

**FRAMING THE DEGREE:  
AN AUTOETHNOGRAPHY OF TRAUMA IN THE GRADUATE STUDENT  
EXPERIENCE**

---

A Dissertation

Presented to

The Faculty of the School of Education

The College of William and Mary in Virginia

---

In Partial Fulfillment

Of the Requirements for the Degree

Doctor of Philosophy

---

by

Kristen Layne Tarantino

April 2016

**FRAMING THE DEGREE:**  
**AN AUTOETHNOGRAPHY OF TRAUMA IN THE GRADUATE STUDENT**  
**EXPERIENCE**

by

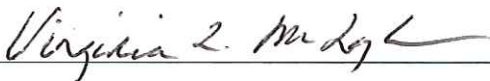
Kristen Layne Tarantino

---

Approved April 12, 2016 by



James P. Barber, Ph.D.  
Chairperson of Doctoral Committee



Virginia L. McLaughlin, Ed.D.  
Committee Member



Tony E. Adams, Ph.D.  
Committee Member

## DEDICATION

This dissertation is dedicated to my husband and two children who gave me the courage and inspiration to complete this study, and without whom I would not have started or finished my program.

## TABLE OF CONTENTS

	Page
DEDICATION	iii
TABLE OF CONTENTS	iv
ACKNOWLEDGEMENTS	viii
LIST OF FIGURES	xii
ABSTRACT	xiii
CHAPTER	
I DEVELOPMENT OF A DISSERTATION	2
Trauma in Higher Education.....	5
Statement of Purpose.....	7
Research Questions.....	8
Theoretical Framework.....	9
Using Theory and Story.....	12
Definition of Terms.....	13
Design of Study.....	14
Format of Findings.....	16
Significance of Study.....	16
Organization of Study.....	17
II LITERATURE REVIEW	18
College Student Development.....	20
Kegan’s Theory of Self-Evolution.....	20
Baxter Magolda’s Theory of Self-Authorship.....	21
Demands of Life Require Self-Authorship.....	23
Trauma.....	24
Impact of Trauma.....	25
Posttraumatic Growth Theory.....	27
Psychological Domains of Growth.....	29
Appreciation of Life/Change in Priorities.....	29
More Intimate Relationships with Others.....	30
Greater Sense of Personal Strength.....	31
Recognition of New Possibilities.....	32
Spiritual Development.....	32
Social Support and PTG.....	33

CHAPTER		Page
	Trauma in the Graduate Student Experience.....	35
	Graduate Student Experience and Doctoral Programs..	37
	Female Doctoral Students.....	37
	The Challenges of the Unexpected.....	38
	Doctoral Mentoring.....	38
	Summary.....	40
III	METHODOLOGY	42
	Dual-Paradigmatic Referent.....	43
	Interpretivism.....	43
	Postmodernism.....	44
	Interplay of Paradigms.....	46
	Why Autoethnography?.....	47
	Assumptions of Autoethnographies.....	49
	Form and Process.....	51
	Criteria for Autoethnography.....	52
	Truth.....	54
	Memory.....	54
	Data Sources.....	55
	Analysis and Interpretation.....	56
	Coding.....	57
	Layered Account.....	58
	The Writing Process.....	61
	Ethical Considerations.....	62
	Addressing Relational Ethics.....	64
	Consent.....	66
	Writing Tensions.....	67
	Summary.....	68
IV	SEARCHING FOR TRUTH	69
V	THE START OF A NEW NORMAL	96
VI	“RING THIS BELL”	139
VII	PROCESSING TRAUMA	168
	Before and After Trauma.....	169
	Pre-Trauma Me.....	170
	Trauma Me.....	171
	Post-Trauma Me.....	172
	Reflecting on Pre-Trauma Me.....	173
	Relationships with Others.....	175

My Posttraumatic Growth Process.....	177
Cognitive Processing.....	178
Automatic and Intrusive Thinking.....	181
Disengagement from Goals.....	182
Deliberate Processing.....	183
Cognitive Schema Change.....	184
Social Supports and Self-Disclosure.....	186
Domains of Growth.....	189
Appreciation of Life and Change in Priorities.....	189
More Intimate Relationships with Others.....	190
Greater Sense of Personal Strength.....	192
Recognition of New Possibilities.....	194
Spiritual Development.....	194
Enduring Distress.....	196
Addressing My Research Questions.....	197
RQ1: How did the psychological impact of trauma affect my graduate student experience?.....	197
RQ2: How did my traumatic experience affect my assumptions about reality, in relation to the graduate student experience?.....	198
RQ3: Within my graduate program, where, and in what form, was social support present during the cognitive processing of my traumatic experience?.....	199
Wisdom from Trauma.....	199
 VIII      SHARING WISDOM	 201
Implications for Posttraumatic Growth Processes.....	202
Implications for Graduate Programs.....	204
Implications for Institutional Policy.....	207
Increasing Communication with Students.....	207
Medical Leave of Absence Process.....	208
Services Affected by MLA.....	208
Reinstatement as Student.....	209
Departmental Coordination.....	210
Aligning with Student Status.....	212
Implications of Sharing Stories.....	214
Finding Wisdom from Trauma.....	215
My Wisdom for Faculty.....	215
Balance Challenge and Support.....	216
Establish Open and Personal Communication.....	217
Embrace Vulnerability.....	217
Support the Decisions Students Make Following Traumatic Experience.....	218
Be Present for the Entire Journey.....	219
My Wisdom for Graduate Students Experiencing	

Trauma.....	220
It Is Okay to Share.....	220
Life and School Are Not Separate.....	222
Processing Requires Time and Space.....	222
Disclosure Is Easier When You Have an Outlet You Trust.....	223
Personal Wisdom.....	223
Conclusion.....	226
 IX       EPILOGUE	228
 APPENDIX A: Informed Consent Form	244
 APPENDIX B: Child Verbal Assent Form	246
 APPENDIX C: Parental Permission Form	247
 APPENDIX D: Taylor & Francis License Terms and Conditions	249
 REFERENCES	252
 VITA	266

## ACKNOWLEDGEMENTS

Writing this dissertation has been a labor of pain, love, and late nights. It is also a reflection of my time as a doctoral student, and as such those who supported both endeavors are owed tremendous gratitude. However, this may be the most difficult ‘Thank You’ card I have ever written.

I could not have embarked and finished this dissertation without the sage advice and guidance of my dissertation committee: James (Jim) Barber, Virginia (Ginnie) McLaughlin, and Tony Adams. Each of you are phenomenal writers, and I am blessed to be able to benefit from your expertise and sound contributions. Ginnie and Tony, I appreciate your willingness to accompany me on this journey. I was incredibly nervous that a lack of prior working relationships would result in a resounding “no” when I asked both of you to consider joining the committee. You have both been instrumental in the vision and success of this dissertation.

Jim, both of our journeys at the School of Education are linked. We learned the ropes and policies together, though from different points of view. I am forever indebted to you for agreeing to see this dissertation through to its end. Neither this dissertation nor this program was easy for me, but you have always been supportive and willing to help me through a challenging situation. I am lucky to have been able to work with you, learn from you, and write with you. And I thank you sincerely.

There are several staff and faculty members at the School of Education who supported me and my family: Jim Barber, Sharon deFur, Pam Eddy, Leslie Grant, Judi Harris, Wendy Pearson, James Stronge, and Tom Ward. Each has pushed my writing to be better, my motives to be stronger, and my resolve to be well-intentioned. I could not



ask for more accomplished mentors in the art of education and research. But true to my belief that education is about the whole person, each of you are truly good and decent people who care for your students. Thank you for extending your caring nature to my family and for seeing me as more than a student.

I am not sure I could have survived my program without the company of a truly dedicated cadre of future educators: Elizabeth Auguste, Leslie Bohon, Laura Feltman, Jess Hench, Paige Hendricks, Diana Hernández, Tehmina Khwaja, Kerri Mahoney, Julie Marsh, Amy Morgan, and Diana Theisinger. Between road trips, tea parties, birthday celebrations, late nights at the School of Education, and meaningful conversations, we have developed a bond that has served to keep my head on straight and remind me that I am not alone. You all provide the ultimate confidence booster when I am feeling down, and some of the most poignant life wisdom when I am trying to make sense of the world. To Diana H., Paige, and Diana T., you will always be the women who know me the best, and I thank you for your friendship, counsel, and support. To Leslie and Laura, if I ever need a debrief over Chinese food or a willing roommate for a conference, I will always ask you first.

To my friends, near and far, who have been my constant companions, sorority sisters, and unending supports: Amanda DeBres, Michelle Crownover, and Jayme Watkins. To my little sapphire sister, Jayme, you always know what I need to hear in order to smack me out of a funk and get down to business. You are also the one who inspires me to be courageous even when I lose faith in myself. Thank you for showing me the value of personal pride and confidence. To Michelle, you have an uncanny sense of when I need a good phone chat. You have never wavered in your belief that I can do

whatever I set my mind to, and I truly thank you for believing in my abilities. To my best friend, confidante, and sister from another lifetime, Amanda, thank you for being who you are and for loving my family. There is no one else with whom I would rather laugh, cry, or stay up until 4:00 AM talking about life. We have spent over half our lives together, seeing both joy and sorrow. Thank you for supporting me, teaching my children, and offering perspective when I needed it most.

I would never have made it this far in my education without the love and support of my family. To my grandparents, John and Rochelle Grey and Elizabeth Layne, thank you for instilling in me the importance of education as well as the importance of family. I would not be who I am today had it not been for your example. To my parents, Stephen and Eileen Layne, thank you for encouraging me to finish my college degree when I was a new mother, for caring for my children when I needed space to write, and for supporting me and Brian when Nathan was diagnosed with Autism and then cancer. You have been my two most devoted advocates, and I love you both very much.

All of these acknowledgements would be pointless if not for the most important people in my life: Brian, Nathan, and Owen. I have to thank my loving husband, Brian, for the years of schedule shifting, late nights, daycare checks, and frozen dinners he had to survive on behalf of my graduate education. Brian, you are my soulmate and could not have travelled this journey without you. To my little Owen, your enthusiasm and knowledge astounds me and always finds a way to encourage me to do my best. Your wit keeps me smiling, and often times laughing, and I am so proud of how you have grown into such an intelligent little boy. Thank you for being a responsible brother and for being patient with me as I finished my degree. I also have to thank Sweet Pea for the endless

therapy and amusement she has provided for the family. Some days, you just know when I need a good cuddle. Finally, I have only ever wanted to better support my family. So to my dearest Nathan, you have inspired me to be the best mother I can be. You have given me the courage to fight for what is right, to advocate for those beyond myself, and to love unconditionally. Thank you for being you. I love you all so very much.

## LIST OF FIGURES

	Page
Figure 1. Model of Posttraumatic Growth	10
Figure 2. Model of Posttraumatic Growth	28
Figure 3. Dual-Paradigmatic Referent for Autoethnography	47
Figure 4. Model of Posttraumatic Growth	59
Figure 5. Model of Posttraumatic Growth	179
Figure 6. Components of My Posttraumatic Growth	180

**FRAMING THE DEGREE:**  
**AN AUTOETHNOGRAPHY OF TRAUMA IN THE GRADUATE STUDENT**  
**EXPERIENCE**

**ABSTRACT**

Traumatic experience among graduate students is overlooked as a factor impacting the graduate student experience. This study uses autoethnography to examine the psychological impact of my own traumatic experience in relation to my graduate student experience. I rely on personal narrative layered with theoretical literature on posttraumatic growth processes (Tedeschi & Calhoun, 2004) to illustrate the power of trauma in redefining my internal schema within the graduate student experience. Posttraumatic Growth (PTG) requires that an individual cognitively process and make new meaning from traumatic experiences. In this autoethnography, I share and examine my personal story of trauma and how I made sense of those experiences, both as an individual and within the context of my graduate program.

Wisdom from trauma revealed recommendations for graduate students experiencing trauma and their faculty. For faculty, helping students process and develop posttraumatic growth requires (a) balancing support and challenge, (b) establishing open and personal communication with graduate students, (c) embracing vulnerability, (d) supporting the decisions students make following traumatic experience, and (e) being present in the journey toward growth. Wisdom for graduate students experiencing trauma include (a) knowing that it is okay to share their experiences, (b) realizing that life and school are not separate, (c) understanding that processing takes time and space, and (d) identifying trustworthy outlets to practice self-disclosure. This autoethnography further

shares implications for institutional policy, advocates for using PTG as a developmental process within graduate programs, and emphasizes the value of sharing stories.

Keywords: *autoethnography, trauma, graduate student experience, posttraumatic growth*

KRISTEN LAYNE TARANTINO

DEPARTMENT OF EDUCATIONAL POLICY, PLANNING, AND LEADERSHIP

HIGHER EDUCATION ADMINISTRATION

THE COLLEGE OF WILLIAM AND MARY IN VIRGINIA

FRAMING THE DEGREE:  
AN AUTOETHNOGRAPHY OF TRAUMA IN THE GRADUATE STUDENT  
EXPERIENCE

## CHAPTER ONE

### DEVELOPMENT OF A DISSERTATION

“So when are you coming back to school?” *When indeed.* I can feel my blood pulsing from the initial reaction to the question. The thought of making a decision almost a year in advance is enough to make me break into hives.

“Barring a serious complication, I’m planning to come back in the fall,” I say.

I see and hear happy exultations from my peers. But I don’t join in. I keep part of myself closed away, not letting myself be comfortable with the idea that everything is back to normal. What if something happens? Can I even do this school thing after everything that has happened? I can barely concentrate on a book, how am I going to manage finishing up classes? What does *normal* even mean?

I think about all of the things my peers get so worked up about. Deadlines, assignments, feedback. The complaints I’ve heard over the last five years are enough to make me think, is it really worth it?

There is nothing like a cancer diagnosis to make you question your priorities. Have my priorities really changed all that much? Was I the person who got wrapped up in work so much that I couldn’t think about anything else? How has this experience changed my perspective on the program? On my life?

I am scared. Scared of so many things. Scared of making huge decisions that in a moment’s notice could be shattered. Scared of being mediocre. Scared of being seen as a



pity case. All of which is ironic since I feel strong. How could I not feel strong to have survived the last year? The last 11 years? So why am I so afraid of proving myself?

*Because you're afraid you'll fall short of where you thought you'd be.*

It is lonely being in a place where you can't relate to others. In a way, I long to be absorbed fully by my work like so many of my classmates. And yet, there's a part of me that has never understood nor wanted the complete loss of self to work, to research. I want balance. I want the merits of an intellectually challenging life and the joys of being a mother, a wife, a friend. But in order to do that I have to make a decision, to live with a decision, accepting that it might change without notice.

"You should be almost done though, right?" *Ha.* If only it were that simple.

"I have several incompletes to work on, and a couple more classes, but next fall will be my last semester of class. Hopefully." I cross my fingers in a prayer gesture that is all too familiar.

"So when will you finish?" *The litany continues. Is this what the program is about? A race to the finish?*

"Hopefully, next spring," I say. *So much hope for someone who has felt so much hopelessness.* The conversation has become a burden, a trial that I must repeat for each friendly face. It succeeds in maintaining my discomfort, my uncertainty about the future. My attempt to give direct answers doesn't deter further probing about my ability (and desire) to complete the program. My only recourse is to jump ship on the conversation by announcing my escape or changing the topic. I opt for the first choice. "Well it was good to see you, I have to get home..."

\*\*\*

There are few women in my graduate program who have children, let alone a spouse. Some days I consider my spouse an additional child I must parent. Those women in my program who do have children, most often have grown children or are just starting their families. At 31 years old, I have both an 11 year old son and a five year old son. I neither fit in with those students fresh out of their undergraduate programs, nor do I feel that I fit in with those women who are in their mid- to late thirties (or older) and have real career experience or older families. I play both parts depending on who I am with at the time, but I know which identity to assume and which to leave out. Some days I enjoy feeling carefree, having dinner with friends or going to conferences that allow me to “play” professional. But then I also enjoy sharing stories of my children with other parents, knowing that they have faced some of the same school or behavior problems. It becomes difficult then to also assume the role of student, adult learner, professional in training. Before I achieved my new designation(s) as caregiver, nurse, psychiatrist, interpreter, doctor, I felt as though I had found a decent balance.

Knowing who to be, at a given time, has become complicated, such that I have felt off-kilter, struggling to find purchase on uneven ground in the dark. More often than not, I find myself feeling ill-prepared, blind to every eventuality even though I actively create scenarios in my mind that allow me to play out each outcome.

When I began my doctoral journey, I had no concerns about the process, the coursework, the expectations. Perhaps I was insanely naïve. Perhaps I was merely moving through my education like a typical adult would: worrying about being competitive in the job market, pursuing new career paths, learning for the sake of learning. Pursuing a doctoral degree was less about my individual growth and

development and more about how I could provide a better life for my family. I had little expectation beyond entering a career that would allow me to support my children, and provide me with some much needed adult interaction.

How idealistic of me! Or perhaps my reaction to what and who I used to be has been tarnished, offering a more cynical interpretation of how I had hoped to be at and beyond graduation. But then, who could have anticipated the trauma of the last couple years?

### **Trauma in Higher Education**

Psychological trauma is disorienting, forcing individuals to reassess their assumptions about their lives as well as reality at large. Although types of trauma may differ by individual, trauma, in general, can produce negative or positive psychological effects depending on the individual's ability to process experiences in a way that re-engineers personal schemas to accommodate changes in thinking (Tedeschi & Calhoun, 2004). Negative psychological effects most often include the development of depressive symptoms but can also be a precursor for psychiatric disorders. Positive psychological effects of traumatic experiences, however, stem from a process of *posttraumatic growth* (Tedeschi & Calhoun, 2004). This autoethnographic study situates a personal experience within the posttraumatic growth framework to illustrate how trauma can impact the graduate student experience.

Unfortunately, research on posttraumatic growth in higher education has been limited to undergraduate college students and has provided little insight into how graduate students experience posttraumatic growth. The experiences of undergraduate students are among the highest in reported severity of trauma, but can vary greatly due to

the developmental level of the student as well as college environment itself (Parks, Cohen, & Murch, 1996). Students entering college have their assumptions challenged in every assignment, class, and reading in which they engage, to say nothing of the impact of the highly social environment associated with college. In fact, since the posttraumatic growth process mirrors the developmental progression of several established college student development theories (Baxter Magolda, 2008; Kegan, 1994; Pizzolato, 2005), the severity of traumatic experiences reported by college students, and the ability to perceive growth from those experiences, may also be a function of the level of their identity development and corresponding maturation (Tedeschi & Calhoun, 1996).

In contrast, graduate students may not be as affected by identity development and maturation as undergraduate students, given that they are typically older than the traditional aged, 18-22 year-old undergraduate student on which many student development theories are based, leaving little indication for how theoretical models may help explain growth when subject to more traumatic life events outside of the higher education environment. For example, these graduate students may experience job loss, divorce, personal or family illness, or even death. As an undergraduate student, I had already been exposed to the meaning-making process that occurs as a result of trauma. Not only was my first son, Nathan, born while I was an undergraduate student, he was also diagnosed with an Autism Spectrum Disorder at the age of four. This pre-exposure to trauma may not be present for all graduate students, and, in my case, it may have replaced the non-trauma related identity formation process that can occur in the typical 18-22 year-old undergraduate student population. Acknowledging that pre-exposure to trauma can create a foundation from which to make sense of future traumas is an element

that makes my story important for other students who may experience trauma. It may also have better prepared me for the next traumatic event that occurred during my doctoral program, in which Nathan was diagnosed with a brain tumor. Such traumatic events, in conjunction with the high programmatic expectations already established by graduate programs, pose a threat to graduate student retention and completion (Spaulding & Rockinson-Szapkiw, 2012), including extended leaves of absence, all but dissertation (ABD) designations, and incomplete coursework that may result in a failed course.

Processing a traumatic experience, however, is difficult to achieve in isolation (Tedeschi & Calhoun, 2004). Graduate programs that promote self-disclosure provide opportunities for students to seek support in the posttraumatic growth process. Programs that do not encourage disclosure fail to understand the depth of a student's traumatic experience, creating a culture that disregards the value of traumatic events as "provocative moments" in students' lives (Pizzolato, 2005). Social support is necessary for individuals to be able to process the psychological impact of trauma on their lives (Tedeschi & Calhoun, 2004). A graduate student experience under the strain of trauma can be vastly different from that of a student with no traumatic experience. Specific traumatic events, as well as the processes of how a student makes meaning of trauma within the graduate student experience, are rarely examined, and arguably undervalued, as a factor in graduate education.

### **Statement of Purpose**

There are two primary purposes for this autoethnography on the impact of trauma within the graduate experience. First, in sharing my story, I am choosing to offer my experiences as a resource for other graduate students who have made or are in the process

of making meaning of similar traumas. Because personal traumatic experiences are often unseen or expressed, this study brings to life a real trauma to examine how it can impact the graduate student experience. Second, this autoethnography has value for graduate educators and institutional administrators who may enroll students who experience personal trauma. Having an understanding of students' experiences and meaning making of trauma can prepare educators and administrators to support these students, as well as provide implications for approaches to student advising, course expectations, and even graduate student policies. My experience, as a graduate student caring for a child with chronic, and life-threatening, medical conditions provides a specific example in which to explore the impact of trauma on the graduate student experience.

### **Research Questions**

The narrative analysis of my traumatic experiences related to the diagnosis of and treatment for my son's illness is guided by the posttraumatic growth process (Tedeschi & Calhoun, 2004), as well as the following questions:

Overarching Question: *How did the traumatic experience of my son's diagnosis and subsequent care affect my personal life narrative, particularly as related to my graduate student experience?* More specifically, the questions to be investigated in this study are as follows:

1. How did the psychological impact of trauma affect my graduate student experience?
2. How did my traumatic experience affect my assumptions about reality, in relation to the graduate student experience?

3. Within my graduate program, where, and in what form, was social support present during the cognitive processing of my traumatic experience?

### **Theoretical Framework**

Posttraumatic growth seeks to explain the ability of an individual to develop after a traumatic experience has occurred. Tedeschi and Calhoun (2004) described posttraumatic growth as both process and outcome, predicated by a significantly traumatic or “shattering” experience (p. 4). The main premise behind posttraumatic growth is the ability to cognitively process a traumatic experience by weighing it against pre-established assumptions, discarding the old assumptions or schemas, and creating new schemas to better fortify the individual against a subsequent trauma. This cognitive processing ultimately involves the narrative development of an individual’s new identity. In order to accomplish this process, Tedeschi and Calhoun (2004) stipulate the necessity of social supports to promote disclosure and to provide models for coping, as well as schema development (See Figure 1).

Posttraumatic growth theory begins with an understanding of an individual pre-trauma. This understanding includes self-knowledge and assumptions the individual has, existing values and frameworks, and personality characteristics such as optimism and extraversion (Tedeschi & Calhoun, 1995, 2004). Although these pre-trauma characteristics may support posttraumatic growth as an outcome post-trauma, they do not guarantee that an individual will experience growth following a traumatic event. Trauma, termed a “seismic event,” effectively shatters the individual’s assumptions about the world, leading the individual to question their life narrative and beliefs, and produces emotional distress (Calhoun & Tedeschi, 1999, p. 2). Following a traumatic event, the

Figure 1. Model of Posttraumatic Growth

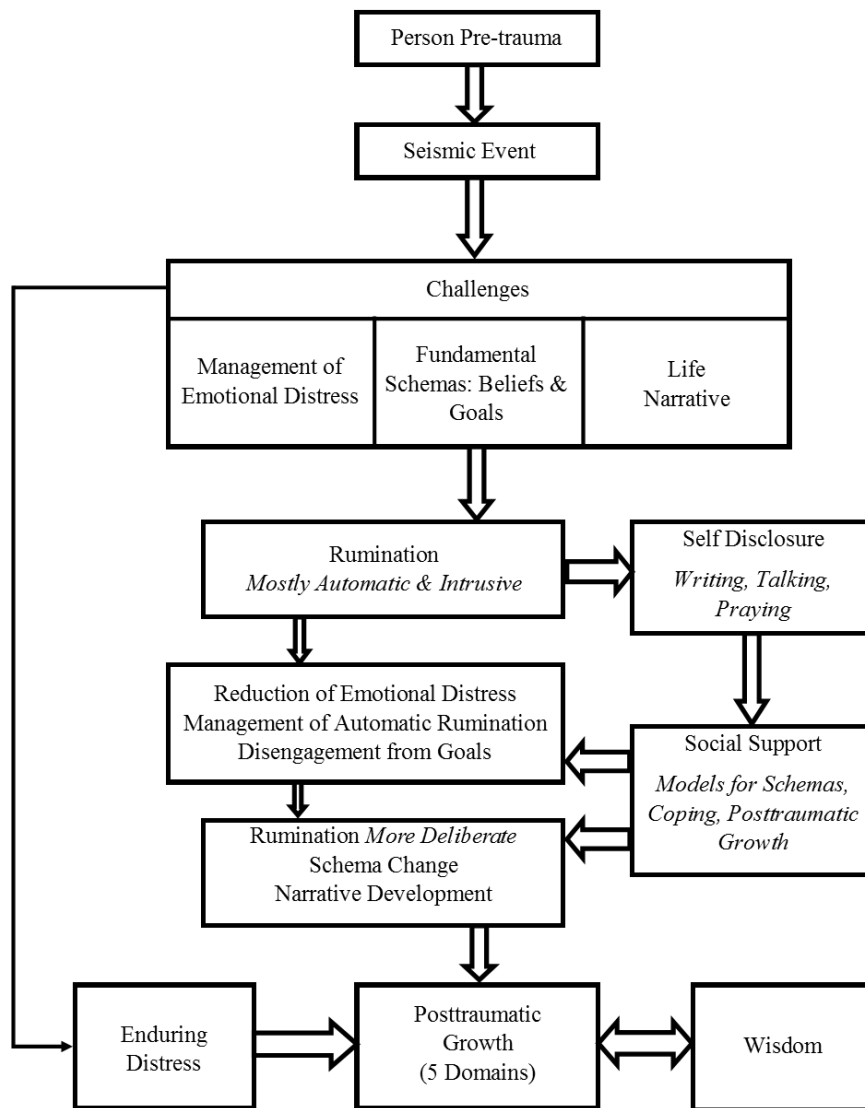


Figure 1. Theoretical model of posttraumatic growth that explains the psychological processes that contribute to growth when an individual experiences trauma (Tedeschi & Calhoun, 2004). From “Posttraumatic Growth: Conceptual Foundations and Empirical Evidence,” by R. G. Tedeschi and L. G. Calhoun, 2004, *Psychological Inquiry*, 15(1), p. 7. Copyright 2004 by Taylor and Francis. Reprinted with permission.

individual moves through a series of cognitive processes, from automatic and intrusive



thoughts, to letting go of previously held goals that are contributing to emotional distress, and moving towards a new schema in which the self-narrative is made stronger and prepared for future traumas (Calhoun & Tedeschi, 1999; Tedeschi & Calhoun, 2004). These cognitive processes are successful in leading towards growth if there are adequate sources of social support as well as avenues for disclosure from which individuals can model new schemas and coping skills (Tedeschi & Calhoun, 2004).

According to Tedeschi and Calhoun (2004), growth occurs as a result of the individual struggle with reality after a trauma, not as a direct result of the trauma itself. In this instance, posttraumatic growth compliments existing student development theories in which students must grapple with challenges to their assumptive worlds. Kegan (1994) described a holistic model of personal development in which an individual moves through more complex stages of thinking as a result of being faced with challenges that do not fit a current stage of thinking. These challenges may be referred to as “provocative moments,” where an experience or challenge disrupts one’s established assumptions and leads to a reevaluation of identity (Pizzolato, 2005, p. 265). Additionally, the importance of social supports in the growth process following a traumatic experience mimics the *good company* that Baxter Magolda (2002, 2009) described as a necessary component in the development of self-authorship, or moving from externally defined formulas toward the negotiation of internal foundations. While posttraumatic growth is inherently individual and psychological, there remains a social element to the model that relates, in the case of graduate education, to the role that graduate culture plays in supporting positive growth in the aftermath of a trauma. The posttraumatic growth model, then, is not only a means by which to explore how graduate students process traumatic

experiences, but can also inform how social structures within the graduate experience may support or inhibit growth.

### **Using Theory and Story**

The theoretical framework and corresponding model presented in Figure 1 is utilized in two ways for this study. First, posttraumatic growth as a process informs the literary development of the study itself. Within posttraumatic growth theory, there are three main categories: before trauma, during trauma, and after trauma (Tedeschi, & Calhoun, 2004). These categories define and characterize the plot structure of the narrative itself, moving from my knowledge of self prior to trauma, through a series of traumatic episodes, and ending with the process of meaning making after the bulk of the trauma had passed. Second, although posttraumatic growth theory is robust, the majority of cognitive processing is internal (Tedeschi & Calhoun, 1995; 2004), which is reflected in the narrative. However, fit into an autoethnographic approach, posttraumatic growth allows for interpretation of the role of support networks in cognitive processing. Therefore, connections to the larger higher education culture can be drawn from analyzing where and in what format disclosure and support systems are present to support graduate students experiencing trauma.

However, given the lack of research available on trauma in the graduate student experience, and given the unique characteristics of my traumatic experience, this study also relies on the use of story as theory (T. E. Adams, Jones, & Ellis, 2015; Bochner, 1997). Although much of social science research focuses on objectivity as a source of expertise, the nuance and subjectivity of personal story provides room for readers to think *with* story as opposed to thinking *about* story (T. E. Adams et al., 2015; Bochner, 1997).

Engaging with a story in this manner allows a reader to use story as a framework, letting the reader be a part of the story in order to understand and interpret other experiences (T. E. Adams et al., 2015). Thus, instead of using story as data to test a theory, this study uses story for readers to analyze their own lives or policies, the moral implications, and the contradictions that may be presented (Bochner, 1997; Ellis, 1995).

### **Definition of Terms**

*Autoethnography:* A qualitative approach that emphasizes the positioning of personal experience within the research in order to better understand cultural experience (T. E. Adams et al., 2015; Ellis, 2004). In this study, autoethnography uses personal, evocative writing (Ellis, 2004) woven together with reflexive thought in order to provide a performative text of personal experience within a cultural context (i.e., the graduate student experience).

*Cognitive processing:* Cognitive activity in which individuals process how an event impacts or changes that individual's worldview (Calhoun & Tedeschi, 1999).

*Graduate student experience:* Refers to the rigorous and mature academic focus, professional development, and socialization processes experienced by a student during a graduate program.

*Personal development:* The process through which an individual moves through more complex meaning making in order to better understand the self in relation to others (Kegan, 1994).

*Posttraumatic Growth (PTG):* An ongoing process, and outcome, of individual growth that occurs as a result of a major crisis, triggering transformative life changes experienced as a "shattering" of existing schemas and producing psychological distress.

Growth is indicative of an individual's development beyond the pre-trauma baseline (Tedeschi & Calhoun, 2004, p. 4).

*Self-authorship:* The end result of addressing epistemological, interpersonal, and intrapersonal dimensions of personal development in which an individual moves from an externally defined sense of self to a more internally defined sense of self (Baxter Magolda, 2001, 2009).

*Social support:* The social networks, both previously established and emergent following a trauma, that support an individual's coping with a traumatic event as well as the development and integration of new worldviews following an event (Tedeschi & Calhoun, 1995, 2004). These networks may include, but are not limited to friends and family, "mutual help" or those others who experienced a similar trauma, and professional help (Tedeschi & Calhoun, 1995).

*Trauma:* Events that are sudden or unexpected (McCann & Pearlman, 1990; Weiss & Parkes, 1983); uncontrollable or perceived as such (Slaby, 1989; Tennen & Affleck, 1990); lacking familiarity or are out of the ordinary (McCann & Pearlman, 1990; Tedeschi & Calhoun, 1995); irreversible or chronic (Davidson, Fleming, & Baum, 1986; Tedeschi & Calhoun, 1995); and, responsible for producing a sense of blame (Tedeschi & Calhoun, 1995). In this study, the trauma under examination includes my experience of my son's diagnosis of illness, as well as the subsequent care and treatment for that illness.

### **Design of the Study**

Autoethnography is a qualitative approach that uses particular experiences and stories of the self to understand the greater societal culture (T. E. Adams et al., 2015; Ellis, 2004). It is both a process and product of sharing lived experiences about a

particular situation, context, or circumstance, most notably through the lens of the author. This particular autoethnography employs personal narrative as a means through which to examine the impact of traumatic experience on students who are engaged in graduate study. Autoethnographies can range in the degree of literary composition, from autobiographical to more traditional ethnographic formats (T. E. Adams & Ellis, 2012; Denzin, 2014; Ellis, 2004). My autoethnography leans more towards the autobiographical end of this spectrum in compositional format, but also ties my story to the greater cultural context of higher education.

Autoethnographies are often structured around epiphanies, “interactional moments and experiences which leave marks on people’s lives” (Denzin, 2014, p. 52). These epiphanies can be ritualized, cumulative, emergent, or minor, and may have a positive or a negative effect (Denzin, 2014). It is in these epiphanies that we question ourselves, our identities and beliefs. We then situate ourselves and our epiphanies within story, moving in and through time to develop a storyline, characters, and plot around an experience that is missing (T. E. Adams et al., 2015). Denzin (2014) suggested that “the meanings of these experiences are always given retrospectively, as they are relived and re-experienced in the stories persons tell about what has happened to them” (p. 52). Thus, as an author writes an autoethnography, the story holds a version or interpretation of reality that is determined by the author and, consequently, by the reader. This interpretation is developed through the narrative as well as by using existing evidence to compare and contrast with the narrative (T. E. Adams et al., 2015). For this study, existing evidence and scholarly references do not serve to validate or objectify the

narrative, but instead are used to contextualize the narrative in a way that readers may make conclusions regarding connections or contradictions to other experiences.

### **Format of the Findings**

This study provides a subjective view of events that occurred during my doctoral program. For this autoethnography, it is important for me to explore my own experiences and the vulnerability required to relive those experiences. The story that follows begins in the fall of 2013, during my second year of doctoral study. Because trauma is, by definition, chronic, the ending of the story varies a little each day that I write about it. For purposes of this study, the “ending” is characterized by the dissertation writing process itself. Throughout the narrative, reflexive thinking and personal meaning making or processing is noted in italics. Autoethnographies are typically written using the first-person voice and move between action, dialogue, emotion, and reflexive thought to provide a holistic expression of the experience (Ellis, 2004). This study relies heavily on dialogue, both external and internal, to provide a sense of what happened, as well as how I experienced what was happening. Throughout the body of the narrative, any attempts to link to additional resources will be made in the use of footnotes so as to keep the story intact.

### **Significance of the Study**

The personal lives of graduate students are mostly private, kept in a bubble because they are not suitable for a professional environment. For those students who experience significant trauma, finding support from within a graduate program may be difficult or non-existent. This study provides my personal account of traumatic experience so as to give program stakeholders—faculty, administrators, and students—

real-life evidence that graduate students are facing “real-life” problems outside of their studies, and to detail how I made sense of such an experience while enrolled in academic study. My experience, while perhaps unique in its details, is one of many types of traumatic experience that graduate students may encounter. Sharing my story gives voice to the unspoken, often disregarded experience of trauma within academia, and calls for a change in cultural expectations for and perceptions of graduate students.

### **Organization of Study**

Chapter One provides a general introduction to the focus of the study, both from a personal perspective as well as the general problem to be researched. Chapter Two provides a review of the relevant and extant literature on college student development and how it relates to the idea of posttraumatic growth. An introduction to autoethnography as method as well as the specific methodological conditions for this study are included in Chapter Three. My story begins in Chapter Four, where readers get a glimpse of my pre-trauma self. Chapter Five explores my traumatic experience in detail, and Chapter Six describes my experience of surviving and making sense of that trauma. Chapter Seven analyzes my autoethnography using the posttraumatic growth framework and will situate the experience within the limitations of the higher education culture. Chapter Eight concludes this study with lessons learned and recommendations for other graduate students experiencing trauma, graduate educators, and institutions in general. Finally, Chapter Nine (written post-defense) provides an epilogue to my narrative and describes my experiences in the final stages of dissertation writing, including the dissertation defense.

## CHAPTER TWO

### LITERATURE REVIEW

Understanding how college students make meaning of particular events and information, and how to challenge students to expand that meaning making, is one of the main responsibilities of educators in colleges and universities. Knowing how students think, understand their personal identity, and relate to others is a function of how students develop in relation to external authorities and influences (Pizzolato, Nguyen, Johnston, & Wang, 2012). Although research on student development has shown that development shifts from external to internal meaning-making processes (Baxter Magolda, 2001, 2009), there is little research on the impact of external or situational factors, particularly traumatic experiences, on the development process.

Competing meaning-making systems may be more easily navigated by traditional-aged undergraduate students (18-22 years of age) because they have yet to claim their own voice (Baxter Magolda, 2001; Twamley, Hami, & Stein, 2004). Undergraduate students have not fully developed their internal meaning-making schemas and are still taking in and assessing other sources of information to determine who they are and what they believe. Trauma experienced as a traditional-aged undergraduate student may be one more source of information to draw from, making undergraduates more resilient than an older graduate student who might be closer to the advanced stages of identity development such as self-authorship (Baxter Magolda & King, 2012; Twamley et al., 2004). Trauma at the more advanced stages might cause an individual to



revert to previous ways of meaning making that are not in line with the established internal voice. Individuals who regress to previous methods of meaning making may take longer to assimilate and make sense of these new experiences, leading them to be less resilient than a traditional aged college student (Abes & Jones, 2004; Twamley et al., 2004). Thus, incorporating new knowledge from trauma as an older adult or graduate student poses a significant challenge to existing, linear models of college student development (Baxter Magolda & King, 2012). How these graduate students make sense of trauma and redefine their identity following traumatic experiences is less a function of developmental processes and more related to how an individual reacts psychologically in the aftermath of trauma.

This chapter begins with a review of the literature about college student development and the related theories that explain how individuals develop more complex systems of meaning making. In general, meaning-making systems move from a focus on external reference to reliance on internal modes of meaning making (e.g., Baxter Magolda, 2002, 2009; Kegan, 1982, 1994; Perry, 1968). Following this discussion of the models typically used for college student development is an introduction to trauma and its effects on individuals. This chapter further discusses trauma in relation to college students by making connections between student development theory and posttraumatic growth theory. These connections and similarities to existing student development theory can be seen in a description of psychological domains of growth and support networks necessary to facilitate growth. This chapter ends with a discussion on the focus that trauma research has had in relation to graduate students and an examination of how the graduate student experience is separate from the undergraduate experience.

## **College Student Development**

Several theoretical models suggest how students develop identity. Typically, “theories addressing epistemological development begin when the students are in college” (Wawrynski & Pizzolato, 2006, p. 687). Because this study focuses on the psychological impact of trauma, it is important to consider the primary identity development theories that utilize a holistic, yet psychological, approach to development. Specifically, Kegan’s (1982) theory of self-evolution and Baxter Magolda’s (2009) theory of self-authorship exhibit parallels with posttraumatic growth theory, suggesting that older students may display alternative methods of meaning making in the aftermath of a particular traumatic event. Therefore, it is helpful to provide a point of comparison by introducing these two student development theories.

### **Kegan’s Theory of Self-Evolution**

Kegan’s (1982) theory of self-evolution described the developmental process of negotiating the ways in which one functions and makes meaning in relation to the world. Including five stages or orders of complex knowing, each stage of Kegan’s theory (1982) represents an “evolutionary truce” (p. 107) between inclusion and differentiation in society. Kegan’s (1982) theory also suggests a bridge or “holding environment” (p. 116) between stages so that individuals are both supported within their current stage of development and challenged to move to the next. Development, in Kegan’s theory, progresses from impulsivity at order one to self-transformation at order five and occurs across three domains: cognitive, intrapersonal, and interpersonal (Kegan, 1982). Order two (instrumental mind) is characterized by an ability to organize one’s thinking and a personal awareness and relation to others as a separate being (Kegan, 1994). An

individual in order three (socialized mind) would be able to utilize cross-categorical thinking to relate to new ideas as well as to other individuals (Kegan, 1994). Supporting development from order three to order four (self-authored mind) requires encouraging individuals to embrace independence and make their own decisions based on personal beliefs and values as opposed to codependence on external authorities (Kegan, 1994). Kegan's (1994) research suggested that few college students move beyond a third order perspective to reach order four. In fact, Kegan (1994) found that anywhere from one-half to two-thirds of the adult population has not reached the fourth order of consciousness.

### **Baxter Magolda's Theory of Self-Authorship**

Baxter Magolda (2009) built on Kegan's (1982) fourth order of personal development by examining how college students progress toward self-authorship. Baxter Magolda's (2009) longitudinal study found that students entering college relied on external sources for how to engage in relationships, what to believe, and to define who they are, and gave little consideration to self-determined knowledge. For college students, this means that professors, parents, and other authority figures play a significant role in defining who students become, namely being able to challenge students to think for themselves. Baxter Magolda (2001) inferred from her study that many students do not reach self-authorship within their undergraduate college years; instead students leave college "with an internal awareness that they would have to make their own decisions but without the internal mechanisms to do so" (p. 36). Supporting Kegan's (1994) work that found many college students do not reach self-authorship while in college, elements of self-authorship did not emerge until individuals were in their thirties (Baxter Magolda, 2008).

External formulas, however, can cause pain, or a feeling of unhappiness, from the tension between needing to follow one's own path and following the path determined by others. When external formulas leave individuals feeling unhappy or unfulfilled, they begin to listen to their internal voice (Baxter Magolda, 2009). Individuals in this crossroads without a strong inner voice can waver developmentally between external authority and internal voice. The process of strengthening their internal voice requires that individuals get to know themselves more fully, and be willing to discard those practices or beliefs that no longer fit with their internally defined values (Baxter Magolda, 2009). Pizzolato (2005) suggested that a provocative moment may be the impetus to leave the co-occupied space of externally and internally defined values and push an individual out of the crossroads. Such a provocative moment may be a single event or trauma, or an accumulation of moments that finally encourage an individual to make a developmental decision.

Self-authorship not only requires that an individual choose to follow the internal voice and strengthen that voice, but also to trust that internal voice enough to build commitments with it. Trusting the internal voice involves recognizing that reality is not within an individual's control (Baxter Magolda, 2008, 2009). This understanding, and the realization that one's reaction can be controlled, is modulated by the presence of others along the way who can reinforce or discourage trust in the internal voice (Baxter Magolda, 2009). Trusting in one's beliefs, knowledge of self, and philosophy of life allows an individual to commit to responding to reality in a way that is compatible with the internal voice (Baxter Magolda, 2008). Feeling secure in the commitments made to

the internal foundation, then, provides a framework from which individuals can make decisions about how to live out their lives (Baxter Magolda, 2008, 2009).

### **Demands of Life Require Self-Authorship**

The theories of Kegan (1982) and Baxter Magolda (2009) suggest two main points about individual development that are relevant to this study. First, dissonance is necessary for developmental growth. Kegan's (1982) model suggested that in order for individuals to move to a more complex stage of knowing and meaning making, the individual must encounter challenges to their current ways of knowing. Barber and King (2014) found that college students experienced developmental effects both from exposure to new ideas that challenged preconceptions about the world as well as from moments that produced feelings of discomfort. These challenges are meant to encourage growth to the next stage, however they can also create pain for an individual. Baxter Magolda's (2009) longitudinal study found that dissonance between what individuals had automatically accepted based on how they were socialized and what actually happened in their lives resulted in tension or pain. Additionally, Barber, King, and Baxter Magolda (2013) found that individuals' beliefs about personal identity, knowledge, and relationships can be challenged by extreme life disruptions or tragedies, such as the death of a loved one. Development (i.e., self-authorship), or learning, then, results from a process of resolving this pain and redefining an individual's personal perspective.

Second, individuals need a particular level of developmental growth in order to deal with the complexities of life. Kegan's (1982) orders three and four are necessary for engaging in identities associated with adult life that are complex (e.g., parenting, work). The demands of modern life require more complex meaning making that can be stressful

for individuals who have yet to attain a higher order meaning making such as self-authorship (Kegan, 1994). Baxter Magolda (2009) found that even individuals who had strengthened their internal voice wavered in the trust required to use it every day and in the presence of new experiences. However, these complex life demands may not be present in the current undergraduate student experience. Graduate students, an under researched population in developmental literature, represent an adult population within higher education that may have more complex life demands beyond coursework. Additionally, traumatic experience may be categorized as a complex demand of life and may also require that individuals be situated in a self-authored perspective in order to grow from trauma instead of deteriorating psychologically.

### **Trauma**

Traumatic events can be defined in a variety of ways and can also refer to moments of physical, mental, and emotional crisis. As defined in Chapter One, trauma consists of events that are sudden or unexpected (McCann & Pearlman, 1990; Weiss & Parkes, 1983); uncontrollable or perceived as such (Slaby, 1989; Tennen & Affleck, 1990); lacking familiarity or are out of the ordinary (McCann & Pearlman, 1990; Tedeschi & Calhoun, 1995); irreversible or chronic (Davidson et al., 1986; Tedeschi & Calhoun, 1995); and, responsible for producing a sense of blame (Tedeschi & Calhoun, 1995). Those individuals who do not experience trauma firsthand can be said to have a secondhand traumatic experience or vicarious traumatization (S. A. Adams & Riggs, 2008; Pearlman & Mac Ian, 1995). In a secondhand experience, it is important to note that the impact of the trauma is no less real than it would be for the person actually

experiencing the event, and can produce the same symptoms as those exhibited in posttraumatic stress disorder (PTSD) (Wilson & Lindy, 1994).

### **Impact of Trauma**

Trauma has been associated with various negative impacts. From a cognitive perspective, trauma can lead to intrusive, negative thoughts or dreams, can decrease self-esteem, and can be psychologically numbing, leaving the victim struggling to understand how the event could have happened (Calhoun & Atkeson, 1991; McNally, 2005; Tedeschi & Calhoun, 1995). Those individuals who experience traumatic events are more likely to seek treatment and suffer from poorer psychosocial functioning (Twamley et al., 2004). However, existing cognitive functioning may play a role in influencing coping style and subsequent posttraumatic stress disorder development (Twamley et al., 2004).

Emotional effects of trauma vary from person to person, but are the most likely consequence of traumatic experience. Individuals may suffer from guilt such as believing “that certain actions may have prevented the event or that certain actions would have made the loss more bearable” (Tedeschi & Calhoun, 1995, p. 21). Individuals may also feel remorseful about things that were said or done, as well as by those things not said and not done in reaction to trauma. Additional emotional reactions can include anger, whether specific or diffuse, fear and anxiety, and depression (Tedeschi & Calhoun, 1995, 2004). In the case of anxiety and depression, the more significant the loss or threat, the more likely it is that these reactions will be present. However, because depressive symptoms are so common, the absence of depression as an emotional reaction can be an indication of a mental disorder (Tedeschi & Calhoun, 1995).

Individuals may also exhibit new behaviors such as substance abuse, withdrawal from others, or aggression in response to trauma. Substance abuse, of both prescription and non-prescription drugs, is likely particularly when difficulties of trauma are long-lived (McCann & Pearlman, 1990; Tedeschi & Calhoun, 1995). Withdrawing from others can be a response to feeling as though others cannot understand or help in a significant way (Tedeschi & Calhoun, 1995). These behaviors may be experienced in tandem with physical complaints because trauma or stress results in an increased fight or flight response (Tedeschi & Calhoun, 1995). This increased arousal can be triggered as an unwanted response by later experiences that remind the person of the trauma, and, over time, this hyperarousal can lead to extreme fatigue. Other physical complaints include headaches, body aches, gastrointestinal issues, loss of appetite, and difficulty breathing which may have longer lasting implications for developing physical disease later in life (Herbert & Cohen, 1993; Spitzer, Barnow, Völzke, John, Freyberger, & Grabe, 2009; Tedeschi & Calhoun, 1995).

While the literature has mostly focused on the ways in which trauma can negatively impact individuals, these traumas ultimately test individuals' ability to cope. Though individuals who experience trauma are more likely to develop a psychiatric disorder, most of these individuals will not because of coping mechanisms and support networks (Quarantelli, 1985; Tedeschi & Calhoun, 1995). Pollard and Kennedy (2007) found that individuals who suffered spinal cord injury were less likely to develop long-term depression if they were able to use strategies to cope with the initial trauma of injury. Thus, individuals who can successfully cope with high levels of stress caused by traumatic situations also have an opportunity for posttraumatic growth.



## **Posttraumatic Growth (PTG) Theory**

Although there appears to be a stable understanding of the negative effects of trauma, there are also reported benefits to experiencing and coping with traumatic experiences. However, this does not negate the fact that trauma is distressing or that one *can* grow from a traumatic experience. Tedeschi and Calhoun (1995, 1996, 2004) developed a theoretical model (see Figure 2) to describe how an individual might experience posttraumatic growth outcomes as opposed to the negative effects of trauma. Posttraumatic growth focuses on conditions associated with major crises that constitute a significant threat to existing schemas and can coincide with significant psychological distress (Tedeschi & Calhoun, 2004). Because children may not have established schemas to make meaning of particular events in their lives, posttraumatic growth, as a construct, may be less applicable to children and more applicable to adults or adolescents (Tedeschi & Calhoun, 2004). Additionally, posttraumatic growth is referred to as an ongoing process that includes transformative changes in an individual's life, not just the illusion of change (Tedeschi & Calhoun, 2004).

The growth process includes three key aspects: how an individual makes sense of the world, some form of psychological crisis, and the cognitive processing required to build new meaning-making structures following a traumatic event. Individuals develop schemas in order to understand and make sense of reality. From a developmental perspective, these schemas may be externally or internally defined but do provide some sense of structure for understanding reality (Baxter Magolda, 2009). When an event or experience calls into question the fundamental beliefs that inform those schemas, the individual may be challenged to redefine the ways in which reality is understood. Taking

Figure 2. Model of Posttraumatic Growth

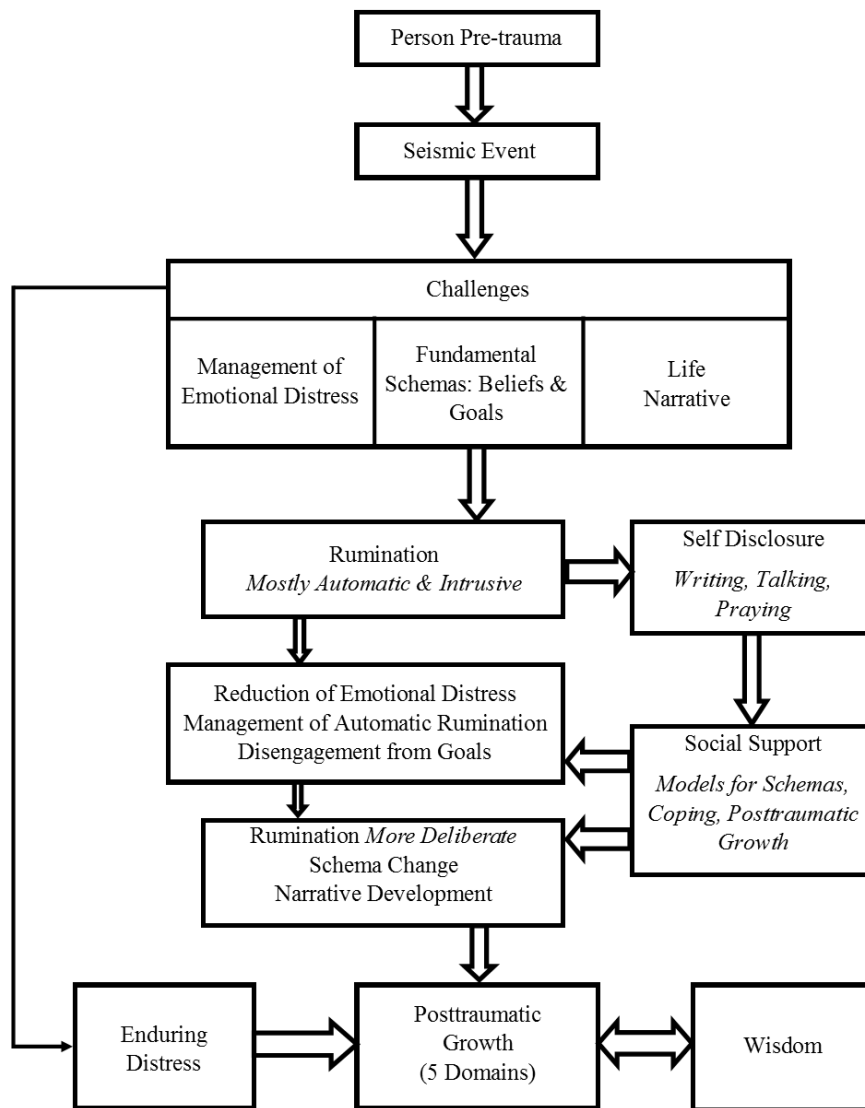


Figure 2. Theoretical model of posttraumatic growth that explains the psychological processes that contribute to growth when an individual experiences trauma (Tedeschi & Calhoun, 2004). From “Posttraumatic Growth: Conceptual Foundations and Empirical Evidence,” by R. G. Tedeschi and L. G. Calhoun, 2004, *Psychological Inquiry*, 15(1), p. 7. Copyright 2004 by Taylor and Francis. Reprinted with permission.

in new information and deciding how to revise schemas can be externally or internally

driven depending on the presence of social supports. Supports that suggest models for coping mimic an external authority, whereas supports that allow for self-disclosure can represent the strengthening of an internal voice (Baxter Magolda, 2009). The process of filtering old schemas through the lens of a new experience (i.e., trauma) requires an examination of emotional distress, a letting go of previously held schemas that no longer work in conjunction with traumatic experience, and a re-writing of personal schemas to organize one's life. Growth, then, is a response to the individual struggle "with the new reality in the aftermath of trauma" and involves affective as well as intellectual reflection (Tedeschi & Calhoun, 2004, p. 5).

### **Psychological Domains of Growth**

In developing a quantifiable means of assessing posttraumatic growth, Tedeschi and Calhoun (1996) defined five primary psychological domains where individuals may experience growth: "greater appreciation of life and changed sense of priorities; warmer, more intimate relationships with others; a greater sense of personal strength; recognition of new possibilities or path's for one's life; and spiritual development" (Tedeschi & Calhoun, 2004, p. 6). Each domain has a corresponding paradoxical element that relates to the growth process. For example, an individual who has developed more intimate relationships with those around a traumatic experience may also discard those relationships that were not perceived as supportive during the traumatic experience or in its aftermath. These domains, while indicative of posttraumatic growth, also correspond to the developmental processes that exist in models of self-authorship.

**Appreciation of life/change in priorities.** Following a traumatic event, growth can be experienced as a radical shift or change in priorities or as an appreciation for life

in general (Tedeschi & Calhoun, 2004; Tedeschi, Park, & Calhoun, 1998). This appreciation often takes the form of paying increased attention to the little things in life or recognizing the importance of things previously taken for granted (Tedeschi & Calhoun, 2004). Tedeschi, Park, and Calhoun (1998) suggested that for individuals where trauma has been severe or has heightened their sense of vulnerability, survivors would rather not “waste their time on the inconsequential” (p. 14). This shift highlights the change in priorities that for some may mean spending more time with loved ones or changing detrimental habits. This alignment of priorities with a newfound appreciation for life compares with Baxter Magolda’s (2009) theory of self-authorship, in which strengthening the internal voice led to “[taking] risks to bring life into alignment with [individuals’] growing internal desires” (p. 316). Such internal desires may be reimagined through the lens of posttraumatic growth. Additionally, a change in priorities may demonstrate growth in the cognitive domain of development due to the ability to make meaning of and evaluate competing priorities for fit with this new appreciation of life.

**More intimate relationships with others.** Another outcome of growth can be the development of closer, more intimate relationships. Often these relationships are forged with individuals who have experienced similar traumas or who empathize with the individual in a showing of solidarity. The development of new relationships can also coincide with the loss or deterioration of other relationships. Calhoun and Tedeschi (1999) suggested that relationship changes result from a change in social identity, in which the new self is formed in relation to others and as a result of the vulnerability and perspective changes caused by trauma. Additionally, “survivors find that *being themselves again* is probably impossible” (Calhoun & Tedeschi, 1999, p. 100). Thus, new

relationships are formed from creating deeper, more profound bonds that reach individuals on an affective level. This deeper connection with others suggests developmental growth in the interpersonal domain, in which relationships are authentic and appreciative of individual experience.

Individuals who participate in these relationships might be considered *good company* because they help to sort through complex experiences while respecting feelings and thoughts in order to collaboratively work toward solving mutual issues, in this case the aftermath of trauma (Baxter Magolda, 2002, 2009). The presence of good company in the developmental journey allows individuals to strengthen their internal voice so that they can participate freely in relationships by being true to themselves (Baxter Magolda, 2009). Because developing a deeper sense of compassion towards others who share similar traumatic experiences is also an outcome associated with posttraumatic growth, those who achieve growth in this area may also be good company for other survivors of trauma.

**Greater sense of personal strength.** Growth in the area of personal strength comes from realizing that one has already survived trauma before. However, recognizing that one possesses personal strength also comes with an increased sense of vulnerability because the individual also realizes that bad things can and do happen. Thus, vulnerability can call into question the trust an individual places in others as well as internally (Bryant-Davis, 2005). However, out of vulnerability, one can possess personal strength as a result of surviving trauma. From a developmental perspective, the pain and tension caused by a traumatic event can lead to the strengthening of the internal voice by identifying limitations that are externally defined (Baxter Magolda, 2009). Barber and

King (2014) found that developmentally effective experiences may result in uncomfortable emotions, challenging students to take actions to better understand and address their emotional reactions to situations. Developing inner strength, then, suggests growth in the intrapersonal domain, in which an individual comes to know the self through an understanding of personal vulnerability and how to address that vulnerability. Personal strength, then, coincides with the strength of the internal voice.

**Recognition of new possibilities.** Posttraumatic growth is also seen in the identification of new paths for one's life (Tedeschi & Calhoun, 2004). The process of experiencing and making sense of trauma can lead to the opening of different options with regard to one's future and allows the individual to embrace a degree of creativity in the choices to be made post-trauma. Baxter Magolda (2009) found that individuals gained perspective from taking risks and engaged in other experiences that opened up new ways of understanding. Through this process, individuals reflected on their life philosophy to negotiate changes in the things they want to keep or discard suggesting development in the cognitive domain. This negotiation included "what to believe, what to value, who to become, and how to relate to others" (Baxter Magolda, 2009, p. 318). It can be speculated then that traumatic experience, although not ideal, can open up new ways of perspective taking that facilitates the strengthening and cultivation of the internal voice.

**Spiritual development.** Individuals may also experience growth in spiritual or existential matters during and after a traumatic experience. While the experience of trauma can lead to a deepening of faith or spirituality, those individuals who are not religious may also experience growth by engaging with existential questions, such as "what happens when I die?" (Tedeschi & Calhoun, 2004). Prati and Pietrantonio (2009)

found that religious coping is a strong predictor of posttraumatic growth, suggesting that religion could provide a useful framework for individuals to make meaning of a trauma in order to cope. Such a framework may be referred to as a psychological context where personal development can occur. Pizzolato, Nguyen, Johnston, and Wang (2012) referred to the interactional nature of the interpersonal and intrapersonal domains in the development of self-authorship as being mediated by psychological context. As a psychological context, religion and spirituality may suggest ways in which an individual may evaluate methods of meaning making related to trauma (Pizzolato et al., 2012).

### **Social Support and PTG**

The cognitive processing that occurs in the posttraumatic growth process can be aided by social contexts that support self-disclosure (Tedeschi & Calhoun, 2004). Self-disclosure provides an opportunity for individuals to continue engaging in discussions about the consequences of traumatic events and how to cope with them. Growth happens when self-disclosure occurs to the most appropriate people in one's support network. (Tedeschi & Calhoun, 1995). Further, sustained support over time can positively influence the development of posttraumatic growth as opposed to those instances where disclosure is inhibited, limiting the degree of cognitive processing that occurs for the trauma victim (Tedeschi & Calhoun, 2004). Support, characterized as a set of social resources, enables individuals to draw from successful coping strategies in order to take a new perspective on a traumatic event (Schaefer & Moos, 1998). Individuals who have access to more social resources such as more education, pre-existing social networks, secure marriages, and stable family units have been found to receive more support and thus benefit from growth post-trauma.

Tedeschi and Calhoun (1995) identified three broad categories of social support: “the existing social network, other people who have experienced similar traumas, and professionals” (p. 94). In the case of existing social networks, family and friends constitute the majority of this support category. However, “the quality of the relationships with family and friends before and after the traumatic event plays a role in determining the likelihood for growth” (Tedeschi & Calhoun, 1995, p. 94). Pre-existing relationships that are healthy and supportive can contribute to growth when these relationships are maintained or improved. Additionally, family and friends may be the only support network that knew or had a relationship with an individual prior to the traumatic event (Tedeschi & Calhoun, 1995). Similar to facilitating personal development through a combination of challenge and support (Sanford, 1962), family and friends can best facilitate growth when there is a balance between caring for the individual and encouraging the individual to self-manage (Tedeschi & Calhoun, 1995).

Support also exists with those individuals who can provide mutual help based on a shared, similar experience. Individuals who have experienced similar traumas can provide insight on coping strategies and are able to engage in discussions about emotions in ways that can support other trauma victims. Tedeschi and Calhoun (1995) explained that,

Those who have confronted similar circumstances can provide a springboard to capable coping and ultimately to perceiving benefits from the crisis. These veterans of trauma accomplish this by offering reassurance about the normality of emotional distress, modeling specific understandings and actions that can be used to cope, and providing evidence that the crisis can be managed. (p. 98)



Having a network of individuals who can understand how a victim is feeling and can provide guidance in managing the post-trauma period can be invaluable to developing a sense of growth.

The importance of support in the journey of posttraumatic growth is comparable to the idea of good company (Baxter Magolda, 2002, 2009). The role of supportive partners or good company in the developmental journey is to help individuals strengthen their internal voice. Good company also facilitates interpersonal growth, a key factor in self-evolution and self-authorship models (Baxter Magolda, 2002, 2009; Kegan, 1982, 1994), by modeling relationships that are reciprocal and authentic. In the case of posttraumatic growth, good company or support networks creates a safe place for individuals to test coping strategies, develop and refine new schemas, and explore the emotional turmoil caused by trauma. Because support networks provide the necessary encouragement to strengthen one's internal voice, victims of trauma can self-disclose in ways that are authentic and true to their internal voice.

### **Trauma in the Graduate Student Experience**

Research on trauma and graduate students has focused on two main topics: training or preparing students to deal with traumatic events in their future careers like journalism (Barnes, 2013; Maxson, 2000), counseling (Black, 2008; Shapiro, Brown, & Biegel, 2007), and social work (Cunningham, 2004); and how students experience or re-live trauma as part of a course (Didham, Dromgole, Csiernik, Karley, & Hurley, 2007; O'Halloran & O'Halloran, 2001; Shannon, Simmelink, Im, Becher, & Crook-Lyon, 2014; Zosky, 2013). Training graduate students for how to manage trauma either firsthand or vicariously seems to be important particularly in the helping professions where students

may be serving in professional support roles. S. A. Adams and Riggs (2008) found that graduate students training for clinical therapy positions were more likely to be self-focused earlier in their programs and thus more susceptible to transference of trauma effects compared to more advanced graduate students. Those students who have no prior experience with trauma, then, are less prepared for future clients who may need professional support to work toward posttraumatic growth (Pearlman & Mac Ian, 1995). Because of this lack of training and experience, Courtois and Gold (2009) argued for the inclusion of psychological trauma in the psychology curriculum from baccalaureate to graduate level. However, viewing trauma as an external force to prevent against, instead of an experience that is occurring among graduate students, does not provide suggestions for how to support students who are experiencing trauma, either firsthand or vicariously.

Minimal research has explored treatment implications for students in the aftermath of traumatic events such as war (Jackson & Seeman, 2009) or campus violence (Yoder, 2008). Jackson and Seeman (2009) examined the impact of political trauma on international students and found that these students may have development disruptions as a result of their traumatic experiences. This suggests that trauma has implications for the developmental processes that students experience, but does not address the unique characteristics of the graduate student population. Yoder (2008) discovered the importance of an internal community of support during events of on-campus violence. As Tedeschi and Calhoun (1995) noted, communities that have shared experiences are often situated in positions to provide the most support. Although Yoder himself was a graduate student at the time of the crisis, there is little evidence to suggest that current

research exists to address the impact of individual *trauma* on graduate students or how these students respond, whether through growth or maladaptive psychological behaviors.

### **Graduate Student Experience and Doctoral Programs**

Doctoral programs are generally accepted as being intellectually and emotionally stressful for students. Additionally, the misconception that students are *only* students can interfere with the identification of a variety of student needs outside the academic realm. In reality, 41% of graduate students in the United States were enrolled in degree programs part-time in 2013 (Kena et al., 2015). The majority of these students (approximately 60% for both public and private institutions) were of non-traditional age (age 30 or older) (Kena et al., 2015), and are likely to have simultaneous employment and/or family responsibilities while completing their degree programs. These simultaneous responsibilities require that students sacrifice or make trade-offs between schoolwork and family time or personal wellness (Martinez, Ordu, Della Sala, & McFarlane, 2013; Spaulding & Rockinson-Szapkiw, 2012).

**Female doctoral students.** In the 2013 academic year, female students made up an estimated 59% of the graduate student population in the United States (Kena et al., 2015). In the case of female students, there is an increased pressure on work-life-school balance due to the competing role as a mother or family caretaker (Carter, Blumenstein, & Cook, 2013). Within the family system, the care of any children typically falls under the purview of “maternal labour” (Lupton, 2013, p. 234). Female students who are mothers or mothers-to-be must balance the time and responsibility of childcare with the demands of a graduate program (Martinez et al., 2013). Complicating childcare are cases

in which children have special needs or medical conditions that require specialized care management, creating more stress for students who are parents.

**The challenge of the unexpected.** High expectations of doctoral programs introduce an added layer of stress for graduate students (Schmidt & Umans, 2014), which can lead to lower rates of degree completion and higher rates of student attrition (Carter, et al., 2013). In addition to the expectations for a given program, graduate students reported the influence of unforeseen life events that challenge them to complete their programs (Spaulding & Rockinson-Szapkiw, 2012; West, Gokalp, Pena, Fischer, & Gupton, 2011). West Gokalp, Pena, Fischer, and Gupton (2011) found that doctoral students who experienced more challenges while in a program were more likely to seek support, and there is evidence to suggest that a number of support resources are utilized by graduate students. For example, Spaulding and Rockinson-Szapkiw (2012) suggested that support systems at home, such as family members, were able to take over when a student needed help with childcare. Additionally, supports within a doctoral program, such as student peers, dissertation chairs or advisors, and centers designed to support the dissertation writing process were found to be useful support networks in completing doctoral degrees (Spaulding & Rockinson-Szapkiw, 2012; West et al., 2011).

**Doctoral mentoring.** Much of the literature on doctoral mentoring has stressed the importance of career mentoring, which focuses on professional preparation (Jairam & Kahl, 2012), researcher identity development, and successful degree completion. However, Nolte, Bruce, and Becker (2015) noted that psychosocial mentoring, which focuses more on the individual needs of the student such as confidence and effectiveness, is often separate from career mentoring. In fact, students are more likely to seek out a

mentor if they are already at a developmental level that has an espoused identity (Nolte, Bruce, & Becker, 2015). Graduate students who participate in mentoring relationships are often highly self-aware and highly self-motivated, which contributes to successful degree completion (O'Meara, Knudsen, & Jones, 2013). Additionally, students who are highly self-motivated take more initiative in their faculty-student relationships (O'Meara et al., 2013). Although mentoring is the current model of faculty-student support in graduate education, students who experience trauma have their internal foundations shifted in a way that leads to a re-prioritization or re-negotiation of internal schemas. Mentoring relationships that do not provide psychosocial or emotional support for these students may not fit with the reality of a student who no longer trusts his or her strengths and finds more personal weaknesses in their perception of success at the graduate level. Instead, a broader conceptualization of mentoring that encompasses career, psychosocial, research, and intellectual functions (Carpenter, Makhadmeh, & Thornton, 2015) may be useful in providing more holistic support for graduate students who experience trauma. However, even when emotional or psychosocial support has been included in the mentoring relationship, there still remains a focus on how such support can facilitate degree completion (Doloriert, Sambrook, & Stewart, 2012), instead of addressing how to help a student process trauma.

Among support networks in graduate education, students most often seek support from professional mentoring relationships with faculty. However, faculty-student mentor relationships are only one part of the support network that may be available to graduate students. Although the majority of graduate students may point to faculty advisors as being mentors, students also indicate mentors in other faculty and non-faculty roles

(Nolte et al., 2015). Peer networks are also a point of reference for students to assimilate into programs, learn from and with peers, and establish a working community that can support their degree journey (Jairam & Kahl, 2012).

### **Summary**

This chapter has examined the ways in which college student development and posttraumatic growth theory are related so as to provide a theoretical framework for exploring the impact of trauma on the graduate student experience. The five domains of psychological growth, as well as the role of social support in the growth process, serve as the primary points of reference in this study, to determine how the graduate student experience can be impacted by traumatic events. Because the experience and impact of trauma can vary by individual, it is necessary to consider how such experiences are lived and understood from the point of view of the person who experienced trauma. Even though the graduate student experience may represent a collective experience, the varied demographics and experiences of graduate students illustrate the importance of exploring the individual point of view.

Autoethnography provides an opportunity to engage in an individual's experience (e.g., trauma) while also grounding the experience within a particular culture (e.g., graduate student experience). Posttraumatic growth is an inherently personal and psychological process that involves resolving cognitive turmoil, coping with emotional distress, and supportive relationships. Thus, examining the impact of trauma on my experience as a graduate student provides a window into the cognitive, intrapersonal, and interpersonal processing that occurred while making sense of trauma. Chapter Three

describes the conditions under which autoethnography was employed as a methodology, as well as the procedural, analytical, and ethical considerations that governed this study.

## CHAPTER THREE

### METHODOLOGY

This chapter describes, in detail, the method used to complete this study. It begins with a discussion about the paradigmatic viewpoints in which this study is situated. This is followed by a description of why autoethnography is appropriate for this study, the assumptions of the methodology, and the criteria against which it is typically evaluated. A review of ethical considerations as well as the form and processes used for this study, including my analytical approach to narrative data, is described followed by a discussion of the data sources used for this study. This study aims to provide personal narrative evidence that answers the following research questions, previously identified in Chapter One:

Overarching Question: *How did the traumatic experience of my son's diagnosis and subsequent care affect my personal life narrative, particularly as related to my graduate student experience?* More specifically, the questions to be investigated in this study are as follows:

1. How did the psychological impact of trauma affect my graduate student experience?
2. How did my traumatic experience affect my assumptions about reality, in relation to the graduate student experience?
3. Within my graduate program, where, and in what form, was social support present during the cognitive processing of my traumatic experience?



### **Dual-Paradigmatic Referent**

Two paradigms serve as referent for this study: interpretivism and postmodernism. Autoethnography, as a method, relies on an exclusive and interactional understanding of both paradigms. That is, while the purpose and product of an autoethnography may utilize either an interpretivist or a postmodern referent to suit a particular purpose, the method itself also demonstrates how both paradigms may interact within a solitary methodology. It is necessary, then, to discuss each paradigm in reference to autoethnography to better understand how they interact in this study.

### **Interpretivism**

The interpretivist approach “looks for culturally derived and historically situated interpretations of the social life-world” (Crotty, 2003, p. 67). The interpretivist approach can be explored through symbolic interactionism, phenomenology, and hermeneutics. Symbolic interactionism and phenomenology are concerned with the use of culture as a meaning-making system. Hermeneutics, however, relies on drawing interpretation from text and language in which identifying the underlying meaning of a text may go beyond an author’s own understanding (Crotty, 2003). For this study, hermeneutics provides the paradigmatic context through which to understand autoethnography as the methodology.

Autoethnography uses the concept of story as data, evidence, and theory. Stories told are inherently interpretative because the storyteller makes decisions based on what to tell, what not to tell, and how to tell the story. Interpretivism, and specifically hermeneutics, emphasizes language and the ways in which we speak as those factors that “shape what things we see and how we see them, and it is these things shaped for us by language that constitute reality for us” (Crotty, 2003, p. 88). Since stories are merely

interpretations, they cannot truly represent or duplicate the exact experience (Denzin, 2014). However, an empathetic approach to hermeneutics allows us to “enter into the mind and personage of the author, seeking to see things from the author’s perspective” (Crotty, 2003, p. 109).

Stories are told through the language chosen by the author, filtered through the experience of the individual. Additionally, Denzin (2014) noted that “stories are shaped by larger ideological forces which put pressures on persons to establish their individuality (and self-control) in the stories they construct” (p. 60). Not only are stories interpreted by the author, but readers also interpret the stories that are told by “[engaging] with what the author has to say” (Crotty, 2003, p. 109). This double layer of interpretation further limits the replicability of storied experiences because “the stories told are never the same as the stories heard” (Denzin, 2014, p. 60). The uniqueness of autoethnography, and of storytelling in general, lies in providing a nuanced, individualistic perspective into a generalized cultural experience that, while intended to reflect what is factual and true, has characteristics of fiction.

### **Postmodernism**

Postmodernism differs from interpretivism in its emphasis on progressive fragmentation. In this way, the essence of postmodernism is not a generalized cultural experience, but rather the “loss of totalising [*sic*] distinctions and a consequent sense of fragmentation” (Crotty, 2003, p. 212). Unlike modernism, which focuses on “generalised [*sic*], indubitable truths about the way things really are, postmodernism abandons the entire epistemological basis for any such claims to truth” (Crotty, 1998, p. 185). In deference to “espousing clarity, certitude, wholeness, and continuity, postmodernism

commits itself to ambiguity, relativity, fragmentation, particularity, and discontinuity” (Crotty, 2003, p. 185). Such discontinuity distorts and deletes boundaries between contents, as well as forms, seeking to find new presentations of the unrepresentable (Lyotard, 1984). Autoethnography, as a methodology, reflects a new presentation as a result of this deletion of boundaries.

Autoethnography relies on multiple definitions of storytelling that are governed by disciplinary boundaries, as well as the degree of self, culture, and research process present (Ellis & Bochner, 2000). Postmodernism reflects this variation of forms in its emphasis on particularity and ambiguity (Crotty, 2003). Further, Lyotard (1984) claimed that in postmodernism, the “grand narrative has lost its credibility” (p. 37). The meta-narrative approach to understanding reality provides an outlet for autoethnographies and narratives told from a position that may have previously been silenced or ignored (Ellis, 2004). Stories, then, and autoethnography specifically, have the power of examining the particulars of living, not the generalizations of life (T. E. Adams et al., 2015).

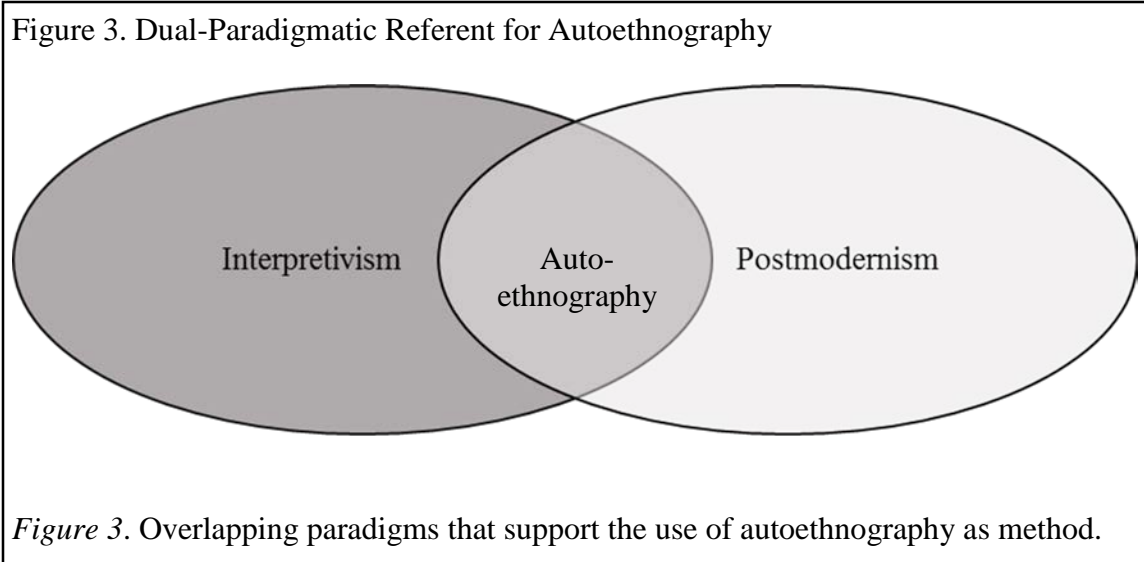
With fragmentation taking the place of totality, *knowing* an experience is particular to the individual who tells the story relative to whatever the grand narrative had been. Ellis and Bochner (2000) explained that “stories show us that the meanings and significance of the past are incomplete, tentative, and revisable according to contingencies of our present life circumstances, the present from which we narrate” (p. 745). This implies that we cannot *know* an entire experience, merely pieces of it. Even when someone tells a story, there are pieces missing that live with the individual. By fragmenting a story and rearranging its parts, autoethnographers can tell the story that is truthful if not historically accurate (Ellis & Bochner, 2000). This rearrangement

emphasizes that there is not one way of telling a story, that it can be told from a variety of perspectives and for a variety of audiences (T. E. Adams et al., 2015).

### **Interplay of Paradigms**

Autoethnography bridges the divide between the self and culture through the process of writing, analysis, and discovery. Social science research assumes an objective standpoint in order to show a larger truth. It seeks to objectify the essence of lived experience in order to generalize or show commonalities within a particular culture or institution. In contrast, autoethnography emphasizes the experience of the researcher or author as it interacts with and is part of a culture or institution. It redefines reality from the perspective of the researcher, showing nuance and subjectivity in order to learn more about the individuals within a culture. In this way, autoethnography follows a more postmodern paradigm by de-emphasizing the prioritization of a single, objective truth in favor of exploring the many truths that may exist.

In stories, like mine, where the experiences are characteristically different from my peers, yet may not be the only types of trauma that exist among graduate students, autoethnography served as a vehicle to share and contextualize my story within the graduate student experience. In addition to presenting a different perspective on the graduate student experience (postmodernism), my story was also informed by how I lived the experience, as well as the language I have chosen to represent that experience (interpretivism). The interplay of both interpretivism and postmodernism to support the autoethnographic method is presented in Figure 3.



### Why Autoethnography?

There are many reasons why a researcher might conduct an autoethnography. T. E. Adams et al. (2015) suggested there are four main reasons for doing autoethnography:

1. To critique, make contributions to, and/or extend existing research and theory;
2. To embrace vulnerability as a way to understand emotions and improve social life;
3. To disrupt taboos, break silences, and reclaim lost and disregarded voices;
4. To make research accessible to multiple audiences. (p. 36)

These purposes highlight the potential benefits posed by autoethnography. As a process, autoethnography can be therapeutic for the author who may be processing a trauma or may be in the process of making meaning of a particular situation (T. E. Adams & Ellis, 2012; Ellis, 2004; Flemons & Green, 2002). Additionally, autoethnography can call attention to particular voices that are marginalized in the research literature (Ellis, 2004).

In this particular study, I chose to use autoethnography to show readers how I processed and worked through familial trauma during my graduate student experience.

The unique and individual nature of trauma required a methodological approach that values the individual expression of an experience without reducing the experience to themes that are read out of context. Autoethnography provided me methodological room to interact with research that was personally connected to my experience. Using autoethnography to move seamlessly between research, theory, and story provided a contextualized truth to understand more completely the graduate student experience.

Because my research questions focus on the individual experience (trauma) in relation to a larger cultural experience (graduate student experience), autoethnography is the best fit for this study. The uniqueness of my personal experience, and the impact it has had on me psychologically, required an approach that embraces the positioning of the self as the primary unit of analysis. Since the trauma under examination in this study is my own, I was able to provide a first-hand account of an experience that might otherwise be lost because of generalizability. Additionally, I was able include my internal reflections with the written expression of my experience so that readers can see how I reacted, processed, and made meaning during trauma. Unlike other methods, autoethnography allowed me to purposefully examine multiple layers of consciousness. My purpose in choosing autoethnography was to add my experiences to existing research on the graduate student experience, to give voice to an underrepresented population of graduate students, and to use the emotional vulnerability created by trauma to represent these experiences in a manner that is accessible<sup>1</sup> by a variety of readers.

---

<sup>1</sup> My definition of accessibility includes providing a story that readers can understand and in which readers can easily engage. However, Chapters 1, 2, 3, and 7 do not meet this definition of accessibility. Academic practice requires that these sections are written in language and organized in a way that is suitable for a dissertation.

## **Assumptions of Autoethnographies**

Like other narrative and qualitative methodologies, there are assumptions about autoethnography as a method that suggest the type and form of content presented.

Denzin (2014) offered nine assumptions that are important to disclose here. First, autoethnographies are “written with an ‘other’ in mind” (p. 7). This primary assumption dictates that writing an autoethnography comes with two different perspectives: that of the author and that of others. In my autoethnography of trauma and the graduate student experience, I had to be aware of the others who are included or implicated within and around the story. Specifically, I wrote my story about my experience with my son’s cancer treatment and diagnosis, inherently drawing him into the story.

A second assumption already highlighted in the discussion of postmodernism, is the idea that autoethnographic texts reflect bias. Because stories are individualistic or come from a particular perspective, stories are not free of the influences of race, gender, or other ideological values, nor are they free of the influence of context and temporal positioning. These biases provide the context in which the story occurs and cannot be separated from the individual experience being portrayed. In addition to individual biases, family beginnings provide a necessary contextual element to autoethnographies. Stories of the individual are grounded in the purpose and development of the family, supporting the assumption that in order to situate an autoethnography, an author must situate life stories in the structure provided by the familial context. An author’s family beginnings provide underlying context for the storied life in relation to a larger social context.

Autoethnographies have a number of assumptions regarding the construction of a story. Stories should have visible points of reference, a beginning and an end. A text should follow some form of plot developed through the use of textual turning points. In the case of my autoethnography, the beginning of my traumatic experience was identified as my son's cancer diagnosis. The ending of the story is defined by the writing of this dissertation and the monitoring of his condition post-treatment. The turning points (or epiphanies) of a particular story reflect the permanent marks left by an experience and are assumed to be a primary element of storytelling.

The nature of reality in an autoethnography, then, is assumed to be that in which the author can describe. It is assumed that the writer of the story "knows his or her life, and hence is in the best position to write about it" (Denzin, 2014, p. 9). However, it is also assumed that a real experience will be characterized by both objective and subjective markers. These markers, such as dates and critical points about the experience being told, suggest evidence that there is a *real* person whose existence can be recorded and given meaning (Denzin, 2014). Additionally, language used to tell a story is merely a device through which one creates a text. Autoethnographies do not reflect the *real* experience or the *real* person to whom the experience occurred, but they suggest that such a person exists "who has lived a life, and this life can be written about" (Denzin, 2014, p. 12). As a final assumption of the method, those life markers that are objective and more truth-like can be rearranged or altered by the individual telling the story. For example, an author may choose to rearrange or eliminate parts of the story to make the story more interesting, to provide foreshadowing, or to highlight the significance of a particular



event. The form in which a final autoethnography takes will be dependent on the goal of the author but will generally conform to these basic assumptions.

### **Form and Process**

Autoethnographies are typically written using the first-person voice and move between action, dialogue, emotion, and reflexive thought to provide a holistic expression of the experience (Ellis, 2004). Stories that are used in autoethnography to convey personal experience have certain conventions. Denzin (2014) explained that stories have characters, context, epiphanies which provide tension and point toward a resolution, an ordering of events, and a point or moral to “give meaning to the experiences depicted” (p. 4). T. E. Adams et al. (2015) explained that autoethnographers have common priorities and ways of doing research:

1. Foreground personal experience in research and writing;
2. Illustrate sense-making processes;
3. Use and show reflexivity;
4. Illustrate insider knowledge of a cultural phenomenon/experience;
5. Describe and critique cultural norms, experiences, and practices;
6. Seek responses from audiences. (p. 26)

These priorities provide a guideline for how researchers might engage with and write about personal experience in a way that is meaningful to a larger audience.

My autoethnography takes on a dialogic process of storytelling, in which my story communicates with other research and theory. Ronai (1995) referred to a similar approach to narrative form called the layered account, in which many reflexive voices are included to produce, as well as interpret, a text. It was my intention to utilize the layered

account as my narrative form so that I could tell my story while showing the way in which it fits with what is known about both the graduate student experience and the individual events composing my traumatic experience.

### **Criteria for Autoethnography**

Autoethnography emerged from sociology in response to the need to reconcile the voice and experience of the ethnographer in the field with field experiences (T. E. Adams et al., 2015). Ethnography was a means to show how sociological processes played out in real-world settings (Ellis, 2004). However, the representation of fieldwork did not consider how readers would react or the emotional impact of the sociological context on the researcher in the field. Additionally, the emphasis in science on prediction was not applicable to studying the complicated nature of human interaction and social life (T. E. Adams et al., 2015). Autoethnography provided a methodological space to explore the role of the personal experience in research while embracing emotional response and uncertainty (T. E. Adams et al., 2015). As a result, there has been backlash from social science researchers, claiming that autoethnography moves away from a scientific approach in favor of a more aesthetic, literary approach (T. E. Adams & Ellis, 2012; Ellis, 2009). Conversely, narrative methodology, particularly, autobiography, may view autoethnography as being too analytical and systematic (T. E. Adams & Ellis, 2012; Ellis, 2009).

In response to these critiques, a number of researchers have put forth criteria by which autoethnographies may be qualified (see T. E. Adams et al., 2015; Bochner, 2000; Richardson, 2000). Although there are individual differences among criteria, there are similarities, and it is these similarities that are used to qualify this autoethnography. First,

an autoethnography should make a contribution to the knowledge already in existence (T. E. Adams et al., 2015; Richardson, 2000). Although nuanced and complex, these contributions provide insight by extending the boundaries of existing knowledge while also giving credit to the contextualized nature of the autoethnography itself. Second, autoethnographies value the personal experience, particularly through the use of vulnerability and “emotional credibility” (Bochner, 2000, p. 270). These personal experiences detail the individual’s reality (Richardson, 2000), and use the power of story to show reflexivity, meaning making, and changes within the self (T. E. Adams et al., 2015; Bochner, 2000). Finally, there is an ethical component to autoethnography that ensures responsible research practices and reflects compassion for those with whom the story interacts, including the readers (T. E. Adams et al., 2015; Bochner, 2000).

Paramount to the success of an autoethnography is the ability of the author to create verisimilitude, or a sense of truth, for readers. In autoethnographies that achieve verisimilitude, readers feel the experience is real or could actually happen (Ellis & Bochner, 2000). The story, as told, is believable. In order to create a sense of verisimilitude, I as the author used rich detail in which readers can *see* what I am talking about, smell the smells, and feel the emotion evoked by the writing. Much like fictional storytelling, this form of writing does not conform to traditional notions of reliability and generalizability. However, an author who includes others in the story may conduct reliability checks with those individuals as a way to comment, make changes and interpretations to the written product (Ellis & Bochner, 2000). Likewise, although lives are specific, “they also are typical and generalizable, since we all participate in a limited number of cultures and institutions” (Ellis & Bochner, 2000, p. 751). Therefore,

generalizability is addressed by asking whether the story speaks to readers about their experiences and the experiences of those they know. Generalizability is also addressed by asking whether the story tells readers about unfamiliar others (Ellis & Bochner, 2000).

**Truth.** A common concern held outside of the interpretivist/postmodern referent is whether or not an autoethnographic text is truthful. Is the author of an autoethnography trustworthy? Remembering that stories are interpretations of reality and are created using language to express a particular interpretation, “autoethnographers assert that narrative truth is based on how a story is used, understood, and responded to” (Denzin, 2014, p. 70). Narrative truth is composed of an author’s willingness to tell the subjective truths and feelings about his or her life, the historical accuracy of an event or experience, and the *real* truth represented by fictional language (Denzin, 2014). When an author establishes a sense of verisimilitude with readers, is faithful to historical facts of an experience, and creates a story that is used by others to think about their own lives, the story can be said to have achieved narrative truth.

**Memory.** It is also important to note the role and quality of memory in the autoethnographic writing process. Denzin (2014) stated that “memory is fallible” (p. 70). Additionally, when people recall particular stories, they may share different stories of the same experience (Ellis, Adams, & Bochner, 2011). Reliability, then, refers to the author’s “credibility as a writer-performer-observer; that is, [whether] an event [has] been correctly remembered and described” (Denzin, 2014, p. 70). Unfortunately, memory rarely works in a way that allows us to recall explicit details in temporal order. Instead, individual recall of past experiences is interpreted from the present condition in which we are positioned (Ellis & Bochner, 2000). Recalling details of experiences, however, can be

done through emotional recall, in which the author “imagine[s] being back in the scene emotionally and physically” (Ellis & Bochner, 2000, p. 752). My study is fortunate to have a number of data sources that were written at the time of my experiences; however, there are specific instances where there is little written data to draw from because certain experiences were so powerful in the moment and evoked emotional responses that were too disturbing that I could not write about them in the moment.

### **Data Sources**

This autoethnography relied on the following data sources: my memories of the experiences during my tenure as a graduate student in which my son was diagnosed and treated for a cancerous brain tumor; the journal and blog entries that I composed during that time period; the events that occur as I write my dissertation, including ongoing medical tests and doctoral student obligations; email and text correspondence between myself and family members, professors, peers, my son’s teachers, and medical professionals; social media updates posted by myself and my husband; and medical summaries outlining my son’s care from the doctors who treated him. In addition to data on the experiences themselves, reflexive thought about how I wrestled with experiences occurs throughout the story. These thoughts occurred as a result of both living the experiences and writing the story. Reflexive thought and inner dialogue stand in for personal meaning making and interpretation throughout the story.

All data are situated within the time period of my doctoral studies. These particular experiences began in November 2013 and conclude with the writing of this dissertation in the 2015-2016 academic year. Dates are used when possible to provide objective markers and substantiate the accuracy of memories. All correspondence was

either paraphrased to assure anonymity or was used with permission of the corresponding individual.

Although the use of others' voices can be viewed as adding to a more complete, objective perspective, this particular autoethnography focused on the psychological impact of trauma on *my* graduate student experience. The primary issue with conducting interviews of individuals around the experience is the need for them to separate the traumatic experience itself from my growth as a result of the experience. In the case of my family, there are members who prefer to not dwell on the traumatic experience and would not necessarily be able to separate their experiences from mine. For my peers and faculty, there was a real concern that any perspective they may have of my growth would be dependent on what they have observed. For example, if I were to pretend to act normally in class, complete my work as if nothing had changed, how would they know whether I had experienced growth? A secondary issue related to interviewing others around the situation flows from the interpretivist/postmodern referent described earlier. It was the goal of this study to provide a new but related truth about the graduate experience, interpreted through an individual lens of trauma and posttraumatic growth.

### **Analysis and Interpretation**

Unlike traditional data analysis in social science research, this autoethnography provides an alternative perspective of data analysis. In this autoethnography, I did not reduce my story into a series of themes or codes that disassemble and disaggregate the larger story. Instead, this study focused on merging my story with posttraumatic growth theory, "to consider the ways theory supports, elaborates, and/or contradicts personal experience" (T. E. Adams et al., 2015, p. 94), and situating these growth elements in the

higher education context in which this trauma story occurs. As a result, I critiqued existing educational structures and policies by using elements of my story that detail my traumatic experience within the higher education context. Such a critique required a “custom-tailored’ approach that is absolutely necessary in autoethnographic data analysis and interpretation” (Chang, 2008, p. 130).

Chang (2008) described analysis and interpretation in autoethnography as both mutually exclusive and yet balanced. Analysis is indicated by a fracturing, organizing, and coding of data, where data is reduced to individual and specific parts. In contrast, interpretation involves *connecting* data to identify how data fits in a larger context. In this autoethnography, I used both analysis and interpretation simultaneously in the development of the narrative. For this study, analysis began with a holistic reading of all data sources to get an idea of what the bigger picture was first (Chang, 2008). The next step of analysis included memoing and the coding of data sources based on elements of the PTG theory. As an analysis strategy, framing autoethnography with theory “can guide the process of data organization, analysis, and interpretation, and the structure of writing” (Chang, 2008, p. 137). Interpretation followed this analysis by reconnecting coded data so that the theoretical foundation provided by PTG theory elaborated on the meanings and implications of my personal narrative (T. E. Adams et al., 2015).

### **Coding**

Initial coding began with an incident-by-incident analysis of data sources (Charmaz, 2006), in which codes were determined a priori and represented two main foci. First, incidents that categorized the chronological process of posttraumatic growth were coded using identifiers for pre-trauma, traumatic event, and post-trauma. Second, coding

focused on the elements that characterize posttraumatic growth as described by Tedeschi and Calhoun (2004). Specifically, codes identified the five psychological domains of growth (including paradoxical elements), the presence and interaction of social supports and moments of self-disclosure, and the levels of rumination or cognitive processing present in the psychological meaning making that occurs as a result of traumatic experience (see Figure 4). Emergent codes were also used in areas where the theoretical constants provided by PTG theory did not match the experience expressed in the data.

Scrutinizing each data source by hand and conducting an incident-by-incident analysis provided an opportunity to code and compare similar incidents in order to identify patterns (Charmaz, 2006). Following the incident analysis, I conducted a focused coding that related those incident codes to the graduate student experience. Focused coding allows for synthesizing incident codes to “explain larger segments of data” (Charmaz, 2006, p. 57). By layering the graduate student experience on top of incident codes related to trauma, I was able to determine those incidents where the graduate student experience was most impacted by trauma. Patterns were compared with the posttraumatic growth process and expressed in storied form following the additional layer of coding.

### **Layered Account**

Following the coding process, I reconnected and interpreted the data in order to generate a larger story within the sociocultural context of higher education and the graduate student experience. The format of such an interpretation is that of the layered account (Ronai, 1995). In a layered account, the analysis is emergent with the



Figure 4. Model of Posttraumatic Growth

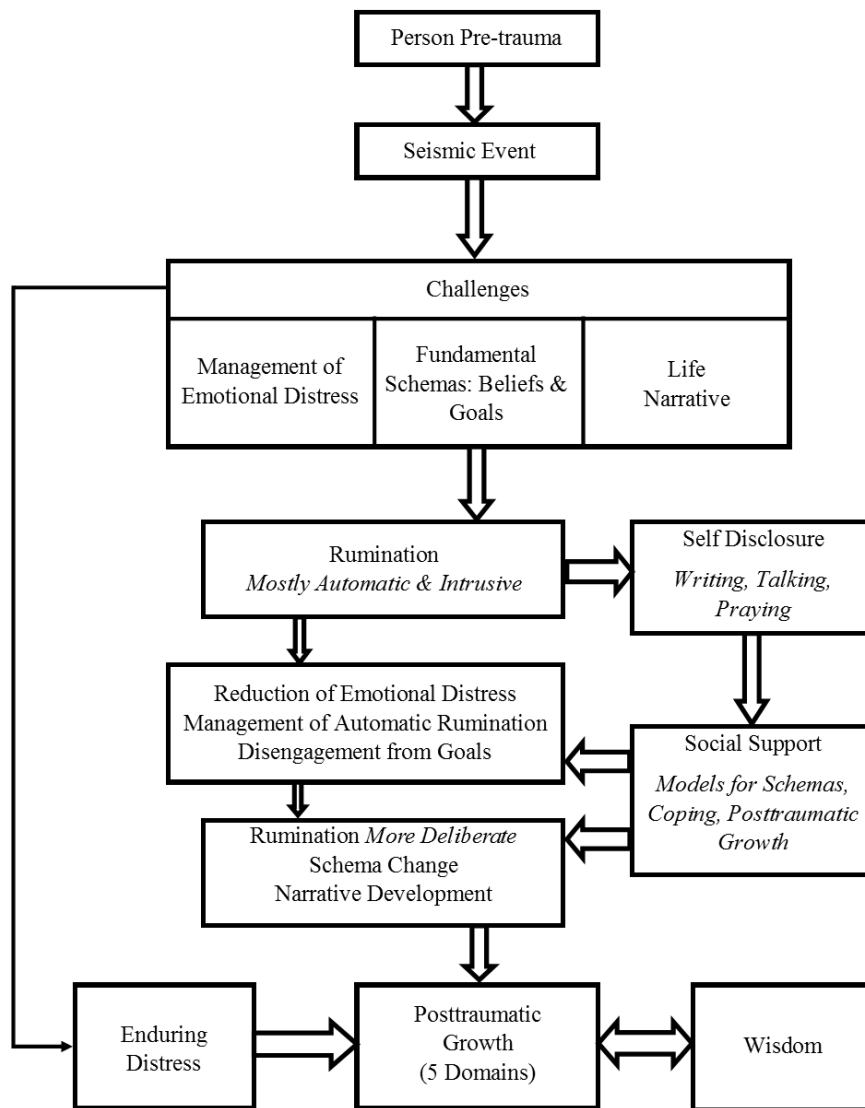


Figure 4. Theoretical model of posttraumatic growth that explains the psychological processes that contribute to growth when an individual experiences trauma (Tedeschi & Calhoun, 2004). From “Posttraumatic Growth: Conceptual Foundations and Empirical Evidence,” by R. G. Tedeschi and L. G. Calhoun, 2004, *Psychological Inquiry*, 15(1), p. 7. Copyright 2004 by Taylor and Francis. Reprinted with permission.

development or composition of the story itself. In this way, a layered account is similar to grounded theory in which the goal is to construct a theory that is grounded in the data

(Charmaz, 2006). The conceptual frame for this study is that of story as theory. Thus, the individual data sources tell a story and suggest a theory. Similar to the constant comparative method (Glaser & Strauss, 1967) in which data is compared to determine distinctions in analysis, I compared my story with an existing theory, posttraumatic growth theory, as well as existing literature to explain and interpret my story (Chang, 2008). Thus, the fracturing of data into incident codes was then interpreted within the larger sociocultural context using the layering of story with research and theoretical literature.

Although similar in its approach to analysis, grounded theory is not the same as a layered account or autoethnography. The grounded theory process relies on a researcher's ability to provide an unbiased, objective analysis of data (Charmaz, 2006). In the case of an autoethnography, the author is inherently subjective, alluding to, if not obviously stating, the personal connection with a larger cultural experience. In order to be true to the data and emerging findings of the data in a grounded theory, the researcher must be able to view data from an objective stance to prevent personal bias from disrupting the analysis (Charmaz, 2006). Though a layered account provides objective perspectives for comparison purposes, such as theoretical and research literature, the analysis of a personal experience does not control for bias (Ronai, 1995). Additionally, autoethnography has the prerogative to omit parts of a story, parts of the data, which leaves out vital information from the perspective of grounded theory. A grounded theory approach would require complete and total immersion in data that focuses more on actions and contexts. Conversely, fully capturing an experience in autoethnography would include documenting emotional responses and reflexive thought.

## **The Writing Process**

Producing an autoethnography often begins with personal writing about an experience (T. E. Adams & Ellis, 2012; T. E. Adams et al., 2015). Personal writing is experienced in this study by journals, blogs, and other data sources that I produced while engaged in traumatic experience. These writings, over time, presented a logic or pattern that were used to construct a meaningful story. In this study, incident codes identified the chronological patterns describing pre-trauma, during trauma, and post-trauma, which guided the organization of Chapters Four, Five, and Six. I used the PTG theoretical framework as a guide to organize my experience. For example, I knew that that there would be three chapters, separated into pre-trauma, trauma, and post-trauma. I also knew that I needed to include my graduate student experience within the traumatic experience, but I did not directly tie my experiences to the elements of the PTG framework until after I had written the story.

I did not let the elements of the theory or the theorized growth outcomes steer what I chose to include. I made literary decisions on what experiences to include based on my personal judgment of whether I could write them, and still be emotionally safe, and whether they were pertinent to the overall storyline. At suggestions from selected readers (e.g., my dissertation chair, my husband, and my parents), I made subsequent additions to the content of the story. I waited to do analysis or comparison to the framework until after the story was written. The story that was constructed as a result illustrated how I was psychologically impacted by trauma, as related to my graduate student experience.

In piecing together coding patterns, this autoethnography, as written product, reflects both realistic and expressionistic writing styles. From a realistic perspective, I pieced together and wrote the story chronologically. The form of this autoethnography is not separate from the content, nor can the written content be separated from the context in which the experience occurred. In this study, realistic writing involved layering or juxtaposing personal narrative with supplemental explanations (T. E. Adams et al., 2015; Ronai, 1995). It involved both story and analysis (T. E. Adams et al., 2015). Thus, analyzing the incidents of posttraumatic growth within the context of the graduate student experience was a concurrent process with writing. My autoethnography is also expressionistic because it included internal meaning making that was determined through emotions, reflection, and introspection (T. E. Adams et al., 2015). Therefore, my study not only *showed* the interpretation of my analysis through emotionally rich detail and expressive dialogue, but it *told* my story with thick descriptions to facilitate an understanding of both the traumatic and graduate student experience (T. E. Adams & Ellis, 2012).

### **Ethical Considerations**

As with any research project, there are ethical concerns to consider when engaging in autoethnography. Although one might perceive research about the self as solitary and therefore including no other subjects, autoethnographic research, by the nature of the stories shared, implicates others (T. E. Adams et al., 2015). For this reason, autoethnographers must consider not only procedural guidelines presented by Institutional Review Boards (IRB), but also must consider situational and relational ethics when conducting a study (Ellis, 2007).

Situational ethics concerns the unpredictable moments that occur while in the field and is otherwise known as ethics in practice (Ellis, 2007). Situational ethics emerge from the context within which the researcher is involved and cannot be identified in advance (Ellis, 2007). An example of situational ethics, with regard to this study, involved the question of asking faculty to serve on my dissertation committee where the methodology is in contrast to the norms of the institution or department. Is it ethical to ask non-tenured faculty to participate on a committee with such a methodology where the decision to participate may impact their tenure status at the institution? Addressing this question involved discussing the implications of using non-normed methodologies and establishing a working understanding of the methodology in practice so that faculty could make an informed choice on participation.

More pertinent in autoethnographic studies is relational ethics, or those ethical considerations that relate to the inclusion of special participants in written representations, such as family and friends (Ellis, 2007). As noted earlier in this chapter, autoethnographies are not written in isolation. They inherently implicate others through the storytelling process. Relational ethics, then, is concerned with how an author takes care of those intimate others who are implicated within the story. For example, in this study I made specific reference to family members, some of which are minors and/or are not mentally capable of providing assent. Addressing these concerns in an ethical manner was achieved through narrative strategies, informed and parental consent, child assent, provisions of trust, and allowing those identified to review and offer feedback on the final written product.

## **Addressing Relational Ethics**

In many cases of ethical considerations, the general maxim of “do no harm” relates to the ethic of care necessary to work with human subjects in research that is qualitative and narrative in nature. Ascribing to this notion requires that researchers, particularly those engaged in narrative and autoethnographic research, identify their “narrative privilege” in the research and writing process (T. E. Adams, 2008, p. 180). According to T. E. Adams (2008), narrative privilege includes those privileges that researchers have as a result of their abilities to conduct research, write the narrative in a literary and interpretive manner, and disseminate research to audiences beyond the participants involved. Narrative privilege also recognizes the degree of care necessary when working with intimate others, such as family members. In the case of my study, my narrative privilege required that I acknowledge the level of care that I needed to provide for talking about my son, Nathan, who cannot reasonably give his assent due to his neurological disability. I have additional narrative privilege in my ability to understand the implications of sharing this story. Addressing my narrative privilege required that I explain to my family, as well as others implicated throughout the story, the full implications of sharing this story, particularly the emotional recall it may evoke. My narrative privilege also called me to personally address the assumption that at some point those implicated may read the story.

The primary means of addressing my narrative privilege and working with the intimate others involved in the story was through the formation of an “implicit trust provision” (Freadman, 2004, p. 143). The best example for the use of such a provision is the relationship with my husband, Brian. Our trust agreement has two component parts:

what is shared and how that information is constructed for others. My trust provision with Brian had a dual purpose. First, we had a collective agreement on what information would be shared about our relationship and about us as a couple. Second, we also had an agreement on what information would be shared about our family, specifically about Nathan and his treatment.

In addition to my trust provision with my husband, I also had a similar provision with my dissertation chair. In my autoethnography, my dissertation chair has the additional roles as my graduate supervisor and my program advisor. It was important to acknowledge his roles within the context of the story as separate yet related to our relationship throughout the dissertation process. As my dissertation chair, he was able to read all of the parts of the story as well as my reflections on the graduate experience. We agreed that in order to tell the story of my experience, it was important to be truthful about our past interactions and my reflections on those experiences. I also agreed to respect and address his feedback on the writing of those experiences when they needed additional context or differed from his own perceptions of the experience.

For others who are implicated throughout the story but are not so intimately tied to the story, ensuring that proper care had been taken in constructing their role in the story was paramount to addressing the relational ethics concerns posed in autoethnography. There are a number of tactics that were used to meet the standard of care necessary to protect those implicated. The specific tactic or degree of protection was dependent on the individual. First, I worked to gain consent from those written about to share their involvement in the story. Individuals implicated had the opportunity to choose a pseudonym or use their real name. In this autoethnography, most individuals chose to

use their real name. However, all medical personnel were given pseudonyms to protect them from any potential medical liability.

Another option for those implicated was to speak generically or compositely about individuals within the story who may wish to remain private. Relying on the use of pseudonyms, composite characters, and general or third person references in those cases where identification may have been possible (e.g., doctors, peers, faculty) was an effective means of protecting individuals who were implicated. Finally, in cases where an individual was uncomfortable with their inclusion, I had the option to omit specific events within the story as a means of protecting those being written about without losing the meaning of the story.

## **Consent**

Procedural ethics dictates the convention of a Human Subjects committee review. For this study, I submitted a protocol to the School of Education Internal Review Committee (EDIRC) in recognition of individuals who, while not interviewed or providing data, were implicated within the story. Outlined in my EDIRC application were those tactics previously identified, including gaining consent from those implicated and developing trust provisions with family members, to address the protection of these individuals. Additionally, my EDIRC included a request to gain permission for the use of written correspondence germane to the study, specifically emails and text correspondence.

At the request of the EDIRC committee, I gained consent from every individual who was implicated in this autoethnography. Consent forms detailed the ability to declare a pseudonym and notified individuals that they may be asked to read portion of the



narrative in which they were included (See Appendix A). A child assent script was created for both of my children and orally delivered by my dissertation chair as a third party (See Appendix B). Both children were able to give verbal consent and opted to sign their names on the form. My husband was present during this process, as he had already given parental consent for each child (See Appendix C).

### **Writing Tensions**

I was faced with a number of tensions in the development of this study. First, I had to balance what I knew about research and analysis with idea of crafting a story that made literary sense. There were times in which I could not decide which came first: analysis or storytelling. I had to fight the urge to give in to either side fully. That is, I had to ensure that my creativity was not adversely ruled by theory, and, conversely, I had to ensure that my study still maintained a rigorous approach to examining my experience. I noticed in the writing of this dissertation a clear juxtapositioning between subjective, personal storytelling and objective analysis. When I wrote Chapter Seven, in which I offered an analysis of my experience, I had to tie my story to theory. Writing a personally challenging story and making sense of it from an objective viewpoint was hard for me to conceptualize. Additionally, I had to describe my own personal growth, declare how I developed growth now that I have “processed” my experience. I realized that maybe I was still in the process of figuring out who I am and what I have gained from the experience.

Only after I had written the narrative did I face the issue of the tense in which to write the remainder of my dissertation. Although the experience occurred in the past, I wrote the narrative as if I was presently experiencing it. When I moved to analysis, I

realized that there were incidents where the distress caused by trauma is still active. Still making sense of trauma in the present made talking about analysis in the past difficult, which is acknowledged in Chapters Seven and Eight.

Finally, the EDIRC review process demonstrated that autoethnography still poses many questions from researchers who operate on the positivistic end of the research continuum. This was illustrated by the labeling of my study as oral history, yet requiring consent forms from anyone who might be implicated. Such a decision seemed at odds with the creativity that is necessary to construct a story that is interpretive yet accurate. On the one hand, I needed to gather these consents so that I could complete my dissertation. But I still felt as though I was asking individuals for permission to tell my own experience.

### **Summary**

This study, ground in the dual-paradigmatic referent of interpretivism and postmodernism, used autoethnography to relate my personal experience with trauma to the graduate student experience. The story that is shared uses primarily subjective experience to focus on the traumatic experiences that occurred during my graduate student experience and the resulting psychological impact of those traumas. Using a layered account to narrative analysis, this autoethnography merged my authorial voice with those found in research and theory to develop a multiple perspective story that allowed for deeper connections between individual student experience and a more general graduate student experience. In the next chapter, I begin the narrative to support this analysis.

## CHAPTER FOUR

### SEARCHING FOR TRUTH

*November 4, 2013:* My phone vibrates in my pocket. I ignore it so that I don't appear rude. The guest speaker is almost finished with her talk, and I know my peers will want to chat when it's over. Twenty minutes go by, and I am finally walking out of the building. I glance at the text message I received earlier:

*get your ass home. nathan threw up everywhere!!!!*

I sigh. I feel irritated that my husband Brian feels the need to inform me of Nathan's vomit, as if I could do something about it while I'm 25 minutes away from home. I feel concerned that this isn't the first time my ten-year-old son has thrown up this week, this month. *Throwing up once a day doesn't seem normal.*

When I open the front door of the house, the smell smacks me in the face. The lights upstairs are on and I can hear splashing in the bathtub. I can feel Brian's frustration bouncing off the stairwell as he attempts to get one of the kids washed. I glance in the dining room, where the smell seems to emanate. The vomit sits on the floor, the chair, the wall, the table. Waiting.

I've never liked cleaning up vomit. The warmth, the smell, the texture. It's a sensory experience that rivals a horror movie. I can feel annoyance trying to infringe on my motherly duties. I don't have time to clean this up. I have assignments to finish, articles to read. Why didn't Brian clean this up? Why did he leave it sitting here, congealing on the floor?

Pushing my annoyance aside, I go to the kitchen for paper towels and Clorox wipes. I wish Nathan would stop being so picky about the things he eats. I wish he wouldn't gorge himself on water after eating. I wish he would know to throw up in the bathroom and not on the carpet, on the kitchen table, in his bed.

\*\*\*

*December 19, 2013:* I sit next to Nathan in the pediatrician's waiting room. The vomiting has continued at home. It has been the same for the last few months. He has no other apparent symptoms that would make me think it's a virus, but, then again, I don't have a medical degree.

Dr. Scott shuffles into the exam room, weighed down by Nathan's medical file.

"Hello, how are we today?"

"Well we seem to be throwing up regularly," I explain.

Dr. Scott jots a note. "Is he throwing up after he eats?"

"It tends to vary. Sometimes he throws up first thing in the morning before breakfast, but more often than not, he throws up after dinner."

"What about lunch time?"

"Not that I've witnessed, I couldn't tell you what happens at school. I would hope his teachers would tell me if he threw up at school." *There's a thought I had yet to imagine.*

Dr. Scott nods and continues writing her notes. "Well let's see what we have going on then."

I roll my eyes inwardly as Dr. Scott attempts a thorough examination of his eyes, ears, and some of his throat. Cooperative is not Nathan's middle name. "It doesn't look

like he's sick. He's not running a fever. His ears look good. There's no sore throat. What we might be seeing is acid reflux."

*Wait, what?* "Okay." I nod.

"Children with autism tend to also have gastrointestinal problems, like acid reflux.<sup>2</sup> Does your family have any history of acid reflux?"

"No, but Brian had reflux as a child," I explain.

Dr. Scott nods and makes another note. "So what we can do is give him some Zantac and see if that makes a difference. Okay? If there's no change in a week or two, come back. Okay?"

*Acid reflux*, I think. *All of this fuss for acid reflux*. I feel vaguely relieved that it's just reflux, but also annoyed that this required a visit to the doctor. I take the prescription she hands me and lead Nathan out of the office.

\*\*\*

*February 26, 2014*: We're sitting in the exam room again. Same room, different day. The Zantac had been working for a few weeks, but Nathan's vomiting has returned. Dr. Scott asks me the same questions about his vomiting. "How long has this been happening? What time of day? Is he still taking the Zantac?"

I give her answers the best way I can, and hope that they mean more to her than they do to me. "He's also been peeing a lot,<sup>3</sup> and so I was concerned that he might get dehydrated," I share.

---

<sup>2</sup> Boucher (2009) identified a number of other disorders that can accompany autism, including epilepsy, autoimmune disorders, gastrointestinal disorders, and metabolic disorders.

<sup>3</sup> Dysfunctions in the pituitary gland can present with polyuria, the excessive passage of urine, and hormone and endocrine dysfunctions such as diabetes insipidus, or an inability to regulate the body's

Dr. Scott jots another note. “And when was the last time he pooped?”

I can feel myself blushing. Apparently, I can be embarrassed by a simple word. I thought I had been doing so well talking about Nathan’s vomiting and urinating. “I don’t know.” My embarrassment deepens. *How can I not know this about my child? I am supposed to know this, right?* “He doesn’t exactly tell me when he has to go.” My excuse makes me feel only slightly better.

Dr. Scott jots some more notes. I shift anxiously in my seat as if I’m taking a test and giving all the wrong answers. “Do you think he’ll let me examine his belly?”

No. “We can try,” I say. Dr. Scott walks over to Nathan and reaches for his midsection. He yells and pushes her hands away.

“So I have two concerns,” she starts, as she sits back down and picks up her pen. “One is that we might have a blockage somewhere. The other is that we might have an issue with his kidney function.”

Somewhere in my mind I’m laughing at the absurdity of this conversation. If he weren’t throwing up once a day, he’d seem like a normal-ish kid. Why are we talking about blockages and kidney function?

She gives me directions to get an abdominal x-ray and blood work done. *Great, Nathan will just love that.*

\*\*\*

The lab technician hands me a pair of paper shorts. “He needs to undress completely and put these on.”

---

sodium levels (Christmas & Horwich, 2003; Hastings, Torkildson, & Agrawal, 2012; Legault & Allen, 2012).

*Crap.*

I manage to get Nathan's shirt and pants off with minimal screaming and cringe when my ears are assaulted as I try to get him to wear the paper shorts instead of his underwear.<sup>4</sup> Still crying, he is now clad only in the paper shorts as I usher him into the x-ray room.

The table is ice cold, and Nathan strongly protests lying down on the firm surface. After much coaxing, I tell him that we're just taking a picture of his tummy. "No Ow-ies." Just as he gets settled, the technician snaps the picture and we're done.

*Almost done.*

He eagerly dresses in his clothes and I lead him to the hallway where we await the blood draw.

\*\*\*

Later that afternoon I get a phone call from Dr. Scott. "His blood work looks good, so there's no kidney problem that we can see, but his x-ray does show a lot of poop."

---

<sup>4</sup> Autism is also associated with challenges in sensory processing. Individuals with autism may experience hypersensitivity across their senses (Boucher, 2009) creating barriers for medical personnel to gain cooperation. Complicating this sensitivity is the limited ability to process more than one input or sense at a time, causing some individuals with autism to "overload" from too much stimulation (Boucher, 2009). Attempting to provide medical treatment can easily push an individual with autism into sensory overload given the numerous smells, textures, and inevitable touching that can occur (Muskat et al., 2015; Scarpinato et al., 2010; Soulders, Freeman, DePaul, & Levy, 2002; Vaz, 2010). Many medical tests also include some measure of discomfort or pain, such as a finger prick, injection, or blood draw. Pain, coupled with confusion and anxiety, can be a complex emotional process, which individuals with autism may have an inability to process (Boucher, 2009; Scarpinato et al., 2010).

I'm starting to wonder how she can say that and not think it sounds ridiculous. I mean, we are two adults talking about poop. *Maybe you're not much of an adult.*

She finishes telling me instructions to give Nathan Miralax twice a day for the next two weeks. I hang up the phone thinking at least this will solve the throwing up problem.

\*\*\*

*March 24, 2014:* I'm sitting in the carpool line, waiting to pick Nathan up. The sun is beating down on me, but I resist the urge to flip on the air conditioning. It's been a long day of running kids to school, complying with requests from faculty members, and stressing over my latest research assignment. I muse for a moment that the semester is almost over, and I will soon be starting my dissertation.

The line creeps forward and soon I am watching Nathan trudge toward the car. I smile and wave at him as he opens the car door and clambers into his seat. I wait patiently for him to buckle his seatbelt and then we are moving again.

"Did you have a good day?" No response. I brake at the stop sign and turn in my seat. "Nathan, did you have a good day?" I repeat. He nods at me and smiles slightly.<sup>5</sup>

---

<sup>5</sup> Despite the heterogeneity of an autism diagnosis (Waterhouse, 2013), there are common challenges in autism, specifically with regard to social communication and interaction. In addition to impairments in interpreting social cues, individuals with autism can also have difficulties with expressive language and comprehension (Boucher, 2009). The inability to read facial cues or to comprehend explanations given by medical professionals can be challenging in an inpatient setting (Scarpinato et al., 2010). Likewise, a patient's inability to convey pain or discomfort can result in delayed diagnosis or inappropriate treatment (Muskat et al., 2015; Owley, 2004). It was my experience that advocating for my son as an "Expert on Nathan" was the only way we were able to receive a final diagnosis. The burden to ensure the health and



Satisfied, I turn back around and continue through the intersection, turning up the radio as I drive home.

We stop at our first red light and the long line of cars suggests we will be sitting here for at least two light cycles. I turn around to ask Nathan about what he did at school. His eyes are fluttering as if he is asleep, but he's sitting straight up in the backseat. *Weird.* I gently rub his knee, "Nathan?"

His eyes open and focus on me for a brief moment before fluttering shut again. I frown, but before I have the chance to do anything else, the traffic is moving around me.

We stop at the next red light and I whip my head around to see if Nathan's demeanor has changed. It hasn't. I reach for his book bag lying on the backseat floorboard. Casting glances up at the stoplight, I search for the communication notebook Nathan's teacher and I use frequently to discuss Nathan's progress. I flip through the notebook to the last written page.

*Nathan had a rough day today. He fell asleep after lunch and slept until dismissal. We tried to get him up, but he would fall back to sleep once we woke him up. Just wanted to let you know.*

A honk from behind me signals the light has changed.

\*\*\*

---

appropriate care of children like Nathan rests heavily on parents' ability to know their child (Muskat et al., 2015; Owley, 2004; Scarpinato et al., 2010; Vaz, 2010).

*April 8, 2014:* Nathan's sleepiness has me concerned enough to take him to the pediatrician. *It's just not like him to sleep so much.*<sup>6</sup>

"Hello, how are we today?" Dr. Scott shuffles into the exam room.

"Well, we've been sleeping *a lot*. He's even falling asleep at school."

"Is he still taking the Clonidine?"

*The only drug that helps him sleep at night?*<sup>7</sup> "Yes."

"And he's still taking the Periactin to stimulate his eating, correct?"

"Yes."

She jots a note and then looks at Nathan, who at this point is awake and reciting lines from a movie. "So the Periactin can make you sleepy. And what we might be seeing is a drug interaction with the Clonidine and the Periactin, where two of them together might be causing him to be sleepy all day, instead of only sleepy at bedtime."

"Okay." I'm not sure that I buy into this explanation.

"So let's try this."<sup>8</sup> Let's remove one of the medications and see if his sleepiness improves." She stares at me expectantly. When I don't answer, she asks, "Which would you rather take away?"

---

<sup>6</sup> A number of studies have found that signs and symptoms of illness recognized by parents tend to be vague or non-specific (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001), and that the first sense that something is wrong is a child's behavior change or affective cue (Irvine & Cunningham-Burley, 1991; Neill, 2000).

<sup>7</sup> Also common among individuals with autism are sleep disturbance and maladaptive or challenging behaviors (Boucher, 2009).

<sup>8</sup> In waiting for a confirmation of diagnosis, doctors of children with autism tend to gather more information over a longer period of time (Simon & McNicholas, 2014). Eiser, Parkyn, Havermans, and

*As if this is a question that needs considering.* “Well, he still needs to be able to sleep at night. And if the Periactin is contributing to him sleeping during the day, then he’s not eating anyway, which defeats the purpose of taking the Periactin in the first place.” She nods at me expectantly. “So I think I want him to stay on the Clonidine.”

“Okay, then, let’s take him off the Periactin. And then come back in two weeks so we can see how he’s doing.”

\*\*\*

*April 16, 2014:* A week later, I manage to schedule a last minute appointment with the pediatrician at the end of the work day. He has still been sleeping, regardless of the medication changes. My initial reservations about a drug interaction being the culprit have been confirmed. *At least, in my mind.*

“So I think maybe we should check his electrolytes and be sure he’s not dehydrated, since he’s been sleeping and not eating or drinking as usual.”

“Okay.” *Progress! An actual test!*

“But the satellite office isn’t going to be able to give him fluids if his electrolytes are low, so you’ll have to go to the emergency room downtown. I’ll call ahead and tell them that you’re coming in.”

I look up directions to the hospital on my phone and start driving. At last, I feel as if we’re doing something.<sup>9</sup>

---

McNinch (1994) found that parents reported their child’s doctor prescribing other treatment or medications for different conditions than what was later ruled as the confirmed diagnosis.

<sup>9</sup> Since common symptoms can have multiple, and more probable, explanations, doctors may not initially order tests that can be expensive or invasive (Dixon-Woods et al., 2001).

The emergency room isn't overly crowded when we arrive because it's after five o'clock. After checking Nathan's vitals, a nurse shows us into a large exam room and instructs Nathan to put on a green hospital shirt. I get a brief glimpse of the "old" Nathan as he throws his shirt across the room in protest. With Nathan spending most of his time sleeping these days, I sometimes forget that he can put a decent fight when he wants to. The television is playing *The Lion King*, and eventually Nathan settles onto the gurney and falls asleep.

The doctor on shift comes in and asks me questions about Nathan's current state. I tell him what I've told everyone else, "He's sleeping *all* the time. His pediatrician said we should check his electrolytes."

The doctor switches out with a technician who comes in to draw blood. Nathan cries as he tries to jerk his arm away from the grasp of the technician. I manage to climb behind Nathan and hold his arms so he doesn't hurt himself. *Be quick dude*, I think.

\*\*\*

When we get home, the phone is ringing. Brian has answered it, and I hear him tell the caller that I just got home. I glance at the clock on the oven as I take the phone from his hand. 9:30. Inwardly, I groan, and my stomach growls in response.

"Hello?"

"Hi, It's Dr. Scott. I just wanted to find out how it went."

"They didn't find anything noteworthy," I start. "His sodium was a little high, and they ran a thyroid panel, but those results won't come in until tomorrow."

"Okay, I will check in about those results in the morning. But if anything changes, just come in."

\*\*\*

*April 17, 2014: It's been a long day of worrying. I can't seem to quiet my mind enough to get ready for bed. Something is itching at the back of my mind, a worry that ceases to rest. I boot up my laptop and open my email. Maybe I should give my faculty supervisors a heads up about Nathan, just in case. I feel slightly guilty that I haven't been at the school of education to do work for my graduate assistantship. Hopefully, Jim and Sharon won't be too upset that I've been gone so much.*

-----Original Message-----

From: Kristen Tarantino  
Sent: Thursday, April 17, 2014 10:43 PM  
To: Barber, Jim; Sharon H. deFur  
Subject: GA Update

Hi Sharon & Jim,

I wanted to send you both an email to let you know what's going on, particularly if you don't see me at my desk in the next few days. I mentioned to Sharon after the Brown Bag that Nathan has been having medical problems, namely sleeping *all* the time. His teacher even told me today that he seemed off-balance and needed to have help with his motor coordination.

We went to the ER at [hospital] yesterday evening for some blood work, all of which came back normal. The doctors initially thought this might be a drug induced reaction, but I'm not sure how likely that is not that we've taken him off two medications. His pediatrician has a call in to the pediatric neurologist who specializes in sleep disorders, and she's even talked about the possibility of having him admitted to the hospital for observation. We have an appointment with her tomorrow morning, so hopefully we can talk about a game plan. We currently don't know what's wrong with him; it's a best guess sort of scenario.

All of this, to tell you that if I'm not at the school of education, I'm most likely with him somewhere. I'll try to give you a heads up if I know I won't be in, like tomorrow and Monday (school is closed for him), but at the moment, I'm not sure what will happen. When I know what his prognosis will be, I will pass it along so that you'll at least be able to gauge my emotional state (ha!).

You both have been very understanding with previous child-related absences, and I hope you both know that I truly appreciate it. I will keep you both posted and hopefully will see you on Tuesday.

Kristen

-----

\*\*\*

*April 18, 2014:* It's the Friday before Easter, and I'm sitting in the carpool line again. But this time I'm not thinking about the sun or my schoolwork. I'm not thinking about the half-day of school which messes up my schedule. I'm thinking about Nathan. Worrying has been generous in delivering misery, giving me a sleepless night, a dull headache, and a burning chest pain. He has continued to sleep. At school. At home. At mealtimes. I have already succumbed to my need for answers by Googling Nathan's symptoms repeatedly, but I don't like the answers I have seen: sleep disorders, seizures.

Nathan's teacher walks to the car. *Uh oh.* I roll down my window and smile in greeting. She doesn't smile back.

"Something is not right. His balance is really off. I had to hold his hand when we were out on the playground so that he wouldn't fall over."

*Great.*

"Hmm, okay," I say. My chest constricts and the resulting burn makes me wince.

"And he's still sleeping in school, like falling asleep at his desk while he's supposed to be doing work."<sup>10</sup>

---

<sup>10</sup> Doctors of children with autism may rely on other informational sources, such as teachers, to help get the full picture of a child's symptoms and overall condition (Simon & McNicholas, 2014).

“Yeah, they didn’t find anything when we went to the ER on Wednesday, but I think I’m going to have to take him back to the doctor, because this just isn’t like him.”

Nathan manages to climb in the car and buckle his seatbelt before falling asleep. His teacher and I both glance in the backseat at him. I can see my own worries on her face.

\*\*\*

When we arrive at the house, Nathan is asleep in the backseat. I sit in my seat, absentmindedly rubbing my chest bone, and watch him, hoping that the cessation of car movement will wake him up as it usually does. But he continues to sleep, uninterrupted. Sighing, I know I will have to be the one to wake him up.

We make our way into the house, and I set about making him lunch. “Nate, have a seat at the table so we can eat lunch.”

I place his lunch in front of him and watch as he ignores it. He sits cross-legged in his chair, leaning his chest against the table with his mouth parted and head tilted back slightly. His eyes are slits, but I can see them rolling and twitching beneath the lids. I watch him for several moments, torn between fear and uncertainty. I try gently to wake him enough to eat his lunch. Somehow I think that if I can just get him to eat, everything will be fine. He hasn’t been eating his lunch lately, but a few bites would be better than nothing.<sup>11</sup>

---

<sup>11</sup> The hypothalamus is the part of the brain that is responsible for the circuitry providing controls over sleep, feeding, and energy metabolism, as well as hormone and blood chemistry balance (Saper & Lowell, 2014). Dysfunctions in this region of the brain can present as increased lethargy and somnolence (Christmas & Horwich, 2003).

Each attempt to stir him results in a temporary awakening. Not knowing what else to do, I grab the phone and call the pediatrician.

\*\*\*

*April 20, 2014:* Mom hugs me as we walk in the back door. “Happy Easter!” I hug her briefly and turn to help Nathan through the door. He starts towards the stairs that lead to his “room” at Grandma’s house. I go to him, taking his left hand and wrapping my right arm around his back for support. He grips the railing for support.

Mom follows me up the stairs. “Nathan, I have a surprise from the Easter bunny for you.” He turns to look at her, trying to process her statement. We make it up the last step and turn towards his room. A new box of Legos is lying on the bed. I imagine his face lighting up in a big grin when he sees them, arms flapping in excitement, eager to open the box and get started. But I am disappointed.

“Look Nathan!” I point at the box, trying to engage him. “Legos!”

He smiles blandly and nods. “MmHmm.”

“Do you want to open them?” Another nod. He sits on the floor, swaying from imbalance or exhaustion I can’t say. I open the box and proceed to dump tiny Lego pieces on the floor. The set has pieces to create a mountain hut. Challenging for an adult, let alone a child. But I am confident that Nathan can put it together with little help. He has at least three of these sets at home and usually refuses my assistance when building them.

He sits staring at the Legos, while Mom and I watch him. I expect him to dive right in and start putting pieces together according to the accompanying design book. *Maybe this set will take him longer than an hour to put together, unlike his other sets.* But instead his eyes start to close as he sits, unmoving. I try to keep him awake, per Dr.



Scott's instructions. "Would you like mommy to help?" Maybe the threat of having help from someone else will be enough to spur him into action.

His eyes open briefly. "Do you want mommy to help you?" I repeat. At least his eyes stay open.

I turn the pages in the accompanying Lego book, with no resistance from Nathan, and hand him the pieces one at a time to put together. As I hold out the next piece, he reaches for it with his fingers. And misses. He tries again to grab the piece but finds empty space three inches away from my own fingers.<sup>12</sup>

"Here it is, Nathan." I place the Lego in his outstretched fingers.

After three more attempts to get Legos from my hand, I turn to look at Mom who is still standing behind me and shake my head at her.

"Mom, something is wrong. He can't even grab a Lego from me." I glance back at Nathan only to find his eyes closed.

\*\*\*

*April 21, 2014:* We sit, again, in the pediatrician's office. The nurse asks about our weekend, and all I can think about is those stupid Legos.

Dr. Scott walks in. "So how are we doing?" I replay the story about the Legos for her and watch while she nods and takes notes.

"Let me see if I can get in touch with the neurologist." Dr. Scott stands and leaves Nathan and me in the exam room. From my chair, I can hear her talking on the phone in

---

<sup>12</sup> Directly in front of the hypothalamus and pituitary gland is the optic chiasm, where the optic nerves meet. Disturbances in visual acuity can be symptomatic of damage to either optic nerve or to the optic chiasm (Christmas & Horwich, 2003; Hastings et al., 2012; Legault & Allen, 2012).

the next room. Nathan leans into my side and closes his eyes. *Sure, now he wants to be cuddled.* Only now does he let me pull him close to me. I close my eyes and pray that someone has an answer.

After about fifteen minutes, Dr. Scott comes back in the room. “So they can’t do anything for him right now. And the fastest way for him to be seen is to go to the emergency room for a CT scan.”

\*\*\*

Ironically, we suffer through no traffic congestion on the way to the emergency room. I realize I’m gripping the steering wheel too tight, and I force myself to relax my fingers slightly. I take a deep breath, and just because I don’t feel that’s enough, I make myself do it again. Nathan is sleeping in the backseat, his head resting against the passenger side door. I start to feel my eyes burn as I glance at him in my rearview mirror.

*Don’t.* I warn myself. *Don’t go there.*

The emergency room is bustling. Kids are crying, parents are trying to keep them happy with the lure of snacks and games on their phones. The three televisions bolted to the wall play a non-stop assortment of Disney movies. I hear Nathan’s name called above the noise and I rouse him from his snoozing.

The nurse leads us through a set of double doors requiring a special key card, and shows us into a different, smaller exam room than the last time we paid a visit. At first, Nathan doesn’t want to sit on the gurney, so I attempt to reassure him. “You can go back to sleep, Nate.”

The nurse wants me to exchange Nathan’s clothes with a hospital shirt and bottoms. The gauzy green fabric clings to my fingers, but I manage to change Nathan’s

attire with little fuss. Remembering the outburst from his abdominal x-ray in February, it hardly seems like the same child. *If he were awake, he'd probably be letting you know how he feels about changing clothes.*

A man in green scrubs comes in to take us to CT. The process goes well until we explain to Nathan that he has to lay on this special table with a strap velcroed across his forehead and special pillows placed around his head to keep it from moving. The strap sets him off. He jackknifes to a seated position shoving the man in the scrubs away from him.

I try to soothe him as a technician begins wrapping a lead apron around my front. Nathan must not have much fight in him because he lies back down. The man rests his forearms gently on Nathan's chest to keep him still and talks to him about not moving his head as the machine whirrs to life. Nathan jerks his head and they say they will have to do it again.

\*\*\*

We are back in our exam room watching the *Princess and the Frog*. I have never seen the movie, but the audio is muted while Nathan sleeps so I don't think this viewing counts.

The door opens and a woman in a lab coat walks in. "Hello, I'm Doctor Hubbert from neurology. I spoke with Dr. Scott about Nathan." I shake her hand and introduce myself as Nathan's mom.

"So the CT was abnormal and fuzzy, probably because he was moving a little bit. What we'd like to do is get an MRI so we can get a better picture. You won't have to worry about him moving because we'll sedate him for that scan."

I nod but don't process what she is telling me.

"For now, we're waiting to get him in for the MRI. If he doesn't get in today, then we're going to move him up to the PICU for monitoring overnight and do the MRI first thing in the morning."

After Dr. Hubbert leaves, the room feels hollow, as if she sucked all the life out of the room when she closed the door behind her. I send a text to Brian:

*CT was abnormal and they want to do a MRI – sedated which means we may have to be admitted for the night but I'll let you know*

\*\*\*

Later that evening, with Nathan sleeping in the hospital bed next to me, I send a short email to Jim and Sharon. After my last email to them, both had reassured me that my graduate assistant work could wait while I took care of Nathan. They also had indicated wanting to be kept informed of progress in Nathan's condition. This seems like a good time to give them an update.

-----Original Message-----

From: Kristen Tarantino  
Sent: Monday, April 21, 2014 8:53 PM  
To: Barber, Jim; Sharon H. deFur  
Subject: Nathan

Hi Jim and Sharon

Nathan had a CT scan today and it showed a mass in his brain. We're staying overnight in the ICU and having an MRI tomorrow morning to find out more. I just wanted to let you both know.

Kristen

Sent from my iPhone

\*\*\*

The night stretches on, teasing me with thoughts of rest, the promise of dreams. But there is no rest, no dreams; not in this place. I glance up from my laptop screen to watch the heart rate numbers rise and fall with Nathan's troubled slumber. The beeping down the hall in the pediatric ICU further chases sleep from my mind as I return to the email I had been trying to write to my field research professor for the last two hours.

...I wanted to ask you what the policy/guidelines are for taking an "incomplete" for the spring, and finishing my project later (although how much later I don't know at this point). I know you had said at the beginning of the semester to let you know if it was going to take longer, but something serious has happened and there's just no way I can even think about schoolwork right now...

The cursor on the screen winks at me as if it knows a secret I don't. Too bad I already know the secret. Sighing, I close the laptop and then my eyes. How could this have happened? What had I done to deserve such heartbreak? Why is this happening to Nathan? Hasn't he earned a break?

The sliding door to the room eases open and the nurse slips in. "Just another neuro check."

I nod as if her words mean something to me. All I know is they wake him up, shine a flashlight in his eyes, and check his temperature. He doesn't even look like a child, like the active Nathan I'm used to seeing. I want him to get up, push the nurse, shout, "No, no, no!" But he does none of this.

"I'll be back in an hour, do you need anything?"

"No, I'm fine." *You're not fine.* "Thank you. What time is the MRI scheduled for?"

“I don’t see a time, but the doctor said he would be first. They’ll probably come get him at seven.”

I nod again.

“Would you like me to get you a blanket?”

“Sure.” But I won’t sleep. I can’t. The idea makes me ill. What if I miss something? What if something happens while I’m asleep?

I can’t stop seeing the CT scan in my mind, replaying the ICU doctor’s words. “A mass,” the doctor called it. “We can’t be sure what kind of mass until we get an MRI, but you can definitely see a midline shift here.” He points at the center of the brain scan, at the large C shaped curve in what should have been a straight line between the two hemispheres of Nathan’s brain.<sup>13</sup>

How could I not have known? *But you did know. Deep down, you knew.*

I reach out and rub the back of Nathan’s hand. *Keep it together, you don’t know anything for certain yet. Just wait until you know for sure.*

\*\*\*

*April 22, 2014:* Today, I feel alone. I pass my sleeping child off to the anesthesiologist who will keep Nathan under while he goes through the MRI. As I relinquish my watch to

---

<sup>13</sup> Central nervous system (CNS) tumors are the second most commonly diagnosed cancer in children after leukemia (Hastings et al., 2012). Germ cell tumors occur primarily in the testes and ovaries, however, they can present in extragonadal regions, including the brain (Hastings et al., 2012; Leibowitz, Shivdasani, & Kantoff, 2003; Malogolowkin, Monforte, Kovanlikaya, & Siegel, 2003). Intracranial germ cell tumors make up about 3-5% of pediatric brain tumors (Hastings et al., 2012; Legault & Allen, 2012). These tumors mostly present near the pineal gland and/or in the suprasellar regions surrounding the pituitary gland and hypothalamus (Leibowitz et al., 2003; Penn, Jenney, & Nicholson, 2014).

the doctor, I am left empty, with no other family around me to absorb the loss. The separation guts me, as if I know everything will be different after this moment. I imagine the loss feels similar to giving birth – one moment you have life within you, and the next, it's gone, wriggling and crying in your arms. The symmetry is startling. I imagine Nathan being terrified by all the new sights, sounds, and smells of the hospital, riding his anxiety into overdrive with each new face and professional he meets along the way. But he sleeps, so my worries, thus far, are unwarranted.

It is a short while later that I'm sitting by Nathan's side again in the ICU. My mom is sitting on the other side of Nathan's bed, rosary in hand. A man in a lab coat walks in and introduces himself as Dr. Caesar. He's a neurosurgeon.

"So he definitely has a tumor in the middle of his brain."

"How big of a tumor are we talking about?" Mom asks.

"Well, it's sizeable." *What do you mean it's sizeable?*<sup>14</sup> My eyes dart between the doctor, Mom, as she scribbles down every word, and Nathan, asleep in the bed. I can feel my nerves racing underneath my skin. *I wish he would leave.*

"We let oncology know, they should be coming down to talk with you soon." He leaves the room as abruptly as he had walked in, and I lock eyes with Mom. She looks as lost as I feel. I can see the confusion and questions on her face, but before I have a chance to say anything, Dr. Caesar pops back into the room.

---

<sup>14</sup> Nathan's tumor measured 4.0 x 4.5 x 3.6 cm on his initial MRI scan, slightly larger than the size of a golf ball. It was located above the pituitary gland and splayed into the hypothalamus. Though there was no clear diagnostic evidence, it appeared that the tumor may have been interfering with Nathan's optic nerves, resulting in visual impairments, as it was located immediately behind the optic chiasm (Christmas & Horwich, 2003; Hastings et al., 2012; Legault & Allen, 2012).

“Do you want to see it?” Mom and I indicate that we would, and he pulls over a computer screen, scrolling through brain images until he finds the one showing the tumor. It’s like a physical blow. An image I can’t erase, permanently etched in my mind.

When Dr. Caesar finally leaves a second time, I collapse into my chair again. The thoughts screaming in my head combat with the acid in my stomach, threatening to erupt, eating away at who I was and swallowing the “old” me whole. I will myself not to be sick in the middle of the room. “I’m going to throw up,” I say and close myself in the adjoining bathroom.

When I return to room, the oncologist is standing at the end of Nathan’s bed introducing herself to Mom. *How can this possibly be happening to me, to my child, to my family? This sort of thing happens to other people, not me. Isn’t having autism enough?*

“You must be mom, I’m Robin McAllen. I work in oncology and my specialty area is brain tumors.” Mom is writing again. I shake Dr. McAllen’s outstretched hand and sit back down, not trusting myself to be able to stand up. I hear her tell me that we don’t know what kind of tumor Nathan has yet. That we’re going to do another MRI, this time of his spine. That we’re going to do a spinal tap and schedule a biopsy.

I feel dumb. As if I can’t quite understand what she is saying. *What do you mean you have to biopsy it? Are you telling me it is cancer? Are you telling me he’s going to live? Die? What exactly are you telling me? What aren’t you telling me? Are you sure these are his results and not those belonging to some other child? Did you make a mistake?*



I feel the shock of the doctor's words like a live wire. My face twitches with the need to release my hard-fought control on my emotions. They scream along my nerve endings, calling out for release. It is a burn I want to keep to myself, not willing to let anyone else share in the exquisite pain. I force my fingernails into my palms in an effort to make my control last just one more minute, just thirty seconds, until the doctor has left.

The instant Dr. McAllen has left, Mom looks at me and I can see the tears she's been holding back. She makes a move to come hug me, and I manage to say, "I need a minute." I barely escape into the bathroom before the raw emotions I have been struggling to contain explode. I can't control the outburst that is violently wrenching sobs from my core. I'm not able to catch my breath, not able to draw air into my lungs as if they protest my ability to live while Nathan lays incapacitated. I grasp the edge of the sink, doubling over with the need to breathe. I don't want to be comforted, I don't want the comfort of someone's arms around me, the security of being held in someone's embrace. I want to be alone, untouchable; to grieve in my own way because it is my burden to carry, as his mother.<sup>15</sup> I hear the bathroom door open and feel my mother's arms wrap around me. I can hear her sobs echoing my own. Every touch, every word of comfort clashes horribly with the desolate helplessness that threatens to engulf me, but I cling to her anyway.

\*\*\*

With my mom and dad watching over a sleeping Nathan in the ICU, I escape from the hospital. My initial reaction to the MRI results flirts with my consciousness as I drive.

---

<sup>15</sup> Shortman et al. (2013) found that mothers of children with diagnosed brain tumors reported not wanting or seeking counseling as they felt it conflicted with their ability to stay positive or in control.

I can't control the tears that begin to fall, but I manage not to unleash them fully, not again. The fresh air seems at odds with my current state, and the setting sun leaves a warm glow on the evening that does not ease my pain.

Pulling into my parking spot in front of the house, I manage to sneak in the house before my neighbor can ask me where I have been. The house is silent. *Brian must be picking up Owen from daycare.* I remove my shoes with a remoteness that belies my calm facade on the verge of collapse. The clothes I have worn for the past 48 hours are shed in favor of scalding water. The heat is intense but I resist the urge to turn down the temperature. *Maybe I can scrub this nightmare away.* That thought, and the realization of its impossibility, releases another round of sobbing. All thoughts of showering vacate my mind, and I just barely succeed in not falling over from grief.

Eventually, I realize the heat and tears, in addition to the unfortunate vomiting at the hospital, have left me dehydrated, and I shut the water off. Once dressed, I walk down the short hallway to Nathan's room. Standing in the doorway, I almost can't make myself walk into his room. I shake off the desire to lie in his bed and weep some more. Instead, I pick up his blanket, pillow, stuffed otter conveniently named "Weasel," and his buddies. These I place in a duffle bag with a few toiletries and spare clothes that I will take back to the hospital.

Just as I bring the bag downstairs, I notice Brian pulling up to the house. I watch as my three-year-old, Owen, clambers out of his car seat. His blonde hair is damp at the ends and around his neck from playing outside. His face still shows baby fat, making his cheeks even rounder when he breaks into a grin of surprise at seeing me. I open the door for him as he runs toward the house in excitement. "Mommy!"

“Hey buddy!” I pull him close and wrap my arms around his little body. He reciprocates by throwing his arms around my neck. He smells like sweat and cooked vegetables. *He must have smeared lunch on himself somewhere.* My eyes begin to water, and I hug him for longer than usual. When he tries to pull away, I let him go and blink away the moisture from my eyes, not wanting to let him know something is wrong. Brian walks in and I repeat the MRI results that I had given him over the phone. “I was getting ready to head back,” I say. He looks at me, as helpless as I feel. I hug him too, and we stand in the doorway for several moments in silence, just clinging to each other.

\*\*\*

-----Original Message-----

From: Barber, Jim  
Sent: Tuesday, April 22, 2014 11:18 PM  
To: Kristen Tarantino  
Subject: RE: Checking in

Hi Kristen,

Just checking in to see how you, Nathan, and the family are doing. We’re thinking of you guys. Please let me know if I can help by contacting your professors to let them know what is going on. I hope today brought some answers for you. Don’t worry about things at W&M if your priorities need to be with your family. I’m also more than happy to help arrange incompletes for your courses if that will be helpful to you at this point in the semester.

Jim

-----Original Message-----

From: Kristen Tarantino  
Sent: Wednesday, April 23, 2014 2:14 AM  
To: Barber, Jim  
Subject: Re: Checking in

Hi Jim

I appreciate all the thoughts and prayers, looks like we're going to need them. Nathan's got a substantial tumor right in the middle of his brain. We don't know what kind of tumor yet although the neurosurgeon has made it clear this isn't the kind of tumor we can just go in and cut out; we're scheduled for a biopsy on Thursday at noon but the oncologist said it might take some time to get the results. For now we're still in the ICU until further notice. This is probably the most scared I have ever been for him. I think I can safely say my semester is officially over at this point. I tried to email [professors] tonight to ask about incompletes but the Wi-Fi at the hospital is sketchy so I don't know if they went through. Dr. Ward is aware of the circumstances because I had to relay that I was missing class tonight but I never asked about an incomplete. And I emailed Pam last night about the refund policy for the Italy trip. I just am not sure how much of my brain is going to be left to function after Thursday, so I was trying to take care of school matters now. But really anything past Friday is just not on my radar.

We're just trying to normalize this experience as much as possible for him. Luckily he's slept the majority of the time. When I know more I'll certainly let you know - if only to normalize this for myself in a way. Our family really appreciates all the prayers, looks like this is going to be a difficult road for us.

Kristen

Sent from my iPhone

-----Original Message-----

From: Barber, Jim  
Sent: Wednesday, April 23, 2014 1:51 PM  
To: Kristen Tarantino  
Subject: RE: Checking in

Hi Kristen,

You're all set with your courses for the semester; I've been in touch with all of your faculty and you'll have incompletes for the term with the opportunity to finish at a later date without penalty. Pam is working on details of reimbursement for the Italy trip, though I think you will need to do a flight cancellation personally.

When you have time, let me know what projects you have in progress for me, Sharon, or others. If you tell me where to find work that needs to be wrapped up on your desk, I can take care of those items.

Which hospital are you guys at? Can we bring you meals or help with childcare for Owen? Lots of people here at the SOE want to know how to best help and support you and your family, so please let us know how we can.

Best,

Jim

\*\*\*

*April 24, 2014:* Dr. Caesar, the neurosurgeon, pops into Nathan's room at 7:00 AM with a large coffee cup in his hands. I struggle to wake up enough to make conversation with him while he reviews Nathan's vitals.

"So we're going to do the biopsy today, probably around noon, but I have a case ahead of him. It just depends."

*Oh good, no verbal response needed.* I nod.

He nods at me and then leaves.

At around 11 o'clock, the nurse is gathering Nathan's things to prepare him for surgery, and I'm signing consent forms. The neurosurgeon's assistant comes in.

"So one of Nathan's tumor markers came back positive. We've cancelled the surgery for now and Dr. McAllen, from oncology, should be coming down to speak with you soon."

I feel shocked and slightly relieved. *Surgery is cancelled. Wait, what's a tumor marker?*<sup>16</sup> I text Brian the update:

*No surgery today I'll have more to say after we talk to the oncologist*

---

<sup>16</sup> Tumor markers are an integral part of the diagnostic and staging process for germ cell tumors. While tumor markers can be elevated in the blood serum, it is common practice to utilize cerebral spinal fluid (CSF) to test for marker elevation as the blood-brain barrier can limit serum levels. Tumor marker elevations in CSF coupled with positive findings on an MRI can rule out the need for a surgical biopsy, as they are indicative of nongerminomatous germ cell tumors (Hastings et al., 2012, Penn et al., 2014).

## CHAPTER FIVE

### THE START OF A NEW NORMAL

*April 24, 2014:* The family conference room is small. Perhaps even cozy, if it were a happy gathering. The plastic covered couch maintains its shape as I sit across from Brian. Mom sits next to me, pen poised and ready to begin a detailed note taking. Dr. McAllen files into the room followed by two nurses and a social worker. She carries a three ring binder and a spiral bound notebook.

*Here it comes. Breathe, just remember to keep breathing.*

I take a deep breath and release it slowly. Everyone is acting so calm. The irony makes me want to laugh, but I swallow the bubble of laughter that tries to come out.

“So now we know what we’re dealing with,” Dr. McAllen says. “Tell me what you know, or think you know already, and we’ll go from there.” I feel like I’m about to begin an oral exam.

“Well,” I start. I lick my lips and try to swallow but the saliva I need doesn’t materialize. “I know you said not to Google, but I couldn’t help myself. I knew that his tumor markers came back positive and you mentioned it was a germ cell tumor, but I didn’t know anything else, so I wanted to find out more about what we were dealing with.”

“Good. So, germ cell tumors are of two types, generally speaking. They are either

secretors, of tumor markers that is, or they are non-secretors.<sup>17</sup> Since we were able to find tumor markers in Nathan's blood, we are looking at a secretor or a nongerminomatous germ cell tumor. But because both his HCG and AFP were so high, it's likely that we are looking at a mixed germ cell tumor.<sup>18</sup>”

Mom is furiously scribbling notes as if her life depended on it. Any other day I might make a jab at her for being such a bookworm. *Look who's talking*. Silently, I thank her for being the one to put this nightmare into words, to ask the obvious questions that seem to be less obvious to me. So, now I must learn something else. I didn't sign up for this class. I never wanted to be in the medical field. Aren't the stakes a little too high for something like this? Pass, fail, live, die.

I hear Dr. McAllen giving percentages of overall survival rates and event-free rates. I wonder what my statistics professor would say right now. Dr. McAllen hands me a print out with the numbers she just described. *Oh goodie! A graph!* She continues

---

<sup>17</sup> Histological tumor type can be determined through a combination of MRI scans, presence of tumor markers, and/or surgical biopsy. Germ cell tumors are categorized by whether it is a germinoma, nongerminoma, teratoma, or some mixture of those three types (Echevarría, Fangusaro, & Goldman, 2008). The most valuable and commonly used tumor markers are alpha-fetoprotein (AFP) and beta-human chorionic gonadotropin ( $\beta$ -hCG). Certain tumor types secrete different tumor markers (Malogolowkin et al., 2003).

<sup>18</sup> Tumors that are found to secrete AFP, in addition to MRI findings, have chemical evidence of nongerminomatous germ cell tumor (NGGCT) (Hastings et al., 2012). However, when chemical evidence finds more than one tumor marker present, such as the additional presence of  $\beta$ -hCG, this suggests a mixed germ cell tumor (Leibowitz et al., 2003). Identification of tumor type is important for designing an appropriate treatment plan (Legault & Allen, 2012).

talking about the clinical trial that produced such “great” results. I try to follow along but my brain gets hung up on “essential” details. *How many participants was this based on? Did they all have the same type of tumor or did it vary?*

I suppose it helps that I just took comprehensive exams and that my inclination is to critique the study in terms of how it directly affects my child. I doubt this is the kind of situation my professors had in mind when they made an article critique part of the exam.

“Generally speaking, these tumors require a treatment plan that is a combination of chemotherapy and radiation. We’ll place a port-a-catheter in his chest so that it can deliver the medicine he needs quickly. Central nervous system tumors aren’t likely to spread throughout the body because of the blood-brain barrier. However, lesions in the brain can lose cells that may migrate within the central nervous system. So we typically get a spinal tap to check for free cancer cells in the spinal fluid. We’ll also do a spinal MRI to see whether the cancer has spread to his spinal cord. The chemotherapy drugs themselves are specific because there are only a few that can cross the blood-brain barrier. He’ll have six cycles of chemotherapy, alternating those drugs. Once chemo is complete, the next step will involve radiation treatment that takes four to six weeks. We can talk about what that means later, but for now we’ll focus on check his spinal fluid, getting the spinal MRI, and scheduling his port placement surgery.”

Mom is still writing. I feel numb. I am glad that others know what to do because I feel like I’ve been dropped into the middle of the ocean with no sense of direction.

\*\*\*

Mom and Brian’s mom are sitting with Nathan in the PICU. I am staring out the window in an outer hallway next to Dad. He seems tense. I feel like a dish rag.



“This is just... As if he didn’t already have enough to work through, cancer? He shouldn’t have to go through that too. No kid should have to go through this. None of these kids should be here,” he says. If I didn’t know him better, I would probably mistake that statement as sadness. But I recognize the anger lacing his words. Dad is furious and frustrated. *How could he not be? His grandson, who already has autism, now has to face cancer.*

“No he shouldn’t,” I respond.

\*\*\*

-----Original Message-----

From: Kristen Tarantino  
Sent: Friday, April 25, 2014 12:10 PM  
To: Barber, Jim  
Subject: Re: Checking in

Hi Jim

We are hanging in there. A little tired, but I told one of the nurses it's like having a newborn again.

They canceled the biopsy yesterday because a blood test (tumor marker) came back, making it fairly conclusive what kind of tumor it is. In a way that's good news because it means no brain surgery for now. But it's about the size of an egg and sitting in his hypothalamus area. The oncologist called it a germ cell tumor. The good news is it most likely won't spread beyond the central nervous system, the bad news is it means they needed to check his spinal cord for cancer cells to see if it has spread already. The oncologist said given the results of the first tumor marker, this is a serious cancerous tumor probably a grade 3 (4 being the worst). We've already begun talking about what treatment of this kind of cancer looks like (chemo + radiation)<sup>19</sup>, so the rest of 2014 is going to be really tough. And hopefully we can reduce the size of the tumor so that we won't need to think about shunts in his brain. When I know the exact status of this cancer I'll probably send

---

<sup>19</sup> Treatment for NGGCTs utilizes a combination of both chemotherapy and radiation therapy. Treatment plans that focus on either chemotherapy or radiation alone have demonstrated poor prognosis for patients (Echevarría et al., 2008).

some sort of notice out to friends at the SOE - the more I talk about it the more I can normalize all this.

I'll take care of canceling my flight. I don't think I have any ongoing projects with Sharon, your AERA receipts are still on my desk in the "To Do" folder. I didn't get to finish that reimbursement form. I have one of the fraternity interviews partially transcribed and I think the pedal is at home because I was working on it there where it was quieter. I can send you what I have already. (Nathan sleeps a lot, so it's not a big deal - we're in the surgical waiting room now waiting for him to finish his tests and go to recovery)

I think that was it... Or that I can remember for now. I managed to register for fall classes before all this happened on Monday, but I may need to reconsider that at this point. I'll have a better idea hopefully once we start treatment, but my guess at this point is that I might take the fall off.

Anyway, that's what's been going on here.

Kristen

Sent from my iPhone

\*\*\*

*April 28, 2014:* Nathan's sodium levels have normalized enough that he can begin chemotherapy. The process of transferring him to the oncology floor takes several hours, but eventually, we are all packed and leaving the pediatric ICU. After settling Nathan in to his new room, it takes twenty minutes for me to fully realize the differences between the PICU and the oncology wing.

In the PICU, a nurse is assigned to each child, and the nurses rotate every 12 hours. These nurses sit outside the child's "room" and keep an eye on them all the time. There is little privacy, but always an extra set of eyes. There are more machines, beeping and signaling the slightest changes. More wires and tubes and, certainly, more light. It is not a restful place.

In contrast, the oncology wing has more privacy. A door with no windows to the nursing staff. Pods of rooms with a common set of nurses and clinicians, who check patient vitals. When the door is shut, the silence is deafening. There are still tubes and beeps, machines and other equipment but the atmosphere seems to promote privacy. The largest difference beyond the quiet is the loss of an additional, dedicated set of eyes on my child. It's a loss that I don't realize until I need to shower or take a break. I suppose some kids can be left to supervise themselves, with the doors open. In fact, several rooms are parentless, leaving me to wonder how those children feel about receiving and surviving treatment on their own.

Nathan has incorporated his own belongings to his room. His bed is adorned with a *Finding Nemo* blanket, his pillow and buddies at the head of the bed. He has taken up wearing his own pajamas instead of the hospital clothes provided in the PICU. He has even managed to "borrow" an iPad from the Child Life staff.

At night, I plug in his solar system night light and turn on his sound machine to drown out the nurses' voices outside his room. Eventually, he drifts to sleep and I lay awake on the parent cot, listening to the rainfall of his sound machine, the clicking of the IV machine, the occasional siren of an ambulance bringing another life to the hospital. Nathan refuses to let me close the blinds, so I stare out at the city, watching cars, helicopters, and the night sky. My thoughts are too active to let me sleep, so I doze off and on, in between visits from the clinician checking Nathan's vitals throughout the night.

\*\*\*

*May 2, 2014:* I get a break from the hospital long enough to shower and sleep in my own bed. Spending time with my typically cheerful three-year-old son Owen also helps. But, even after he is snoozing, dreaming happy dreams, even after I have relaxed under scalding hot water that has turned my skin pink and wrinkly, even after I have lain in between the cool bedsheets and extinguished the light, my eyes and mind are awake. The efforts to relax have done little to soothe my nerves, to treat the fear and anxiety slithering along my consciousness.

I bring my laptop to bed, something I almost never do. I shy away from Facebook, contact is not what I crave. Answers, peace is what I crave. Search after search produces minimal research results, but I save each entry, greedily pouring over abstracts that should have been too discouraging and challenging to read if only because I have no prior medical or scientific knowledge. This is my peace. Knowledge. I refuse to rely solely on the trained professionals who claim they know best. I refuse to sit by and let them give drugs and treatments, about which I know nothing, to my ten-year-old. For all the talk about making an educated decision, my decisions will be based on research. Not just one doctor's opinion, but many opinions.

I feel better now that I have found information, I feel more in control. But I still can't sleep.

\*\*\*

*May 12, 2014:* Brian and I drive to the School of Education. It is my first time back to the building in over two weeks, and I'm nervous. I need to clean out my desk and return my key, knowing that I may not return.

We run into Dr. Ward in the hallway. I introduce Brian and share Nathan's treatment plan. Dr. Ward assures me I don't need to be concerned with school, that I can finish my coursework when I'm ready. I thank him and lead Brian upstairs to my desk. I only have one bag with me and as I meticulously pack each item, I wonder if everything will fit. For a Monday, it's relatively quiet. Few faculty are in the building and even fewer students, considering it is the week after graduation.

I notice Brian looking around as he asks me questions about the building. I realize he may never have been to the third floor. "Do you want a quick tour?" I ask.

I stack my desk calendar on top of the filled bag and lead him through the hallways, noting where my faculty members' offices are along the way. As we move to the back of the building, I see Dr. Stronge and Dr. Grant in conversation. They greet me and I introduce Brian. They inquire about Nathan and I share his treatment plan with them. The repetition is both helpful and annoying. They echo Dr. Ward's comments with regard to not worrying about school. I nod, half believing.

Part of me is frustrated because I had worked so hard to achieve an aggressive timeline. I'm upset that my academic plans are in limbo and that my faculty don't share my sense of outrage. But then I'm grateful that there is no pressure to focus on something that is paltry compared to the life and health of my child.

Dr. Grant mentions that I can file for a leave of absence that will stop the graduation clock for a period of up to a year if I need it. *Well, that's news to me.* She agrees to share it with me.

Brian and I thank them for their support and head back to my emptied desk. The trip and social interactions have exhausted me, and I long to be safe at home, away from others.

\*\*\*

*May 22, 2014:* Nathan is snoozing when I receive a text from Brian about his dad wanting to visit. This weekend is Memorial Day weekend. My reaction was a firm no. I can understand wanting to be supportive and check in on Nathan's progress. But visitors inevitably mean that I have to entertain someone besides Nathan. All of my attention and energy is focused on Nathan; making sure he doesn't hurt himself, pee on himself, yank out his central line. I have nothing else to spare including play hostess or be polite, which, let's face it, requires energy I just don't have. I'm not against tangible help from those who can handle Nathan, which is sadly a select few. But I am not able to be social. There's time for that when we're at home. I can't think about anything else beyond our hospital stay, his needs and treatment. I can't even send text messages or answer phone calls because Nathan clues in to the fact that I'm distracted and makes a grab for his port. Many of my interactions with others occur when he sleeps or is eating a meal.

As I silently fume about the indelicacy of a social visit, the nurse comes in and tells me they need to check Nathan's glucose levels, which are rising, mostly because of the high dose steroid he has been receiving. She brings in the clinician and another nurse to assist. Nathan must sense something is happening because he opens his eyes and sits up. The nurse informs me they will have to do a finger prick because the doctor doesn't want the blood drawn from his IV line where he is receiving the last ten minutes of his

chemotherapy for the day. I nod, expecting this stick to be similar to the one the pediatrician performs in her office.

I am wrong.

Instead of a simple slide that collects the blood sample, the nurse produces a thin tube about three inches long that reminds me of the ink reservoir in a pen. After raising the bed so they don't have to bend over, each of us has a job to do. Two nurses work on the blood sample while the clinician and I try to hold Nathan still. The moment the needle pricks Nathan's finger, he lashes out. Violently. He yanks his hand from the clinician and hauls it across the nurse's face. His body, taking on a life of its own, pushes and pulls, working himself free of our grasp. He screams and bares his teeth like a wild animal, causing other nurses to come into the room. His foot, kicks away from the hand and collides with the side of my head, sending my glasses flying off my face and across the floor.

They finish getting the blood sample, but Nathan is beyond control, furious and terrified at the same time. He leaps from the bed in an attempt to escape from the room but realizes his IV is connected to his port. Through my blurred vision I see him reach for the IV line, knowing that his chemo has not finished, and I rush to stop him. He hisses and shrieks at me at decibels not meant for human ears and attempts to throw himself on the hard floor. I catch his head in my hands seconds before it collides with the tile. Pushing my hands away he tries to hide beneath the hospital bed, then beneath the sink, all the while trying to pull on his IV.

A nurse tries to help me get him out from under the sink and he smacks her. I register the shock on her face but don't take the time to apologize on Nathan's behalf.

Another nurse and a doctor come in to find out what is happening, and in the split second that I turn my face toward the doorway, Nathan tugs hard on his IV, screaming as he pulls the IV needle and connected tubing from his chest, de-accessing his port. He refuses to calm down and the violence of his reaction is too much for me to bear. The nurse takes one look at my face and tells me it's okay if I need to step out. Never believing that I would be that mom, I nod and flee the room. I can hear Nathan screams chase me down the hallway as I hurry to the family room. Blessedly, there is no one inside. I'm crying before I even shut the door behind me, hyperventilating as if I can't cry or breathe any faster.

After I have calmed my breathing, I splash cold water on my face and head back to the room. The hallway is silent. They have given him a dose of Versed<sup>20</sup> to calm him down, and he is sleeping on his bed when I come back to the room.

“We'll have to get him accessed again, but we'll let him rest for a minute.”

\*\*\*

*June 4, 2014:* It is day fifteen, following our last cycle of chemotherapy, which requires a trip to the oncology clinic for labs. Each time they test his blood chemistries and cell counts<sup>21</sup>. The nurses have figured out how important routine is for Nathan, and they call

---

<sup>20</sup> Versed, also known as Midazolam, is a benzodiazepine used to calm or sedate a patient. In Nathan's case, Versed was used to calm him down so that he would not hurt anyone else, including himself.

<sup>21</sup> During chemotherapy, Nathan's blood cell counts were frequently checked. The chemotherapy drugs effect the bone marrows ability to produce new cells, including red blood cell, platelets, and white blood cells. Neutrophils are of particular concern in checking white blood cell counts as these cells fight off bacterial infections. When his hemoglobin (one measure of checking red blood cell count) was below a nine (Normal levels > 11), Nathan would need a transfusion to replenish his blood supply. Similarly, when



him back to a private room for the blood draw instead of taking it in triage where other children are being weighed and having blood pressure measured.

Nathan stands in the open doorway of the treatment room, watching the two nurses who enter before him to set up for the blood draw. He refuses to sit on the gurney, and I remind him that we have to do “blood first, then iPad.”

“Go home! iPad!” he yells.

“Come sit with mommy,” I say patting the mattress and sitting in the middle of the gurney.

“No!” he shakes his head and attempts to bolt from the room, but the second nurse has blocked access to the closed door. Nathan hisses and throws his baseball cap across the room.

Calmly, I remove my shoes and glasses, straddling the gurney. I repeat, “Come sit with mommy. Let’s do blood first so we can play iPad.” Reluctantly, he sits in front of me, between my legs.

The first nurse picks up his hand, and he jerks it from her grasp.

“Nathan, can you show mommy your arm?” I ask, extending my right arm, palm up. He complies and mimics my action.

The nurse thanks him for showing his arm and she wraps a bright blue tourniquet around his upper arm. He starts to resist, but I encourage him. “Great job, Nathan! We’re just looking right now, okay?”

---

his platelet counts were below 75,000 (Normal levels > 150,000), he would receive platelets to bring his numbers back up to normal. Nathan’s blood chemistry was also checked to ensure that his sodium, glucose, and chloride levels were within normal ranges.

Nathan lets the nurse run her fingers over the inside of his elbow, tapping to find an accessible vein. When she finds one she likes, she looks at me expectantly and nods to the second nurse. I wrap my arms around his chest, pinning his left arm and hugging him close to me. He begins to struggle in an effort to free himself, using his legs to push himself into a position that facilitates kicking. I cross my legs over top of his and link my ankles, securing Nathan's limbs beneath mine.

The second nurse holds his right arm straight so they can get a good stick. When the needle pierces his skin, he shrieks and bucks, throwing his head backwards toward my face. I manage to hold my head back out of reach, knowing that if I were an inch closer and he would have connected with my nose. His feet try to kick out at the nurses, but they move out of striking range as they fill up each vial, one by one, with his blood.

When he realizes that he can't connect his blows, he turns his head and sinks his teeth into my arm. Unprepared for the sharp pain, my arm jerks in response but I manage to hold on.

The nurse is finished and covers the site with a Band-Aid. I release a tear-stained, red-faced Nathan, who grabs his iPad from my bag and runs down the hallway toward the recliners in the back of the clinic. I gather our things, locating the items that have been discarded by myself or thrown by Nathan, thank the nurses, and follow Nathan.

His crying has ceased, but I can see the upset clearly on his face as I sit by him and try to bribe him into a pleasant mood by offering Cheerios and water.

An hour later, the results come back. "His hemoglobin is 7.2," Mary says.

I groan inwardly, knowing that he will need a transfusion and that the rest of the day will be spent in the clinic.

\*\*\*

*June 9, 2014:* Nathan is dozing in the backseat while we sit in rush hour traffic on the interstate. Being sedated for his MRI and spinal tap<sup>22</sup> caused him to be excessively sleepy. I wonder if he will sleep the rest of the evening. The discharge paperwork suggested I start slowly with introducing foods again. *If he's awake enough to eat.*

My cell phone rings, and I turn the radio off so I can answer it.

“Hello?”

“Hi Kristen, it's Mary. I have your MRI results, but don't tell Dr. McAllen. I didn't want you to have to wait until Wednesday.”

“Oh, okay, thanks,” I respond. I find myself smiling at her even though she can't see me.

“The tumor has decreased<sup>23</sup> in size by half,” she says.

“Really? Oh that's good news!” I manage to release the breath I didn't realize I had been holding.

“Very good news! We don't have the tumor marker results back yet, but we know the chemo is working.”

\*\*\*

-----Original Message-----

---

<sup>22</sup> Chemotherapy consisted of six cycles that alternated drugs every other cycle. Each 21-day cycle began with a chemo infusion that was either three days long (Cycle A) or five days long (cycle B). After every B cycle, Nathan would have a full brain and spine MRI, as well as a lumbar puncture, or spinal tap, to measure cerebrospinal fluid (CSF) for cancer cells and tumor marker levels.

<sup>23</sup> Nathan's tumor decreased in mass, measuring 2.6 x 2.9 x 1.7 cm (previously 4.0 x 4.5 x 3.6 cm). It went from a size that was a little larger than a golf ball to a size that was closer to a large gumball.

From: Kristen Tarantino  
Sent: Thursday, June 19, 2014 12:09 PM  
To: Sharon deFur  
Subject: Fall...

Hi Sharon

I hope you're having a lovely summer. I feel like my time is dictated by hospital visits. Nathan's doing as well as can be expected, I guess. I don't have any firsthand experience of cancer treatments, so I imagine he's on par. The three to five day long hospital admissions are the hardest.

I wanted to give you a heads up on the situation for the fall. It looks like Nathan will be starting radiation treatment during the fall for a period of 4-6 weeks. Since I'm not sure what to expect, I decided that I don't think I can handle a full course load for the fall. Which ultimately means that I won't be eligible to hold a [graduate assistant] GA position since I won't be full-time. Not only does this decision affect my GA options, it also affects the courses I've signed up for in the fall - in this case, the independent study I am scheduled to complete with you. At this point, I was only planning on taking one class in the fall (the three 1 credit teaching courses) since they can be completed remotely. I haven't decided what to do about a second course, but I'm still thinking about it. As I told Jim, there's a decent amount of down time in between treatments - at least over the summer - which is why I'm trying to finish up my spring classes now.

I know it's not the ideal situation, but I've sort of run out of options at this point. So much for having a plan, right? If you ever want to chat, I'm around, just not on Wednesdays. Our next hospital stay is over July 4th - boo. But I do miss our little chats 😊

Kristen

-----

\*\*\*

*July 3, 2014:* It's six o'clock in the morning. Nathan is still dozing but the summer sun is shining through the hospital window. I sneak a pair of clothes out of my bag and tiptoe to the bathroom for a quick shower. I move quickly, praying that he doesn't wake up before I finish and pull out his freshly accessed port IV.

When I am dressed again, I open the bathroom door and peer out. His eyes are closed. Heaving a sigh of relief, I finish in the bathroom just in time for him to sit up, immediately asking for his iPad.

“Do you want breakfast?” I ask. He nods and I locate the box of Poptarts we packed for this six-day hospital stay. He’s happily munching when I notice blood on his shirt and tape on the floor. I pick up the tape which has a five inch tube connected to it. I recognize it immediately as his port access line. The clinician comes in to take his vitals and I tell her he has de-accessed his port. Luckily, no fluids had been connected, but it sets back the timing of his chemo treatment, which had been set to start early this morning.

“We’ll have to get him re-accessed.”

“Well you’ll have to give him something to calm him down because he won’t let you do it otherwise,” I respond.

After giving Nathan a dose of Ativan<sup>24</sup>, they try to access his port. He fights the procedure, assaulting our ears with his screams and pushing us away as hard as he can. When the new line access is placed and taped down, he reaches for it, instinctively knowing how to remove the foreign body from his chest. I try to keep his hands away from the line but he bolts to the bathroom, intent on locking me out of the bathroom long enough to remove the line again. My foot catches in the door before he can shut it and it

---

<sup>24</sup> Ativan, also known as Lorazepam, is a benzodiazepine that was prescribed for Nathan to use to minimize any nausea he might experience as a result of the chemo drugs. Since he did not experience nausea but instead exhibited extreme amount of distress over hospital stays and port accesses, he was given Ativan to calm him down enough to access his port but not fully sedate him. It acts quickly and the effects were not longstanding.

bounces open. Realizing he can't have what he wants, Nathan throws himself to the floor. I catch him and sit on the floor with him in my lap. Attempting to soothe him results in a smack on my nose, knocking my glasses to the ground. He tries to head butt me to release him, but I wrap my body around his. The clinician holds his feet to keep him from lashing out. He cries and screams in protest.

I notice the nurse standing in the doorway. "Is there anything we can do to calm him down?" she asks.

"He's just going to keep trying to remove the IV," I say.

"The doctors are talking about options<sup>25</sup> now."

I can't decide whether to be angry or devastated that I have to do this to my own child. I opt for anger, it feels safer, and lace my words with enough emphasis that I know I'll have to apologize to someone later. "Someone needs to come up with a better plan because I can't do this for the next five days," I say.

\*\*\*

*July 6, 2014:* I return to the hospital after spending two nights in my own bed, alone. It was a relief to be away from the hospital. The staff has provided a sitter in Nathan's room as a second set of eyes and hands in the event that Brian or myself has to step out for any reason. It's a small consolation considering they will neither consent to restraints nor to calming medication. Brian looks tired and weary as I relieve him from duty. Nathan,

---

<sup>25</sup> One of the chemo drugs in Cycle B, ifosfamide, required increased hydration in order to flush the drugs from Nathan's body (Hastings et al., 2012). Ifosfamide can be known to cause nephrotoxicity and bladder irritation and therefore needs to be flushed from his body as soon as possible (Hastings et al., 2012). The question over giving Nathan drugs that would sedate him was whether a drug would inhibit his ability to urinate during the chemo infusion. The doctors were concerned that this would compromise his bladder.

however, is not relieved that someone else gets to leave and it's not him. *I'll pay for this tonight.*

\*\*\*

*July 11, 2014:* We are finally home after a grueling week of chemo. Brian and I are downstairs when I first hear the crying. It's soft, but audibly coming from a child. At first, I think it is Owen because the sound is innocent and there is no screaming. I climb the stairs quickly, as any mother with a crying child would. But the sound emanates from Nathan's room. I open the door to see him curled on his side. He lays there crying, tears dripping onto the pillow.

This crying makes my heart ache. It is not angry or frustrated crying. It is soul-full, full of immobilizing pain. It has been a few days since Nathan's last Neulasta<sup>26</sup> shot.

I stroke his legs, knowing that the Neulasta would cause pain in his largest bones, like hips and femurs. Ascertaining that the pain is stemming from the shot, I tell Nathan I am going to get the Tylenol.

He swallows down the liquid and quiets for a moment, eyes still watering from pain that I can neither assess fully nor feel.

For the first time in weeks, I pray. Selfishly asking that Nathan's pain cease. Offering to take the burden of that pain, if it would mean he could find peace. Begging and pleading that Nathan not suffer anymore from the ministrations of the doctors or even from myself.

---

<sup>26</sup> Neulasta is a colony-stimulating drug that is delivered via injection. In Nathan's treatment, Neulasta was used to stimulate his bone marrow to produce more white blood cells, including neutrophils. Within 48 hours after every B cycle, Nathan would have to receive a Neulasta shot. Stimulating the bone marrow can cause intense bone pain, particularly in the larger bones such as the pelvis and femurs.

I can't bear this kind of crying. I can't bear his obvious physical discomfort. I pray until I realize I too am crying.

I tell Brian to sit with him while I grab a blanket and pajamas from our room.

"I'm going to stay with him," I say.

\*\*\*

-----Original Message-----

From: Kristen Tarantino  
Sent: Tuesday, July 29, 2014 4:26 PM  
To: Eddy, Pam  
Subject: Updates

Hi Pam

Thank you for your note about tomorrow. I'll keep an eye out for Wendy ☺

I hope your summer is going well so far. I'm sure you're busy reading dissertations and planning for the coming year. I want to thank you so much (and really everyone who went to Italy) for thinking about me and my family. I truly appreciate the thoughtful souvenirs and postcards to make me feel included. I only wish I could have shared the experience with you all.

I actually wanted to touch base with you about two things. One, I contacted the bursar's office about processing the Italy trip refund, and they said that the individual/department that led the trip would have to file the paperwork. Please let me know if you need anything from me to make that process smoother.

I also wanted to let you know I've decided to take a leave of absence for the next academic year due to the extreme amount of supervision and aid Nathan needs during his care. We've had several complications over the summer with regard to his IV access, mostly keeping him from ripping it out. I sort of anticipate the 4-6 weeks of radiation with sedation starting in September to be extremely exhausting... for me. I asked for an entire year of leave, but plan to evaluate whether to return in the spring when it's time. That being said, I do want to make the global studies credits work. I've been playing with the available credits I have left and I may reorganize my cognate as a teaching and learning cognate instead of special education. It seems to fit better with the sorts of courses I've taken thus far, as well as future goals. My point, however, is that I may take the next year to finish up my incompletes from the spring, including working on the global studies credits.



I already shared my intention to leave for the year with Jim, but I sort of, unintentionally have this co-advisor thing going with you both ☺ So I wanted to be sure you knew. I would be happy to set up a visit when you're on really on sabbatical ☺

Kristen

-----

\*\*\*

*September 9, 2014:* Nathan is having his post-chemotherapy MRI and spinal tap today. It has been a long four months since May. Six cycles of chemotherapy along with weekly clinic visits have blurred together into a nightmare masquerading as summer. Each day is a repeat of the day before with little hope for a different tomorrow. As I wait for Nathan in the surgical waiting room, a harpist sets up.

I watch her, slightly detached from the reality of the waiting room where *Good Morning America* is on and the lady next to me is playing Candy Crush on her cell phone. My coffee is closer to room temperature than when I bought it, and I begin to feel a dull cramp in my wrist as I write my latest "to do" list. The phone rings periodically, and one by one, a child's mom is called over for an update. Nearby, a surgeon talks with a mom about her child's procedure. The emotion and feeling coursing through the room can only be described as anticipatory anxiety. Parents try to distract themselves with their breakfasts or by entertaining their other children. Meanwhile, the harpist tunes her strings.

The windows that span the length of the room overlook a wet and dreary city street. Professionals walk through the waiting room, chatting happily about Monday Night Football as if we were just furniture, decorations neither to be admired nor engaged. A father uses the outlet next to my chair to charge his cell phone and walks

back to his chair, leaving the phone behind, a level of trust not normally given to a random stranger. There is a culture of understanding and empathetic respect here; where, when a parent cries, we all understand.

The harpist has finished tuning and plays a tune reminiscent of “Scarborough Fair.” It neither soothes nor irritates, it just is. And now my coffee has dropped to a temperature below tasteful.

\*\*\*

*September 12, 2014:* The house is silent. The kids are both at school, Brian is at work. I can’t quite get myself interested in the novel I’m reading and I toss it aside. I’m frustrated and admittedly bored. I hunt for an empty notebook, thinking this might be a good time to write what I’m thinking:

I believe I may be changing my topic from the transition to college for students with ASD to an autoethnography of *adult learning in times of crisis/trauma*. The latter part in squiggles is still a work in progress. I’m not sure I have a full grasp on that aspect of it just yet.

At Jim’s suggestion, I will try to keep up with this journaling. As I was ready to start my dissertation on the aforementioned topic, Nathan was admitted to the hospital with the brain tumor. Even now, after 4 months of chemotherapy, I still can’t open a book on autism to finish my projects from the spring semester. At this point, I’m not sure whether it’s because I’m burnt out from school or if it’s because the pain from Nathan’s diagnosis and treatment is too raw. Hell, it could be a combination of both.

But then I got concerned: I had spent a good six months plus on my topic. I had put in a field research project intent on validating an interview questionnaire. And now I had to find a brand new topic? It seemed very overwhelming, and quite frankly, like a wasted effort. Honestly, I don’t know that I can go back to it or if I want to. I think that part of me is concerned that if anything happens to Nathan, I would be stuck – there’s no way I’d be able to complete research on autism when my inspiration for doing so is no longer living. But I’m also concerned about tackling something new, where I don’t know the literature as well. It will take time that I don’t want to spend.

And yes, that's selfish because I already took a year off. But it's disappointing to have become so invested in a research idea that now I'm afraid of.

I'm pretty sure I can say it is fear. God help me, I'm terrified of what may happen. And I know I won't be able to distance myself in the way that I would need to if I went through with my initial topic.

While I don't know enough about autoethnography at present, I do know that I won't have to distance myself.

I tried thinking of new research ideas that weren't related – that I might be interested in. I tried thinking of ways to make this experience with Nathan meaningful – beyond what it means for me or my family. I'm still not sure that I *have* a research agenda – at least not a reliable one, not anymore.

But then I also have to figure out the big question: How does it relate to higher education?

The decision to take the year off wasn't easy. I had a plan – ambitious though it was. I was going to be done. August 2015. And honestly, the easiest decisions were the ones I needed to make – take incompletes for the spring, cancel my trip to Italy. But with treatment up in the air after chemo, and all the complications with Nathan's IV access – I had a tough time making decisions about the fall. By July, I had convinced myself I could do it part-time. But then Nathan had a particularly hellacious admit, where it was all we could do to medicate and not restrain him from tearing his IV out.

I then realized I didn't have a choice. There was no way I could commit to school – even part-time – and do 4-6 weeks, daily, sedated radiation at the same time.

\*\*\*

*September 16, 2014:* It's been a week since Nathan's post-chemo testing, and I'm still waiting on Nathan's latest spinal tap results. The wait is slowly chipping away at my resolve to be productive. I reach for my journal again and begin to write:

I'm feeling emotional today, though I can't pinpoint why. Perhaps it's because I spent all day home, alone. Maybe it's because I've been waiting for a week for test results that are the determining factor in Nathan's next phase of treatment. Maybe it's because I feel like a bad mother for not knowing whether Nathan got breakfast and medicine this morning. Or it could be that my lack of human companionship began last night after I yelled at Brian for caring more about football than playing with the kids.

For whatever reason, I feel as though crying is in my best interest. That I could erupt into tears at any moment.

Except that I never allow myself to. Even when I'm alone, I rarely allow myself to break down, give in to the tears in the hope that it will make me feel better. Because it won't. Crying doesn't really solve anything – if anything, it makes me feel worse. But then I'm frustrated with myself and others because it's not suitable or appropriate for me to be less than strong, less than emotionally stable. I'm the one who has to keep it together – for everyone else.

I can't give in to my emotional needs and expect someone else to pick up the pieces. Never having done that, I'm not sure what others would do. Who would take over everything that I do? Brian could try, but he has low patience and is extremely stubborn – particularly when it comes to the kids. Some days these are characteristics we share.

When I imagine something bad happening to one of the boys (even Brian), it feels like the bottom of my stomach has dropped out. And by "bad," I mean if one of them gets hurt – because really, I can't even imagine anything worse in this life. Everything else is inconsequential compared to a reality without any of my boys.

Perhaps that's why the potential to lose one makes me sick. My stomach at that point feels like a hollow pit, swallowing any sense of hope. I think it is intensified when I can't do anything else but wait.

But in those moments, when I have not occupied my brain with a book or some mindless television series, it's easy to fall into the trap of acting and feeling like there's no hope. Really, despair and depression are easy. And when you let them, they settle over you like a suffocating blanket – providing neither comfort nor release from the emotional prison.

What's truly terrifying is acknowledging the ease and presence of such emotions and yet welcoming them. Sometimes it's just easier to live in that world – where no matter how hard you try, there is no explanation – there is no reasoning.

But like I said, that part is easy.

What's not easy, is coming back. It's easier not to fight, to remain trapped, even when you know it's not where you ought to be. Coming back takes courage, and an understanding, even an acceptance, that you may never be whole again.

I began reading Ellis' book on autoethnography. Thus far, it's a good read. I like the way she decided to write this text as a novel. It appeals to me. But I also noticed that she refers to interviewing others – which doesn't really fit what I had in mind. But I'm going to refrain from judgment/throwing out my methodology for the time being because I still need to know more.

Perhaps after I read it, I will email her.

\*\*\*

*September 25, 2014:* Brian has been fielding phone calls from family all week. The general tone is always the same: *Are you sure you're making the right decision?* We had met with Dr. McAllen about Nathan's latest test results. The tumor didn't quite make the 65% shrinkage requirement, but his tumor markers are normal. Since the tumor is still present, Dr. McAllen recommends a biopsy on the remaining tissue to determine what kind of radiation treatment<sup>27</sup> is most appropriate. For Brian and me, the decision to go forward with a biopsy is easy. But it seems that some members of our extended family believe they know more about the risks than we do. I can sense Brian's obvious distress like a dark cloud. He's frustrated and the tenor of his voice takes on a defensiveness that grabs my attention.

"Maybe we should just issue a blanket statement to everyone," I suggest. "You know, explain the reasons behind our decision and why it makes sense. I don't want to upset anyone because I know they're just trying to help, but they need to know that we're competent adults and we can make this decision on our own." He doesn't respond. "You

---

<sup>27</sup> The protocol used for Nathan's treatment made explicit suggestions for radiation treatment depending on patient response to chemotherapy. The options for radiation treatment included craniospinal irradiation, which would deliver radiation to the entire brain and spine (as well as anything in the beam's path), or whole ventricle radiation. Within the brain are four CSF filled spaces called ventricles. Whole ventricle irradiation (WVI) would irradiate these areas as well as deliver an additional radiation boost to the primary tumor site.

don't have to do it, Brian. I'll take care of it, and then if we don't end up sending it, that's okay too."

"Okay."

\*\*\*

I stare at the computer screen, absorbing the words that I just wrote, judging them for clarity and insult.

To our family:

There seems to be a bit of discontent and misunderstanding about our decision (and it is *our* decision) to move forward with Nathan's surgery. I recognize that this is not the majority opinion; nevertheless, I told Brian that I felt an email explanation may be needed in case details have been misconstrued over multiple renditions of the same story. Before I explain the reasons for surgery, let me be quite clear about one thing – Brian and I love Nathan immensely, and there is no single individual in this world who cares more about his well-being than we do. Just because we are consenting to surgery does not mean we are impervious to the fear that such a procedure induces. However, please understand that this was a decision weeks in the making, after thorough research and careful consideration of all the "what if" scenarios – and believe me, I've thought of every single horrible scenario possible. And if I were to be honest, this explanation is a courtesy. One that I shouldn't have to give because of others thinking we aren't doing "the right thing." One that I *should* give because I *want* to – because we are family, and we all care for Nathan.

That out of the way, the next thing everyone needs to understand is that the current standard of care for a tumor like Nathan's is to treat it with chemotherapy, radiation, and possibly surgery. There is a current clinical trial looking at the benefit of a reduced level of radiation in treating these tumors. Let me further explain that the difference between a reduced level (and scope) of radiation and a full, craniospinal radiation is noticeable. Craniospinal radiation has a horrible array of side effects that can occur both immediately and over time. They include (just to name my favorites) memory loss and potential cancerous developments in other parts of the body. Personally, I'd like to preserve as much working brain and memory that I can – to say nothing of the fact that the autism has already made a mess of things in that department. If I can spare him any of that, I will.

The protocol for the clinical trial previously mentioned, indicates two requirements to be eligible for the reduced scope radiation (honestly that's the easiest way for me to explain that at this point): (1) reduced or negative tumor markers in the spinal fluid and (2) a reduction in the size of the tumor by 65%.

I'm explaining the protocol because even though Nathan is not in the trial, we are following the same protocol because of the option for reduced radiation. When Nathan had his post-chemo MRI and spinal tap, we learned two things: the tumor markers were negative and the tumor had only reduced in size by about 60%. Let me explain what that means.

At the beginning of all this, the location of the tumor and the presence of tumor markers allowed us to conclude that Nathan had a nongerminomatous germ cell tumor. These tumors (just so we're all on the same page) are more malignant, are more difficult to treat successfully, and have a poorer prognosis when compared with germinomas (non-tumor marker secreting germ cell tumors). Because both tumor markers were present, it was likely that Nathan had a mixed germ cell tumor.

The negative tumor marker results indicate that the malignant parts of the tumor are probably gone. I say "probably" because we still don't know what's left up there. Many mixed germ cell tumors include some form of teratoma (either mature or immature – which I won't explain right now). In the case of teratomas, the only treatment option proven to "cure" a teratoma is to surgically remove it. They do not respond to chemotherapy or radiation. However, since the tumor size has not shrunk more than 65%, treatment protocol suggests a surgical look at the tumor. \*Please note that we don't know what they are going to find. It is important to know what is up there so that we know how to treat it.\*

The goal of the surgery is not to remove the whole tumor. In fact, they *can't* remove the whole thing without hurting Nathan. The goal is to remove as much as they can *safely* and test it to see what it is. Once we know what it is, we can make the next decision about radiation, which I'm not going to explain in this email.

I know that everyone is concerned. Believe me, I could lead the campaign. But, I am also not going to blindly subject Nathan to potentially unnecessary craniospinal radiation when I don't know what we're even dealing with. And quite frankly, nothing about radiation or surgery is appealing. I don't like either treatment. I didn't like chemo. But I don't really get an "opt out" option, and, as Nathan's parents, it's a decision that Brian and I have to make and live with. I know that each of you are worried, and some may be trying to make sense of this situation by comparing it to situations you've previously faced. Please don't judge our decisions based on your past or your experience. This is not the same. It is a difficult, heart-wrenching decision that scares the living hell out of both of us. But, I couldn't ask for better doctors and surgeons than the ones Nathan has on his team. Trust me, if I thought he wasn't getting the best possible care, I would take him somewhere else.

I wrote this email with the intent of clarifying and explaining our decision. We don't need anyone's permission to treat our son. We need your support and

prayers. We have been blessed with a very large, very loving family. Be that. If not for us, then for Nathan.

Brian & Kristen

I save the file in a Word document and close my computer. It never gets sent.

\*\*\*

*October 3, 2014:* It's 3:00 AM when I wake Nathan up to administer his medicines. He won't be allowed to eat or drink anything after this point. His surgery is scheduled for 7:00 AM, and it's raining.

We leave the house at 4:30 AM, encountering a four car accident on the interstate on our way to the hospital. Just like our MRI visits, we make our way to the third floor to Day Surgery. The nurses and administrators greet us warmly, recognizing us from Nathan's last MRI. They weigh Nathan, check his blood pressure and temperature, and collect from me a list of Nathan's medications. We are given matching bracelets detailing Nathan's name, birthdate, and admitting doctor.

We are escorted into a small room in the anesthesia unit and the nurse hands me a set of green clothes for Nathan to wear. Nathan fusses about changing his clothes, but the nurse distracts him by asking whether he wants to pick out a toy to keep. He waddles down the hallway with her and picks out a blue and yellow stuffed lizard. A new nurse comes in and asks about Nathan's medications and tells me that Dr. Caesar is on his way. They prescribe a "pre-med" of Versed and wait for him to drift off. Dr. Caesar asks me if I have any lingering questions about the surgery, and I say that I don't.

"It will be a few hours, but we'll call out to the waiting room every hour or so and let you know how things are going," he says. "Our goal is to certainly get a piece of it, but then we'll also assess whether we can take any more of it out and go from there." I



nod, starting to feel like I might never see Nathan after this moment. I glance at him lying on the gurney, his eyes fluttering in drugged sleep.

They wheel him away, and I carry his clothes, lizard, and other belongings to the surgical waiting room where I acquire a stuffed bear from the lady at the desk. After signing in and figuring out which four digit number on the surgery board corresponds to Nathan, I pick a seat towards the back of the waiting room and make myself comfortable.

\*\*\*

By about noon, I am no longer by myself. The waiting room has filled substantially for a Friday. I am sitting with my mother and grandmother who chat about one of my cousins. Brian is in conversation with Dad, and Grandpa is sitting opposite from me, audibly snoring. I smile as he lets out a rather large snort and the lady next to him glances his direction.

I have had two calls from the OR. Both were vague.

“He’s doing great.”

“Dr. Caesar is closing up now.”

I notice Dr. Caesar and his colleague walking across the waiting room to us. I sit up and lock eyes with him. “So we got a couple pieces of it. It looks like fibrous<sup>28</sup> tissue.”

“What does that mean?” Mom asks.

“Dead tissue. It was really tough. I really had to saw at it to get a piece of it. It was sort of like trying to cut rubber, but a hard rubber like you were cutting into a tire.”

We all nod in recognition.

---

<sup>28</sup> Fibrous tissue in this case was indicative of dead tumor tissue, meaning it was no longer malignant.

“The mass is right by a significant artery, so we took our time getting to it. But there’s no way we were going to try and take it out.” *But he’s out of surgery and doing fine.*

“We’re going to keep him sedated for the next 24 hours just to keep an eye on him. I don’t anticipate any problems, but they’ll keep him intubated and check his neurological function every hour, just in case.”

\*\*\*

When I finally get to come into the PICU to see Nathan, I’m not prepared. During our first PICU stay, Nathan had a room in the back of the PICU, with a door. This time, Nathan is in a curtained bay right up front where they keep many of the critical cases. I walk around the curtain to see Nathan’s head wrapped in fluffy white gauze under what looks like a white hairnet. There’s a strap around the lower half of his face, attached to the breathing tube protruding from his mouth. A long metal arm is bent over his body, holding his breathing tube secure. The tube scares me more than the bandaging.

Nathan sports two IV lines, one on his right arm and the other at his left wrist. The nurse tells me the wrist line is his arterial IV line. Both of his arms are gently, but securely, strapped to the side rails. The nurse explains that when they do a neuro-check, they use an IV medication to wake him up. “When they wake up, they try to pull out the breathing tube. So the restraints keep them from pulling it out,” she explains.

At first, I’m horrified. *Won’t he choke if you wake him up with the tube in?* When I watch the next neuro-check, his eyes open and he starts to gag like he’s choking. Once they see him awake, the nurse immediately sedates him again. The process is awful to watch, and I long to switch places with one of Nathan’s other visitors.

\*\*\*

*October 7, 2014:* Nathan is released from the hospital today. He had been moved from the PICU back to the oncology floor the day before because they couldn't get his blood glucose under control. Eventually, Nathan's sugar dropped enough that they felt comfortable releasing him.

He has managed to remove the bandages on his head, and the physical trauma of surgery has left the right side of his face swollen and heavily bruised. Coupled with the eight inch incision and accompanying black stitches, he looks like Frankenstein.

Once home, Nathan seems to be his happy self, requesting his favorite meals and dressing in his own pajamas once again. Brian and I take turns sleeping in Nathan's room to keep him from pulling out his stitches. So far he has left them alone, but the more he messes with the incision site, the more we have to fear from infection.

\*\*\*

*October 9, 2014:* It's 5:30 in the evening on Thursday. Nathan is lying on the couch watching television. Brian and Owen are sitting together on the opposite couch playing a game on the Kindle. The oven has finally finished preheating, and I slide in the frozen lasagna. I dry my hands on the kitchen towel as I walk around the corner toward the living room. I look first to Nathan on the couch. He's shaking.

"Nathan?" I cross the distance the couch quickly and sit beside his convulsing body. Any breathing he may be doing sounds like snorts and his eyes twitch furiously. I wrap my arm around his body and pull him so that he is lying on his left side instead of his back. I can feel the rigidity of his muscles and limbs as they move of their own accord.

“He’s having a seizure,” I tell Brian.

“Should we call 911?” he asks.

“I don’t know. I don’t know what to do.” I look up at him helplessly as I try to keep Nathan from falling off the couch. Brian grabs the phone and calls the emergency number. As he speaks to the dispatcher, Nathan’s convulsing slows and I can hear the wail of the ambulance as it pulls up to the house.

Brian shows two paramedics into the house, trailing a gurney. The female paramedic asks Brian general questions about Nathan, his birthdate, previous medical conditions. The other paramedic kneels in front of Nathan next to me and starts checking his vital signs. He asks me how long the seizure lasted. Did he ever lose consciousness? How long? I begin to wish I had thought to look at the clock and time the damn thing.

Nathan is awake as we try to move him to the gurney. The paramedics tell us that Nathan will be taken to the nearest hospital. Not the children’s hospital downtown. The local hospital will have to make the decision on whether to transfer him to the children’s hospital.

Owen has been silent the entire time, clinging to Brian as if he was afraid to let go. I grab a couple water bottles, Nathan’s iPad and my phone charger, shoving them into my bag before sliding on my tennis shoes. Nathan is wrestling with the paramedics who are trying to seatbelt him to the gurney. He lets out a piercing scream as they raise the gurney up and begin rolling towards the door.

Owen’s eyes are wide open, staring at the scene. I rush over to him and hug him. “Don’t worry, we’re going to take good care of Nathan,” I tell him.

“Is Nathan going back to the hospital?”

“Yes sweetie.”

“I want to come with you.” My heart breaks hearing his plea and I pull back to look him in the eyes.

“I can’t take you with me right now. I need you to be a big boy and take care of Daddy, okay? I think Daddy is a little scared. Do you think you can do that for Mommy?” Owen nods, and I tell him to give me another hug. “I love you, be good for Mommy.”

The gurney has made it to the doorway and Nathan is gripping the doorframe, his knuckles turning white from the pressure of holding on. I pry his fingers away from the doorframe and nod to the paramedics to continue toward the ambulance. The flashing lights of the ambulance bounce off the cars and houses in the neighborhood, illuminating the faces of neighbors who have come outside to watch the spectacle. Nathan continues to scream like he’s in a horror movie. *Aren’t we all?*

Even when the gurney has been pushed into the back of vehicle and the doors have been closed behind us, Nathan’s shrieks echo around the inside of the ambulance. The paramedic tells me he won’t try to get a line on Nathan just yet, but he’s prepared in case there’s another seizure. *Can you sedate me so I can escape this nightmare?*

\*\*\*

After two ambulance rides and a CT scan, we spend the night in the emergency room at the children’s hospital, waiting. It is close to 11:00 PM before Brian arrives, having waited for Mom to come to the house to be with Owen.

Brian manages to lie on the tile floor and snooze while I struggle to keep my eyes on Nathan. The nursing staff had decided to get an IV line started, a contentious

argument that began with the paramedics who couldn't get a good stick. When I mentioned that he has a port, they agreed that accessing the port would be better. In true Nathan fashion, he resisted the process and began trying to tear the needle out of his chest.

He's been laying on the gurney with his wrists strapped to the side rails in an effort to protect his line. The sight of him in restraints is difficult to process, but I know it will be necessary.

Around 4:30 AM, they finally move us from the emergency room to the oncology wing. Exhaustion sets in and Brian takes over watching Nathan while I lay down in the recliner. Nathan must also be exhausted because he finally shuts his eyes and falls to sleep.

At 6:00 AM, Dr. Caesar walks into the room, coffee cup in hand per usual. "So what happened?" he asks. Brian proceeds to retell the same seizure story that we've been telling since the 911 call the previous evening. Dr. Caesar furrows his brow, deep in thought. "It could be that his blood sugar may have triggered the seizure. The CT scan shows some air in his brain, so that may have irritated it enough to have a seizure." *It sounds like he's trying to answer his own question.* "But this wasn't the kind of procedure that would typically have seizures as a potential aftereffect. We weren't in an area where that would be likely."

"Air?" Brian asks.

“Sure, in the procedure, we have to inflate<sup>29</sup> the region we’re working in so that the brain opens up more and we can see what we’re doing. It will dissipate as the incision heals. But if you were to say to me, could the surgery itself have cause the seizure, I don’t think that’s likely.”

Dr. Caesar checks Nathan’s incision and leaves the room after mentioning that neurology would be coming to see us.

\*\*\*

A nurse walks in a few hours later to tell us we’re making a trip downstairs to EEG.<sup>30</sup> Nathan is lying quietly in the bed, hardly moving. We push his bed up and down hallways until we reach the back entrance to EEG. The technician describes that she will connect electrodes to Nathan’s scalp and record his brain activity.

Once Nathan’s new “hat” has been connected, they watch the screen for several minutes before suggesting that he keep it on over the next couple hours. They will monitor it from downstairs. *At least he’s not awake for this.*

\*\*\*

Around 10:30 AM, Mom arrives with food and questions. I do my best to answer her, but things have been moving so fast that there has not been enough time to process everything. *Not to mention you haven’t really slept.* She hasn’t been in the room more than 20 minutes when the neurologist walks in and introduces himself.

---

<sup>29</sup> Nathan’s craniotomy removed the front right section of this skull. Because the tumor was located in the middle of the brain, the surgeons had to inject air around the brain so they could work under the frontal lobe and reach the tumor site.

<sup>30</sup> An electroencephalogram (EEG) measures the brain’s electrical activity.

“I’m Dr. Avant,” he says. We watch him expectantly while he reviews the EEG reports that have been produced by Nathan’s brain. “So he’s been having a nonconvulsive seizure for a couple hours now, so we’re going to start him on an anti-seizure medication and see if that helps.”

*What?!* “He’s been having a seizure this whole time?” I ask, trying desperately not to sound incredulous. *Has this been happening all night?* Dr. Avant nods.

“It seems his blood glucose levels are still a little elevated, so that could be part of the reason why he’s still seizing. We’ll also get endocrine in here to get that under control.”

\*\*\*

After waiting two days in the hospital to see if Nathan’s blood sugars will correct themselves, the endocrinologist suggests that they will only release him if we agree to monitor his levels at home and administer insulin as necessary. Reluctantly, Brian and I agree. *Because how could you possibly refuse?*

The nurse brings in a number of items and sets up a demonstration for us to learn how to test Nathan’s blood as well as to draw and administer insulin. We both get to practice delivering insulin to an imitation piece of skin. By the time we have completed our crash course and learned what a correction factor is, it is time for the nurse to test Nathan’s blood for real. She suggests that I do it so that she can address any issues or questions we might have.

With little time to worry about the process or have any sort of feeling about the fact that I have to treat my child like a diabetic, I grab the meter and prick Nathan’s



fingertip. I do the math to determine if he needs insulin and tell the nurse my answer. *It's like a quiz. Do I have to show my work?*

The nurse brings me the vial of insulin and has me draw the correct amount. She tells me I can give the insulin in Nathan's stomach or on the back of his arm. Having watched the nurses give the shot in his stomach, I opt for that location. Brian and the nurse try to hold Nathan still while I pinch a layer of fat on his stomach and insert the needle. *I just gave Nathan a shot. I inflicted pain on my own child.* Nathan's tears subside and I collapse into the nearby recliner.

I look at Brian. "You get to do the next one."

\*\*\*

*October 13, 2014:* Nathan, Brian, and I are sitting next to each other in the small consultation room. Nathan is playing on the Kindle when the radiation oncologist comes in to discuss Nathan's radiation treatment. He asks us to tell him about Nathan. I give him a brief overview about Nathan, the fact that he has autism, and the questions we have about radiation treatment.

Dr. Lewis tells us he has no experience working with anyone with autism. *Well, at least he's honest.*

We discuss the decision of whether to use craniospinal radiation or ventricular radiation and what the risks of each are. Given the reduction of his tumor size, Dr. Lewis would be okay with the decision to choose ventricular radiation, even though it didn't quite meet the 65% decrease required by the treatment protocol. But it's our decision to make.

Nathan would receive six weeks of radiation, Monday through Friday. Because he can't move when receiving treatment, he would need to be sedated every day.

We discuss the problems associated with sedation, namely IV access. Dr. Lewis tells us that the children's hospital would be responsible to determining how to address IV access. Though not a frequent occurrence, Dr. Lewis explains that once sedated, the child is escorted to the radiation center, receives treatment, and then sent back to the children's hospital for recovery.

I can't help but think that Dr. Lewis sounds purposefully detached. *I suppose you have to be in this business.*

\*\*\*

-----Original Message-----

From: Kristen Tarantino  
Sent: Monday, November 10, 2014 6:28 PM  
To: Dr. Macy  
Subject: Incomplete from Spring 2014

Dr. Macy,

I just wanted to touch base with you about my incomplete. Nathan, my son, just started a six week radiation therapy last week. I don't think it's possible to finish my incomplete coursework from the spring semester by the end of the year. I know you and I had briefly touched base back in June, but things got a little complicated with Nathan's treatment plan. Assuming things start to go back to normal after the first of the year, I'd like to try and get things finished up by the summer. Do you think that would be alright? I do still need a confirmation of what remaining assignments need to be submitted.

I took the whole academic year off from the program just in case, and I didn't sign up for classes in the spring. I'm hoping to get back in the regular habit of getting coursework done once Nathan's treatment is completed, but I'm happy to keep you informed on how things progress. Please let me know how you'd like to proceed.

Thank you!

Kristen

-----

\*\*\*

*November 24, 2014:* It's our fourth week of radiation treatment. The ladies who work the check-in desk in day surgery greet me warmly as Nathan and I enter the waiting room. It is 11:30 AM on a Monday, which means Nathan's radiation treatment will be slightly longer today as the radiation technicians re-align the beams for the remainder of the week. As usual, Nathan and I receive our matching bracelets and the clinician weighs him, asks for his list of medications and measures his blood pressure.

We know many of the anesthesia nurses by name and wave to those we pass on the way to our private treatment room. The staff has figured out the right combination of seclusion and sensory deprivation necessary to keep Nathan calm. *Drugging him helps too.*

In our room, I tell the nurse that I've brought his hospital shirt with me. After the first week of radiation, we learned that asking him to only change his shirt was easier and less traumatic than removing all of his clothes. We also determined that if I bring the clothing with me, he is less inclined to have an outburst. He receives a daily cocktail of Benadryl, Ativan, and some combination of Versed and Ketamine<sup>31</sup> so that he can have his port accessed. Anything less and he fights the procedure with guns blazing.

---

<sup>31</sup> All of these medications were necessary in order to calm him down enough to have his port accessed on a daily basis. The Benadryl and Ativan were given in route to the hospital so that I could keep him calm in the car. Daily exposure to these drugs made it difficult to know his tolerance level. Over the course of the six weeks during which he received radiation, the Versed and Ketamine cocktail was increased to accommodate his changing tolerance and drug metabolism.

Once Nathan is almost snoozing, Mary arrives with her bag of supplies. The more she tries to access his port, the more difficult it becomes. At some point, his port must have shifted and now sits at an angle under his skin. She sets up each piece of the process, tossing the parts she won't use into the trash can. When she's ready, she turns to me, mask covering half her face, sterile gloved hands held at her shoulders. My own mask in place, I nod silently and pull Nathan's shirt down to reveal the upper portion of his left chest.

She scrubs the site and waits for it to dry before she places her fingers to his skin and pinches until she finds the port. Nathan groans and tries to squirm away in his drug-induced sleep. I gently hold his hands to his sides to keep them out of the way. The needle is one and a half inches long with a butterfly shaped clasp in between the needle and the IV line. Holding the port in her left hand, she holds the needle poised over Nathan's chest and takes a deep breath.

"Okay, Nathan, here we go," she whispers. The needles goes in and she tries to flush with saline but nothing happens. She missed. It would be unusual if she didn't, given the location and direction of his port. I can hear her whispering, "Oh please, God, please," as she pulls the needle back enough to insert it again slightly to the left. I watch a trickle of blood ooze from the site where the needle pierced Nathan's chest.

"I think I got it this time," she says, flushing the saline through the line and drawing it back out again. We both release our breathing and I notice the visible tension in both of our bodies subside. *At least he didn't fight this time.*

\*\*\*

“Did you know that adult hospitals smell different from children hospitals?” asks the anesthesiologist.

“No, I didn’t,” I reply. “I guess I never noticed before, it’s been a long time since I’ve been in an adult hospital.”

I had heard that as people age, their bodies release chemicals that smell differently. The anesthesiologist claims the difference can be attributed to the constant renovations at children’s hospitals to make them bright and cheerful places that appeal to the kiddos. Either way, it’s not really a distinction I’d want to know about. Just file it under useless trivia and move on. Only, I can’t move on because the hospital is like an appendage. You can’t ignore it because it’s part of you, whether you want it or not. I wouldn’t go so far as to call it a second home; homes should feel safe and warm, loving. The hospital feels constraining and lifeless. And for Nathan, the hospital is where people invade his space, where sensations are at an all-time high and, more importantly, where all the sharp, pain-inflicting devices are. Where he gets bombarded with questions that he doesn’t understand or can’t answer. Where other people establish the rules and nothing is ever consistent. The hospital is the autistic child’s nightmare.

\*\*\*

We arrive at radiation and the technician leads us through a large steel doorway. Nathan has gained 40 pounds since April as a result of the high dose steroids he was given during chemo and surgery to minimize swelling in his brain, and it takes four of us to move him from the gurney to the radiation table. The table reminds me of the table they use in CT or MRI, but the machine is very different. Nathan is snoozing, thanks to the anesthesiologist. Once on the table, the radiation technicians pull large Velcro straps

across his knees and chest to keep him from falling off. They position a hard plastic, netted mask over Nathan's head. If he were awake, he would be screaming. *You would be too if you couldn't move your head and shoulders.*

When the technicians and anesthesiologist are satisfied that Nathan is secure and asleep, everyone leaves the room and the steel door locks behind us.

Ten minutes go by. I check my phone, impatiently waiting for Nathan to be released from his steel prison. The technician comes out of her booth and tells me he's all done.

The anesthesiologist, nurse, and I wheel Nathan towards anesthesia recovery, where it will be at least two hours before Nathan is awake enough to go home. They can't find the pre-med dosage Nathan was given before his port was accessed. I tell them it was 20 Versed and 150 Ketamine. As the anesthesiologist gives the remainder of his report to the recovery nurse, I hear him say if she has any questions she can ask me, since "Mom's going to be a doctor." I laugh and say, "Not that kind of doctor." *Never that kind of doctor.*

The anesthesiologist looks at me, surprised, and asks what kind of doctor I am going to be. I tell him I'm a Ph.D. student in education. He nods, as if it explains why I know so much about Nathan's medical condition and treatment. I forget that to these people I'm just a mom. *A well-informed mom, but still just a mom.* The fact that I am with Nathan every day and know so much about his medications and what they do endears me to them as a favorite parent with whom to work. It's evident when other nurses or anesthesiologists, who aren't assigned to us, pass by and stop to see how we are

doing, when they reach for a hug. One nurse calls me by my first name, “It’s like you’re one of us.”

\*\*\*

*December 14, 2014:* It’s Sunday, and the boys are watching football. I can’t quite get into the game because my brain is working. I pull out my journal and start to write:

Four more days of radiation.

I should feel ecstatic, but I mostly feel apprehensive. Maybe even afraid. Both because I’m worried this tumor might not be “finished” and because I’m afraid of not being able to psych myself up for school – my school.

Lately, I’ve been thinking whether I’m on the right road in life. I hate that I think like this because it means... What does it mean? What does it say about my career and schooling choices in the last 4-5 years? Have I wasted my time? My family’s financial resources? Pursuing a dream that was never mine to begin with? What, also, does that say about my character, that I can’t stick with something for the long run?

I’m afraid to go back only to find out I don’t have the drive, the desire to continue.

I envy those who know what they want and go get it. I can’t say I’ve ever been that person. I’m not the go-getter. I make decisions about my personal future based on how it impacts others – namely my kids and husband. I don’t seek their approval, but I tend to think in terms of “how will this impact/benefit them?”

The last 7-8 months have really made me think about what it is I truly want to do. And the scary part is that I still don’t have an answer.

When I started this whole graduate school journey, I wanted to work with students, prove that I could do what others do – and, in some cases, better. I chose to move away from that idea because I didn’t want my family to suffer from my working late nights and some weekends. I knew that I needed something far more flexible to be able to *be* the kind of mom I needed to be (and my kids needed me to be). So I shifted to the idea of faculty.

I mean to be honest, I always wanted to teach in college. Just not this field. That may be one of the more depressing ideas. I feel like I settled for a field I wasn’t sure I wanted just because it’s here and close by. I feel like I’ve missed that opportunity.

It's discouraging. Though it's not the first time I've felt adrift. Usually someone much smarter tells me to stop feeling sorry and just finish.

Agreed. But what if I've lost my spark? I already feel like my research agenda went out the window. I suppose it doesn't help to have nurses and doctors tell you every day that you could be one of them, that you fit in.

Too bad I never had an interest in medicine, I guess.

It's also quite a bit of pressure to do well when others look up to you – though I haven't the faintest idea why. I feel like I'm not living up to this picture or idea of me that they must have in their heads. It's not a stress that bothers me frequently. But at times when my insecurities are riding roughshod over my good judgment, it does tend to rear its ugly head.

But Nathan's treatment will seemingly be complete in four days. Which means I have to go back to pretending like I fit in, like I belong. It feels like an internal countdown is just ticking away the seconds until I have to pretend. It brings me little peace to know treatment will be done. Instead, I'll just be waiting for the other shoe to drop.



## CHAPTER SIX

### “RING THIS BELL”

*December 18, 2014:* I’m sitting in one of the four blue chairs outside of the radiation suite, waiting for Nathan to finish his final treatment. His nurse is sitting next to me and asks if I will ring the bell for Nathan. I stare at the wall across from me where a small brass bell is fixed to the wall. About eight inches of rope hang from its center and there is a plaque immediately below which reads:

Ring this bell, three times well.

It’s to clearly say, my treatments done,

This course is run, and I am on my way.

It is followed by Psalm 118:24:

“This is the day which the Lord hath made,

We will rejoice and be glad in it.”

“When patients finish their radiation treatment, they get to ring the bell,” the radiation technician says as they wheel a sedated Nathan down the hall towards me. They position his gurney beneath the bell and wait expectantly for me to ring the bell.

I reach across Nathan and take hold of his right hand. Clasping his limp hand in mine, I warp our overlapping fingers around the end of the rope and pull. The bell makes a sharp clang as the clapper connects with the inside of the bell. I relax the rope and tug again. *Nathan wouldn’t let you do this if he were awake.*

A third clang signals the final pull on the rope and I release Nathan's hand slowly back to the bed. The nurses and anesthesiologist clap, and I thank the technicians for their hard work.

*I hope I never have to ring that bell again.*

\*\*\*

*January 2, 2015:* The kids go back to school on Monday, which means I have to start thinking about schoolwork again. The thought of going back to school makes me nervous and reach for my journal to capture my thoughts.

I still question whether I have what it takes to be a faculty member. I just don't know if I have the right drive, the right motivation. I never felt I was *good* at something. I never was the person someone could point to as being good at "that." With the exception of my sorority sister, Jayme – she's always said I was someone to be compared to. Though I don't really see why – I'm not exceptionally intelligent; I'm not overly ambitious or outspoken. I don't even know that I have great time management skills – even if she thinks otherwise.

I'm the person who does what needs to be done. Not because other people tell me to, but because I think it should be done. I do things that I think will benefit my family.

I've never had a dream to be a [fill in the blank]. Growing up, I never said I wanted to be a "...". Because I didn't know – and I still don't.

I'm afraid that I'm just a quitter. That everything I set out to do, or get good at, I get bored with and decide I shouldn't do it anymore.

I pause in my writing. *Good grief you're whiny.* Re-reading the last sentence makes me angry. Is that what I think others think about me? Or do I really feel this way about myself? I turn the page, thinking about how I must appear to others and how my previous thoughts may be perpetuating that impression. Instead, I want others to see me as I am.

Channeling that thought, I write:

I am not fragile.

I don't know why people think they need to protect me from an apparent emotional breakdown. I guess it's not so apparent to me.

\*\*\*

Sifting through Facebook, I notice that my peers are making progress with their careers. The thought makes me sad that I might have missed out and I can feel the sadness wrap itself around my mood. It's nice to feel included – between texts, emails, social media – I still feel a part of the program. But it's also painful.

It's painful to watch my peers move on to their dissertations, complete classes, get published, or present at conferences. It's painful because I should be right there with them. I should be keeping pace and sharing in those moments. But I'm not.

And when I realize that I'm sad about missing out, I feel guilty. Guilty because I know my place, right now, is at home. That I'm needed at home – to take care of Nathan and all of his medical and educational needs. I feel guilty because I'd rather be off finishing my degree, starting a career, earning accolades in the field.

It's also lonely. Some days, I feel dreadfully alone, like there's no one else in the world who could possibly understand how it feels to deal with these family (and personal) challenges. When really, the truth is that I could share with others who are going through this – support groups and the like. But instead of talking to strangers, I want share with my friends, my colleagues, and, at the same time, I feel selfish for wanting to unburden my thoughts and feelings on others, including my peers at school. Why should I expect them to wait for me? Why should they give up their valuable time to hear a lot of the same information rehashed each time I talk to them?

So, I don't say anything. What right do I have to impose my drama, to share uncommon stories, when we could be discussing common problems – research problems?

It seems both impersonal to not share the deepest parts and also shallow to only focus on the commonalities between us. But that's also not something I want to insist on because they have a right *not* to know my drama. It doesn't affect them. Just me.

Some days, I wonder what my purpose is. Have I traveled my pursued career path in vain? Was I destined to be a stay-at-home mom regardless of how I tried to exist otherwise?

I've never been one to settle, or make excuses for behavior. I don't intend to start now, but I could see how easy it would be to give up my pursuits and just be "mom."

But I never wanted to be *just* "mom." I wanted to feel and be important to someone other than my children or husband. To be valued for something I said, did, wrote, or was good at.

I want to be *needed* beyond my family.

\*\*\*

*January 7, 2015:* I'm having tea with Tehmina and Montse, classmates from my doctoral program, today. I welcome the visit, but also dread it. Nathan is still at home because we ran into issues with getting his medications filled for use at school. He is upstairs watching movies while I bustle about in the kitchen making scones and tea sandwiches. The doorbell rings and I drop the puppy in her crate so she won't be too afraid of the visitors.

I open the door and Tehmina walks in, her arms filled with quiche and shortbread. The smell is warm and savory and I show her to the table where she can deposit the food. Monste follows Tehmina into the house and I greet her with a hug. I have missed spending non-academic time with my friends. We *are* friends, even if Montse likes to

refer to us as colleagues and scholars, which I find amusing. I place trays of sandwiches, tarts, and scones on the table and ask them which tea they would like to try.

When everyone's plates are full and we've started our second pot of tea, Montse tells us about her latest independent study and how it's been stressful for her to get it "right." I listen to her speak about her research, her aims and goals for helping a specific population of students and begin to wish we hadn't started talking about school.

Montse has asked for our thoughts on her project, and I defer to Tehmina first. *Should I even be giving advice?* Tentatively, when Tehmina looks to me to answer, I offer a couple suggestions. Once I start talking, though, I feel myself become more assertive in my thoughts. *It must be like riding a bike.*

We are finishing our conversation when Nathan appears on the stairs, asking for a snack. I secretly had hoped he wouldn't come downstairs because now I see eyes turn to me and the questions about Nathan's progress begin. I dodge them with short answers.

"Yes we're finished with treatment."

"No, it's not really remission, I don't think."

"There's still residual tissue left."

"He'll go to school Monday."

"He's hanging in there."

It occurs to me, after they leave and I'm cleaning the dishes, that no one ever asks how *I* am doing. *Because you weren't the one with cancer.*

\*\*\*

*January 26, 2015:* I've spent the last week doing school related stuff (that is, my school). I managed to submit two journal articles, collect all my resume/CV information in a central document, and deal with the atrocities of email.

Among my email, I have three main ongoing correspondences: one with Jim (my program advisor), one with Pam (my unofficial program advisor and mentor), and one with Dr. Macy (a faculty member in my program). Each has its own timetable, schedule, and decisions to be made, work to be completed.

For Dr. Macy, I really need an answer about finishing my class. On the one hand, I'm super annoyed because she let my incomplete lapse to an "F" and hasn't responded (after six months and multiple reminder requests) to the question of "what assignments do I have left?" But on the other hand, I dread getting the response because it's like saying, "yep, you still have to do this and now you've called attention to it, do it now." No pressure.

My email with Jim is about getting a graduate assistantship in the fall, and ultimately ensuring that I *am* coming back in the fall full-time. There have been enough times, before and during this program, where I've had to make this kind of decision far too early. I understand needing to plan for the next academic year, but that's eight months away! How could I make a comfortable decision about coming back full-time? *Maybe you can't*. I can make the decision to come back, but I'm ill at ease with it. Too many things could happen between now and then. The question of "what kind of assistantship" is not really important at this point because quite frankly I've been stuck doing weird jobs before – in four years I don't know that I have a lot to show for my assistantship experiences, except a healthy bank account because it paid my tuition.

Then there's Pam, who wants to help take care of my Italy credits by offering me opportunities to work on a number of different research projects with her.

But as I read through each email, there's this undertone of "I can work around your 'Nathan' schedule – he comes first, don't worry about it."

It's a tone that doesn't sit well with me. Yes, I worry about what might happen before the fall semester, or over the course of the next year, or over the next five years. But I can't put my life on hold. People want to give me space to cope and be with my family – be a mom. I can abide that I need to be "mom," but part of coping is finding a way to be normal again. Just *being* isn't enough. Successful coping is showing that you can get through it in spite of other things. Life doesn't stop because Nathan has cancer – it certainly didn't stop because he has autism. In fact, I made him go back to school. We can't give up just because we have to deal with something tough.

That's certainly not the kind of person I am, or want to be. I'm not saying I want to do it all, but I need balance. I need to be *Kristen*, outside of being "mom." Somehow, I get lost in the mix when something happens in our family. And for the most part, I don't mind. I don't mind taking kids to appointments, staying home with them. But on days when they are their best selves, I want to be me again – put "mom" away for a few hours and be important to and for some other cause.

I feel like I get a lot of pity and sympathy from my colleagues and it drives me nuts. Why do we have to assume I'm going to be or feel a certain way?

Just now, I'm wondering if I've changed at all over the past year. I know one thing hasn't changed – my knowledge of my children – although I may never before have recognized the trait. I may not be confident about a lot of things, particularly my

knowledge of a specific topic or subject. But I *know* my kids. It is the one piece of knowledge that I can say, 100% - I know this, and no one can prove me wrong.

As much as I need to be “me,” “mom” is more confident about her knowledge than “me.”

\*\*\*

*January 15, 2015:* Nathan’s oncology nurse, Mary, calls me while I’m making dinner with the results of Nathan’s first post-treatment MRI. The tumor is still hanging out. It shrunk a little after radiation, primarily because there was a cyst on the tumor, and the liquid from the cyst was reabsorbed, resulting in a slightly smaller tumor.

It’s not the best news, but it’s the best I’m going to get. The tumor is fibrous, so it is essentially dead. *Or at least it better be.*

She has no news on tumor markers yet, but as soon as they come in, she will let me know. Negative tumor markers would let us know for sure that we’re in “monitoring” mode, which means he will have to go back every three months for a full MRI and LP.

But it also means we could take out his port.

Somewhere deep down, I should be super happy that we’re done. And I’m sure that if the tumor were completely gone, I would be. But I can’t help feeling like we haven’t seen the last of this tumor, of this cancer. And that keeps me from being happy. It scares me. I hate knowing that for the next seven to ten years, I’m going to be thinking about this tumor. Living with the knowledge that it might not be done. That we survived 2014 only to have to relive the nightmare—or worse. That I’m constantly going to be questioning whether Nathan is showing symptoms or just being Nathan.

It’s like psychological torture – all the “what ifs.”



Perhaps I need counseling.

\*\*\*

*January 22, 2015:* During Nathan's trip to the neurologist, I learn that the CSF markers have come back—yet I have not been called by the oncologist. The neurologist remarks that his HCG is elevated (9 mIU/ml not <8mIU/ml)<sup>32</sup>. Although he doesn't mention more than the passing comment, inside I'm freaking out.

Why did Dr. McAllen not call me?

What does that mean, that it's elevated?

The minute we get home, I'm on the computer Googling any sort of mention about elevated HCG levels in CSF. All results turn up “may indicate a HCG secreting tumor.”

I try not to overreact. I mean, Dr. McAllen hasn't called yet, maybe I'm just overreacting. But deep down, I can't stop worrying. It's too soon for a reoccurrence, right?

Part of me wants to cry. But I can't. There's too much I don't know yet. Best not to give in until I know more. I'm also afraid to give in to the fear. The ever-present fear that this tumor might take Nathan away from me, permanently.

I also can't talk to anyone yet. Mostly because I don't know anything, but also because I can't bear the thought of sharing bad news. The thought of sharing bad news almost has me laughing. “Sharing” implies goodness, kindness. It's not a kindness to tell

---

<sup>32</sup> Different labs use different levels for identifying increases. In this case, Nathan's CSF sample was sent to a different lab than had been used before, which made interpreting the results compared to previous spinal fluid results difficult. However, each spinal tap continued to test Nathan's HCG and AFP levels, as they had been the primary indicators of Nathan's tumor type.

anyone bad news. Perhaps that's why someone "gives" bad news. Better to give it away than to keep it for yourself. Although, "giving" implies goodness too.

Either way, I have to be the bearer and ultimately the one who comforts everyone and reassures everyone. I can't be in that place right now.

I feel jittery and unsettled with the lack of medical knowledge combined with the Google-supported knowledge I have. They war with each other in my head. It's a wonder I don't go crazy.

Knowing, or not knowing, makes me dread my phone call this afternoon with Jim. How will I concentrate? How will I modify my responses to his questions?

I should eat lunch, but the idea makes my stomach revolt. How can I possibly eat when my child may have a positive tumor marker? What do I do? What *can* I do now, besides wait? Some days I wish I could be more like Brian and put it out of my mind. To be optimistic and just want it fixed so we can all move on.

\*\*\*

Mary called this afternoon. We're doing another run of scans and tumor markers in a month. They don't know why the HCG is elevated.

That's not encouraging.

\*\*\*

-----Original Message-----

From: Kristen Tarantino  
Sent: Monday, February 2, 2015 1:37 PM  
To: Barber, Jim  
Subject: time to chat

Hi Jim

So I'm going to be on campus tomorrow to review IOL [integration of learning] papers with the team among other things. Do you have some time to chat? Nothing serious happened, so there's no need to be worried. I've been doing serious thinking about my dissertation plans and I want to discuss them with you to see if you'd be on board. I'd like to think you would be, but I'd rather be safe than sorry. Plus, I may want to pick your brain about the topic in more detail than what I've already thought about - also something I plan to do with the dissertation group. If not tomorrow, just let me know if/when you might have some time.

Thanks!  
Kristen

-----

\*\*\*

*February 3, 2015:* I walk the short hallway towards Jim's office from the conference room where my research team members were meeting about plans for our latest paper. I can feel my heart pounding so hard in my chest that for a brief instant I wonder if my heartbeat is visible. *Chill out.*

I take a deep breath. I am nervous about our meeting. *But you called the meeting, so suck it up and do it.*

I knock on the open door, announcing my arrival. We exchange greetings and Jim leads off with, "How are things?"

"Okay. Nathan's back at school."

"Oh, good!"

I nod. "They want to do another MRI in February. They got a test result back that they were confused about, so they want to re-check it in a month."

Jim nods, processing what I've shared.

"So, I wanted to talk with you about my dissertation. As I shared back in September, I have been giving serious thought to my ability to work on my previous

topic.” *Slow down, take a breath. It’s not like he’s going to yell at you for changing your mind.*

“I’ve been journaling, like you suggested,” I continue, “and I’ve also been reading a lot about autoethnography as a method. I’d like to write about this experience with Nathan, as it relates to my being a graduate student. I don’t know at the moment what the connection between the two is, but I just don’t think I’m going to be able to write about anything else.”

I pause, gauging whether I should add anything else. Before I can say more, Jim says, “I think there would be a lot of value in looking at your experience and what implications faculty and administrators could draw about supporting students in similar situations.”

I release a breath I didn’t realize I was holding. “Is this a change you would be comfortable with?” I ask.

“I don’t know much about autoethnography, but I’m happy to still be your chair if that’s what you want to do. The key will be figuring out what the connection to higher education is,” he responds.

I feel a vast sense of relief that he didn’t say no. We discuss the method a little longer and he gives me an assignment. “See what you can find about other dissertations that may have been written using autoethnography. That may give us a starting point to begin thinking about structure and format.” I make a note and thank him for taking the time to meet with me. *Now go do it.*

\*\*\*

*February 27, 2015:* Last Friday, Nathan had another MRI and spinal tap. I haven't received any phone calls about results, and it makes me nervous. I keep trying to stay positive. *No news is good news, right?* And yet in the back of my mind, I'm thinking that maybe they haven't called because they found something they don't want to share yet.

Although I would hope that if the MRI showed something new they would tell me as soon as possible instead of waiting for the tumor markers to come back.

Nathan's blood sugars have not shown any indication that they are correcting on their own. Dr. Brown, his endocrinologist, suggested we start factoring in his carbohydrate intake when giving him insulin. It's rough. Sometimes I feed him in his room and forget to go back upstairs to give him insulin. I feel like I run around like a crazy person at meal times, mostly because I fix more than one dinner a night, and then have to remember to count Nathan's carbs and deliver insulin, which involves doing math.

I've spent the last couple of weeks coming up to campus, trying to involve myself in academic discussions. It's hard. I just feel so disconnected. It's not that I don't belong. I can have advisory conversations with people about things they're interested in or people they are trying to contact. But, I just don't feel that spark of "oh, I want to be inspired and motivated to do all these things." And maybe I never was. I don't remember ever being ambitious or wanting to seek out opportunities to be important. That drive, if it ever existed, is probably even less apparent now. I don't want to be over-involved or be "important." I just want to be done. It's nice to have things to do – school work, research, deadlines; but I find that I can do without it too.

I can't ignore that the tumor played a part in this change. This whole experience has a serious way of shifting perspectives. But it's more of a change towards – who am I now? I've made it this far only to be... whom, exactly?

Even my research interests have changed. Will they ever change back? Will I ever get back to where I was? And if I do, will that mean I never really changed? That I never learned anything new about myself? If I don't get back to where I was, then what? Do I keep trying to go back to where and what and who I was? Or do I try to make the 'old me' work and give up any authentic changes?

It's a thought I continuously struggle with, much like my doctorate. I don't want to *not* finish, but finishing, in its own right, has lost much of its previous importance to me. It's really disconcerting to not know where and who and what you are, will be, and will go.

I wonder if my peers and colleagues can see through my façade. I don't want them to see me as an uncaring, unmotivated, disillusioned student. Is that it? Have I been disillusioned? Have I finally been desensitized to the reality of academic life only to come out on the other side with little compassion (or passion) for it?

I almost want a mind-numbing job just so I can feel secure in knowing that what I do isn't that important. Whereas everyone here takes themselves a little too seriously.

Maybe I take myself too seriously.

\*\*\*

*March 19, 2015:* Today is Nathan's port-a-cath removal surgery. The surgeon assures me it's a routine process and won't take longer than an hour. Still, I sit in the waiting room

gnawing on my fingernail. I realize that the waiting room is really not my favorite place and begin to ponder the implications of removing Nathan's port.

On the one hand, I am ecstatic. Accessing Nathan's port, and keeping it accessed, has been the most difficult and challenging part of treatment. The fact that he won't have to endure that trauma anymore is a vast relief.

I've also been told that removing his port is the last step in completing treatment. Once it is removed, Nathan is officially done with treatment. Completing treatment is a conflicting thought because, although it brings the knowledge that he will no longer be subjected to chemo and radiation, it feels artificial. We will continue to monitor Nathan's progress with MRIs, spinal taps, and blood draws. We will continue to see his doctors as they managed his medications. The port removal does not mean the nightmare is over. It is an arbitrary finish line, marked with singing, a team signed t-shirt, and a medal. None of which convey the significance of completing treatment to Nathan.

Maybe the artificial feeling comes from knowing that there is residual tissue still in his brain. Maybe I wouldn't be so conflicted if there was nothing in his brain at all. But I still can't make myself feel carefree and happy that we're removing his port.

\*\*\*

*March 20, 2015:* My best friend from high school, Amanda, and I are sitting at the kitchen table eating nachos. She's been spending her spring break at the house, a treat we don't get often because she lives so far away. I start to tell her about my concerns about the port removal.

"I just feel like something could still go wrong. I mean, sure he's done with treatment, but what if it comes back? What if one of the other conditions that the tumor

caused takes him away from me? Even if the tumor doesn't come back, he's at risk for heart disease, stroke, a secondary cancer. And then what happens? What do I do then?"

Amanda nods along, letting me air my frustrations. "Do you think I should talk to Brian about a plan in case something were to happen to Nathan?" I ask her.

She munches her forkful of nachos, considering my question, before replying, "It couldn't hurt. I mean, when my sister died, they had someone from the hospital help with end-of-life arrangements and everything, but my sister made all of the decisions. So when the time came, we didn't have to figure out what her wishes would have been or make arrangements. She had taken care of it." She takes a swallow of water. "Most likely if something were to happen to Nathan, the hospital would do something similar. But he can't make those decisions for you, so you and Brian will have to do it."

I grimace and nod to indicate I understand, even if I don't like what she's saying. "He won't want to talk about this," I say.

"No, I can't imagine he would," she replies.

\*\*\*

*April 27, 2015:* Since Nathan's next MRI is in June, I decide to re-enroll in classes and try to finish my degree before I have a chance to change my mind. I have to reconfigure my coursework and schedule six summer classes to make the timeline work.

I go online to register for the summer classes, but the system won't let me.

Confused, I send an email to the graduate registrar:

-----Original Message-----

From: Kristen Tarantino  
Sent: Monday, April 27, 2015 9:50 AM  
To: Pearson, Wendy  
Subject: Registering for classes



Hi Wendy

I know you're busy today, but I wanted to ask you a (hopefully) quick question. I am hoping to register for summer/fall classes, and I know my medical leave was approved through August. Does that affect my ability to register for classes now? And if so, is there something I need to do in order to be able to register?

Thanks!

Kristen

-----

Within ten minutes, she responds telling me that she will have to re-activate my status as a current student. But before she can reinstate me, I have to complete course registration forms by hand and submit them to her, instead of online. I also have to fill out the domicile application for in-state tuition eligibility, again. *It's not like you haven't been a student here for the last four years.* Annoyed that I have to "re-apply," I sit down and complete the forms for the summer and fall and send them back.

\*\*\*

*August 26, 2015:* Today is my first day of "class" since the tumor. I've been working on my incompletes from the spring semester when Nathan first was diagnosed and took a few low-weight courses online over the summer, but those don't really prepare me for the anxiety of today.

I'm suddenly nervous. I know most, if not all, of the students in my class, but I feel as if I am the new kid. I also worry about feeling like I'm under a microscope.

It's my last course, so it shouldn't be that bad. But I just feel like it's going to be a culture shock being in a classroom environment again. The focus of the course is to work on dissertation writing, particularly developing a proposal. The professor is one who is

familiar with my new dissertation direction, but that doesn't stop him from trying to poke holes in it.

Going around the room, each student provides a tentative title for their dissertation. Following each title, the professor asks questions and critiques the study before it has even begun. The student next to me is under scrutiny now and I have a mild panic attack sitting next to her. My palms turn cold and clammy, and I can feel my heart racing. *You know this better than anyone, why are you such a chicken?*

When it's my turn, I give my title to the room, "Framing the degree: An Autoethnography of Trauma in the Graduate Student Experience." You can hear a pin drop as the room digests what I've just said. I am asked to repeat the title. My heart is thundering so loudly, I'm positive the students next to me can hear it.

The professor asks me to describe for the rest of the class what I mean by an autoethnography. He tells me to consider the validity of the method I'm using, telling the rest of the class that I would need to find a way to provide objectivity in my study, implying that without it, my study would be just a bunch of journal writings and not really research. I grimly smile in response, not wanting to say what I really think. That autoethnography is just as valid as a multiple regression or a case study. That there is research value in examining the personal experience. Nodding in acknowledgement that I am finished speaking, he turns his attention to the next student. It's nothing he hasn't told me before, and I begin to relax as the next student offers his title. I heave a sigh and sit back in my chair, all of the tension fleeing as I focus on the next student's topic. *If you can justify this method to him, you can justify it to anyone.*

\*\*\*

*August 31, 2015:* As part of my “return” to being a full-time student, I sign up to co-teach a class with Pam. I’m nervous. Not just because it’s Pam’s class, but because I’m not sure I’m ready to be “front and center.” On anything. Luckily, it’s only the first day of the class, and I only have to introduce myself. *Baby steps.*

Watching Pam I briefly wonder how she can manage to do everything she does. Is that what I want to do as a faculty member? I admire her tenacity and drive, but I don’t know if that fits with who I am.

\*\*\*

*September 21, 2015:* I sit at the table attempting to work up the energy to write Chapter One of my dissertation. I can hear the traffic outside the house – large trucks rumble by, engines are gunned, a siren calls out, screaming past the house. The dog is plastered to the living room floor. Sounds of smacking and clicks indicate that she’s engaged in the mastication of a rawhide. Every now and then a truck goes by and the noises from the living room pause, highlighted by the jingle of her collar as she perks up to identify the noise from outside.

Meanwhile, I’m still sitting at the table. On my left is my cell phone. On my right, the house phone. Both are silent. Under normal circumstances this would be a welcome blessing. But instead, I wait painfully for one or both to ring. A phone call would mean that someone has a thought, a suggestion, an answer. Then again, if it’s the school nurse calling back, a phone call would signal more problems, more answerless questions.

At 10:55 the phone rang. When I looked at the caller ID, I recognized the middle school name and picked up the phone. It was the nurse.

“Nathan’s teacher said he was in a lot of pain and came to see about using the wheelchair,” she states. She wants more information from me about Nathan’s leg pain. I tell her about Nathan’s obvious distress and the suspected pain in his lower body that I witnessed over the weekend.

*He was screaming, tears flowing down his cheeks, as he walked to the bathtub.*  
*“Go to bed!” The bath took no more than two minutes, but the physical trauma we were putting him through was not worth having a clean body. It took two adults to remove him from the bathtub.*

“I don’t know what’s causing his pain,” I say to the nurse.

“Well, I don’t usually let students use the wheelchair unless they have a doctor’s note indicating the reason for its use,” she responds.

For a moment, I want to snap at her. But I let the moment pass. She’s never dealt with a child like Nathan, of that I am sure. So I refrain from giving her a piece of my mind. For the moment.

I place calls to the endocrinologist, the neurologist, and the oncologist, hoping that one of them will tell me what I should be doing in the meantime. But the phone is still silent.

I think about what I should be writing as part of my dissertation chapter, but I can’t seem to make myself focus on it long enough to write something that would be valued by my faculty. The dog wanders into the kitchen where I sit. Sometimes I think she senses when I am distressed. I pause to scratch her back and rub my fingers through her fur while she lies down beneath my feet. For the span of a few breaths, I try to calm my mind instead of giving in to the worst case, what-if scenario. I also take a brief second

to remind myself that I have many other things to do today so as to stem the rush of worry that threatens to overwhelm me.

*You have to pick up the kids at 2 o'clock. Mom will be here around 3:30 because Brian is in Delaware for the week. You have to teach class at 4:30, and come home in time to put kids to bed and pack lunches for tomorrow. You don't have time to waste by giving in to your feelings right now, so just stop it.*

The miniature scolding helps, and I sit back down to write.

\*\*\*

*October 9, 2015:* I was ready for today, but not prepared. I make my way to the surgical waiting room to wait for Nathan. There's a lady seated nearby. She's on the phone, audibly agitated, and speaking about death certificates and funeral homes. She's not talking about a child who has died, but the discussion of death unsettles me while I sit, waiting for Nathan. He should be done, or almost done with his latest MRI by now, but he still has a spinal tap to go.

The longer I wait the antsier I become. I know this wait is routine, that it's just a matter of time before they tell me they're ready to bring me back to recovery to be reunited.

The lack of a working Wi-Fi also makes me itchy to be out of the building. Without it, I can't review conference papers or do work on Chapter Three of my dissertation. And then I'm frustrated with myself for thinking about schoolwork today.

\*\*\*

*December 3, 2015:* I'm blissfully engaged in preparing for my dissertation proposal defense. It hasn't yet become real that I'm about to write one of the hardest "papers" of

my life. But for me it's hard for two reasons. It's hard because it's a *dissertation*, and there's structure and requirements and you have to sound like you know what you're talking about. But it's also hard because it uses my experiences as data. Initially, I felt okay about this. Now I wonder how removed I will feel from myself and my emotions when I write it.

Blissfully engaged because I had yet to receive the notice of Nathan's next MRI. In fact, the lack of communication spurs me to look it up on the hospital's online medical chart. "January 15" it reads.

Crap. There goes my bliss right out the window.

\*\*\*

*January 5, 2016:* Knowing when the next MRI is and planning for it psychologically are two different experiences. I wrote it on all of my calendars, posted the notice on the fridge. I think it won't be so bad, he's been fine so far. But there are events that I can't predict.

I arrive at Nathan's school early to pick him up. It's aquatic physical therapy day. He's been going for the last five weeks and making great progress. As we walk from his classroom to the car, I can feel him lean into my hand as his knee gives out. I look down because the motion felt as if he had tripped. But he's not dragging his feet. I assist him into the car and rush to our appointment.

We sign in five minutes late. Nathan is still hobbling, slowly. I make him take a seat and palpate his knee and ankle. "Does this hurt?" I ask.

"Hurt."

“Nathan, does your ankle hurt?” I press slightly on his ankle. “Or does your knee hurt?” I move my hands up and press gently on the sides of his knee.

He pats his hand on his left knee. “Knee.”

The therapist comes up behind me and I explain my concern. She concedes in not making Nathan wear ankle weights today.

By the end of the session, he’s moving in the pool like he had before, even if his left knee was not fully bent during the exercises.

We walk to the car, again slowly. When I open the car door for him to climb in, he pauses, unsure of how to climb into the vehicle while in pain. I reach under his left arm and lift the left side of his body into the car as he pulls on the passenger headrest with his right hand.

When we arrive home, I gather my things and prepare to exit the car. In the backseat, Nathan wails in pain as he turns his body toward the door. Walking around to open his door, Nathan sits crying in his seat and looks afraid to move. Gingerly, we slide him off the seat so that his feet are on the ground. He cries and moans as we walk the 15 feet toward the house.

Ascending the stairs to his room is a challenge that elicits more wailing. I follow him to his room where he insists on putting on his pajamas. Only this time he can’t bend his leg to remove his pants or put on his pajamas. I make him sit on the bed. His face is flushed from the pool exercises and wet from his tears.

“Nathan, look at mommy.” His watery, red eyes collide with mine. For an instant, I wonder if he thinks I can solve the problem. That depressive thought will have to wait.

Maintaining eye contact I tell him to “take a deep breath.” I follow through with my own command and watch as he imitates my actions. The crying ceases for a moment.

I remove his pants and replace them with his pajama bottoms. The shirt is easy and he takes care of that effortlessly. I tell him to sit on the bed and go downstairs to find the Children’s Motrin, wondering how long this new development will last.

\*\*\*

*January 11, 2016:* I just finished typing two journal entries from the summer of Nathan’s treatment. Being emotionally and mentally back in that place makes me feel low. There’s a raw energy about those entries that strike at the heart of how I felt on any given day: conflicted, frustrated, worried, distraught, introspective. It’s a place I don’t like to revisit. I have never been decisive, so to say that being conflicted is in opposition to how I normally feel wouldn’t be an accurate statement. But, I like to think that I generally know what I should be doing. I know how to plan for events and for what’s coming next.

But reading those entries brings back the feeling of incomprehensible chaos, not knowing what was going to happen from day to day and how to prepare for it.

In truth, I don’t relish reliving these memories. Although Nathan’s follow up is still ongoing, I will never truly be free of these memories. I can never allow them to rest. And so I *do* relive them. Every MRI. Every doctor visit. Every form I fill out for a new therapist, a new teacher, a new school nurse. Every time someone asks what year of school I’m in, or when I will finish. I must repeatedly relive the agony of his diagnosis and treatment. Of the preceding symptoms and the aftermath from both the treatment and the tumor.

Nathan will never be off hormone replacement medication.



Nathan will never be off insulin.

Nathan may never be off seizure medication.

Nathan has already received two installments of physical therapy.

Nathan will never be free from anxiety.

I will have to buzz Nathan's hair to his scalp every week.

The wheelchair may never leave the back of my car.

These are facts. They are not in any way romanticized. I can't even drop Nathan off at school without him bursting into tears. I live with this trauma every hour of every day. It's like an extra layer of skin that has been permanently fused to my body. I can't remove it.

Typing those entries has made me sad. Sad that I cannot change these facts. That I have to accept them for what they are and live with them. I don't want to. But I don't want to live without Nathan either. For every tear he sheds in anxiety, frustration, anger, confusion, I get an "I love you mommy." A phrase that at one point I never thought I would hear. A phrase that soothes the angry monster that lives within, that laughs at me when I can't help Nathan more. A phrase that both makes me stronger and weaker. Because although it brings joy in its telling, it also brings a frightening realization that perhaps Nathan thinks I *am* doing the best job. What if this is his way of saying, "I know you're doing the best you can mom, it's okay. I'll be okay." And that is the saddest thought of all.

\*\*\*

*February 8, 2016:* I am faced with considering death today. A colleague and dear friend must tackle it head on, but I have to watch and contemplate the reality of what death

means. I watch her emotional struggle and I wonder what it would be like to encounter death in my own family. The thought scares me.

I remember thinking there's no way to prepare yourself for death. There's no way to be at peace or mentally fortified for the actual event. It hits like a tidal wave.

"Preparing" is a convenient distraction and even valid illusion.

I wonder if my friend would want contact. Or would she be like me and want solitude. I am unable to know which method is best for her solace. Perhaps it is the same for many others who did not know whether to offer me comfort or to avoid the conversation of my family's tragedy.

My friend's loss is a palpable wound on my own skin. One that doesn't bleed but has the appearance of pain. It's not real for me. But I can imagine it. And the imagination makes it harder to stem the pain.

It's a sensation I am readily familiar with and recognize like an old friend. An old friend with a history of betrayal. I don't want to feel such helplessness again. If I cry, for who am I crying? Her loss? Or my imagined loss?

\*\*\*

*March 11, 2016:* I look back at what I wrote. Should I be concerned that it was easy to write such a gruesome tale? Should I be worried that I had little difficulty expressing my deepest thoughts? Did I overdramatize what happened? Did I do the story justice? Did I tell it truthfully? I can't really know for sure. It seems like those days are burned into my memory, the watching as well as the waiting. It is oddly poetic that I write this story exactly two years later. I think about whether I would have been able to write such a story in a year ago when Nathan was having his port-a-cath removed. In December 2014, when

Nathan was finishing radiation. In October 2014, when he was having a craniotomy and subsequent seizures. In August 2014, when he was finishing his last round of chemotherapy.

I ask Brian to read what I have written. It is important to me that he be able to share this story with me. I worry that it will upset him to read about the experience all over again. But instead of being upset about the experience, he is able to comment about the vividness of the storytelling.

“Too vivid?” I ask.

“No, it’s just... I wasn’t there for much of this. Some of these parts, I don’t remember because I just wasn’t there.” He pauses for a minute before adding, “I’m sorry I wasn’t there.”

I process that statement while he leaves the room to walk the dog. I was not expecting that sort of reaction. Should I have expected it? Did I intentionally leave him out of the story? Or was it accurately portrayed? Was Brian really not around for many of the experiences that were so hard for me? I wonder briefly if Brian really was upset by reading this story, not because of the story itself, but because he was experiencing the process all over again, through my eyes, my words.

\*\*\*

*March 17, 2016:* It’s strange to be at my parent’s house without the boys. I came specifically for the quiet, so that I could work on my dissertation. But I’m so accustomed to checking on them before I go to bed, making sure the nightlight in the bathroom is on.

I asked Mom and Dad to read Chapters Four through Six of my dissertation. I know they aren't easy to read, even less easy to re-live. I warn them that Chapter Five is rough.

"No," mom says when she is finished. "Six was the hardest."

I hadn't realized that in writing Chapter Six, I was putting words to fears that we shared – the loss of Nathan. I tell her it's my least favorite chapter. But now I know why. It gives life to the insecurities I have about succeeding in anything when I don't feel successful in protecting my own child from harm and disease. It sheds light on my inability to control the situation and the frustration and confusion that a lack of control causes.

Dad finishes reading and says, "Your mom is right. Six is it."

They head to bed. I glance at the clock. *1:00 AM*. I feel slightly guilty that I asked them to read it. I feel as if I have placed a burden on them that doesn't belong to them. Was that fair of me? If I can't ask them to read it, how can I expect others to read it?

I head upstairs to quiet my mind and try to sleep. I scroll through Facebook and notice Brian has re-posted a picture from today, a year ago. It's a picture of Nathan's end-of-treatment celebration. He's grinning at the camera with a marathon medal around his neck. Looking at the picture I replay Dad's last words to me before he went up to bed.

"You're grandpa told me once, 'You have persistence,'" he said. He hugged me and said, "You have drive."

*There is hope.*

I realize I do not feel ashamed for having written about my experience. Self-conscious, perhaps; but not ashamed. For me, it will always be a question of, could I have

been a better parent? Could I have noticed the signs earlier, advocated more? Did I fail Nathan by initially brushing off my concerns, by not pushing the doctors harder? But then I re-read this story, and I think about how much I have learned by traveling this journey, how much I have grown. I may never know the answers to my “what ifs,” but I do know that this experience has *made* me a better advocate out of necessity, a better parent for learning the value of perspective, a stronger mom for making it to the other side in one piece.

## CHAPTER SEVEN

### PROCESSING TRAUMA

This chapter moves beyond the narrative presented in the preceding three chapters in order to examine the degree to which my story of trauma reflects posttraumatic growth. Returning to my theoretical framework, which includes Posttraumatic Growth Theory (Tedeschi & Calhoun, 2004) as well as an understanding of story as theory, I suggest specific instances in my story where my experience aligns, and in some cases does not align, with existing theory. I shared my story in great detail in the preceding chapters to illustrate a specific example of a trauma that a graduate student might face during their academic program. Without a thorough presentation of the traumatic experience, it would not have been possible to accurately describe and analyze my psychological growth.

The decision to utilize past tense in the writing of this chapter was the result of a tension between realizing that my personal growth is ongoing and that these traumatic events and subsequent processing have already occurred. Although the experience occurred in the past, the presence of ongoing distress and trauma creates a need to analyze the experience as I do presently, understanding that this analysis may evolve in the future as I continue to refine my new internal schemas that were created as a result of this experience. However, since the cognitive processing of traumatic experience has, for the most part, already occurred, I decided to write primarily in the past tense to analyze my growth as I have come to view it through the development of this study.

In addition to the posttraumatic growth process (Tedeschi & Calhoun, 2004), the narrative analysis of my traumatic experiences related to Nathan's diagnosis and treatment is guided by the following questions:

Overarching Question: *How did the traumatic experience of my son's diagnosis and subsequent care affect my personal life narrative, particularly as related to my graduate student experience?* More specifically, the questions to be investigated in this study are as follows:

1. How did the psychological impact of trauma affect my graduate student experience?
2. How did my traumatic experience affect my assumptions about reality, in relation to the graduate student experience?
3. Within my graduate program, where, and in what form, was social support present during the cognitive processing of my traumatic experience?

### **Before and After Trauma**

In analyzing my autoethnography, I began by characterizing my experience as being before trauma, the traumatic event itself, or post-trauma. Tedeschi and Calhoun (2004) identified a temporal distinction that "for persons who have experienced major life crises, their lives are often conceptualized as having a before and after" (p. 12). My autoethnography was thus separated into three distinct chapters based on their chronological components. Chapter Four captured those experiences that I determined to be pre-trauma. Chapter Five detailed the traumatic experience as a whole, and Chapter Six characterized the aftermath of my traumatic experience.

## **Pre-trauma Me**

Understanding who I was before trauma highlighted the role of my family in my graduate student experience. My family was and still is an essential part of my life narrative that is the basis for the majority of my decision-making. The narrative in Chapter Four showcased my already-present ability to manage Nathan's medical needs, particularly with regard to his autism. Having a pre-exposure to trauma, as noted in Chapter One, when Nathan was diagnosed with autism, allowed me to access coping models and schema that helped me manage the new trauma of Nathan's cancer diagnosis. This pre-established ability to cope with stressful situations, both in graduate study and in handling family problems, may have been an early indicator of posttraumatic growth (Aldwin, 1994; Tedeschi & Calhoun, 2004).

As written in Chapter Four, my pre-trauma life consisted of those experiences that occurred prior to, and up until, the point that Nathan received his cancer diagnosis. Although my pre-trauma experiences are degrees of traumatic experience, particularly those instances in which I was waiting for a diagnosis, they were not traumatic enough to re-evaluate my life narrative or personally held schemas. However, writing about the diagnostic process illustrated the ways in which I initially managed distress. Specifically, I went into survival mode, blocking out emotional reactions for six months, from November 2013, until there was finally a diagnosis at the end of April 2014. I did not allow myself to feel emotions other than worry until I knew what was happening with Nathan's medical condition. After receiving Nathan's diagnosis, I had to rely on reflection and psychological dialogue to process the whole of the traumatic experience, including my emotional reactions.



## **Trauma Me**

Chapter Five, then, detailed the specifics of my traumatic experience. Although the diagnosis and treatment process belonged to Nathan, I shared his experience and vicariously experienced the traumas that were inflicted during that time. In addition to vicariously experiencing Nathan's trauma, I also experienced trauma as a parent needing to make decisions on behalf of my child and defending those decisions to family members. The treatment process lasted for eight months, from the April to December 2014, and included six cycles of chemotherapy that were punctuated by weekly clinic visits and blood testing. MRIs and spinal taps were performed after cycles two, four, and six. Nathan also underwent a craniotomy in order to biopsy the remaining tumor tissue. Once Nathan had recovered from surgery, he received six weeks of radiation, five days a week.

The treatment plan itself, only represented part of the traumatic experience as detailed in Chapter Five. Treating Nathan's cancer characterized the elements of trauma because it was unexpected (McCann & Pearlman, 1990; Weiss & Parkes, 1983), out of the ordinary (McCann & Pearlman, 1990; Tedeschi & Calhoun, 1995), and uncontrollable (Slaby, 1989; Tennen & Affleck, 1990). Though the tumor itself was not irreversible or chronic (Davidson et al., 1986; Tedeschi & Calhoun, 1995), the damage that both the tumor and treatment caused resulted in chronic medical conditions that are still in effect. Finally, identifying the cancer produced a sense of self-blame (Tedeschi & Calhoun, 1995), a sense that I should have known something was seriously wrong earlier than I did.

Related to the trauma of Nathan's treatment, Chapter Five detailed the additional experiences that were associated with this time period. Specifically, Chapter Five explored the decision to leave my doctoral program and the implications of leaving coursework unfinished. Personal communications, both in face-to-face interactions and in written correspondence, demonstrated the effect of trauma-related stress on my relationships with family and peers. Chapter Five also illustrated the challenge of learning to be a new person in light of the trauma. Although these corollary events were not traumatic per se, they were integral components of the overall traumatic experience.

### **Post-Trauma Me**

Chapter Six began with the end of treatment in December 2014, signifying an end to the traumatic event. However, as illustrated in the rest of the chapter, the "end" of trauma did not equate to the end of traumatic stress. Additionally, there were moments in my experience that reflected on-going trauma, such as MRI follow-up scans and physical therapy. Also captured in Chapter Six is the way in which I psychologically began to process the experience of Nathan's diagnosis and treatment. Whereas in Chapters Four and Five I focused primarily on the events that encompassed my experience, there is a shift in Chapter Five that reflects an increasing degree of personal reflection and psychological questioning, which became more prevalent in, and ultimately the focal point of, Chapter Six. These reflections and psychological questions were important to highlight because they detail the ways in which I processed and re-negotiated my internal meaning-making schemas. This processing allowed me to re-write my life narrative in a way that both prepares me for a future trauma and gives meaning to the experiences that I described in Chapters Four and Five.

## **Reflecting on Pre-trauma Me**

The Posttraumatic Growth process is marked by a reformation in internal schema and meaning making as a result of trauma. In order to provide context for my evolving schema that resulted from traumatic experience while a graduate student, it is necessary to understand my schemas when I entered my graduate program. This view of my pre-trauma self is crafted through reflecting back on my life experiences and previous ways of knowing and seeing the world.

I became a mother at 18. It was not planned, and I had no idea what I was doing. Like many first-time parents, I struggled with feeling like I was doing the right thing, but unlike other first-time parents, I was still trying to figure out who I was as an adult. Having Nathan so young, he became part of me, and my identity latched on to him as an integral part of my existence and net worth. He was nothing without me, and I was nothing without him.

During my last year of college, Nathan started early intervention services for a developmental delay. I had studied psychology enough in college to understand childhood development and know that he his growth was behind compared to his typical-aged peers. But caring for his developmental needs took a toll on my relationship with Brian. We had been together since our junior year in high school and had never understood adult life without each other or without Nathan.

Nathan was diagnosed with Autism Spectrum Disorder (ASD) when he was four and a half years old. Adjusting to the weight of the diagnosis and how it manifested in Nathan became a very real challenge for our family of three. For five years, I felt as if I were the sole caretaker for Nathan: attending Individual Education Plan (IEP) evaluations

and meetings at his school, pushing for the best special education services we could get, driving him once a week to speech and occupational therapy. I understood his mannerisms and language patterns like the back of my hand. But I also burned out from being Nathan's person and not my *own* person for all those years. I was still coming to terms with my identity as a mom of a child with ASD.

I had determined that long-term plans never seem to work out for me, and so I tried to avoid making plans that lasted longer than a year. But I had spent four years post-undergraduate study being a stay-at-home mom, and I felt stifled with the need to be my own person instead of being attached to my child 24 hours a day. I enrolled in graduate study as a Master's student studying Higher Education Administration initially as a way to get out of the house and make a difference for myself as well as my family.

I had my second child, Owen, a month prior to starting my first graduate course. To me, it was like my undergraduate experience all over again – having a newborn, infant, toddler while also going to school. I was familiar with the process of doing both at the same time, and although it was frustrating at times, coordinating schedules and balancing schoolwork, I did not think it was overly difficult to complete the program with a child under the age of two. I made accommodations to deal with his needs, and sacrificed the things I wanted to do to take care of him when I had no other alternatives. The day before his first birthday, Owen broke out in hives in a severe allergic reaction. The next year he was wheezing so badly from allergies that I had to take him to the emergency room for treatment. I was not unfamiliar with hospitals, or seeking medical treatment for my children.

I knew that I wanted to work with college students, but realized after a year into my Master's degree program that I needed a future position that would be more conducive to supporting family life. So I began looking at traditional-style career options in higher education (i.e., those that operated between the hours of 9:00 AM and 5:00 PM). However, when I was working on my culminating Master's project, I realized I enjoyed doing research and wanted to pursue a doctorate. At this point, I had not yet decided that I wanted to be a faculty member.

After my first year as a doctoral student, I took a transition IEP course that made me consider what Nathan's postsecondary education opportunities would be when he graduated from high school. This thought made me want to contribute my knowledge of ASD in real life to the college literature. After completing the transition course, I explored what ASD in the college experience looks like in my qualitative research sequence. Using my qualitative study as a test-run, I decided that I wanted to see how students with ASD transition into college for my dissertation. Once I determined this was an area of interest for me, I sank into it as if it fit me perfectly. Before realizing that ASD in college was an interest, I had a difficult time trying to figure out what my "thing" was. In Fall 2013 I was in the process of preparing for a qualitative dissertation that would include interviewing exiting high school students with ASD or first-year college students with ASD when Nathan started acting unusual.

### **Relationships with Others**

Faculty during my graduate studies, both at the Master's and Doctoral levels, served mostly as teachers because I had not expectation of mentorship or forging a lasting bond. My first graduate assistantship (GA) position was with a new faculty member to

the program, Jim. What was nice about working with Jim during our first year at the College was that he knew I was navigating the process of being a student and a parent. At the same time, he was navigating being a faculty member and a relatively new parent himself. We shared an understanding of what it meant to be a parent and that made it easier to transition to my graduate studies. When I became a doctoral student, I returned to an assistantship position working with Jim. I felt as though he valued my intellect and ability to contribute meaningfully to the research and writing process. It was the first time, post-motherhood, that I felt more than just a mom.

Pam was my first advisor at the College. She understood what it was like as a mom to also be a student and future professional, and although she pushed me to do my best work, she always asked about my family in every conversation we had. When I became a doctoral student, she still kept in touch with me, and provided helpful information about career development strategies, but during my final year in the doctoral program I became her GA and we spent more time getting to know each other.

Sharon was my first graduate assistantship position outside of my degree field. She had a background in middle school students with developmental disability and autism spectrum disorder. We bonded over the fact that Nathan fit the exact type of student she was interested in helping, through preparing future special educators. I shared about Nathan, his IEP, how he reacted to certain situations, and I felt like she knew him before she even met him.

With peers, I was not one to talk about myself in my degree program. I often did not contribute to class discussions for fear of being wrong or misinterpreting the conversation or question. I did not make “friends” with those in my Master’s program, in

the sense that we were friendly at school but did not communicate beyond the school environment. I still relied heavily on my previous relationships with family and friends from high school and my years as an undergraduate. I made little effort to become one with the school environment or culture. I resisted the attachment that others claimed to have with the institution and the program. I was only in school to get my degree and get a job. I chose the College out of pure convenience, in that I lived within driving distance.

At the doctoral level, I began to be a little freer with the idea of making connections with others. But not until my second year as a doctoral student did I really feel as though I had made significant and lasting connections with peers. To me, I had always viewed these connections as fleeting – proving helpful while I was a student but certainly not any kind of relationship that would be long-term. Looking back, I felt as though I was going through the motions in order to be the expert on college students with ASD. I wanted to be known as making a significant contribution in that area. I was not really interested in anything else besides building my resume and being practical about lining up experiences that would put me into a career. Although it was pleasant to have friendly faces in my work environment, those relationships stayed in that environment and did not come home with me at the end of the day. My perspective on my graduate program and pre-trauma schema are important to understand here, before moving to the second layer of analysis which compares my growth process with my theoretical framework.

### **My Posttraumatic Growth Process**

The second layer of analysis in this autoethnography centered on how my process of posttraumatic growth matches the characteristics of the growth process outlined in

Tedeschi and Calhoun's (1995, 2004) Posttraumatic Growth Theory (see Figure 5). In particular, I examine where my experience highlights cognitive processing, social supports and self-disclosure, as well as psychological growth. Figure 6 details how my experiences with trauma and posttraumatic growth fit within Tedeschi and Calhoun's model.

### **Cognitive Processing**

Tedeschi and Calhoun (2004) used the term *cognitive processing* to refer to the internal thinking that occurs as a result of making meaning from trauma. Drawing on Martin and Tesser's (1996) concept of rumination, cognitive processing involves "thinking that (a) is conscious; (b) revolves around an instrumental theme; and (c) occurs without a direct cueing from the environment, but is easily and indirectly cued because it is connected with important goals, leading to recurrent thoughts" (Tedeschi & Calhoun, 2004, p. 9). Though my cognitive processing was most evident in Chapter Six, the dissertation writing process itself was also an act of rumination because I consciously worked through the traumatic experience with the intent of making connections to a larger context.

Cognitive processing occurs in layers, beginning with automatic and intrusive thinking. In an effort to manage emotional distress, individuals involved in processing a traumatic experience disengage from previously held goals most often through the social support provided by others (Tedeschi & Calhoun, 2004). Once an individual has disengaged from previous goals, the process of identifying a new schema and recognizing the role of a new personal narrative characterizes posttraumatic growth.



Figure 5. Model of Posttraumatic Growth

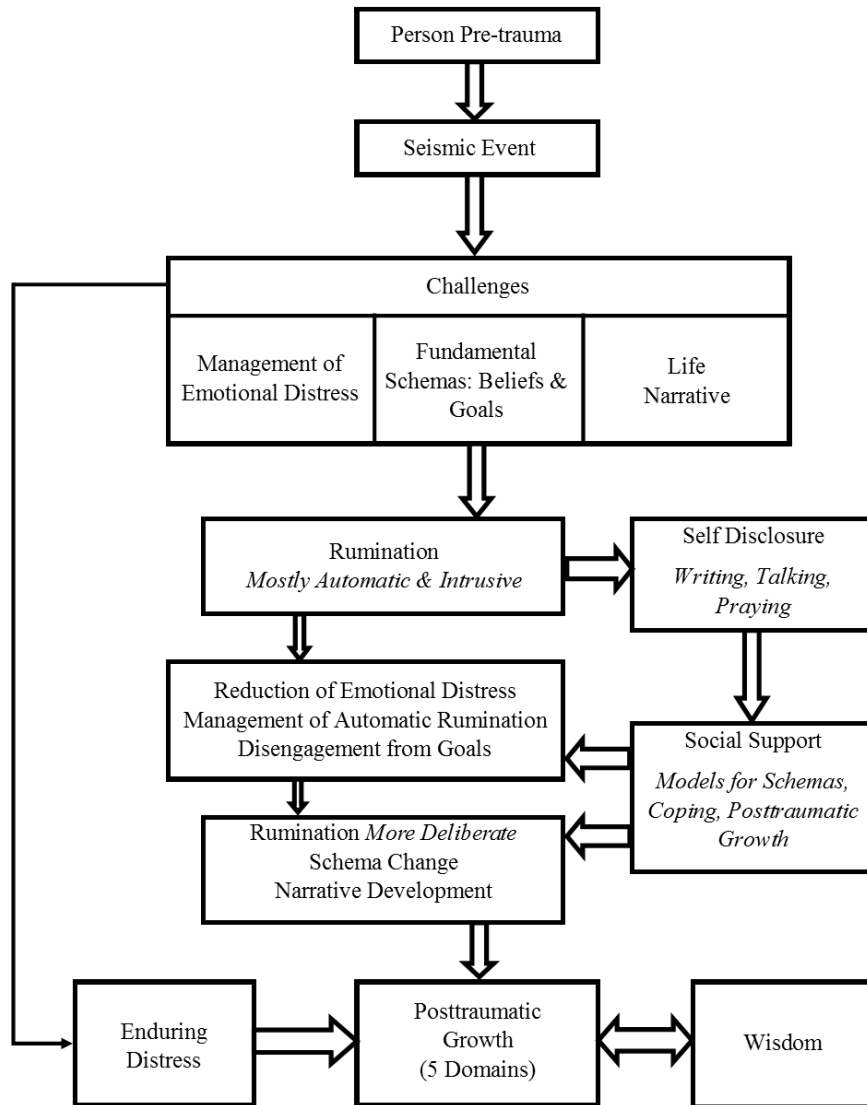


Figure 5. Theoretical model of posttraumatic growth that explains the psychological processes that contribute to growth when an individual experiences trauma (Tedeschi & Calhoun, 2004). From “Posttraumatic Growth: Conceptual Foundations and Empirical Evidence,” by R. G. Tedeschi and L. G. Calhoun, 2004, *Psychological Inquiry*, 15(1), p. 7. Copyright 2004 by Taylor and Francis. Reprinted with permission.

Figure 6. Components of My Posttraumatic Growth

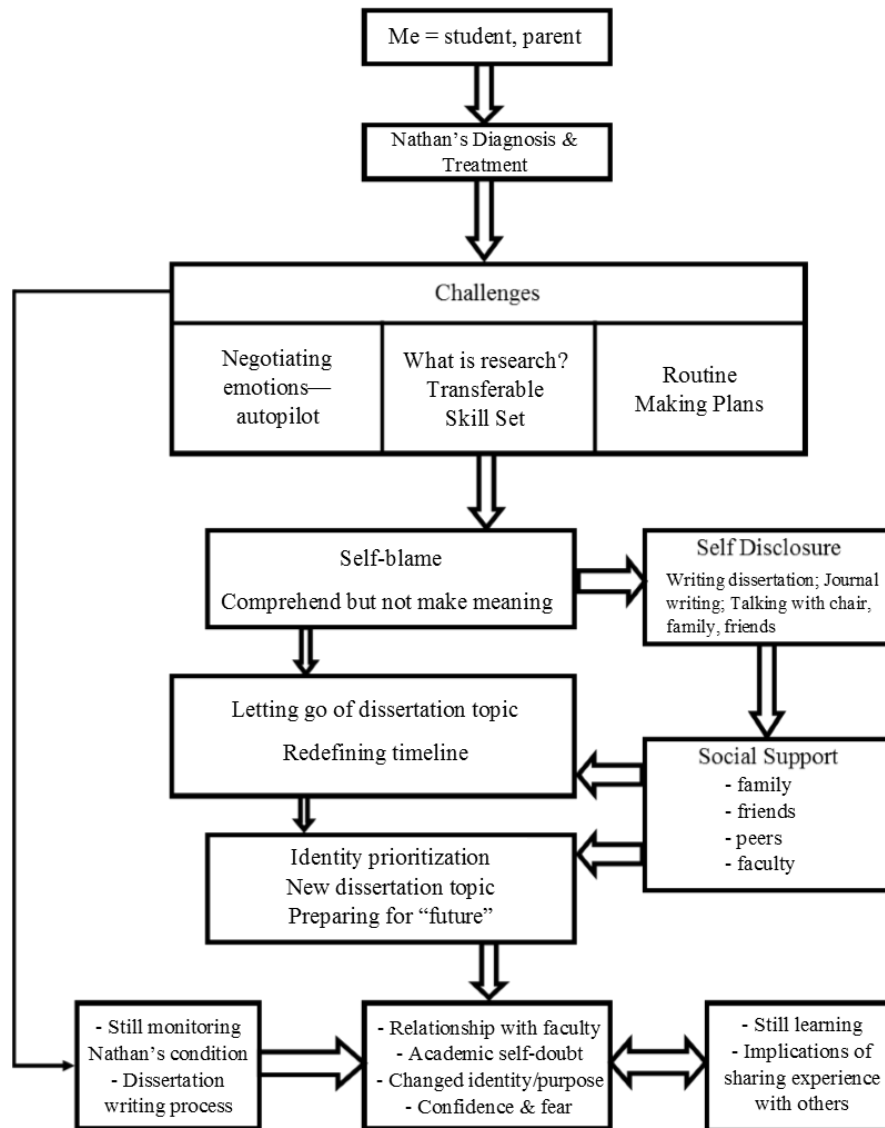


Figure 6. My model of posttraumatic growth compared to the theoretical model presented by Tedeschi and Calhoun (2004). Boxes use my own experiences and meaning making to illustrate how growth occurred. From “Posttraumatic Growth: Conceptual Foundations and Empirical Evidence,” by R. G. Tedeschi and L. G. Calhoun, 2004, *Psychological Inquiry*, 15(1), p. 7. Copyright 2004 by Taylor and Francis. Adapted with permission.

**Automatic and intrusive thinking.** Prior to receiving a diagnosis for Nathan's condition, the process of testing each possible cause of Nathan's symptoms provided a constant source of worry and anxiety for me. Not knowing what was happening to my child allowed me to conjure up the worst case scenarios until I was convinced Nathan's condition, whatever that was, would kill him. Additionally, I experienced moments of feeling like I had missed something as a parent, questioning myself on how I failed to notice the severity of his condition earlier. Tedeschi and Calhoun (2004) found that "initially, trauma survivors typically report intrusive thoughts and images that are highly distressing" (p. 10). In an attempt to stem the flow of these intrusive and distressing thoughts, I relied on the research skills I developed in graduate coursework to read more about the medical symptoms that Nathan was presenting. Similar to cognitive development theories, relying on external sources was my way to comprehend the situation, but not necessarily to draw meaning from the experience (Baxter Magolda, 2009; Perry, 1968). However, Tedeschi and Calhoun (2004) indicated that establishing comprehensibility may be part of the posttraumatic growth process, suggesting a potential developmental application of PTG.

Automatic thinking in my traumatic experience revealed a sense of disbelief paired with a desire to keep things as they were. Although I understood the severity of what doctors were telling me, I still thought I could keep my graduate student lifestyle intact. Immediate decisions were the first step in realizing that I could not continue as such. For example, upon hearing that Nathan had a stage three brain tumor in April, requiring several months of chemotherapy and four to six weeks of radiation, I knew that I would not be able to finish my classes that semester and that I would have to cancel a

long-awaited study abroad trip. By focusing on the logistical requirements of taking care of Nathan, I spent little time and thought on my emotional stability. Although individuals engaged in cognitive processing utilize coping mechanisms to manage emotions (Tedeschi & Calhoun, 2004), I initially did not rely on positive coping mechanisms. Instead, I operated on autopilot, tabling my emotions for a later date because I knew that I would not have time to manage them upfront. This autopilot, or survival mode, allowed me to focus on meeting Nathan's needs for medical care, but neglected my emotional needs when it came to cognitively processing the experience.

**Disengagement from goals.** As I continued to process the traumatic experience, it became clear that there was a distinct delineation between the before trauma time period and the after-trauma time period. The demarcation of time on either side of traumatic experience illustrated the realization that some goals that were attainable before, like finishing my degree, may not be attainable now. The reality of the traumatic experience, including the physical and emotional effort involved in surviving treatment, made the decision to take a leave of absence in July easier than it would have been when I initially received news of Nathan's diagnosis in April 2014. Another goal that was affected by this dichotomy of time included a change in my dissertation topic. Prior to Nathan's cancer diagnosis, I had been developing a dissertation that focused on college students with autism. The psychological impact of potentially losing my child, who happens to have autism, to cancer was so strong that I could not finish that line of research inquiry. I needed to let go of that topic if I wanted to make it through his treatment and post-treatment. When I finally did let my dissertation topic go, I was able to see new possibilities that had surfaced as a result of my experience with Nathan.

My disengagement from concrete goals differed from Tedeschi and Calhoun's (2004) conceptualization of disengagement from goals, which characterized goals as being higher order or fundamental to the individual. Higher order goals, "appear not only to be unattained, but not because of trauma, are unattainable" and are "related to identity and purpose" (Tedeschi & Calhoun, 2004, p. 10). The traumatic experience under examination in this autoethnography did not appear to prompt me to question my higher order goals or schemas beyond that of negotiating and questioning my identity as a mom, as well as a student or future professional and researcher. It may be that my previous experience with trauma, when Nathan was diagnosed with autism, was at an age of emerging adulthood when my identity formation was still in progress (Kegan, 1982, 1994), allowing me to better equip my internal schema to support meaning making for subsequent traumas in the future. Kegan (1994) described personal identity development as a process of challenging assumptive world, in which an individual moves through increasingly complex stages of thinking in order to assimilate new knowledge. Since I was still in the process of assimilating the knowledge of myself as a parent, being exposed to new knowledge (namely, Nathan's autism diagnosis) added complexity to my understanding of myself as a parent. When I established a firm grasp on my identity as a parent of a child with autism, this identity served as my internal meaning-making guide, or schema. Having a schema in place that was familiar was negotiating and managing trauma, helped me to process through Nathan's cancer experience.

**Deliberate processing.** Although Tedeschi and Calhoun (2004) presented deliberate processing and schema changes as a third layer of processing, they also described the overlapping that occurs in disengaging from previous goals while also

“building new schemas, goals, and meanings” (p. 9). An overlap in these two processes better categorizes my experience, particularly in negotiating my dissertation topic. As previously noted, I needed to disengage from my previous topic in order to support my emotional needs. As a result, I explored the significance of this traumatic experience in the context of my graduate studies. I deliberately spent time thinking about how my experiences with Nathan impacted my graduate student experience and what faculty and other students might be able to learn by sharing my story. I also made conscious efforts to read about a methodology that would allow me to study my own experience.

Deliberate cognitive processing is crucial to growth outcomes because it allows individuals space to determine meaning behind experiences, as well as opportunities to re-define internal schemas. Even though deliberate processing plays a vital role in posttraumatic growth, there is debate about the form this processing can take. Ullrich and Lutgendorf (2002) found that college students who journaled about emotional aspects of trauma showed evidence of growth. For me, the journaling process was important not only to capture events as they were occurring, but also to capture cognitive processing that I did not share verbally with my family, peers, or faculty advisors. Journaling provided a private space to examine my inner thoughts and to put words to how I felt or processed a given aspect of the larger experience. Additionally, my faculty advisor encouraged me to keep a journal as I refined my thinking about dissertation topics. Having both encouragement, as well as specific instruction, to engage in journal writing was important for me to actually sustain the effort.

*Cognitive schema change.* With regard to schema changes, it is unclear, even now, the extent to which my schema truly changed. Certainly, I prioritize my family time

even more now than I did before Nathan's diagnosis. I would even say that I value my family role more than that of being a future professional. However, I do credit my pre-existing research skills in being able to find more information on Nathan's condition and make informed decisions. For example, prior to trauma I used to think that the research skills I was learning in my coursework would atrophy if I did not use it for educational research. During trauma, I was thankful that I had access to research through the institution's library, and that I was able to read and understand medical articles that were beyond my field of knowledge. After trauma, I realized that research skills are transferrable and that I use them fluidly regardless of the field or discipline in which I am working.

The most identifiable change for me is my perspective on my future career path. I better recognize that while I want to be recognized for my importance beyond my family, I also do not wish to compromise what is important to me in order to be successful. To illustrate, I used to think that I was working towards a career to better support my family and find something beyond my family life of which I could be proud. During Nathan's diagnosis and treatment, I could not think of anything else except for caring for my family; school and future careers were no longer foremost in my mind or priorities. After processing the experience of Nathan's treatment, I realized that I needed both family and vocation, and that sought a career that would allow for flexibility and room for both.

I have also changed in the way I think about death. Before Nathan was diagnosed, I was terrified that something would happen to one of my children and could not comprehend what that would mean to me. During Nathan's treatment, I approached his treatment plan and prognosis from a realistic standpoint, leaving emotion out of my

thinking as much as possible. There was a chance that his treatment would not be successful, but there was also a chance that he could have a complete response and be cancer-free. After the experience with Nathan's diagnosis and treatment, I think that, although I would still be impacted emotionally by Nathan's death, I am prepared mentally for such an event in a way that I would not have been prepared for prior to this experience.

### **Social Supports and Self-Disclosure**

The cognitive processing of my experience was supported through interaction with family, peers, and faculty who, in most cases, provided opportunities for self-disclosure, even if I did not take advantage of each opportunity. Because of the extended length of time over which this traumatic experience occurred, the most supportive individuals were those that "remain[ed] stable and consistent over time" (Tedeschi & Calhoun, 2004, p. 11). Over the course of my experience, I relied on a variety of supports; however, some of the most important supports were individuals *outside* of higher education. In fact, while higher education supports were certainly not the sole source of support, they were also not the most utilized source of support, particularly from an emotional perspective. Although faculty and peers, as a whole, were not the primary source of support in processing my experience, there were key individuals, such as my advisor, Jim, who made frequent attempts to check-in with me during and after Nathan's diagnosis and treatment.

For me, social supports offered a means of escape, space to process, and a reluctant acceptance that school was not my first priority. Supports included my family and friends, my peers from my program, and my program faculty. Identifying my



network of support, although not directly related to the higher education environment, is important in understanding how I processed my traumatic experience. Tedeschi and Calhoun (2004) suggested that,

the individual's social system may also play an important role in the general process of growth, particularly through the provision of new schemas related to growth, and the empathetic acceptance of disclosures about the traumatic event and about growth related themes. (p. 12)

My friends and family were present for me to have meaningful conversations about Nathan's progress and implications of his diagnosis. Their support allowed me to express my thoughts and emotions when I was at my most vulnerable in processing the experience.

Similarly, peers reached out to provide support, even if I did not always take advantage of the opportunity to disclose my inner feelings about the circumstances. For example, when classmates Tehmina and Montse came to my house and specifically asked about Nathan, I tried to dodge the questions by giving as little information as possible in an effort to protect myself. Other peers offered support in more tangible ways such as offering to provide dinner on a night when Nathan and I had spent an entire day at the hospital. There were also peers who did not reach out to offer support when I thought that they would.

Many of my faculty supported the idea of coming back when I was ready. They offered to make the transition in and out of school very easy by giving me the option to take incompletes in my coursework (essentially pausing my courses so that I could finish them later instead of failing those courses outright) and by pointing me to resources that

would allow me to take time off from the program. However, similar to the idea of providing challenge and support for student development (Sanford, 1962), I wanted there to be a corresponding push from my faculty that was similar to the way in which my family and peers challenged me by asking, “when will you finish?” By not challenging me to consider when I would continue classes, they left me to decide on my own, where I felt less secure about my ability to come back to school and be successful.

What has proved to be different in my experience compared with Tedeschi and Calhoun’s (2004) posttraumatic growth theory was my reticence toward self-disclosure. In writing this autoethnography, I now realize that I have disclosed more in written form than I did, either verbally or written, during the entire time I was involved in and processing the experience. Although it helped to have the option to disclose how I was trying to understand the new me in the aftermath of trauma, I was disinclined to participate in that self-disclosure. I also felt a fear of judgment or rejection from my peers and faculty influencing my decision to disclose how I was processing the experience that was not present among my intimate friends and family. However, there were also parts of my experience that I did not share with those intimate friends and family because I wanted to spare them the pain associated with my cognitive processing.

As a tool, I found personal writing to be the most effective way to balance my conflicting concerns about shielding others from additional pain, while also overcoming the potential for rejection or judgment from my peers or faculty. In contrast, public writing, in the form of the dissertation, was a way to digest my experience for larger truth and meaning. I found that I was more critical of my experience and the ways in which I represented it in the dissertation, whereas my journal writing would leave parts of the

experience unwritten because it was assumed that I *knew* the experience and did not need to put words to it.

### **Domains of Growth**

The five psychological domains of growth theorized to be indicative of posttraumatic growth include: (a) an appreciation of life and change in priorities; (b) more intimate relationships with others; (c) a greater sense of personal strength; (d) recognition of new possibilities; and (e) spiritual development (Tedeschi & Calhoun, 2004). I focused on where my experience fit and did not fit within these domains, with specific emphasis on where these growth domains were present in relation to my graduate student experience. However, it was important to also identify the ways in which these domains of growth were reflective of my personal growth because these areas of growth have implications for how I engaged with the graduate environment in the aftermath of my traumatic experience. Next, I use examples from my experience to detail the ways in which each of these domains resulted from the processing of my trauma.

**Appreciation of life and change in priorities.** Making sense of this traumatic experience has changed my perspective on what is important. Watching my family go through this trauma made me realize that my role as “mom” is a vital part of my personal identity. Moreover, I am confident that I know who *mom* is. Knowing that my identity as a mother is of utmost importance in my life allowed me to reprioritize other roles and responsibilities without feeling guilty that I left something behind. Although letting go of my connection to graduate study, even in the short-term, was difficult, when I embraced the new knowledge that I was doing what I was supposed to do by focusing solely on Nathan, I felt more confident in myself. This confidence transferred to my graduate

studies when I returned to my program in that I was assertive, but not without apprehension, that I needed to change my dissertation topic to something more meaningful to me. I did not have to use my dissertation to launch my career as some faculty had suggested. I could make it both personally meaningful and academically relevant.

In contrast to my newfound appreciation for my identity as a mother, a changed sense of priorities also coincided with a fear of what can happen in the future. Appreciating life, then, also corresponded to a recognition that life has an end. Although my experience was influential in helping me to re-prioritize my life around my identity as a mother, it also made me realize that I needed to prepare for future traumas by being present for Nathan as much as possible while I still can. In order to do that, I reflected that my future career work could overtake my personal priorities. I realized that making time for my family was important and that I needed to work towards a professional career that would respect that decision.

**More intimate relationships with others.** A significant challenge in developing deeper relationships with those not in my family was a perceived lack of connection to my experience. Survivors of trauma “generally want company at least some points in the aftermath of their trauma, as long as the company is someone who is seen as really being able to understand. Otherwise they would rather be left alone” (Calhoun & Tedeschi, 1999, p. 93). In my experience, it was difficult to forge deeper, more meaningful relationships with individuals who could not, or made no effort to, understand my experience, regardless of whether they were faculty, peers, family, or friends.

However, there were specific faculty members, such as my graduate assistant supervisors, who made significant efforts to accept my experience, my reactions to it, and to share their perspectives as they related to both the traumatic experience and my persistence in my graduate program. By asking me for information during the experience and, in the case of my dissertation chair, reading my personal disclosures about processing the experience, “the emotional aspects of the events and the survivor [were] revealed, resulting in an intimacy that may be surprising” (Tedeschi & Calhoun, 2004, p. 9). Offering a “nonjudgmental attitude” about my decisions and the changes I made in the aftermath of the experience, faculty members like Jim, Pam, and Sharon, also provided indirect support for the ways in which I was processing the experience (Calhoun & Tedeschi, 1999, p. 97). Such faculty relationships are characteristic of the *good company* required to move from externally defined schema to more internally defined schema (Baxter Magolda, 2002, 2009). Knowing more about my experience potentially forged stronger relationships between me and these faculty members, ultimately providing a higher degree of support for my cognitive processing.

Other relationships that were impacted by this experience included those relationships with family members, friends, and peers. However, unlike faculty members who needed to be intentional about personally investing in creating deeper relationships with me, many of my non-academic relationships (such as those with family members) were pre-existing, meaningful relationships. Where these relationships were impacted the most by this experience, when not actively involved in the experience itself, was when I asked these individuals who read about the experience as I had written it in Chapter Four, Five, and Six. As they read about the experience through my perspective, many relived

the experience and remembered how they felt during the trauma. Although these relationships were already intimate and strong, seeing that I was processing the experience in similar ways strengthened existing relationships. In some cases, such as with my parents, viewing how I processed the experience was affirming for how they also processed and still think about the experience with Nathan's treatment and his opportunities for a healthy future.

**Greater sense of personal strength.** The writing of this narrative came from a place of personal strength. But, I realized that in order to work on things that are personally meaningful, I have to achieve them for myself. Choosing autoethnography as my methodology was discouraged by a number of faculty, but I invested the effort to justify its use in this dissertation, with the support of my advisor. Because I recognized the value in exploring my personal trauma, I had a "greater respect for [my] own instincts and [was] able to trust them and act on them" accordingly (Calhoun & Tedeschi, 1999, p. 77). Additionally, I realized the importance of sharing this story with others. Although my private journal writing was helpful to my personal meaning making, the public process of disclosing my experience in this dissertation created an opportunity for me to reflect on how others could benefit from my story. Calhoun and Tedeschi (1999) suggested that "survivors also learn what has been helpful for them, what to do and what not to do for others. Therefore, they may relate differently to others than they have in the past" (p. 93). When I encountered other students who were experiencing similar traumas, I was able to share my experience with them because we could each understand what the other had been through.

By contrast, I experienced a definite degree of self-doubt in my ability to be successful in my graduate program. For me, this doubt involved the difficulty in seeing myself as a researcher again after fully identifying as a mother and caretaker. What I did not realize during my experience was that I was still a researcher, developing my research and writing skills while I was engaged in the traumatic experience. I did not fully let go of my researcher identity because I looked up medical journals and digested them for a better understanding of Nathan's condition. But, I needed to make a shift in my identity roles to see myself as both a mother *and* a researcher in order to be successful in coming back to my graduate program. The lack of control and fear of the unknown contributed to this lack of faith in my school-related abilities.

From a personal perspective, I gained a sense of strength in my emotional control and in my ability to do things I did not think I could do. For example, I never wanted to go into a medical career because I could not see myself using needles. But I was able to give Nathan insulin daily. I was able to push back my insecurities and fears in order to be the best advocate and caregiver for my child when it was imperative that I do so. I also demonstrated an unwillingness to accept depression as a potential reaction to Nathan's diagnosis and treatment. For the most part, I was able to set aside my fears and emotions regarding Nathan's condition and be conscientious of his needs. For me, this was a realization that Nathan had no one else to rely on to communicate his wants, needs, or how he was feeling. Nathan was experiencing trauma with no way of letting others know what and how he was thinking or feeling. I had to be that translator for him, and therefore had to set aside my desires for his benefit.

**Recognition of new possibilities.** The possibilities that arose from this trauma, with regard to my graduate student experience, centered on the redesign of my dissertation. In letting go of my initial dissertation topic, I was able to explore the opportunity to try a new methodology in which I could share an experience that is seldom, if ever, discussed in higher education. Although I “let go” of my previous dissertation topic, I did not abandon its importance or the opportunity to pursue it in the future. Instead, it was important for me to recognize my personal need to digest the whole of my experience and give other graduate students and faculty insight into the impact traumatic experience can have for a graduate student.

Although I never had a desire or intention to pursue a medical career, the identification by medical professionals that I could be one of them was enough to at least consider a potential career if I chose to leave education. I recognized that I have many of the same personality characteristics as nursing staff, namely compassion for and patience with others. Having the anesthesiologist point to my ability to know detailed information about Nathan’s medications and to recall vital information about Nathan’s condition was a satisfying compliment beyond being seen as just a “good mom.”

Though the recognition that of new possibilities was generally positive, it was also paired with a fear of new possibilities. As illustrated in Chapter Six, I frequently questioned why things could not go back to “normal.” The difficulty in such questions, for me, was wondering what “normal” looked like before the trauma and wondering whether the new normal fully replaced the previous version.

**Spiritual development.** There was little to no direct connection to my graduate experience in the domain of spiritual development. Raised in the Catholic faith, I was an



active participant in the Church growing up, and explored an academic study of theology while pursuing my undergraduate degree. I had even taught religious education and confirmation courses for adolescents. My religious and spiritual knowledge has always been deeply personal and important to me and who I am. As a result, and throughout my traumatic experience, my faith in God never wavered, but it also did not play a large part in my growth process. I had already questioned “why?” when Nathan was diagnosed with autism. I relied on prayer in moments where I felt helpless to care for Nathan, specifically when he was in tremendous pain and there was nothing I could do to help him. While I did not question my faith, I also did not pray for a miracle. I did not believe, unlike some family members, that Nathan would or could be healed through a prayer. Instead, I prayed that if it was God’s will to take Nathan, that He not let Nathan suffer and to give me the strength to survive his loss.

However, while I may not have developed in a religious or spiritual manner, there was evidence of development in reference to existential matters. For example, in realigning my priorities with my most important identity as a mom, I experienced an “increased sense of purpose and meaning” (Calhoun & Tedeschi, 1999, p. 121). Additionally, I thought about death, both in the context of Nathan’s treatment, as well as in the aftermath of the experience when my friend was coping with her own family loss. I did not question death as a life stage, but I examined my reactions and feelings toward death so as to better understand the need to cherish every day that I have with Nathan, as well as with the rest of my family.

## **Enduring Distress**

The Posttraumatic Growth Theory (Tedeschi & Calhoun, 2004) suggested that it is not necessary for the trauma to have ended in order to grow from an experience. This enduring trauma or distress is reflected in the written expression of my experience; however, the extent of my enduring distress seemed to emanate from the lack of control I had throughout the trauma. Additionally, the closer to dissertation writing and a defense date I get, the less in control I feel because there are more elements (e.g., scheduling defense meetings and waiting for IRB approval) that I cannot control beyond those in my personal life. Even as I began writing the dissertation, Nathan was still having MRIs, and medical concerns crept up that were distracting and upsetting. For example, needing to address Nathan's leg pain by pursuing physical therapy was an additional moment of distress that I had not anticipated. Because there was continual exposure to experiences that connected back to the initial trauma, I would intentionally push back writing on my dissertation.

When I wrote Chapter Five, reliving those experiences was enough to make me physically ill, and I had to stop writing for a few days so that I could "return to normal." For me, the process of disclosing and reliving the trauma was "an extension of the trauma experience" (Calhoun & Tedeschi, 1999, p. 96). Although reliving the trauma did not result in the same emotional explosion that I experienced when going through Nathan's treatment, the original traumatic experience was not one I was ready or willing to forget. Tedeschi and Calhoun (2004) explained this extended period of cognitive processing:

Many people who survive traumatic events report that many months later they can still be stuck by a sense of disbelief. To an extent, this process many involve

“grief-work” in the sense that the loss involved in the trauma is gradually accepted. This often lengthy process during which distress persists may actually be important for the maximum degree of posttraumatic growth to occur. This distress keeps the cognitive processing active, whereas a rapid resolution is probably an indication that the assumptive world was not severely tested, and could accommodate the traumatic events. (p. 8)

In processing my experience, this ongoing distress is what allows me to continually refine my newly determined internal schema even though it is also responsible for emotional reactions that may not be reflective of posttraumatic growth.

### **Addressing My Research Questions**

My overarching research question for this autoethnography was: *how did the traumatic experience of my son’s diagnosis and subsequent care affect my personal life narrative, particularly as related to my graduate student experience?* This chapter has illustrated the connections between trauma and my graduate student experience. To further analyze this overarching question, I addressed the three sub-questions to the overall findings of this study.

#### **RQ1: How did the psychological impact of trauma affect my graduate student experience?**

In response to my first research question, I found that trauma produced a feeling of self-doubt that made the completion of my degree program difficult. The trauma of Nathan’s diagnosis and treatment forced me to reconsider my dissertation and research topics surrounding students with autism because I was unsure I could appropriately handle the personal bias inherent in such a topic. Finally, this traumatic experience made

me realize that I could not be in two places at once. Recognizing that I was needed, first and foremost, to care for Nathan, I had to take a leave of absence from my academic program, inevitably pushing back my pre-determined timeline for graduating.

**RQ2: How did my traumatic experience affect my assumptions about reality, in relation to the graduate student experience?**

Prior to Nathan's cancer diagnosis, I assumed that a dissertation was supposed to be a launching point for my academic career. It was supposed to be the seminal work that identified my research agenda and allow me to be a leading scholar in the field. There was also an assumption that dissertation research had to be free from personal bias in order to be valuable. In the midst of receiving Nathan's diagnosis, my dad told me, "it's too bad you can't use this for your dissertation." I agreed with him at the time because he was right. But the more time I spent involved in trauma, the more I realized that there was a place to study trauma in higher education. I also found books on autoethnography that showed me how writing about the self can also be valuable *research*, which challenged my assumptions about what research really means.

A second assumption was thinking that any setback in my graduate education would be traumatic. However, after processing and reflecting on the experiences I detailed in Chapters Four through Six, I did not see the leave of absence and associated academic delay as "trauma" in the same sense. I also did not find it particularly traumatic to let my previous dissertation topic go. Those pieces of the experience are byproducts of the traumatic experience itself, meaning that my assumptions about what constitutes trauma changed when I restructured my priorities to be "mom" first. Everything else no longer seemed as important.

**RQ3: Within my graduate program, where and in what form, was social support present during the cognitive processing of my traumatic experience?**

There were three primary social supports present during the processing of this trauma: faculty, family, and peers. Faculty support primarily centered on logistical and programmatic support. Without my faculty, I would not have known how to take a leave of absence or how to negotiate the extension of my coursework. My advisor also encouraged me to engage in journal writing. Whether he realized how much the journal writing would aid in my growth process is unknown. My family, especially my husband, was immeasurably supportive. Family members knew me so intimately that I could share the experience and how I was feeling with them. They were instrumental in providing emotional support in a way that was not offered by either faculty or peers. Finally, those peers within my program who *did* reach out during my trauma offered opportunities to talk about my experiences even though I did not take full advantage of the opportunity. This may have been due to the fact that I felt less certain they knew me as well as my family and personal friends did.

**Wisdom from Trauma**

The growth process, as conceptualized by Tedeschi and Calhoun (2004), ends with the wisdom one has gained from processing a traumatic experience and developing a new life narrative. However, I do not conceive of the growth process as having an end. For example, even as I engaged in the process of writing this dissertation, I discovered new insights for how I might make continued meaning from my traumatic experience. This continuation of making meaning ultimately develops into a new concept of self that is better prepared to address a subsequent trauma. This implies that the posttraumatic

growth process is more of a loop than a linear process because the new individual who emerges from processing a trauma will be the next pre-trauma self that experiences a future traumatic experience. The process of gaining wisdom from trauma, then, is ever-evolving as an individual refines the personal narrative to reflect new meaning and learning resulting from each subsequent trauma.

There is much to be learned from seeing the personal evolution that occurs in posttraumatic growth. For me, this experience has not been bound by my educational experience. Instead, I conceptualize my educational role as embedded within the traumatic experience. Realizing that there has been a priority shift between my personal and academic identity leads me to consider how my experience might be useful for other students who may experience trauma while enrolled in their graduate programs. There is also much to be learned about the ways faculty can provide appropriate support and facilitate the student disclosure of trauma.

In the next chapter, I will focus on the wisdom that I have gained from both my traumatic experience and as a result of writing this dissertation. I will detail implications for graduate programs and the importance of storytelling as it relates to valuing the traumatic experiences of students. Chapter Eight will conclude with my wisdom for faculty and graduate students who are experience trauma as well as my own personal wisdom gained from this experience.

## CHAPTER EIGHT

### SHARING WISDOM

As I continue to deliberately examine elements of my experience, I continue to grow and make new meaning about my experience. The analysis of my experience showed me that while I can draw conclusions about the growth I have experienced as a result of trauma, my personal meaning making from the trauma is ever-present and ongoing. This enduring examination adds to the life narrative I have sketched while creating my new internal schema that erase or permanently inscribe parts of my narrative as I process them.

The continued development of the personal life narrative is reflected in Tedeschi and Calhoun's (2004) Posttraumatic Growth Theory, which suggests that "as individuals experience posttraumatic growth, these changes have an ongoing, mutual influence with the development of general wisdom about life and further development of the general framework, the narrative, people have for thinking about their lives" (p. 12). To demonstrate my continued meaning making, in this chapter I draw upon my lived experience to highlight the implications of the posttraumatic growth process in graduate education. This chapter concludes by sharing the *wisdom*, to use Tedeschi and Calhoun's term, I have gained as a result of both my traumatic experience and the process of writing this autoethnography.

### **Implications for Posttraumatic Growth Processes**

For the most part, my experience with trauma and the subsequent growth process aligns with Posttraumatic Growth Theory (Tedeschi & Calhoun, 1995, 2004). My experience diverged from PTG theory in two areas: (a) conceptualization of goals and (b) growth in spiritual development. This divergence may be attributable to my pre-exposure to trauma, including experiences such as having a child while still an undergraduate or having a child diagnosed with autism. The trauma of having an unplanned child at 19 may have allowed me to disengage from higher order goals early on in my life narrative. For example, becoming a parent so young meant not having some of the typical experiences a college student would expect to have during her 20s like internships or an opportunity to study abroad. Now that I have experienced additional trauma, my schema are more fluid to accommodate future traumas. That is, my life goals are not as severely impacted because I had developed schema over ten years ago that allowed me to adjust to new traumatic experiences.

Individuals who have yet to examine or question the depth of their faith or spirituality may indeed show growth in the spiritual development domain as theorized. However, for those who have had pre-exposure to trauma or have already had reason to question their beliefs, the domain of spiritual development may exhibit less growth than other domains of growth. For example, the preexisting trauma of finding out about Nathan's autism made me question whether God was punishing me for having a child outside of marriage. When I was processing the current experience with Nathan's brain tumor, I had already examined the spiritual questions associated with trauma in an effort to better understand my experience and make meaning from it, and I understood that



Nathan's cancer was not a punishment. I also did not have to wonder how God could let something like cancer happen. Instead, I examined existential questions without blaming God and without making accusations of intentional suffering.

It is my assertion that pre-exposure to trauma played a significant role in my ability to grow from the current trauma. In my experience, pre-exposure to trauma, characterized as both unplanned parenthood and Nathan's diagnosis of autism, gave me access to coping mechanisms that I might not have had otherwise. Additionally, my previous traumatic experiences provided a stronger foundation from which to build subsequent schemas. However, other students may not have been exposed to traumatic experience in the past. In this case, students would be experiencing trauma first-hand without available coping models, which could prove more challenging or take longer for the student to progress through the growth process (if that student even moves in the direction of growth). It is also likely that without support, including coping and schema models, and opportunities for self-disclosure, a student may not be able to grow from trauma, increasing the potential of developing a psychiatric disorder (Tedeschi & Calhoun, 1995).

It is also important to examine *what* experiences a trauma includes. Throughout the writing of this autoethnography, my peers and my dissertation chair challenged me on whether certain program-related experiences, such as defending my dissertation proposal or choosing a different dissertation topic, were also traumatic. After reflecting on the experience as a whole, the definition of trauma, and my personal processing of these experiences, I found that others may see parts of my story as traumatic, where I did not find them to be. This has implications for the personal nature of trauma, for example

assuming that a student might find a dissertation proposal defense traumatic may not be accurate. It is important to recognize that how the individual defines trauma may not be the same way others might define or view trauma.

Variety in definition or conceptualization may prove challenging for others, such as faculty or other students, who seek to provide support based on their own conceptualization of trauma. This means that in working with students, faculty need to be aware that students may or may not find certain experiences traumatic. Student peers and faculty also should not make a similar assumption that a personal life experience is or is not traumatic. Tedeschi and Calhoun's definition of trauma can include events that are sudden or unexpected (McCann & Pearlman, 1990; Weiss & Parkes, 1983); uncontrollable or perceived as such (Slaby, 1989; Tennen & Affleck, 1990); lacking familiarity or are out of the ordinary (McCann & Pearlman, 1990; Tedeschi & Calhoun, 1995); irreversible or chronic (Davidson et al., 1986; Tedeschi & Calhoun, 1995); and, responsible for producing a sense of blame (Tedeschi & Calhoun, 1995). Even though my experience is characteristic of this definition, the range of experiences that may fit within these categories can be particular to the individual.

### **Implications for Graduate Programs**

Understanding the graduate student perspective of trauma is important for faculty and institutions of higher education because graduate students are typically older than traditionally-aged, 18-22 year-old undergraduate students and are more likely to experience events that characterize adult life (e.g., family or parental death, childbirth, marriage, divorce, job responsibilities). Providing support only geared toward career success, in the case of graduate student mentoring, may be limited, leaving out

opportunities to address complex adult developmental needs that include a redefinition of self, internal schemas, or meaning making. Understanding trauma as a possible influencer in student success requires acknowledging the impact trauma has on the psychosocial processes of students. When students are left to navigate those processes by themselves, the potential for growth, and ultimately degree attainment, decreases.

The personal examination and reflection I have undertaken in this autoethnography provide evidence to suggest that PTG is indicative of a developmental process. PTG aligns with many of the features of personal development (Kegan, 1994) and self-authorship (Baxter Magolda, 2008, 2009) theories but allows specific experiences (trauma) to be examined. This may be of particular utility for graduate students who may have reached adulthood or a higher stage of identity development prior to experiencing trauma. PTG gives insight into the processes that adults have to navigate in order to reformulate their internal foundations that may have shifted as a result of trauma. Because student identity may shift as a result of trauma, graduate programs must be able to address the varied needs of students at a given point in their program of study.

The changing internal schemas of students who experience growth following trauma also has important implications for the *learning partnership* that characterizes many graduate mentoring relationships (Baxter Magolda & King, 2004). Students who have experienced trauma may have less confidence in their previously defined strengths and more concern about their weaknesses—as well as a diminishing internal motivation or sense of initiative following a traumatic experience. If this is the case, as was in my experience, then assumptions of graduate student performance and engagement may not be reflected by students post-trauma. As a result, faculty must also redefine their

assumptions and expectations of students in the aftermath of trauma to reflect this change in student motivation and self-awareness.

Higher education as an environment does not respond well to change—neither in its structure nor its students. Faculty, and students who may encounter trauma, need to be flexible with their expectations because trauma and distress caused by prolonged engagement with trauma can take more time than expected. Anticipating a “quick” recovery may gloss over a great need to process an experience, leading to an overwhelming resurgence of repressed emotions and cognitive thoughts when least expected.

Faculty may assume that posttraumatic growth has positive implications only. However, Tedeschi and Calhoun (2004) explained:

Posttraumatic growth is not the same as an increase in well-being or a decrease in distress. In addition, the impetus for growth is the individual’s struggle with a highly distressing set of circumstances that significantly challenges people’s understanding of the world and their place in it. The maintenance of growth may also require periodic cognitive and emotional reminders that are not pleasant, of what has been lost, but paradoxically, also of what has been gained. (p. 13)

Although a traumatic experience may be complete, the paradoxical elements of growth and loss occur simultaneously, creating a feeling of uncertainty with one’s newly formed narrative. This uncertainty can bleed over to academic performance or influence the graduate student experience in a way that may cause additional distress for the student. Recognizing the changing needs of graduate students who experience trauma can better serve faculty and graduate programs seeking to retain students. Programs and faculty

members that cultivate opportunities for student growth following trauma may find that students are better able to persist toward degree completion.

### **Implications for Institutional Policy**

Existing *and* non-existent policies in higher education can create barriers for students who experience trauma. For institutions to best support these students, making adjustments to institutional policies may be necessary. Based on my experiences, I make three recommendations for institutional policy. First, there needs to be increased and *clear* communication with students about how to take a medical leave of absence (MLA), the implications for student services, and the procedures for reinstatement as an enrolled student. Second, institutions should work toward better coordination and communication between departments that play a role in student service delivery or have authority to grant MLA. And third, institutions should work to establish alignment between student status and services provided to those students on MLA.

### **Increasing Communication with Students**

Higher education institutions should communicate policies that clearly outline student options in the event of traumatic experience, such as requesting MLA, affected services, and the process of re-enrolling as a student. Although administrators may not be able to anticipate a student's need for MLA, the option to do so should be presented and made available for students. Additionally, clear policies about what will happen when a student's request for an MLA is approved and guidelines for reinstating as an active student are necessary details that would better prepare students for what to expect if considering an MLA.

**Medical leave of absence process.** Within my experience, a policy existed that allowed me to request an MLA; however, the form to request MLA was not readily available to a student who did not know of its existence. In my case, a faculty member mentioned that I consider filing the form, but I had no prior knowledge of the form or what was required to complete it. The policy that would grant such a leave required a 30-day advance notice prior to the requested start date. Although I had time to gather the required materials, this advance notice caused me to wonder whether a sudden medical problem, like a car accident or unexpected death, would also require 30-day advanced notice. Having a blanket requirement for everyone does not adequately meet the needs that a traumatic experience might present, for students or faculty.

Additionally, the process of filing an MLA form seemed to be an unnecessary and invasive breach of my privacy. It required that I disclose why I needed to take a leave from the program in order to certify that my reason for leaving was justified. I had to include a note from Nathan's doctor to corroborate his diagnosis and treatment. Providing extensive personal information about what was going on in my family, without any reciprocal support services from the institution, made me feel as though the institution did not trust me enough to take a medical leave for a medical reason. Instead, I had to prove that I did, in fact, have a medical reason for taking a leave from the program. This form of disclosure is antithetical to the self-disclosure supporting posttraumatic growth.

**Services affected by MLA.** Although the MLA process was straightforward, there should have been additional information about what to expect once the leave had been approved. Institutions should be candid about any student services that are removed during the leave period and should offer opportunities for students to request that those

services remain intact. In my experience, the student services that were affected were my library access, specifically the use of online journal databases off-campus; Blackboard (our Learning Management System) access; my college-housed storage drive; and my College ID card, which I needed in order to use library services and childcare services (where my four-year-old Owen was in pre-school at the time).

One of the most inconvenient results of taking a MLA was that I lost off-campus access to the College's library. This meant that I had to physically be on-campus in order to utilize any journal databases. Losing the convenience of accessing the library from home or the hospital made it difficult to work on my incomplete coursework from the Spring semester. It also made it hard to fall back on my research training to make sense of the diagnosis and treatment because I could not search for the latest information or research from the medical community.

Even though I was not required to work on my incomplete work during my medical leave, it provided a much needed distraction at difficult times. Unfortunately, not having access to materials made that process a lot harder. Additionally, when treatment was over, I still had to come to campus in order to begin work again. I was still on leave, but I was actively working on course work, requiring access to library databases that I could only access from on-campus. This meant I had to drive to campus, be around other students and faculty, maybe before I was really ready, in order to gain access to important course information.

**Reinstatement as student.** A third area where more communication from the institution would have been helpful is the expectations for re-enrollment. For example, my leave period was approved until the following Fall semester (2015); however, I

needed to register for courses in the Spring semester that preceded the end of my leave. There was not written policy that stated the procedures for officially ending my leave of absence, nor was there any indication that I would need to file more paperwork with the College.

When I was finally ready to resume coursework and begin my final classes, I could not sign up for classes. Instead, I was told that I had to re-apply to the program so that I could register for classes. I should have been notified prior to the course registration date that I would need to re-apply in order to register for classes. Since I did not know, I felt blindsided by having to complete more paperwork to certify that I was still a student. The ending of a leave of absence in this case, did not coincide with the timeline to register for classes, and the process to officially end my leave was never communicated. Having an official correspondence or policy that outlines these procedures would have been extremely helpful both during the reinstatement process and when I initially requested the leave.

### **Departmental Coordination**

Better coordination among departments across an institution can improve leave and service extension processes, ultimately providing support for students experiencing trauma. Different departments play a role in the MLA process with no clear indication of which department has primary ownership over coordinating a student's leave and service provision. In my experience, each department seemed to have its own forms and procedures. Institutions should designate a single department to oversee students with MLA. There seemed to be mixed signals, in my experience, over which department had the discretion to terminate or reinstate my student services. For example, I filed my MLA



with the School of Education, submitted a petition for extended services with the Dean of Students Office, and negotiated reimbursements from both the bursar and study abroad offices. Alternatively, institutions could streamline the MLA process by informing students of the procedure upfront, as previously suggested. Part this streamlining process would require determining which department will take primary responsibility for the MLA and related processes.

This lack of coordination between departments was most evident in role played by the Dean of Students Office, which tried to terminate my remaining student services three months into my leave period, in the middle of Nathan's radiation treatment. The College notified me that, due to my alumna status, it would be terminating my access to student services that included Blackboard access and ID card access. When I initially called the Dean of Students Office, I had to explain that I was a doctoral student still working on research and needed those services. I was told I needed to file a petition to keep services, but, because of the timing of the service termination notice, the petition I submitted was never filed appropriately because it was too close to the holidays and winter break. When services were supposed to terminate at the beginning of January, I had to call the Dean of Students Office to be sure they processed my petition, proving that I was not actually an alumna, but rather a student on medical leave for the year. When the petition was finally approved, the College allowed me to keep my storage drive, Blackboard access, and ID card access. I had also requested for my library access to be reinstated, but was denied access to the off-campus library access with no explanation provided.

Additionally, there were no guidelines to assist with the reimbursement of and negotiation of my student bill. Since I had registered for fall classes and already pre-paid

for a study abroad trip, I had to negotiate the reimbursement of funds for the trip and the removal of charges from my student bill at a time when I was also trying to pay Nathan's medical bills. There was a lack of coordination between the School of Education, bursar's office, and the study abroad office, each pointing to the other for whose responsibility it was to initiate reimbursement.

For graduate students, it is imperative to identify which department will take primary responsibility for the student's request. Instead of operating separately from each other, it would have been helpful for there to be a single MLA form or contact that also addressed the extension of student services and any billing concerns. Including the option to request necessary services on the MLA form, which is granted for a specific timeframe, may reduce the need for additional petitions from students. Additionally, graduate students who live off-campus or are on leave from a degree program may find it difficult to respond to petitions or billing statements in a timely manner. By addressing these needs upfront and coordinating across departments to streamline the process, students can spend more time processing their traumatic experience and less time worrying about paperwork to retain their student services.

### **Alignment with Student Status**

A final recommendation for higher education institutional policy includes aligning student status with the appropriate service provisions. In my experience, when I took a leave of absence, I lost services and was not notified in advance that those losses would occur. By creating a student status that reflects a leave of absence, students will not be subjected to the termination of services that correspond to alumna and inactive student statuses. Both of these categories (inactive and alumna) suggest that students are

not returning to the institution. While this may still be a possibility, it would have been helpful if my MLA status had extended my student services at least until my leave was scheduled to expire.

If, as previously suggested, students can file service extensions at the time of requesting leave, there may be no cause to guarantee this alignment. However, by cataloging MLA students as such, administrators have an opportunity to follow-up with students at the beginning of each semester to ascertain whether the student wishes to re-enroll or extend the leave. This may be a way for administrators, who may not work with graduate students as frequently as faculty members do, to provide social support for the student who took a leave of absence due to trauma. Just because a student is not enrolled in classes, does not mean that the student is no longer “active.” Structuring student status in a way that is respectful of the student’s leave, and by association the reason for such a leave, would show that the institution is providing support that could facilitate the posttraumatic growth process.

Taking an MLA from my program was only the first step in a policy-deficient system of taking time to care for my family. In each of these instances, I was unaware that these actions were a result of requesting a MLA. There was no communication or delineation of policy that notified me of the impact of taking an official leave, which led to a significant degree of distress related to my graduate studies. At a time when my attention should have been on helping and caring for my family, I had to file petitions and provide documentation that legitimized my trauma for the College. Understandably, taking an official leave would provide a level of protection for the student, in that the time to degree completion is paused and or extended until the student resumes

coursework. However, additional protections should be in place to preserve a student's ability to contribute meaningfully to their degree even if on a leave of absence.

### **Implications of Sharing Stories**

Using a narrative approach to present my experience of trauma and posttraumatic growth was helpful to *show* the experience to others, but also as a way for me to consider how I felt about the experience and how I would translate my experience to others. The process of writing this dissertation has encouraged me to put words to feelings and experiences so that others might begin to feel how I felt. Readers would be able to experience my trauma through the language I have chosen to represent those experiences.

Sharing stories allows a broader community to enter into the individual experience in order to extrapolate larger meaning from the experience. Storytelling creates a shared space for author and reader to interact (T. E. Adams et al., 2015; Denzin, 2014). It broadens our knowledge base by showing nuances and unique experiences that are often overlooked in favor of the larger group experience or narrative. Sharing stories in higher education can begin to break the assumptions governing faculty-student interactions, student expectations, and who students are at their core. Sharing trauma shows individual vulnerability and begins to view experience as innately humanistic, to view students as human beings with emotions and personal lives beyond their degree programs. Additionally, Tedeschi and Calhoun (2004) suggested that “the narratives of trauma and growth may also have the effect of spreading the lessons to others through vicarious posttraumatic growth” (p. 9). In sharing my process of growth following trauma, my story can serve as an example for other students who are experiencing, or have experienced, a traumatic event.

## **Finding Wisdom from Trauma**

I am a different person now than I was in November 2013 when Nathan's symptoms started. As a result of traumatic experience associated with Nathan's diagnosis and treatment, as well as the subsequent research and writing of this dissertation, I have developed new internal schema, ways of making meaning, and ultimately, wisdom. This section details the wisdom that I have gained from the processes of both experiencing trauma as a graduate student and writing this autoethnography. In some cases, wisdom has been a direct result of my personal experience, while in other cases wisdom is a product of engaging with my experience a second time in this autoethnography. I focus primarily on wisdom for faculty as well as for other graduate students who may experience trauma.

### **My Wisdom for Faculty**

I will begin with wisdom I have gained from my experience that I wish to share with faculty members. I encourage faculty to balance support and challenge, establish open and personal communication with students, embrace vulnerability, support the decisions students make following traumatic experience, and be present for the entire journey. Faculty who wish to better support students who experience trauma will need to assess their own abilities to accommodate these recommendations. In some instances, faculty may not be ready to meet the challenges inherent in these recommendations; however, from my experience, these were the areas in which I feel faculty could have better supported my growth. Additionally, addressing these challenges may be crucial for faculty who want to encourage students to persist in their programs and, ultimately, complete their degrees.

**Balance challenge and support.** Based on Tedeschi and Calhoun's (2004) PTG theory, support is necessary for growth. Being supportive, though, can be interpreted in different ways. My reference to support here is through tangible actions taken by a faculty member. These actions can include offering meeting or talking with the student when he/she needs it, speaking with the student's other professors if a leave of absence is necessary, or sending forms that the student might need to submit for a leave of absence. By taking the burden of guessing away from students, faculty can be proactive in assisting students. Not only was I emotionally incapable of coordinating my coursework expectations, I physically could not reach out to my professors because I did not have computer access while at the hospital. I had no idea that I could take a leave of absence from my program, nor did I know where to find the form that would allow me to petition for a leave. The faculty who provided guidance and took control when I could not allowed me to focus on my own needs without being overly concerned about my program status.

Given the physical and emotional strain of a traumatic experience, assuming that a student will take a leave of absence or decide not to finish a degree program is understandable. However, in my experience, I also wanted my advisor and faculty members to push back against my initial inclination to retreat entirely from the program. I felt disconnected from the program because there was no impetus driving me back toward getting involved again. Sanford (1962) described the idea of balancing challenge and support to facilitate student development. Building on this idea, I think that faculty who can balance support and challenging graduate students with little nudges can be an effective way of making students feel like they are still valued and needed by the

program. The key to challenging students in the midst of trauma is to be gentle in not letting go of them. Extend invitations to students who are on leave, even if they decide not to come to a class, a meeting, or a social gathering. They may just need a sign that someone is thinking of them and wants them to return to the program.

**Establish open and personal communication.** Like balancing support with challenge, faculty must give students space to figure out “who the new me is” and “how the new me thinks,” but still offer to be available and open to questions and changes that the student presents. One way to achieve this is to check in frequently, without always expecting an answer. When experiencing a trauma, every conversation, communication, and interaction matters. Someone experiencing trauma could fall off the growth path at any moment if they do not have at least opportunities to talk about their experience or encouragement to seek disclosure in some other form, such as writing.

My advisor and graduate supervisors sent me an email every couple weeks just to let me know they were thinking about me and my family. Often I didn’t have time to respond back, but that never stopped the emails from coming. Occasionally, my advisor would send me a text message when he knew I was taking Nathan for an MRI or going in for surgery. These were personal connections that were not required by the faculty role as my advisor or supervisor. Making those personal connections was key for me to know that I had advocates in my program when I would return.

**Embrace vulnerability.** Faculty who want to support students going through trauma need to assess their own emotional awareness. Being apprehensive or self-protective in a conversation with a student who wants to disclose their trauma, may come off as judgmental or seem like a rejection to that student. Often, a faculty member need

not say anything, just be available to listen to the student with an open heart. In offering a space for that student to disclose the nature of their experience, the faculty member has to be open to the emotions involved in processing trauma.

I found that many faculty with whom I had classes in the past would ask about Nathan in passing but not stick around to hear more than “he’s doing well.” Either they did not have the time or the desire to hear more, or they were uncomfortable with the emotions that might be evoked from talking about such a traumatic series of events. I do not claim to know what the reason was; however, in comparison, my higher education program faculty were much more inclined to hear how things were going with Nathan’s progress, at length. Though I rarely showed much emotion in my disclosures, they took the time to know about me and my family. One faculty member still makes a point of baking special bread without eggs because she knows my youngest, Owen, is allergic to eggs. These faculty members embraced the vulnerability that was needed to connect with me on a personal level, which gave me the strength to be able to share and disclose more of my experience in the future.

**Support the decisions students make following traumatic experience.** In the aftermath of trauma, students may make decisions or act in ways that are in complete opposition with how faculty members knew the student prior to trauma. Though a faculty member may have developed a relationship with the student prior to trauma, there is a need to redefine that relationship with the student post-trauma. Faculty need to understand that the student may not be able to go back to who he/she was before the traumatic experience.



As I processed my trauma, I changed my entire dissertation topic, as well as my cognate area. My advisor was supportive of these changes and answered any questions I had about making the new changes work. Unfortunately, I felt like I needed to defend those decisions to anyone else who questioned my motives for change. It was distressing to constantly be on the defensive with some department faculty, who should have been in a position to help me achieve my goals, not interrogate them. Because my advisor knew that my decisions were tied to my growth following my traumatic experience, he took more care in working with me to achieve those goals.

**Be present for the entire journey.** No matter how long it lasts, be present. When a student needs to take time away from the program, faculty should be guiding and overseeing that process, not only for procedural reasons, but to make that process smoother for the student who is also experiencing personal trauma. When that student reaches the point where he/she is transforming because of traumatic experiences, encourage that transformation in whatever way the student might need (i.e., encourage journaling, counseling, etc.). And when the student chooses to re-engage in the academic program, offer space for the student to get back into the groove, and check in on his/her progress in acclimating back into the program.

Of all of the faculty interactions I have had during my program, my advisor, Jim; my program faculty member and unofficial mentor, Pam; and my graduate supervisor, Sharon, were the three individuals who were present at every stage of this process. They were involved when I chose to take a leave of absence. They talked me through changing my cognate and what classes would best suit that change. They helped me think about the new direction my dissertation would take and supported my decision to use a method that

had not been used previously at the School of Education. They helped me finish outstanding coursework, worked with me to find funding when I came back to classes full-time, and have always been supportive when I would tell them I might have an “off” day or week because I was waiting on test results. Their constant presence, acceptance, and patience have been the sole faculty support that has allowed me to feel a part of my program again and ultimately persist to complete my degree.

### **My Wisdom for Graduate Students Experiencing Trauma**

I struggled in the decision to provide wisdom for a specific group of graduate students. It seemed vital to share wisdom for students who are experiencing or may experience trauma, which includes the value of sharing, recognizing the complexity of life in a graduate program, realizing that time and space are necessary for processing, and utilizing trusted outlets for disclosure. Although this wisdom does not explicitly address peers (those around a traumatic experience, but not experiencing trauma themselves), I believe the lessons shared here are of value for this group of students as well because they are part of the graduate experience, and thus, characters in the life narrative of a fellow student experiencing trauma. The challenge for graduate students is to allow ourselves to be vulnerable enough to learn from each other. It is my intention to provide wisdom that other students can use to build a graduate culture of care, regardless of the influence of trauma.

**It is okay to share.** Too often, I have seen fellow graduate students hide their experiences because they do not wish to be seen as weak, or complaining. Graduate students in particular are often seen as invincible, keeping late hours, doing exorbitant amounts of work all in the name of degree completion. In the rat race that is graduate

school, we forget that we are people and that sharing with others brings us closer together. Only too late did I realize I was not the only student experiencing trauma, particularly with regard to children. I did not know that I had important knowledge to share from my trauma until another graduate student shared her experience with me. I decided to keep this particular interaction out of my narrative to respect the other student's privacy, but sharing stories with another student was a powerful moment in which I realized some else might gain insight from my story too.

The exchange of personal knowledge made stronger connections with my peers that have seen me through the last year of my program. Without sharing my experience and making those bonds, I might not have felt supported to finish the program. Even if you are not yet ready to share your experience, know that you can make an immediate impact on other students. You never know who might need to hear your story.

Sharing might seem easy enough, but it actually required difficult steps in order for me to feel comfortable sharing my story. First, you have to identify someone you trust as the recipient of your story. Not only would this person not violate your story by sharing it beyond the confines of your relationship, but also this person should demonstrate interpersonal care. For example, this person should be able to listen without trying to compare your experience with his/her own. I found that just having someone listen to me was a catalyst for wanting to share more of my story beyond my trusted confidant. Second, it is important to identify a safe space in which to share your experience. Environments carry a climate that either facilitates or does not facilitate sharing. Finding a space that speaks to your comfort level, whether it is a specific building or room, or even an online outlet, such as a blog, can be a key factor in easing

discomfort associated with sharing traumatic experience. Last, sharing does not have to mean telling every detail or emotion that you can put words to. Sharing can be as simple as acknowledging that you are going through a difficult time. The goal, then, is to determine your own comfort level with sharing and find an outlet that will accommodate that initial level of comfort.

**Life and school are not separate.** They are intertwined. When something happens in one, it almost always affects the other. The graduate student experience is common among us, students, by virtue of the fact that we are in graduate programs. It is shared in the rigor of our coursework and the requirements placed on us as students. The graduate student experience, however, may not be shared at the same level in our personal lives. Assuming that all students have the same responsibilities or that all students experience graduate school the same way puts us at risk for marginalizing one another. As graduate students, we must look after each other by stressing the need for self-care, such as taking breaks when personal stressors are impacting school performance or engagement. Allowing the personal life to penetrate the ivory tower of graduate programs can create a balanced experience for students that embraces and values both the intellectual and personal contributions that students offer.

**Processing requires time and space.** It is likely that as a graduate student, you will face a personal challenge that requires you to reconsider your priorities or future goals. The easiest judgment calls will be the ones in which your priorities are in the right order. But when you face an experience that upends your worldview, you need to take the time and space, if you can, to process those changes. Operating as if a trauma has no effect on your experience may actually be detrimental to your ability to grow from the

experience. Some students might not want space or time. Instead, they may try to fill every minute with things to do. They may over include themselves in activities to keep their mind occupied. But, avoiding the disconnect between your worldview and every day actions can only last so long before it comes back to hurt you or those around you. Trying to jump back in to your program before you have a chance to process the full implications of your experience may be additionally traumatic and require that you take a step back for longer than you originally intended.

**Disclosure is easier when you have an outlet you trust.** First, disclosure is never easy. However, it seems to be a necessary part of making sense of trauma. Second, having a trustworthy outlet to begin this disclosure was key for me to feel I would be accepted. For me, I trusted my journal writing in a way that I could not trust talking to someone else about how I felt. My journal would never betray my innermost feelings. For others, talking with a counselor or a significant other might be important to achieve that initial disclosure. Take advantage of the time, space, and opportunity for disclosure. Brushing these off in the processing of trauma may mean a lack of support later when you do need it.

### **Personal Wisdom**

Throughout my experience with trauma and posttraumatic growth, I have also gained vital wisdom about myself. Often, these personal truths emerged through my own internal dialogue as I struggled to make meaning of my new life. As such, I have included them in italics below to mirror the style of my narrative chapters in this dissertation, in which my inner thoughts appeared in italics.

*It's okay to just be mom.* There were times when I was processing this trauma that I felt conflicted over needing to be “mom” and wanting to be “mom.” When I realized that being “mom” was my most important identity role, I was more comfortable with the thought of being *just* a mom. Prior to Nathan’s diagnosis, the thought of only being a mom was stifling. I wanted to be more than just a mother. Being at home and taking on the responsibilities of “mom” all day, every day was suffocating, and I never felt as if I had a separate identity outside of being a mother. Embracing the “mother” role allowed me to see that just because I do mom stuff, I’m not just a mom. And I never will be. I take all of my past experiences, skills, and knowledge with me whenever I enter a new experience. And sometimes, despite all of my skills and knowledge, the most important knowledge and skills I have are associated with taking care of my children.

*It's okay to live outside the pressures of academe.* Although my desire to pursue a faculty career has not changed because of this traumatic experience, I have accepted that I have to be firm with my purpose in that future career. What is most important for my future career and life narrative is to make a difference, to leave a personal mark on an arguably impersonal field. I want to make meaningful contributions by working with students, encouraging them to develop and realize their own growth, whether from trauma or from everyday life. I do not want to be driven by the pressure to compete for accolades, for the most eye-catching research, or for the most grant money. Personal glory is not important to me in my life narrative.

I would like to advance scholarship about personal growth, so that higher education becomes a place that values and embraces the humanity of its students and faculty. I want to be happy in whatever I do, which means I need to strive, as much as

possible, for balance. I need to engage in life pursuits that complement and embrace the deeper parts of myself.

*It's okay to do something different, to do work that speaks to you and not because it fulfills some larger agenda.* So many alumni have come to my classes and spoken about choosing a dissertation topic that is meaningful because otherwise it will be difficult to sustain momentum to complete it. And although I believe such advice to be true, I believe it also to be true that my meaningful work must be acknowledged at the right time. My first dissertation topic was meaningful to me because Nathan has autism. But it was not the right time for me to explore that topic. I knew I was taking a career risk by completing *this* dissertation, but I also knew that if I did not address the importance of trauma in my educational experience, I would be missing a vital piece of the puzzle that make me who I am.

*It's okay to feel, especially in an environment where thinking is lauded over feeling.* There have been moments, especially once I returned to my program, where I saw how academics (both students and faculty) brush over the emotions that make us vulnerable. If we feel uncomfortable or uncertain about our abilities, we reassure each other that we are brilliant so that it encourages someone to move on. If another student is having a bad day, we focus on things that would cheer that person up. There is an assumption that when you return from a traumatic experience, that you are okay. You have processed and are ready to move on with life. But the reality is that the stress of trauma is not easily brushed aside and may come back weeks or even months later. I have learned that I have to be in tune with my emotions, I have to feel them when I feel them. Rationalizing feelings with thinking only prolongs the process.

*It's okay to not be okay.* It seems contrary to the notion of growth, but I find that the pressure to be “okay” is enough to make me hide how I truly feel just so I can pretend to be “okay.” When I think of others who might experience (or have experienced) trauma in their graduate programs, I feel more strongly that we can and must allow ourselves to feel and process the “not okay” feelings. We won’t fully know that we are okay until we know how it feels to not be okay. I think there is value in knowing what pain feels like so that you can recognize the growth and peace that comes after.

### **Conclusion**

My process of developing and gaining wisdom from my traumatic experience does not end with this chapter or even with graduation. I can recognize that I am still in the process of acquiring wisdom and searching for the profound meaning behind my trauma; I realize that this process will continue for quite some time, perhaps for the rest of my life. However, I have already learned several things about myself and about the ways in which future students might be better served if they, too, were to experience trauma.

Faculty who provide unconditional support and embrace the emotional vulnerability that coincides with traumatic experience, play a vital role in the growth process. Understanding that trauma can have many variations, faculty who can facilitate the posttraumatic growth process through their personal connections with students may be able to encourage student persistence, hopefully contributing to successful degree completion. Graduate students represent a unique population of students who may have already made developmental progress according to most student development theories. Posttraumatic Growth Theory, then, is a useful framework for graduate students and



faculty to better understanding the growth process following a trauma because it mirrors the developmental processes of revising internal schema. The posttraumatic growth process is inherently individualistic but can be fostered with appropriate social supports and opportunities for disclosure. Higher education needs to create programmatic supports and to cultivate an atmosphere that facilitates disclosure for students experiencing trauma.

This dissertation has illustrated my challenge of learning to be a new person in the aftermath of trauma. I have interpreted my experience only to find wisdom that has been molded through my interactions with others, through writing and multiple revisions. I have yet to find the wisdom that explains the value of trauma, if only because I can profess having found growth as a result. My journey towards wisdom does not end here.

## EPILOGUE

*March 25, 2016:* Nathan's audiogram is scheduled for today. It's a reminder that his treatment has long-term side effects. He is required to have an audiogram to test his hearing every year. One of the side effects of the high-dose chemotherapy is that, over time, it can damage his hearing.

I had spent the day running errands instead of writing. I know I won't get the weekend to write, and the fact that I had to take today off as well is annoying. But then I am also the one who has to go pick up Nathan from school for the audiogram. In fact, I *chose* to take him to the appointment, telling Brian that I wanted to be the one to take Nathan.

When Nathan and I arrive for the appointment, we are escorted to a room that holds a soundproof box. The box is maybe a six foot cube, carpeted and featuring a door that the audiologist shuts when the test is about to begin. There is a chair for Nathan in the center so that he can see the audiologist through the window, sitting outside of the box. He complies with the testing with minimal resistance, and when the ten minute test is complete, the audiologist tells me all is fine with his hearing.

*Well that's a relief.* I'm not sure I could have handled any other response, but I'm glad I don't have to wonder about his hearing. *Until next year's audiogram.*

\*\*\*

*March 31, 2016:* It's 10:30 PM. My eyes are glazing over from staring at the screen of my laptop, and I long to pack up and go home. I've spent the last four days and nights at the School of Education working on revisions. I miss my kids. I miss my dog. I miss Brian. By the time I get home, everyone will be asleep, and I will fall into bed just like the rest of them, only to wake up the next morning and repeat the process.

My peer and fellow dissertation writer, Montse, sits across from me typing away on her computer. I have been staring at the same revision for Chapter Eight for at least ten minutes. But Montse won't let me leave.

"You have one more hour. Get it done," she tells me. *It's like she knows you're contemplating giving up for the night.*

Sighing, I stretch my back and re-focus on the task before me.

\*\*\*

*April 3, 2016:* Saturdays were meant to be spent at home, away from work. But not for me. I am back at the School of Education. All day, alone. I really have no choice, not if I want to graduate in May. The silence is comforting because it keeps me from being distracted by conversations or the comings and goings of students and faculty. I only have two more things on my list to finish: footnotes and an abstract. I work methodically, moving from each tabbed page to the next, handwriting the footnotes that should be included and where they should be placed. My desk is littered with journal articles and physical copies of my dissertation.

Finally, I finish handwriting in the last footnote and breathe a sigh of relief. *That was more work than I thought it would be.* I scroll to the first footnote section to start typing when a couple walks by and informs me the building is closed. "Okay," I say.

They stare at me for a moment, as if their expectation for me to leave needs to be reiterated. Not wanting to cause problems, but also irritated at how close I was to finishing for the night, I begin to pack my things. I sent a text to Brian:

*Some random people just told me they were closing the building and I had to leave...*

*I still have an abstract to write and footnotes to finish at home –*

*maybe you can help with page numbers after.*

When I get home, Brian is camped out in front of the television playing a video game. He tells me he will stay up with me while I work. The dog, on the other hand, is not as cooperative, wanting to sit all of her 50 pounds on my lap. Eventually, she settles next to me on the couch when she realizes she can't be in my lap.

I work diligently, and once I have typed in all of my footnotes, I turn to writing the abstract. The clock on my laptop reads 2:15 AM. I groan and start writing again. Twenty minutes later, I look up from the screen and ask, "Can you pause your game and listen to this to see if it makes sense?"

Brian looks at me quizzically, "Sure, but you know I don't know what it's supposed to say, right?"

"All you need to do is listen for three things: What's the point of the study, how did I do the study, and what did I find."

"Okay, I think I can do that." He pauses the video game and waits. I get three sentences in when I notice Brian waving his arms for me to stop. "What did that sentence even say?!" he exclaims. I read it again, slowly.

"It makes sense to me," I murmur. "But it *is* almost three in the morning." Brian

tells me to continue reading and when I get to the end, he nods as if my effort meets his approval.

“Okay, so now that that’s done, can you help me with the page numbers?”

\*\*\*

At 2:53 AM I send my finalized draft to my dissertation chair, Jim, for his approval. Once he reviews it and makes any comments, I will be able to send it to my committee. I head to bed, prepared to wait until the evening for a response.

At 3:30 in the afternoon, I receive an email from Jim telling me I can send the dissertation to the committee. I scroll through the comments he made and make any necessary edits before composing an email to the committee.

-----Original Message-----

From: Kristen Tarantino  
Sent: Sunday, April 3, 2014 10:00 PM  
To: Tony Adams; Virginia McLaughlin  
Cc: Jim Barber  
Subject: Tarantino Dissertation

Good evening everyone!

As promised, attached you will find a copy of my dissertation. I apologize for not being able to deliver it sooner, but I hope you will enjoy reading it.

Looking forward to seeing everyone on the 12th! Please let me or Jim know if you have any questions in the meantime!

Kristen

-----

\*\*\*

*April 6, 2016:* I try to sneak out the door with my suitcase, knowing that if Nathan catches me he’ll dissolve into fits of crying. I have only had one day to prepare for my

trip to Washington, DC for the American Educational Research Association conference, and I'm frazzled by the fact that I have conference presentations and a dissertation defense that are not yet written.

Arms laden with my purse, water bottle, my jacket, and directions to the hotel, I almost make it. Nathan appears at the top of the stairs and watches as I pull my suitcase behind me toward the car. I hear him scream his displeasure that I am leaving. I walk back to the house in an attempt to calm him down, but it fails. Tears roll down his cheeks and he says, "Mommy don't go to school. Mommy stay here."

They are words I have longed to hear in the past 12 years. But I know I can't stay. Not if I want to make it to the city before nightfall. I tell him I'm coming back but he bolts to his room, intent on staying upset as long as possible. I hug Owen and Brian, pat the dog on the head, and leave the house.

\*\*\*

*April 9, 2016:* I've been in DC for three days, and I'm exhausted. I managed to make it through my first presentation this morning, but now, sitting at a table in the convention center, I feel the weight of my sleepless nights dragging on my ability to work on my defense presentation. I have another presentation on Monday morning that I have yet to start, but somehow it doesn't bother me. Instead, I'm more concerned about writing my presentation for my dissertation defense.

Earlier, I walked around the exhibit hall, talking with publishers about the kinds of books they publish with an ear towards publishing my autoethnography. I wasn't particularly encouraged by what I heard, but I'll have to save those thoughts for later. *You*

*need to focus on this presentation. It's more important than anything else going on right now.*

Maybe the other graduate students I've met so far are right.

"Your defense is Tuesday and you're *here*? Why?"

I suppose it does sound like bad planning, but there is no use in complaining about the timing. *Pay attention to this PowerPoint slide and start writing!*

\*\*\*

*April 11, 2016:* It's 12:30 AM. My colleague, Clara, and I just finished putting together the finishing touches on our presentation scheduled for 7:45 AM. I like rooming with Clara, and she offers to listen to my dissertation defense presentation. I only have half of it complete, but I read my presentation, knowing that going off-script is not in the cards for me. I can feel my voice shaking and my nerves racing as I try to read my presentation as calmly as I can. I realize that I'm not nervous about presenting my dissertation, I'm nervous about *presenting*. Luckily I am sitting on the bed as I flip through each slide instead of standing up. *Then the shaking would be more visible.*

I come to a stop when I've reached the end of my script and turn to look at her.

"I wouldn't change a single thing," she says. The comment makes me uncomfortable. I have never been comfortable with praise, especially when I expect there to be at least one helpful criticism.

\*\*\*

The next morning, we head to our conference presentation. My mind is only thinking about the current presentation and not my defense, scheduled for the next

morning. By 9:45 AM, the presentation is over, and I manage to squeeze in one more research session before heading back to the hotel to pack for my trip home.

“Make sure you leave no later than one o’clock,” Dad had said. “Otherwise you’ll be sitting in traffic.” I take his advice to heart and begin the two and a half hour drive home just before 1:00 PM.

When I arrive at the house, no one is home. Brian is out picking up kids from school. My best friend, Amanda, must be with him. She has travelled from Tennessee to attend my defense. I get a good 20 minutes alone with the dog. After being gone almost a week, she can hardly contain her excitement at seeing me.

I’m walking the dog when Brian’s car pulls up. Nathan exits the car and walks toward me, arms flapping, and a grin on his face. “Hi Nathan! How are you?” I ask.

“Good.”

“I missed you. Are you happy Mommy’s home?”

“Yes.” I give him a hug before he retreats to his room, as usual.

Owen, having reasoned that I would never leave him, tells me he knew I was coming back.

“Don’t I get a hug though?” I ask.

“I guess.” He gives me a brief hug and runs to play the video game that has occupied him and Brian since Brian’s birthday in March. I shrug and turn to Amanda,

“Typical five year old.”

\*\*\*



After the kids are in bed, I authorize Brian and Amanda to return to their recent Netflix binge watching while I finish working on my presentation, with the caveat that they have to listen to a run-thru when I'm done.

I plug in my headphones to drown out the sounds from the living room and force myself to finish the script for the last five PowerPoint slides. It takes me a solid 45 minutes to finish what I think belongs in the presentation, and I print my notes so I can read them. Brian pauses the show they are watching and I hook my laptop up to the television so they can see the presentation as well.

"Can you time this?" I ask Brian. He nods and pulls out his phone. The dog doesn't seem to understand what's happening and tries to engage Amanda or Brian in a game of tug-o-war with her stuffed toy. I nod to Brian to signal I'm ready and he hits the "start" button on the timer.

About half-way through my mock presentation I hear a loud rip. I immediately look at Brian in time to see stuffing explode from the stuffed toy, which is still clasped in the dog's teeth. I can feel my eyes widen in response, and I see Amanda's reaction is the same. But I keep going, knowing that the timer is still rolling.

When I finish, I tell him to stop the timer. "31 minutes," he says.

"That's too long," I reply. "Do you think it makes a difference if I take out two of the examples and only keep one?"

"Which would you keep?" Amanda asks.

I look through each of the three examples pulled, each one corresponding to one of the three storied chapters. "Maybe the one where I talk about the port removal?" I

suggest. I have Brian time me reading the two examples that I will take out to see how much time that cuts off from the presentation. “Four minutes,” he says.

“Okay, so that means I need to trim down other sections a little bit,” I say to myself.

“Well and there was the dog toy incident. That added on at least 30 seconds,” Amanda jokes. We laugh, and I leave them to finish their TV show while I make edits to my script. I finish close to midnight, and tell them I’m going to bed. Hopefully, I can get some rest.

\*\*\*

*April 12, 2016:* Amanda and I arrive at the School of Education at 9:30 AM. *You defend in thirty minutes.* I lead the way down the hall towards the room where my defense is scheduled. It is empty, and I briefly thank God for not letting anyone else be in the room first.

I feel like I’m rushing as I switch my tennis shoes for dress shoes and toss my rain soaked jacket on a nearby chair. Amanda asks if she can do anything, and I tell her not really. Then I pause in the act of setting up the computer to look over at her.

“Actually, can you find out if today is the feast day for any saint?” I ask.

“Sure.” She uses my phone to run a Google search while I run upstairs to grab a dry erase marker from my desk. I pass Jim on my way out of the room, and he asks me if I need anything.

“I haven’t seen anyone from IT yet to set up Skype.” One of my committee members is in Illinois and the last time we Skyped him in, we had issues with the

technology. Jim tells me he will go find someone, and I run up the four flights of stairs to my desk on the third floor. I'm not really nervous, just antsy to get started.

By the time everything is set to go, Jim asks if I'm ready to start. "Well, we should probably wait for Brian," I say, noticing that he hasn't arrived yet from dropping the boys off at school.

"Here he comes," I hear Amanda say from the back of the room. She's looking out the front window, watching as Brian runs down the hill separating the building from the parking lot. *I hope he doesn't slip and fall on the wet grass.*

With everyone finally seated, Jim welcomes everyone in attendance and provides an introduction to the defense proceedings. I can feel my nerves start to twitch with anxiety and I force a few deep breaths. I glance at the audience and see my parents, my grandparents, friends, and faculty. There are a few in the audience I was surprised to see, especially Sharon. It sets me at ease to see her here. And then just when I'm calming down, Jim turns to me and says, "So Kristen if you're ready, we can go ahead and get started."

I read and speak as if I'm on autopilot. I know what I'm saying but I can't think about it, I just keep going. I make it to the slide where I read the excerpt from Chapter Five when I notice Skype shutting down. *It's like the damn dog toy all over again!* Jim tells me to keep going while he fixes Skype.

When I finally reach the end of my presentation, I feel momentarily relieved. I have spent so much time focused on *my* presentation that I didn't have time to think about anything the committee might ask. That realization smacks me in the face, and I briefly panic that I'm about to be asked a question I don't have an answer to. But my fears are

unfounded. Although there are questions I hadn't anticipated, I am able to answer each one calmly and, surprisingly to me, with confidence.

When the last question has been asked, Jim politely asks everyone leave the room so the committee can deliberate. It's the first time that I feel weightless, as if the tremendous burden that is the dissertation is no longer mine to shoulder.

I take a moment to hug those I had yet to greet, and thank each individual for coming. Each one tells me the presentation was great, that I did a great job, but I brush those aside. I don't really care whether the defense was great or not, I'm more pleased that people actually came to see it. I don't even hear Jim when he walks out, all I hear is "Dr. Tarantino." There's the typical hugging and clapping that follow such an announcement, and then there's Grandpa.

"Hip hip!" He bellows. And everyone present contributes, "Hooray!" And because it is tradition, he proceeds to repeat the cheer twice more. I laugh because I couldn't have imagined his reaction any other way.

\*\*\*

Everyone is gathered on the second floor, just inside the glass doors that lead to the balcony and bell. After a successful defense, the doctoral candidate gets to ring the bell three times. Once for the present, once for the past, and once for the future. It's eerily similar to the bell ringing that performed after Nathan's radiation treatment. I think I'm more nervous about ringing this bell than I was about any other part of today so far. I wish that Nathan was with me to help me ring the bell. I overhear Brian say he wants to ring the bell, and I know that Owen would want to ring it as well.

The first contact between the striker and the edge of the bell startles me. I didn't expect it to be so loud. But once the initial shock dissipates, I strike the bell again, letting the resounding tone echo in the empty, rain-drenched courtyard. When the echo dies, I strike the bell a final time and am greeted by both a final ring as well as the clapping and cheers from my supporters, who are busily taking photographs and videos of the occasion. It is a happy moment, but somewhat unfulfilling, though I'm not quite sure why. It's a sign of a great accomplishment, of hard work. But it vaguely seems like any other day.

\*\*\*

As we walk back into the building, Brian's cell phone rings. It's 12:03 PM. Glancing at the caller ID, I see that it's Nathan's teacher. My adrenaline skyrockets at the sight of her name, and I answer the phone ready to hear bad news.

"Hi, his blood sugar was 531."

"Wow, that's high," I say processing the number in my head.<sup>33</sup>

"We checked, he didn't eat anything more than he usually does before lunch. Was his number high this morning?" she asks me.

"I mean, it was a little higher than it has been, but not high enough that he would end up with 531 at lunch. He's normally around 300 for lunch, right?" I ask.

"Yeah, we're supposed to call the endocrinologist if it's over 500, per his medication orders. But I will call you back when I know what we find out."

---

<sup>33</sup> Target level blood sugars in children can vary. Nathan's target blood sugar number is 150, which means that any number higher than 150 is used in calculating the amount of insulin he receives. Nathan's blood sugars typically range from 200 to 350 when averaging pre-meal and bedtime sugar checks. His lunchtime blood sugar number is typically in the middle to high 200s.

“Do I need to come pick him up,” I say, glancing around at the crowd that is waiting to go to lunch.

“I don’t think so. But I will call you back when I know more.” I hang up the phone and pray that they get through to the endocrinologist.

Ten minutes later, my cell phone rings. It’s Nathan’s teacher again.

“They told us to give him 15 units of insulin and then check his blood again at 2:30 PM.” I thank her for calling me back and hang up the phone. *Of course, something like this would happen today.*

\*\*\*

My family is seated at a table that is meant to seat ten. The hostess managed to place us at a table at the back of the local Italian restaurant. The privacy is comforting and the smells of garlic and butter greet me as I sink into the leather-backed chair. There’s a buzz of conversation about the defense, questions directed at me come and go. I realize I never found out who the “Saint of the Day” is. I turn to Amanda and ask, “Did we ever find out whose feast day it is?”

She smiles and says, “I couldn’t figure it out, but then I realized that there was someone here who would know the answer. So I asked your mom.”

I turn to Mom, smiling. *Of course she would know.*

She pulls out her cell phone and opens the application that features the Saint of the Day. “It’s St. Teresa of the Andes. She is the patron saint against bodily ills, sickness, sick people, and young people in general,” she reads aloud.

“Well that seems to be entirely appropriate for today,” I say. “I should tell Jim, he would appreciate this tidbit of information.”

\*\*\*

*April 19, 2016:* I'm at my desk working on the requested revisions to the dissertation.

There were five. As I glance at the memo detailing each revision, I realize that I never read the first paragraph:

In our deliberations, the committee requested the following revisions to your work before the dissertation is approved. The deadline for submitting your final, formatted and approved manuscript to ProQuest is May 6, 2016 (and the manuscript will need to be reviewed by a formatter between my review and your submission). As such, I would like to see these revision on or before April 22, 2016.

The date jumps from the page, screaming its importance, and it takes me a moment to realize that April 22 is exactly two years after Nathan's original diagnosis. I pause with my fingers poised over the keyboard, momentarily frozen in place by this knowledge.

*How does that make you feel?* I don't really know how that makes me feel. I see flashes of that day two years ago and immediately remind myself I am no longer in that place.

Nathan is no longer in that place.

I have saved the most intensive revision for last—writing this final chapter.

Elizabeth and Montse are chatting about analyzing Elizabeth's grounded theory study for her qualitative class. Being with them brings a sense of purpose when I stay late to write. I long to run home and cuddle with the dog, but I know that the sooner I finish writing the sooner I can feel human again.

I stare at the computer screen. The blinking cursor is back. If it had a face, it would be sticking its tongue out at me, teasing me. I reach for a notepad and a good pen and start writing, anything.

I still haven't given thought to how I feel about the defense being over. I'm making revisions, but I know I will have to provide some introspective viewpoint on how I have changed since the defense. Do I feel relief? Exhilaration? Was the

process invigorating or terrifying? Am I glad it's over or do I feel as if the resulting "high" was anti-climactic?

I've had a number of "congratulations" and frequently heard "Dr. Tarantino," but they feel artificial. Getting a Ph.D. is supposed to be a big thing, right? Why can't I enjoy it? For once, why can't I table my inability to show pride and bask in the accomplishment?

This is probably not the type of introspection my committee is expecting, but the "accomplishment" feels hollow. I can imagine so many of my peers being proud of their work, their achievement.

I'm proud of my work, but I also feel like I exploited my experiences. I wasn't disingenuous, but I feel like I cracked myself open for everyone to see and now I must find a way to stitch myself back together. It's a vulnerability I'm not used to exposing. I like keeping to myself. I like reflecting and doing introspective writing. I'm not comfortable having my innermost thoughts on display for the world to see.

*So why did you do this study?*

Because I needed others to know what I went through, what Nathan went through. I needed others to see the *real* me, and not just the me I present publicly. I needed to put words to the horror I experienced, felt, and saw; words that someone else can understand so they know I *feel* too.

I wanted others to know that these experiences happen in our programs. I wanted to start a conversation about better supporting the emotional and processing needs of adult students. I wanted to learn why the trauma was important for me.

\*\*\*

*April 27, 2016:* It's Wednesday, and I'm submitting my *final* dissertation to Jim today. I scroll through each page, glimpsing pieces of my life that have been forever burned into my memory. It is satisfying to see the end. The end of the dissertation. The end of the program. I notice the date on my desk calendar and think back to what was happening at this time two years ago. Two years ago, my life had turned upside down. There was a tumor in my child's brain and he didn't even seem like my child. Now, he's back to



reciting movies, playing logic and reasoning games on his iPad, and flapping his hands when he sees me come home each day.

The tumor was the beginning of a hellacious year where I felt as though I was torturing my child with every hospital visit. This dissertation marks the end of the academic journey that I survived by focusing on what was most important to me. The process of finding who I was began and ended with my family.

## APPENDIX A

### CONSENT FORM

#### **Study of the Impact of Trauma on the Graduate Student Experience** *The College of William and Mary*

This research study concerns the researcher's own experiences with familial trauma while enrolled in graduate study. In particular, the study will illustrate the impact of trauma on the graduate student experience using personal narrative. The purpose of this study is to share the researcher's personal experience as a resource for other graduate students who have made or are in the process of making meaning of similar traumas. The researcher will focus on telling her own traumatic experience, as a graduate student caring for a child with chronic, and life-threatening, medical conditions. Data for this study includes the researcher's reflective journaling, recollections and interpretations of events, and correspondence collected during time period under study spanning from November 2013 through March 2016. Presentations and manuscripts may result from the analysis of these data. Information gathered through this study may benefit and inform others on understanding and supporting graduate students who experience trauma. There are no anticipated risks or benefits to participating other than those encountered in daily life. The researcher is conducting this study as part her doctoral dissertation at the College of William and Mary.

If you have any questions or concerns about this research, you may contact the principal investigator, Kristen Tarantino, ktarantino@email.wm.edu, 757-719-1455; my faculty advisor, Dr. James P. Barber, jpbarber@wm.edu, 757-221-6208; or Dr. Thomas Ward, chair of the Education Internal Review Committee (EDIRC), 757-221-2358, tjward@wm.edu.

#### **Please read the following statements and indicate your permissions below.**

I understand that my involvement in this study is purposeful in that permissions and consent will be obtained only for those included in the narrative. I understand that I may be asked for additional permissions regarding the use of text communications, such as email correspondence, social media posts, and/or cell phone texts.

I understand that I may be asked to voluntarily read portions of the narrative that are associated with my involvement in the researcher's experience as they are composed. Additionally, I may be asked to offer feedback on the written representation using specific guidelines prepared by the researcher.

I further understand that the researcher will hold my information in strict confidence and that no comments will be attributed to me by name without my specific permission. I have the option to provide a pseudonym of my choice, but I also recognize there is a possibility of identification given the nature of the study.

I recognize that my participation is voluntary and that I can withdraw my participation in this study at any time or decline to give permission in a particular instance. Any artifacts provided or created during the course of the study may become part of the permanent research files unless otherwise requested.

By signing below, I give consent that my involvement and interactions with the researcher during the period under study (November 2013- March 2016) may be included in the study.

Participant \_\_\_\_\_ Date \_\_\_\_\_

Pseudonym (if desired) \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_

APPENDIX B

**CHILD VERBAL ASSENT FORM**

**Study of the Impact of Trauma on the Graduate Student Experience**

*The College of William and Mary*

Hi. My name is Jim Barber. I'm a teacher at your mom's school. Right now, your mom is trying to learn about how she takes care of herself and your family. I would like to ask you to help me by being in a study, but before I do, I want to explain what will happen if you decide to help me.

Your mom will write a story about your family. You don't have to do anything because your dad will make sure that you are safe. By being in the study, you will help us understand the things that have happened in your family and how your mom has taken care of your family.

When your mom writes the story, she will use your name, unless you don't want her to.

Your dad says it's okay for you to be in the study. But if you don't want to be in the study, you don't have to be. What you decide won't make any difference about how I think about you. I won't be upset, and no one else will be upset, if you don't want to be in the study. If you want to be in the study now but change your mind later, that's okay. You can stop at any time. If there is anything you don't understand you should tell me so I can explain it to you.

You can ask me questions about the study. If you have a question later that you don't think of now, you can ask your dad to call me or send me an email.

Do you have any questions for me now?

Would you like to be in the study and be included in the story?

---

**NOTES TO RESEARCHER:** The child should answer "Yes" or "No." Only a definite "Yes" may be taken as assent to participate.

---

**Name of Child:**

\_\_\_\_\_

**Parental Permission on File:** ☐ Yes ☐ No  
(If "No," do not proceed with assent or research procedures.)

**Child's Voluntary Response to Participation:** ☐ Yes ☐ No

**Signature of Researcher:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**(Optional) Signature of Child:** \_\_\_\_\_

## APPENDIX C

### **PARENTAL PERMISSION FORM** **Study of the Impact of Trauma on the Graduate Student Experience** *The College of William and Mary*

Your child is invited to participate in a research study conducted by Kristen Tarantino from the College of William and Mary. This research study concerns the researcher's own experiences with familial trauma while enrolled in graduate study. In particular, the study will illustrate the impact of trauma on the graduate student experience using data compiled from the researcher's reflective journaling, recollections, and interpretation of events through personal narrative. These data reflect the time period spanning from November 2013 through March 2016. Your child was selected as a participant in this study because he/she interacted with the researcher during the time period under study.

If you decide to allow your child to participate, your child will not be asked any questions or need to engage with the researcher at all. As the parent, you may be asked to voluntarily read and respond to portions of the narrative that feature your child on your child's behalf. Additionally, you may be asked to offer feedback on the written representation using specific guidelines prepared by the researcher.

Any information that is obtained in connection with this study and that can be identified with your child will remain confidential and will be disclosed only with your permission. I have the option to provide a pseudonym for my child, but I also recognize there is a possibility of identification given the nature of the study.

Your child's participation is voluntary. There are no anticipated risks or benefits to participating other than those encountered in daily life. If you decide to allow your child to participate, you and/or your child are free to withdraw your permission and discontinue participation at any time without penalty.

If you have any questions or concerns about this research, you may contact the principal investigator, Kristen Tarantino, ktarantino@email.wm.edu, 757-719-1455; faculty advisor, Dr. James P. Barber, jpbarber@wm.edu, 757-221-6208; or Dr. Thomas Ward, chair of the Education Internal Review Committee (EDIRC), 757-221-2358, tjward@wm.edu.

Your signature indicates that you have read and understand the information provided above, that you willingly agree to allow your child to participate, that you and/or your child may withdraw your permission at any time and discontinue participation without penalty, and that you will receive a copy of this form.

**Please indicate your permissions by initialing one:**

\_\_\_\_\_ I wish for my child's identity to remain confidential.

\_\_\_\_\_ I permit the use of my child's name in the study.

Parent/Guardian \_\_\_\_\_ Date \_\_\_\_\_

Child Pseudonym (if desired) \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_

## APPENDIX D

### TAYLOR & FRANCIS LICENSE TERMS AND CONDITIONS

May 04, 2016

---

This Agreement between Kristen Tarantino ("You") and Taylor & Francis ("Taylor & Francis") consists of your license details and the terms and conditions provided by Taylor & Francis and Copyright Clearance Center.

The publisher has provided special terms related to this request that can be found at the end of the Publisher's Terms and Conditions.

License Number	3861991500247
License date	May 04, 2016
Licensed Content Publisher	Taylor & Francis
Licensed Content Publication	Psychological Inquiry
Licensed Content Title	TARGET ARTICLE: "Posttraumatic Growth: Conceptual Foundations and Empirical Evidence"
Licensed Content Author	Richard G. Tedeschi, Lawrence G. Calhoun
Licensed Content Date	Jan 1, 2004
Licensed Content Volume Number	15
Licensed Content Issue Number	1
Type of Use	I don't see my intended use
Requestor type	academic/educational
Format	electronic
Portion	Figure/table/questionnaire
Number of figures/tables/questionnaires	1
Figure identification	Figure 1: A model of posttraumatic growth on page 7
Will you be translating?	no
Author of this Taylor & Francis article	no
Order reference number	None
Requestor Location	Kristen Tarantino [REDACTED] Attn: Kristen Tarantino

Billing Type	Invoice
Billing Address	Kristen Tarantino [REDACTED] Attn: Kristen Tarantino
Total	0.00 USD
Terms and Conditions	

**Taylor and Francis: Terms and Conditions for Reuse in a Book/Textbook, Journal/Magazine, Promotional Materials/Pamphlet/Brochure, Newspaper and Newsletter**

Permission is granted for a fee for non-exclusive world rights for one edition only. Use beyond this edition requires obtaining another license. This license is granted strictly according to the details of use you specified during the order process and are found in the order details above.

Unless otherwise stated, entire article electronic reuse is excluded with the exception of eBooks.

This license does not cover usage in a Custom Publishing Programme and or database.

This license does not cover cases in which Taylor and Francis material consists of more than 20% of your new work.

This permission does not cover any third party copyrighted work which may appear in the material requested.

Full acknowledgement must be included showing article title, author, full Journal title, date of publication and publisher, reprinted by permission of the publisher (Taylor & Francis Ltd, <http://www.tandfonline.com>).

All reasonable efforts must be made to contact the author(s) to notify them of your intentions and confirm they are happy with the permission being granted.

No alterations may be made to our work without written consent.

Permission is valid only when payment has been received.

Permission is granted by Copyright Clearance Center Inc. (CCC) on Taylor and Francis's behalf and by agreeing to the terms and conditions listed above you also agree to (CCC's) additional terms and conditions as the administrators of this licensing service, these terms and conditions are agreed to as a condition of establishing an account and may be seen at any time at <http://myaccount.copyright.com>.



## Special Conditions

The following terms only apply to signatories of the International Association of Scientific, Technical and Medical (STM) Publishers guidelines. <http://www.stm-assoc.org/about-stm>. Taylor and Francis adheres to STM guidelines, providing some reuse licenses for free as specified in the guidelines. We are pleased to grant you non-exclusive world rights in English and in all languages, in print and electronic editions of this Work in its first and future editions and revisions, on the following conditions:

The original source of publication and Taylor & Francis Ltd., are acknowledged in the caption, including a reference to the Journal's web site: <http://www.informaworld.com>

You do not license to any third party permission to reproduce this copyrighted material, in any form, and at any time.

This permission does not cover any third party copyrighted work which may appear in the material requested.

**Other Terms and Conditions:** Gratis permission granted for educational use. Permission includes electronic rights to post figure adaptation to ProQuest. Please cite adaptation in figure description. Thank you.

v1.8

Questions? [customercare@copyright.com](mailto:customercare@copyright.com) or +1-855-239-3415 (toll free in the US) or +1-978-646-2777.

## REFERENCES

- Abes, E. S., & Jones, S. R. (2004). Meaning-making capacity and the dynamics of lesbian college students' multiple dimensions of identity. *Journal of College Student Development, 45*, 612-632. doi:10.1353/csd.2004.0065
- Adams, S. A., & Riggs, S. A. (2008). An exploratory story of vicarious trauma among therapist trainees. *Training and Education in Professional Psychology, 2*(1), 26-34. doi:10.1037/1931-3918.2.1.26
- Adams, T. E. (2008). A review of narrative ethics. *Qualitative Inquiry, 14*(2), 175-194. doi:10.1177/1077800407304417
- Adams, T. E., & Ellis, C. (2012). Trekking through autoethnography. In S. D. Lapan, M. T. Quartaroli, & F. J. Riemer (Eds.), *Qualitative research: An introduction to methods and designs* (pp. 189-212). San Francisco, CA: Jossey-Bass.
- Adams, T. E., Jones, S. H., & Ellis, C. (2015). *Autoethnography: Understanding qualitative research*. New York, NY: Oxford University Press.
- Aldwin, C. M. (1994). *Stress, coping, and development*. New York, NY: Guilford.
- Barber, J. P., & King, P. M. (2014). Pathways toward self-authorship: Student responses to the demands of developmentally effective experiences. *Journal of College Student Development, 55*(5), 433-450. doi:10.1353/csd.2014.0047
- Barber, J. P., King, P. M., & Baxter Magolda, M. B. (2013). Long strides on the journey toward self-authorship: Substantial developmental shifts in college students' meaning making. *Journal of Higher Education, 84*(6), 866-896. doi:10.1353/jhe.2013.0033

- Barnes, L. (2013). A trauma shake-up: Are NZ graduates being prepared for the real world? *Pacific Journalism Review*, 19(1), 282-289.
- Baxter Magolda, M. B. (2001). *Making their own way: Narratives for transforming higher education to promote self-development*. Sterling, VA: Stylus.
- Baxter Magolda, M. B. (2002). Helping students make their own way to adulthood: Good company for the journey. *About Campus*, 6(6), 2-9.
- Baxter Magolda, M. B. (2008). Three elements of self-authorship. *Journal of College Student Development*, 49, 269-284. doi:10.1353/csd.0.0016
- Baxter Magolda, M. B. (2009). *Authoring your life: Developing an internal voice to navigate life's challenges*. Sterling, VA: Stylus.
- Baxter Magolda, M. B., & King, P. M. (Eds.). (2004). *Learning partnerships: Theory and models of practice to educate for self-authorship*. Sterling, VA: Stylus.
- Baxter Magolda, M. B., & King, P. M. (2012). *Assessing meaning making and self-authorship: Theory, research and application*. *ASHE Higher Education Report*, 38(3). doi:10.1002/aehe.20003
- Black, T. G. (2008). Teaching trauma without traumatizing: A pilot study of a graduate counseling psychology cohort. *Traumatology*, 14(3), 40-50.  
doi:10.1177/1534765608320337
- Bochner, A. P. (1997). It's about time: Narrative and the divided self. *Qualitative Inquiry*, 3(4), 418-438. doi:10.1177/107780049700300404
- Bochner, A. P. (2000). Criteria against ourselves. *Qualitative Inquiry*, 6(2), 266-272.  
doi:10.1177/107780040000600209

- Boucher, J. (2009). *The autistic spectrum: Characteristics, causes and practical issues*. Thousand Oaks, CA: Sage.
- Bryant-Davis, T. (2005). *Thriving in the wake of trauma: A multicultural guide*. Westport, CT: Praeger.
- Calhoun, K. S., & Atkeson, B. M. (1991). Social reactions to the survivor of suicide in the family: A review of the literature. *Omega*, 23 95-107.
- Calhoun, L. G., & Tedeschi, R. G. (1999). *Facilitating posttraumatic growth: A clinician's guide*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Carpenter, S., Makhadmeh, N., & Thornton, L. (2015). Mentorship on the doctoral level: An examination of communication faculty mentors' traits and functions. *Communication Education*, 64(3), 366-384. doi:10.1080/03634523.2015.1041997
- Carter, S., Blumenstein, M., & Cook, C. (2013). Different for women? The challenges of doctoral studies. *Teaching in Higher Education*, 18(4), 339-351. doi:10.1080/13562517.2012.719159
- Chang, H. (2008). *Autoethnography as method*. Walnut Creek, CA: Left Coast Press, Inc.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Christmas, T. J., & Horwich, A. (2003). Presentation of Germ Cell Tumors. In D. Raghavan (Ed.), *Germ cell tumors* (pp. 51-57). Hamilton, Ontario: BC Decker, Inc.
- Courtois, C. A., & Gold, S. N. (2009). The need for inclusion of psychological trauma in the professional curriculum: A call to action. *Psychological Trauma: Theory, Research, Practice, and Policy*, 1(1), 3-23. doi:10.1037/a0015224

- Crotty, M. (2003). *The foundations of social research: Meaning and perspective in the research process*. Thousand Oaks, CA: Sage.
- Cunningham, M. (2004). Teaching social workers about trauma: Reducing the risks of vicarious traumatization in the classroom. *Journal of Social Work Education*, 40(2), 305-317. doi:10.1080/10437797.2004.10778495
- Davidson, L. M., Fleming, I., & Baum, A. (1986). Post-traumatic stress as a function of chronic stress and toxic experience. In C. R. Figley (Ed.), *Trauma and its wake: Traumatic stress theory research and intervention* (Vol. 2, pp. 57-77). New York, NY: Brunner/Mazel.
- Denzin, N. K. (2014). *Interpretive autoethnography*. Thousand Oaks, CA: Sage.
- Didham, S., Dromgole, L., Csiernik, R., Karley, M. L., & Hurley, D. (2007). Trauma exposure and the social work practicum. *Journal of Teaching in Social Work*, 31, 523-537. doi:10.1080/08841233.2011.615261
- Dixon-Woods, M., Findlay, M., Young, B., Cox., H., & Heney, D. (2001). Parents' accounts of obtaining a diagnosis of childhood cancer. *Lancet*, 357, 670-674.
- Doloriert, C., Sambrook, S., & Stewart, J. (2012). Power and emotion in doctoral supervision: Implications for HRD. *European Journal of Training and Development*, 36(7), 732-750. doi:10.1108/03090591211255566
- Echevarría, M. E., Fangusaro, J., & Goldman, S. (2008). Pediatric central nervous system germ cell tumors: A review. *The Oncologist*, 13, 690-699. doi:10.1634/theoncologist.2008-0037
- Eiser, C., Parkyn, T., Havermans, T., & McNinch, A. (1994). Parents' recall on the diagnosis of cancer in their child. *Psycho-Oncology*, 3, 197-203.

- Ellis, C. (1995). *Final negotiations: A story of love, loss, and chronic illness*. Philadelphia, PA: Temple University Press.
- Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: AltaMira Press.
- Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry*, 13(1), 3-29. doi:10.1177/1077800406294947
- Ellis, C. (2009). *Revision: Autoethnographic reflections on life and work*. Walnut Creek, CA: Left Coast Press.
- Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An overview. *Forum: Qualitative Social Research*, 12(1), 1-14. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/1589/3096>
- Ellis, C., & Bochner, A. P. (2000). Autoethnography, personal narrative, reflexivity: Researcher as subject. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733-768). Thousand Oaks, CA: Sage.
- Flemons, D., & Green, S. (2002). Stories that conform/stories that transform: A conversation in four parts. In A. Bochner & C. Ellis (Eds.), *Ethnographically speaking: Autoethnography, literature, and aesthetics* (pp. 87-94, 115-121, 165-169, 187-190). Walnut Creek, CA: AltaMira Press.
- Freadman, R. (2004). Decent and indecent: Writing my father's life. In P. J. Eakin (Ed.), *The ethics of life writing* (pp. 174-194). Ithaca, NY: Cornell University Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago, IL: Aldine.

- Hastings, C. A., Torkildson, J. C., & Agrawal, A. K. (2012). *Handbook of pediatric hematology and oncology: Children's hospital and research center Oakland*. West Sussex, England: Wiley-Blackwell.
- Herbert, T. C., & Cohen, S. (1993). Stress and immunity in humans: A meta-analytic review. *Psychosomatic Medicine*, 55, 364-379. doi:10.1097/00006842-199307000-00004
- Irvine, S., & Cunningham-Burley, S. (1991). Mothers' concepts of normality, behavioural changes and illness in their children. *British Journal of General Practice*, 41, 371-374.
- Jackson, K., & Seeman, D. (2009). Psychotherapy with college student survivors of war and political trauma. *Journal of College Student Psychotherapy*, 23, 40-49. doi:10.1080/87568220802375241
- Jairam, D., & Kahl, D. H. (2012). Navigating the doctoral experience: The role of social support in successful degree completion. *International Journal of Doctoral Studies*, 7, 311-328.
- Kegan, R. (1982). *The evolving self*. Cambridge, MA: Harvard University Press.
- Kegan, R. (1994). *In over our heads: The mental demands of modern life*. Cambridge, MA: Harvard University Press.
- Kena, G., Musu-Gillette, L., Robinson, J., Wang, X., Rathbun, A., Zhang, J.,...Dunlop Velez, E. (2015). *The condition of education 2015* (NCES 2015-144). U.S. Department of Education, National Center for Education Statistics. Washington, DC. Retrieved November 21, 2015 from <http://nces.ed.gov/pubsearch>.

- Legault, G., & Allen, J. C. (2012). Germ cell tumors and other pineal region tumors. In R. J. Packer & D. Schiff (Eds.), *Neuro-oncology* (pp. 95-102). West Sussex, England: Wiley-Blackwell.
- Leibowitz, S. B., Shivdasani, R. A., & Kantoff, P. W. (2003). Management of extragonadal germ cell tumors. In D. Raghavan (Ed.), *Germ cell tumors* (pp. 243-264). Hamilton, Ontario: BC Decker, Inc.
- Lupton, D. (2013). 'It's a terrible thing when your children are sick': Motherhood and home healthcare work. *Health Sociology Review*, 22(3), 234-242.  
doi:10.5172/hesr.2013.2653
- Lyotard, J-F. (1984). *The postmodern condition: A report on knowledge*. Minneapolis, MN: University of Minnesota Press.
- Malogolowkin, M. H., Monforte, H. L., Kovanlikaya, A., & Siegel, S. E. (2003). Pediatric germ cell tumors. In D. Raghavan (Ed.), *Germ cell tumors* (pp. 265-286). Hamilton, Ontario: BC Decker, Inc.
- Martin, L. L., & Tesser, A. (1996). Clarifying our thoughts. In R. S. Wyer (Ed.), *Ruminative thought: Advances in social cognition* (Vol. 9, pp. 189-209). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Martinez, E., Ordu, C., Della Sala, M. R., & McFarlane, A. (2013). Striving to obtain a school-work-life balance: The full-time doctoral student. *International Journal of Doctoral Studies*, 8, 39-59. Retrieved from <http://ijds.org/Volume8/IJDSv8p039-059Martinez0375.pdf>



- Maxson, J. (2000). Training journalism students to deal with trauma: Observing reporters behave like 'creeps.' *Journalism & Mass Communication Educator*, 55(1), 79-86. doi:10.1177/107769580005500109
- McCann, I. L., & Pearlman, L. A. (1990). *Psychological trauma and the adult survivor: Theory, therapy, and transformation*. New York, NY: Brunner/Mazel.
- McNally, R. J. (2005). *Remembering trauma*. Cambridge, MA: The Belknap Press of Harvard University Press.
- Muskat, B., Riosa, P. B., Nicholas, D. B., Roberts, W., Stoddart, K. P., & Zwaigenbaum, L. (2015). Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. *Autism*, 19(4), 482-490. doi:10.1177/1362361314531341
- Neill, S. J. (2000). Acute childhood illness at home: The parents' perspective. *Journal of Advanced Nursing*, 31(4), 821-832.
- Nolte, M. C., Bruce, M. A., & Becker, K. W. (2015). Building a community of researchers using the research mentoring model. *Journal of Counselor Preparation and Supervision*, 7(2), 7-37. doi:10.7729/72.1070
- O'Halloran, M. S., & O'Halloran, T. (2001). Secondary traumatic stress in the classroom: Ameliorating stress in graduate students. *Teaching of Psychology*, 28(2), 92-97. doi:10.1207/s15328023top2802\_03
- O'Meara, K., Knudsen, K., & Jones, J. (2013). The role of emotional competencies in faculty-doctoral student relationships. *The Review of Higher Education*, 36(3), 315-347. doi:10.1353/rhe.2013.0021

- Owley, T. B. (2004). Treatment of individuals with autism spectrum disorders in the emergency department: Special considerations. *Clinical Pediatric Emergency Medicine*, 5, 187-192. doi:10.1016/j.cpem.2004.05.003
- Parks, C. L., Cohen, L., & Murch, R. (1996). Assessment and prediction of stress-related growth. *Journal of Personality*, 64, 71-105. doi:10.1111/j.1467-6494.1996.tb00815.x
- Pearlman, L. A., & Mac Ian, P. S. (1995). Vicarious traumatization: An empirical study of the effects of trauma work on trauma therapists. *Professional Psychology: Research and Practice*, 26(6), 558-565. doi:10.1037//0735-7028.26.6.558
- Penn, A., Jenney, M. E. M., Nicholson, J. C. (2014). Germ cell tumours in children and adolescents. *Paediatrics and Child Health*, 24(4), 148-154.
- Perry, W. G., Jr. (1968). *Forms of intellectual and ethical development in the college years: A scheme*. New York, NY: Holt, Rinehart, & Winston.
- Pizzolato, J. E. (2005). Creating crossroads for self-authorship: Investigating the provocative moment. *Journal of College Student Development*, 46, 624-641. doi:10.1353/csd.2005.0064
- Pizzolato, J. E., Nguyen, T. K., Johnston, M. P., & Wang, S. (2012). Understanding context: Cultural, relational & psychological interactions in self-authorship development. *Journal of College Student Development*, 53(5), 656-679. doi:10.1353/csd.2012.0061
- Pollard, C., & Kennedy, P. (2007). A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury:

- A 10-year review. *British Journal of Health Psychology*, 12, 347-362.  
doi:10.1348/135910707X197046
- Prati, G., & Pietrantonio, L. (2009). Optimism, social support, and coping strategies as factors contributing to posttraumatic growth: A meta-analysis. *Journal of Loss and Trauma*, 14(5), 364-388. doi:10.1080/15325020902724271
- Quarantelli, E. L. (1985). An assessment of conflicting view on mental health: The consequences of traumatic events. In C. R. Figley (Ed.), *Trauma and its wake: The study and treatment of post-traumatic stress disorder* (Vol. 1, pp. 173-218). New York, NY: Brunner/Mazel.
- Richardson, (2000). Evaluating ethnography. *Qualitative Inquiry*, 6(2), 253-255.  
doi:10.1177/107780040000600207
- Ronai, C. R. (1995). Multiple reflections of child sex abuse: An argument for a layered account. *Journal of Contemporary Ethnography*, 23(4), 395-426.  
doi:10.1177/089124195023004001
- Sanford, N. (1962). Developmental status of the entering freshman. In N. Sanford (Ed.), *The American college student* (pp. 253-282). Hoboken, NJ: Wiley.
- Saper, C. B., & Lowell, B. B. (2014). The hypothalamus. *Current Biology*, 24(23), 1111-1116.
- Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., & Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. *Journal for Specialists in Pediatric Nursing*, 15(3), 244-254. doi:10.1111/j.1744-6155.2010.00244.x

- Schaefer, J. A., & Moos, R. H. (1998). The context for posttraumatic growth: Life crises, individual and social resources, and coping. In R. G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 99-125). Mahwah, NJ: Lawrence Erlbaum Associates.
- Schmidt, M., & Umans, T. (2014). Experiences of well-being among female doctoral students in Sweden. *International Journal of Qualitative Studies on Health and Well-being*, 9(23059). doi:10.3402/qhw.v9.23059
- Shannon, P. J., Simmelink, J., Im, H., Becher, E., & Crook-Lyon, R. E. (2011). Exploring the experiences of survivor students in a course on trauma treatment. *Psychological Trauma: Theory, Research, Practice, and Policy*, 6(S1), S107-S115. doi:10.1037/a0032715
- Shapiro, S. L., Brown, K. W., & Biegel, G. M. (2007). Teaching self-care to caregivers: Effects of mindfulness-based stress reduction on the mental health of therapists in training. *Training and Education in Professional Psychology*, 1(2), 105-115. doi:10.1037/1931-3918.1.2.105
- Shortman, R. I., Beringer, A., Penn, A., Malson, H., Lewis, S. P., & Sharples, P. M. (2013). The experience of mothers caring for a child with a brain tumour. *Child: Care, Health and Development*, 39(5), 743-749. doi:10.1111/cch.12005
- Simon, C., & McNicholas, N. (2014). Children living with chronic disability. *InnovAiT*, 7(8), 502-508. doi:10.1177/1755738014541972
- Slaby, A. E. (1989). *Aftershock: Surviving the delayed effects of trauma, crisis and loss*. New York, NY: Villard.

- Soulders, M. C., Freeman, K. G., DePaul, D., & Levy, S. E. (2002). Caring for children and adolescents with autism who require challenging procedures. *Pediatric Nursing*, 28(6), 555-562.
- Spaulding, L. S., & Rockinson-Szapkiw, A. J. (2012). Hearing their voices: Factors doctoral candidates attribute to their persistence. *International Journal of Doctoral Studies*, 7, 199-219. Retrieved from <http://ijds.org/Volume7/IJDSv7p199-219Spaulding334.pdf>
- Spitzer, C., Barnow, S., Völzke, H., John, U., Freyberger, H. J., & Grabe, H. J. (2009). Trauma, posttraumatic stress disorder, and physical illness: Findings from the general population. *Psychosomatic Medicine*, 71(9), 1012-1017.  
doi:10.1097/PSY.0b013e3181bc76b5
- Tedeschi, R. G., & Calhoun, L. G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. Thousand Oaks, CA: Sage.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9, 455-471.  
doi:10.1002/jts.2490090305
- Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, 15(1), 1-18.  
doi:10.1207/s15327965pli1501\_01
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (1998). Posttraumatic growth: Conceptual issues. In R. G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 1-22). Mahwah, NJ: Lawrence Erlbaum Associates.

- Tennen, H., & Affleck, G. (1990). Blaming others for threatening events. *Psychological Bulletin*, 108, 209-232. doi:10.1037//0033-2909.108.2.209
- Twamley, E. W., Hami, S., & Stein, M. B. (2004). Neuropsychological function in college students with and without posttraumatic stress disorder. *Psychiatry Research*, 126, 265-274. doi:10.1016/j.psychres.2004.01.008
- Ullrich, P. M., & Lutendorf, K. (2002). Journaling about stressful events: Effects of cognitive processing and emotional expression. *Annals of Behavioral Medicine*, 24, 244-250.
- Vaz, I. (2010). Improving the management of children with learning disability and autism spectrum disorder when they attend hospital. *Child: Care, Health and Development*, 36(6), 753-755. doi:10.1111/j.1365-2214.2010.01144x
- Waterhouse, L. (2013). *Rethinking autism: Variation and complexity*. London, England: Academic Press.
- Wawrynski, M. R., & Pizzolato, J. E. (2006). Predicting needs: A longitudinal investigation of the relation between student characteristics, academic paths, and self-authorship. *Journal of College Student Development*, 47(6), 677-692. doi:10.1353/csd.2006.0071
- Weiss, R., & Parkes, C. M. (1983). *Recovery from bereavement*. New York, NY: Basic Books.
- West, I. J., Gokalp, G., Pena, E. V., Fischer, L., & Gupton, J. (2011). Exploring effective support practices for doctoral students' degree completion. *College Student Journal*, 45(2), 310-323.

- Wilson, J., & Lindy, J. (1994). Empathetic strain and countertransference. In J. Wilson & J. Lindy (Eds.), *Countertransference in the treatment of PTSD* (pp. 5-30). New York, NY: Guilford Press.
- Yoder, M. (2008). Helping in the wake of disaster: A graduate student's perspective in the aftermath of the VT tragedy. *Traumatology*, 14(1), 25-31.  
doi:10.1177/1534765607309941
- Zosky, D. L. (2013). Wounded healers: Graduate students with histories of trauma in a family violence course. *Journal of Teaching in Social Work*, 33(3), 239-250.  
doi:10.1080/08841233.2013.795923

Vita  
Kristen L. Tarantino

Birthdate: August 3, 1984

Birthplace: Richmond, Virginia

Education:	2012-2016	The College of William and Mary Williamsburg, Virginia Doctor of Philosophy
	2015-2016	The College of William and Mary Williamsburg, Virginia College Teaching Certificate
	2010-2012	The College of William and Mary Williamsburg, Virginia Master of Education
	2002-2006	Virginia Commonwealth University Richmond, Virginia Bachelor of Arts