myself healthy, I am not infallible. I have my own health issues yet I must endure them alone. Here I am facing two crippling flair-ups, yet I sit alone. There is no one near me – no one to hear me – no one to help me manage. I expect my body to keep going even when I am ill. As I sit alone fiddling with my now cold soup, I ponder the thought: Who takes care of the caregiver? Already knowing the answer is me; the self.

Frozen

April 12, 2017

Yesterday after work, my plan was to stop by Walmart to get Dad's prescription, then stop by home to change into my running gear, and then drive out to Dad's place to give him his script and then run on the trail by his apartment. I made it to Walmart and picked up the prescription. I made it home and headed upstairs to change. Instead of immediately changing into my running gear, I decided instead to take a short break and sit on the spare bed in my office and comb Frida, my small black cat. As I was sitting combing her face, I looked across the room at the wall that housed all my large Post-It's with all my notes for my dissertation. I focused on the large Post-It with all my short stories I had planned for my dissertation. After about fifteen minutes, I felt the urge to write (not following my initial goal outset for the evening which was to come home, change, leave to head over to my dad's, and go run). I turned to open the window by the bed/desk so Frida and I could hear the birds outside and I got hit with a massive anxiety attack.

I was frozen on the bed; my heart and chest felt like it was squeezing while also feeling like it was going to pound right through my skin. I felt the beat through my back, into my arm, down my side. This overwhelming throbbing, yet my body wouldn't move. I could feel the bed move when Frida moved, I could feel the bed jiggle when Stanley jumped up onto the bed, I saw Stan when he moved into my line of sight, but my body was frozen. I don't know how much time passed between the onset of the attack and when I was able to move my hands to send a message. It felt like only a short amount of time but looking back at my message log, it was a solid two hours before I could move. When I did try to get up around 9:30 p.m. (after I thought the attack had subsided), I got hit with yet another round when I sat up.

I wanted to write about this as it was happening, but I couldn't. I knew what I wanted to type as I was experiencing it, but I couldn't. I wanted to reach out to family, but I couldn't. I was totally isolated from all beings but my cats. Looking back on this moment from last night, I felt totally isolated from those I love. For the first time, I felt what my dad feels every day, lying in bed . . . alone

In Memory of Stanley, a.k.a. Stan

Figure 18. Andrea Iaccheri, personal photograph, 2015.

On December 15, 2017, I said goodbye to my fur companion, Stanley. A piece of my heart died this day. Stan was part of my life for fifteen years. He stayed with my mom for some time but returned to me in May of 2015 when my mom moved to Lincoln to live with my sister. Stan soon got the nickname Old Man Stan as his arthritis started to set in and he slowly began to lose weight. Stanley slept next to me every night I was home for two and a half years. He comforted me during sadness, through anxiety-filled moments, and sat with me while I celebrated moments of joy. Stan was always near. Whether it be sitting next to me when writing, sitting on my lap when taking a break, or trying to sit on my keyboard when he wanted attention and I was busy working on my dissertation, he was always there. Old Man Stan greeted me when I got home every day and waited patiently for his morning hugs. He often woke me up with the soft pat, pat, pat of his paw on my arm or cheek. He was not able to see me through the end of my dissertation. His rhythmic purrs are no longer heard, only remembered in my heart and in my mind. Stanley, you are missed. You will always be my Stanley. You will always hold a place in my heart.

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The narratives in Part II keep leading me to ask the same question: Are the feelings of isolation and anxiety my doing or is it “done” unto me due to the experiences I am facing daily? I’m not suggesting that I blame my feelings of isolation or anxiety on any other person, rather I question if these feelings are created by me or if the experiences that I have with my dad have created me to feel these mindsets. As a scholar, I am always seeking to find answers for my questions. The next section, Reflections, explores the connection between published scholarship and my personal narratives from Part I and II.

Reflections

When I set out to complete my analysis for this project, I struggled. I could not find my voice. I knew what I was seeing across the texts, yet I could not write. I spoke of this concern to my advisor and he suggested I write out my own experiences. I was hesitant at first. I questioned why anyone would want to read about my experiences, yet I found myself wanting to write. From the outset of my journey with my dad I took my journal everywhere. I used it in meetings, doctor appointments, in waiting rooms. I journaled in the E.R., at home – sitting on the kitchen counter or in bed, in the car (when not moving of course); I was writing all the time, looking for answers, but I was not yet able to see the connection. I would notate where I thought my own experiences link to authors I have read and/or ideas and theories I had studied, but that was as far as I got. It was not until I began to write out my own experiences (from notes I had taken in various places) in storied form that I truly began to see the connection between what I study and myself. It is out of my advisor's suggestion that I truly found my voice as an author/scholar.

Helen O'Grady believes "When authors are transparent about the motivation informing their interest in a topic, the reader is offered an explanation of why that particular subject is a focus of concern . . . this type of transparency also helps avoid any assumption of author neutrality" (3). My original intent for this project was to study various health topics communicated in the comic form. As I was working on the initial analysis of these texts, I struggled. I was interested in each topic but my heart wasn't quite all the way in it. My eyes gravitated toward caregiving memoirs in the comic form.

It should be no surprise that my interests gravitated toward these caregiving narratives as that is what I was entrenched in. Yet, as I still struggled to sit and write. My own experiences were at the forefront of my mind. In using my own stories, I found my purpose in the analysis I wanted to complete and in my own research. My personal experiences ground me in the literature and assist me in identifying the value of health narratives for a larger audience – both academic and non-academic. My personal experiences told in narrative form, story form, personal journal entries, and/or poems are not neutral as they exemplify my experiences with my dad, with the American medical system, and my own internalization of the responsibilities associated with being a caregiver.

As a scholar, I found myself gravitating toward the works of Michel Foucault, Deborah Lupton, Arthur Frank, and Raymie E. McKerrow to guide my critical analysis of my own experiences. Some may argue that my reliance of Foucault, Lupton, Frank, and McKerrow limits my analysis and my work; I would disagree. This chapter is me. As each of my experiences played out, as I reflected on my own personal feelings/fears, as I recalled family history or learned of new family information, my mind (whether I liked it or not) recalled information and ideas from each of the authors listed above. Foucault, Lupton, Frank, and McKerrow guide my research, my view, my understanding; how I process and now see the world. Can I view an experience without one of these authors filtering the moment? Yes. But for this project, I did not want this sociocultural, critical-rhetorical, narrative frame from which I operate from absent from my work. The reason?

How I live my experience as caregiver is developed from my sociocultural, critical-rhetorical, narrative understanding.

As explained earlier in this chapter, the stories in Part I reflect on an ‘other’ orientation of caregiving while Part II reflects on a ‘self’ orientation. The ‘other’ and ‘self’ orientations of caregiving help explain how I was able to give visible and/or tangible form to the idea, feeling, and quality of the role of the caregiver. My own journey as a caregiver has exemplified both – ‘other’ and ‘self’ orientations; ‘other’ being the lived experiences of caregiving that include the projected social expectations when in this role of caregiving, ‘self’ being my self-reflexive lived experiences surrounding being a caregiver (how I feel/felt as a caregiver; how I internalized this role).

Upon completion of Part I, I realized that my daily life was continually being interrupted by aspects of my dad’s care. While this may seem selfish to admit to, there is no denying the level of interruption(s) that take place. These interruptions can be in the form of phone calls from dad, from doctor’s, calls regarding housing or medications. Interruptions can also be in the physical form – assisting with various daily tasks. I hear it is similar to having a child. Yet, in my experience my dad (a.k.a. child in adult body) still believes he does not need assistance, can make his own decisions, and believes he is still correct in all things.[77]

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[77] This might be a universal father trait.

I also recognized that my stories communicate various aspects of medical information by embedding both specific and general information within the stories.[78] I use this tactic for a few reasons: first, I want you (the reader) to understand the specific medical information I have gone through with my dad; second, by sharing detailed information, my hope is that you can learn from my experiences and apply to your own life; third, I hope that by sharing this type of information, you can begin to feel some level of connection to the stories (if not to my personal experience, then to an experience of your own or that of someone close to you). A benefit of writing in this style is that it provides the space for you, the reader, to connect to topics and/or situations you may not have the privy of experiencing firsthand. My hope is that my personal journey moves you in a way statistical data cannot.

Including autoethnographic accounts in my dissertation was a difficult decision for me to make. I knew that my accounts included family members, physicians, and myself in good and not so good light. During the initial drafts of each moment, I was drawn to key ideas/concepts I had previously read. These included the notion of risk as discussed by Deborah Lupton, Arthur W. Frank's work on *"Illness as a Call for Stories*

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[78] My inserting medical information follows the theoretical perspective known as social constructionism. Debora Lupton states the social constructionist approach emphasizes that disease or illness states as well as bodily experiences "are inevitably knowing and interpreted via social activity and therefore should be examined using cultural and social analysis" (*Medicine* 9). In the case of my own narratives, I am using my social and cultural understandings of illness, health, and the medical system to navigate through each experience.

and The Quest Narrative" (*The Wounded Storyteller*), and Foucault's idea of self-policing. Each framework provides insight to how I see my own autoethnographic accounts operating as a means for analysis as well as an avenue for understanding.

It is no secret that I share personal information in my own narrative accounts. Sharing this information, at this detailed level, has been labeled as a risk by some. The notion of risk has been a concept that has been at the forefront of my mind throughout this project. I have been asked by various people, why I am sharing personal information about both myself and my dad? Why do I risk putting this information out there for others to read? These questions prompted me to revisit Lupton's work on risk. While others have written on this subject, I use the work of Lupton specifically because of her Foucauldian influences as well as her inclusion of socio-cultural histories and understandings of health and other various topics she writes about; risk being one of these topics. In her book *Risk,* Lupton shares the following about risk, concluded from her personal research on the subject:

> In contemporary western societies, where control over one's life has become increasingly viewed as important, the concept of 'risk' is now widely used to explain deviations from the norm, misfortune and frightening events. This concept assumes human responsibility and that 'something can be done' to prevent misfortune. Feelings of insecurity are common, just as they were in pre-modern times, but we now harbour [sic] somewhat different fears, different targets and causes for our anxiety. (3)

She goes on to say:

> Risk and uncertainty tend to be treated as conceptually the same thing: for example, the term 'risk' is often used to denote a phenomenon that has the potential to deliver substantial harm, whether or not the probability of this harm eventuating is estimable. (9)

Sharing medical information of self and others can be deemed as a risk, under Lupton's umbrella. My dad's medical diagnoses and my own experiences with anxiety and isolation can be viewed as both frightening and misfortunate. Frightening in the sense as they are uncontrollable and experienced as they happen. Misfortunate as they were not planned and are unwelcomed. In my own writing, there is a level of risk in the fact that I am sharing personal health information. While this is becoming more accepting in the communication discipline, it is still viewed as a deviation of a norm – that of keeping our personal health information private. At a very basic level, I am engaging in a level of trust with you, the reader. I am also activating trust in my dad's doctors and in our medical system regarding his health and wellbeing, as seen throughout Part I of this chapter.

Incorporating the work of Anthony Giddens, Lupton speaks to the idea of trust as a factor in our ability to accept risk and act within risk-based situations. Lupton, with the influence of Giddens, suggests that trust incorporates a level of emotional security. She continues by stating:

> Trust, therefore may be regarded as a means of dealing psychologically with risks that would otherwise paralyse [sic] action or lead to feelings of engulfment, dread

> and anxiety. Without trust, people could not engage in the 'leap of faith' that is required of them in dealing with these expert knowledge systems of which they themselves have little understanding or technical knowledge because they have not been trained in them. (78)

Lupton continues:

> Trust may result from reflexive calculation or else simply from choosing to invest faith in an individual or organization. It allows individuals to develop a cocoon of invulnerability which enables them to get on with life, to fend off their knowledge of the risks that await them at every turn. This protective cocoon is sometimes pierced by experiences that highlight the existence of these risks and call into question established routines. (78)

She suggests that we create everyday routines to establish and maintain a level of security through our development of trust to manage our fears (79).

I see my writing as a cocoon. It is a safe place where I found solace and trust in myself and my abilities to handle my dad and his needs. I use my writing as a means to manage and cope with the challenges I faced, and still face, on a daily basis. My writing also provides me the space to reflect on my experiences and link my academic self to my non-academic self; daughter, legal guardian to my dad, and caregiver. It is through trust, within the unknown world of risk, that I could finally step outside the structures that were prohibiting me from seeing the value of my own stories, experiences, and accounts of being a caregiver (from both the external and internal view) and lead me to find purpose in my writing and work. One way I discovered purpose is by identifying my accounts as what Arthur W. Frank classifies as *"Illness as a Call for Stories."*

In his book *The Wounded Storyteller: Body, Illness, and Ethics*, Arthur W. Frank believes that at least two types of stories are in answer to a call that emerges from serious illness. When seriously ill, "stories have to *repair* [emphasis in original] the damage that illness has done to the ill person's sense of where she [they] are at in life, and where she [they] may be going. Stories are a way of redrawing maps and finding new destinations" (53). Stories also have a very immediate and literal purpose (53). Stories provide information to various individuals including family, friends, medical personal, etc. Frank names the illness as a call for stories as narrative wreckage as stories of illness tend to be a wreck; suggesting that repair must be done.

In my own writing, I can see the idea of wreckage at the forefront of the overarching body of my stories. Frank suggests, a narrative wreck exists when the author loses:

> . . . the central resource that any storyteller depends on: a sense of temporality. The conventional expectation of any narrative, held alike by listeners and storytellers, is for a past that leads into a present that sets in place a foreseeable future. The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable. (*Wounded* 55)

Frank provides a solution on how to escape narrative wreckage which is to tell stories; "specifically those stories that Schafer calls 'self-stories'" (55). He continues by explaining, "The self-story is not told for the sake of description . . . the self is being *formed* [emphasis in original] in what is told" (55). The importance of the self-story is reaffirmation – reaffirmation of the self and our relationships with others. "The ill person needs to reaffirm that his story is worth listening to by others. He must also reaffirm that *he is still there* [emphasis in original], as an audience for himself" (55). Frank believes reaffirmation takes place by identifying that the illness has caused interruption and purpose.

Identifying the interruption will open various possibilities for the narrative purpose. It is through writing out my stories and narratives and identifying them in both the external and internal sense, that I was able to find their purpose; yet, I was stuck. My narratives are split between external and internal aspects of caregiving. Following Frank's work, I am working through narrative wreckage as I am forming the idea of self in my stories by identifying as a caregiver but my story as a caregiver is not yet finished. The other issue I face is that my caregiving story is not about my illness, although I do share personal moments of my own narrative embedded in my journey as caregiver for my dad. Instead, I am writing about my experiences as a caregiver for my dad – whose illness narrative is documented. While I am not writing my own illness narrative, I do believe that illness – that of my dad's – called me to write.[79] Per Sayantani DasGupta and Masha Hurst:

> The Illness narrative does not merely reflect the experience of illness; it contributes to that experience by giving coherence, symbolism, and meaning to what might otherwise have been a chaotic experience. Telling stories about illness

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[79] Caregiving is not an illness but in most instances, it is connected to illness.

> puts the experience in personal and social contexts, reflecting the individual's symbolic cultural interpretation of events. ("*The Gendered Nature of Illness*" 1)

So, while I write about illness, my narrative is not a prototypical illness narrative, as the illness is not mine (though my internal personal narrative could be considered the normative "illness narrative").

Using the framework of DasGupta and Hurst, my stories contribute to the larger body of work on caregiving, providing a synthesized and realistic portrayal of the daily experiences of caregiving. DasGupta and Hurst also connect the importance of self-stories in their work. They state:

> Self-stories allow individuals to construct meaning from otherwise devastating life events, repair the disruption caused by illness to their healthy life narrative, and reclaim power from other narratives of the experience, including the medical narrative. (1)

I find that if I include DasGupta and Hurst's view of the self-story and combine with Frank's writing on the topic, the self-story can also be viewed as a tool for an individual that is assisting an ill or sick person(s). Combining ideas on the self-story provides a way for the non-ill individual to construct meaning of the illness they are experiencing with the sick as well as aid in repairing disruption in life that takes place when ill or caring for an ill person. Writing out my own caregiving experiences allows me to reclaim power, not only from my own experiences but from other's as well as we will see in the next chapter.

Writing my stories has provided me with the ability to look and analyze myself from the outside in. While I cannot be fully separated from my own experiences, the act of writing and reading/re-reading allowed for me to process what had taken place. Within the stories I shared in this chapter, I referenced theoretical ideas of Foucault. At times they were short mentions, where other times his ideas grounded aspects of my dad's care I was trying to process and understand. What I was unable to see when writing in the moment was the level of self-policing I engage in as a caregiver.

At the core of self-policing is surveillance. It is self-surveillance. Foucault explains:

> There is no need for arms, physical violence, material constraints. Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorizing to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself. (*Power/Knowledge* 155)

As a caregiver, I am constantly turning my gaze inward to monitor, reflect, adjust levels of care that I am providing. There is no need for an external body to do so, as I am already enacting self-surveillance to the highest level. Helen O'Grady speaks to this idea in her book *Woman's Relationship with Herself: Gender, Foucault, and Therapy*. In a discussion on self-policing, she identifies:

> The contemporary power of self-policing can be understood, in part, in terms of the pervasive western ethos of individual responsibility and autonomy . . . While taking responsibly for various aspects of one's life is clearly important . . . the overriding individualistic impulse of much of western culture tends to trivialize

> and obscure the very real effects of social structures which privilege some groups and disadvantage others. A lack of societal acknowledgment of this increases the likelihood of individuals blaming themselves, and being blamed by others, for aspects of life over which they have no control . . . this type of blame merely compounds the feeling of disempowerment that often accompanies failure to measure up to mainstream standards. (18).

She continues by suggesting, "self-surveillance has become such a taken-for-granted part of psychic make up that it is mostly invisible to conscious awareness" (18-19). While I believe this to be true, I have been privileged to understand enough about self-surveillance and self-policing to know that I, although unwillingly at times, engage in this behavior. My feelings of isolation and anxiety can be connected to the blame I put on myself and the blame that others place on me when I fail to meet or believe I failed to meet an aspect of my father's care or an aspect regarding my own personal life. The blame is the innate response to the level of individual responsibility and autonomy that O'Grady writes about.

Foucault's original writing on the power structures embedded in the acts of disciplining and punishing follows the act of public torture to a more privatized form of both discipline and punishment. O'Grady brilliantly articulates the impact self-policing has on the individual stating:

> Foucault's portrayal of self-policing importantly highlights the less brutal but nonetheless soul-destroying effects of this modern practice of power. In societies whose basic organizing principle is the group norm, self-surveillance reproduces

> the constant monitoring, differentiation and ranking of individual conduct "as better than or below average, normal, deviant, and so on" (Allen, 1998, p. 175). (qtd. In O'Grady 19)

When looking back to the question I proposed earlier in this chapter, that being: Are the feelings of isolation and anxiety my doing or is it "done" unto me due to the experiences I am facing daily? The overwhelming feeling of personal responsibility due to the level of self-policing I place on myself daily could be a reason why I feel isolation and anxiety as a caregiver. I'm trying to constantly measure myself against the norm of what society deems as a "good caregiver," holding to those principles. If I do not meet those self-constructed constraints I place on myself, blame enters the picture allowing for feelings of isolation and anxiety to manifest likely due to feelings of disempowerment for I could not control the situation around me to the level I desired.

Conclusion

Writing my own stories as they are presented in this chapter allowed me to reflect and use various theoretical views to aid in critically analyzing my own experiences of caregiving. By doing so, I have been able to identify possible reasons why I feel the isolation and anxiety I feel as a caregiver as well as why interruption of daily life happens to those in the caregiving role and possible reasons for the desire to share medical information and learning moments within my narratives. I understand that the ideas and theories proposed in this chapter are one way of looking at the themes I have identified in my own work but it is important to recognize my orientation toward the topic. Guiding my work is a critical ideology. An ideology grounded in Foucault and McKerrow. In this context, Foucault allows me to situate my narratives in the larger social sphere. McKerrow, as discussed in detail in Chapter One, provides principles that guide my orientation to the subject. In the next chapter, you will see me utilize this framework to accomplish my analysis of the selected comic memoirs and again as guiding principles for my final discussion chapter where I integrate my personal stories with the comic memoirs

Chapter Two utilized my personal narratives to explore both the ‘other’ and ‘self’ orientations surrounding the experiences of caregiving. Chapter Three continues to explore the topic of caregiving by analyzing the works of three comic memoir authors focusing on orientations of ‘other’ within caregiving experiences. Each author narrates, in comic form, their personal caregiving experience while caring for an ill or aging parent(s). Using critical rhetorical techniques within a Foucauldian frame, I seek to further understand the role of the caregiver in our society.

CHAPTER THREE: THREE NARRATIVES ALIKE AND DIFFERENT - LIVED EXEREINCES THROUGH ORIENTATION(S) OF THE 'OTHER' SURROUDING CAREGIVING

"It's a quirk of the memoir that its narrator can never be its hero . . . the narrator is the protagonist – not the hero."

Patricia Hampl *I Could Tell You Stories* (205)

After writing about my initial experiences with my dad, I took a step back. I realized that what I have personally gone through, others have as well. While the illness or health issue may be different, the common threads are the same. I decided to re-read the works by Roz Chast, Brian Fies, and Dana Walrath - specifically focusing on their caregiving experience. I wanted to explore what they faced and see if I might have as well. Within each story, I was reminded that I was not alone in my experiences. Rather, I found myself more and more present in their stories. Some moments made me laugh, others made me cry; most made me stop and realize that each author was facing a life changing moment – the illness of or decline of a mother and/or father they deeply loved and cherished. Within my own stories, as well as the stories of Chast, Fies, and Walrath, two common themes emerged with regard to how a person experiences caregiving from an 'other' orientation. The first is their response to the illness of an Other, in this case a family member; second is their response to managing that illness. Both responses deal with experiences from an external sense connected to the role of caregiving (as previously outlined in Chapter One, the next chapter reverses this orientation in examining the 'Self" in its reaction to these issues). It is to their stories that I now turn.

Through a more detailed discussion of their narratives we can find common ground with my father's journey.

Response to Illness – Caring, Truth, and Confession

Present within each narrative was response; response to the illness of the author's parent(s). How Chast, Fies, and Walrath responded were similar yet different. Two common experiences emerged within this category: the interruption of the daily life of the child, now caregiver; sharing medical information and learning moments.

Interruption of Daily Life of the Child, Now Caregiver

While at first it may seem selfish to identify, there is a level of interruption that takes place when a child discovers their parent is suffering from illness or a health issue. Each author writes of this event in a different way. As you may recall, I wrote about the call I received from my dad while at school. This recollection is rooted in the reality of the moment when I found out my father was ill. The news came as a shock, also causing worry, confusion and concern. After getting over those initial thoughts, my goal switched to learning as much as I could about this new diagnosis. Finding time to research and reach out to friends in the medical field caused an interruption in my daily life and schedule as a doctoral student.[80] Fies, although a professional writer and not a student, speaks to this same idea.

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[80] I would not change how I handled the news of my father being ill, nor would I see the interruption as negative or impeding. I use the term interrupt as by definition it means "to break the continuity of" (*Oxford American Dictionary* 465). The focus was now split between school and Dad.

Fies brings to light the interruption of daily life of not only himself but of his two sisters when learning of his mother's potential illness and then the news that she has cancer. In the game image, Fies denotes the idea of interruption by phone calls in a board game design.[81]

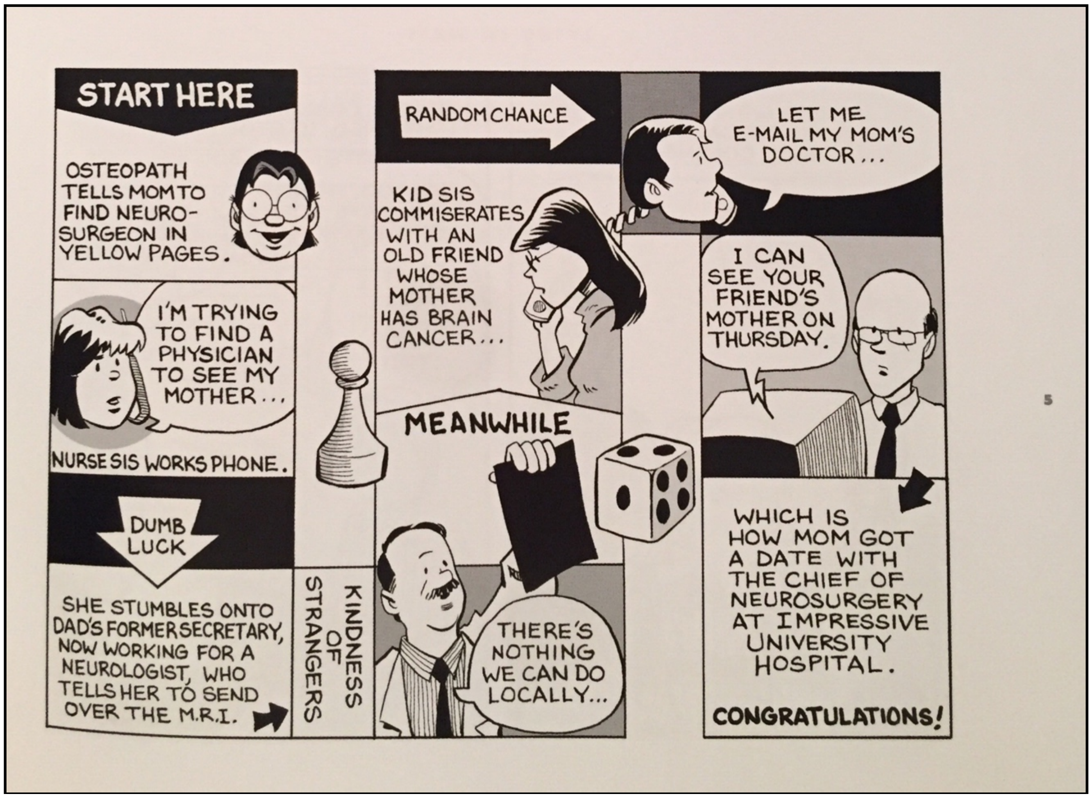

Figure 19. Brian Fies, page from *Mom's Cancer*, 2006, p. 5.

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[81] This specific image reminds me of the many phone calls between my sister, my aunt, and various doctors once we learned of my dad's diagnosis. These calls still happen to this day – depending on the circumstances and the level of need to communication information to various individuals.

While it may not seem like much of an intrusion, finding time in your day to call physician offices (especially when you work) can be difficult. This task may also cause discord at your job, impede on your work responsibilities, or could cause major conflict if you are at a job where you are not allowed to make or take personal calls.[82] Putting another before yourself can also cause a level of internal conflict. In this instance, we can see Foucault's notion of Care of the Self operating in Fies game image. Part of caring for the self requires knowing the self (Foucault *Ethics Subjectivity and Truth* 285). At a very basic level, Fies and his sister needed to know what knowledge they had in order to know they were able to take care of their mother's needs; in this instance – getting their mother an appointment with a specialist. Also, operating in this page is the Foucauldian notion of Pastoral Power. A basic theme of Pastoral Power is the unique relationship between pastor and sheep. There is a level of shared knowledge between the sheep and the pastor, one level being that the pastor has knowledge of the needs of his/her sheep (Foucault *Security* 126-129). Fies's depiction of the game board articulates the idea of knowing the need of the sheep (his mother). Both he and his sister understand the importance and urgency of getting their mother an appointment with the specialist as soon as possible. Fies's board game image stressing the importance of a phone call is one example of the interruption that may occur in the daily life, another is the family meeting.

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[82] From personal experience, reaching someone at the doctor's office is a challenge of its own. Having the doctor call you back is yet another challenge. If you happen to miss the call, the cycle starts all over again and you must call in, leave your message, and then wait for the return call. I call it the phone call dance.

In the historical sense, the family meeting occurs when there is a topic or topics of importance to discuss with family members. This formal meeting style is one that families use when parent/parents and child/children are under the same roof. Family meetings do occur when topics of importance come to fruition that all family members desire to be privy to. In the page, “A Family Meeting,” Fies explains, “Amid the flood of phone calls and appointments, Mom calls a family meeting. It was time to discuss some things” (Fies 9).

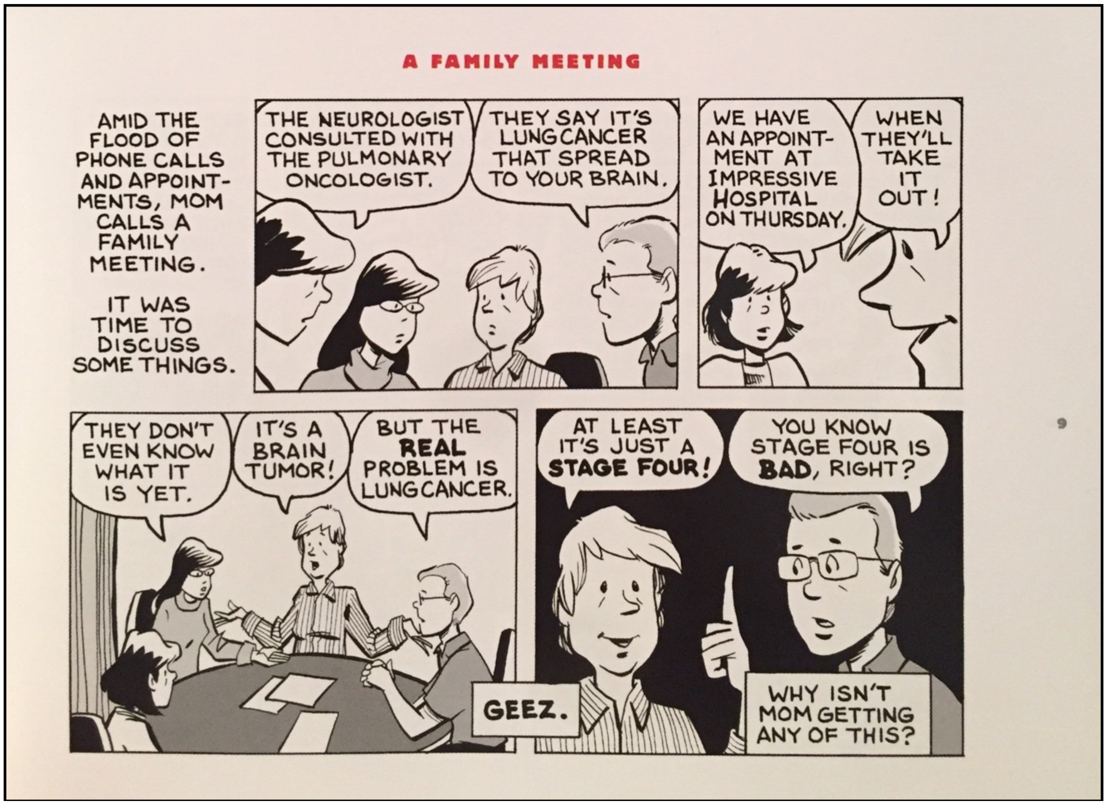

Figure 20. Brian Fies, page from *Mom’s Cancer*, 2006, p. 9.

In this page, Fies specifies the topic of this family meeting, that being his mother's diagnosis and treatment.[83] How Fies depicts the meeting is that of fact-based information from the children and delusion from his mother.[84] In this page, all children are operating within a frame of reference that Foucault (*Security*) would term "Pastoral Power," their intent is to provide care. The conversation focuses in on what the doctors have been saying, which doctors have talked to whom, the type of cancer and location of cancer, and identifying the "real" problem for their mom (who was having difficulty understanding the severity of the issue). Foucault's notion of power suggests that "It is a power that guides towards an end and functions as an intermediary towards this end" (*Security* 129). In this sense, the children are using power to provide answers to their mother and identify what the problem is and what can be done within their family meeting. As Foucault notes regarding how power operates within Pastoral Power, "It is therefore a power with a purpose for those on whom it is exercised" (*Security* 129). In *Mom's Cancer*, the family meeting was called to provide a place to discuss their mother's health and current treatment plan. The children are wielding their power in this situation to ensure the health of their mother. The concern is articulated in the last frame on this

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[83] Ah, the family meeting. So much truth to this moment depicted by Fies. I cannot count how many family meetings we have had at various stages of my dad's illness. When there is the need, we meet.

[84] In Fies's depiction, we see what Interpersonal scholars Ascan Koerner and Mary Anne Fitzpatrick identify as a pluralistic family. The pluralistic family communicates in open ways discussing a wide variety of topics and explores them in depth. In this specific family meeting, the topic is focused on their mother's health and diagnosis. We see the open communication as well as a peek at the depth of this conversation.

page as Fies himself asks, “Why isn’t Mom getting any of this?” (Fies 9). In the two pages that follow “A Family Meeting,” we get the feeling that these meetings continue with the design and outcome being the same; communication of fact-based information from the children, confusion from his mother. While all children are operating within the theoretical ideas of Pastoral Power for the good of their mother, their lives are still exhibiting a form of interruption from the normalcies of their existing lives, pre-cancer diagnosis. Fies also depicts another form of interruption from his daily life, that of research.

Fies brilliantly illustrates his research as shown in in the page below blending his short, descriptive narrative with photograph copies of the articles he pulled while researching his mother’s illness.

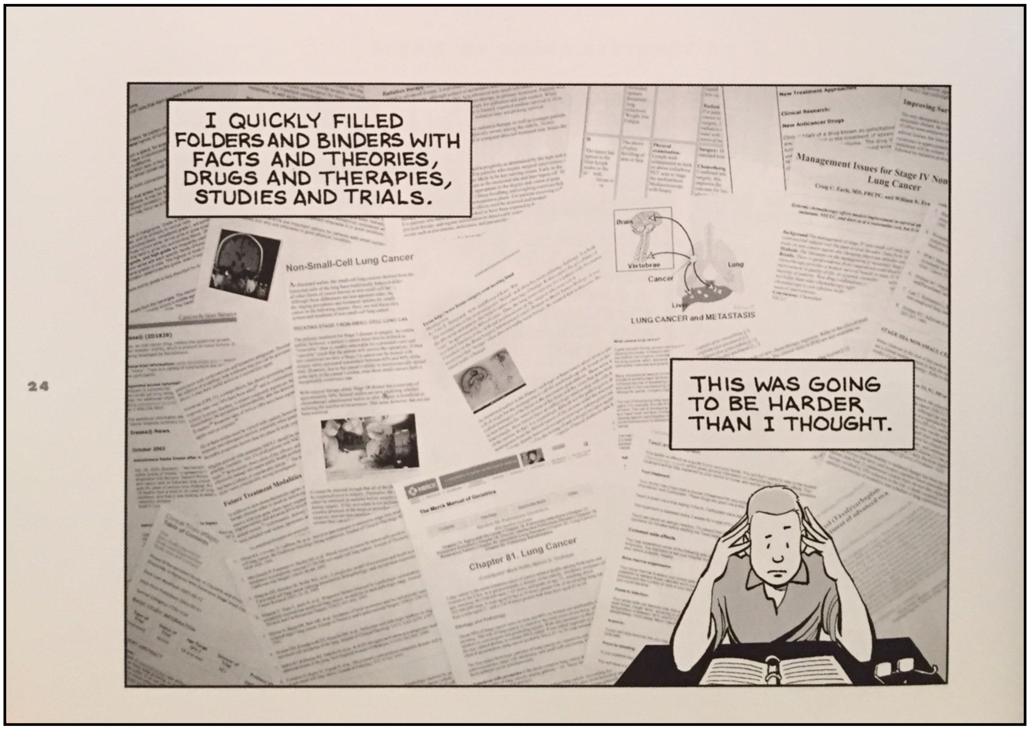

Figure 21. Brian Fies, page from *Mom’s Cancer,* 2006, p. 24.

The page portrays Fies himself, in a thinking and perplexed state while the background is layered with photograph copies of multiple journal articles, web pages, etc. covering his mother's illness.[85] Layered on top of the articles is Fies disclosure of what he researched and the realization that this would be harder than he thought. Although Fies does not come out and say researching interrupted his life, it is alluded to with his realization that the project would be more difficult than he originally anticipated and in the depth of what his research covered: facts, theories, drugs, therapies, studies, and trials.[86] For Foucault, an important characteristic of Pastoral Power is the notion that "Pastoral Power initially manifests itself in its zeal, devotion, and endless application" (*Security* 127). As seen in Fies's page above, we witness what Foucault references in Fies's endless quest to learn as much as he could from as many avenues as he could. As Foucault believed, Pastoral Power exists in ". . . doing good, in order to do good" (*Security* 126). We see this very idea visually represented in Fies's depiction of his quest to learn for the sake of his mother. In this page, the very essence of Pastorship is encapsulated in the frame of this

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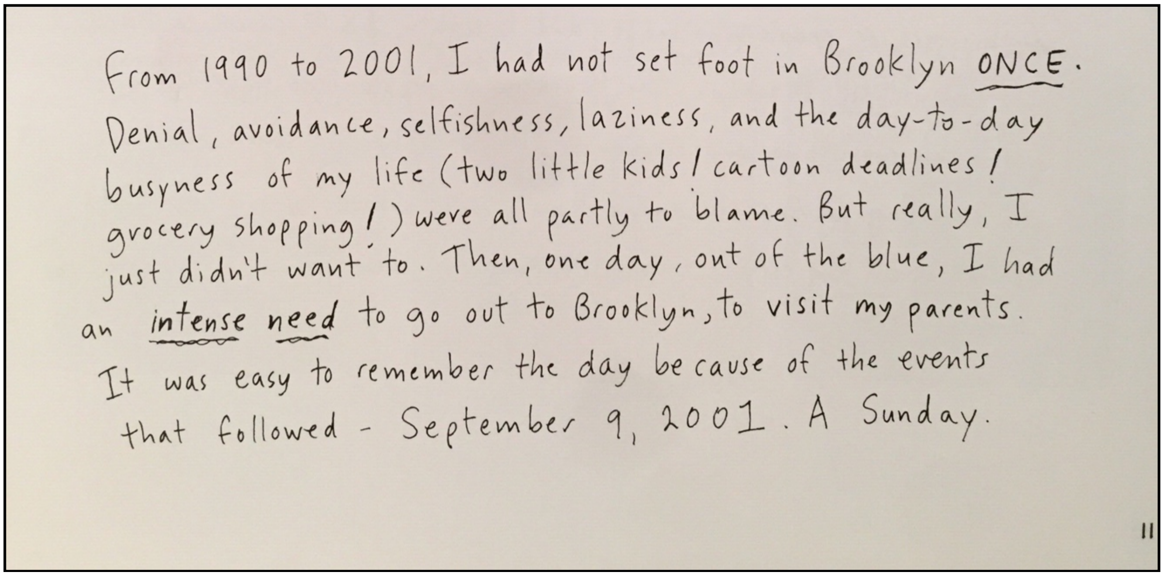
[85] This page speaks volumes to me. I see myself in this page. I still have binders and folders on my computer of various articles both lay and academic covering various aspects of liver and kidney disease. Although only one page, I see Fies communicates a level of deep emotion through his own facial expression and the feeling over being overwhelmed and lost.

[86] From personal experience, I understand the amount of time and energy it can take for an individual to do personal research on an illness. From an academic perspective, the amount of knowledge that is available to one individual can have them researching for days, weeks, months, and in my personal case, years. While this is not an eight hour a day occurrence (in past times it has been for me), a few hours a day quickly adds up. The time you once had for daily tasks or chores, often gets replaced with research and reading.

page. While Fies does exhibit how his daily life has been interrupted to assist in his mother's care, in each exemplar shown here is the deeper-rooted demonstration of Pastoral Power. Like the selected pages/panels of Fies work, there is a level of interruption of his daily life that is taking place; daily interruption that also resembles Chast's narrative accounts.

In Chast's memoir, she discloses to readers upfront that visits to her parents were not something she did on a regular basis. She confesses that she had not been to visit them in over eleven years.



From 1990 to 2001, I had not set foot in Brooklyn ONCE.
Denial, avoidance, selfishness, laziness, and the day-to-day
busyness of my life (two little kids / cartoon deadlines /
grocery shopping!) were all partly to blame. But really, I
just didn't want to. Then, one day, out of the blue, I had
an intense need to go out to Brooklyn, to visit my parents.
It was easy to remember the day because of the events
that followed - September 9, 2001. A Sunday.

11

Figure 22. Roz Chast, panel from *Can't We Talk About Something More Pleasant?,* 2014, p. 11.

In her narrative account, she lists excuses such as avoidance, selfishness, and the day-to-day busyness of her life as reasons why she did not go visit her parents for such a long time.[87] When in reality, as she voiced, she just did not want to go visit. As she describes in the above panel, one day she felt an intense need to go visit them. It was after this visit on September 9, 2001 that her daily life began to change. After her visit on September 9, 2001, the desire to visit her parents regularly hit her. At a very basic level, we see Foucault's Pastoral Power operating in this exemplar. Foucault states, "Pastoral power is a power of care" (*Security* 127). I believe one could argue that a power of care moves Chast to go visit her family. In a way, it was as though Chast could sense some greater change in her parents' health was about to take place and the power of care was activated within her, motivating her to go see her parents. With this motivation, she puts aside her past life reasons and implements a core principle of Pastoral Power: care.[88]

In her chapter, "Return to the Fold," Chast describes the small changes she makes in her life to keep an eye on her mother and father. After her visit in September 2001, Chast began "regular pilgrimages to the old neighborhood" (22). She describes in detail the financial, emotional, and physical commitment these visits took.

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[87] In this exemplar, I can understand Chast's view of being burdened with everyday tasks; tasks that keep us from seeing our parent(s). I especially find a personal connection to her voicing the truth regarding her denial, laziness, avoidance, and selfishness; all feelings I have felt from one time to another. The level of guilt that consumes me on a daily basis is beyond what I would consider normal and yet, I often find myself avoiding going to see my dad.

[88] In this exemplar executing care, Chast used an active approach by physically going to see her parents. This action – visiting – is an 'other' focused orientation as she placed her focus on her parents rather than herself.

Figure 23. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 22.

Initially, guilt and time between visits were the driving motivators for her visits. She soon realized the financial, emotional, and physical complexities of regular visits[89] were becoming too draining for her, so she opted for regular check-ins via the phone.

Figure 24. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 23.

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[89] Defined as visits "'in person' more than once every couple of weeks" (Chast *Can't We Talk* 23).

While check-ins via the phone helped reduce the interruption of her daily life, they did not always help ensure the safety of her parents.

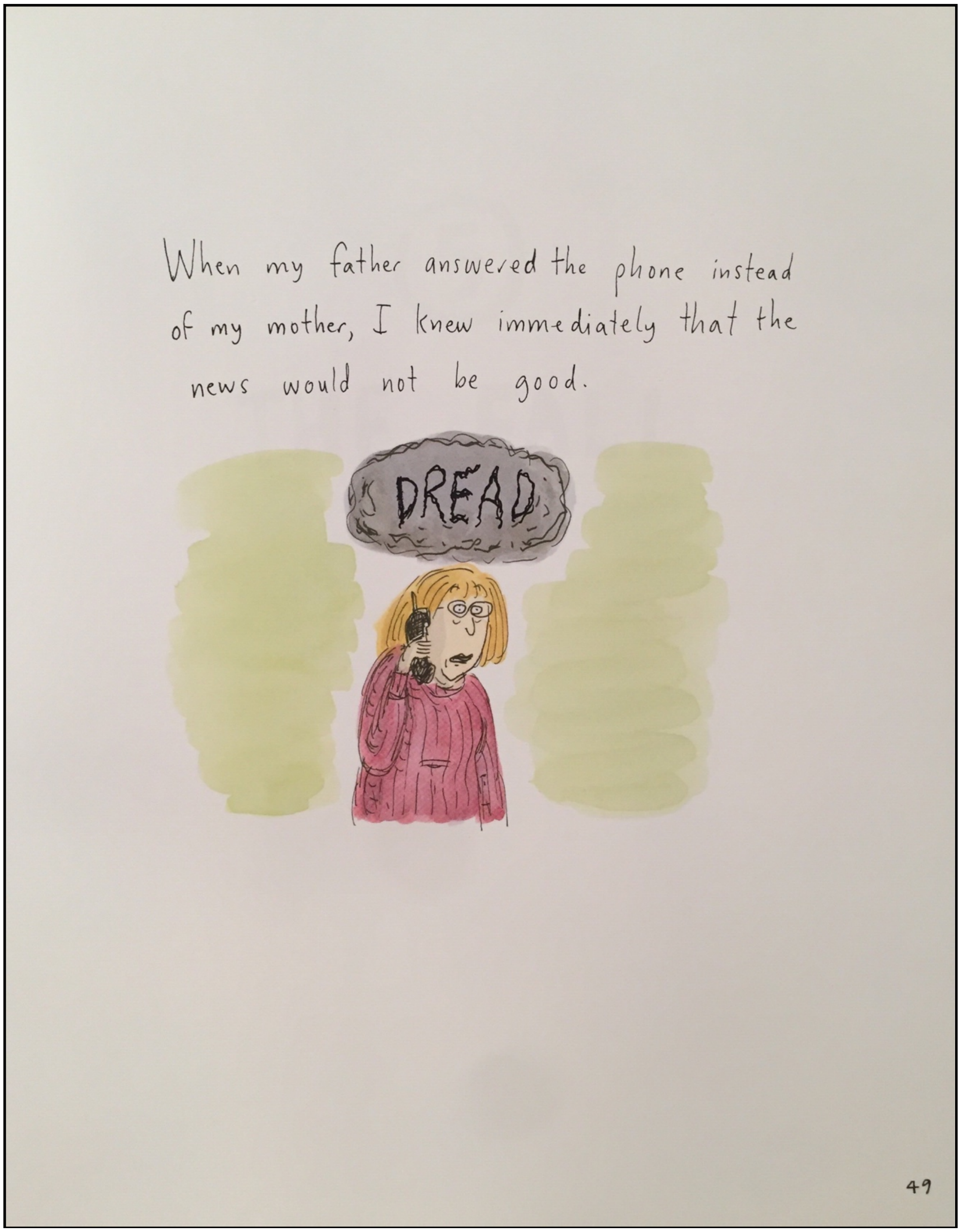
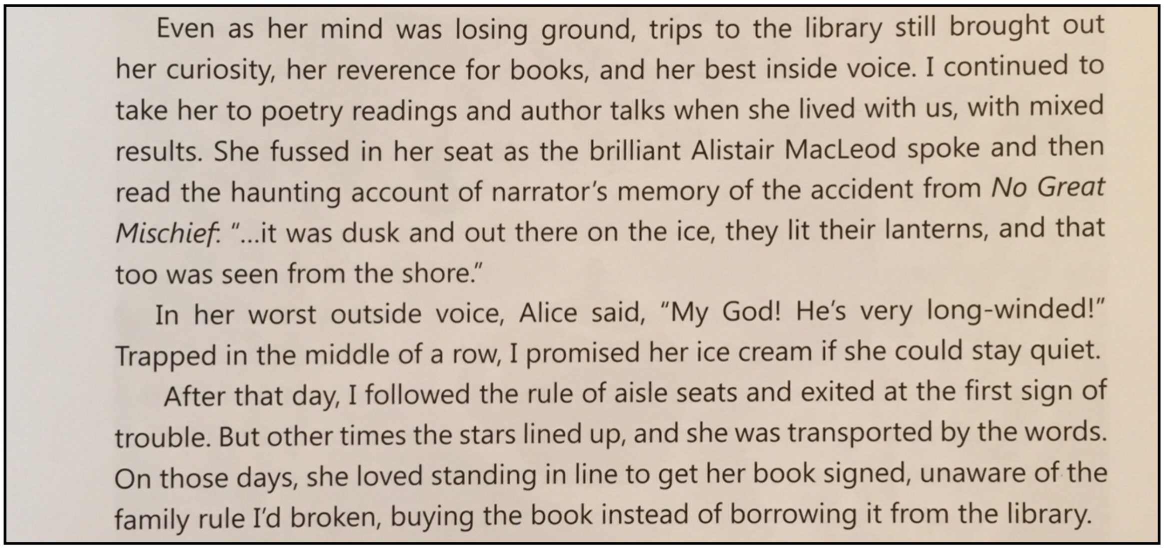


Figure 25. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 49.

Chast realized when her father answered the phone, it was not a good sign. In one instance she recalls the feeling of dread as she learned of her mom's fall during a call in which her father answered the phone. Soon after, Chast's responsibilities soon increased and her daily life was once again, interrupted.

In the previous three exemplars from Chast's work, we can see the power of care, as described by Foucault, working in Chast. Foucault further defines this power of care stating, "It [Pastoral Power] looks after the flock, it looks after the individuals of the flock, it sees to it that the sheep do not suffer, it goes in search of those that have strayed off course, and it treats those that are injured" (*Security* 127). Chast's check-ins via phone did help her keep normalcy but did not provide the level of care she was after. Her calls did not ensure the safety of her parents that she desired nor did it provide her with the desired power of care she needed to exhibit for her parents. Exhibiting care over a parent/s might be easier if one has assistance of other family members. In the case of Fies's account, we see his sisters helping him out in caring for his mother. Chast writes of her personal accounts including only herself in the narrative of acting as caregiver for her parents. Like Fies's experience, Walrath's accounts are inclusive of her and her family's experiences with her mother yet the interruption of daily life that is felt is no different for Chast's or Fies's.

For Walrath, learning coping mechanisms was one way she managed the interruption of her daily life due to the type of illness her mother had. With Alzheimer's there are many physical changes that take place in the person with the illness. Memory loss is unavoidable and people also experience loss of the "internal governor" . . . "they say exactly what's on their mind" (Walrath 11). In her story "Alice Ungrounded" (21), Walrath recounts one instance where her mother expressed her thoughts, rather vocally.



Even as her mind was losing ground, trips to the library still brought out her curiosity, her reverence for books, and her best inside voice. I continued to take her to poetry readings and author talks when she lived with us, with mixed results. She fussed in her seat as the brilliant Alistair MacLeod spoke and then read the haunting account of narrator's memory of the accident from *No Great Mischief*: "...it was dusk and out there on the ice, they lit their lanterns, and that too was seen from the shore."

In her worst outside voice, Alice said, "My God! He's very long-winded!" Trapped in the middle of a row, I promised her ice cream if she could stay quiet.

After that day, I followed the rule of aisle seats and exited at the first sign of trouble. But other times the stars lined up, and she was transported by the words. On those days, she loved standing in line to get her book signed, unaware of the family rule I'd broken, buying the book instead of borrowing it from the library.

Figure 26. Dana Walrath, panel from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 21.

Being prepared for any moment where her mother may respond in a way unsuitable to the formalities of the event creates a possible interruption of Walrath's daily life, yet Walrath exhibits aspects of Foucault's Pastoral Power seamlessly. A key component of Pastoral Power is the notion that the shepherd keeps watch. "He [she] will keep watch over the flock and avoid the misfortune that may threaten the least of its members" (Foucault *Security* 127). In Walrath's narrative, we see this basic principle in action. Furthermore, Foucault states that "He [she] will see to it that things are best for each of the animals of his flock . . ." and that "The shepherd (*Pasteur*) directs all his care towards others and never towards himself" (*Security* 127-128). In Walrath's example, we see her devotion to her mother by watching over her to ensure there is no misfortune when her mother expresses her thoughts about losing the ability to internally govern. Walrath executes her pastoral nature by always being prepared to react to whatever situation may present itself when with her mother to ensure she is kept safe.

Another example of daily interruption for Walrath is in the story "Aliceheimer's." In this story, we can see similar patterns of Walrath's Pastoral nature, as identified in the previous paragraph, operating in how she handles repetition with her mother.[90]

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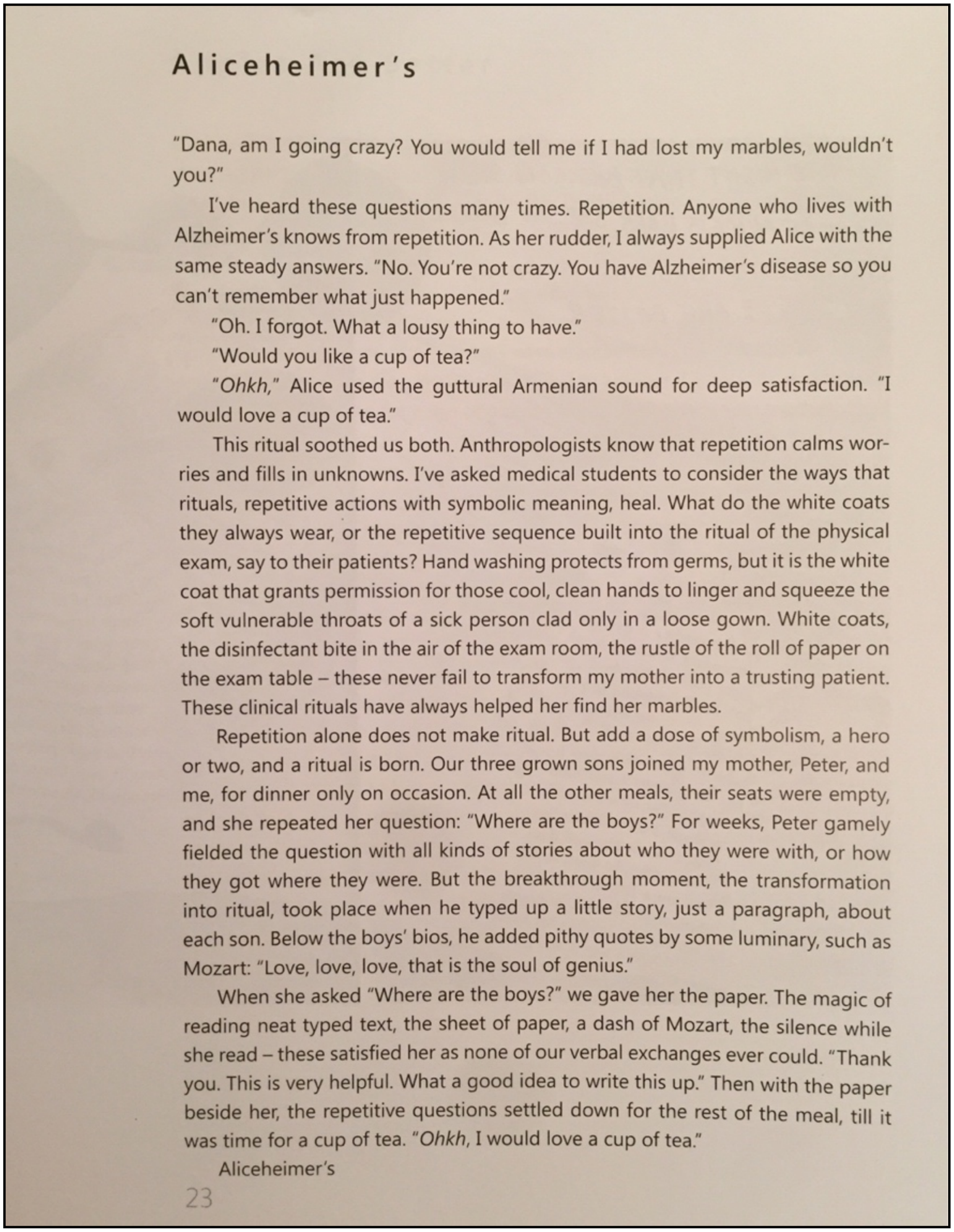
[90] While my dad does not have Alzheimer's, he does suffer from memory loss due to his diagnosis and was recently (early 2018) diagnosed with vascular dementia. When reading this story, my heart hurt. I could see myself in her writing. I could reflect on ways I tried to manage conversations when my dad's memory was faltering. So much truth spoken in this once piece regarding how a caregiver learns to manage and cope with life changes.



Aliceheimer's

"Dana, am I going crazy? You would tell me if I had lost my marbles, wouldn't you?"

I've heard these questions many times. Repetition. Anyone who lives with Alzheimer's knows from repetition. As her rudder, I always supplied Alice with the same steady answers. "No. You're not crazy. You have Alzheimer's disease so you can't remember what just happened."

"Oh. I forgot. What a lousy thing to have."

"Would you like a cup of tea?"

"*Ohkh,*" Alice used the guttural Armenian sound for deep satisfaction. "I would love a cup of tea."

This ritual soothed us both. Anthropologists know that repetition calms worries and fills in unknowns. I've asked medical students to consider the ways that rituals, repetitive actions with symbolic meaning, heal. What do the white coats they always wear, or the repetitive sequence built into the ritual of the physical exam, say to their patients? Hand washing protects from germs, but it is the white coat that grants permission for those cool, clean hands to linger and squeeze the soft vulnerable throats of a sick person clad only in a loose gown. White coats, the disinfectant bite in the air of the exam room, the rustle of the roll of paper on the exam table – these never fail to transform my mother into a trusting patient. These clinical rituals have always helped her find her marbles.

Repetition alone does not make ritual. But add a dose of symbolism, a hero or two, and a ritual is born. Our three grown sons joined my mother, Peter, and me, for dinner only on occasion. At all the other meals, their seats were empty, and she repeated her question: "Where are the boys?" For weeks, Peter gamely fielded the question with all kinds of stories about who they were with, or how they got where they were. But the breakthrough moment, the transformation into ritual, took place when he typed up a little story, just a paragraph, about each son. Below the boys' bios, he added pithy quotes by some luminary, such as Mozart: "Love, love, love, that is the soul of genius."

When she asked "Where are the boys?" we gave her the paper. The magic of reading neat typed text, the sheet of paper, a dash of Mozart, the silence while she read – these satisfied her as none of our verbal exchanges ever could. "Thank you. This is very helpful. What a good idea to write this up." Then with the paper beside her, the repetitive questions settled down for the rest of the meal, till it was time for a cup of tea. "*Ohkh*, I would love a cup of tea."

Figure 27. Dana Walrath, page from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 23.

In this specific story, we witness interruption take the form of repetition of questions and repetition of answers. While Walrath describes how rituals can be born out of repetition, the recognition that change in life's daily moments suggests that there occurred an interruption of how those moments were experienced before her mother's Alzheimer's and after. One example of this change is the introduction of the short typed paragraphs about Dana and Peter's children. Instead of answering the question of "Where are the boys?" Walrath and her husband created short stories to hand to her mother when she asked that question. In this example, we see how changes had to be made, how new rituals needed to be created for Walrath and her family to co-exist with her mother and her Alzheimer's.

Sharing Medical Information and Learning Moments

One commonality between all authors is the beauty of honesty. Honesty in their experiences, the honesty of sharing what they went through with their parent(s), and the detail and careful explanation of medical information that related specifically to the illness or health issue they are facing as a family. While each author's narrative is in and of itself the sharing of their personal experiences, there is a level of shared experience specifically regarding the medical intricacies of the illness/health issue being faced, as well as more basic medical knowledge and information.

In *Aliceheimer's: Alzheimer's Through the Looking Glass*, Walrath uses her short story approach to include examples, as well as medical information and terminology specific to those dealing with Alzheimer's, and what I will term learning moments.[91] In her story, "It takes a Village (with a Dog)," Walrath explains how their dog Herbie provided her mother abilities she would have not otherwise had. Walrath does clearly identify what the medical community suggests is the correct way to help block wandering (a symptom of Alzheimer's); following this, she details how her family dealt with this aspect of the disease in the story, "It Takes a Village (with a Dog)."

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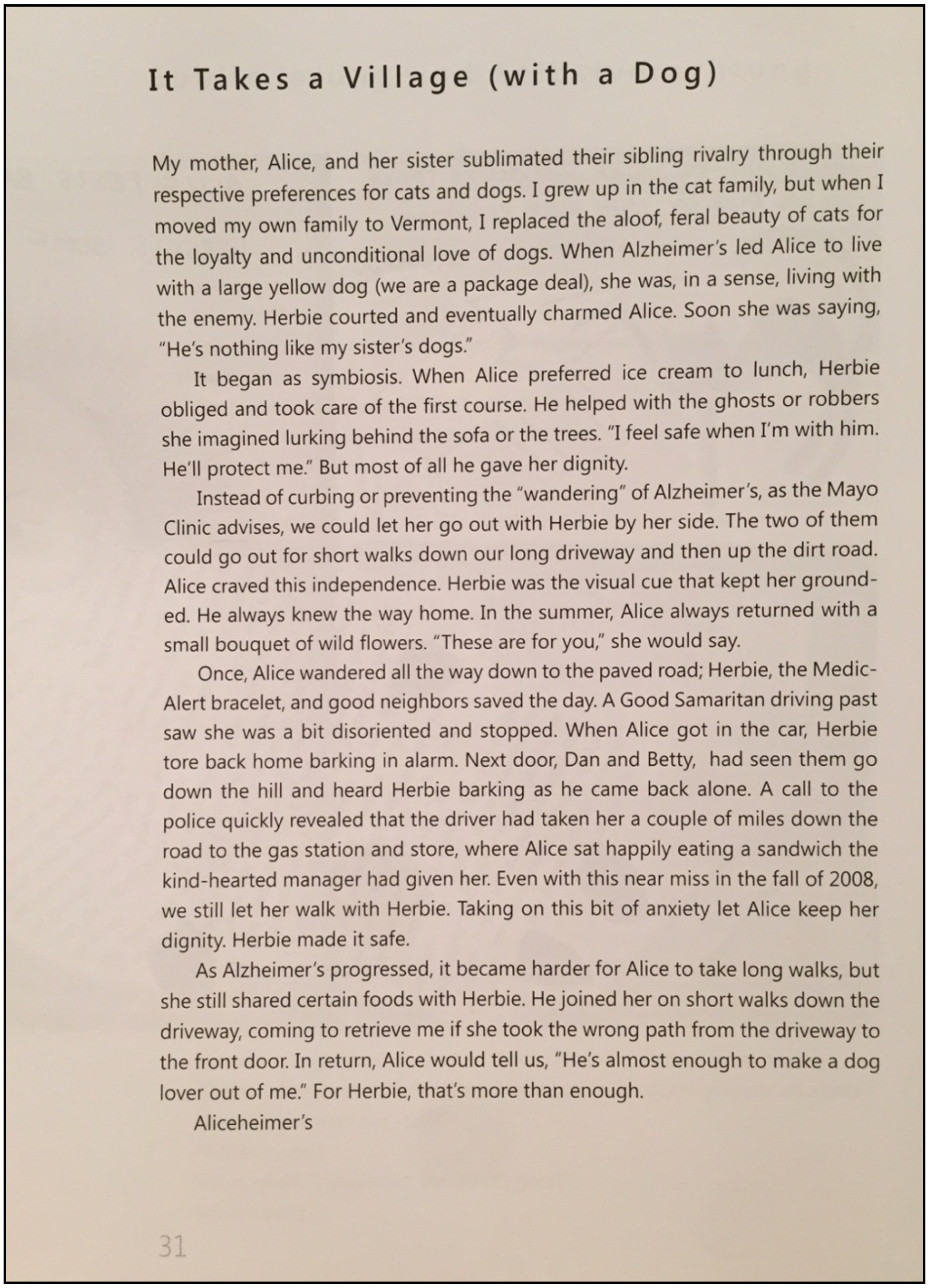
[91] Learning moments are defined as providing the reader with information from a third party or information they themselves have discovered through their time as a caregiver. This information is communicated directly to the reader, often citing sources.



It Takes a Village (with a Dog)

My mother, Alice, and her sister sublimated their sibling rivalry through their respective preferences for cats and dogs. I grew up in the cat family, but when I moved my own family to Vermont, I replaced the aloof, feral beauty of cats for the loyalty and unconditional love of dogs. When Alzheimer's led Alice to live with a large yellow dog (we are a package deal), she was, in a sense, living with the enemy. Herbie courted and eventually charmed Alice. Soon she was saying, "He's nothing like my sister's dogs."

It began as symbiosis. When Alice preferred ice cream to lunch, Herbie obliged and took care of the first course. He helped with the ghosts or robbers she imagined lurking behind the sofa or the trees. "I feel safe when I'm with him. He'll protect me." But most of all he gave her dignity.

Instead of curbing or preventing the "wandering" of Alzheimer's, as the Mayo Clinic advises, we could let her go out with Herbie by her side. The two of them could go out for short walks down our long driveway and then up the dirt road. Alice craved this independence. Herbie was the visual cue that kept her grounded. He always knew the way home. In the summer, Alice always returned with a small bouquet of wild flowers. "These are for you," she would say.

Once, Alice wandered all the way down to the paved road; Herbie, the Medic-Alert bracelet, and good neighbors saved the day. A Good Samaritan driving past saw she was a bit disoriented and stopped. When Alice got in the car, Herbie tore back home barking in alarm. Next door, Dan and Betty, had seen them go down the hill and heard Herbie barking as he came back alone. A call to the police quickly revealed that the driver had taken her a couple of miles down the road to the gas station and store, where Alice sat happily eating a sandwich the kind-hearted manager had given her. Even with this near miss in the fall of 2008, we still let her walk with Herbie. Taking on this bit of anxiety let Alice keep her dignity. Herbie made it safe.

As Alzheimer's progressed, it became harder for Alice to take long walks, but she still shared certain foods with Herbie. He joined her on short walks down the driveway, coming to retrieve me if she took the wrong path from the driveway to the front door. In return, Alice would tell us, "He's almost enough to make a dog lover out of me." For Herbie, that's more than enough.

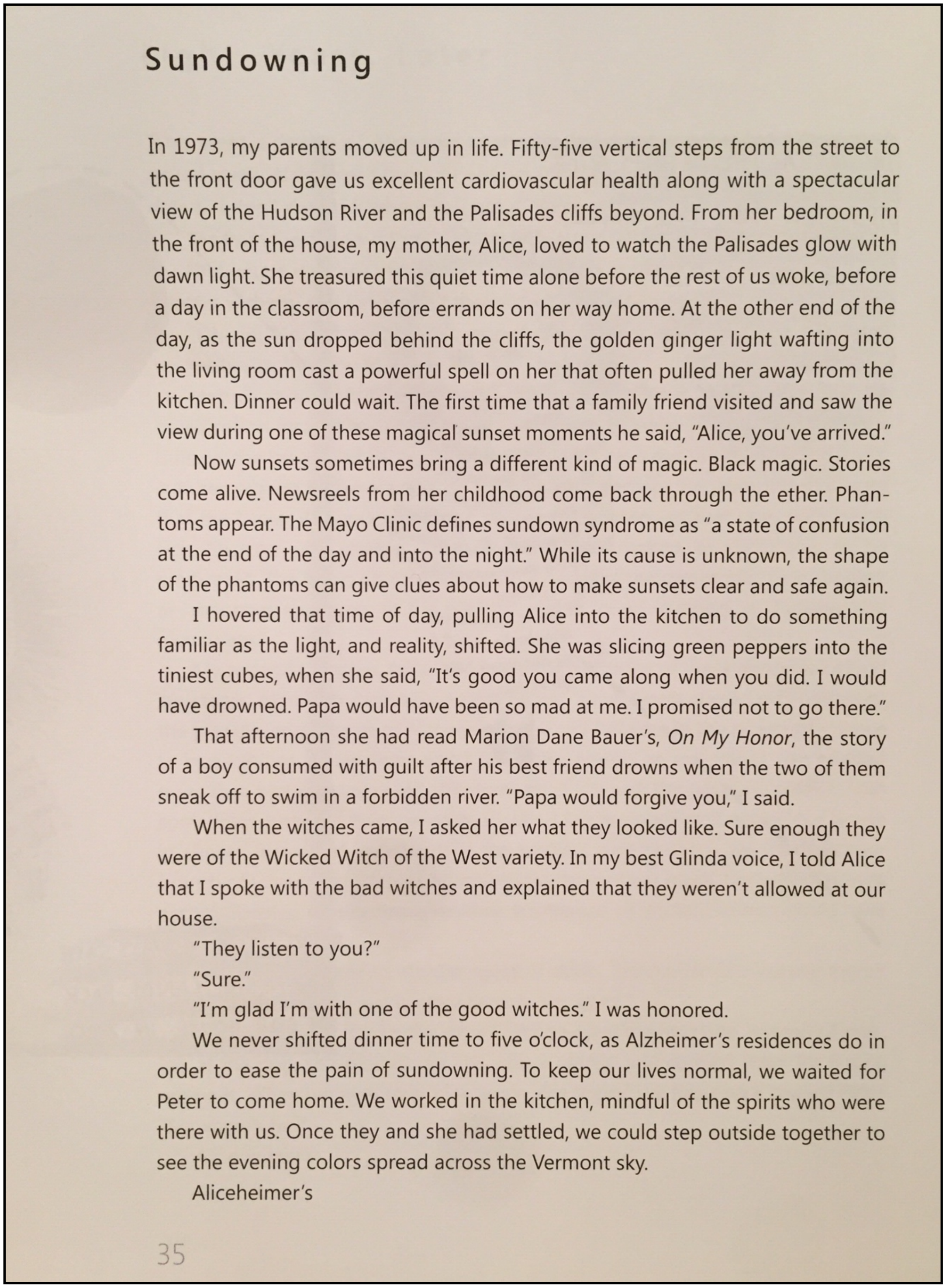
Aliceheimer's

31

Figure 28. Dana Walrath, page from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 31.

Walrath lists what the Mayo Clinic advises to curb or prevent wandering and then provides her solution to the wandering, letting her mother go out with their dog Herbie at her side. Walrath's story further speaks to the independence her mother desired and how she provided a way for her mother to achieve that independence, with Herbie. While this setup did not last forever, it did provide her mother with the independence she looked for at a moment in time. In this short story, we see Walrath share medical information with the reader about an aspect of Alzheimer's, wandering, while also providing her approach to the issue.

We see a similar approach to communicating medical knowledge by Walrath in her short story "Sundowning." In this specific story, Walrath identifies how sunsets have changed meaning for their family since her mother's diagnosis with Alzheimer's. She recalls how her mother once viewed sunsets and the new meaning they take on now that she is living with Alzheimer's. Walrath provides the reader with the definition of sundown syndrome as defined by The Mayo Clinic. She then provides a short sentence about the cause of sundowning and how to make the time during sunsets manageable once more for her mother.



Sundowning

In 1973, my parents moved up in life. Fifty-five vertical steps from the street to the front door gave us excellent cardiovascular health along with a spectacular view of the Hudson River and the Palisades cliffs beyond. From her bedroom, in the front of the house, my mother, Alice, loved to watch the Palisades glow with dawn light. She treasured this quiet time alone before the rest of us woke, before a day in the classroom, before errands on her way home. At the other end of the day, as the sun dropped behind the cliffs, the golden ginger light wafting into the living room cast a powerful spell on her that often pulled her away from the kitchen. Dinner could wait. The first time that a family friend visited and saw the view during one of these magical sunset moments he said, "Alice, you've arrived."

Now sunsets sometimes bring a different kind of magic. Black magic. Stories come alive. Newsreels from her childhood come back through the ether. Phantoms appear. The Mayo Clinic defines sundown syndrome as "a state of confusion at the end of the day and into the night." While its cause is unknown, the shape of the phantoms can give clues about how to make sunsets clear and safe again.

I hovered that time of day, pulling Alice into the kitchen to do something familiar as the light, and reality, shifted. She was slicing green peppers into the tiniest cubes, when she said, "It's good you came along when you did. I would have drowned. Papa would have been so mad at me. I promised not to go there."

That afternoon she had read Marion Dane Bauer's, *On My Honor*, the story of a boy consumed with guilt after his best friend drowns when the two of them sneak off to swim in a forbidden river. "Papa would forgive you," I said.

When the witches came, I asked her what they looked like. Sure enough they were of the Wicked Witch of the West variety. In my best Glinda voice, I told Alice that I spoke with the bad witches and explained that they weren't allowed at our house.

"They listen to you?"

"Sure."

"I'm glad I'm with one of the good witches." I was honored.

We never shifted dinner time to five o'clock, as Alzheimer's residences do in order to ease the pain of sundowning. To keep our lives normal, we waited for Peter to come home. We worked in the kitchen, mindful of the spirits who were there with us. Once they and she had settled, we could step outside together to see the evening colors spread across the Vermont sky.

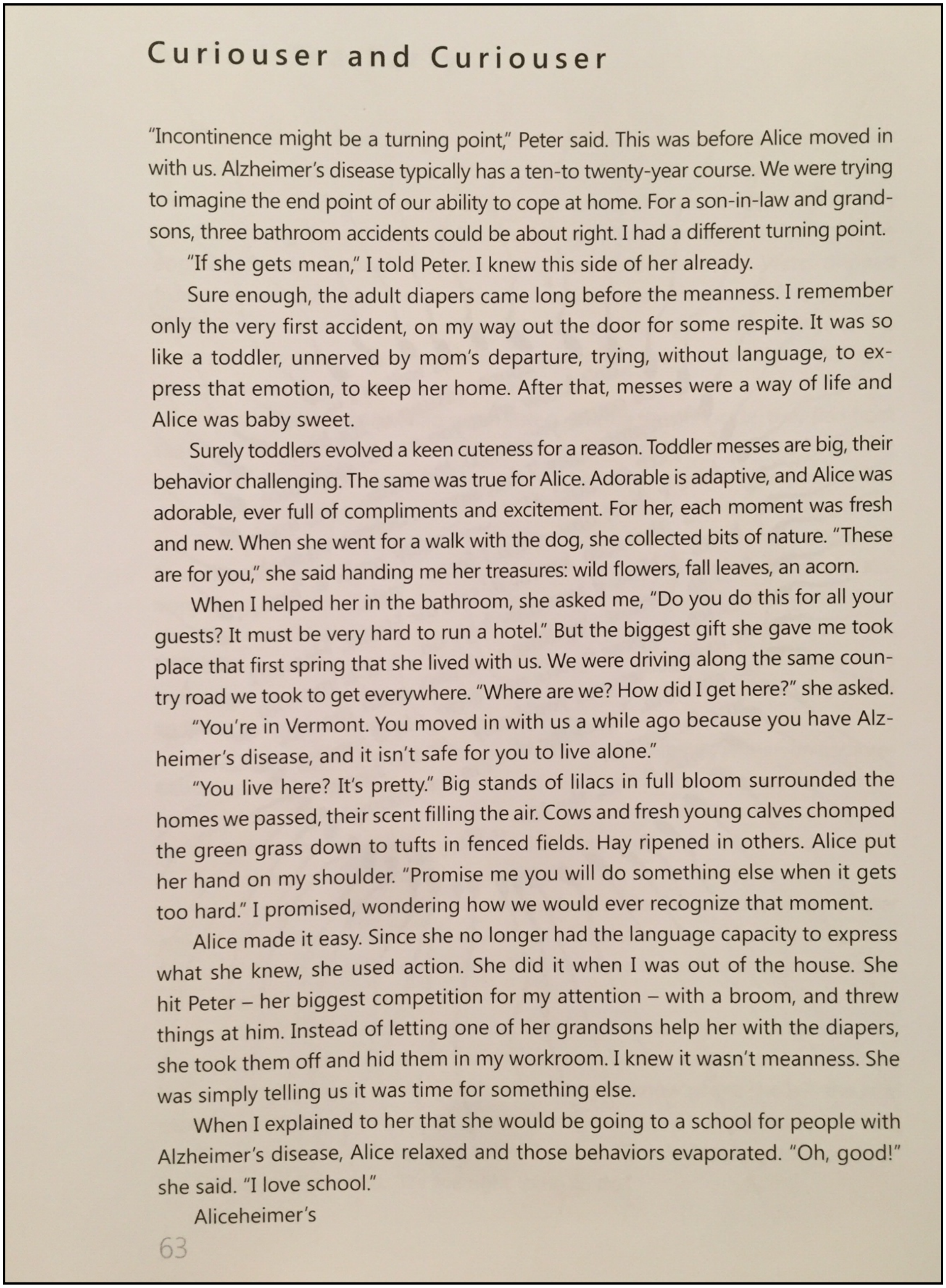
Aliceheimer's

35

Figure 29. Dana Walrath, page from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 35.

At the end of the story, Walrath shares another medical insight regarding how Alzheimer's residences shift the time in which they eat dinner. She identities her decision to not follow a common shift in dinner time (to that of 5 pm) to reduce the pain of sundowning, which other Alzheimer's residences often do. Rather, Walrath, her mother, and her family were mindful of what to expect and they learned to cope with what the sundown syndrome would bring.

A difficult aspect of caregiving is knowing your limits; knowing when you are no longer able to provide a level of care the person for which you are caring needs. In Walrath's story "Curiouser and Curiouser," we see the contemplation of these exact issues between Walrath and her husband, Peter. Within the narrative, the reader is privy to aspects of Alzheimer's that we might not realize take place or that we might want to forget take place. Topics of incontinence, meanness, toddler-like behavior, assistance with daily personal chores (bathing, etc.), and physical violence.



Curiouser and Curiouser

"Incontinence might be a turning point," Peter said. This was before Alice moved in with us. Alzheimer's disease typically has a ten-to twenty-year course. We were trying to imagine the end point of our ability to cope at home. For a son-in-law and grandsons, three bathroom accidents could be about right. I had a different turning point.

"If she gets mean," I told Peter. I knew this side of her already.

Sure enough, the adult diapers came long before the meanness. I remember only the very first accident, on my way out the door for some respite. It was so like a toddler, unnerved by mom's departure, trying, without language, to express that emotion, to keep her home. After that, messes were a way of life and Alice was baby sweet.

Surely toddlers evolved a keen cuteness for a reason. Toddler messes are big, their behavior challenging. The same was true for Alice. Adorable is adaptive, and Alice was adorable, ever full of compliments and excitement. For her, each moment was fresh and new. When she went for a walk with the dog, she collected bits of nature. "These are for you," she said handing me her treasures: wild flowers, fall leaves, an acorn.

When I helped her in the bathroom, she asked me, "Do you do this for all your guests? It must be very hard to run a hotel." But the biggest gift she gave me took place that first spring that she lived with us. We were driving along the same country road we took to get everywhere. "Where are we? How did I get here?" she asked.

"You're in Vermont. You moved in with us a while ago because you have Alzheimer's disease, and it isn't safe for you to live alone."

"You live here? It's pretty." Big stands of lilacs in full bloom surrounded the homes we passed, their scent filling the air. Cows and fresh young calves chomped the green grass down to tufts in fenced fields. Hay ripened in others. Alice put her hand on my shoulder. "Promise me you will do something else when it gets too hard." I promised, wondering how we would ever recognize that moment.

Alice made it easy. Since she no longer had the language capacity to express what she knew, she used action. She did it when I was out of the house. She hit Peter – her biggest competition for my attention – with a broom, and threw things at him. Instead of letting one of her grandsons help her with the diapers, she took them off and hid them in my workroom. I knew it wasn't meanness. She was simply telling us it was time for something else.

When I explained to her that she would be going to a school for people with Alzheimer's disease, Alice relaxed and those behaviors evaporated. "Oh, good!" she said. "I love school."

Aliceheimer's

63

Figure 30. Dana Walrath, page from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 63.

In her story, we see the challenges she and her family faced when being full time caregivers to her mother. We are witness to the struggles, the emotion, and the choices that each individual/family must make and what action would be a turning point for that person/family. While this specific story did not provide a definition or medical knowledge direct from a trusted source as other stories do in her work, Walrath's detailed and often heart wrenching personal experiences provide a level of insight a medical website or brochure could not. One full of detailed description and honesty; honesty in the sense of representing to the reader how the idea of caregiving comes into being when living with and caring for a parent with Alzheimer's.

In each exemplar provided from Walrath's work, the Foucauldian notion of truth is evident. In the book *Lectures on the Will to Kn*ow,[92] Foucault states, "Truth is thus nominated as that which founds knowledge as well as the desire to know. It is on the basis of the truth that all the other elements are set out and ordered" (25). Walrath includes medical information in her individual stories yet she also provides her own solution to problems that occur when caring for someone with Alzheimer's. She is providing knowledge to the reader via medical truth as well as her own personal truths while also exercising her knowledge and desire to know by addressing what the medical society says on specific topics related to Alzheimer's. Walrath also includes her own personal, lived knowledge through her stories of her, her mother, and her family. In these instances, she is contributing to the discourses of truth with her own stories. As Foucault argues, "We are forced to produce the truth of power that our society demands, of which

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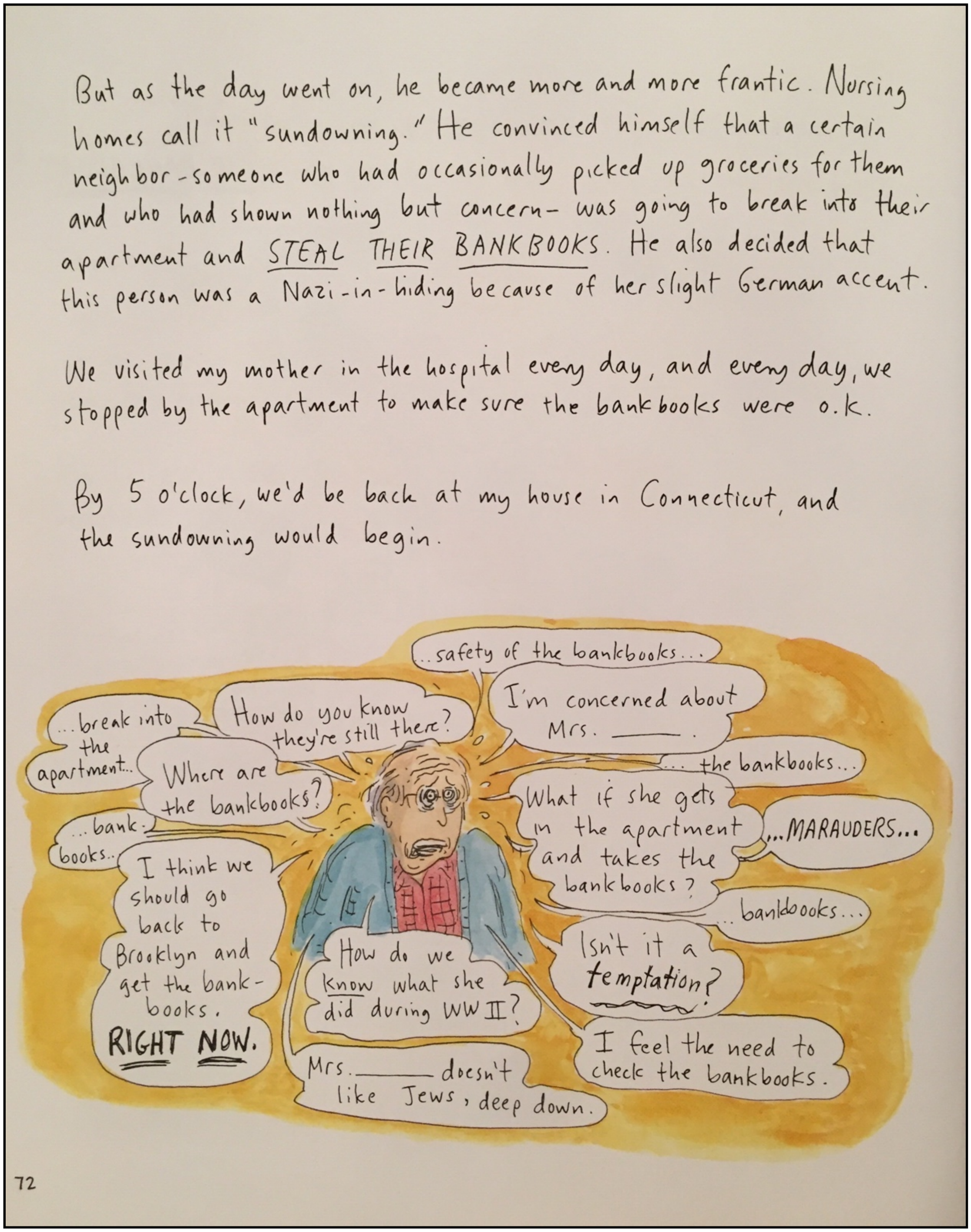
[92] Book Edited by Daniel Defert and Translated by Graham Burchell.

it has need, in order to function: we *must* speak the truth" (*Power/Knowledge* 93 [emphasis in original]). As seen in the three examples from Walrath's text, she speaks her own truth of how she and her family went against the medical suggestions and did what worked for her mother and their family. Each story Walrath tells speaks a level of truth, truth that provides the reader with knowledge and examples of not following mainstream medical advice for certain Alzheimer-related issues faced daily by those caring for someone with the disease.

While Walrath's stories are presented as individual moments of her caregiving journey, Chast uses a chronological approach that is filled with humorous and honest moments. In *Can't We Talk About Something More Pleasant*, Chast covers similar topics as Walrath, yet in a different style. As described earlier, Walrath writes the short story "Sundowning." Chast also covers this topic in the framework of her father's bankbooks. Chast provides a short definition of "sundowning" from the perspective of the nursing home and then describes the type of behavior and provides multiple examples of her father's communication about his bankbooks in her narrative.



But as the day went on, he became more and more frantic. Nursing homes call it "sundowning." He convinced himself that a certain neighbor-someone who had occasionally picked up groceries for them and who had shown nothing but concern- was going to break into their apartment and <u>STEAL</u> <u>THEIR</u> <u>BANKBOOKS</u>. He also decided that this person was a Nazi-in-hiding because of her slight German accent.

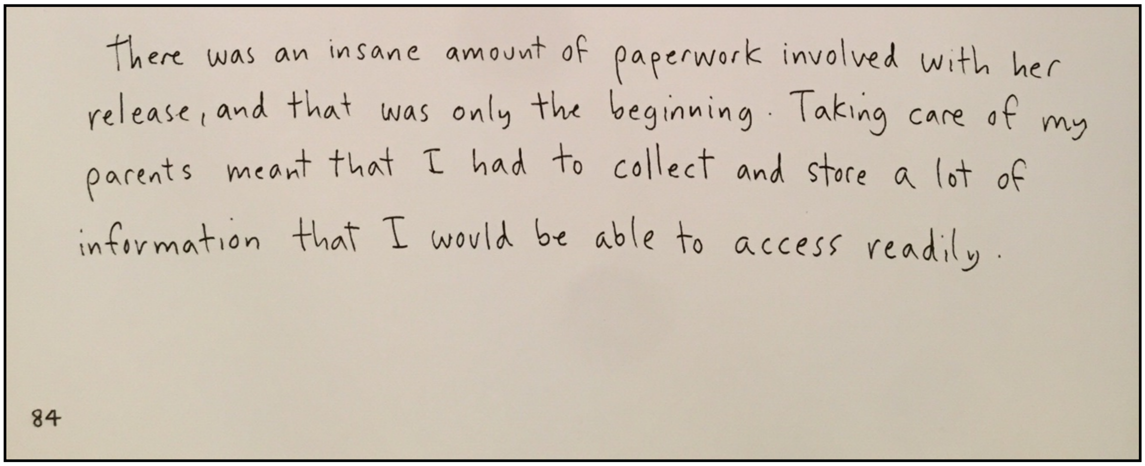
We visited my mother in the hospital every day, and every day, we stopped by the apartment to make sure the bankbooks were o.k.

By 5 o'clock, we'd be back at my house in Connecticut, and the sundowning would begin.

Figure 31. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 72.

While her definition of sundowning is simple, Chast supports it with examples of what one can expect when being around/with someone who is experiencing this syndrome.[93] Her image depicts the level of anxiety surrounding someone that is experiencing sundowning as well as the franticness of their experience. Chast uses imagery to communicate medical information to the reader that would otherwise go unstated.

Like the sundowning example, Chast uses her personal narrative to communicate information to the reader about arranging hospital releases as well as the larger task of taking care of her parents. Within the larger task of caring for her parents is the realization of the level of detailed information one must know about their parents.



There was an insane amount of paperwork involved with her release, and that was only the beginning. Taking care of my parents meant that I had to collect and store a lot of information that I would be able to access readily.

84

Figure 32. Roz Chast, panel from *Can't We Talk About Something More Pleasant?,* 2014, p. 84.

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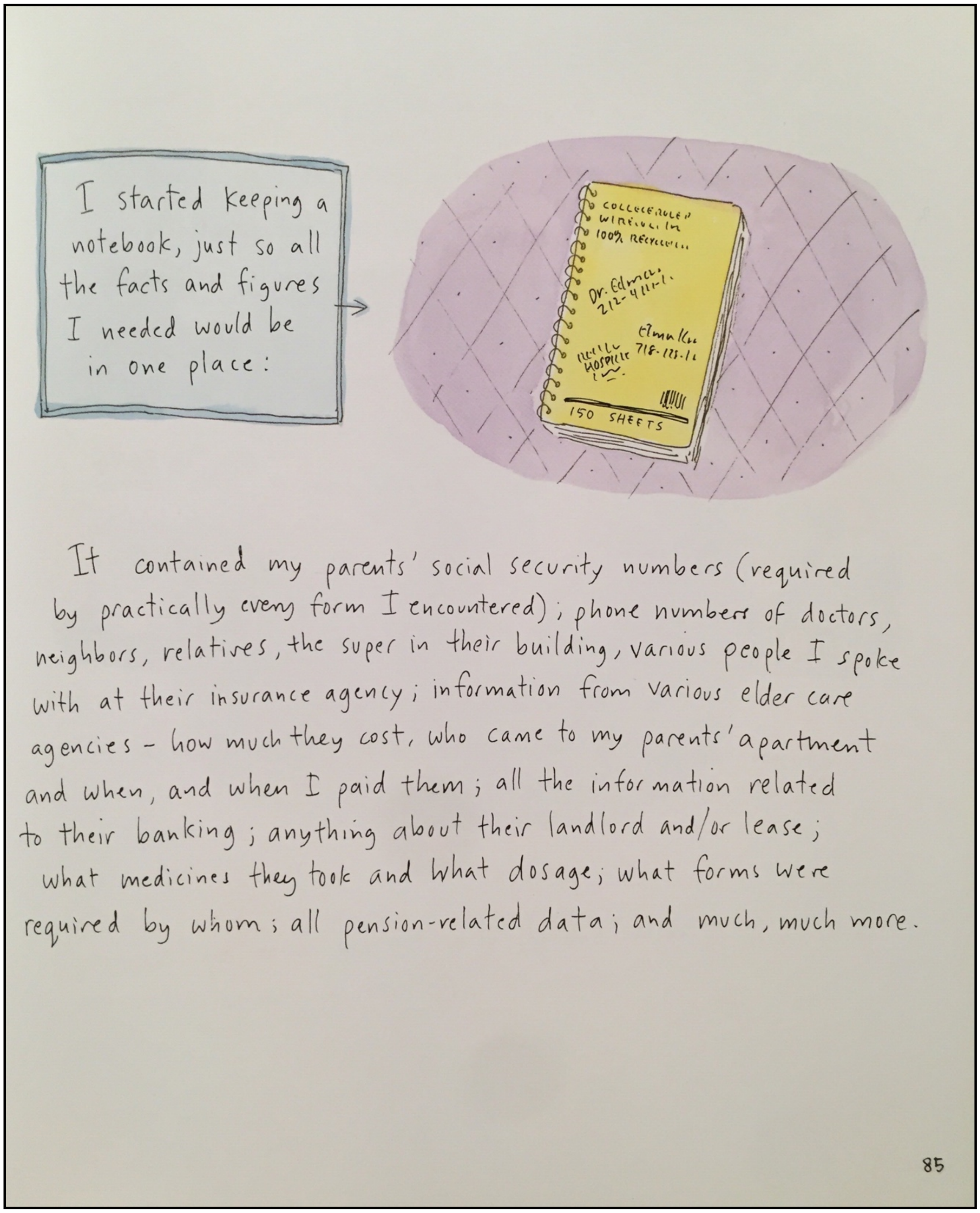
[93] Oftentimes, websites (like The Mayo Clinic) will provide a reader with knowledge of the syndrome. In the instance of sundowning, author Jonathan Graff-Radford for The Mayo Clinic provides the definition, factors that may aggravate late-day confusion and tips for reducing sundowning. The website does not provide any true to life examples of what can occur by the individual experiencing the syndrome.

She continues on the next page by providing the reader with suggestions on how to arrange information about their parent(s) and what type of information to keep.



I started keeping a notebook, just so all the facts and figures I needed would be in one place:

It contained my parents' social security numbers (required by practically every form I encountered); phone numbers of doctors, neighbors, relatives, the super in their building, various people I spoke with at their insurance agency; information from various elder care agencies – how much they cost, who came to my parents' apartment and when, and when I paid them; all the information related to their banking; anything about their landlord and/or lease; what medicines they took and what dosage; what forms were required by whom; all pension-related data; and much, much more.

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Figure 33. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 85.

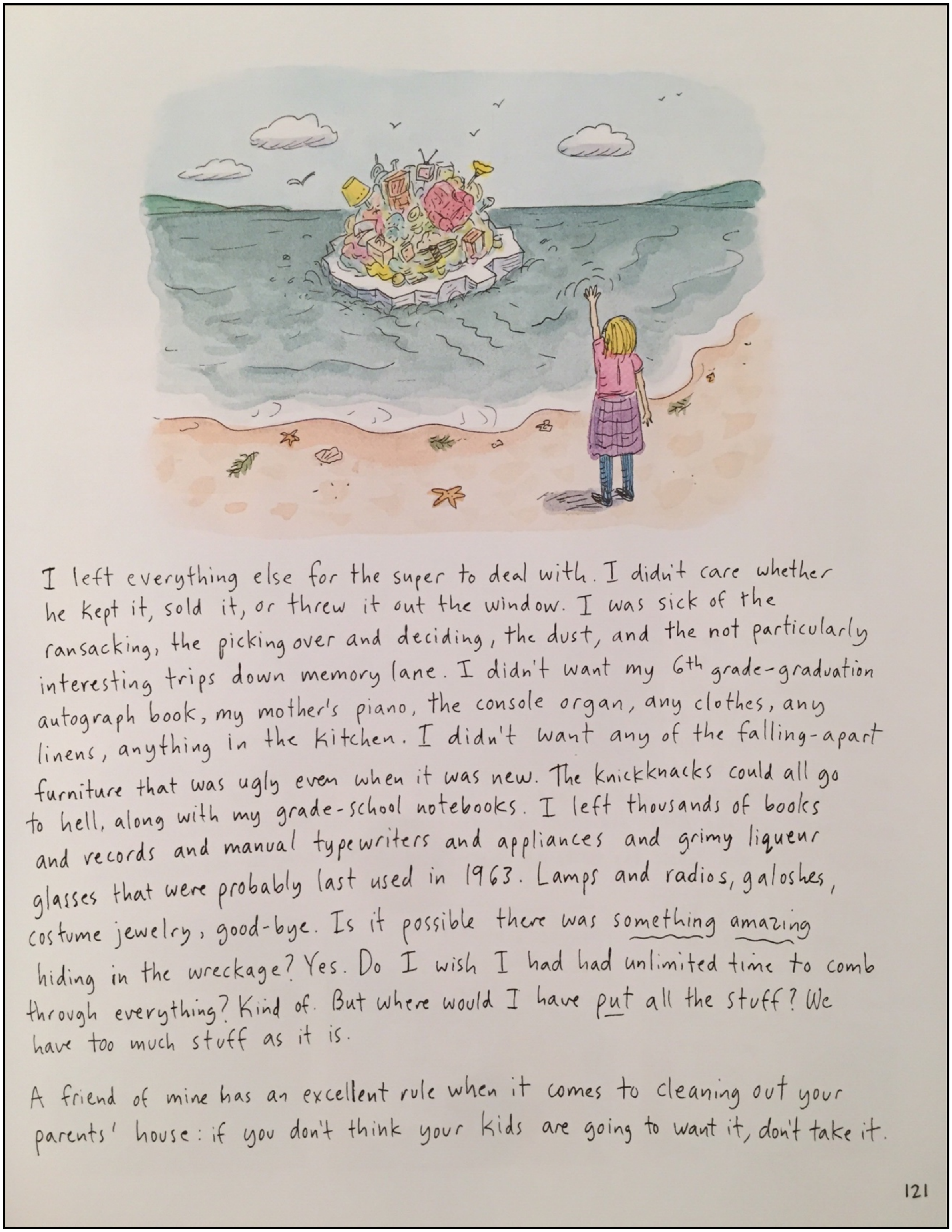
Although there is no medical information being disseminated in the pages above, there is basic knowledge (that one may not know or think to prepare themselves for) being communicated about what is needed when caring for aging parents. Chast goes through a list of items that she collected knowing that she may need this information for future encounters and she suggests how to keep all the information.

As Chast moves us through her experiences of caring for her parents, she identifies the struggles surrounding her parent's still trying to live on their own, without assistance. After she convinced her parents to into an assisted living facility under a "trial stay," she identifies what items of her parents she could move to their new home, while also listing what she had to buy new. She describes this moment in heartfelt detail; "It all felt very strange. Almost like helping your kid set up their first apartment" (Chast 107). In the chapter "The Old Apartment," Chast artfully narrates cleaning out her parent's old apartment. She describes and photographs items she discovered during this process. She identifies what her parents were keeping, where they were keeping it, and the level of stuff they accumulated over the past forty eight years they lived there. After an inventory like style of items displayed to the reader in picture style, Chast then lists the items she decided to keep from their old apartment.

Figure 34. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 119.

While some may find this approach to the handling the property of others disrespectful, there is a level of honesty and truth that Chast narrates. This level of honesty and truth also has layers of confession built in. In his book *The History of Sexuality,* Foucault brings to the forefront that “Western societies have established the confession as one of the main rituals we rely on for the production of truth . . .” (58). In the examples above, Chast shares her honest feelings with the reader about her experience. Foucault continues by explaining, the notion of truth telling via confession has become a valued technique in Western Societies (58) and that “The confession . . . plays a part in justice, medicine, education, family relationships, and love relations, in the most ordinary affairs of everyday life” (58). Foucault reminds us that it [confession] is “the things people write books about” (58). He continues by suggesting literature has the “infinite task of extracting from the depths of oneself, in between the words, a truth which the very form of confession holds out like a shimmering mirage” (59). Within the examples above, there is a layer of confession and truth-telling in Chast’s writing.

As witnessed in Chast’s chapter “The Old Apartment,” the art of caring for an aging parent(s) is having to one day go through their personal property. This may happen when they have passed or may happen when they are living. Medical staff do not prepare you for this but the process is part of the transition. The painful truth of the matter is that no one can prepare you for having to handle this moment. Chast reflects on her experiences and prepares the reader for what is to come.



I left everything else for the super to deal with. I didn't care whether he kept it, sold it, or threw it out the window. I was sick of the ransacking, the picking over and deciding, the dust, and the not particularly interesting trips down memory lane. I didn't want my 6th grade-graduation autograph book, my mother's piano, the console organ, any clothes, any linens, anything in the kitchen. I didn't want any of the falling-apart furniture that was ugly even when it was new. The knickknacks could all go to hell, along with my grade-school notebooks. I left thousands of books and records and manual typewriters and appliances and grimy liqueur glasses that were probably last used in 1963. Lamps and radios, galoshes, costume jewelry, good-bye. Is it possible there was something amazing hiding in the wreckage? Yes. Do I wish I had had unlimited time to comb through everything? Kind of. But where would I have put all the stuff? We have too much stuff as it is.

A friend of mine has an excellent rule when it comes to cleaning out your parents' house: if you don't think your kids are going to want it, don't take it.

Figure 35. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 121.

Throughout Chast's narrative, we see her desire to share her personal experiences in hopes that others can learn from those experiences and be prepared for what is to come. While she does cite definitions in some places in her narrative, much of her shared knowledge is based on her personal experiences, her deep personal confessions,[94] and "her learning as she went" mentality.

In *Mom's Cancer*, Fies blends the styles of Walrath and Chast by sharing medical information through his narrative. Fies's narrative approach documents (in detail) moments of his mother's medical diagnosis and treatment using medical terminology but he does not cite medical or lay-medical sources.[95] The medical information is disseminated via moments of his mother's diagnosis and treatments described in Fies's story. Fies often depicts moments in the exam room or when his mother is receiving treatments for her cancer. In the section, "Impressive Hospitality," Fies recalls a moment when he and his sisters took his mother to see specialists at the hospital for a series of exams. His two-page spread depicts the details in the various exams. The first page goes through the physical exam while the second page addresses the patient's history.

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[94] Foucault speaks to Chast's deep personal confessions by identifying, "Confession frees, but power reduces one to silence; truth does not belong to the order of power, but shares an original affinity with freedom . . ." (*History of Sexuality* 60). In the examples used from Chast's work, we can see the need for Chast to feel a sense of freedom from her thoughts and decisions that she was burdened with while caring for her mother and father. Her ability to speak the truth through the act of confession, allowed her to be freed from her own thoughts and actions.

[95] I define the term lay-medical source as websites such as The Mayo Clinic, Web MD, and other various web-based data portals that communicate medical information from trusted sources.

Figure 36. Brian Fies, pages from *Mom's Cancer,* 2006, pgs. 18-19.

In both pages, Fies provides detailed description regarding the medical evaluation of his mother and her pre-diagnosis. Fies also poses the question to the physician, "Can you tell what caused it?" For which she answers, "In my experience, one of five things: Smoking, smoking, smoking, smoking, or smoking" (19). In these final two frames of the page, Fies provides the reader with the cause of small-cell carcinoma. The reader is left to understand this is accurate information due to the way in which Fies writes his narrative.

Through Fies's narrative, detailed medical information is shared with the reader about the type of cancer, what the treatment plan consists of, and how the treatment impacts the body. For example, we see the outcome of his mother's biopsy.

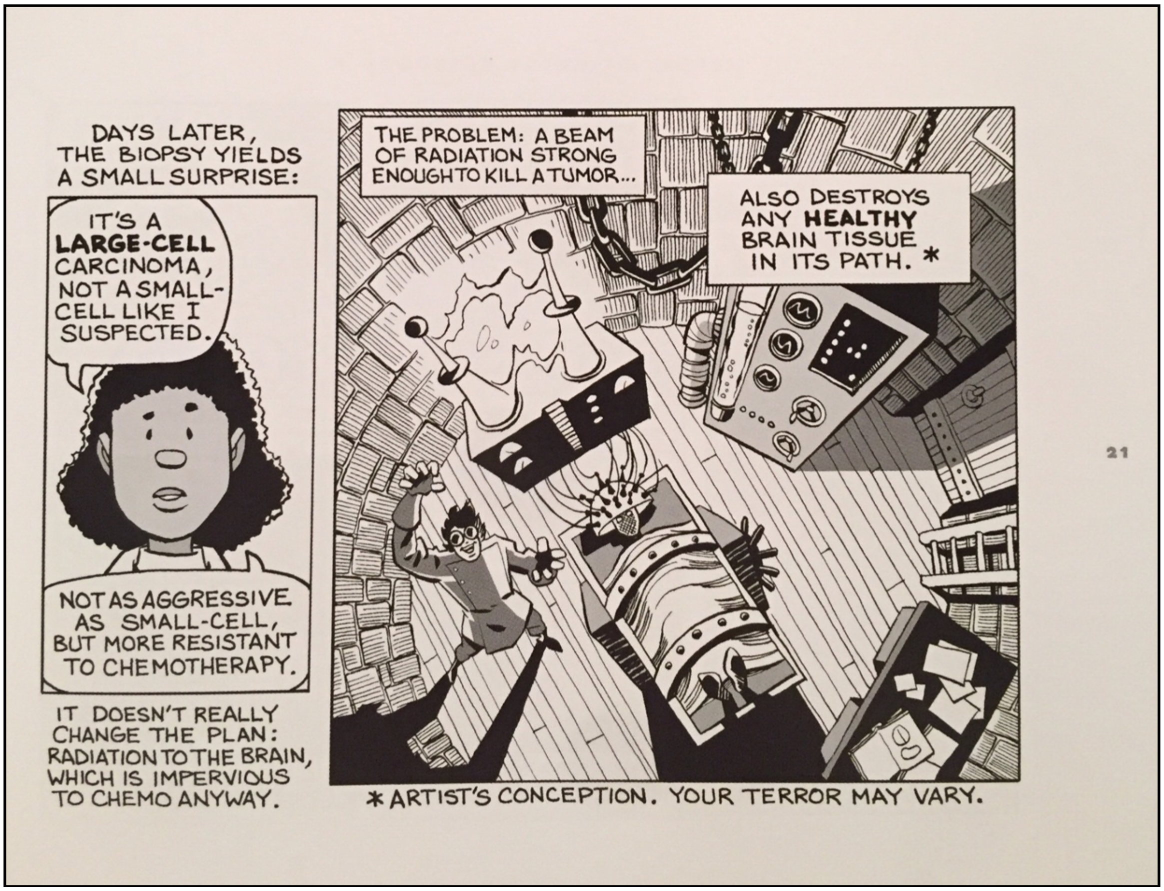

Figure 37. Brian Fies, page from *Mom's Cancer,* 2006, p. 21.

Fies shares that the type of carcinoma is now diagnosed as large-cell, not small-cell and he proceeds to explain the rate of aggression, its response to chemotherapy, and how chemotherapy impacts the body. In another page, Fies shares the conversation with the doctor after the six-week regime of chemotherapy has concluded.

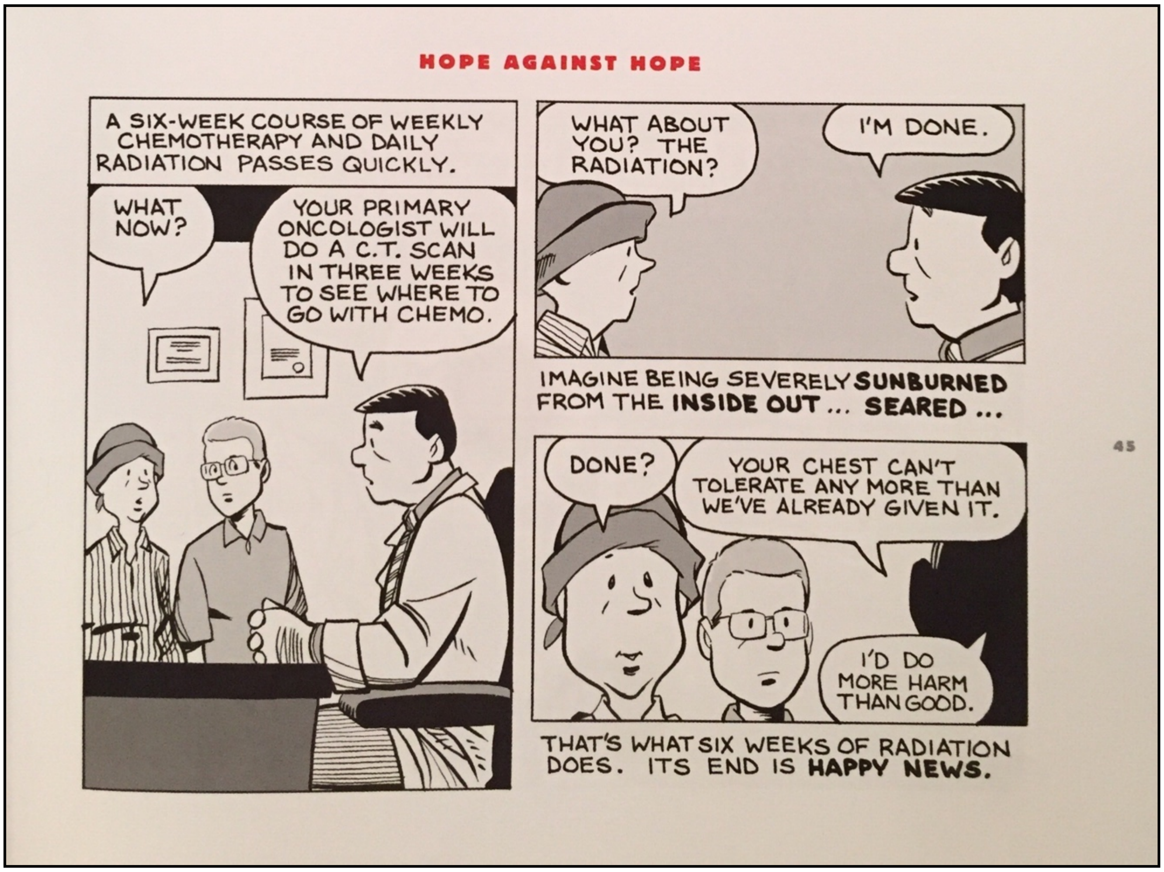

Figure 38. Brian Fies, page from *Mom's Cancer,* 2006, p. 43.

Again, Fies communicates detailed medical information by a medical doctor through his narrative explaining the next steps that occur now that the initial round of chemotherapy has ended. He provides both the doctor's explanation of what happens next as well as Fies's description of the physical outcome the treatment had on his mother's body – "Imagine being severely **sunburned** from the **inside out** . . . **seared** . . .that's what six weeks of radiation does" (Fies 45 [emphasis in original]). His truthful recollection provides the reader with an honest depiction of what chemotherapy does to the body.

In a three-page spread found later in Fies's narrative, we see the depiction of the balancing act of treatment, the outcome of treatment and the side effects of treatment. In the first of this three-page spread, Fies identifies the problem, P.E.'s – Pulmonary Emboli, defines the problem, and provides the reader with a visual clue of the balancing act that will ensue.

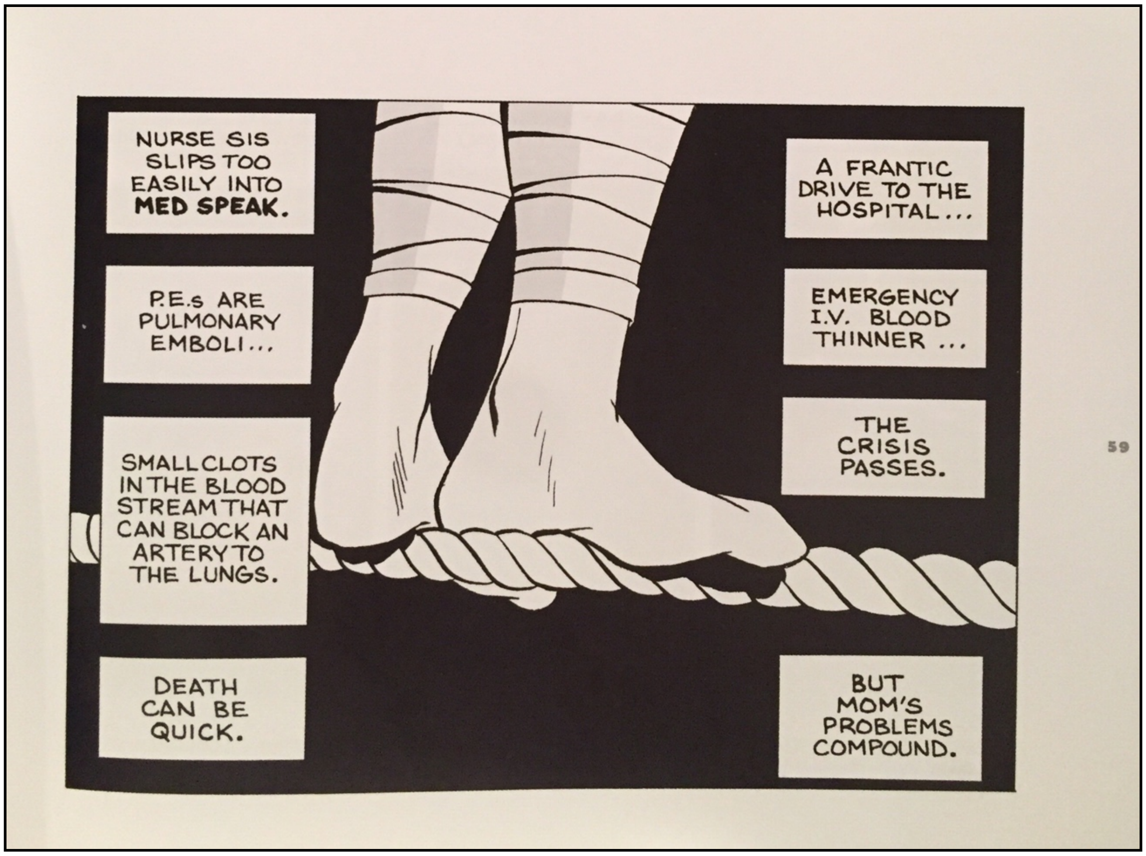

Figure 39. Brian Fies, page from *Mom's Cancer,* 2006, p. 59.

At the end of the page, Fies narrates “But Mom’s problems compound” (59). On the next page – a two-page spread depicts a balancing act; his mom dressed in circus attire and on a tight rope. Fies splits the narrative above and below the imagery. Each narrative can be read one of three ways: separately across both the top of each panel and the bottom of each panel or the narrative can be read top to bottom per panel. This specific narrative device allows Fies to communicate up to three different narratives.

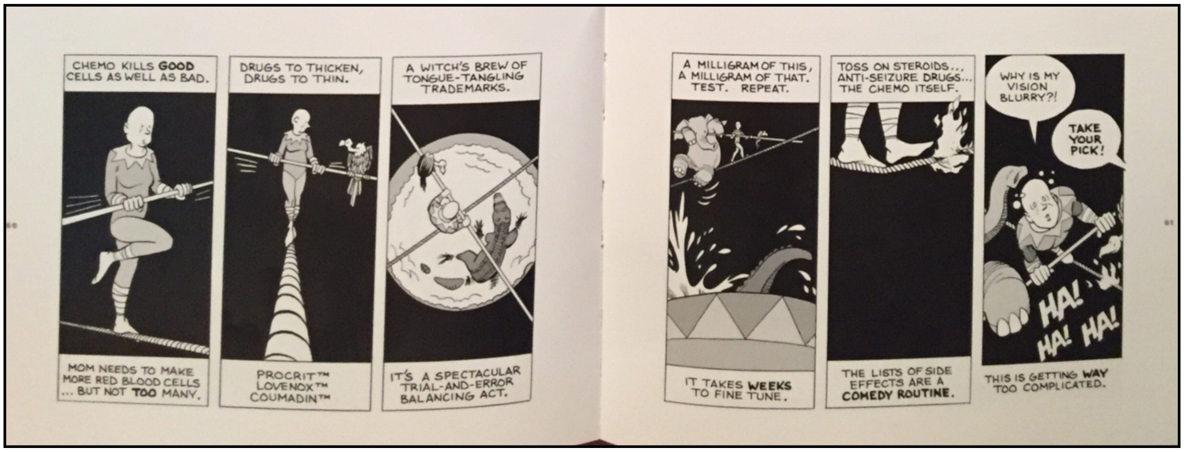

Figure 40. Brian Fies, pages from *Mom’s Cancer,* 2006, pgs. 60-61.

The top narrative is poetic yet vague. The bottom narrative provides more detail on what his mother is going through medically, what medicines are prescribed, the trial and error of the treatment, how long it takes to get the medicine and dosage correct, as well as the magnitude of side effects. When you combine the two narratives, Fies provides the reader the ebb and flow of the treatment. True to Fies’s writing style, in this three-page spread, we see detailed medical information being communicated to the reader through his personal experiences, rather than via a doctor’s depiction. Fies’s narrative continues in this format, providing more detailed medical information communicatively represented by either physician's nurses and himself, or other family members (specifically Nurse Sis).

Foucault's notion of examination can be applied to the examples from *Mom's Cancer* (as shown and described above). In each panel and page, as described above, there is both the public and private form of examination taking place. While I do believe the inclusion of examination is in part due to the type of disease Fies's mother had, I chose to explore the specific theoretical notion of examination brought forth by Foucault.

As seen in the examples above, Fies communicates medical information to the reader from the framework of examination. In each page/panel, his mother is being examined for the betterment of her health. Fies and his sisters were in constant observation of his mother, by way of her progress, her downturns, and her medications. Foucault defines this as the act of examination: "The examination combines the techniques of an observing hierarchy and those of a normalizing judgment" (Foucault *Discipline* 184). In the instances provided by Fies, we see the observing hierarchy to be that of the doctors, nurses, and medical staff and the normalizing judgement to be made up of both the trained medical persons as well as Fies and his family. Foucault notes that "In all mechanisms of discipline, the examination is highly ritualized. In it are combined the ceremony of power and the form of the experiment, the deployment of force and the establishment of truth" (*Discipline* 184). The idea of discipline is different in Fies's narrative, yet the outcome is the same. The medical team working to heal Fies's mother uses the same tactics to ensure she follows the treatment plan outlined for her. Part of the treatment plan is to be disciplined in all facets of her life – at home and in the care of medical professionals. Part of that plan is the constant examination and re-examination of her body and her overall health. While Fies depicts various medical examinations by the attending physicians, he also provides medical information about the treatment of cancer for the reader. Fies is communicating the medical code for the various aspects of his mother's treatment. Foucault speaks to this code as well, noting there are physical codes for signaling and medical codes for symptoms (*Discipline* 189-194). He suggests that this code "marks the first stage in 'formalization' of the individual with power relations" (*Discipline* 190). If we use these ideas to help understand the level of surveillance as seen in the above examples from Fies's work, we can make the claim that he is providing the reader insight to understand and move within the power relations that exist within the medical structure and the medical encounter. Foucault believes that "The examination is at the center of the procedures that constitute the individual as effect and object of power, as effect and object of knowledge" (*Discipline* 192). By using examination to both address what is medically happening within his mother's treatment as well as communicate medical knowledge to the reader, Fies is using the notion of examination to his advantage – to express what currently takes place in the medical system but also as a means to provide key medical information that may not be shared with everyone.

Response to Managing Illness: Recognition of Decline and Devotedness

As I began thinking and analyzing my own experiences, I went on a short run. On my run, I went past a pond. At the pond were three families of geese. One set of geese parents had six or so goosling they were caring after. Another set had eight. Each family carefully watched over their flock. As the goosling were eating, one parent would keep a watch about the perimeter, the other would watch the babies. The other family was the same. I was privy to watching a family cross the road. One parent lead the way while the other parent trailed behind the row of goosling waddling to their next destination—the patch of grass across from the pond. Almost gone unseen, there was yet another family. This family had one baby. From the looks of it, they got a later start at their family making as the baby was quite young and much smaller than the other two families around the pond area. I observed this family of three and compared their behavior to the other two families I had observed. Nothing differed. As the baby goose ate, one parent took watch of the surrounding area while the other kept its eye on the baby. As they crossed the road, one parent lead the way while the other parent followed after the chick. The goose family watched over their youngling as they would an entire flock, yet their flock was one. Their natural survival skills were present no matter the size of their flock. Caring for their young was natural and organic.

I share this story as I believe, like the geese looking after their young, there is an organic process that takes place between a caregiver and the person receiving the care. Additionally, there exists an added dimension when the relationship is between family members. Furthermore, I believe something special happens when that relationship is between child and parent; specifically, when the child becomes the caregiver of the parent. As seen with the example of the geese, the parents instinctively want to care for their young; they want to ensure their young's survival. Keeping watch is a major aspect of how geese ensure their young's survival.

The personal narratives I included in Part I of Chapter Two reflected on my experiences managing my father and his illness. More specifically, I explored how I dealt with the management of his illness within my role as caregiver focusing on the recognition of my father's declining health and my devotedness to caring for him. These themes are also present in the works of Chast, Fies, and Walrath identifying the similarities in caregiving experiences. While there are similarities present regarding recognition of declining health and devotedness, difference is also present.

As simplistic as it may seem, the relationship between caregiver and the receiver of the care is one of keeping watch, caring, and ensuring survival. The caregiver instinctively wants to see the receiver of care be cared for in the best way possible. In the instances of my narrative and the narratives of Chast, Fies, and Walrath, each author pens their caregiving experiences of their parent(s). All authors have the common desire of watching over their parent(s) - of wanting to see their parent(s) survive. This commonality adds specific layers[96] to the narrative possibly not present in other

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[96] This layer is what Foucault identifies as Pastoral Power. As previously mentioned in Chapter One, and noted earlier in this chapter, Foucault's writes about the notion of Pastoral Power. More specifically, Foucault identifies four common themes of Pastoral Power in the Chapter "Pastoral Power and Political Reason (1979)" in the edited book *Religion and Culture Michel Foucault*. First, the shepherd works, s/he

caregiving examples where the ill person is not a parent. Two common experiences are found within the selected comic memoirs as well as within my own stories. These common experiences can be themed by recognition of decline –physical and mental and devotedness to parent(s) for both proper medical care and mental well-being.

Recognition of Decline – Physical and Mental

Decline in the health of the individual who is receiving care is natural. Decline, both physical and mental, is part of illness.[97] When a caregiver is involved with an illness that is in the critical or terminal state, or in the case of caring for an aging parent(s), decline of health is expected. In the case of my father, and as in the cases of the selected authors, evidence of this decline, both physical and mental, is penned through both the written narrative and through drawn/created images.

Physical decline.

Physical decline can happen to anyone, at any given age. In the case of the ill or aging, physical decline can be gradual or can come on suddenly. In either instance,

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"wields power over the flock" (137); second, the shepherd watches over the flock, s/he "guides and leads' (137); third, the shepherd's role is to ensure salvation – taking place by "constant individualized and final kindness" (138); fourth, the shepherd exudes kindness through devotedness, "everything the shepherd does is geared toward the good of the flock" (138). These four themes are seen throughout the selected comic memoirs as well as within my personal stories, often shared by common experiences within the contexts of caregiving or by similar shared experiences.

[97] In rare instances, someone who is ill might overcome aspects of their illness, or overcome their diagnosed illness entirely. For example, someone that overcomes Cancer often uses the phrase, "I beat Cancer."

physical decline is difficult for both the ill and the caregiver. *Mom's Cancer* begins with recognition of physical decline by Fies' mother. In the chapter, "How to Diagnose Lung Cancer, Step One," Fies describes the physical change his mother felt one night while watching a movie at home. His mother suddenly felt a difference in her leg, and then the whole left side of her body, describing the feeling as though the entire left side of her body was gone.

Figure 41. Brian Fies, page from *Mom's Cancer,* 2006, p. 1.

The step by step guide provided by Fies exemplifies what Foucault names as disciplining; specifically, through the act of self-surveillance.[98] As previously discussed in Chapter One, self-surveillance acts as a means of disciplining the self to behave, act, and/or monitor the self in various ways (Foucault *Discipline* 167). As shown in the above page, we see the act of self-monitoring taking place by Fies' mother. She notices a difference in how her body feels, thus prompting calls that lead to a cancer diagnosis.

While Fies does describe subtle changes in his mother's body after her cancer diagnosis and during her cancer treatment, it is not until after the chemotherapy treatment is over that he shares major signs of physical decline. The first major moment of physical

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[98] Further discussion can be found in Foucault's work Dis*cipline and Punish: The Birth of the Prison.*

decline is after her six-week course of weekly chemotherapy and daily radiation. In a visit with the physician, she asks "So…you think you might have gotten it all?!" The doctor responds, "I'm sure we made a big difference. We'll know in three weeks" (46). Fies concludes the interaction between his mother and her doctor by stating, "Mom hears only what she wants to – **needs to** – hear. She doesn't catch the rest: Either way, there's nothing more he [the doctor] can do" (46).

In the page that follows, we see the outcome of weekly chemotherapy and daily radiation; physical and mental decline of her body.

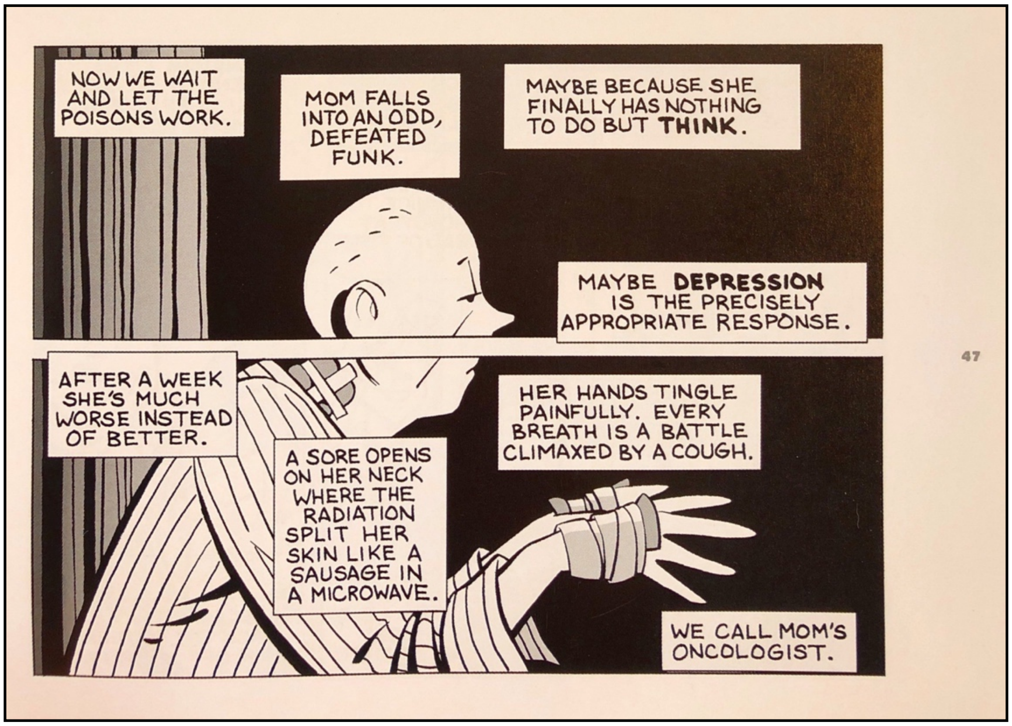

Figure 42. Brian Fies, page from *Mom's Cancer,* 2006, p. 47.

The physical decline described includes opening of sores, painfulness and tingling of her hands, as well as increased cough. Fies also identifies a change in his mother's mood suggesting depression possibly caused by too much time to think. While the image above places emphasis on both the physical and mental decline in his mother, shown as an image split into two,[99] I placed emphasis on the physical decline. This choice provides connections to the beginning of Fies's narrative which opens with his mother noticing physical changes in her body. These changes can again be connected to Foucault's writings on disciplining, surveillance, and self-surveillance. Foucault states, "Thus discipline produces subjected and practiced bodies, 'docile' bodies" (*Discipline* 138). This page, like others from Fies's work, exemplifies the notion of discipline by way of the 'docile' body as Fies and his sisters become a force (in a sense) that monitors the health of their mother. At the very basic level, the body of Fies's mother is being monitored and controlled; one of the basic elements of discipline from a Foucauldian sense.

Like Fies's artistic and narrative renditions of his mother's illness, Chast also describes attributes of physical decline while narrating the aging of her parents. The first sign of physical decline Chast shares with the reader regarding her aging parents is the recognition of the lack of cleanness of her parent's home. She starts out saying, "What I

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[99] This intentional split between the image of his mother, focusing on the mental and physical attributes of illness follows the dualistic view of the body brought forth by Descartes. Descartes theory (originally published as *Discourse on Method* in 1637) suggests that the mind is split from the body (*Discourse on Method and Meditations on First Philosophy*). While this may not have been Fies intention in his image, it begs to question if he identifies a split between the mind and body as he artistically depicts in this panel/page.

noticed first was the level of GRIME" (Chast 15). She then goes on to describe where the grime was located and the intensity of the unclean environment her parents were living in.

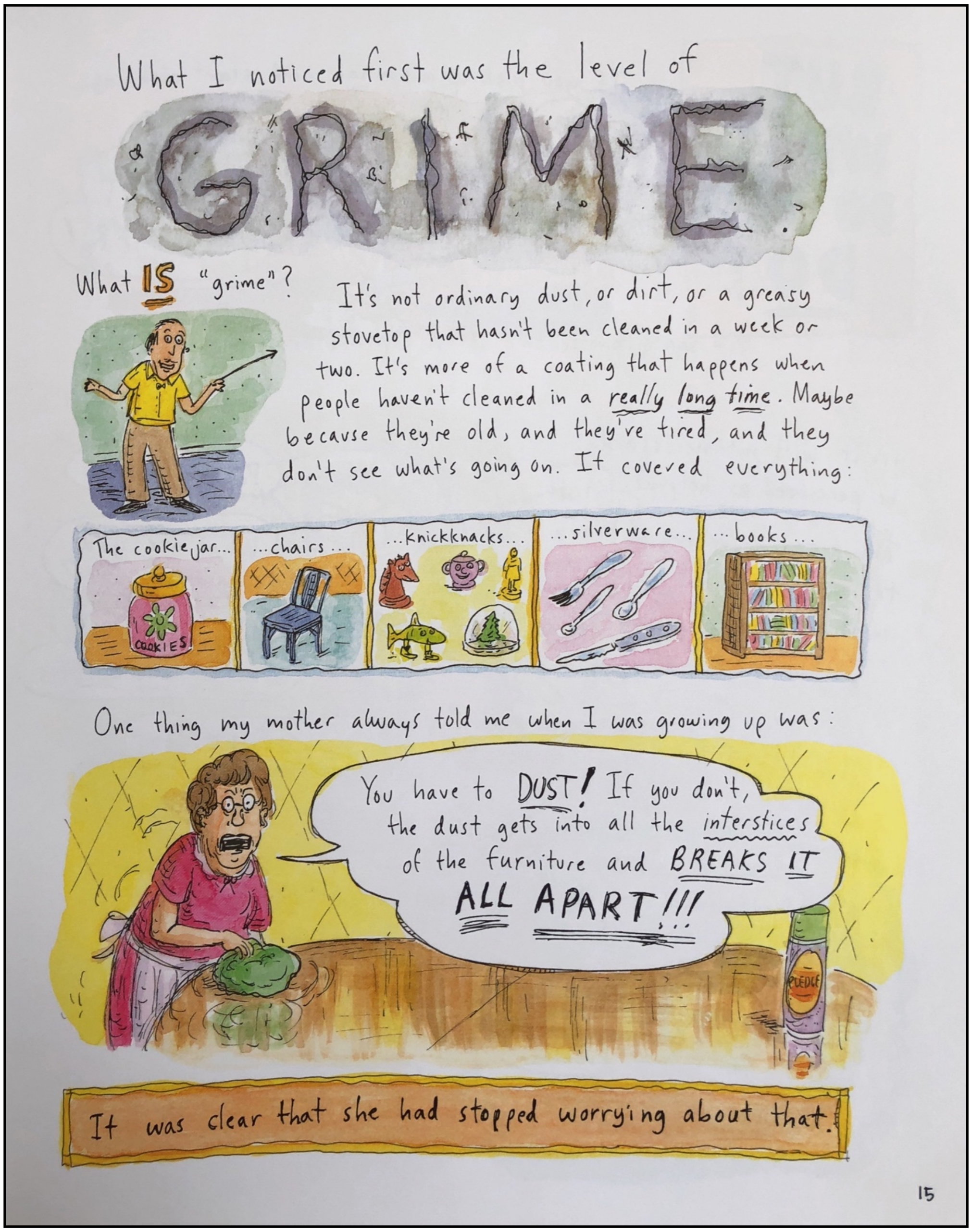

Figure 43. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 15.

Chast makes a point to recognize the difference between the level of grime her parent's home had developed versus normal dust accumulation if a space had not been cleaned in a few weeks.[100] She describes the grime as, ". . . a coating that happens when people haven't cleaned in a **really long time**. Maybe because they're old, and they've tried, and they don't see what's going on" (15). Chast recognizes that this coating is everywhere and on everything; from chairs to silverware to books. She goes on to state, "It was clear that she [her mother] had stopped worrying about that [dusting]" (15). On the following page, Chast asks the question, "But what do you do?" Chast goes through various outcomes of answering this question identifying that she may be seen as the "perfect daughter," or that her parents may feel "insulted or embarrassed." She concluded: "I wasn't great as a caretaker, and they weren't great at being taken care of" (16).

In the page shown above as well as the narrative that follows on the next page trying to answer the question how does one handle the grime, we see Chast using surveillance on her parents in the form of observation. As previously discussed in Chapter 1, the act of observation is part of the apparatus of disciplinary power. Foucault argues that we observe others to act as surveying bodies (*Discipline* 170-228). By doing so, we become part of a larger apparatus – monitoring others. In the instance shown above of Chast monitoring the cleanliness of her parent's apartment, we see disciplining and surveillance taking place; disciplining in the form of her parent's not keeping up with

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[100] The inability to keep a space clean is often a first sign of age decline. Lack of cleanliness can take place due to energy, inability, illness, size of space or lack of care/concern. In the case of my father, these issues compounded and created the unclean home environment.

cleanliness standards set by society and surveillance in form of Chast monitoring the space. These acts of disciplining that Chast is using, uphold the notion of disciplinary power as Chast is holding power over her parents – power in the sense of deciding their safety as well as their physical abilities.

In her work, Chast blends in honesty about the typical ailments and health decline aging individuals often face. In her skiing image, we see a clear summary of decline and ailments as she lists out her parent's illnesses. She speaks with honesty to the reader sharing, "Things were going downhill, but for many years, the decline was blessedly gradual" (27).

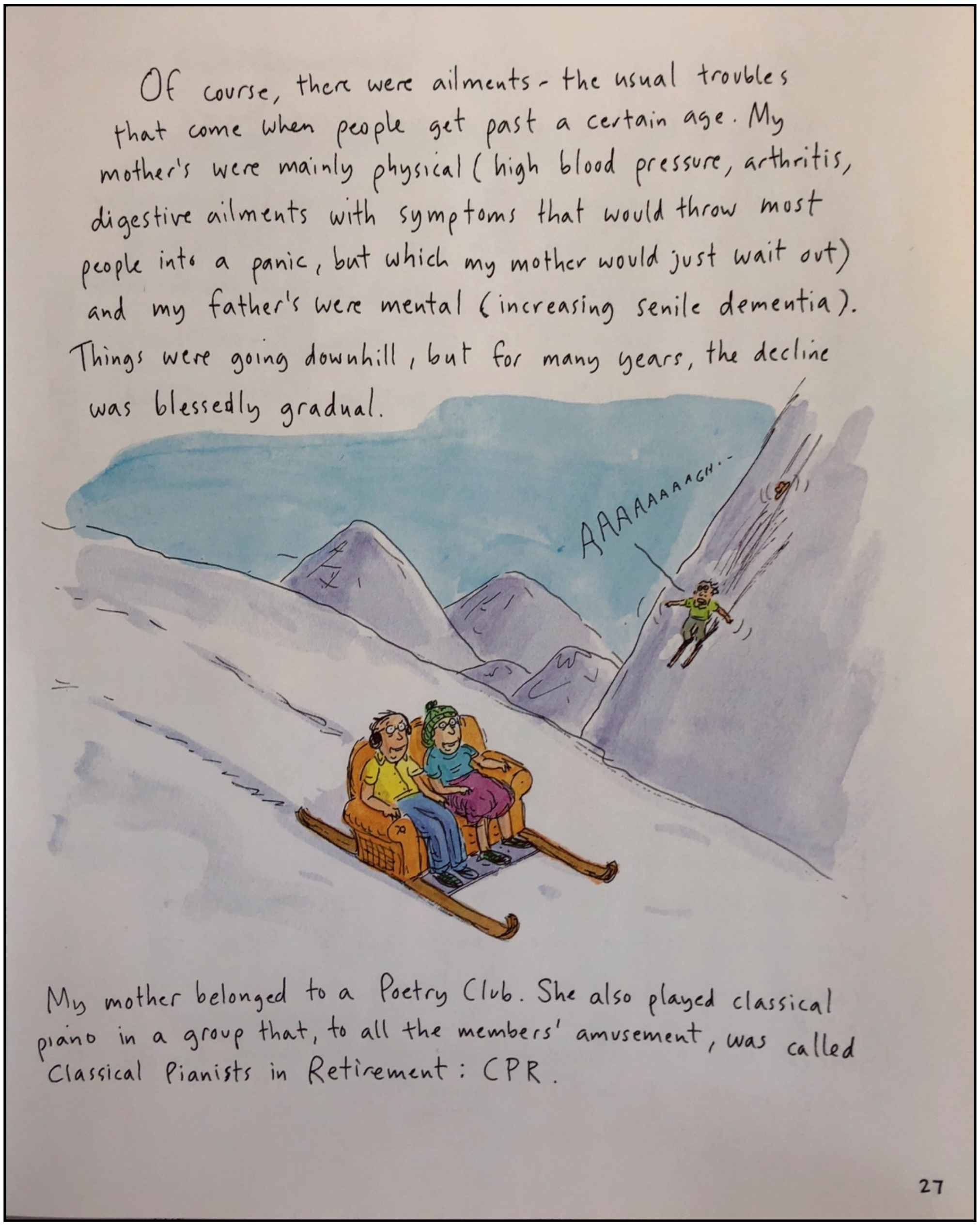

Figure 44. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 27.

In this image, the reader is brought into the daily trials of an elderly person by being introduced to the various health issues, both physical and mental, an aging body is subjected to. Her imagery connected to her narrative paints two images for how a person can age; gradually, as we see with her parent’s on the ski couch, or rapidly, as seen with the gentleman on the steep slope screaming “AAAAAAAAGH . .” (27). In this page, we are witness to Chast noticing and acknowledging the decline of her parent’s health; both physical and mental. This acknowledgment is also exemplified in the next two selected pages from Chast’s book.

In the chapter titled “The Fall,” Chast tells the story of when her mother fell off a ladder when in search of a certificate she was looking for. She recounts the call she receives from her father telling her of the incident, the poem her mother wrote about it, and the “strong aversion her mother has to doctors and hospitals” (54). In the chapter, the pages following these recollections about the fall explain how her mother was not getting better; specifically, Chast describes the signs of her physical decline.

Figure 45. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 55.

On the next page of the story, Chast confesses that she did not know what to do as her mother was stubborn.[101] Instead of seeking medical care, Chast recalls the steps she took to help her father care for her mother. Chast helped with grocery shopping, spending time with her mother, and she provided comfort for her father.[102]

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[101] In previous pages in this chapter, Chast explains her mother's aversion to doctors and hospitals. See page 54 of *Can't We Talk About Something More Pleasant?* for the full story.

[102] These caregiving acts can be best understood by the Foucauldian notion of Pastoral Power as previously discussed in this chapter and previous chapters.

Figure 46. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 56.

It was over the course of these few weeks of providing care to her parents when she concluded that, "Things were getting worse. My mother was sick, and my father was losing it" (56). It was in this moment that Chast recognized that decline both physical (with her mother) and mental (with her father) was taking place.[103]

In all three exemplars, Chast engages in the Foucauldian act of surveillance, specifically that of examination. As noted earlier, Foucault states that examination is the combination of techniques of observation and judgement. Foucault continues by suggesting, "It is a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish" (*Discipline* 184). Although Chast's main goal is not to punish, she does use the act of examination to qualify and classify the level of decline in her parents. She uses her observations to make an informed choice regarding her parent's overall health and their abilities to live alone. As viewed in the pages of Chast's narrative as well as in the pages of Fies and Walrath, we see how physical decline can easily blend into and with mental decline of the ill and aging. It is now that I switch the focus of the analysis to focus on the mental decline of heath as depicted in the works of Chast, Fies, and Walrath.

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[103] Chast comments earlier in her work about noticing the physical and mental decline of her parents – as also shown in exemplars within this chapter. It is in the Chapter, "The Fall," that Chast begins to take notice and remark of how the physical and mental decline can compound making each aspect of decline significantly worse.

Mental decline.

In the chapter titled “Sundowning,” Chast honestly depicts the mental decline of her father. She describes how her father becomes chattier, has increased paranoia (specifically regarding his bankbooks), and has increased memory issues, including memory loss. She highlights how she becomes more stressed out having to deal with this change in her father and how her patience and sympathy toward her father can wane.

Figure 47. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 74.

In the above page, we see Chast begin to be worn down with the repetition of conversations due to her father's forgetfulness. This example specifically exhibits the memory issues that are often associated with the mental decline of the elderly. Mental decline can also happen to individuals who are ill but who are not considered elderly.[104]

Although brought on by different circumstances, mental decline is seen in the pages of Fies's *Mom's Cancer*. In the three-page sequence "One Night at the Condo," Fies depicts how cancer affects the brain.

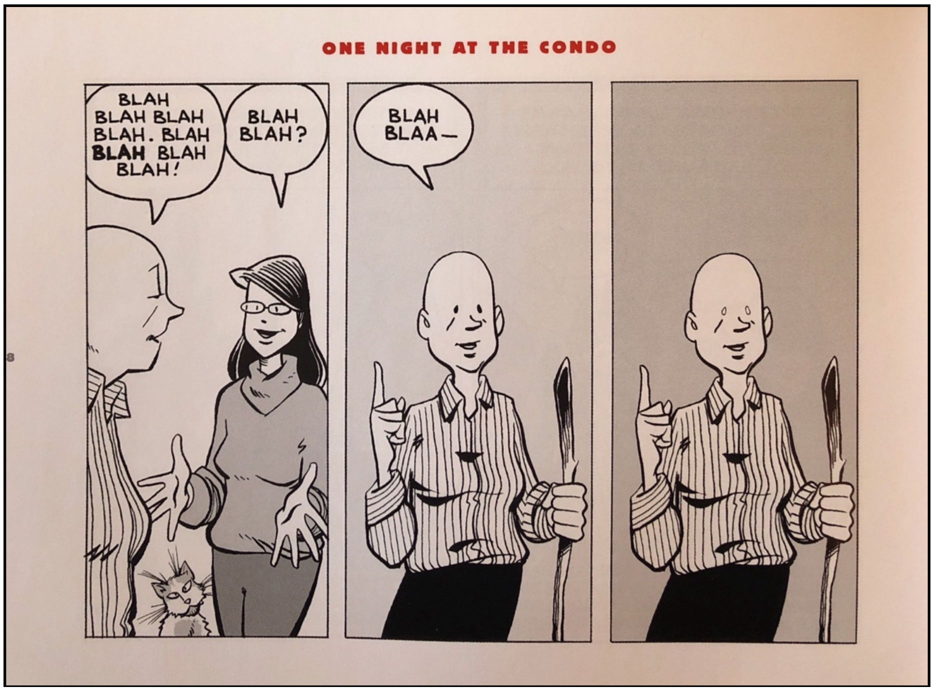

Figure 48. Brian Fies, page from *Mom's Cancer,* 2006, p. 68.

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[104] Per the articles by Richard W. Besdine, M. D. and Linton Weeks, the term elderly is often used to describe the population that is over the age of 69. The term geriatric is used to describe the age population >65 but in medical circles, geriatric care is often not needed until a person reaches the age of 70 – 75.

Figure 49. Brian Fies, page from *Mom's Cancer,* 2006, p. 69.

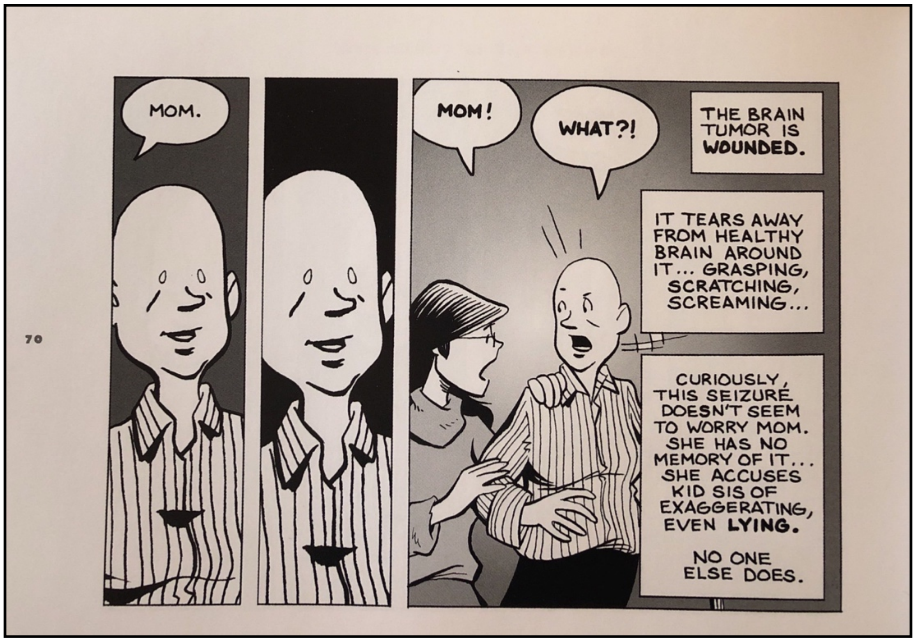

Figure 50. Brian Fies, page from *Mom's Cancer,* 2006, p. 70.

We see the effects of this decline represented as slowness to respond, lack of response, lack of memory of recent health episodes (a seizure), and accusations, such as exaggerating and lying, toward her youngest daughter. While these symptoms were brought on by the type of cancer his mother had as well as the brain tumor she developed due to her cancer, mental decline is still a prevalent health issue and concern that Fies includes in his narrative.

While each selected comic memoir provides exemplars[105] for each theme, one narrative from author Dana Walrath in her book *Aliceheimer's: Alzheimer's Through the Looking Glass*, captures all themes within one vignette titled "Disappearing Alice." In this vignette, Walrath simplistically, yet with a level of emotion a child would have for their parent, identifies her mother's decline, making decisions on behalf of her mother while never faltering from her devotion to her mother.

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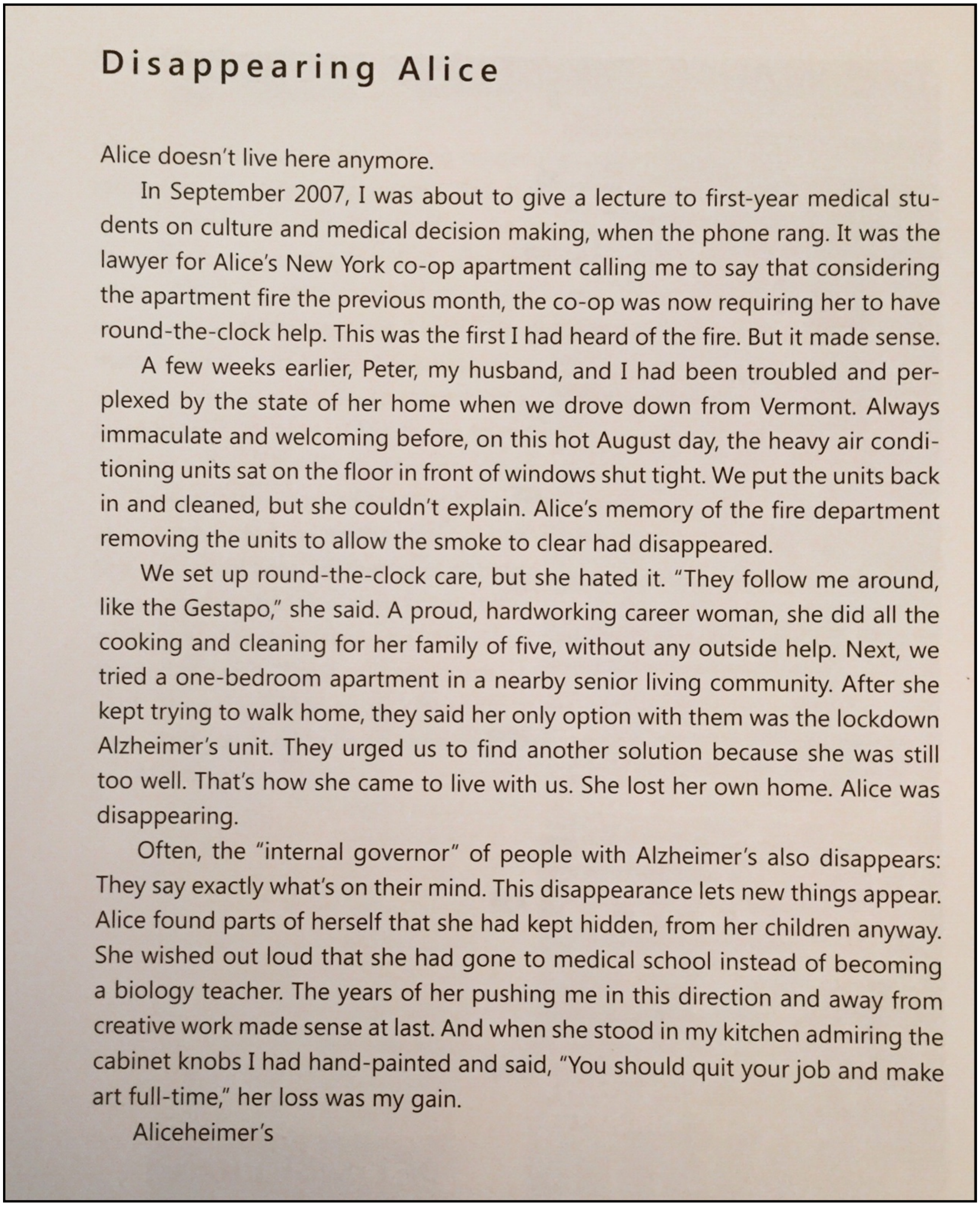
[105] Oftentimes numerous exemplars are available. For purposes of the work, I have selected the exemplar(s) I felt fit the best with the other's selected, as well as my own.



Disappearing Alice

Alice doesn't live here anymore.

In September 2007, I was about to give a lecture to first-year medical students on culture and medical decision making, when the phone rang. It was the lawyer for Alice's New York co-op apartment calling me to say that considering the apartment fire the previous month, the co-op was now requiring her to have round-the-clock help. This was the first I had heard of the fire. But it made sense.

A few weeks earlier, Peter, my husband, and I had been troubled and perplexed by the state of her home when we drove down from Vermont. Always immaculate and welcoming before, on this hot August day, the heavy air conditioning units sat on the floor in front of windows shut tight. We put the units back in and cleaned, but she couldn't explain. Alice's memory of the fire department removing the units to allow the smoke to clear had disappeared.

We set up round-the-clock care, but she hated it. "They follow me around, like the Gestapo," she said. A proud, hardworking career woman, she did all the cooking and cleaning for her family of five, without any outside help. Next, we tried a one-bedroom apartment in a nearby senior living community. After she kept trying to walk home, they said her only option with them was the lockdown Alzheimer's unit. They urged us to find another solution because she was still too well. That's how she came to live with us. She lost her own home. Alice was disappearing.

Often, the "internal governor" of people with Alzheimer's also disappears: They say exactly what's on their mind. This disappearance lets new things appear. Alice found parts of herself that she had kept hidden, from her children anyway. She wished out loud that she had gone to medical school instead of becoming a biology teacher. The years of her pushing me in this direction and away from creative work made sense at last. And when she stood in my kitchen admiring the cabinet knobs I had hand-painted and said, "You should quit your job and make art full-time," her loss was my gain.

Figure 51. Dana Walrath, page from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 11.

Within her words, Walrath exudes elements of Foucault's notions of Pastoral Power. First, we can identify different components of Pastoral Power in Walrath's short vignette. Walrath has an element of power over her mother as her and her husband "set up round-the-clock care, but she hated it" (11). Another example of the power that Walrath exhibits over her mother is through her ability to select the living situation for her mother. "After she kept trying to walk home, they said her only option with them was the lockdown Alzheimer's unit. They urged us to find another solution because she was still too well. That's how she came to live with us. She lost her own home" (11). Within Walrath's short explanation of her mother denying round-the-clock care and still being healthy enough to not be in the locked Alzheimer's unit, evidence of guidance and leadership as well as ensuring salvation is present.

As Foucault articulates in his wrings on Pastoral Power[106] the shepherd both guides and leads and is also charged with ensuring the salvation of the flock; in this instance the person being cared for. As noted earlier, Foucault states the care given is all-encompassing in looking after the flock and protecting it from harm. In Walrath's work, we see her guide and lead the care for her mother by watching over her and making sure she makes the best decision for her mother's health; having her mother move in with her. We also see Walrath exhibit kindness at a constant level toward her mother. First in her care, second with her compassion toward her mother's loss of daily abilities such as cooking and cleaning on her own and living on her own. The display of kindness via the acts of cooking and cleaning were also present in the narrative of Chast and Fies. Chast

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[106] See Chapter One for a detailed discussion of Pastoral Power.

and Fies also exhibit pastoral care by constantly looking out for the health and wellbeing of their parents as previously exemplified throughout this chapter. The examples selected provides evidence that each author exhibits Pastoral Power over their parent(s) when recognizing the physical and mental decline of their parent(s).

Devotedness

Any caregiver knows there is a level of devotedness that must exist toward the person they are caring for. In the works of Fies, Chast, and Walrath their devotedness is exemplified throughout their writing. Throughout Walrath's entire vignette, "*Disappearing Alice*,"[107] we see the level of devotedness that she has towards her mother. This devotedness is evident through Walrath's presence in her mother's life on a constant basis and making sure her mother is taken care of emotionally and physically. We are also privy to being shown another layer of devotedness as Walrath explains:

> "She [her Mom] wished out loud that she had gone to medical school instead of becoming a biology teacher. The years of her pushing me in this direction and away from create work made sense at last. And when she stood in my kitchen admiring the cabinet knobs I had hand-painted and said, "You should quit your job and make art full-time," her loss was my gain." (11)

In this example, we see Walrath admitting to her long-standing devotedness to her mother's wishes, going back to when she was pushed toward science, away from creative work.[108] Like Walrath's depiction of devotedness, we see Fies and Chast share similar

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[107] See previous section for the full vignette, "Disappearing Alice."

[108] Walrath is a trained medical anthropologist.

levels of devotion. Devotedness as caregiver to their parent(s) is often manifest in two forms: proper medical care and the overall mental well-being of the person.

Proper medical care and mental wellbeing.

When we think of proper medical care, that phrase can hold many meanings to one or to many. In the context of this work, proper medical care is the care best suited for the individual who is ill or aging.[109] Each author approaches this topic from different views. Fies expresses his devotion by his desire to research and to shield his mother from possibly unwelcome news. When Fies first learns of his mother's diagnosis, his first instinct is to "figure things out" (23). In the page titled "A Terrible thing to waste," Fies narrates the moment when he and his mother learned the size of her brain tumor.

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[109] Proper medical care may vary from person to person, family to family. The treatment plan or choices that are expressed in these works may not work for others in the same situation, therefore I feel it is important to emphasize that the care plans selected by each author/author's families was their decision and selected for the individual(s) they were caring for. These choices may not suit every person, but often their decision matches common societal choices for the various health topics selected for this work.

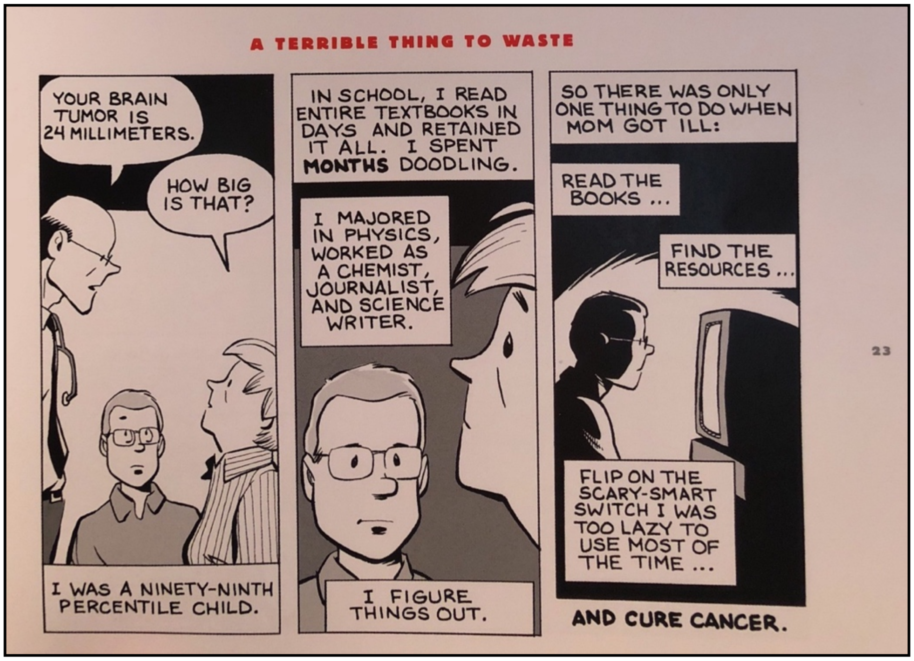
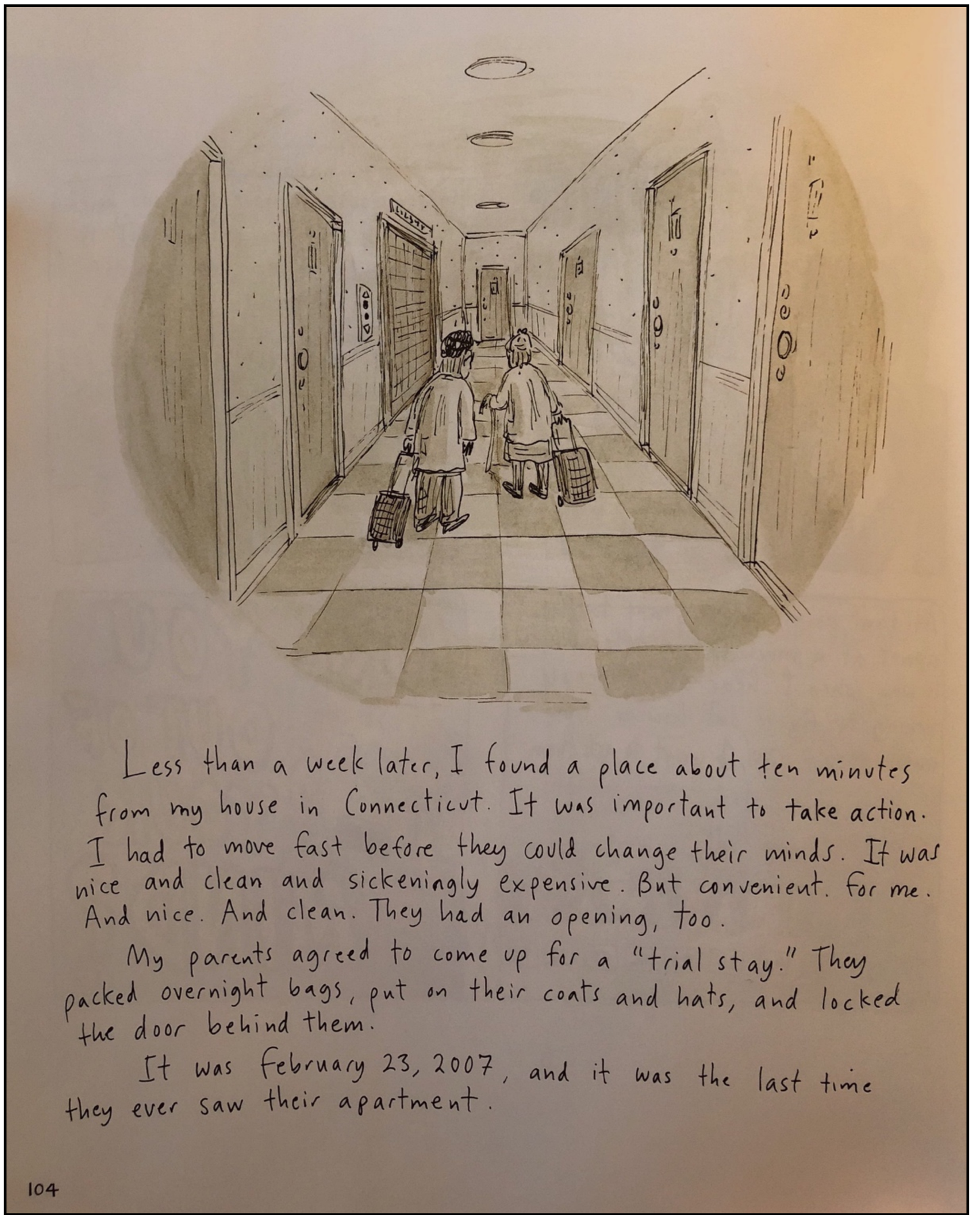


Figure 52. Brian Fies, page from *Mom's Cancer,* 2006, p. 23.

In this page, we see Fies's recognition of the diagnosis and size of the tumor; his background in physics, chemistry, and as a science writer; and his overall drive to learn as much as he can to "cure cancer" (23). He was determined to research and learn as much as he could on the topic through various resources to ensure his mother was getting proper medical care and treatment for her diagnosis. This page exemplifies both his devotedness to his mother's medical care but also his desire to ensure his mother was getting the best care for her.

Chast also expresses devotion to her parents through proper medical care via different means. Chast's devotion is evident through the act of decision-making. Chast narrates two very difficult decisions in her time as caregiver to her parents. The first decision was to move her parents out of their New York apartment. In previous pages of her chapter titled "The Move," she discusses how she first visits an elder home that is close to their current apartment building. She describes the place as depressing: “torn carpet; dirty, flaking walls; and lots of OLD, <u>OLD</u>, **<u>OLD</u>**, **<u>OLD</u>** people. Decrepit, hobbled, sad old olsters. Yep. **OLD**” (100). She realizes that for the safety and health of her parents, they needed to be in a place that could provide the care they needed, that she could not give. It was then that she decided to move her parents closer to her in Connecticut.



Less than a week later, I found a place about ten minutes from my house in Connecticut. It was important to take action. I had to move fast before they could change their minds. It was nice and clean and sickeningly expensive. But convenient. For me. And nice. And clean. They had an opening, too.

My parents agreed to come up for a "trial stay." They packed overnight bags, put on their coats and hats, and locked the door behind them.

It was February 23, 2007, and it was the last time they ever saw their apartment.

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Figure 53. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 104.

In the above page, we see the juxtaposition that Chast so beautifully narrates both through her words and image. Visually, we see her parents leaving their apartment with overnight bags. Below the drawing is the narration that provides the details to the difficult decision Chast had to make to ensure her parents were medically cared for;

moving them out of their apartment for good. While the decision to move one's parent(s) is never easy, Chast expresses the importance of knowing they are physically closer to her and properly cared for from a medical perspective.

Chast also conveys devotedness to her mother and her medical care after her father passes. In the next image, we see the idea of medical care take on a different meaning. Chast communicates to her mother, who is now in hospice care, that "It was "o.k. to let go," a phrase I learned from the hospice people" (173). This heartbreaking moment in Chast's narrative expresses the deep devotion and care she has for her mother. She tells her mother it is okay for her to let go, to pass. Although not typical or even an expected example of proper medical care toward a parent, I believe this page from Chast does exemplify her view of what she believes is the best care for her mother at that time; letting her mother know it is okay for her to go if that is what her mother's heart desires.[110]

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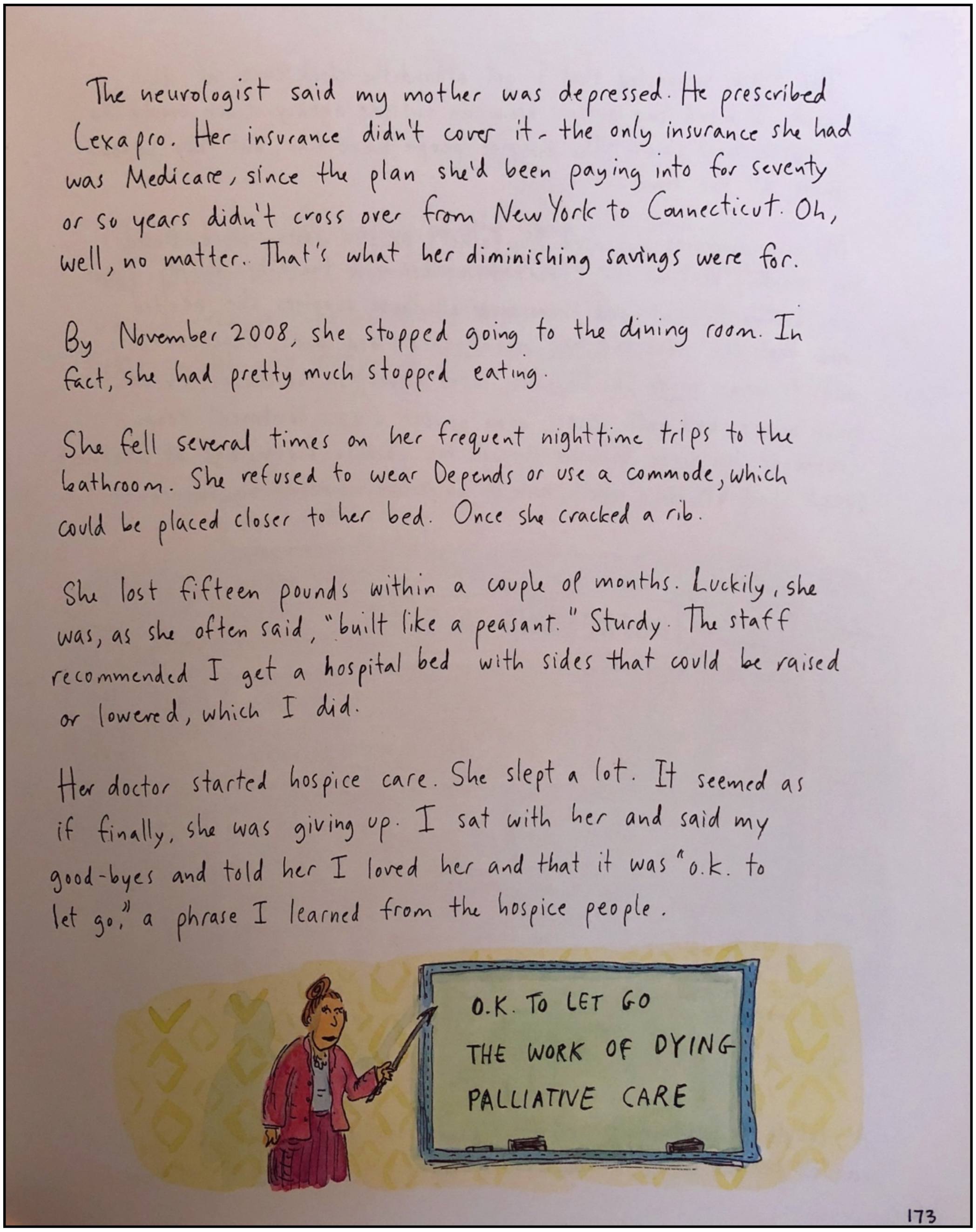
[110] I believe it is important to note that palliative care works with both the ill/dying as well as the families of the ill/dying. Part of the treatment provided within palliative care is focused on letting go. These views are expressed by Chast on page 173 in her small image that accompanies her narrative, as well as other literature on palliative care. For further discussion on this topic see Elaine Wittenberg-Lyles, Joy Goldsmith, Sandra L. Ragan, and Sandra Sanchez-Reilly's *Dying with Comfort: Family Illness Narratives and Early Palliative Care.*



The neurologist said my mother was depressed. He prescribed Lexapro. Her insurance didn't cover it - the only insurance she had was Medicare, since the plan she'd been paying into for seventy or so years didn't cross over from New York to Connecticut. Oh, well, no matter. That's what her diminishing savings were for.

By November 2008, she stopped going to the dining room. In fact, she had pretty much stopped eating.

She fell several times on her frequent nighttime trips to the bathroom. She refused to wear Depends or use a commode, which could be placed closer to her bed. Once she cracked a rib.

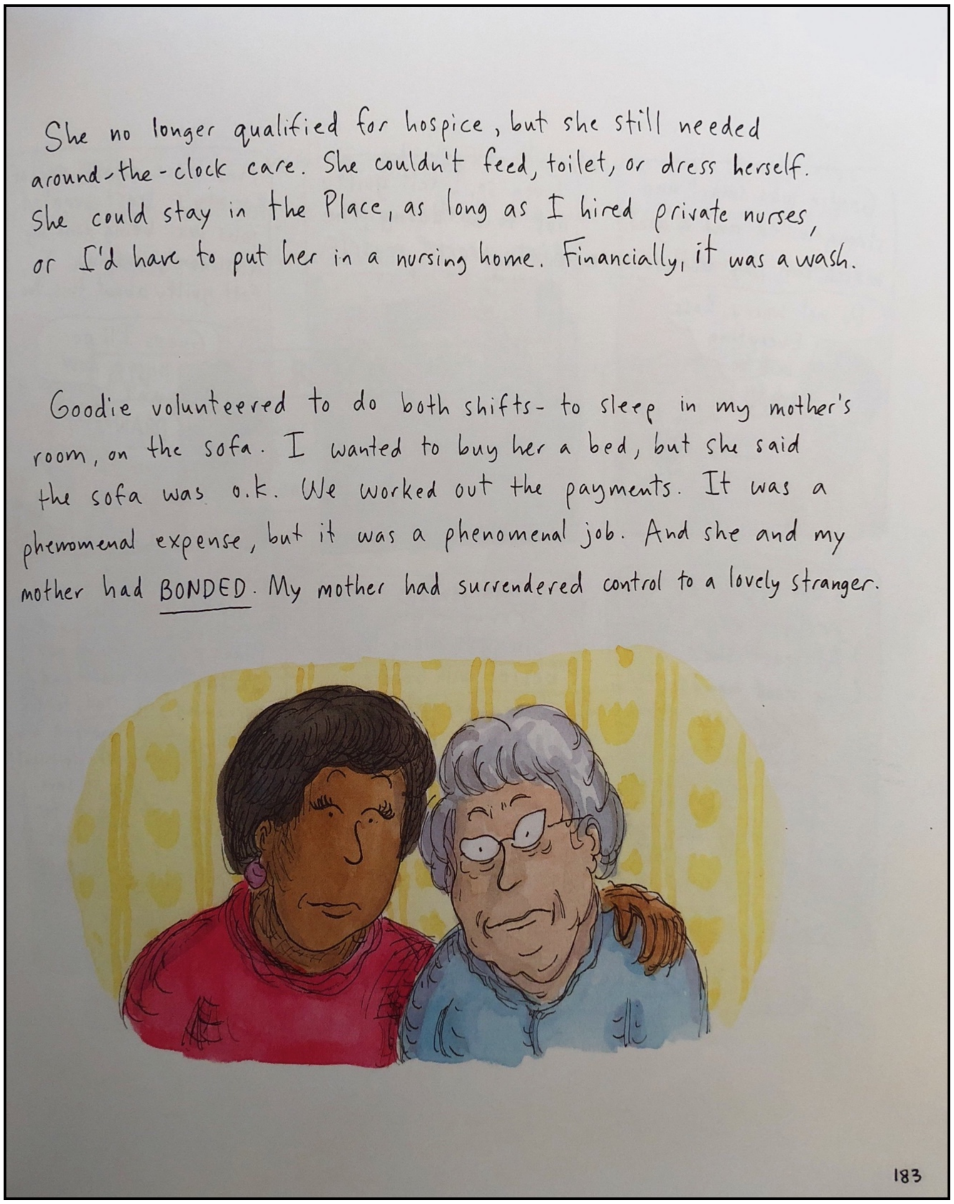
She lost fifteen pounds within a couple of months. Luckily, she was, as she often said, "built like a peasant." Sturdy. The staff recommended I get a hospital bed with sides that could be raised or lowered, which I did.

Her doctor started hospice care. She slept a lot. It seemed as if finally, she was giving up. I sat with her and said my good-byes and told her I loved her and that it was "o.k. to let go," a phrase I learned from the hospice people.

Figure 54. Roz Chast, page from *Can't We Talk About Something More Pleasant?,* 2014, p. 173.

Not only do we see evidence of Chast's devotedness to her mother's medical care I this page, but we also see devotedness to her mental well-being.

After Chast’s mother no longer qualified for hospice care due to increased wellness, her mother still needed around-the-clock care. Her mother had become attached to a private nurse named Goodie. We see Chast explain the intricacies of making sure her mother’s mental well-being was intact.



She no longer qualified for hospice, but she still needed around-the-clock care. She couldn't feed, toilet, or dress herself. She could stay in the Place, as long as I hired private nurses, or I'd have to put her in a nursing home. Financially, it was a wash.

Goodie volunteered to do both shifts - to sleep in my mother's room, on the sofa. I wanted to buy her a bed, but she said the sofa was o.k. We worked out the payments. It was a phenomenal expense, but it was a phenomenal job. And she and my mother had BONDED. My mother had surrendered control to a lovely stranger.

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Figure 55. Roz Chast, page from *Can’t We Talk About Something More Pleasant?,* 2014, p. 183.

To provide for both the physical care her mother as well as mental care that Chast knew her mother needed for her own well-being, Chast continued to use the services of Goodie, her mother's full-time private nurse. While Chast had the ability and desire to hire external help for her mother, Fies shows a different side to devotedness to his mother's mental well-being.

Fies's experience with his mother's illness was handled by himself and his sisters. While Chast hired external help, Fies and his family handled things within the family, with each taking on various roles. This is one aspect of ensuring the mental well-being of his mother through the various phases of her treatment. In the section, "Never Tell Me the Odds," Fies identifies the one question that lingers through every exam, "How long to live?" (31). In this two-page section, Fies describes frame by frame how they approach the lingering question. His mother never asks; the doctors never volunteer the answer. Instead, Fies and his siblings ponder if they should force the issue of the un-broached question.

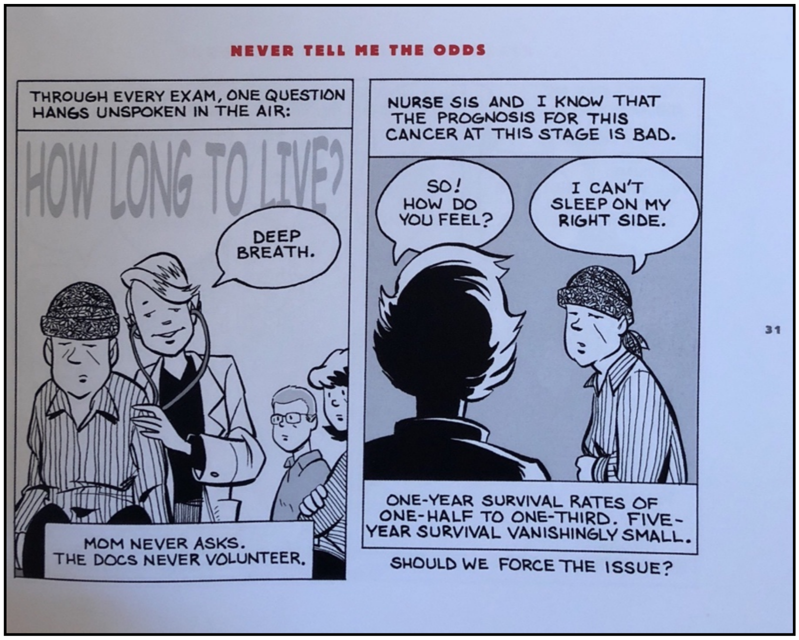

Figure 56. Brian Fies, page from *Mom's Cancer,* 2006, p. 31.

In the second page of this two-page section, Fies identifies that his mother does not want to know the answer to the question, and so it goes unanswered.

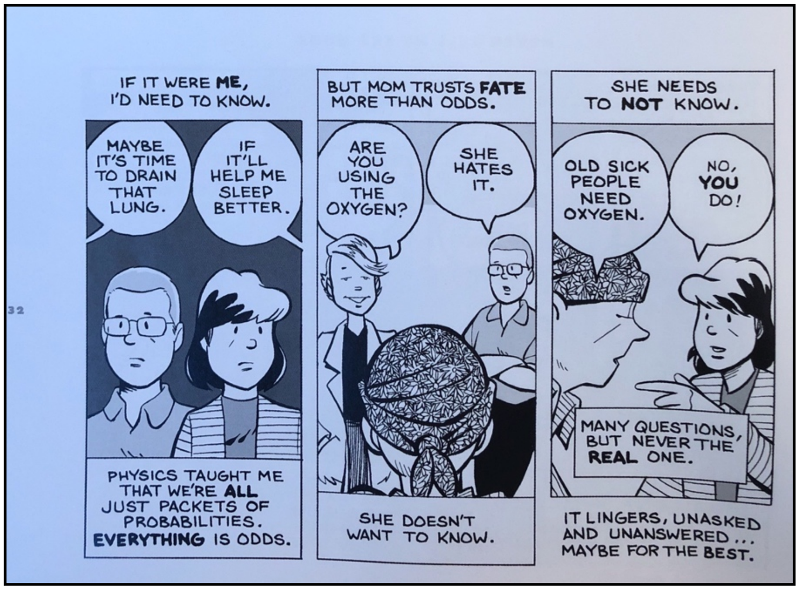

Figure 57. Brian Fies, page from *Mom's Cancer,* 2006, p. 32.

As Fies states “She doesn’t want to know. She needs to not know. Many questions [are asked], but never the real one. It lingers, unasked and unanswered . . . maybe for the best” (32). As these sentences are broken out between the frames on page 2, we can visually see how the one question not asked, plagues each visit, each interaction with the doctor’s. Although Fies articulates that “If it were me, I’d need to know” (32), he does not push the issues with his mother. This decision is done for the mental well-being of his mother. As seen with this two-page example from Fies, there are moments when we must put the mental well-being for the ill or aging person above our own desires to know the answer to a question or the outcome of a medical test.

At the core of devotedness – either by providing proper medical care or ensuring mental well-being is the idea of care. As previously quoted, Foucault believes “Pastoral power is a power of care” (*Security* 127). For Foucault, Pastoral power is a “power with purpose for those on whom it is exercised” (129). It is evident that each author exhibits care toward their parent(s) for whom they are writing about. Care manifests itself in the various narratives in the form of self-recognition: recognizing the interruption of daily life; honesty: sharing medical information and learning moments; and recognition: recognizing the decline of the health of the parent(s), and level of personal devotedness. Guided from Christian principles, the notion of Pastoral power also includes responsibility, dependence, and a level of submission (“Pastoral Power” 142). We see the level of personal responsibility taken on by each author in the various of exemplars provided in this chapter. We also see evidence of dependence and submission; dependence of the parent(s) on their child and submission by the parent(s) to their child.

Each story embodies how the parent(s) depend on their child/children for various aspects of their care and health and how each parent(s) submits to their child. The ideas of submission and dependence bring forth and highlight the power component of pastoral power. If "Pastoral power is a power of care" (Foucault *Security* 127) as Foucault believes, that power of care is now transferred from parent to child. Care that was once the parental duty is now transferred to the child - requiring a level of submission and dependence; key components of Pastoral power.

Reflections

While reading the works of Chast, Fies, Walrath as well as my own writings, I am taken aback by the similarities between the works. Each author expresses themselves in their own unique way – using humor, honesty, and sincerity. These stylistic choices aid in their communication of basic and detailed medical information about each illness/medical issue being faced, sharing learning moments while also expressing the changes that occurred in their lives; specifically, the interruption of their day to day life.[111] Each author also placed emphasis on the recognition of decline as well and communicated stories of devotedness to their parent(s). Foucault provided avenues to further interrogate each individual experience as I have explored within this chapter. What I did not anticipate in each narrative was the discovery of each author including teaching moments about death, the depth of personal disclosure, and how closely each narrative followed

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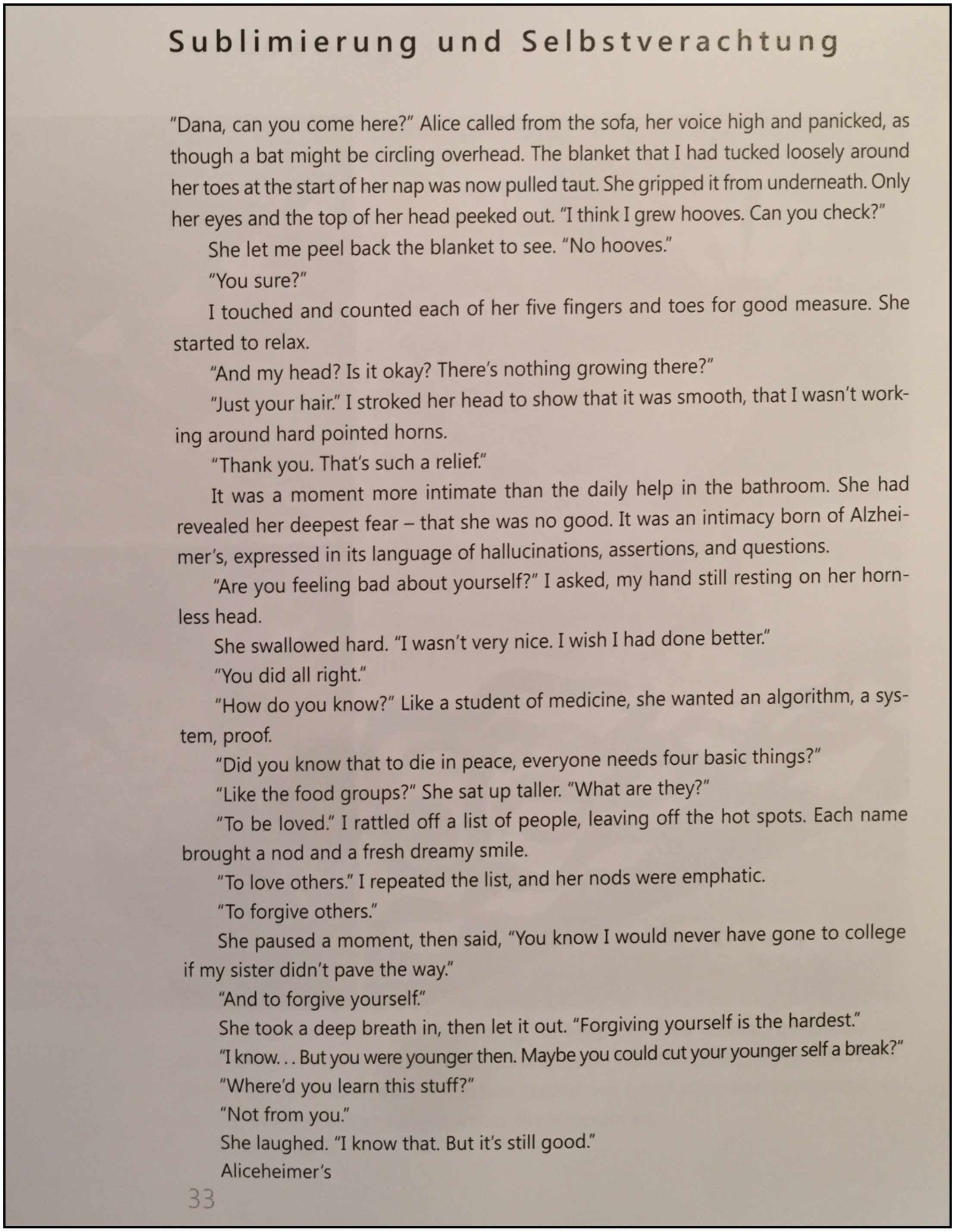
[111] In each narrative, the changes that occurred in each author's life is connected to the health issues that they are facing while caring for their ill/aging parent.

our sociocultural understanding and preconceived notions of each illness/health issue depicted (Alzheimer’s, Cancer, and Aging).

The first discovery was the notion of a teaching moment spoken by each author. While many teaching moments exist in and throughout each narrative, one teaching moment stood out; teaching about death. Walrath teaches to the idea of death in her story “Sublimierung und Selbstverachtung.” She focuses on what every individual must possess in order to die in peace.



Sublimierung und Selbstverachtung

"Dana, can you come here?" Alice called from the sofa, her voice high and panicked, as though a bat might be circling overhead. The blanket that I had tucked loosely around her toes at the start of her nap was now pulled taut. She gripped it from underneath. Only her eyes and the top of her head peeked out. "I think I grew hooves. Can you check?"

She let me peel back the blanket to see. "No hooves."

"You sure?"

I touched and counted each of her five fingers and toes for good measure. She started to relax.

"And my head? Is it okay? There's nothing growing there?"

"Just your hair." I stroked her head to show that it was smooth, that I wasn't working around hard pointed horns.

"Thank you. That's such a relief."

It was a moment more intimate than the daily help in the bathroom. She had revealed her deepest fear – that she was no good. It was an intimacy born of Alzheimer's, expressed in its language of hallucinations, assertions, and questions.

"Are you feeling bad about yourself?" I asked, my hand still resting on her hornless head.

She swallowed hard. "I wasn't very nice. I wish I had done better."

"You did all right."

"How do you know?" Like a student of medicine, she wanted an algorithm, a system, proof.

"Did you know that to die in peace, everyone needs four basic things?"

"Like the food groups?" She sat up taller. "What are they?"

"To be loved." I rattled off a list of people, leaving off the hot spots. Each name brought a nod and a fresh dreamy smile.

"To love others." I repeated the list, and her nods were emphatic.

"To forgive others."

She paused a moment, then said, "You know I would never have gone to college if my sister didn't pave the way."

"And to forgive yourself."

She took a deep breath in, then let it out. "Forgiving yourself is the hardest."

"I know. . . But you were younger then. Maybe you could cut your younger self a break?"

"Where'd you learn this stuff?"

"Not from you."

She laughed. "I know that. But it's still good."

Aliceheimer's

Figure 58. Dana Walrath, page from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 33.

Like Walrath, Chast focuses her teaching moment about death in her page titled "Last Things," on the idea of letting go and to express concerns and worries.

Figure 59. Roz Chast, page from *Can't We Talk About Something More Pleasant,* 2014, p. 208.

Similarly, Fies alludes to death on his two-page section titled “Who’s Life Is It Anyway.”

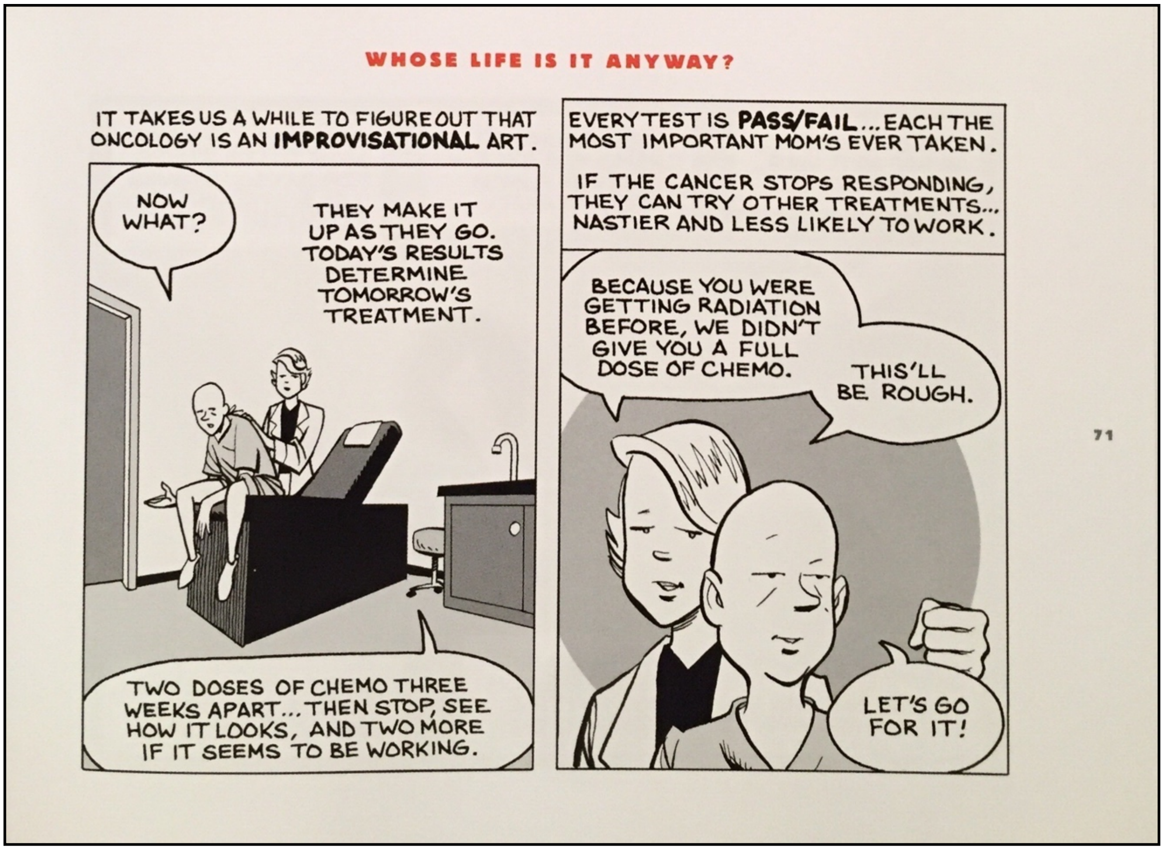


Figure 60. Brian Fies, page from *Mom’s Cancer,* 2006, p. 71.

In his first page of “Who’s Life Is It Anyway?” the idea of death is present, but not spoken of. The topic is avoided yet alluded to in the statement: “If the cancer stops responding, they can try other treatments . . . nastier and less likely to work” (Fies 71). Treatments not working would lead to the outcome of death from the cancer in most cases. On the following page of Fies section “Who’s Life Is It Anyway?” there is a brief mention of death.

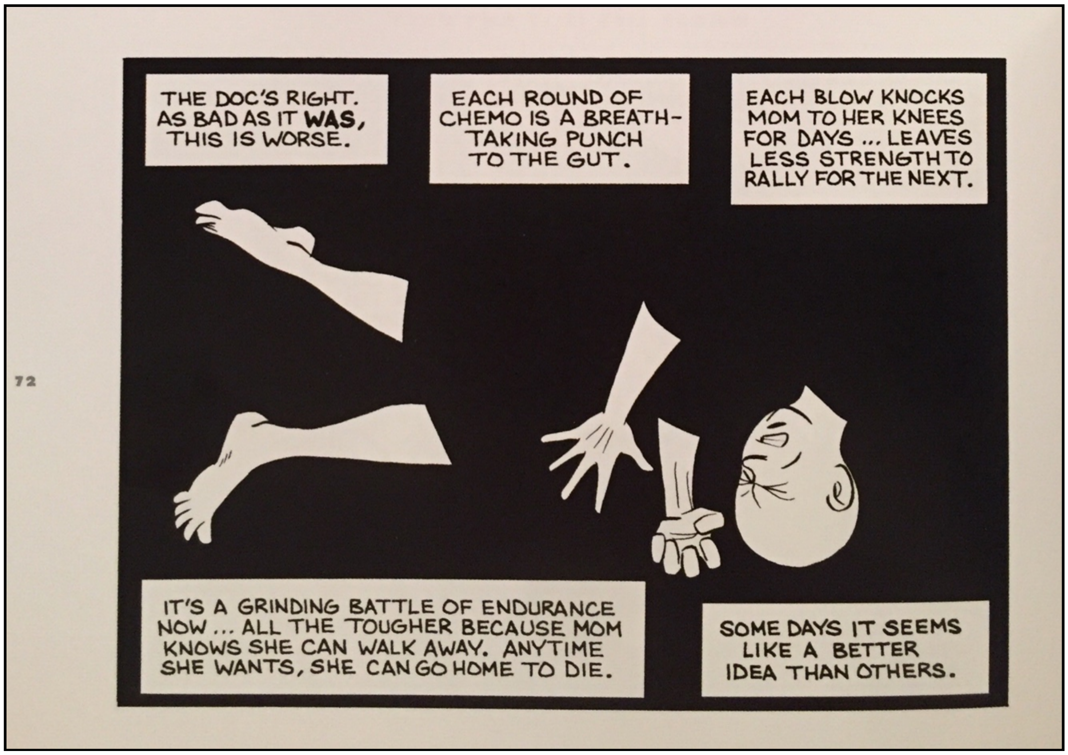


Figure 61. Brian Fies, page from *Mom's Cancer,* 2006, p. 72.

Death being the other choice if his mother decided to walk away from the Chemotherapy treatments.

Each example addresses the notion of death in a different way, one that our modern medical society so often tries to avoid. In my research on the topic of death, I came across three different arguments made by medical doctors/scholars. The argument (each made individually) is that the topic of death is one that is often avoided in our culture. Each text is revered for their honest approach to the subject of death.[112] Sherwin

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[112] The three texts are Sherwin B. Neuland's *How We Die: Reflections of Life's Final Chapter*; Atul Gawande's *Being Mortal: Medicine and What Matters in the End; Haider Warraich's Modern Death: How Medicine Changed the End of Life.*

B. Nuland M.D., author of *How We Die: Reflections on Life's Final Chapter*, notes that there is vast literature on the subjects of coping and the emotional trauma associated with death but that the specific details of death are found only in medical journals. His book seeks to "demythologize the process of dying" (xvii). In *Being Mortal: Medicine and What Matters in the End*, Atul Gawande M.D., approaches the subject of mortality. Gawande explores "the modern experience of mortality – about what it's like to be creatures who age and die, how medicine has changed the experience and how it hasn't, where our ideas about how we deal with our finitude have got the reality wrong" (9) in hopes to understand what has happened to our understanding of mortality. In his book, *Modern Death: How Medicine Changed the End of Life*, Dr. Haider Warraich tackles our modern sense of death. He delves into what makes it so difficult for us, society, to talk about death and how the notion of death has transposed over the past hundred years. He explores the language and rituals associated with dying and how modern technology has changed death; our understanding and our conversations. As each memoir brings the topic of death into their writing, it is: Why? Why do we skim the surface on this topic? While they are brief moments, each author does bring up the topic of death and dying – a topic so easily passed during conversations at doctor offices or between family members. Again, I asked myself: Why is the mention of this topic so brief? The works of Nuland, Gawande, and Warraich bring valuable insight to this question and the previous question I proposed: Why do we skim the surface on this topic? By looking at how American's culturally approach (or avoid), come to understand, and view the topic of death, we can begin to evaluate and further explore a topic so often skimmed over and most often avoided in our culture.

In synthesizing the narratives of illness and aging, I also discovered the inclusion of personal disclosure. This disclosure is unique in that the author discloses personal information about the ill/aging family member(s) they are caring for through their first-person disclosure; A disclosure within a disclosure. What makes this form of disclosure unique is that we are learning of personal health information about the ill/aging, not from the person experiencing the health issue but from an interested party experiencing the illness with the ill/aging. Previous literature in health communication[113] addresses the topic of disclosure from various viewpoints including the patient/provider context, yet does not consider if the disclosure of health information is coming from an interested party of the ill person. This finding allows for the following question to be posed for a future study: "How does non-patient disclosure of patient health issues (both within and outside of the medical context) fit into the health communication literature on disclosure?"

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[113] For a more robust conversation on the topic of disclosure in health communication literature see Roxanne Parrott's work *Talking About Health: Why Communication Matters* and "Topic-Centered and Person-Centered 'Sensitive Subjects': Recognizing and Managing Barriers to Disclosure about Health" in *Communicating About Communicable Diseases*; Kathryn Greene's chapter "Disclosure of Chronic Illness Varies by Topic and Target: The Role of Stigma and Boundaries in Willingness to Disclose"; Kathryn Greene et al. article "Assessing Health Diagnosis Disclosure Decisions in Relationships: Testing the Disclosure Decision-Making Model".

Another discovery was how closely each narrative followed our sociocultural understanding and preconceived notions regarding each illness/health issue being addressed in the selected texts. While each illness/health issue is separate (Alzheimer's, Cancer, and Aging), each author described their experiences in line with our social understanding as well as our preconceived notions about each individual illness. In *Aliceheimer's: Alzheimer's Through the Looking Glass*, Walrath shares numerous examples of our sociocultural understanding of Alzheimer's including but not limited to: the loss of memory; the choice of specialized care; outbursts; incontinence. In *Mom's Cancer*, Fies does not stray from our sociocultural choices of treatment, rather he describes in-depth his mother's journey. He begins with the diagnosis, proceeds on to the various stages of treatment, how the body responds to treatment (including the reactions to the specific medications given for treatment), and the after-care (as she was a survivor). Chast's narrative in *Can't We Talk About Something More Pleasant* accurately depicts our sociocultural assumptions about aging. Chast brilliantly weaves her thoughts about caring for her aging parents and her observations of her parents declining health with her parents' views on the same topics. Chast also includes social nods to aging with the inclusion of products specifically used for the aging (Ensure advertisement) as well as social and medical practices (the Elder Lawyer, Power of Attorney, the choice of Do Not Resuscitate (DNR). The inclusion of these social practices and ongoing ideas of how each illness progresses or how we treat illness allows for the following questions to be posed: In what ways is our understanding of illness predetermined? How do preconceived ideas about illness/health issues impact our abilities to understand how caregivers experience this role through ‘other’ orientations?

Conclusion

This chapter provided numerous exemplars of how the caregiving experience includes orientations of ‘other.’ Orientations of the ‘other’ includes how the individual(s) the caregiver is responsible for impacts the daily life of the caregiver, sharing of medical knowledge and information with others, managing the care of the ill/aging parent via third-parties, and recognition of decline of their ill/aging parent. Themes of caring, truth, and confession were explored through the ideas of recognizing the interruption of the daily life of the caregiver as well as vis a vis honesty; specifically, that of sharing medical information and learning moments. The themes of recognition of decline, both physical and mental, as well as devotedness were also explored. Each author narrated their own lived experiences with these topics from the context of the illness and/or disease their parent(s) were facing at that time. While each illness experience is vastly different from the other, similarities exist between and among the caregivers’ personal experiences. Those similarities being recognition of decline and devotion to the ill.

As each narrative develops, we begin to see into the lives of each narrator on a more personal level. Some author’s may choose to express their experiences by using humor while others may select the option of gripping honesty. Either approach expresses their experiences in connection to how they managed to navigate their role of caregiver in the orientation of the ‘other’ – trying to uphold the social expectations of the role of caregiver.[114] No matter their approach to stories, one element remains the same: they are the shared personal experiences of the author (often-times highly personal) that allow us, the reader, to become captivated with their personal stories of caring for the ill and aging and how they externally embodied their journey.

Chapter Three expanded on the ideas of set forth by my own personal narrative shared in Chapter Two by analyzing the works of three comic authors. The purpose of this critical analysis was to further explore how caregivers experience this role by focusing on ‘other’ orientations connected to the role of caregiving. Chapter Four continues to expand on the idea of caregiving experiences moving the focus to self-reflexive lived experiences - how the authors’ perceive their own role. Using the same analysis structure as found within this chapter, I seek to further understand how the caregiver functions and experiences their role in our society.

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[114] I explore this idea further in Chapter Five.

CHAPTER FOUR: THREE NARRATIVES ALIKE AND DIFFERENT - LIVED EXEREINCES THROUGH ORIENTATION(S) OF THE 'SELF' SURROUDING CAREGIVING

"What bothers me . . . is that I ended up writing memoir (even the poems were routinely autobiographical) when that was the last thing I wanted to do. Wasn't it? . . . How did I come to believe that what I knew was also what mattered? And, more to the point for the future, is it what matters?"

Patricia Hampl *I Could Tell You Stories* (200)

Even before I was assigned the role of Legal Guardian to my father, I saw myself as his caregiver and was often referred to as his caregiver. During this time, I would journal or write in a creative fashion about being present with him during his diagnosis and treatments for his then-liver disease and now liver and kidney disease diagnosis. I found that writing helped me reflect on what I was going through – on a personal level. It provide me the space to grapple with feelings of not being enough or not being good enough. In a sense I was self-policing, as Helen O'Grady would define it. Call it what you will, self-policing, journaling - I was being self-reflexive about my own experiences as caregiver. What I found is that I needed a space to express and communicate my personal reflections of what I was personally experiencing as a caregiver.[115] As I was experiencing my moments of isolation and anxiety I tried to rationalize my thoughts,

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[115] Even as I write, I still find the need to write out my feelings, my fears, my anxieties, my moments of joy and sorrow in a self-reflexive capacity. I do this through journal entries, poems, and short stoires. This is what I would describe as self-reflexive lived experiences.

feelings, and emotions. To rationalize, I did what I did best; I researched. I searched for theoretical explanations for what I was experiencing.[116] I questioned myself, my feelings, and my reaction to my (at that time) new(er) role I was given; that of caregiver, and more particularly, guardian. I knew that other caregivers felt the same or had similar reactions through the personal conversations I was privileged to share with them. Yet, I felt that I was still missing the connection.

I went back to notes from my independent study with Dr. Harter and the missing connection started to become clear. It was the use of stories that aided in my understanding of this new role and the feelings I was having; not the feelings themselves. The use of storytelling is one of the most influential and meaningful ways we can begin to express to others the feelings and experiences that are part of being human. In my certain circumstance, I was (and am) focusing on the caregiver experience. Lynn Harter believes "narrators focus attention on experience and interpret it, creating a representation from raw experience" (*Imagine* 14). I can attest to this belief first hand as my stories of both the external and internal embodiment focus on raw experience and the creation of representing these experiences just as the works of Chast, Fies, and Walrath do. If stories have the ability to "instruct us about what to notice, and how to judge actions and outcomes," as Harter (*Imagining New Normals* 5) suggests, the action of sharing stories has the potential to provide insight to how a caregiver internally embodies the role of caregiving.

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[116] Most common is the connection to caregiver burnout. Yet, caregiver burnout does not specify feelings of isolation and anxiety.

After authoring the five mini narratives covering self-reflexive lived experiences that disclose my own hurdles through my role as caregiver (see Chapter Two, Part II), I reflected on my own writing. My goal was to identify any overarching themes that were taking place within the stories that, as I was writing each individual moment, I was not able to recognize. What I noticed within each story was the idea of isolation and/or anxiety. While the major theme(s) may be clear to you, the reader, in some of my personal stories, major theme(s) might be less clear in another (for example in the vignette: *Bathrobes and Cat Purrs*). The act of reading my own work to name themes was challenging. I had to table my own emotion and self-criticism while reading in order to interact with my own words enough to see what was truly taking place for me during each of these moments. I permitted myself to acknowledge and own my feelings of isolation and anxiety during this specific time in my life. I allowed myself to recognize that my own stories were providing me the space to explore knowledge and interweave my own personal experiences with the literature I have come to know and live. My stories and the analysis of my stories allowed me to produce knowledge at a deeper level than it would have been achieved otherwise. Questions at the forefront of my mind while reading and writing were: In what ways can social isolation and/or anxiety occur and how does social isolation and/or anxiety manifest itself as a factor of the ability for one to care for another? If isolation and/or anxiety is occurring, does it help strengthen a caregiver's abilities or does it in fact weaken them, on one level or another? How does an orientation focusing on 'self' manifest itself in the caregiving experience?

In my own experience, the act of wanting to share feelings regarding the experience of being a caregiver manifested itself in the form of social isolation and anxiety. Isolation and anxiety was how I internally embodied the role of caregiver to my father. After writing about my own experiences in Chapter Two, I wondered if Chast, Fies, and Walrath experienced caregiving the same way. I went back to each text, reading their narratives multiple times and recognized both social isolation and anxiety operating in a self-reflexive capacity in *Can't We Talk About Something More Pleasant*, *Mom's Cancer,* and in one instance in *Aliceheimer's: Alzheimer's Through the Looking Glass*. The description of isolation and anxiety may not be as raw and forthcoming as my own stories told in Chapter Two, but isolation and anxiety are found within each of the narratives. The following section outlines these themes as the authors expressed them.

Themes of Isolation and Anxiety[117]

Prevalent in all three texts were the feelings of isolation and anxiety. While these feelings manifest themselves differently by each author, the feelings are still present in their narrative. It is important to note: Isolation produces anxiety; anxiety produces isolation. Each cohabitate the same space. What follows will be in some cases individual expression of one or both of these from the view of the comic memoir authors.

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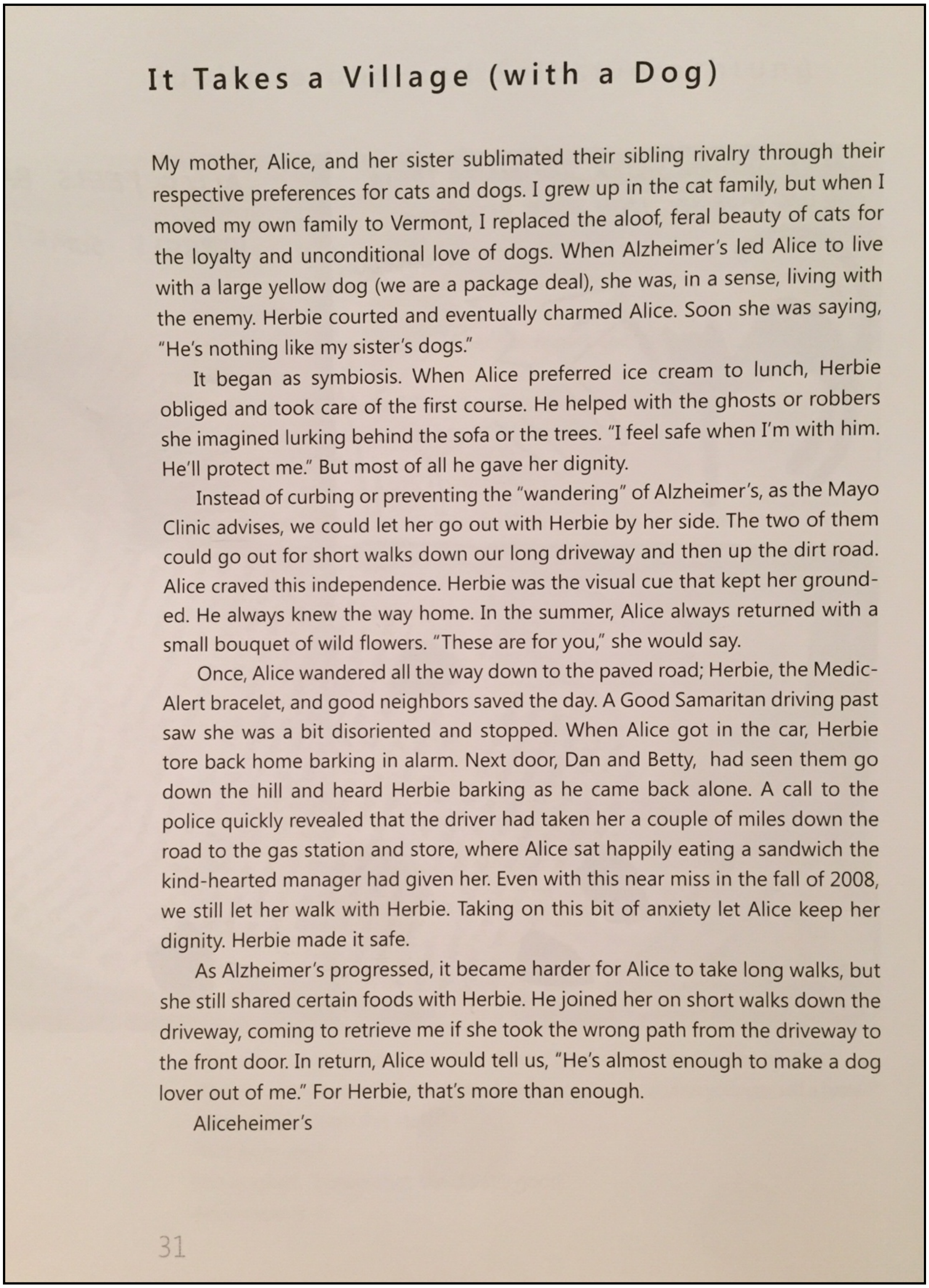
[117] The analysis will at times focus on an individual feeling (either isolation or anxiety) or may focus on both. For most, it is nearly impossible to talk about one term (either isolation or anxiety) in a solo sense as they cohabitate the same space. Often isolation comes with feelings of anxiety or anxiety may produce feelings of isolation or the need to isolate the self.

While I did not find any outward exemplar of isolation in Walrath's narrative, *Aliceheimer's: Alzheimer's Through the Looking Glass*, I did locate one mention of the feeling of anxiety in her vignette, "It Takes a Village (with a Dog)." In this story, Walrath expresses how she took on anxiety to allow her mother, Alice, to keep her dignity by continuing to go on walks with the family dog Herbie. Walrath shares this moment of anxiety with the reader recalling how she almost lost her mother:

> Once, Alice wandered all the way down the paved road; Herbie, the Medic-Alert bracelet, and good neighbors saved the day . . . A call to the police quickly revealed that the driver had taken her a couple of miles down the road . . . Even with this near miss in the fall of 2008, we still let her walk with Herbie. Taking on this bit of anxiety let Alice keep her dignity. Herbie made it safe. (31)



It Takes a Village (with a Dog)

My mother, Alice, and her sister sublimated their sibling rivalry through their respective preferences for cats and dogs. I grew up in the cat family, but when I moved my own family to Vermont, I replaced the aloof, feral beauty of cats for the loyalty and unconditional love of dogs. When Alzheimer's led Alice to live with a large yellow dog (we are a package deal), she was, in a sense, living with the enemy. Herbie courted and eventually charmed Alice. Soon she was saying, "He's nothing like my sister's dogs."

It began as symbiosis. When Alice preferred ice cream to lunch, Herbie obliged and took care of the first course. He helped with the ghosts or robbers she imagined lurking behind the sofa or the trees. "I feel safe when I'm with him. He'll protect me." But most of all he gave her dignity.

Instead of curbing or preventing the "wandering" of Alzheimer's, as the Mayo Clinic advises, we could let her go out with Herbie by her side. The two of them could go out for short walks down our long driveway and then up the dirt road. Alice craved this independence. Herbie was the visual cue that kept her grounded. He always knew the way home. In the summer, Alice always returned with a small bouquet of wild flowers. "These are for you," she would say.

Once, Alice wandered all the way down to the paved road; Herbie, the Medic-Alert bracelet, and good neighbors saved the day. A Good Samaritan driving past saw she was a bit disoriented and stopped. When Alice got in the car, Herbie tore back home barking in alarm. Next door, Dan and Betty, had seen them go down the hill and heard Herbie barking as he came back alone. A call to the police quickly revealed that the driver had taken her a couple of miles down the road to the gas station and store, where Alice sat happily eating a sandwich the kind-hearted manager had given her. Even with this near miss in the fall of 2008, we still let her walk with Herbie. Taking on this bit of anxiety let Alice keep her dignity. Herbie made it safe.

As Alzheimer's progressed, it became harder for Alice to take long walks, but she still shared certain foods with Herbie. He joined her on short walks down the driveway, coming to retrieve me if she took the wrong path from the driveway to the front door. In return, Alice would tell us, "He's almost enough to make a dog lover out of me." For Herbie, that's more than enough.

Aliceheimer's

31

Figure 62. Dana Walrath, page from *Aliceheimer's: Alzheimer's Through the Looking Glass,* 2013, p. 31.

For Walrath, allowing herself to experience the feeling of anxiety as a caregiver in connection to the safety of her mother was worth having her mother be able to keep her dignity. While Walrath was able to clearly identify her "taking on anxiety," the anxiety manifested in Fies's experience was less realized.

In the vignette, "A Terrible Thing To Waste," (*Mom's Cancer*) Fies describes his feelings of anxiety and isolation. In the page below, anxiety and isolation are alluded to by Fies in the form of daily tasks and care he is able to provide for his mother.

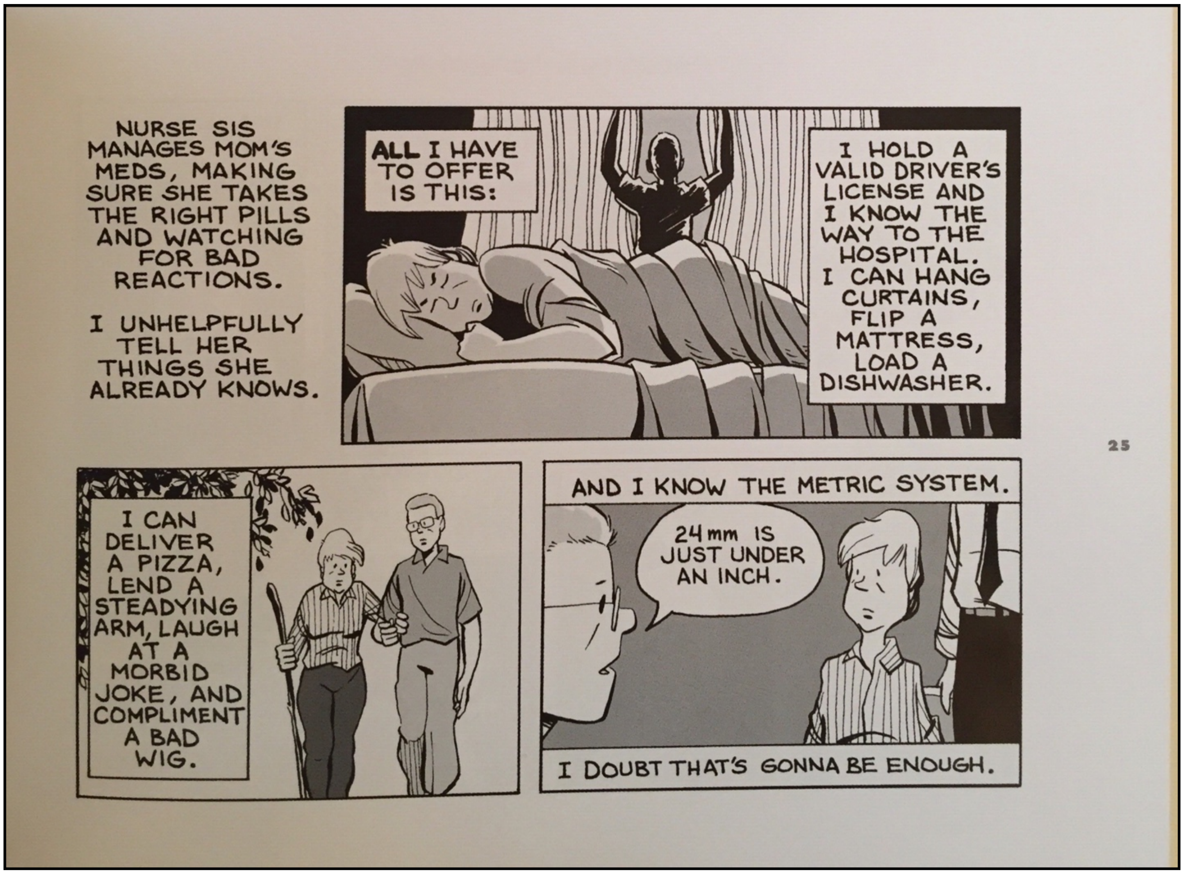


Figure 63. Brian Fies, page from *Mom's Cancer*, 2006, p. 25.

The feeling of anxiety is prevalent in Figure 63 from Fies's work with the selection of his choice of words in his narrative account. While Fies does not self-identify as having anxiety, his narrative supports subtle signs of anxiety when describing his role as caregiver for his mom. One way we see his anxiety manifested is through his introspective self-narrative. This type of narrative can be viewed as reflective and fixated – characteristics of the melancholic as described by Foucault (*Madness* 125). In the book *Madness and Civilization: A History of Insanity in the Age of Reason*, Foucault covers the history of madness as it aids in our current social understanding of the mentally ill, also deemed throughout history as "the mad." Historically, madness included melancholia and mania.[118] Those suffering from melancholia (known today as depression) had the characteristics of avoiding the company of others, "prefer solitary places, and wander without knowing where they are going . . ." (*Madness* 125). Foucault continues to describe the historical description of those suffering from melancholia and mania with writing from the classical period stating:

> The mind of the melancholic is entirely occupied by reflection, so that his imagination remains at leisure and in repose; the maniac's imagination, on the contrary, is occupied by a perpetual flux of impetuous thoughts. While the melancholic's mind is fixed on a single object, imposing unreasonable proportions upon it, but upon it allow, mania deforms all concepts and ideas; either they lose their congruence, or their representative value is falsified; in any

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[118] For a full history on the term madness, see Foucault's chapter "Aspects of Madness" in his work *Madness and Civilization.*

> case the totality of thought is disturbed in its essential relation to truth. Melancholia, finally, is always accompanied by sadness and fear; on the contrary, in the maniac we find audacity and fury. (*Madness* 125)

While Fies is not melancholic and does not suggest he is, his narrative choices suggest he may be feeling and experiencing depression (melancholia). As previously explained, Foucault suggests a person suffering from melancholia isolates themselves and is occupied by reflection. As Fies is already isolated with his new responsibilities as caregiver to his mother, he can reflect on his abilities as caregiver. It is out of this introspective reflection of Fies's own abilities as caregiver that anxiety could manifest itself. Two examples of the anxiety manifested by Fies are his feelings about the situation and his personal abilities[119] seen in the lines "ALL I have to offer is this:" and "I doubt that's gonna be enough." The feeling of anxiety is communicated to the reader with his narrative account and is supported with the visual depiction of the narrative being visually blocked and backgrounded with white. The blocking of the narrative may

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[119] Anxiety can manifest itself in many forms. Anxiety can be felt internally, as seen with my personal stories, or it can manifest in external forms such as feelings of doom, worthless, the inability to perform. As seen with Fies's narrative, the internal anxiety felt by Fies manifested itself externally by the recognition and presentation of his fears by stating his fear and worry.

produce an uncomfortable feeling or may cue the reader to be more aware of the narrative[120] - creating a feeling of anxiety (and isolation) for the reader.

To understand how isolation is operating in Fies work, and later on in Chast's work, it will be helpful to frame the analysis via a detour into Foucault's work on madness. Over the course of ten years, Foucault wrote and lectured on the topics of madness, abnormalities (in the realm of mental health), and psychiatry. Foucault explains that doctors of the time tried to cure this new disease by curing the entire individual (*Madness* 159). They worked on "moral therapeutics of the body" (159) that included: Consolidation (weakening of the spirit); purification (cleansing the body with various medical procedures); immersion (purification through immersion into water); regulation of movement (limitation of movement to cure body) (*Madness* 159-177). When these efforts did not prove successful, the madman was identified as a "social individual" and he was questioned (200). Questioning the madman developed into a social fear. This created fear identified a difference between the mad and the sane. Fear of the mad was set to protect the sane from the mad; "Unreason was once more present; but marked now by an imaginary stigma of disease, which added its powers of terror" (*Madness* 205). The goal: confine the mad – isolate them. The descriptions provided by Foucault of how those suffering from melancholia (now known as depression) and mania act frames not only

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[120] Physical feelings like being uncomfortable, being more aware (or hyper aware), feeling restlessness, among others are physical symptoms of what a person may feel like when anxious (see additional literature on anxiety and anxiety attacks found on websites such as: themayoclinic.com; gracepointwellness.org).

our past understanding of these illnesses but sets the tone for how society "dealt" with the (un)known.

Reviewing the history of madness from a broad sense provides an understanding of the connection between isolation and the ill. Not only did we isolate those deemed with having mental illness from society (and continue to do so today), but we also isolated (and still isolate) the sick/ill – in structures that include but are not limited to: hospitals, hospice, care facilities, independent living communities, or home (if resources are available). In the instance of Fies and his narrative of caring for his mom while undergoing treatment for cancer, we see isolation take the form of self-isolation when caring for an ill parent.

In the work of Fies, using the same figure as previously used to explain anxiety (see Figure 63), we can also see isolation manifest itself for Fies. In this image, Fies textually explains to the reader what skills he can offer his mom: transportation, assistance in her home, fending for food, compassion during conversations, stability when walking, and math (for doctor's visits). These physical abilities he knows he can provide to his mother are reliant upon him being with her on a consistent basis. The need for the caregiver to be with the ill parent on a consistent basis creates a form of isolation for the caregiver as they, in this case Fies, spend most of their time alone with their parent. Fies is aware of the isolation that will ensue due to his newfound responsibilities.

The isolation Fies experiences can best be explained with Foucault's writings in *The Birth of the Clinic: An Archaeology of Medical Perception*. Foucault documents how our previous understanding of medicine as a mathematical science came to be understood as a social and cultural embodied idea. Foucault confirms that prior to the French Revolution, medicine could only be observed by those trained in the science of medicine. He explains that medical consciousness took place in a centralized structure (30) and that ". . . the medical gaze circulates within an enclosed space in which it is controlled only by itself; in sovereign fashion, it distributes to daily experience the knowledge that it has borrowed from afar and of which it has made itself both the point of concentration and the centre (sic) of diffusion" (30-31). It was during the French Revolution that this idea changed. Due to people living in both the countryside and the city, it was realized that doctors could not be the only people privy to medical information, even in its most basic form. Foucault identifies that "a consciousness of each individual must be altered; every citizen must be informed of what medical knowledge is necessary and possible" (31). Furthermore, Foucault references the shift in medicine for curing illness to medicine as a means of understanding health. He states:

> Medicine must no longer be confined to a body of techniques for curing ills and of the knowledge that they require; it will also embrace a knowledge of *healthy man*, that is, a study of *non-sick man* and a definition of the *model man*. In the ordering of human existence it assumes a normative posture, which authorizes it not only to distribute advice as to healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives. (*Birth* 34)

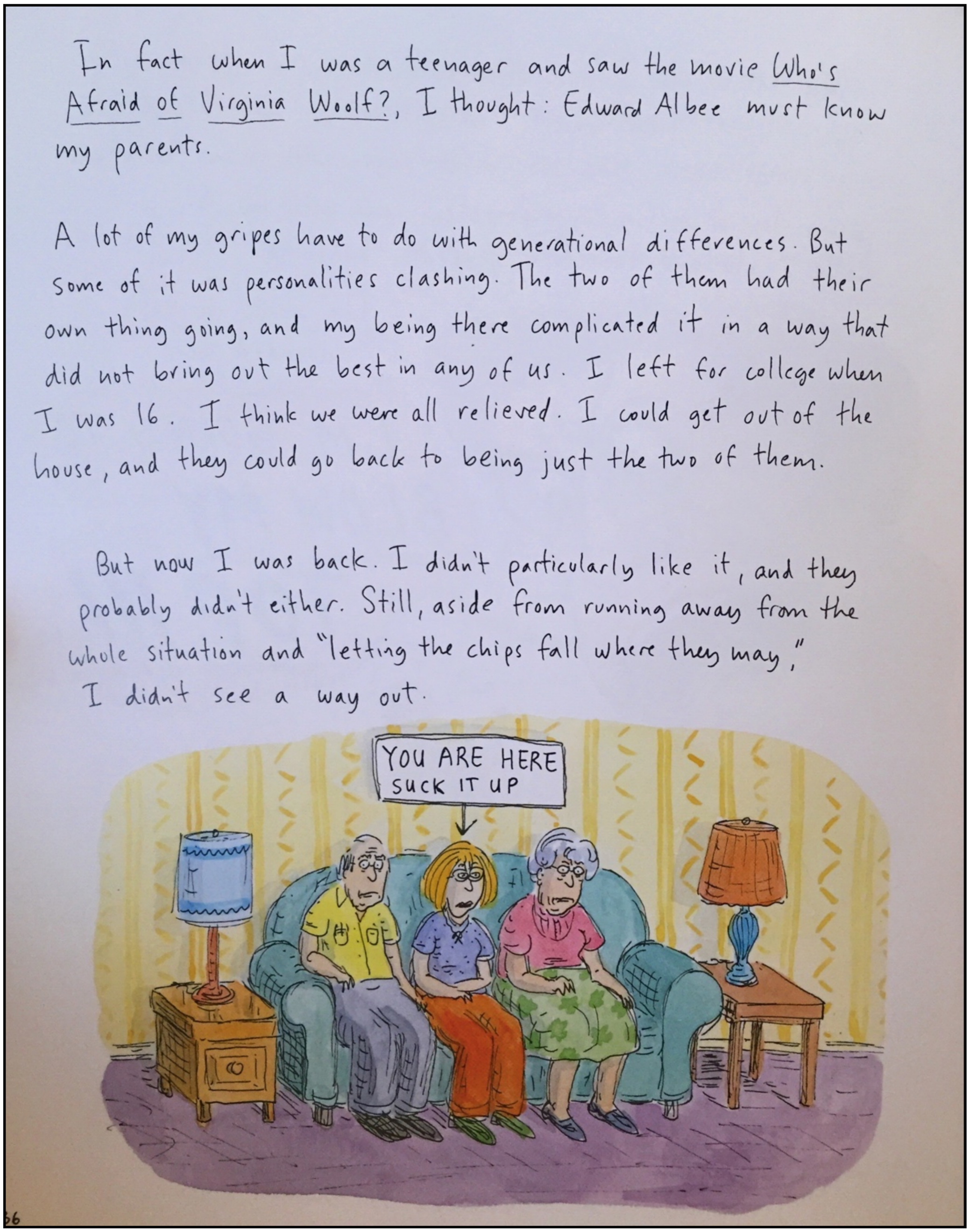
Out of this Foucauldian frame, medicine as a social structure, we can begin to comprehend how Fies can consciously recognize the isolation that he is experiencing and will continue to experience being his mother's caregiver. One way Fies recognizes isolation is through understanding the cultural norms of caring for an ill parent. He knows what his mother will need during her treatment and realizes that he has the ability to provide those to her. Fies also understands that when caring for a parent, you must often provide around the clock care. Care can be done by the caregiver themselves, other family members, or with paid outside help. We do not know what prompted Fies to personally care for his mother rather than hire outside help, but he did. Fies took on the role of caregiver knowing the ramifications of this type of role; one being isolation.

Isolation as a state of mind can be felt if the individual experiencing it is going through change to their daily routine or their role in life as seen with Fies. In the above example, Fies emphasizes the word all, penning the word in both capital and bold letters. The word choice **ALL** depicts his unstated feeling of isolation as being a caregiver to his mom. This feeling of isolation is again emphasized at the end of the page when he voices, "I doubt that's gonna be enough" (Fies 25). Within this page, Fies' artistic images support his narrative of assisting in the home, providing emotional and physical support, and explanation of math in the doctor's office. Artistically, Fies boxes the narrative and lays the narrative account over the images he draws. The boxes have a white background emphasizing the descriptive narrative creating isolation of the words from the image; supporting the idea of isolation.

Earlier in this chapter, I explained how medical knowledge expanded from a doctor-only privilege to a social understanding. With this newfound change, the social body comprised of individuals now have the ability to recognize and normalize health.

One aspect of the definition of health is mental health. With recognition and normalization comes the act of classification and stigmatization. We see the cultural understandings, classifications, and sadly the stigmatizations of isolation and anxiety in Chast's writing.

In her memoir, *Can't We Talk About Something More Pleasant*, Chast is more forthcoming than Fies about her feelings of isolation and anxiety. In the following exemplar, we see her description of isolation through her narrative and her artistry.



In fact when I was a teenager and saw the movie Who's Afraid of Virginia Woolf?, I thought: Edward Albee must know my parents.

A lot of my gripes have to do with generational differences. But some of it was personalities clashing. The two of them had their own thing going, and my being there complicated it in a way that did not bring out the best in any of us. I left for college when I was 16. I think we were all relieved. I could get out of the house, and they could go back to being just the two of them.

But now I was back. I didn't particularly like it, and they probably didn't either. Still, aside from running away from the whole situation and "letting the chips fall where they may," I didn't see a way out.

Figure 64. Roz Chast, Page from *Can't We Talk About Something More Pleasant*, 2014, p. 36.

Visually, Chast places herself sitting between her parents on a couch that is framed between two end tables. Her use of space communicates to us that she is stuck; isolated in her parent's world. To emphasize this (negative) feeling, she places the sign above her head that reads, "YOU ARE HERE suck it up" (Chast 36). The use of capital letters for "you are here" supports the idea of being isolated, trapped. Foucault speaks to isolation as being negative and a form of punishment in his writings covering the topics of discipline and punishment as well as madness and psychiatry.[121] As explained earlier in this chapter, isolation was used as a form of punishment for criminals and for the mad (also known as the insane). Chast's narrative supports the view of 'isolation as punishment' as her narrative identifies her feelings of isolation and entrapment as she writes, "But now I was back. I didn't particularly like it, and they probably didn't either. Still, aside from running away from the whole situation and 'letting the chips fall where they may,' I didn't see a way out" (36). The word selection of "I didn't see a way out" depicts being stuck as well as being isolated in their world; the world of her parent's. Chast's choice to bubble her artistic rendition in a cutout-like fashion and place the comic on a white background with the narrative penned above also assists in the creation of feeling isolated. The layout of the page communicates openness as there are no panels;[122] yet, Chast uses the white space between her narrative to create unconventional gutters between her written narrative. This white space naturally produces a feeling of isolation;

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[121] Full discussion of the penal system can be found in Foucault's work *Discipline and Punish: The Birth of the Prison.*

[122] The lack of panels prohibits the creation of gutters by physical lines. For more information on gutters and the use of gutters in comic writing refer to Chapter Three, Blood in the Gutters, in Scott McCloud's book *Understanding Comics: The Invisible Art*.

isolation from the outside world that is being established as Chast decides to care for her parents. Not only does Chast share moments of isolation, but she also narrates the feeling of anxiety.

Anxiety is illustrated during various moments in Chast's work. Two prevalent moments of anxiety for Chast are narrated in the chapter: "The Fall." The first account of anxiety, as seen in the page below, is when she decides to leave her parents to go home.

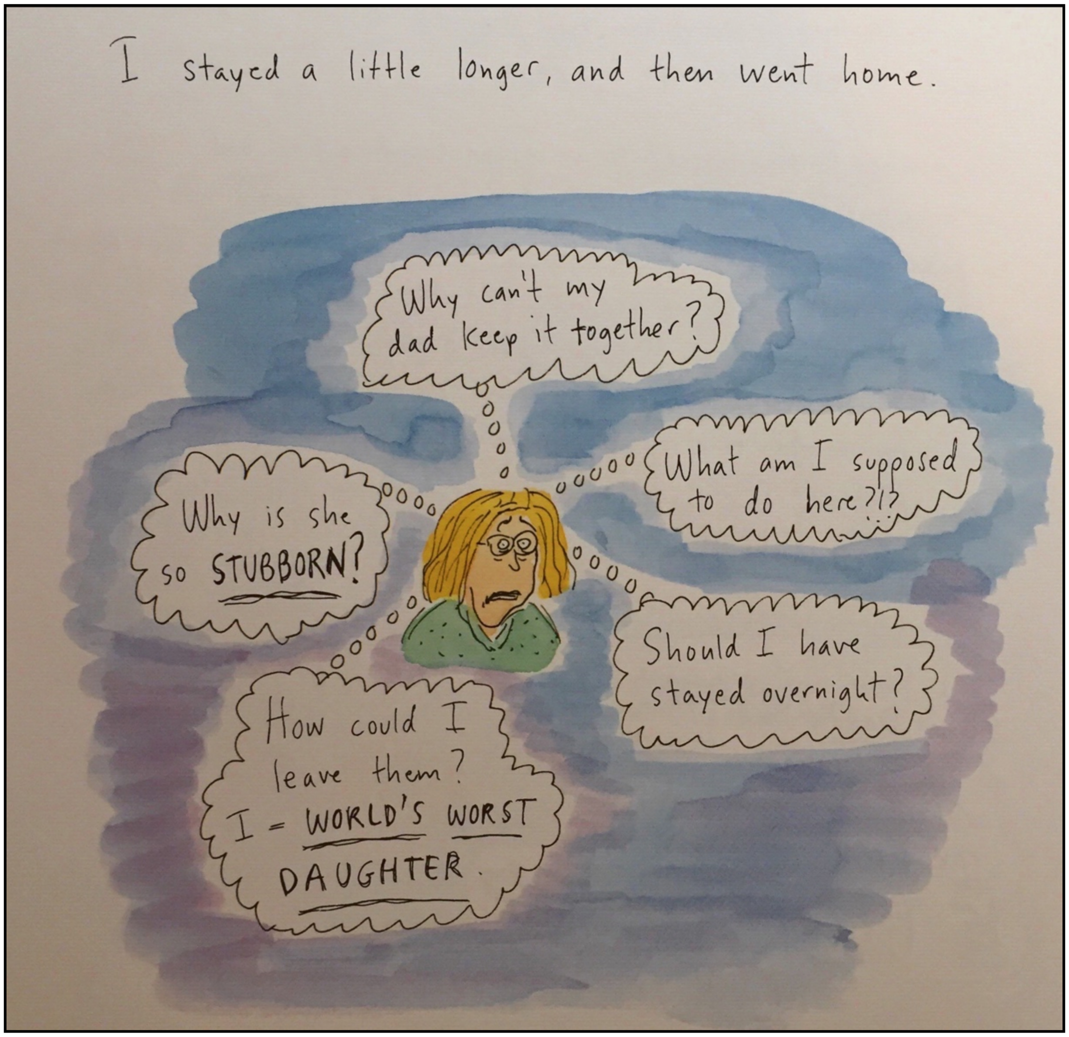
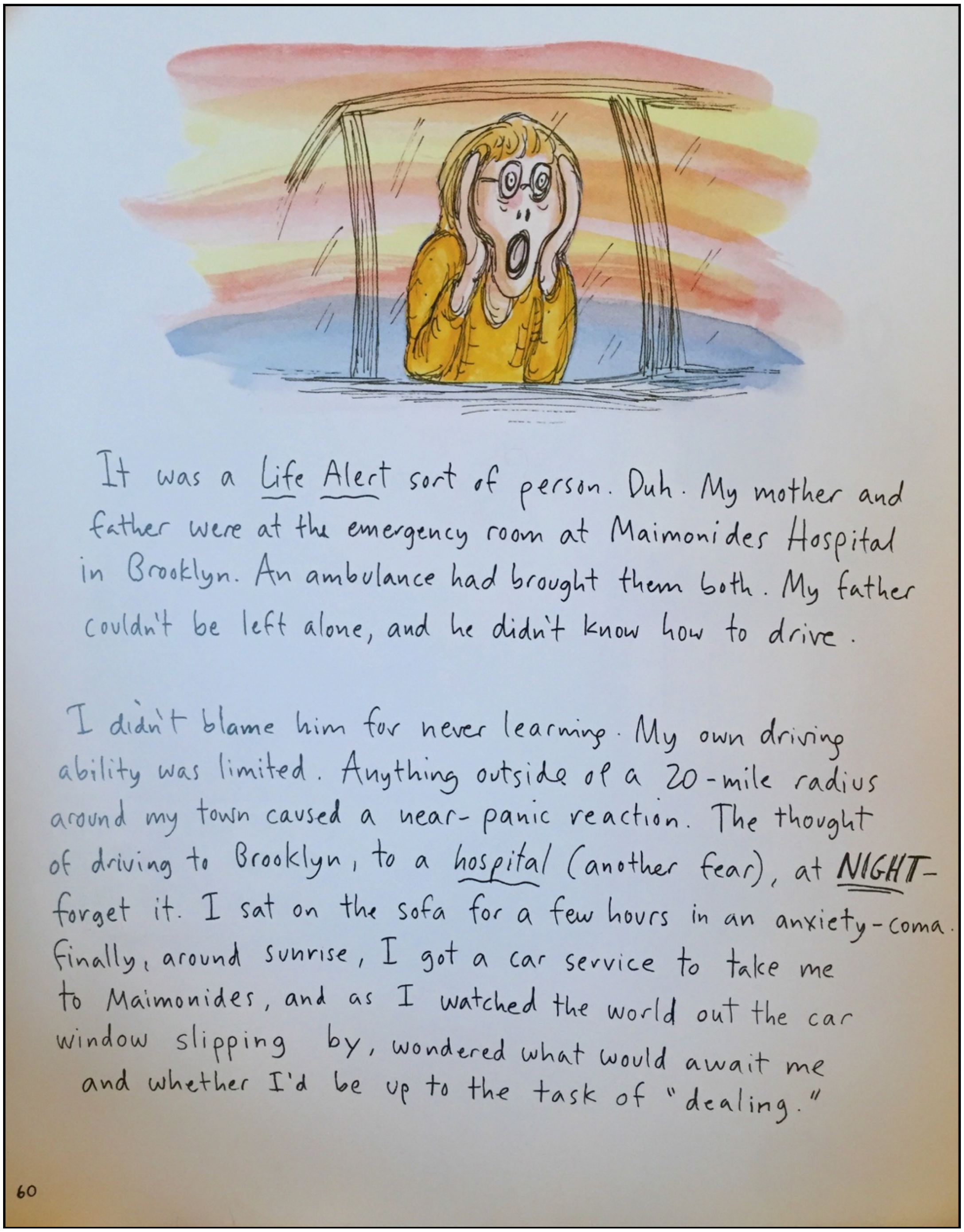


Figure 65. Roz Chast, page from *Can't We Talk About Something More Pleasant*, 2014, p. 58.

Chast communicates to the reader what types of questions crossed her mind regarding her decision to leave. The questions Chast proposed to herself, exhibits an awareness of self. Foucault writes to the idea of self-awareness in connection to the ill and healthy [wo/]man. In *The Birth of the Clinic,* Foucault writes of this consciousness when historicizing the development of norms in dictating "the standards for physical and moral relations of the individual and of the society in which he lives" (34). In other words, the normative standards are internalized by the individual and named as healthy behavior. Anything outside of the normative standard would be categorized as unhealthy. The questions Chast asked herself, including: "What am I supposed to do here?!?; Should I have stayed overnight? How could I leave them? I – World's worst daughter" (Chast 58), exhibit the internalization of the normative standards our society has regarding caring for an ill/aging parent. The fact that Chast is questioning her personal decision to leave her parents exemplifies the dictation of standards Foucault speaks of regarding how an individual understands, internalizes, and relates to the society around them in a health context. In Chast's case, each question exhibits levels of anxiety regarding her personal (non-normative) decision to leave. Despite the anxiety she felt, and knowing that her decision was going against the normative pattern when caring for ill/aging parent(s), she kept to her decision and went home. As she narrates beautifully on the next page of the chapter, her decision may not have been the best.

Figure 66. Roz Chast, page from *Can't We Talk About Something More Pleasant*, 2014, p. 59.

The sequential page from Chast's chapter "The Fall" captures the anxiety she feels when she hears the phone ring after midnight, "Later that night . . ." (59). Already anxious about her decision to leave and not stay with her parents that night, the ringing of the phone and her thought of: "God! What sort of person calls AFTER MIDNIGHT?!?" "One half-second before thought process kicks in" (59) is when the second prevalent moment of anxiety is narrated by Chast. On the next page of the chapter, we learn that the caller is "A Life Alert sort of person" (60).



It was a *Life Alert* sort of person. Duh. My mother and father were at the emergency room at Maimonides Hospital in Brooklyn. An ambulance had brought them both. My father couldn't be left alone, and he didn't know how to drive.

I didn't blame him for never learning. My own driving ability was limited. Anything outside of a 20-mile radius around my town caused a near-panic reaction. The thought of driving to Brooklyn, to a *hospital* (another fear), at ***NIGHT***– forget it. I sat on the sofa for a few hours in an anxiety-coma. Finally, around sunrise, I got a car service to take me to Maimonides, and as I watched the world out the car window slipping by, wondered what would await me and whether I'd be up to the task of "dealing."

Figure 67. Roz Chast, page from *Can't We Talk About Something More Pleasant*, 2014, p. 60.

The three-page sequence just shown and described provides insight to the ongoing feeling of anxiety that Chast was experiencing while caring for her parents. Chast felt anxiety with the decision-making process of choosing to stay with her parents or leave. Her anxiety is expressed through the multitude of thoughts and feelings going through her head in that moment. Chast depicts this moment with various questions. Questions regarding her decision, making the right choice, about her father's mental state, her mother's behavior, and her overall measure of worth of being a daughter. These questions are exemplary of anxiety as she is overcome with feelings of fear and worry that interfere with her daily activities. We see the culmination of these feelings of anxiety in her narrative account (as seen in the page above) when she receives the call from a "Life Alert sort of person" (Chast 60).

Upon receiving the call that her parents are in the emergency room in a hospital in Brooklyn, Chast's anxiety hits a peak in the form of a debilitating attack. It is not entirely clear if the event of the phone call produced the anxiety attack for Chast or if it was the combination of the call and the idea of driving to Brooklyn at night, to a hospital. She identifies the hospital as "(another fear)" (60). No matter what the cause, the anxiety produced during this moment caused her to have a physical reaction; one that prohibited her from doing anything during that moment. She recalls: "I sat on the sofa for a few hours in an anxiety-coma. Finally, around sunrise, I got a car service to take me to Maimonides, and as I watched the world out the car window slipping by, wondered what would await me and whether I'd be up to the task of 'dealing'" (60). Chast names her feelings and reaction in that moment calling it "an anxiety-coma" (60). Chast categorizes her feelings to connect to what she has learned and come to understand of what anxiety is.

In his writings on the history of insanity, Foucault explains how medicine and society have come to know the traits of psychological illness,[123] specifically mania and melancholia, through categorization. He describes:

> If mania, if melancholia henceforth assumed the aspects our science knows them by, it is not because in the course of centuries we have learned to "open our eyes" to real symptoms; it is not because we have purified our perception to the point of transparency; it is because in the experience of madness, these concepts were organized around certain qualitative themes that lent them their unity, gave them their significant coherence, made them finally perceptible. We have passed from a simple notional description . . . to a qualitative realm, apparently less organized, simpler, less precisely limited, but which alone was able to constitute recognizable, palpable units *really present* in the total experience of madness. (*Madness* 130-131)

Foucault believes that by theming and structuring the concepts surrounding the idea of madness and melancholia, the experience of madness was organized – giving society means to categorize and describe these two mental health illnesses. Applying Foucault's

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[123] Foucault's work *Madness and Civilization* specifically focuses on the topic of mania and melancholia in connection to the idea of the mad or the madman. I am extending his theoretical arguments of how medicine and society has learned to categorize and classify to the idea of anxiety to provide explanation of how society has learned to categorize symptoms to other forms of mental health diagnoses.'

theoretical structure of theming experiences qualitatively to moments of anxiety that have been endured, we can begin to comprehend how Chast determined that the feelings she was experiencing were connected to those of panic and anxiety. Her words expose the reality of how debilitating panic attacks can be.

Reflections

As isolation and anxiety prove present in Fies and Chast's caregiving experiences and anxiety being present in a single narrative account of Walrath's, I discovered that the authors provide possible ways of overcoming feelings of isolation and anxiety or the onset of these feelings. The possibility of overcoming feelings of isolation and/or anxiety is done by creating a desired outcome within various moments of caregiving they are experiencing. The desired outcomes vary depending on the situation, yet they all have one commonality: a shift of focus. The shift of focus is to the reader, specifically giving the reader insight to the author's reasoning or justification for choices made in the caregiving moment. These focus shifts can be understood from a theoretical perspective using Foucault's notion of Ethics.

Foucault provides one plausible way of critiquing the discourse of the comic memoirs and the idea surrounding desired outcomes of a shared caregiving experience. Each author willingly shares feelings regarding the experience of being a caregiver. One can argue that the willingness to share feelings could be driven by the desired relationship the caregiver wants to have with oneself. The notion of a relationship with the self is the core idea behind Foucault's orientation toward Ethics.

In this orientation, Ethics refers to the relationship one has with oneself (Foucault *Ethics*). As Foucault suggests, it is driven by the desire “by which one attempts to develop and transform oneself, and to attain to a certain mode of being” (*Ethics* 282). A common theme of Ethics is the individual’s moral reflection of the self. It is a basis for Foucault’s idea of caring for the self, a component of Ethics. Foucault further identifies four components of how a person views the self from a moral stance to reflect on actions of the self. These four components are: 1) the individual focuses on the moral conduct of the self; 2) the recognition of moral actions; 3) how the individual recognizes areas of possible transformation and work on bettering the self; 4) interests the self on who they desire to be (*Ethics* 284-287). The four components provide a possible explanation for the focus shifts identified in the comic memoirs. The choice to shift focus in the narrative and have a communicative outcome (self-sacrifice, creating rules, rationalization, sharing truthful moments/journey with others so they have a guide) is creating a moral subject for the author that is guided by his/her own actions (*Ethics* 282-287).

Within the vignettes, pages, and/or chapters of the memoirs of Fies, Chast, and Walrath we can see moments where focus shifts occur in their narratives. When these shifts happen, it can be argued as a conscious choice by the author to selectively change the outcome of the moment. These selective changes can be self-driven or power-driven. Each focus shift has a communicative outcome chosen by the author and identifies how the moment is to be perceived by the reader as will be shown in the examples that follow. The focus shifts that take place within the narratives can be critiqued by using the previously explained four components of Foucault’s view of Ethics.

Foucault’s idea of Ethics can be identified within the pages of the comic memoirs as seen in the following exemplars. In his Preface, Brain Fies explains the reason for the creation of *Mom’s Cancer*:

To begin his book, Fies states at the start of the preface “You are not alone.” These four words are centered and separately spaced above the written preface. This simple statement sets the tone for the rest of the book and provides personal connection to the reader. The statement also allows for a level of vulnerability to be expressed by Fies to the reader. Fies also articulates in the preface a desired outcome of his book to be a tool for the reader. He writes:

> You are not alone.
>
> I created *Mom’s Cancer* because I wish someone had created it for me. I began serializing *Mom’s Cancer* on the Internet in early 2004 as a kind of underground journalism: dispatches from the front lines of a battle into which my family stumbled unprepared. I worked anonymously to protect my privacy and my family, who never asked to become cartoon characters, and also to suggest that the story could be about anybody anywhere. Readership grew by word of mouth. People who needed it found it.
>
> Although *Mom’s Cancer* is very specifically about my family and our experience fighting my mother’s metastatic lung cancer, I was astonished by how many readers saw their own stories in ours. I was also gratified to get letters from medical professionals and educators saying that *Mom’s Cancer* helped them understand their patients’ perspectives and asking permission to use it in their

> curricula. That was an unexpected privilege, as is the opportunity to reach even more readers through print.
>
> When I started writing and drawing *Mom's Cancer*, I didn't know how the story would end. I resolved to be a good reporter and tell it as squarely as I could. *Mom's Cancer* is not a nuts-and-bolts medical manual. Tests and treatments vary; the emotional and practical impacts of a serious illness are nearly universal. Members of my family remember some of these events very differently, and my portrayals of them aren't always flattering. The fact that my mother, father, and sisters still graciously and even enthusiastically support *Mom's Cancer* means everything to me – another unexpected privilege.
>
> *Mom's Cancer* is an honest, earnest effort to turn something bad into something good. Although I distrust stories with lessons, here is one: No one will care more about your life than you do, and no one is better qualified to chart its course than you are. You are the expert. (Preface 2006)

These narrative choices described by Fies in the Preface of his book outline the desired outcome that Fies has for his book. The desire for wanting to help others is an example of wanting to be more as a person. Fies desires for his work to be utilized and shared with others and hopes that others can learn from his personal trials. Fies is shifting away from the anxiety that surrounds the topic of cancer to viewing his experience as learning moment. This exemplifies the Foucauldian principle of acceding to one's moral obligation.

The Foucauldian principle of moral obligation is also present in the two-page vignette "*We Learn By Doing*." Fies uses a split panel design to recall a conversation with his father.

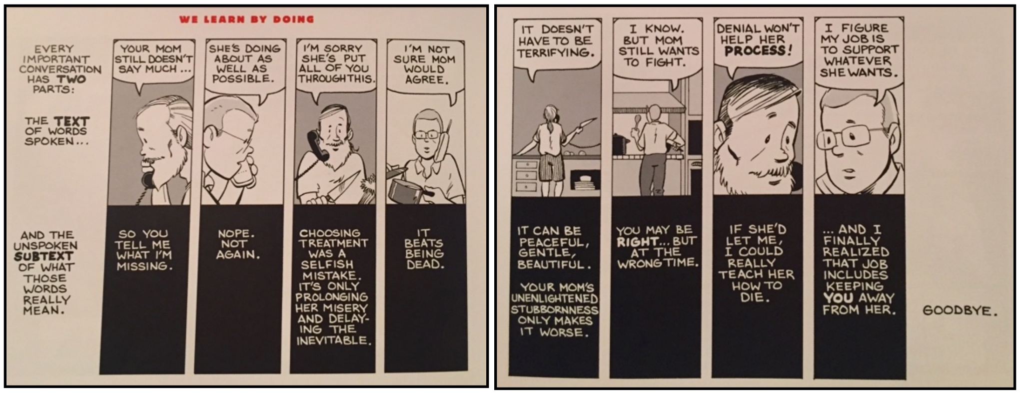

Figure 68. Brian Fies, sequential pages from *Mom's Cancer*, 2006, pgs. 86-87.

As seen in the two-page spread above, Fies states, "Every important conversation has **two** parts: The **text** of words spoken…and the unspoken **subtext** of what those words really mean" (86). The panels are then split between the text (above) and subtext (below). Fies chooses to bold the words "two," "text," and "subtext" for emphasis. This sequence provides insight into the level of care and protection that some caregivers feel toward those they are caring for. In the case of Fies, the desire to protect his mother is evident in the subtext script. Fies shares with the reader his internal realization of wanting to protect his mother from further hurt. Shifting the focus to his internal thought process exemplifies the shift for a desired outcome: expressing his internal realization with the reader.

Foucault's notion highlighting the recognition of the individual's moral obligation is one way to analyze Fies's decision to keep his father away from his mother. Fies feels a sense of moral obligation to his mother to keep her away from harm and undo stress during her illness. Also present in this sequence are elements of Foucault's Pastoral Power. Fies expresses a level of knowing the needs of his mother as well as a level of keeping watch over his mother – two roles that mark Pastoral Power. As Foucault identifies within his writings on Pastoral Power, the element of power operates in a distinctive form as the shepherd, in this case Fies, exerts power over his sheep (his mother) for the primary purpose to guide her and keep her from harm. In this panel, Fies is directing who will, or in this case will not, have contact with his mother to ensure her protection and safety. While exemplars of Pastoral Power and moral obligations are present throughout Fies book, this sequence connects these Foucauldian ideas to provide evidence of the desired outcome presented by Fies. In this sequence, Fies's desired outcome can be identified as the realization of and the need to express the difficulties surrounding the choice to not communicate with family members during tremulous times.

In the final pages of *Mom's Cancer*, Fies expresses his aspiration to share his journey with others. As seen in the page below, he narrates: "Early in the course of Mom's Cancer, I began making notes and sketches to record my family's experience. I knew we weren't alone" (103). Fies articulates the drive to record his experiences as he knew they were not the only family facing cancer and everything that goes along with it. Here again we see Fies communicate his sense of moral obligation to self and to others.

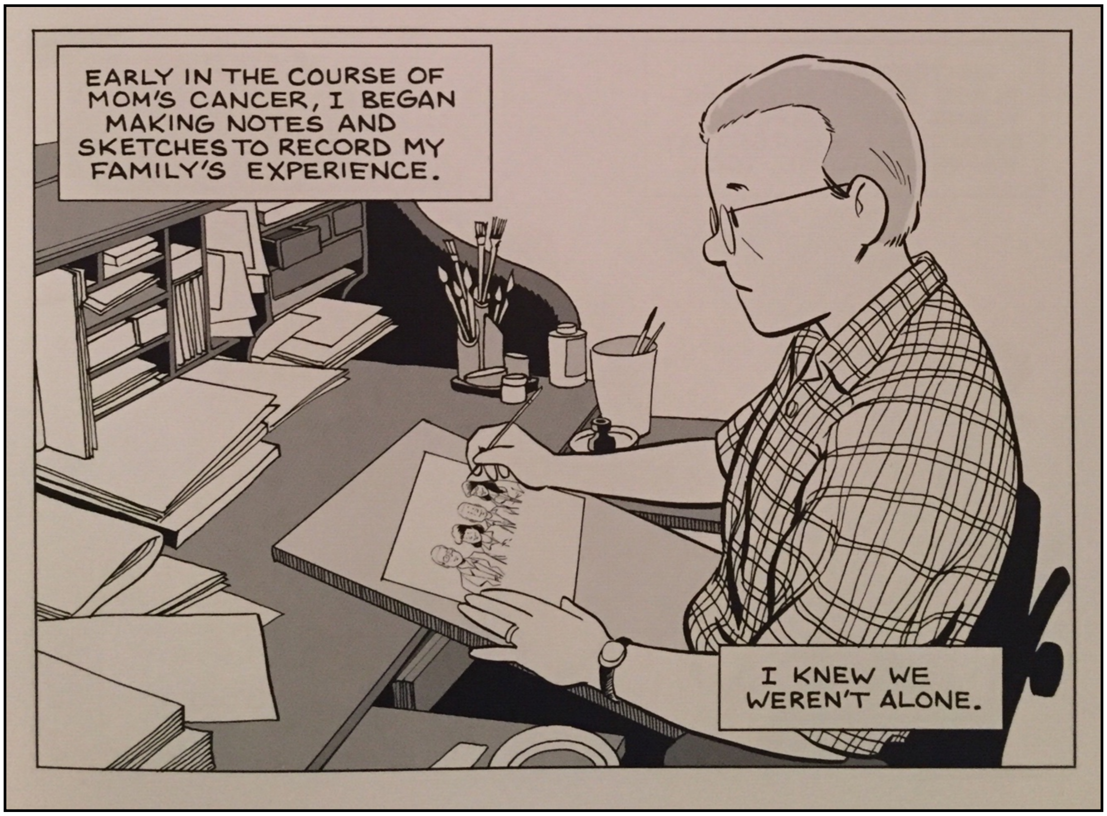

Figure 69. Brian Fies, page from *Mom's Cancer*, 2006, p. 103.

Fies's direct communication and openness regarding his decision to begin making notes and sketches (as seen in above page) can be understood through the Foucauldian idea of self writing.[124] Self writing develops from the Greco-Roman culture of aesthetics, focusing on "the government of oneself and of others" (*Ethics* 208). Self writing developed from the idea of ethopoetic writing which had two functions: *hupomnëmata*

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[124] The notion of self writing comes out of Foucault's work on Ethics and can be found in the text, *Ethics: Subjectivity and Truth*, edited by Paul Rabinow. Foucault provides the historiography of self writing by documenting the technique found in Christian literature linking to the writings of Seneca, Plutarch, and Marcus Aurelius (*Ethics* 208).

and *correspondence.*[125] The act of self writing allows for the writer to transcribe what he/she has written into a form of truth. Foucault cites Seneca identifying that the process of personal writing allows for an absorption of the moment at a deeper level. He believes that the writer must digest the knowledge s/he is writing about so the memory can be accessed through reasoning power, rather than just a mere memory of the moment (*Ethics* 213). Foucault continues to explain, "Yet, conversely, the writer constitutes his own identity through this recollection of things said" (*Ethics* 213). In this instance (as seen in the exemplar above), Fies is performing the act of self writing by two means. First his notes and sketches were serving as memory aids. These notes and sketches provided him the memory aids to write his full book at a later time. Second, Fies is forming his own identity through documenting his journey and his family's journey with his mother through her cancer treatment. Through the act of self writing, Fies is creating an account of himself and his actions. From a Foucauldian sense, when one develops an "epistolary account of oneself, it is a matter of bringing into congruence the gaze of the other and that gaze which one aims at oneself when one measures one's everyday actions according to the rules of the technique of living" (*Ethics* 221). In this page (Figure 69), we see Fies developing a written account of his time as a caregiver to satisfy his desire to ensure his actions are aiding others in times of health trials; in this specific case the health trial of Cancer.

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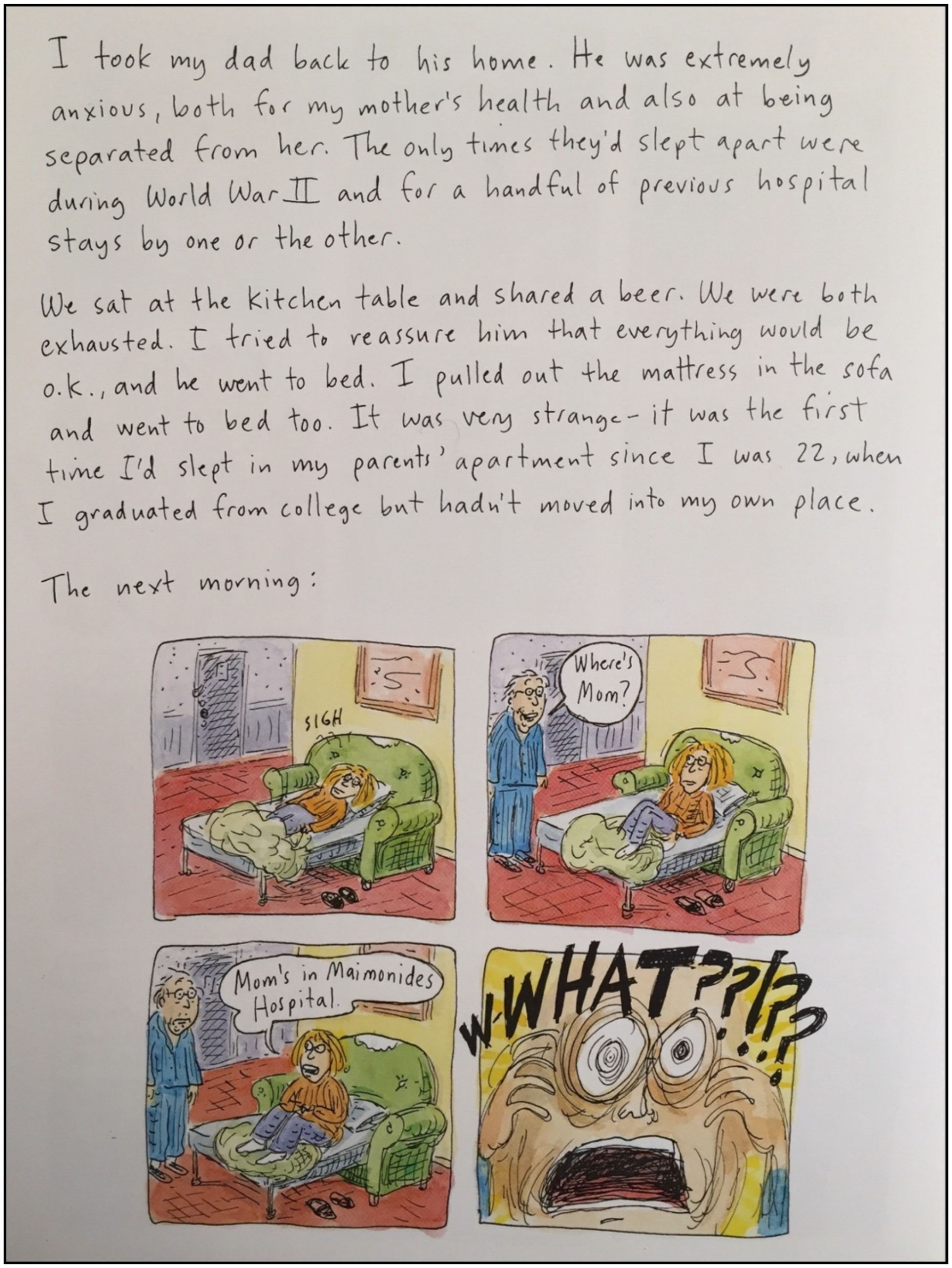
[125] Hupomnemata could be written in the form of individual notebooks, public registers, etc. (*Ethics* 209). For the purpose of my work, I will focus on the hupomnemata writing form of personal notebooks.

Like Fies's accounts, we can also see Ethics at play in Chast's writing. Chast's narrative accounts bring in a level of humanization different from Fies's accounts. Where Fies's writing has an overarching desire for his work to be received by others so they have a guide and can feel connected to others who have experienced a similar situation, Chast depicts "in the moment" realizations and choices that impact the reader's perception of the moment she is experiencing. As discussed earlier in the chapter, Chast recalls her anxiety when hearing about her mother's fall in the chapter "The Fall." In the next chapter "Maimonides," Chast's story continues documenting her trip to the E.R. and the decision to stay with her father until her mother returns from the hospital. In the page below, Chast depicts her choice to say on the sleeper sofa to provide reassurance to her father.



I took my dad back to his home. He was extremely anxious, both for my mother's health and also at being separated from her. The only times they'd slept apart were during World War II and for a handful of previous hospital stays by one or the other.

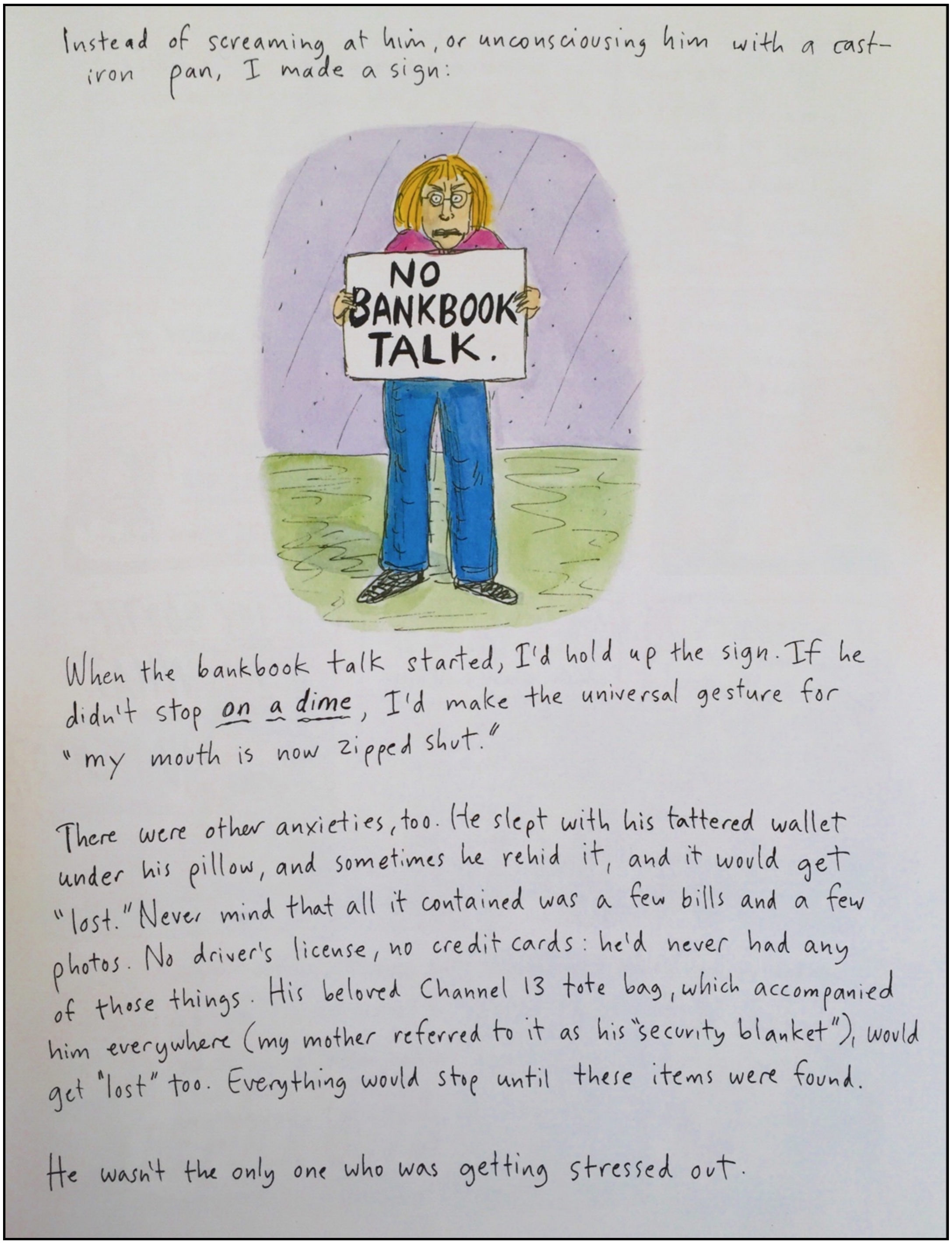
We sat at the kitchen table and shared a beer. We were both exhausted. I tried to reassure him that everything would be o.k., and he went to bed. I pulled out the mattress in the sofa and went to bed too. It was very strange - it was the first time I'd slept in my parents' apartment since I was 22, when I graduated from college but hadn't moved into my own place.

The next morning:

Figure 70. Roz Chast, page from *Can't We Talk About Something More Pleasant*, 2014, p. 64.

She identifies this experience as strange as ". . . it was the first time I'd slept in my parents' apartment since I was 22, when I graduated from college but hadn't moved into my own place" (64). In the above page, the element of self-sacrifice is present in Chast's decision to stay with her father. A decision based off the need to provide reassurance and reduce her father's anxiety of being alone. Using Foucault's work on Ethics to assist in analyzing this decision made by Chast, we can identify the recognition of her moral obligation to her family. While this moment could have been depicted as a feeling of anxiety (as she expresses in other areas of her narrative account), Chast makes a conscious choice – she creates the desired outcome of moral obligation to family - to sacrifice self on behalf of her father's comfort and sanity showing both empathy and the practice of Ethical living from a Foucauldian perspective.

Another example of the creation of a desired outcome is the focus shift in Chast's narrative with the development of rules with her father. As she admits in her page in the chapter titled "Sundowning" rather than scream at him or knocking him out, she made a sign with a rule: "No bankbook talk" (73).



Instead of screaming at him, or unconsciousing him with a cast-iron pan, I made a sign:

When the bankbook talk started, I'd hold up the sign. If he didn't stop on a dime, I'd make the universal gesture for "my mouth is now zipped shut."

There were other anxieties, too. He slept with his tattered wallet under his pillow, and sometimes he rehid it, and it would get "lost." Never mind that all it contained was a few bills and a few photos. No driver's license, no credit cards: he'd never had any of those things. His beloved Channel 13 tote bag, which accompanied him everywhere (my mother referred to it as his "security blanket"), would get "lost" too. Everything would stop until these items were found.

He wasn't the only one who was getting stressed out.

Figure 71. Roz Chast, page from *Can't We Talk About Something More Pleasant*, 2014, p. 73.

Chast portrays her creation of rules to assist herself in handling her father's obsessiveness of his bank books, as well as other anxieties experienced by her father. Her rule creation is an exemplar of Foucault's sense of ethics in two ways. First, Chast recognizes her moral obligations to her father and mother thus creating a system where she will not act out under stress or pressure. She expresses that her father was not the only person becoming stressed, so she initiated a system to assist her in handling the various incidents that may be stress producing (in this specific example the bank book talk). Second, Chast uses signage and universal gestures for not saying anything (making the universal gesture for zipping her mouth shut) that suggests evidence of her choice to actively work on herself and transform herself. Foucault identifies a person's drive to work on the self and transform the self as an aspect of ethics. In this narrative account, Chast provides the reader with an account of how she shifted the possibility of a negative reaction to her father's obsessiveness to an achievable outcome without negative consequence. While the sign creates non-communication about the issue(s) concerning her father, Chast decided non-communication was a better outcome than possible verbal altercations.

In the chapter "End of An Era," Chast narrates the events leading up to the decision to move her parents into an assisted living community. At the beginning of this chapter, Chast sets the mood in expressing both relief and joy as this was the evening before her mother was to be released from a two week stay at the hospital. She explains the paperwork involved in her mother's release, how she had to set up transportation from the hospital back home (by way of ambulette), the anxiety of filling out medical paperwork, and her father's expression when he found out her mother, Elizabeth, was coming home. In the page below, Chast tells of her father's reaction to his wife coming home while also expressing her internal thought process of how she came to make the decision to not stay with her parent's the night her mother came home.

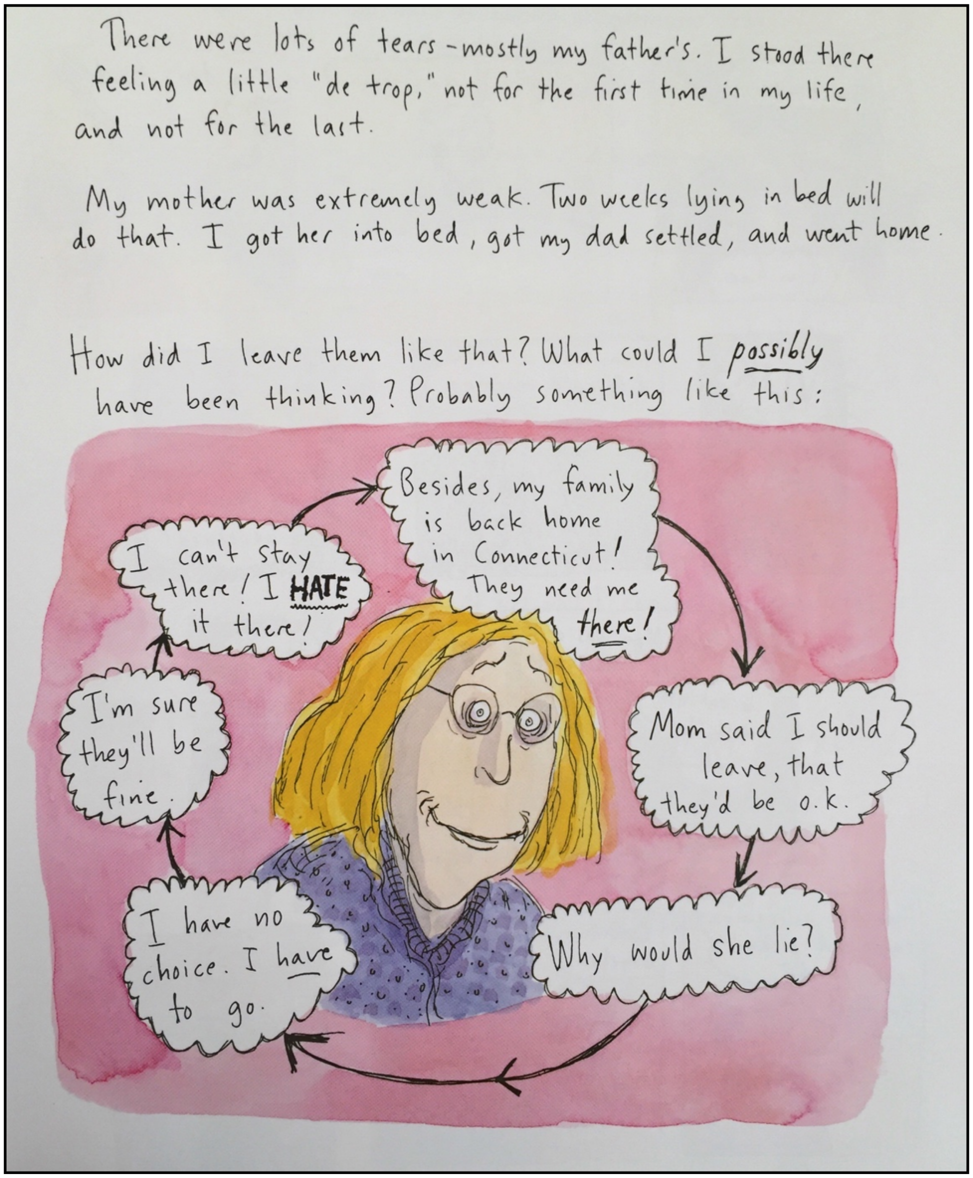


Figure 72. Roz Chast, page from *Can't We Talk About Something More Pleasant*, 2014, p. 89.

As explained by Chast in the above page, once she arrived back at her parent's apartment with her mother whom she described as " . . . extremely weak" as "Two weeks lying in bed will do that" (89), Chast poses the following questions to the reader regarding her decision to leave: "How could I leave them like that? What could I possibly have been thinking? Probably something like this:" (89). What follows is Chast's rendering of her internal thought process of rationalization regarding her decision to leave her parents alone. One way to explain Chast's rationalization is through Foucault's writing on ethics.

Foucault believes that an essential component of ethics is freedom of choice (*Ethics* 284-285). While in this specific instance of Chast's caregiving experience, one could argue that she was practicing unethical behavior as it can be identified that she is not focusing on her moral conduct, she is discounting her moral obligations to her family, and that she is moving away from whom she might want to be in the caregiving context. After further analysis, we can see evidence of her wanting to transform and work on herself. This comes in the form of being with her family, rationalizing that her mom and dad will be fine, and that she has no choice but to go home. Chast is rationalizing the decision to care for herself and her family. The desire to transform and work on the self is an essential component of Foucault's approach to ethics. Foucault argues: "Taking care of oneself requires knowing … oneself" (*Ethics* 285). In this narrative account, Chast was taking care of herself by rationalizing leaving her parent's so she could go home.

Approaching their writing in similar fashion, Fies and Chast provide a cohesive narrative of their experience in caring for their parent(s). Walrath's narrative method was different. Walrath uses short stories (vignettes) about her mother to explain the variances of Alzheimer's disease. In very few instances, she injects intrapersonal moments into her writing. As noted, Walrath's approach to storytelling is different from Fies and Chast in five ways. First, she presents her stories by topic or theme, not chronologically. Second, her stories are short vignettes. Third, in her introduction to her book she explains that her book is a vehicle to "rewrite the dominant biological story of dementia and how we approach aging globally" (5). She continues by explaining the power of bringing the written and visual form together to capture "the complexity of life and death, of sickness and health. Going back and forth between the subconscious and conscious, between the visual and the verbal, lets us top into our collective memory, an essential element of storytelling" (4). Fourth, Walrath argues:

> The most amazing property of stories is their power to heal. Facing death, people crave ways to find forgiveness and to heal, just as my mother and I have done over the course of Alzheimer's. Healing is not the same as curing a disease. Healing involves creating shared social meaning. It does not take place inside of individual bodies. It doesn't involve surgery or taking a pill. This social process depends on sharing stories with others, on letting our collective memories meet. By meeting through story, we make peace and move on even if we are sick, hurt or dying. (6)

Finally, Walrath encourages the reader to:

> Read the book in several ways: Page through to feel the storyline as it exists in the drawings on their own; read it from cover to cover, feeling the long narrative carried in the next that was inspired by the images and written over several years;

> and finally, when your attention is short, as it is for anyone with memory challenges or you are simply pressed for time, leaf through the book to any page and take in a single vignette along with the image that set that story into motion. (6)

Walrath's introduction frames what her book sets out to accomplish while also suggesting ways to approach the reading – marking her book different from the work of Chast and Fies. While Walrath does write herself into her short stories to support the narrative she is telling of her mother, the expression and identification of her internal embodiment of caregiving is minimal in comparison to the writing and narrative style of Fies and Chast.

Walrath's narrative choices can best be explained by the Foucauldian perspective of self writing. As explained earlier in this chapter, the performance of self writing provides the writer a space to record what was written into a form of truth. In her introduction, we see Walrath create her truth by reflecting on how she came to write her stories, how her perspective connects to societal understandings of illness, specifically dementia, and her own identity as a storyteller. Foucault emphasizes that through self writing, " . . . the writer constitutes his[/her] own identity through this recollection of things said" (*Ethics* 213).

Conclusion

In the various narrative accounts authored by Fies, Chast, and Walrath similarities can be identified between their caregiving accounts and my own. Although my experiences blend the situational aspects of accounts by all three authors, each author (myself included) expresses isolation, anxiety, and a desire to create a desired outcome in various moments in our personal caregiving experiences. At the very core of analyzing these narrative accounts was my desire to understand how power is operating within and through the caregiver experiences and the caregiver relationship with whom they are caring for.[126] Using Foucault's work provides one framework to analyze how caregiving is internally embodied. Foucault's ideas provide an avenue to aid in examining how the caregiver may overcome feelings of isolation and anxiety. By practicing Ethics of Self and the desire to be transformed, caregivers work on who they might want to be in the caregiving context.

Chapter Four extended the notion of orientations connected to the experiences of caregiving by turning to the 'self.' The chapter explored themes of isolation and anxiety focusing on examples of isolation and anxiety as narrated by all three comic authors. Each example was supported with a Foucauldian analysis to further explore how isolation and anxiety can part of the caregiving experience with the 'self' orientation. The chapter

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[126] I completed my analysis using McKerrow's Principles of Praxis as outlined in his article "Critical Rhetoric: Theory and Praxis." While I did not use his principles as a step by step guide, his principles did move through my thoughts as I was developing the design of this portion of my analysis and during the completion my analysis. McKerrow's principles live within the analysis as they are present within me. As a critical scholar, I am unable to separate my theory from my practice. I am forever and always looking at myself, my experiences, the experiences of others (using Fies and Chast for this specific analysis), and my everyday interactions through this lens. I am not certain if this is a determent to my work or if this is a blessing as I am able to analyze and view the world without having to "put on a metaphorical critical hat," as the hat is always on.

concluded with how the caregiving experience extends the idea of ‘self’ orientation with focus shifts in various internally driven desired outcomes during the caregiving experience.

Chapters Two, Three, and Four explored personal narratives of the caregiving experience. Chapter Two emphasized my own lived experiences as caregiver from an ‘other’ and ‘self’ orientation, while Chapters Three and Four analyzed three comic memoirs focusing on experiences caregiving through the same ‘other’ and ‘self’ orientation. Chapter Five extends these arguments seeking to critically reflect and analyze the potential implications my analysis of my own experiences and the experiences of the comic memoir authors may have for how we understand caregiving in connection to its role in coping with another’s health issues.

CHAPTER FIVE: DOMINATING BODIES, RESTRICTING FREEDOM

"For meaning is not "attached" to the detail by the memoirist; meaning is revealed."

Patricia Hampl *I Could Tell You Stories* (31)

I sit, a blank word document on my computer screen stares back at me. I'm surrounded by my handwritten notes strewn on copy paper, notebook pages, journal pages, and sticky notes. Some of the pages are outlines, some are big picture "ah, ha" moments, some are poems reflecting my emotion during my research and writing process. Reoccurring words span the multitude of pages – *the system, death, life, power* – often there is more reflection or thought after the words and at times there is not. What would be viewed as jumbled, disorganized, rambling to many is viewed as normal to me. These are my thoughts, written out. My thoughts come in various forms at various times. I often write in poetic, reflective, or analytic form depending on how the content is understood by me at that time.

The decision to start this chapter with the short reflective piece above was to provide an understanding regarding the depth of my internalization of my own work and research.[127] For the past four years, I have worked on my dissertation and have been my

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[127] This chapter contains my views unless otherwise noted. My views are based on my current and past experiences and knowledge of our medical system. I am speaking of the system as a whole, not specific people within as I understand they operate inside the system for the greater good of the people they are serving. I am, and will always be, grateful for the team of physicians, nurses, medical staff, and social work staff that assisted me and my family during this time.

dad's legal guardian – truly embracing the ideas that I write about. Initially, I set out to argue that mainstream publishing houses select tragic health narratives (normalized discourse in our society) told in the graphic form (viewed as non-normative discourse) as a means to further condition readers, also known as society members, into docile bodies (*Discipline*). In order to support my argument, I was going to analyze four comic memoirs by female authors that addressed various prominent health issues. As I started the analysis process, I realized that while the topics were interesting and I was connected to each topic, I was not engaged. I went back to the various comic memoirs I owned and found myself re-reading the works of Chast, Fies, and Walrath. I came to a crossroads; should I keep with the plan or make a move to analyze the memoirs focusing on the experiences surrounding caring for an ill and/or aging parent(s)? I decided to shift narrowing the focus to experiences surrounding caring for an ill and/or aging parent(s). After completing my critique, I went back to my guiding argument developed for my dissertation. In analyzing my own argument, I came to the conclusion that as written, the argument could not have been supported. I came to this conclusion for the following two reasons: First, I cannot know the reasoning behind why publishing houses select the books they do; Second, if I were to make a claim regarding this, it would be done under assumption only weakening my argument or possibly misleading using false claims. After I internally processed this realization I reflected on my own experiences, the experiences of Chast, Fies, and Walrath, the claims I made in Chapters Two, Three, and Four, and what I came to learn by completing the analysis. I ended up here – surrounded by handwritten notes, free writing, journal entries, single words and a re-developed central argument: Each author is predispositioned to conform to and operate within the power structures embedded in our sociocultural understandings of health.

The goal of this chapter is to work through the central argument that emerged during my analysis. In order to support and advance this argument I will complete the following: First, I will support how the central argument is advanced by identifying two major discoveries; these discoveries will be supported with evidence from the works of Chast, Fies, and Walrath, or my own writing. This may be done with additional personal narrative, using additional exemplars from the texts, or referencing back to already previously analyzed exemplars or personal narratives explaining the critical implications of the major claims; Second, I will explore the major contribution of the analysis revisiting the central argument in relation to what difference these stories (and others like it) might make in helping us understand the role and significance of the stories told and used for this analysis; Lastly, I will speak to the implications of this work and what future research can extend from this work. When necessary, I will incorporate theory, personal narrative(s), and examples from the texts to help support my argument.

Advancing the Central Argument – Emergence of Two Major Discoveries[128]

My own stories and the works of Chast, Fies, and Walrath all speak openly of or allude to the notion of power in its various forms in diverse moments of the caregiving experience; power being both productive and repressive. Contemplating my work of blending/comparing/contrasting (in other words analyzing) my narrative and the works of Chast, Fies, and Walrath – two major discoveries (takeaways) emerged. First, the system is rigged—it presumes free choice while constraining its operation. Second, a prescribed role is attached to experiences surrounding being a caregiver. In the pages that follow, I will attempt to connect how these two discoveries support and advance the central argument stated above.

First Major Discovery – The Health System is Rigged

Writing about my dad's medical diagnosis with liver and later kidney disease and my own personal experiences of being a caregiver (Chapter Two) was eye opening in that I realized just how limited I was in my decisions. I was cognizant of the amount of power that I was granted and the amount of power that was taken away from my dad.[129] I also realized how deeply ingrained we are in the system. Reviewing the works of Chast, Fies,

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[128] The choice to use the term "discovery" to identify advancements to my central argument was purposeful. I see the word "discovery" operating from how I understand my role as a critic and as a knowledge producer. This word is best reflective of my role of critic in the analysis process, thus taking ownership of how I came to understand, process, analyze, and work through theory in relation to real life. The term may be elementary to some, not accurate to others, but for me, this term best reflects my contemplation and ownership of the two emerging factors advancing my central argument.

[129] I was also aware of the limits of my power as guardian, and the power the courts now hold over me.

and Walrath assisted in helping me recognize and realize the issues of power that I was experiencing were also experienced by Chast, Fies, and Walrath at some level or another. Identifying moments of the recognition of power, not only in my own work but in the works of Chast, Fies, and Walrath solidify what I argue is the larger issue at play – individual and social power complexities regarding various aspects of health.[130]

The notion of power operating both within and through the caregiver was something I expected, yet I did not think it would be so big – so far reaching. I speak of this idea of power throughout my analysis citing various works of Michel Foucault to support my arguments. What I failed to flush out in my three analysis chapters, specifically Chapter Two, was the idea of what I term small power, medium power, and large power. Simplistic in linguistic choice, the terms represent how power is operating in and through the role of caregiver. I define small power as power that is harnessed and exerted by the individual – in this case the caregiver. Medium power is the mid-level power in which the caregiver must navigate the care of the ill parent, specifically within

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[130] The question I ask myself time and time again is: How do I begin my argument journey regarding the individual and social power complexities surrounding our health; specifically, the power complexities that come into play when caring for an aging or ill parent(s) and not feel pessimism, anger, sadness, disbelief, and gratefulness at/towards the system? The answer? I can't. I had to make a choice. Do I risk writing my true thoughts or do I play it safe and write a version of my true thoughts – safeguarding myself? Knowing myself and my critically-minded ontology, I approached this chapter embracing myself – all of me. All of me including my pessimism, my anger, my sadness, my disbelief, and my gratefulness at/towards the system. I know myself well enough to know that if I did not include my true voice, my work would not be actualized.

and around medical decisions and situations that directly relate to the ill parent. Large power is representational of governmental control, specifically dealing with financial and placement decisions that rely on financial assistance/funding from the government. While Foucault speaks to similar ideas breaking out the personal, local, and national – all encompassed by his term "governmentality," I chose to use the terms small, medium, and large power as I believe they encapsulate the level of emotion and size that I connect to these levels of power within the caregiving role. Interestingly, these levels are designed to make the caregiver feel and seem as though they have power, although that is not always the case.

Small Power

Starting with small power, I have come to discover that it is at this level of power that the caregiver has the most control (I use this term very carefully). When I say the most control, I mean the following: this is the level where my decision making regarding my dad has the most impact. My power – both repressive and productive – is designed to operate for and with my dad's best interest at heart. I use personal examples of this power in my own narratives and we see this level of decision making present in the works of Chast, Fies, and Walrath. I connected Foucault's idea of Pastoral Power to this level of power in the analysis explaining the main duty of the pastor is to watch over his (her for my purposes) sheep. For example, in Chapter Two – *February 25, 2017* - I wrote about the time I took my dad to the hair salon with me. The decision to take him to my hair appointment with me was to ensure his basic needs were being met, as at the time he desperately needed a haircut (see Figure 12). Another example was described in detail in the story, *Witnessing Decline*. This extended story chronicled my experiences in finding out the true living situation of my dad and the steps I had to take regarding making sure he was properly cared for and was safe. My decisions were (and are) all made from the view of making sure my dad is taken care of and is safe. Similar decisions are seen in the stories told by Chast, Fies, and Walrath.

Each author, in their own way, references various aspects of small power throughout their narrative. Some examples may highlight the decision making they are responsible for, while other examples may emphasize a personal choice that focused on themselves that led to ensuring care for their parent(s) were met. In each work, evidence for both productive and repressive forms of small power can be identified. In *Can't We Talk About Something More Pleasant*, Chast explains her personal choice to make weekly phone calls to her parents to keep an active watch on them (see Figure 24) instead of weekly personal visits (although visits did come later). Another example of Chast's productive use of small power is when she describes helping her parents by going grocery shopping for them during a two week period (see Figure 46). In this specific example, Chast recalls how she not only shopped for and brought the groceries to them, but she stayed with them. While providing food and care to her parents is a productive means of small power, her use of power as productive also became repressive. In the same page as referenced above (see Figure 46), she used the time after delivering groceries to sit with them. In this specific page, Chast identifies her observation (surveillance) of her parents health and wellbeing over the two-week period stating "Things were getting worse" (Chast 56). Chast used aspects of surveillance throughout her narrative. While she may have not been aware of what she was doing, from a theoretical stance, her actions speak to the idea of surveillance (surveillance as framed through Foucauldian theory and as described and referenced throughout this entire work). Two specific examples from Chast's memoir, previously discussed in Chapter Three, were her use of a notebook and her observation of the level of "grime" on her parents' furniture and belongings. While these two examples took place at different times in her memoir, both depict the repressive nature of small power. The first example is when Chast explains her reasoning for keeping a notebook (see Figure 33) stating "I started keeping a notebook, just so all the facts and figures I needed would be in one place:" (Chast 85). She continues by describing what information was kept on her parents in this notebook including, but not limited to, social security numbers, phone numbers, insurance agency information, financial information, and medications (85). The second example of repressive small power is in Chast's page identifying the level of grime in her parents' home (see Figure 43). Chast emphasizes this finding by not only suggesting the level of grime found was beyond anything she had ever seen before but by also providing the definition of grime. She then highlights how her discovery created cognitive dissonance in her mind as she recalls, "One thing my mother always told me when I was grown up was: You have to DUST! If you don't, the dust gets into all the interstices of the furniture and BREAKS IT ALL APART!!!" continuing her observation of "It was clear that she had stopped worrying about that" (Chast 15). The grime example stands out to me as an example of repressive small power in that, while it may seem petty, it provides a larger picture in how observation can be a natural forerunner to surveillance, especially in the case of caring for aging and/or ill parents. For Chast, the fact that there was dust - to the level of grime - was a red flag that her parents were declining and were becoming unable to manage daily tasks for a healthy and safe living environment.

Fies's memoir shares a different view of small power than Chast's. While small power can be viewed as both productive and repressive it manifests differently than the examples from Chast's work. In *Mom's Cancer*, surveillance (often viewed as repressive) is seen as productive. I argue the idea that in Fies's work surveillance is productive as the act of surveillance helps monitor his mother's treatment and possible issues that arise from her type of chemotherapy. Because of Fies's dedication and surveillance of his mother during her treatment and her time between treatments (spent at home) he and his sisters were able to be productive in identifying any issues or possible complications and addressing them with the doctors right away. For example, in the previously analyzed page in Chapter Two, Fies explains the harshness that weekly chemotherapy sessions had on his mother's body (see Figure 42). In this specific page, he identifies that his mother was getting worse instead of better and her symptoms prompted him to call her oncologist. If Fies was not actively using surveillance, he might not have caught her declining health in time. Another example of productive small power is in Fies's pages identifying the use of family meetings and in his dedication to researching his mother's diagnosis (see Figures 20 and 21). Both illustrations emphasize Fies's positive impact on his mother's care and wellbeing. Family meetings aided him (with the help of his sisters) to provide the best care for his mother while his dedication to research also assisted him in his plight to learn as much as possible about his mother's (at that time) newfound diagnosis.

Much like Fies's desire to learn as much as possible about his mother's diagnosis, Walrath speaks to the importance of productive small power in caring for her mother. In *Aliceheimer's: Alzheimer's Through the Looking Glass*, Walrath emphasizes her desire to be prepared for any given situation (see Figure 27). Her specific exemplar highlights the productive aspects of small power in that she offered a reward to her mother: "I promised her ice cream if she could stay quiet" (Walrath 21). Walrath understood the importance of providing her mother a treat (caring for her wellbeing) as a means to calm her after the outburst that took place in a public poetry reading while they were sitting in the middle of the row. She later explained that, "After that day, I followed the rule of aisle seats and exited at the first sign of trouble" (21). Here we see Walrath using her previous experience to prepare her for future possible situations that may cause her mother distress; the essence of Foucault's idea of a pastor watching over their sheep. Walrath also explains the productive elements of small power in her vignette Sundowning (see Figure 29) where she confesses to hovering over her mother during the specific time of day – that of sunsets. While hovering may be viewed as a repressive action, during sunsets hovering is used as productive as it allows Walrath to intercede when she begins to notice any sign of confusion associated with sundowning. Once she observes any level of confusion she acts by "pulling Alice into the kitchen to do something familiar as the light, and reality, shifted" (Walrath 35). This simple action helped Alice avoid the confusion, termed "Black magic" by Walrath, to ensure her mother's safety and comfort.

While my choices, and the choices of Chast, Fies, and Walrath may be productive in regards to ensure the health and wellbeing of our parents, our choices can also be viewed as repressive, as noted above. They limit the level of decision making, among other things. Surveillance was evident in my personal narrative found in Chapter Two as well as in the works of Chast, Fies, and Warlath. In reality, I never did NOT engage in some level of surveillance when with my dad and this idea is also prevalent in the works of Chast, Fies, and Walrath. I believe that surveillance is an active component of caring for an aging and/or ill parent(s). As argued, surveillance can act as repressive or productive when acting in the form of small power. Surveillance, used as productive or repressive, aided me in the decision making process when needed and/or necessary to ensure I had my dad's best interest at heart. The examples provided above from Chast, Fies, and Walrath provide further support to the notion that small power exists and is used by the caregiver to ensure the safety and care of the parent(s).

What raises concern is how quickly I, as well as the other authors, engaged in surveillance. To me, this is worth further exploration. While small power is seen as able to be harnessed and as a means to be productive when caring for an ill and/or aging parent(s), it can also be viewed as repressive as well. The repressive component is due to the fact that in reality, it – power and surveillance - is managed from a larger system (whether wanting to admit it or not). I convinced myself that my constant surveillance of my dad was for my dad's own good, but throughout this journey, I often questioned who's advantage did it really serve? While it is important to manage and keep watch over my dad's wellbeing including his adherence to taking his medicine regularly, monitoring his actions (Were they in line with doctor's recommendations?), and making sure he was adhering to the care plan, was this for his benefit or the benefit of a larger system? If my dad did get off in any aspect of his regimen of medicine, it would cause pure chaos to his body. When the body chemistry was off, dad found himself back in the emergency room (often followed by a lengthy hospital stay). This sequence of events (it has happened more than a few times) impacts my dad, me (as daughter and caregiver), the team of doctors, medical staff, and hospital staff. While surveillance has proven to be a successful means in keeping my dad level (from a medical perspective), it seems that the surveillance has a larger purpose, a larger goal: to help the larger system. Even at the small level – the individual level of power – me managing and acting as a means of surveillance for my dad and his health and well-being has a larger designed outcome – not just to keep dad well and balanced; but to keep him out of the medical system if possible. Viewing power from this lens provides further evidence to support the idea that power is both productive and repressive. In the examples above, power is productive in that my surveillance helped my dad (for the most part) stay healthy until necessary to seek additional medical treatment, yet this power was also repressive in that it limited my dad in his daily actions, decisions, and overall life. He is forever bound to and repressed by the medical treatments that afford him extension of his life. As I have just explained how small power functions within the experiences surrounding caring for an ill/aging parent, I will now explain how medium power operates in this same context.

Medium Power

Medium power is an interesting structure. I say it is interesting in that many of the mid-level decisions the caregiver must navigate directly relate to medical decisions and situations involving care, care choices/planning, and future placement. I stress the medical connection and reasoning to these decisions, as medium power is related to and involved with the medical aspect of care, whether it be medical decisions or living placement decisions due to medical needs. For structural purposes, I will speak of medium power in connection to decisions and navigation within the medical system.

Many of the decisions made by the caregiver, if they hold power of attorney or guardianship over the ill and/or aging parent(s), relate to the following: care of the ill and/or aging parent(s) including decisions involving and surrounding medical treatment and treatment plans. In the case of my dad, I had and still have the final say regarding treatment and end of life wishes. I say my power is productive in that I am able to uphold my father's wishes regarding his end of life plan – that being a Do Not Resuscitate – and other components of end of life care that I address throughout my narrative in Chapter Two. As explained earlier in this chapter, medium power navigates the inquiry and decisions that directly relate to medical decisions and situations (medically driven) involving care, care choices, care planning, and future placement. I call it the medical push. This medical push is evident through my narrative as well as the works of Chast, Fies, and Walrath.

The use of medium power by the caregiver is evident when sharing experiences surrounding caring for an ill and/or aging parent. Throughout my own journey, I can confidently say I am always navigating decisions regarding my dad's medical care with his team of doctors. This level of power is in constant connection with the medical aspects of caring for an ill and/or aging parent. I believe this is the case due to how we have come to know and understand illness from a social and cultural context. There is a vastly socially accepted norm that if you are ill you go seek medical treatment(s): The essence of the biomedical model as discussed by Deborah Lupton in her book *Medicine as Culture* (as also highlighted in Chapter One of this work). In the case of my own experiences caring for my dad, I am in constant contact with my dad's doctors to ensure I am providing him the best care and that I am not overlooking a possible concern or complication with his diseases. I also seek their council regarding his long term care plan, the options of care choices, as well as future placement. Rather than look inward and go with my own feelings and ideas for what is best for him, I – for the most part – listen to his doctors. I will state that my dad's health is very complicated and if it was more simplistic my reliance on medical suggestions may be different but the truth to the matter is that it is not. I have acted on what the doctor(s) suggest.

As a caregiver, you are to navigate those medical decisions that might otherwise not be able to be handled by your parent(s) for them. This is a common theme in the narratives analyzed as well as my own. In my own narrative, I reference many times where I seek medical advice and make decisions on behalf of my father. For example, every doctor visit, being named legal guardian, and monitoring his health during his oxy-coma – which led to an emergency room visit and prolonged hospital stay (all described in detail in Chapter Two). Chast, Fies, and Walrath write of similar experiences and dependence on the medical system to make decisions regarding care for their parent(s).

Chast explains her decision-making process regarding moving her parents into an elder care facility in her chapter “The End of An Era.” She goes through the thought process in her decision to move her parents citing medical concerns as well as their overall health and wellbeing (see Figures 53, 54, and 55). What led her to this major decision in the care process of her parents were previous falls, memory issues, and overall mental health. The decision to move her parents was based on medically driven concerns. Similar to Chast’s narrative, Walrath recalls the moments leading up to her and her husband’s decision to move her mother from her apartment (where she was living alone) to moving in with them and their children in her vignette “Disappearing Alice” (see Figure 51). She recounts the fire in her mother’s apartment and how they:

> . . . set up round-the-clock care, but she hated it. “They follow me around like the Gestapo,” she said. A proud, hardworking career woman, she did all the cooking and cleaning for her family of five, without any outside help. Next, we tried a one-bedroom apartment in a nearby senior living community. After she kept trying to walk home, they said her only option with them was the lockdown Alzheimer’s unit. They urged us to find another solution because she was still too well. That’s how she came to live with us. She lost her own home. Alice was disappearing. (Walrath 11)

Each phase of this decision making process for Walrath and her husband was guided by medical insight and decisions made on behalf of her mother were medically related – the essence of medium power at work.

In the case of Fies's memoir (and similar to my own plan of action regarding my dad's medical care and treatment), he blends the information received by physicians and his own research to manage and make the final decisions regarding his mother's care during her diagnosis, treatment, and aftercare for cancer (see Figure 52). His process of assessment and comparisons of information from his own research endeavors with that provided by the physicians exemplify medium power in that all the research and assessment of information was to make decisions regarding medical treatment and care for his mother.

The notion of medium power is complex in that is also heavily guided and controlled by the system; specifically by the doctors and health care providers. For example, I could not go in and tell the doctor's to stop his weekly parenthesis procedures. While the denial of treatment is within my dad's medical rights, the medical team would question my reasoning regarding this decision. While I would never actually do this, this example brings up a very interesting point. This is where my power, or rather the belief of having power, can quickly be taken from me if I do not follow the norms of treatment set forth by our medical community for my dad's illnesses. This removal of power by medical/legal staff when deemed as improperly used supports my first major discovery – The health system is rigged.

While, for the most part, I do have a say in my dad's treatment plan I view the plan – the reality of the plan – as pre-constructed. The options provided to me and my family fit within the design of how disease(s) are treated by our medical community. Options that are outside the spectrum of traditional treatment are not given as options and are often quickly discounted or ignored. The medical community has a plan in place to treat disease x. You follow this plan to either cure (if possible) or manage disease x. You can have some decision in how the treatment goes but in reality, you must follow said treatment in order for insurance to cover you and for future treatments to be covered. Again, this is where we see a blurring of lines as now I have mentioned components of large power here – specifically dealing with financial issues and long term placement (when the time comes for long term care options). While there is a small percentage of the population that can afford private pay (the two percent), most of our elders are on some form of government assistance. In specific instances with my father's care, we could be denied future care if we did not follow the current treatment care plan suggested (rather given to him). For example, after a lengthy hospital stay, his team of physicians would order short term rehabilitation. If we denied "short-term rehabilitation" after a hospital stay, any future hospital stays that would require rehabilitation could be (and often are) denied by government funded medical assistance (which my father is on). Again, large power in action – at the medium level. Many of the decisions we are given options for – really have "option" as a comfort term. Options do not apply. The system design is what you follow in order to ensure you are covered in future instances.

I do not deny that our medical system is trying to provide the best care possible for my dad and others. And I am very grateful for the treatment my dad has been able to receive, as he has been seen by the very best in their respective fields. But, from a critical perspective, when we are told we have power over our own medical decisions in and by what choices we make, those choices come at a cost. Do you go against a system and risk future denials of care? Or do you work in the system and do as they suggest to ensure a smoother process? Is it all about the financial? No. But what must be considered is what options are provided to you if you are an ill and/or aging senior. The big question to consider is what power do we have over the options provided to us regarding our own care and our own care plan? Are our options truly ours? Or must they fit within the larger system? What medical treatments are provided if you have a terminal illness? What choices are you given for your life? Furthermore, what if you denied all medical care for an illness? What impact would that have on the team of physicians caring for you? They are there to "save you" – what happens to them if that option ceases to exist? I will explore these questions in the next section discussing the value of life.

Large Power

If you are not yet overwhelmed by the structure that is termed our medical system, you might soon be with the discussion of large power - governmental control. The large system dictates the decisions, care, and long term placement because of the financial stake in the matter. While they are productive in providing care and long term placement they are also repressive in that they decide which care plan(s) will be approved along with which type of long term care unit is approved as well its location. If you rely on government assistance for care, while you do have a say in the care and placement of your ill and/or aging parent(s), the outcome is largely dependent on available beds/placement. Your treatment is then determined by where you are placed.

No matter how you advocate, to what level you question, to how determined you are in ensuring what care you desire for your parent, you are (in one way or another) dependent on the system and reliant on the system. In the case of my dad, he is both dependent and reliant on the system as the large portion of his medical care is paid for by the government. He does have supplemental coverage – which we are grateful he is able to afford – that by design, supplements what the initial government policy will not cover. Yet, in all reality, he is reliant and dependent on the government entity for his initial care coverage. Does he get treated any different by his team of physicians? No. Is this the case for others in his position? I cannot answer that. Is his long term care impacted by the fact he has government funding? Yes. Certain long term facilities will not take government assistance without first having a certain number of prior months/years of self-pay. Is this fair? Is this wrong? That I cannot answer, nor is it my place to comment. I can confirm that my experiences are similar to those experienced and narrated by Chast in her memoir. These experiences with large power are present in my own narrative but not mentioned in the works of Fies and Walrath.

I have concluded the absence of large power in the works of Fies and Walrath is likely due to the type of illness each parent was facing at the time. Fies's narrative approaches his mother's experience with cancer as one that can be and is beat. Fies does identify the type of cancer his mother was diagnosed with has a survival rate of one out of twenty.

Figure 73. Brian Fies, page from *Mom's Cancer*, 2006, p. 102.

Even with the number of individuals that succumb to her type of cancer, he does not go into end of life planning due to this percentage. Rather, he emphasizes the treatment plan and the experiences of his mother during her treatment. Similar to Fies, Walrath's memoir style is written in story vignettes. Rather than a chronological narrative of her experiences caring for her mother with Alzheimer's, she weaves in her mother's diagnosis and her personal experiences caring for her mother through short stories. These stories connect back to the diagnosis of her mother's Alzheimer's while writing stories of her mother's and their family's past. I do believe families that face Alzheimer's must talk about end of life care and have conversations about treatment plans. As we see in Walrath's memoir, end of life care conversations were connected to conversations surrounding when external help would be needed; when symptoms of advanced Alzheimer's would be too much for her or her family to endure. We see this conversation taking place between Walrath and her husband in the vignette "Curiouser and Curiouser":

> "Incontinence might be a turning point," Peter said. This was before Alice moved in with us. Alzheimer's disease typically has a ten-to-twenty-year course. We were trying to imagine the end point of our ability to cope at home. For a son-in-law and grandsons, three bathroom accidents could be about right. I had a different turning point.
>
> "If she gets mean," I told Peter. I knew this side of her already. . .
>
> Alice made it easy. Since she no longer had the language capacity to express what she knew, she used action. She did it when I was out of the house. She hit Peter – her biggest competition for my attention – with a broom, and threw things at him. Instead of letting one of her grandsons help her with the diapers, she took them off and hid them in my workroom. I knew it wasn't meanness. She was simply telling us it was time for something else.
>
> When I explained to her that she would be going to a school for people with Alzheimer's disease, Alice relaxed and those behaviors evaporated. "Oh, good!" she said. "I love school."
>
> Aliceheimers (63)

As explained in her short story, we see the conversation taking place regarding placement for care and when a switch was necessary.

Large power can be avoided (in a sense) if medical insurance is not provided by the government or if morbidity is not in the near future. When large power makes itself present is often when a terminal diagnosis is present, when age-related health complication(s) arise, and when the individual seeking medical assistance is largely dependent on government assistance for their income and/or medical coverage. These large power commonalities are what I have begun to face with my dad's care[131] and what Chast experienced when caring for her parents.

Chast's memoir speaks often to the anxieties and fears surrounding end of life care. Her anxiety and fears stem from level of care and financial obligations surrounding end of life care and end of life treatment. She describes the worries she feels in numerous moments during her narrative. Much of the detail takes place in the chapter, "The Next Step." In this chapter, she tackles the medical and financial complexities surrounding hospital stays and nursing home stays. In one page, she specifically recalls her dad's three week stay in the nursing home.

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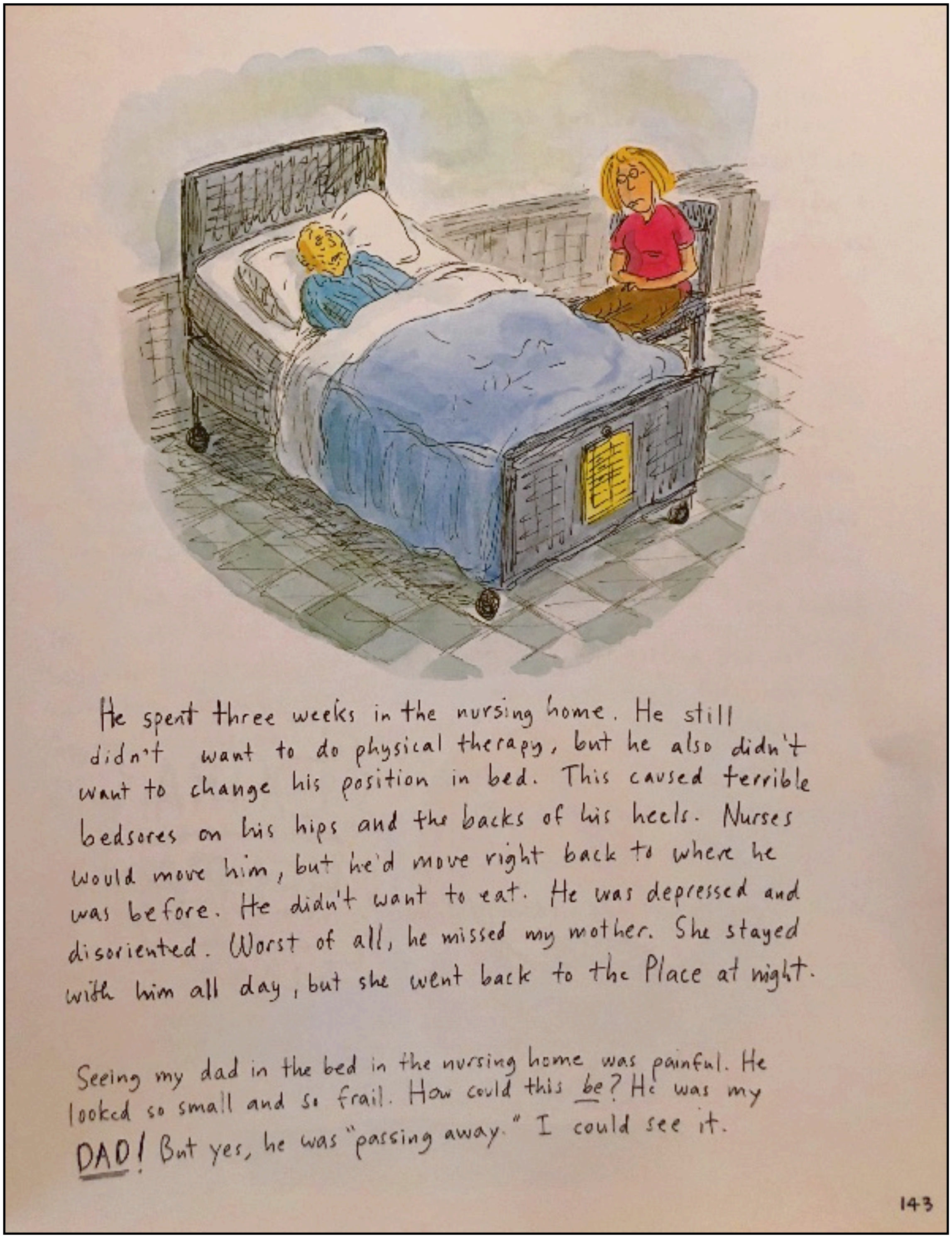
[131] It is important to note that my experiences with large power in regards to my dad's care only recently have begun to take place – May of 2018 to be exact. This shift in dependence is due to the level of care that is now needed to ensure his overall health and wellbeing. My own experiences with this level of power are not included in Chapter Two, therefore the example for this level of power will come from the work of Roz Chast. I will add a postscript following this chapter that brings my story to its current state.

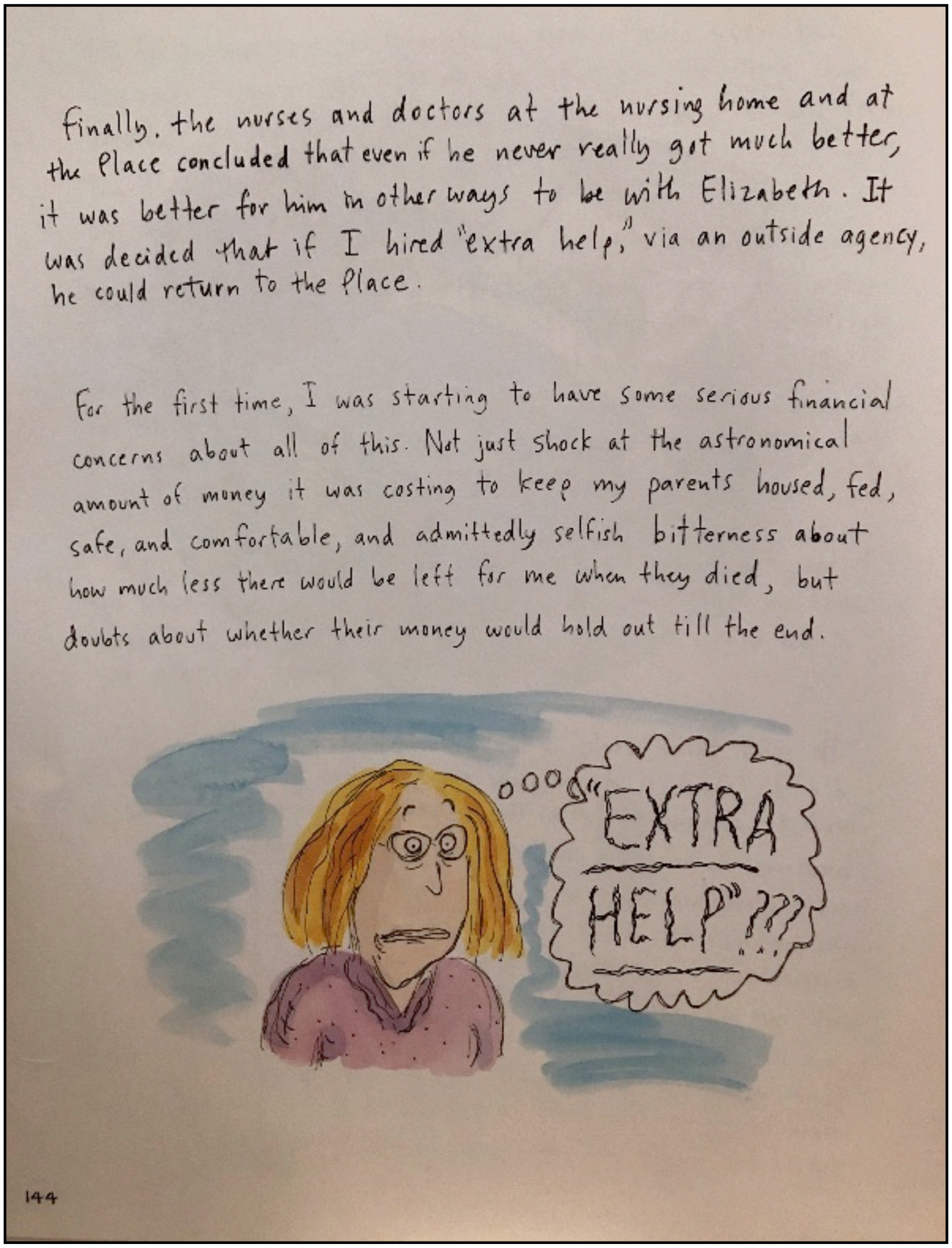


He spent three weeks in the nursing home. He still didn't want to do physical therapy, but he also didn't want to change his position in bed. This caused terrible bedsores on his hips and the backs of his heels. Nurses would move him, but he'd move right back to where he was before. He didn't want to eat. He was depressed and disoriented. Worst of all, he missed my mother. She stayed with him all day, but she went back to the Place at night.

Seeing my dad in the bed in the nursing home was painful. He looked so small and so frail. How could this *be*? He was my **DAD**! But yes, he was "passing away." I could see it.

Figure 74. Roz Chast, page from *Can't We Talk About Something More Pleasant*, 2014, p. 143.

Following her realization that her dad was “passing away,” she recounts the next steps: identifying the need for extra hired medical help.

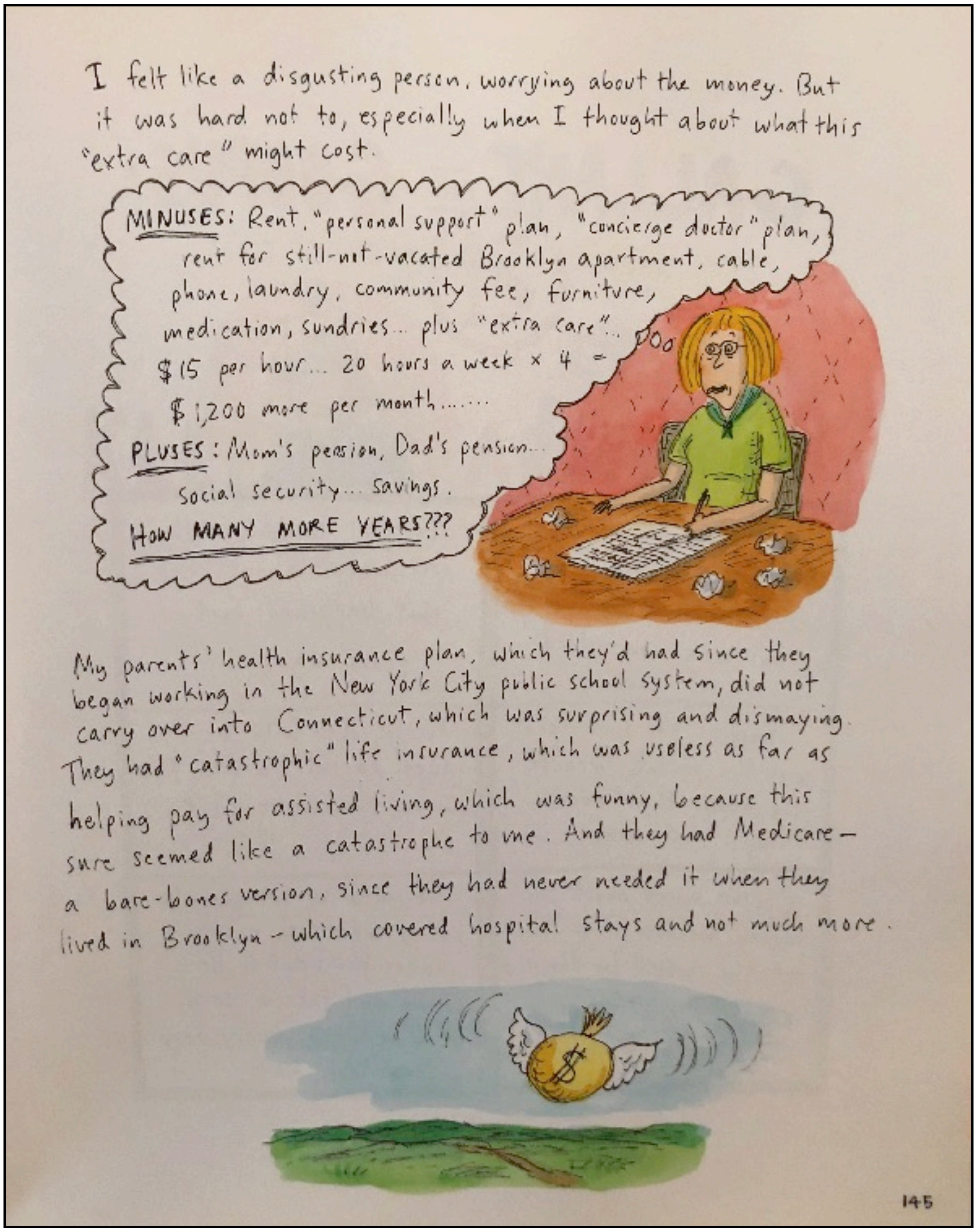


Finally, the nurses and doctors at the nursing home and at the Place concluded that even if he never really got much better, it was better for him in other ways to be with Elizabeth. It was decided that if I hired "extra help," via an outside agency, he could return to the Place.

For the first time, I was starting to have some serious financial concerns about all of this. Not just shock at the astronomical amount of money it was costing to keep my parents housed, fed, safe, and comfortable, and admittedly selfish bitterness about how much less there would be left for me when they died, but doubts about whether their money would hold out till the end.

Figure 75. Roz Chast, page from C*an’t We Talk About Something More Pleasant*, 2014, p. 144.

This added help caused her to consider the financial obligations that were to follow.



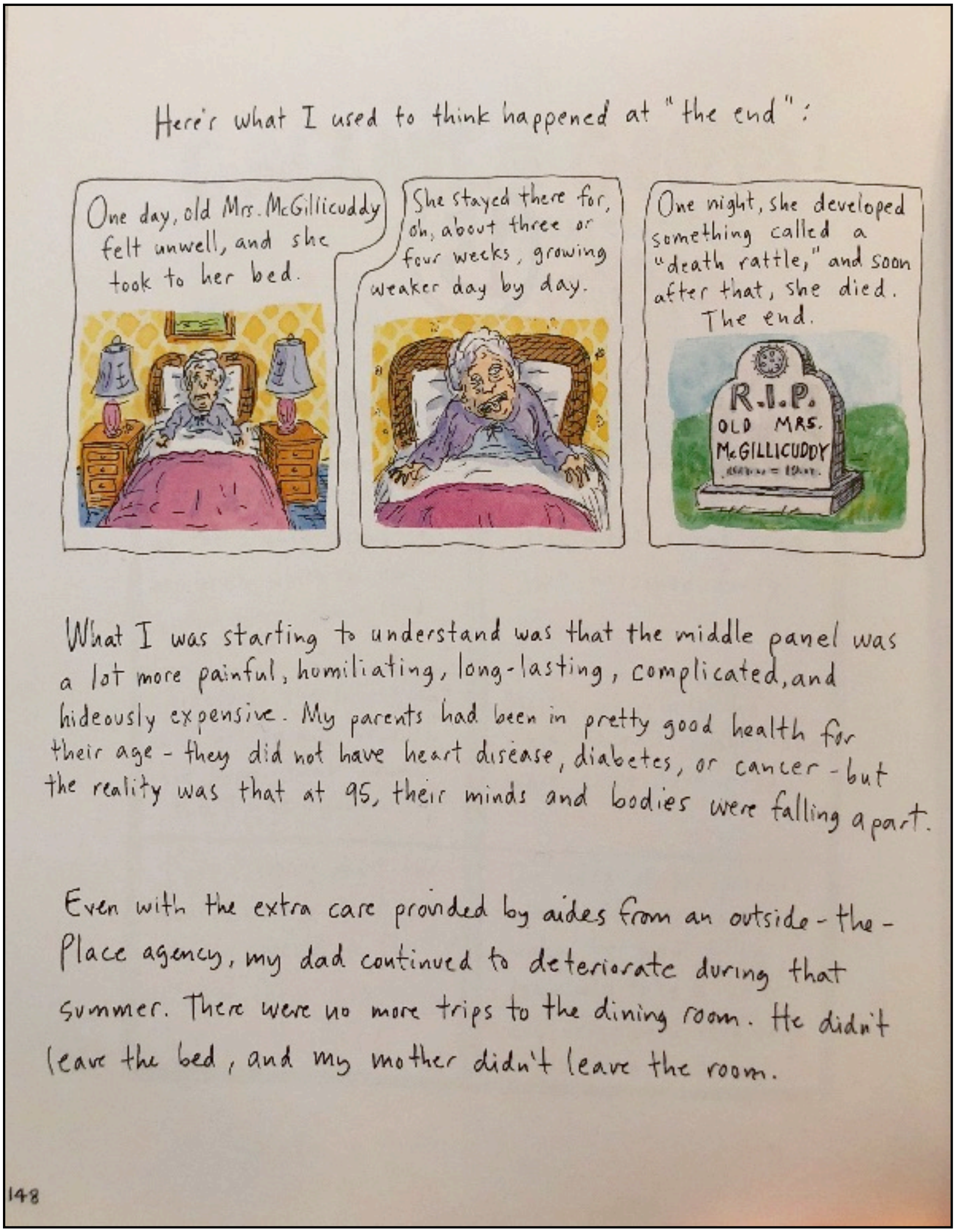
I felt like a disgusting person, worrying about the money. But it was hard not to, especially when I thought about what this "extra care" might cost.

My parents' health insurance plan, which they'd had since they began working in the New York City public school system, did not carry over into Connecticut, which was surprising and dismaying. They had "catastrophic" life insurance, which was useless as far as helping pay for assisted living, which was funny, because this seemed like a catastrophe to me. And they had Medicare – sure seemed like a catastrophe to me... a bare-bones version, since they had never needed it when they lived in Brooklyn – which covered hospital stays and not much more.

Figure 76. Roz Chast, page from C*an't We Talk About Something More Pleasant*, 2014, p. 145.

The chapter ends with her internal monologue of what she was feeling at this moment in her journey as caretaker.

In the chapter titled “Kleenex Abounding,” Chast continues to grapple with the financial complexities. She shares what she “used to think happened at “the end” (148) versus what actually happens.



Here's what I used to think happened at "the end":

One day, old Mrs. McGillicuddy felt unwell, and she took to her bed.

She stayed there for, oh, about three or four weeks, growing weaker day by day.

One night, she developed something called a "death rattle," and soon after that, she died. The end.

What I was starting to understand was that the middle panel was a lot more painful, humiliating, long-lasting, complicated, and hideously expensive. My parents had been in pretty good health for their age - they did not have heart disease, diabetes, or cancer - but the reality was that at 95, their minds and bodies were falling apart.

Even with the extra care provided by aides from an outside-the-Place agency, my dad continued to deteriorate during that summer. There were no more trips to the dining room. He didn't leave the bed, and my mother didn't leave the room.

148

Figure 77. Roz Chast, page from C*an't We Talk About Something More Pleasant*, 2014, p. 148.

She then provides her own advice on "How to prepare for very, very advanced old age" (Chast 149).

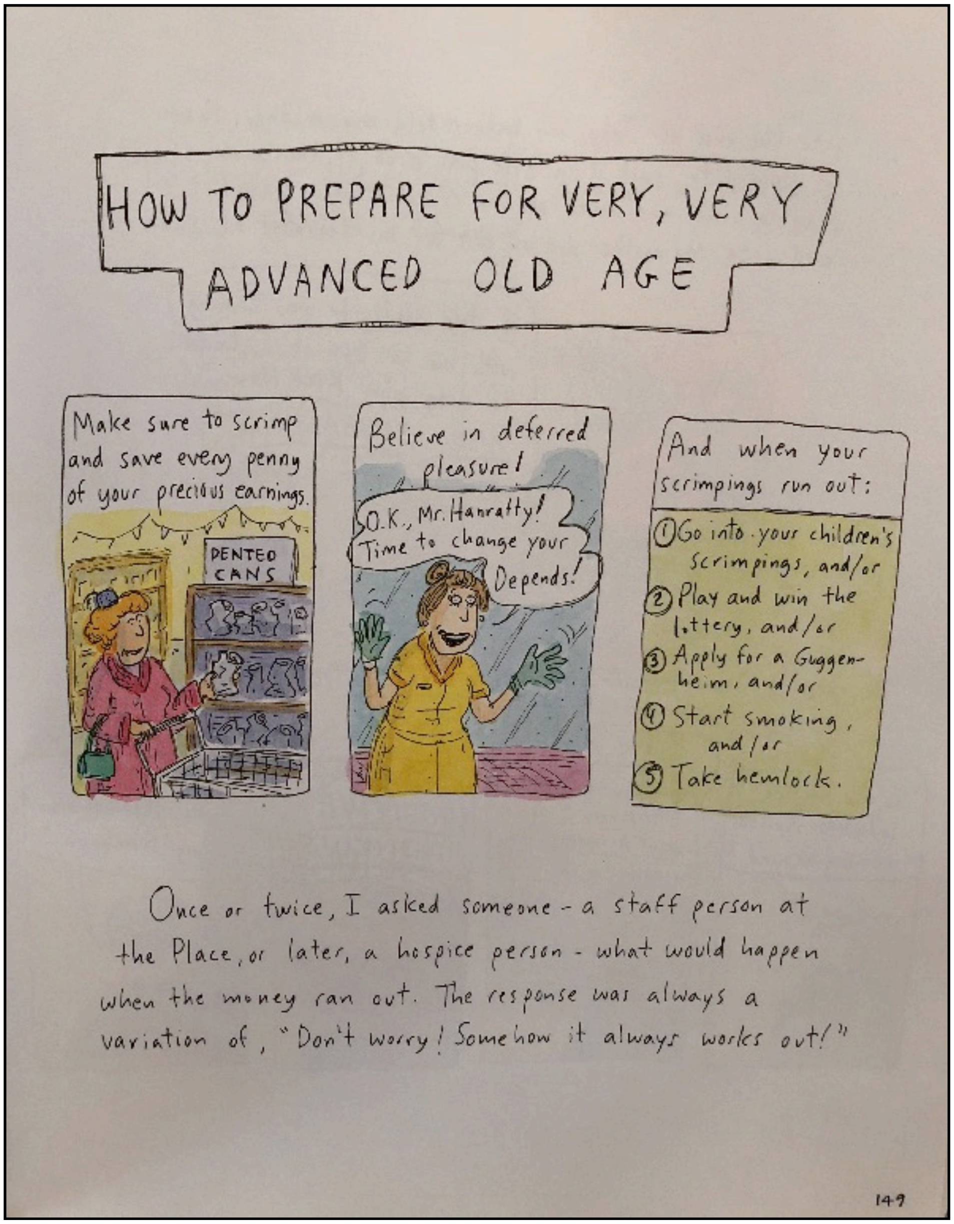


Figure 78. Roz Chast, page from C*an't We Talk About Something More Pleasant*, 2014, p. 149.

In her advice, she adds in a very important aspect to the notion of large power. She recalls the following:

> Once or twice, I asked someone – a staff person at the Place, or later, a hospice person – what would happen when the money ran out. The response was always a variation of, "Don't worry! Somehow it always works out!" (Chast 149)

This response is one I have also heard many times. When the money runs out, the government steps in. The question that lingers in my mind, how long can the government continue to step in before their willingness to spend money runs out? What happens to our care and the options for care then?

Reflections

Upon reviewing the similarities between my experiences and those of Chast, Fies, and Walrath, each being in and working with the health system for managing and helping our parent(s) with the most basic health decision to the most complicated – that of the financial components of paying for long term care - I feel confident in stating that our health system is rigged – our perception of having power (especially in the sense of control over our parent(s) health care is just that: a perception. It has little to no actual existence.

The claim that our health system is rigged is bold. It comes up against potential criticism and the possibility of academic suicide but I feel it must be said. Having to operate within and conform to the health system has afforded me insight not otherwise possible. Unless you are actively navigating the system – large and small and the middle (medium) ground in between, you may not see just how rigged it is. I can safely claim that our medical system is one of the best in the world. Our medical knowledge, our developments in treatments and cures go beyond anything anyone thought imaginable. While medical advancement is important to and key to our nation's success, I question at what cost? By building a system where surveillance is done (consciously and unconsciously), where decisions about personal health are often presented as already selected treatment plans and rarely as treatment options, where the decision to not follow a suggested treatment plan may have an impact on future treatment options or level of care, where you are viewed as mentally unstable (medical personnel might deny this, but the feeling exists, at least in my experience) if you deny a treatment option(s), what is being said about our system? Is the system in place to heal? To cure? Or is the system in place to prolong and treat? When does treatment stop and living suffice? More importantly, how does one operate in the system if the suggested plan is not followed? What does health and life look like for them?

Our sociocultural understandings of health are so deeply embedded in the biomedical model, I question if we could, as a society, move away from this system? Or if we are too embedded in its design. We get sick, we go to the doctor. We treat symptoms, often not addressing the root of the problem. We supply medicine as a fix. Yes, these are large broad sweeping statements that may not include everyone but from a sociocultural view, it is inclusive to the majorities understanding of health and wellness. We as society members are predispositioned to conform to and operate within the power structures embedded in our sociocultural understandings of health because that is what we know. That is what we have come to learn and understand and accept as our normal.

This learned and understood acceptance of how we view health and wellness is our normal. I know that the claim “the system is rigged” is not a completely new discovery; what is ‘news’ in this claim is the extent to which, at every level of power, resistance is constrained by the established medical model.

Second Major Discovery – A Prescribed Role is Attached to Experiences Surrounding Being a Caregiver

The thought that experiences surrounding caregiving could possibly include a prescribed role existed in the recesses of my mind as I started my analysis. What I was unclear of is how, if at all, the notion of a prescribed role would manifest itself in the stories told by each author. Part of me wondered if such a role existed and if so, how did it manifest itself? Furthermore, if such a role exists, why does it manifest across the experience of being a caregiver? A prescribed role is defined as expected behavior(s) associated with a certain position, title or role. In the case of the role and/or position of caregiver, a prescribed role was present in each memoir. This prescribed role included sociocultural understandings surrounding the act of caregiving placed on the caregiver. These sociocultural understandings include family support (taking on the role of caregiver), managing decisions, visits (either by phone or in person) including overnight stays if needed, and seeking information about the medical treatment plan(s).

These discoveries under the heading “A Prescribed Role is Attached to Experiences Surrounding Being a Caregiver” may seem obvious to some; it is what you do when a family member becomes sick or is aging, right? Initially, this was my belief. Yet as I documented my own experiences and read the narratives of Chast, Fies, and

Walrath, I began to question that internal voice telling me “it’s what you do.” I started asking the question “why is it ‘it’s what you do’?” Why do the prescriptions attached to the role of caregiver include family support, managing decisions, visits, and seeking information about the medical treatment plan(s)? Why were these prescriptions assumed by each author? Why is each author’s embodiment of caregiving different yet similar? The best way for me to address these questions is by utilizing Foucault’s writings on power, specifically on Pastoral Power.

It is likely you are thinking, here she goes again – more Pastoral Power. Yes, here I go again with Pastoral Power but for good reason. Foucault’s writing on Pastoral Power can be used as a framework for understanding why the prescribed role exists and possibly for why the prescribed role is assumed by the caregiver. Are there more power components, by Foucault’s definition, at play? Quite possibly, yes. For purposes of this section, I will focus on the aspects of Pastoral Power to help unpack the idea of the prescribed role that is attached to experiences surrounding being a caregiver. To achieve this goal, I will apply the four elements of Pastoral Power explored in Foucault’s lecture “Pastoral Power and Political Reason” (142-143) all leading to the conclusion that the prescribed role attached to the experiences surrounding being a caregiver is that of the pastorate (in a Foucauldian sense).

In his series of lectures titled The Tanner Lectures on Human Values delivered at Stanford University in October of 1979, Foucault delivered a specific lecture titled, “Pastoral Power and Political Reason.” In this lecture, he extended previous ideas on Pastoral Power and the Pastorate given in lectures between 1977 and 1978 at The Collège

De France. More specifically, he examined "the theoretical elaboration of the theme in ancient Christian literature" ("Pastoral Power" 141) connecting to the progression of pastorship and power. Foucault identified four Hebrew themes that were altered in four ways to fit a Christian ideology. These themes are: responsibility; obedience; knowledge of needs; the transformation of self, holding to a Christian mentality of death leading to life in another world (143). I view these four extensions to Foucault's original work as imperative in understanding the prescribed role attached to the experiences surrounding being a caregiver. I argue that these four extensions to the notion of Pastoral Power help us make sense of the assumption of the prescribed role attached to the caregiving experience due to the unstated connection of Christian morality in our culture. Whether we like to admit it or not, many of our cultural norms and beliefs are connected to the Christian doctrine and philosophy our country was founded on. These four extensions, explained by Foucault, provide a theoretical justification for why the prescribed role exists in the manner it does to experiences surrounding being a caregiver.

Responsibility

Under the Christian origin, responsibility includes that "the shepherd must render an account – not only of each sheep, but of all their actions, all the good or evil they are liable to do, all that happens to them" ("Pastoral Power" 142). When one takes on the role of caregiver, you are assuming certain responsibilities. Responsibilities include keeping a record on and for the family member(s) you are caring for but that also you assume responsibility for their actions – good or bad. When I say responsibility for their actions, I do not mean in a legal sense; rather, responsibility is connected to actions that involve their overall health, care, and daily living behaviors. The idea of responsibility is shown in the aspects of the prescribed role including family support (taking on the role of caregiver), managing decisions, and visits. While the level of responsibility assumed by each author differed depending on their respective situation, responsibility (from a Foucauldian sense) was present in all memoirs.

Obedience

Obedience from a Christian perspective is founded upon the idea that the "shepherd-sheep relationship as one of individual and complete dependence" ("Pastoral Power" 142). Following this principle, we see an individualized relationship between caregiver and parent as well as complete dependence of parent(s) on their child, now caregiver. The notion of complete dependence is complex as often the ill and/or aging parent(s) is dependent on other individuals, such as medical staff, during their illness. What is important to differentiate under this extension of Pastoral Power is the emphasis on the relational component between pastor and sheep (child/caregiver and parent(s)). From a relational standpoint, I conclude there is a complete dependence during various times in the caregiving journey as identified by myself, Chast, Fies, and Walrath.

Knowledge of Needs

Part of the uniqueness of the pastor/sheep relationship is the notion of individualized knowledge. The Christian view of knowledge extends beyond knowing the state of the flock and sheep. It emphasizes that the "shepherd must be informed as to the material needs of each member of the flock and provide for them when necessary. He must know what is going on, what each of them does – his public sins. Last and not least, he must know what goes on in the soul of each one, that is, his secret sins, his progress on the road to sainthood" ("Pastoral Power" 142-143). In the context of the pastoral relationship being between the caregiver/parent(s), as I have been analyzing, the Christian take on knowledge within Pastoral Power is dependent on the type of relationship the child has with the parent(s).

While support is present in the works of Chast, Fies, and Walrath for being informed of the needs of the sheep as well as knowing what is going on in the lives of their parent(s) (as shown in the examples above), it is hard to identify if any of the authors know what is going on in the soul of their parent(s). While I can attest to learning of and now knowing some of my dad's internal thoughts, I cannot make the conclusion that I know his secret sins. I therefore cannot conclude this for Chast, Fies, or Walrath either.

The Transformation of Self

The final component to Foucault's extension to his original writings on Pastoral Power is the idea of transformation. Specifically, he addresses the inclusion of "Christian techniques of examination, confession, guidance, obedience" suggesting they "have an aim: to get individuals to work at their own 'mortification' in this world. Mortification is not death, of course, but it is a renunciation of this world and of oneself: a kind of everyday death" ("Pastoral Power" 143). If you look at this idea as a means of assessment of the self, the notion of transformation of self makes sense in the context of the narratives being told. Each memoir, my own included, grapples with the idea of life and death. Each parent is facing a major illness or is facing end of life. Applying Foucault's analysis of the Christian view of this transformation to the stories told by Chast, Fies, Walrath, and myself, we can see elements of transformation in portions of the narratives.

Reflections

You might be wondering the following: Where are the individual examples for each extension of Foucault's Pastoral Power that were just discussed? My response: they are embedded throughout each figure selected for my analysis as well as in each penned page and story that creates the full memoir of each author. As I was reviewing my analysis chapters, I was able to pull out examples – true to traditional style – in order to support each extension as described above. As I was re-reading the analysis chapters, reviewing each image selected from the texts I realized that the extensions Foucault speaks of are ever-present. Yes, I could restate already argued points but rather, I felt it was important to emphasize that responsibility, obedience, knowledge of needs and transformation of self are embodied traits of the reflective commentaries of the experiences surrounding caring for an ill and/or aging parent that Chast, Fies, Walrath, and I write about. There are moments when an entire story within the memoir might emphasize responsibility or obedience, as Foucault explains, but I believe there is a greater theoretical impact of recognizing Foucault's extensions of Pastoral Power as embodied. Recognizing that the four extensions are embodied throughout the narrative of each author supports my second major discovery – A prescribed role is attached to experiences surrounding being a caregiver. I argue this prescribed role can be referenced using Foucauldian theory; specifically that role being Pastoral in nature. As argued here and in previous chapters of this work, Pastoral Power is evident and ever present in all selected texts. This finding forces me to reflect on the experiences surrounding caring for an ill/aging parent. Prescribed or not, where does our internal drive for providing pastoral-like care develop from? Or is it innate to the human experience?

The two "discoveries" discussed above lead us to a final question: how do these contribute to our understanding? What, in other words, are the major contributions this analysis provides? A seemingly simple question with a difficult to articulate answer, as my feelings are conflicted at this moment. More recent events have, as the postscript to this chapter will attest, caused me to rethink how the medical field truly forecloses on the possibility of freedom while maintaining its overt commitment to giving patients and caregivers choices to choose among. Freedom, after all, is not simply the freedom to choose among pre-given choices (though that too is often denied) but rather is the freedom to ***choose the choices.***

Major Contribution of Analysis

Looking back to the beginning of the dissertation process, one of my goals for my work was to advance the importance of using narrative in both autoethnographic and comic form. One of the ways I aimed to achieve this goal was to separate my narrative from the works of Chast, Fies, and Walrath. By doing so, I was able to focus on my personal experiences, apart from the experiences of Chast, Fies, and Walrath. The decision to separate my narrative from the other authors' works afforded me the ability to identify commonalties and differences in our experiences. Identifying the commonalities and differences in our experiences highlighted the major contributions of this work. The major contribution being: The orientations of caregiving.

Orientations of the Caregiving Experience

Both elements of my caregiving narrative were supported with how I experienced and orientated myself with my role as caregiver. The notion of orientations were developed from my socio-cultural, critical rhetoric, and narrative understanding of the environment in which I live and work. Using the orientations of ‘other’ and ‘self’ throughout my analysis afforded me the ability to identify that the ‘other’ orientation can be defined as how the idea of caregiving manifests itself as action for or on behalf of the ‘other’; the ‘self’ orientation can be defined as the self-reflexive lived experiences of how I feel/felt as a caregiver. What follows is my explanation of how my understanding of the orientations of caregiving were developed from my sociocultural, critical rhetoric, and autoethnographic understanding of the environment in which I live. The following also serves as a justification for not encountering or challenging extant caregiving literature. While that is a reasonable expectation, and a concern a reader might have, my purpose was to enter into this analysis from a specific position, not encumbered by or predisposed to analysis from within already given interpretive prescriptions about the nature of caregiving in general. From my ethnographic perspective to the analysis of comic memoirs devoted to caregiving, my approach was one of entering without other’s preconceptions of the nature of the experience.

As a critical scholar, I can separate myself from my theoretical understandings if and when I desire; yet, as a critical scholar, why would I want to? My theoretical knowledge is a part of me. It aids in my comprehension of my own experiences and the world around me. I learned to embrace caregiving from this view, relying on theory to aid in moments of my confusion, sadness, anger, relief, and a variety of other emotions. I must be clear in that I did not run to theory or run to my books during a moment of confusion or anger, rather I allowed myself to experience and embody each moment, coming back to the theory at a later time to assist me in understanding the how's and why's of the moment. How did I come to feel that way? Why did I react that way? And so on and so forth. Using McKerrow's praxis of Critical Rhetoric helped me to not only go easy on myself in the moments following certain responses to my situation, but the principles and praxis aided in how I engaged with the material I wrote after the fact. At times, this may have been shortly after writing or in other instances, it may have been months after. Going back to his theoretical structure provided me the terms and loose structure needed to fully experience the orientations of 'other' and self' in order to further my understandings of my caregiving experiences.

The only way I could get into my personal narrative was from an autoethnographic perspective. Using my own stories allowed me to connect to the topic in ways I was not otherwise able to do. Much of how I come to understand the world and situations around me is by connecting my own experience(s) to a specific idea or subject. In the case of caring for an aging and ill parent, I found myself seeking other stories that dealt with the same topic(s) to help me gain further insight and understanding to this new role I was given and that I also, in a way, took on. Being able to place myself into the topic and subject I am writing about freed my mind – allowing me to connect theory and previous research to further explore the topic of caregiving. I did not set out to write in the form that I did; rather, it chose me. The quote that guides this chapter is testimony to how I came to my writing. As Patricia Hampl believes, “For meaning is not “attached” to the detail by the memoirist; meaning is revealed” (32).

Emphasizing Hampl’s belief that “meaning is revealed” (32), brings me to the final component of how I have developed and come to understand the idea of orientations of caregiving through a sociocultural lens. For me, the orientations of ‘other’ and ‘self’ are experienced both as separate and also together. Becoming a caregiver forced (for lack of a better term) me to become aware of how I care (‘other’) for my ill and aging father. The opportunity also provided me the ability to reflect (‘self’) on how I felt (and feel) as a caregiver. Despite my conscious efforts to not depend on and allow myself to be influenced by sociocultural norms, my social and cultural understandings have guided how I oriented myself with the role of caregiver and how I came to understand the notion of caregiving.

Self-reflection is never an easy task. Add in the aspect of self-analysis and you risk becoming over analytic and hyper-judgmental of self. I have experienced both of these issues first hand. My own awareness and analysis of my experiences surrounding caring for my ill father brought me to a deeper level of reflection than I thought could ever be possible. I viewed my development of the orientations of ‘other’ and ‘self’ within the caregiving context a major contribution. Are these orientations groundbreaking? No. But it does provide a vocabulary to further explore ideas connected to how we experience caregiving. More specifically, this vocabulary assists us to further explore notions surrounding our sociocultural understandings of health, the role or identity one possesses, is assigned, or is given. These terms can also provide autoethnographic and rhetorical scholars a new way to engage with and analyze texts connecting to lived sociocultural experiences by forging new analysis patterns.

Role and Significance of the Stories Told and Used for Analysis

Although I have dabbled in penning my own version of my narrative in comic form, I have not shared these pages with anyone (they may appear as I engage the ‘visual’ in its own terms in future work. Instead, I use the works of Chast, Fies, and Walrath to begin conversations about the experiences surrounding caring for an ill and/or aging parent. I tell their stories, depicting how they articulate their experiences in my own conversations with others. I connect their personal experiences to my own – first describing my own experience, maybe focusing on one moment, one memory. Instead of stopping there, I describe the works of Chast, Fies, and/or Walrath and how they describe, depict, narrate a similar instance. Describing their visual representation provides the listener with the opportunity to put images with words. To create a rendition of their interpretation of what I am explaining to them in pictorial form. I often will pull one of the comics out (if I have it with me) or up on my phone (if handy) and show the people I am conversing with the artistic renditions of Chast, Fies, and/or Walrath. Connecting the personal (my personal) to another person’s published work – further individualizes the story being told; my story and the comic memoir author’s story. Each author presents their experiences vastly different in their comic renditions – further personalizing their story to the listener/reader. The extension of personalization to the visual form, in the instances of Chast, Fies, and Walrath through comic and artistic renditions, in my instance the use of personal photographs (as added in my narrative found in Chapter Two), further connects these isolated narratives as connected stories.

Stories, when told in the memoir form, are often seen as isolated; One story, one experience. Connecting my narrative, establishing my experience as my own, then analyzing the works of Chast, Fies, and Walrath allowed for connections not yet seen to be made. It provided the start to the conversation of how we can begin to integrate the comic memoir into our daily conversations, into our academic research, into our classrooms, and into our lives. Instead of seeing the visual as separate from the textual, this work provides evidence that we cannot separate the visual from the textual because our lived experiences are visual and storytelling, in its basic form, is textual.

Stories of caregiving (specifically those caregiving experiences surrounding caring for an ill and/or ageing parent(s) told in traditional memoir and comic memoir form are meaningful and have purpose. Storytelling is highlighted in traditional memoir form, yet emotion that may not able to be fully communicated in the traditional memoir form can be communicated in comic form. Bodily and facial expressions can be depicted – communicating a meaning all of its own. That meaning may be experienced in our personal interactions with others but cannot quite be replicated in traditional story form. It is out of this blending of the two forms – the textual and visual – that the comic memoir has proven to be a powerful agent in communicating the experiences surrounding caring for an ill/aging parent(s).

Implications for Future Research

A project of this magnitude can be best described as both exhilarating and frustrating. Exhilarating in what is discovered and frustrating in what is discovered. I had to engage in a process of selection. What I could successfully achieve for this project and what I had to notate and place aside for future research projects (e.g., a focus on the visual itself). I found four major extensions to the work in process: extending the growing body of critical rhetorical analysis of memoir and comic memoir, the use of humor in the comic memoir, the use of the visual to communicate lived experiences, and the notion of truth and its function in the memoir.

Extending the Growing Body of Critical Rhetorical Analysis of Memoir and Comic Memoir

Blending the traditional memoir form with the comic form, with a focus as noted earlier on the visual, provides a rich body of literature for critical rhetorical analysis. Analyzing the presence of rhetorical frames and critical implications across texts can possibly provide a deeper and richer understanding of the discursive structures surrounding the role of caregiver as well as other medical contexts. A blended analysis can extend already existing literature by Michel Foucault, Deborah Lupton, and others, specifically targeting our sociocultural understandings of health – by analyzing our textual representation of these understandings as well as our visual understandings. Questions to consider: Are there conflicting presentations between the textual and visual representations? If so, what could cause them to exist? If conflicting representations are present, how might extant perspectives on visual rhetoric be used to help explain these conflicting representations? What can both the visual and textual combined provide us that cannot be learned by looking at each separately?

The Use of Humor in the Memoir and Comic Memoir

Then there is the question of humor. According to Aristotle's Poetics, "Comedy - was at first mere improvisation" (4). He goes on to say that comedy was imitation of a lower type of character. Not bad, per se, but rather consisting of an ugliness or defect not destructive or painful (5). While Aristotle wrote of comedy and tragedy, he did not say much about the use of humor. The term humor, as we define it today, did not develop until the 18th century leaving the early conversations about humor to be connected to the concepts of comedy or laughter (*Stanford Encyclopedia of Philosophy*). Internationally renowned American literary humor scholar Judith Yaross Lee[132] has worked through ideas surrounding humor as her work offers a rich exploration of the use of humor in literature. Using her work may prove useful to help aid in identifying how humor is used in the memoir and the comic memoir. Questions to consider: How is humor used in both the traditional memoir form and the comic form? Rhetorically, why is humor used? How does humor operate in the rhetorical frame in the comics devoted to health concerns? The narrative frame? The comic frame? In what ways does humor operate in similarity as well as difference across texts and between structural styles? What can be learned by how humor is used, accepted, and/or rejected depending on the writing style in which it is presented? How can traditional rhetorical frameworks aid in our understanding of how humor is used in both traditional memoir and comic memoir writing?

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[132] See Lee's books *Twain's Brand: Humor in Contemporary American Culture* and *Defining New Yorker Humor.*

The Use of Visual to Communicate Lived Experiences

I have not commented during the preceding analysis on how the visual illustrations contribute rhetorically to an understanding of the author's purpose or meaning. Rather, my purpose in this study was to focus on the narrative within the comic memoirs and the "lessons" they imparted regarding the 'major discoveries' discussed above. It is clear the visuals are of interest in how they support ideas and convey feelings of the author's experiences. That focus is of sufficient importance deserving its own treatment as an extension of this analysis. A future study would apply comic theory as a framework to analyze how the visual is operating within and through the memoir as its own communicative tool.

The Notion of Truth-telling and its Function in the Memoir and Comic Memoir – The Use of Avowal

Finally there is the notion of truth-telling and its function in the memoir. In Foucault's *Wrong-Doing, Truth-Telling: The Function of Avowal in Justice,* he theorizes about the idea of truth-telling in connection to the ethical implications of truth-telling. He postulates that a shift in the act of truth-telling occurred from the political to the ethical within the practice of "avowal," defined as "a verbal act through which the subject affirms who he is, binds himself to this truth, places himself in a relationship of dependence with regard to another, and modifies at the same time his relationship to himself."" (*Wrong-Doing* 4). Foucault further adds, "Avowal consists of passing from the untold to the told, given that the untold had a precise meaning, a particular motive, a great value" (15). He also suggests "In an avowal, he who speaks obligates himself to being what he says he is. He obligates himself to being the one who did such and such a thing, who feels such and such a sentiment; and he obligates himself because it is true . . . (16). Foucault summarizes “that avowal is a verbal act through which the subject affirms who he is, binds himself to this truth, places himself in a relationship of dependence with regard to another, and modifies at the same time his relationship to himself” (17).

The memoir and the comic memoir exhibit elements of truth-telling and avowal through the use of storytelling – both in written and in artistic renditions of their narrative. Questions to consider upon further exploration of these two topics are: In what ways is Foucault’s notion of avowal used in memoir and comic memoirs? How does truth-telling function in the memoir and comic memoir? How does avowal function in the memoir and comic memoir?

Conclusion

I do not know if I was the child that always asked the question “Why?” I have not actively searched out the answer to this question as I can probably guess what the response would be. What I can confirm is that, without a doubt, my question asking got me into much trouble in my early years. I asked questions of clarity, but most importantly I asked questions that challenged. I see my question asking in my formative years as a precursor to my critically minded interests. I believe my questions asking – the questions of clarity and challenge - led me to my interest in and passion for critical thinking and critical theory.

My interest in critical rhetoric fathered by Raymie E. McKerrow, my fascination and obsession with Michel Foucault, Deborah Lupton, and Jacques Lacan (who did not make it into this work), my lifelong experiences with illness, wellness and the space between, my learning difference that has plagued me and caused me to self-stigmatize since grade school, and my relentless need to learn, ask questions, discover, and never quit has brought me to end of this journey – that of the dissertation.

Final Reflections

March 27, 2018

People say resilience is expressed and shown in how one responds.

~ personal journal entry

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I write as I experience. Experience fuels my writing. I allow myself to feel the emotions connected to these difficult life decisions; to write through the moments of pain, the moments of sorrow, and the moments of joy (although brief and fleeting). I write to comprehend, to analyze, to express, to feel. Most of all, I write to ground myself. Writing allows me to acknowledge that no matter how difficult this journey is at this moment and despite that I do not know how this journey will end, I will be able write about it. I find peace in knowing that I have the knowledge and the ability to not only feel the emotion connected to the moment but that I can connect theory to help analyze what I have experienced, what I may currently be experiencing, and what I might possibly encounter.

At this moment, as I am writing this in May of 2018, my dad and I are at odds. He sees me and my power (being his legal guardian) as repressive. He views me as the enemy. He believes in his heart that I did things to him, that I made decisions on his behalf so I could ignore him, put him away, not deal with him. I know this is in part due to his dementia but it does not make it any less painful. I love my dad. My hope is that one day, he can understand that this was not, and never was, my intention. I hope and pray that he can read this work and see my passion, my level of love, devotion, care, and desire for him to live the best life possible. For without my dad, this journey would cease to exist.

My dad has always supported my love for learning and education. He has always told me I could do whatever I put my mind to. It is because of my dad's unwavering support and pushing me to exceed my own expectations of myself that I applied to my master's program and then to my doctoral program. Was it my dad that sparked my interests? No. But without my dad this journey might never have started.

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May 14, 2018

Dad is in a long term locked unit.
Not where I want him, nor where he wants to be.
Where do we place individuals like him? Those that fall through?
What is this placement doing to him? What does it do to me?

Guilt, sadness, emptiness, anger all consume me.
I try and find happy moments – steal them from the sadness; yet, they are hard to find.
I wish life was different but I often wonder, different how?
A new life would bring new challenges, would it not?
At what point do we accept was is given to us – what our normal is?

I desire happiness, not sadness.

Fulfillment, not emptiness.

Passion, not wealth.

Love, not hate.

Peace, not chaos.

I desire Life.

~ personal journal entry

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I will end my dissertation journey with the quote that begins this chapter from Patricia Hampl:

> "For meaning is not "attached" to the detail by the memoirist; meaning is revealed" (32).

AFTERWORD

April 28, 2018

I, as daughter, must act within the very power structure for which my scholar identity is suggesting is faulty, imbalanced, damaging. Yet I have one of two choices. I either act within the power structure or I go against it. If I go against it, I am now responsible for my father's actions, which his actions become as though they were actions of my own. I am trapped. The system has trapped me to act in accordance to how it wants me to act, how it wants me to respond. Where freedom of choice is touted as a possible outcome in our society, choice is but a veil hiding the reality of preselection; your choices are preselected for you, for outcomes that fit within a framework. Stepping outside, seeking other options lead you to be seen as delinquent. Delinquency, in and of itself, now becomes the new power structure you are subjected within. New terms, new rules, yet the outcome is the same. Capture the delinquent to be placed back into the system; yet, this time with less freedom, less options, less choice.

October 20, 2018

Even though my dissertation writing focusing on my role as caregiver has come to a close, my role as caregiver is still very much an active part of my life. I am back on speaking terms with my dad. As sad as it is to admit, I needed a break; a break to gather my thoughts, to separate myself from the sadness and anger I often felt and still feel, but most importantly to reset - mentally, emotionally, and physically. Although a break was needed – to separate myself from the intense emotion and often mentally exhausting moments - I was (and still am) actively writing. Writing is something that is a continuous activity for me; a way for me to process, reflect, and come to find meaning and understanding in what is taking place. An action that I must do.

My dad is and always will be a huge part in my life. He has supported me, encouraged me, showed me, and provided me with much needed guidance. While I do not always want to listen and take his advice, his voice is still a part of me. I hear it when it is not communicating and when it does. In being my dad’s guardian some aspects of our relationship have shifted, some have remained the same. While I do act as his legal guardian, we are still in communication about his wants, needs, desires. His voice is still present - active or silent in every decision I must make regarding his care and well-being. Despite the power shift that has occurred in my assuming the role of guardian, my dad is still very much active in my decisions about him as well as about me.

You may wonder how someone under guardianship can be active. The need for this role came out of the realization that my dad’s decision-making abilities for his own wellbeing had diminished. His abilities to make decisions were impaired by confusion, declining health, his mental health diagnosis, as well as other factors. With that in mind, he is still rational and can comprehend where and why he is where he is at for this moment, although he does not like it. The necessity of making sure he is okay, not causing harm to himself and others outweighs his desire to be on his own (in this moment of time).

I will never be happy about where he is having to reside or the realization that I am not equipped to have him live with me full time. This is the most difficult realization for me to process, manage, and is a burden on a daily basis - often causing intense pain, anger, and sadness. I struggle with the tension of wanting/needing him to be safe yet feeling as if I have failed him in some way or have failed as a daughter.

My dad is my dad - first and always. My representation of him in this piece of work is a snapshot into my life as his guardian and caregiver in the most difficult of times in this role. The difficult and painful times were the focus of this work as that is where I was at mentally and emotionally during these experiences. That is not to say that positive moments did not occur. Moments of humor were shard, moments of laughter surfaced, moments between dad and daughter were often present - some of these moments were represented in my stories in Chapter Two - in written or pictorial form. I know many more likely occurred but for purposes of this work, they filtered to the back or recesses of my mind as the painful and often bleak outcomes I saw were front and center to me. The role of caring for someone else is difficult. Add in the layer of legal responsibility for this person and you have quite a burden - on heart and mind. I always must keep in mind how I may need to justify any decision I make regarding his care and wellbeing - a very real and often heavy and challenging place to be. Will more difficulties present themselves? I have no doubt they will. Will I have more moments of positive interactions? Yes. That is the ebb and flow of relationships.

The representation of my dad in this body of work focuses on his illnesses and my navigation through them with him. When faced with illness, reality sets in. Bodies start to change - mentally and physically. We often focus on the bad, not the good. That does not mean that good or positive moments do not occur but they are often not the focus. Interestingly with diseases like cancer, there are ways to treat the disease with a possible positive outcome - remission and longer life. Sadly, liver and kidney disease does not have the silver lining - unless on a transplant waitlist and obtaining the needed organs. Instead, these two diseases focus on treatments to help the person be comfortable - through procedures known as dialysis (for the kidney) and parenthesis (for the liver). These are not fixes; rather they are band aids for what is to come - ultimately the failure of the organs themselves. The idea of terminal illness and death is very much a part of our medical disclosure but it is strangely absent in how we, as individuals that possess these terminal illnesses understand and come to terms with the diagnosis, as well as how family members help manage these diagnosis and the inter-relational complexities that develop from these diagnoses. You try and stay positive but in light of knowing that someone you care so deeply for, that has been in your life forever is dying - right before your eyes - it can cloud your vision, your view of life, creating a dense forest that was once an open field. That is often where I situated myself in this representation of my role and journey. Is it a full representation? No. Nevertheless, it does represent the real, raw, painful moments of my realizations that my dad is slowly leaving this earth.

December 10, 2018

On December 10, 2018, I officially became Andrea Noel Guziec Button. The decision to change my formal last name was not without much reflection and internal conflict. At this point in time, I am still married but separated. I knew that I would be changing my name in the future, but when I thought about becoming Andrea Noel Guziec once more, it did not feel natural; staying an Iaccheri did not either. Both sir names hold deep meaning to me as they have both been a part of my identity for long lengths of my life. After much reflection, I decided to take on a new last name, a new identity.[133] I wanted to keep Guziec, moving it to a second middle name An identity separate from my married identity and closely connected to my maiden identity. Guziec in the Polish language has two main spellings – Guziec and Guzik. – The name translates from Polish to English as Guziec – Warthog and Guzik – Button. I decided to go with the more pleasant translation of my Polish maiden name – Button, keeping Guziec a part of me – always and forever.

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[133] I legally added Guziec to be a second middle name. This action provided me the opportunity to keep an identifier to connect me with my previous publication under Guziec-Iaccheri, uphold the Guziec name as part of my formal name, and establish my new last name – Button - with my current work and future publications.

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