

Death of a child to Tay-Sachs or other progressive neurological disorders:
Long-term impact on parents' emotional and personal lives

Master's Thesis

Presented to

The Faculty of the Graduate School of Arts and Sciences
Brandeis University
Department of Biology

Judith Tsipis, Advisor

In Partial Fulfillment
of the Requirements for the Degree

Master of Science
in
Genetic Counseling

by

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May 2014

ACKNOWLEDGEMENTS

Many thanks to my dedicated thesis committee: Blyth Lord, Dita Obler, MS, CGC, and Judith Tsipis, PhD. Your investment in my project and passion for the topic brought greater meaning to my research and personally inspired me. I'm certain I will reflect back on our conversations throughout my career.

Thank you also to the Brandeis Genetic Counseling program and faculty including Judith Tsipis, Gretchen Schneider, Beth Rosen-Sheidley and Missy Goldberg, as well as my classmates. I appreciate all your support on this difficult but rewarding journey!

ABSTRACT

Death of a Child to Tay-Sachs and other progressive neurological disorders:
Long-term impact on parents' emotional and personal lives

A thesis presented to the Department of Biology

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Caring for and surviving the death of a child with a life-limiting illness has a profound and lasting effect on parents' lives. Many studies have explored the emotional changes parents may experience shortly after their loss, but few have examined the long-term effects. It is important for genetic counselors that may work with these families to understand the range of experiences that can come with time. To explore the long-term experience, we designed an online anonymous survey that included questions about the deceased child's illness and death, validated assessments of prolonged grief and posttraumatic growth, as well as questions about relationships with family, friends, work, and faith. We requested the participation of parents whose children died two or more years ago to a life-limiting, progressive, neurological condition through the National Tay-Sachs & Allied Diseases Association (NTSAD) and the National Mucopolysaccharidoses Society (MPS Society). Our study population, on average, experienced a moderate amount of posttraumatic growth, with a mean score of 27.62 on a 0-50 scale with highest scores in the subfactors of "appreciation of life" and "personal strength". Some parents in our study reported difficulty motivating themselves for certain activities and trouble connecting with people who had not experienced a similar loss, but only a small minority of the study population met criteria for prolonged grief disorder (PGD). Since the death of their affected

child, parents widely reported improvement in their relationships with their other children but little change in their relationships with parents, siblings, friends, colleagues and their work. Relationships with their partner or child's other parent, as well as their personal faith and faith community experienced larger proportions of change, resulting in an almost even split between better, worse, and neither. Almost all of our 62 participants reflected on the care of their affected child without regret. The results of this study highlight the coexistence of difficulty and positive change in bereaved parents as well as the importance of support both during and after their child's illness and death.

Keywords: parental bereavement, life-limiting illness, Tay-Sachs Disease, posttraumatic growth, grief, meaning-making

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INTRODUCTION

The death of one's own child can be a deeply traumatic event. Catherine Sanders' 1980 study showed that bereaved parents had the most intense and varied grief when compared with adults who had lost a spouse or parent (Sanders 1980). Most studies focus on the immediate responses to bereavement, which can include anger, denial, guilt and other strong emotions. However, many parents continue to experience an emotional response for years afterward as they mark their lives with what would have been their deceased child's milestones (Rando 1985). Additionally, personal growth can occur as a result of parental bereavement in the form of reordering priorities or reevaluating world-views. An important aspect of world-view reconstruction and subsequent growth is finding meaning in the loss (Lichtenthal et al. 2010). Research into what factors (i.e. education, time since death, support systems, personality) influence these bereavement outcomes is ongoing (Engelkemeyer and Marwit 2008).

A phenomenon known as "anticipatory grief" can occur in situations where a life-limiting diagnosis is made (Rando 1983). Though parents may begin to grieve the loss of their child as soon as they learn the prognosis, the grief response when the child dies can be just as intense as loss due to unexpected circumstances (accident, acute illness, etc.) (Sanders 1980). Though a few studies could be found in the literature involving families affected by what can be considered more common non-infectious illnesses, such as cystic fibrosis and cancer, there are no published studies on the unique aspects of losing a child to a rare, genetic, progressive neurological condition. Disorders that fall into this category include Tay-Sachs, Canavan,

Sandhoff, leukodystrophies, GM-1 gangliosidosis, certain mucopolysaccharidoses and many others. A diagnosis of any of these portends increasing loss of neurological function and eventual death. Studies of these conditions tend to focus on population screening and only contain anecdotal information about affected families (Schweitzer-Miller 2001). Studies of long-term parental bereavement outcomes in particular are infrequent and usually involve a broad, nonspecific range of situations (Rogers et al. 2008).

The purpose of this study is to identify the long-term impact, both positive and negative, on parents after the death of their child to a rare, genetic disease that is incurable and also neurologically progressive. Specifically, we will focus on

- Parents' grief experience and possible impact on mental health (prolonged grief),
- Parents' perceived positive outcomes, such as personal growth and/or shift in life priorities
- Positive or negative changes in personal relationships
- Factors that could be correlated with the positive and negative bereavement responses, such as interval of time between symptom onset and diagnosis and death, time passed since death, sources of support, and demographic factors.

As genetic counselors, we work with families at the beginning of their diagnostic process to help them understand what their future may hold. It is important for us to understand how families evolve following the tragedy of their child dying, not just in the short term, but for the rest of their lives. The results of this study will fill a gap in the literature on how parents grapple with the aftermath of a life-limiting genetic diagnosis, their child's death and the years that follow.

METHODS

We collected data through an online anonymous survey of parents whose children have died from a life-limiting, neurological, genetic disease. To be included in our study, participants had to be at least 18 years old, English-speaking and the parent of a child who was diagnosed with and died from a life limiting, neurodegenerative, genetic disorder two or more years ago. This diagnosis may have been based on clinical phenotype or genetic testing.

We recruited research subjects through the National Tay-Sachs & Allied Diseases Association (NTSAD) and the National Mucopolysaccharidoses Society (MPS Society). Each group sent a mass email to bereaved families within their networks, and NTSAD posted a Facebook message to a bereaved parents group within the organization. The emails and Facebook post included an introduction to the study and hyperlink to the online survey (see Appendix A for recruitment notice). Two committee members, B. Lord and D. Obler, spread word of the study through their personal and professional contacts.

The Brandeis University Institutional Review Board approved this study.

Data Collection

The anonymous online survey was built using Qualtrics software. A welcome page included an explanation of the survey with associated risks and benefits, and prompted participants to give their consent to participate before moving forward (see Appendix B for welcome and informed consent). The questions on the survey were divided into 4 major sections (see Appendix C for survey instrument).

Section 1: The first section included a number of multiple-choice questions to obtain demographic information about the respondents.

Section 2: The second section included multiple choice and open-ended questions about the circumstances of the deceased child's life, onset of symptoms, illness and death.

Section 3: The third section included a series of multiple choice and open-ended questions to learn about the choices each family made in caring for their child, changes in relationships, and what impact their child's death has had on them.

Section 4: The last section was comprised of two validated psychometric inventories, one designed to measure posttraumatic personal growth and the other to screen for symptoms of prolonged grief disorder.

Posttraumatic Growth Inventory – Short Form (PTGI-SF) – The PTGI-SF consists of 10 statements with which the respondent indicates his or her agreement, ranging from “I did not experience this change” to “I experienced this change to a very great degree.” The statements represent five factors, “relating to others”, “new possibilities”, “personal strength”, “spiritual change”, and “appreciation of life.” Responses are scored on a scale of 0-5 and totaled. A zero represents the least posttraumatic growth and a 50 indicates the most (Cann et al. 2010). This instrument had high internal consistency reliability with a Cronbach's α of 0.84.

Prolonged Grief Disorder (PG-13) – The PG-13 is a diagnostic tool used to identify individuals who meet criteria for a diagnosis of prolonged grief disorder based on the elevation of certain symptoms at least 6 months after a loss and associated with significant functional impairment. Respondents are asked to indicate how frequently or intensely they experience certain feelings ranging from “not at all” to “several times a day” or “overwhelmingly” (Prigerson et al. 2009).

All questions, except consent on the first page, could be skipped and respondents could exit the survey and complete it later if desired. We stored the data online under password protection on the Qualtrics site during the three-week data collection period, and then downloaded it to a password-protected computer for analysis.

Data Analysis

The data was uploaded to IBM SPSS Statistics Version 21 and analyzed to find statistically relevant correlations between variables designated as predictor or outcome variables. Below is a sampling of our assorted variables, which we mixed and matched.

Predictor Variables	Outcome Variables
Demographic factors	Presence or absence of prolonged grief symptoms
Length of time between child’s first symptoms until their diagnosis	Current scores on Posttraumatic Growth Inventory (PTGI)
Length of time between child’s first symptoms until their death	Changes in relationships
Length of time since child’s death	Choices in memorializing the child*
Age of child at symptom onset, diagnosis and death	Meaning found in their child’s death*
	Advice given to other parents*

We coded responses to open-ended questions (indicated by *) for quantitative or qualitative analysis, depending on complexity of response.

RESULTS

Participant Demographics

The survey was emailed to approximately 250 families through NTSAD and 36 families through the MPS Society. Of those, 62 individuals completed the majority of survey questions. Most of the respondents were white (96.8%), female (85.5%), married (82.2%) and had an educational level of associates degree or greater (78.7%). Demographics are summarized in Table 1.

TABLE 1: Demographics			
Participant Age (years)	Range= 27-72, Mean= 49		
Gender	N	Percent	
Female	53	85.5%	
Male	9	14.5%	
Total	62	100%	
Relationship Status			
Married	51	82.2%	
Divorced	4	6.5%	
In a Relationship	2	3.2%	
Single	2	3.2%	
Divorced+ In a Relationship	1	1.6%	
Other	1	1.6%	
Total	61	100%	
Ethnicity and Race			
White	60	96.8%	
Other	2	3.2%	
Total	62	100%	
Education			
Some elementary/middle/high school	1	1.6%	
High school graduate	4	6.6%	
Some college	8	13.1%	
Associate's or other 2-year degree	17	27.9%	
Bachelor's or other 4-year degree	20	32.8%	
Master's degree	5	8.2%	
Professional degree (MD, DVM, JD, etc)	4	6.6%	
Doctoral degree (PhD, EdD)	2	3.3%	
Total	61	100%	

Child's Illness and Death

Almost half of the participants had a child affected with the infantile form of Tay-Sachs (44.3%); the next largest group lost their child to Sandhoff Disease (13.1%). Other diseases that participant families had been affected by included GM1 (Types 1 and 2), MPSII - Hunter Syndrome, MPSIII - Sanfilippo Syndrome, Canavan Disease, Juvenile and Late-Onset Tay-Sachs Disease, Metachromatic Leukodystrophy and mosaic Trisomy 13. (Table 2)

Data provided about participants' children is summarized in Table 2. The age of first symptoms onset ranged from 6 months or less (approximated by .25 year) to 11 years, with an average of 1.58 years. Age at diagnosis ranged from 6 months or less (approximated by .25 year) to age 15, with an average age of 2.16. The child's age at his or her death ranged from 6 months or less (approximated by .25 year) to 42 years old.

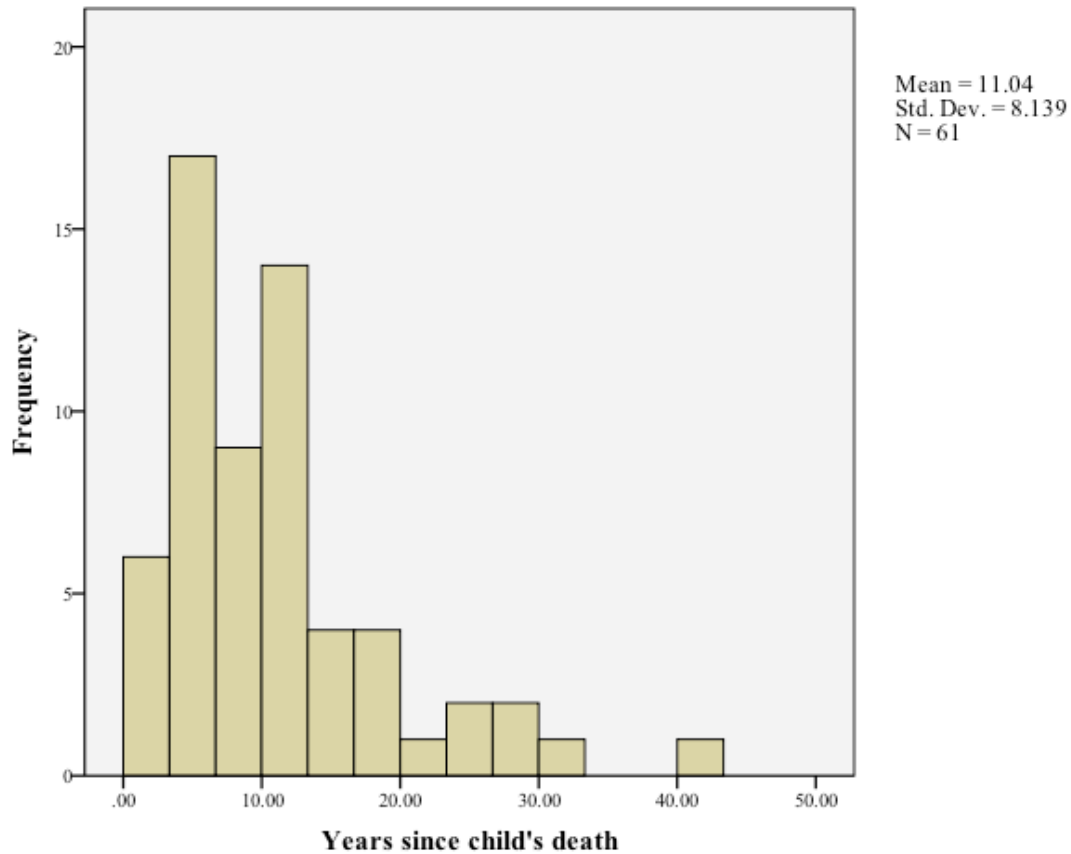
Almost all parents had a biological relationship with their deceased child (61/62), only one parent reported adopting their child. More than half of participants reported having a child or children prior to their deceased child (n= 33, 53.2%). Thirty-nine families went on to have more children after their affected child (63%). Of these, five families reported adopting additional children.

TABLE 2 – Diagnoses and associated time points in child’s illness and death (Mean and range)

Diagnosis (n)	Age of child - first symptoms (years)	Age of child – diagnosis (years)	Age of child – death (years)
Tay-Sachs, Infantile (27)	.61 (.25 - 1)	.91 (.75 - 1)	3.44 (1 - 7)
Sandhoff (8)	.69 (.25 - .75)	.94 (.75 - 1)	3.0 (2 - 6)
GM1 (5)	.65 (.25 - 1)	.90 (.75 - 1)	3.20 (1 - 6)
MPSIII (Sanfilippo) (6)	2.67 (1 - 5)	4.17 (2 - 7)	11.6 (4 - 16)
MPSII (Hunter) (5)	2.0 (1 - 3)	3.4 (2 - 5)	19.0 (12-23)
Canavan (3)	.25 (All .25)	.67 (.25 - 1)	6.08 (.25 - 11)
Tay-Sachs, Juvenile (2)	5.0 (2 - 8)	6.5 (2 - 11)	10.5 (6 - 15)
Tay-Sachs, late-onset (2)	8 (5 - 11)	13 (11 - 15)	37.5 (33 - 42)
GM1, Type 2 (1)	8	1	11
Metachromatic Leukodystrophy (1)	8	10	10
Other: Mosaic Trisomy 13 (1)	0.25	0.25	0.25

The amount of time passed since the child’s death ranged from two to 42 years. Most participants reported 13 or fewer years since the death of their child (Figure 1).

FIGURE 1: Years since child's death

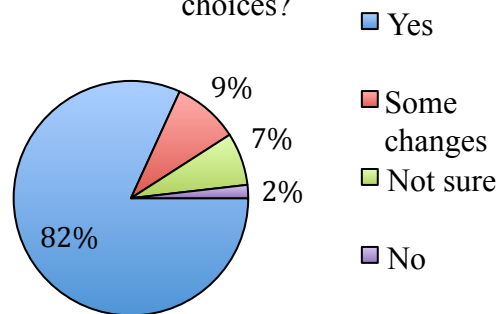


When asked whether, in retrospect,

they would make the same choices regarding medical care for their deceased child, a large majority of parents clearly stated, “yes” (81.8%). Five others mentioned some care decisions they would have done differently (9.1%), four participants said they were unsure if they would make the same choices

(7.3%), and only one participant gave a firm answer of “no” (1.8%). The responses to this question did not significantly relate to any other variables.

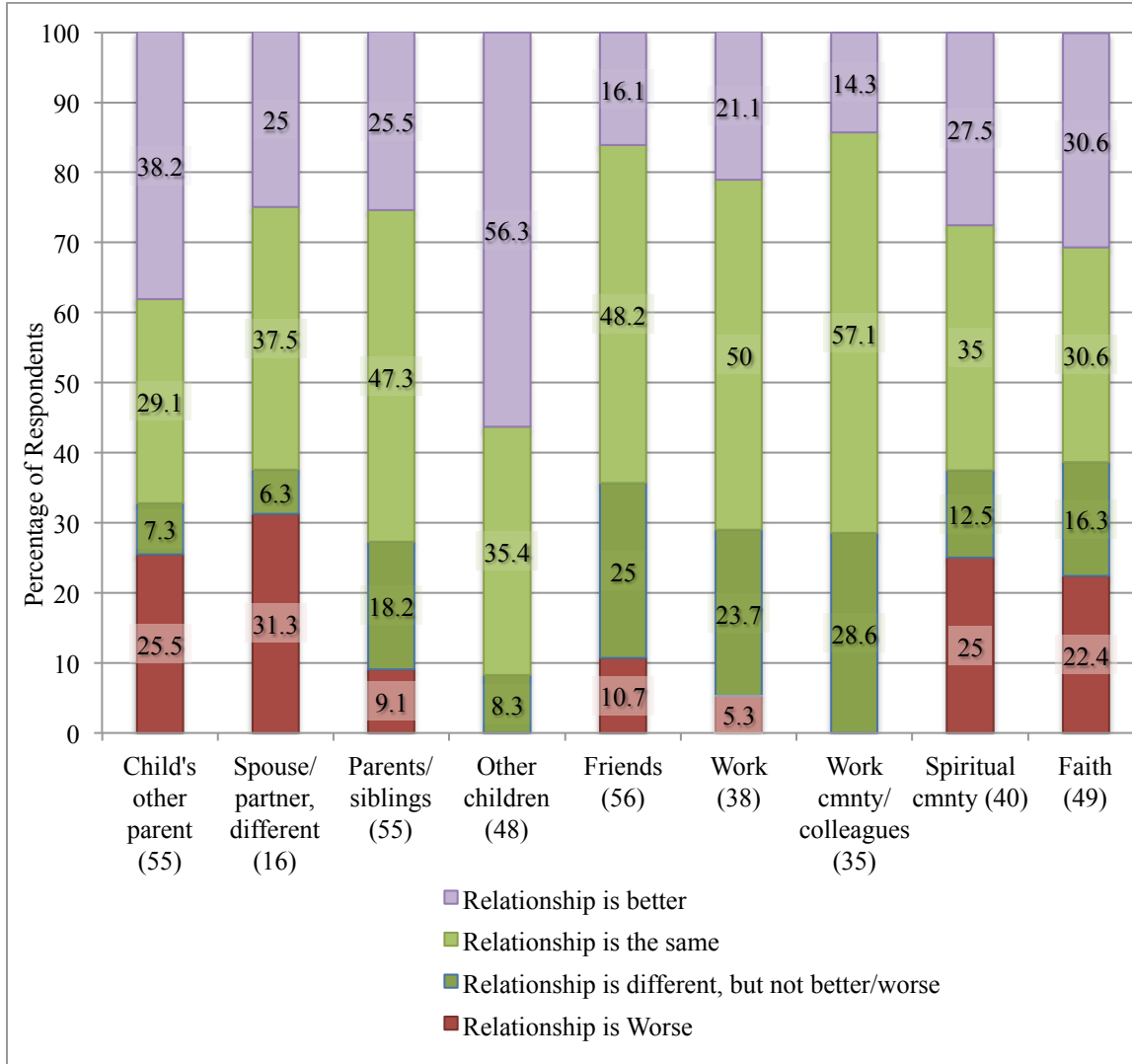
FIGURE 2: Looking back, would you make the same medical care choices?



Relationships

Parents rated how their relationships had changed since the death of their child, summarized in Figure 3. The most significantly improved relationship was with their other child or children. Of the 48 respondents, 56% reported this relationship is better, and none responded that it is worse. The relationship with the next highest proportion reported as better is with the child's other parent. Of the 55 parents who responded to this question, 38.2% reported it is better, 29.1% reported it is the same, and 25.5% reported it is worse. Nonparametric tests of medians and distributions showed that responses on this relationship were not related to length of illness or time since death. Sixteen parents reported on a relationship with a spouse/partner who is not the parent of their deceased child. Of these, 37.5% reported it is the same, 25% reported it is better, and 31.3% reported it is worse. Relationships with friends, other family members (parents and siblings), work and work community were most frequently reported to have stayed the same. Parents' relationships with their spiritual community and their faith also largely stayed the same (35% and 30.6% respectively) but large percentages reported better (27.5% and 30.6%) and worse relationships (25% and 22.4%).

FIGURE 3: Trends in relationship changes



Psychometric Inventories

Prolonged Grief Disorder (PG-13)

We analyzed responses to the PG-13 questionnaire to determine if any participants met diagnostic criteria for prolonged grief disorder. Of the 60 participants who completed the questions, only 4 participants (6.7%) met criteria for a prolonged grief disorder diagnosis. They significantly differed from the others in terms of time passed since the child's death, with a mean of 5.7 years as opposed to 11.7 years. This group also consisted entirely of families affected by illnesses with an onset within the first year of life. Thus, there were significant differences in the mean length of children's illnesses, and mean ages at diagnosis and death (Table 3).

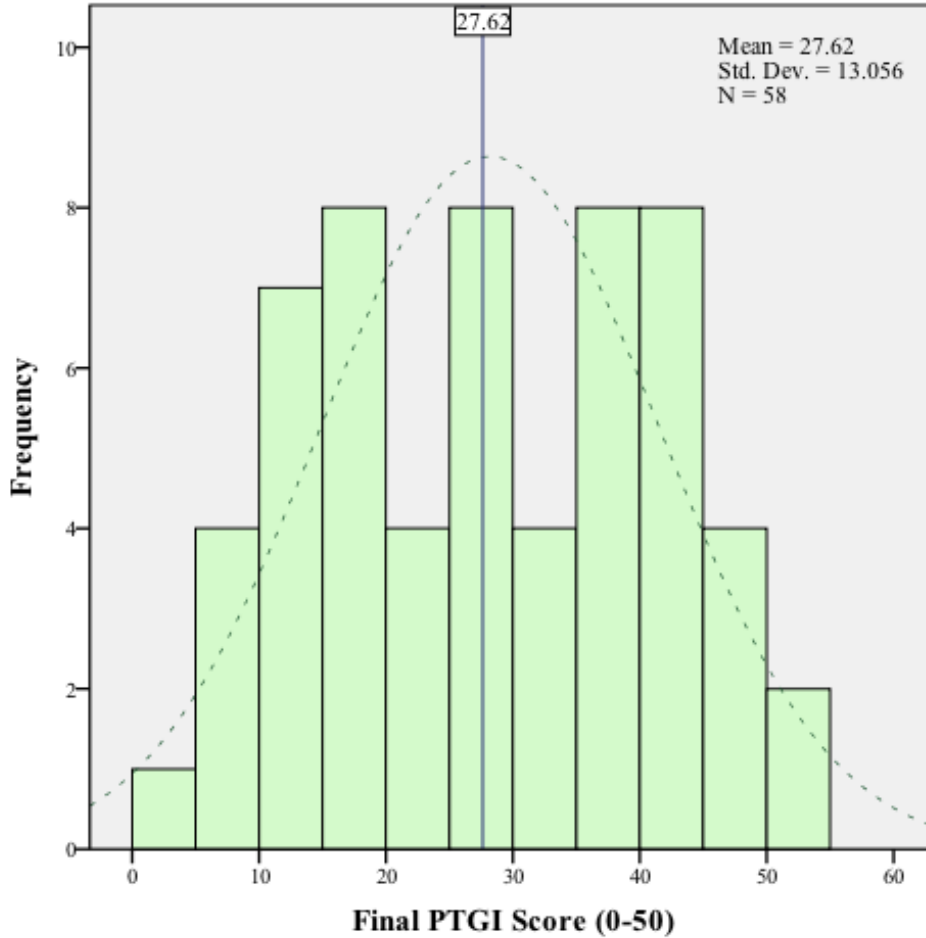
TABLE 3: Comparison of means grouped by presence/absence of Prolonged Grief		N	Mean	Significance (2-tailed)
Age of child - at diagnosis	No prolonged grief	56	2.3	.001
	Prolonged grief dx	4	.75	
Age of child - at death	No prolonged grief	55	7.6	.012
	Prolonged grief dx	4	2.6	
Length of Illness	No prolonged grief	55	5.95	.000
	Prolonged grief dx	3	.83	
Time since death	No prolonged grief	55	11.7	.002
	Prolonged grief dx	4	5.7	

The two groups meeting or not meeting the prolonged grief criteria were not significantly different in other measures of participant demographics, child's illness or PTGI score

Posttraumatic Growth Inventory (PTGI)

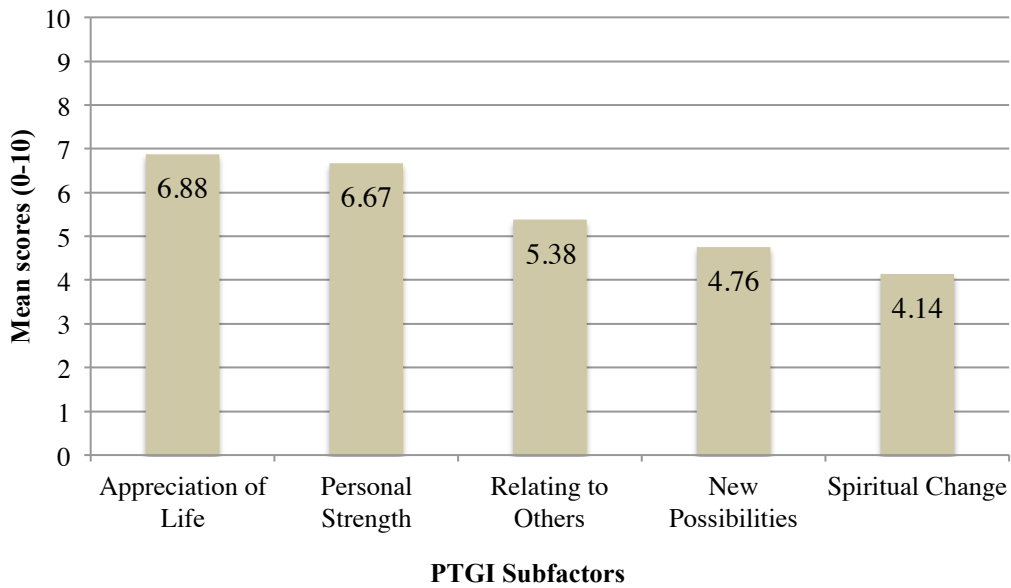
Responses on the PTGI varied widely, with scores ranging from 3 to 50 (on a scale of zero to 50). The mean was close to the middle at 27.62 (std dev. = 13.1).

FIGURE 4: Posttraumatic Growth Inventory (PTGI) score distribution



As shown in Figure 5, the subfactors that participants scored most highly on pertained to “appreciation of life” and “personal strength.” These scores were significantly higher than the other three subfactors of “new possibilities”, “relating to others” and “spiritual change”(with a Bonferroni correction at an adjusted α of .005). The “spiritual change” subfactor garnered the lowest scores and had the greatest standard deviation (3.8), indicating the responses in this category were the most varied.

FIGURE 5: Scores on PTGI Subfactors



Using Analysis of Variance (ANOVA), we determined no significant differences in PTGI scores by gender, educational level or type of illness. Using Pearson’s bivariate analysis, we found no correlation between PTGI score and participant age, number of years passed since the death of their child, or the age of the child at onset of symptoms. We found moderate negative correlations between a person’s total PTGI score and the length of illness ($r = -.282$, sig. = .035), age of child at diagnosis ($r = -.296$, sig. = .024), and age of child at death ($r = -.263$, sig. = .048). The PTGI score was most significantly correlated, also negatively, with the length of time between symptom onset and diagnosis ($r = -.410$, sig. = .002).

DISCUSSION

Relationships

Parents reported the greatest amount of change, for the better and for the worse, in the relationships that could be inferred as the closest and/or most personal. These included relationships with other children, the deceased child's other parent or other partner/spouse, and faith and spiritual community.

The relationship with other children was the most frequently described as being better since the affected child's death. Few parents chose to comment further on this relationship.

Those who did describe how their other children motivated them to move forward after their loss, but also indicate that it did not lessen the pain they felt:

Respondent #37: My healthy child got me out of bed and gave me the will to go on, he still does. The days may get easier, but there are days that something can trigger a memory and it all comes flooding back (not many but they are still there).

Respondent #11: My son was a month old when my daughter died. He forced me to get of bed everyday and push through. I don't know that I have the relationship with him, that I would have if my daughter didn't pass away. Having a dying child changes you.

Parents' responses about their relationship with their child's other parent and/or other spouse/partner were split amongst better, worse and neither ("the same" or "different but neither better nor worse"). Most comments on this relationship pertained to ways the relationship had changed negatively, and almost all reflected themes of individualized grief with difficulty communicating and supporting one another.

Respondent #25: I feel like my husband and I have grown apart. My perception is that we simply couldn't support each other during our grieving, as we were each suffering. How does one help another person when they are suffering, too?

Respondent #32: *It's hard to maintain a marital relationship with all the grief and stress, and hard to emerge from it together. We've done it, though our relationship is not as carefree and easy as it was before.*

Respondent #46: *My child's other parent and I had vast differences in the way we coped with this great challenge in our lives. It was often difficult to support each other because of this.*

Relationships with parents and siblings, friends, work, and work colleagues were most frequently reported to have stayed the same. With regards to parents and siblings, the second most frequent response was that the relationship is better.

Respondent #21: *Her death has drawn the family closer together. We appreciate the time we have together so much more. She touched the hearts of everyone she ever met. To this day, when her name is mentioned, the other person smiles in memory. All of my relationships have been enriched by the life and death of my daughter.*

With regards to friends, work and work colleagues, after “relationship is the same”, the second most frequent response was “relationship is different, but not better or worse.” Some parents described a shift in supportiveness, with some relationships becoming closer, and others more distant. Others described feeling critical or jealous of other families who had not experienced similar tragedies.

Respondent #40: *We found that some of the people we thought we were closest to couldn't handle the death of a child and pulled away. Those that remained are still close and a big part of our lives and I am ever grateful for their love and support. Many people we didn't know very well stepped up and helped when least expected. Help and support often comes from where you don't expect it.*

Respondent #11: *... I think the only thing I might feel sometimes with siblings or friends is jealous. That their lives go on, their kids grow up. They know we lose a child, but it doesn't impact them the way it does us. Wondering what she would look like, how her personality would be etc.*

Respondent #37: *I try not to dwell on the past, but there are times I find myself critical of others that have not walked in my shoes. Especially when they have not experienced loss and seem to take things for granted. I've learned early is not fair!*

There were several participants who marked that several of their relationships were worse. One parent described this worsening as a lack of support from friends and family, which led to pain and distrust.

Respondent #55: Most of our friends disappeared, as did extended family. One friend has been with me throughout it all and is still there. The aftermath of our daughter's death was ugly and a very painful period. I was still caring for our son whose health was quickly ailing. I found that people I thought were my friends were not ...

Several parents chose to comment on new relationships that were made as a result of their child's illness and death within the disease community or with other bereaved parents. The support given from these relationships was also mentioned in the form of advice, in which many parents encouraged those newly diagnosed to become involved in organizations such as NTSAD or the MPS Society.

Respondent #4: After my child was hospitalized I became very involved with the Tay-Sachs organization and the TS testing program that soon followed. That was very therapeutic for me.

Respondent #17: The Compassionate Friends, an international organization, meets monthly. The group I belong to is for parents of children who have died. This has been a source of comfort; everyone understands without saying a word....

Respondent #40: NTSAD - don't know what I would have done without the office staff and especially the other parents. Those of us with children with rare diseases and terminal diseases are the best resources - both for the practical aspects of caring for our children, and also the emotional support we can receive from someone who has walked in our shoes.

Respondent #50: Mainly the support group for MPS was a main source of support.

Discussion of parents' relationship with faith is included in "Growth" section.

Parents' Experience with Grief

The vast majority of participants (56/60) who completed the PG-13 questionnaire did not meet diagnostic criteria for prolonged grief disorder (PGD). These participants did not differ significantly from other participants in terms of demographics or most other survey variables we examined. The four participants who met PGD criteria were notable for being comprised exclusively of mothers whose children had died from a disease with infantile onset, with the child's age at death ranging from under 6 months to 6 years. On average, the length of time since their child's death was significantly shorter than other participants who completed the PG-13 questionnaire. Three of these four parents chose to comment further after the PG-13 questionnaire. Their responses indicated that they continue to experience trouble functioning in their daily life.

Respondent #7: *I have horrible anxiety and do not like meeting new people. I'm lost and desperate for more children. My marriage problems keep my grief real every day.*

Respondent #13: *I have never gone back to work full time. Feel like I cannot be bothered. Have kept the cleaning lady I had when she was here because I cannot be bothered with the housework...[].... I don't enjoy myself the same when and if I go out with friends and quite often turn down invitations...*

Respondent # 35: *I feel as though getting up in the morning I just do not want to because my son is not there to bring a smile to my face or in need of me anymore*

Responses about relationships from these four parents did not vary significantly from the rest of the participants. Open-ended responses regarding their child's illness indicated that these parents tended to be less satisfied than the other 56 participants with their child's healthcare during the child's end-of-life and death and were more likely to indicate they would not make the same care choices in retrospect. This speaks to the importance of supportive care in parents' decision-making at the end of their affected child's life. Of note, these four parents did not have significantly different scores on the posttraumatic growth inventory than the other participants.

Two parents scored 10 or less, but the other two scored 38 and 44 (on a scale of 0-50). This indicates that prolonged grief and posttraumatic growth are not mutually exclusive experiences and bereaved parents may be undergoing positive change even while suffering severe grief.

Parents who did not meet prolonged grief criteria commented on their grieving process in open-ended questions. Many looked back on the experience as having survived a certain phase.

Respondent #2: *My son passed away 8 years ago so I feel that I have "come out on the side". Meaning I have "healed" as much as a parent can. When I think of my son now mostly they are happy thoughts of him. I do get sad but it is less frequent.*

Respondent #5: *It has been many years since my daughter died (28) and time does make things easier. Even though I still miss her (and was more upset than usual because a few days ago would have been her 34th birthday) I can cope better than I could in the first few years.*

Respondent #34: *I did feel all those things, emotionally numb - in the beginning, trouble accepting her death, bitterness (compared to other children who are allowed to live), unfulfilling life, hugely anxious life but I do feel that I have come through the worst of that for the moment.*

Others commented on continuing struggles such as connecting with other people or motivating themselves for activities outside the home (one described herself as a “slug”, another as a “couch potato extraordinaire”)

Respondent #46: *I just feel very different from most people I interact with. They just don't have the same perspective that I do. I feel much more comfortable in the presence of other parents who have lost children.*

Others described feeling like a different person now and growing to accept that they would not return to their “old self.”

Respondent #55: *I know I am not the same person I was before. I have waited for that to change, to be who I was before. I have recently come to the conclusion that is not going to change. I am forever changed, a different person, different viewpoint on life, on people.*

Respondent #33: *I am not confused about my role in life but a part of me did die with my child and I will never be who I was and life has changed. There is a "new normal." A person never really "accepts" the loss of a child. It is what it is.*

The majority of our participants emphatically stated that looking back, they would not change the decisions they made regarding the medical care of their deceased child. Many statements

reflected the importance of support in their individualized care decisions.

Respondent #55: *Yes [would make the same choices, looking back]. I think I can say this without hesitation. We were fortunate to have a caring, compassionate physician who worked with us to achieve our goals.... to keep our child comfortable and to keep her at home so she could die surrounded by her family, in the home she was comfortable in.*

Parents' Experience with Growth

Scores on the Posttraumatic Growth Inventory varied widely, indicative of the vast range of experiences our participants represent. The average score being only slightly higher than the exact middle indicates a moderate amount of growth overall. While there were no obvious trends according to participant's age, gender or education, the child's diagnosis or amount of time passed since the child's death, we did find that parents whose children developed symptoms, were diagnosed and died at younger ages demonstrate more posttraumatic growth. The most highly reported growth experiences related to "appreciation of life" and "personal strength." Feelings about appreciation of life were also reflected in statements parents made in comments after the PTGI as well as in response to open-ended questions about life changes.

Respondent #14: *Life is more precious because we have lived with death. I refuse to compound the tragedy of our son's death by not living life to the full.*

Respondent #21: *Her life taught us about unconditional love, about appreciating the simple things in life, about complete detachment from material things, about finding joy even in suffering, about singing your heart out even when it hurts. We have all been humbled by her lessons.*

Respondent #54: *Nothing I can do will be better than caring for my children. But I consciously chose to improve my life and those around me. I feel that I honor my kids by living life well so they can live on through me.*

Respondent #56: *[Our child] gave us the power of perspective. The lenses that we look through today are different than if we had not had [our child] in our lives. He taught us what's important in life and what true happiness is.*

Though it was the second-highest scoring subfactor, there were few open-ended comments on the topic of personal strength. Of these, many remarks regarded frustration with others'

perception of their strength. The responses indicate that although many bereaved parents do indeed show tremendous strength, they are uneasy with the feeling of being set apart as “stronger” than their peers because of their experience.

Respondent #44: *The question above.... I discovered that I'm stronger than I thought I was. Honestly, this is a question that really bothers me. People tell me this all the time. "Gosh, you are a strong person. I couldn't imagine dealing with what you have. You are the strongest person I know. WHY? Because I "appear" strong? I never thought of myself as being strong, nor do I think I am stronger than anyone else because of what has happened. Stronger in what way? We did what I hope any other parent would have done. We gave our child a life filled with love. Now, our child is gone and because we gave so much to her, I feel a little deflated because I can't give her anymore.*

Respondent #55: *I know that I am strong and can handle difficulties, I just do not want to! However, people think I should be able to take on all the difficult things because of what I have been through. I have always been strong and people have always expected me to take care of everything. I keep wondering, when is someone going to take care of me.*

The PTGI subfactor of “spiritual change” garnered the lowest scores, but also had the widest range of responses. Additionally, relationships with faith and faith community were frequently noted to have changed, both for better, worse and neither. Only a few participants chose to comment further on a lack of spiritual growth or worsened relationship with faith.

Respondent #11: *I was raised Catholic but don't practice and can't understand how God could do this to anyone, so I am not helped by faith.*

Respondent #53: *I was an atheist before her birth, and her life gave affirmation to this belief, and made me an existentialist. A loving God doesn't do this to children. There is no meaning to life, and you can't give it any.*

Many parents described their faith as a great source of support and found comfort in picturing their child healed in heaven. Others received support through their religious community, while some described themselves as “more spiritual”, without organized religion.

Respondent #6: *My faith has carried me through this difficult time... Learn to trust God and know that he is there for you*

Respondent 43: *My faith has been a huge factor in my/our healing process. While we miss our child very much on a daily basis, we know she is fully healed in Heaven. And she is waiting for*

us there. Her life, while short, was meaningful and had a purpose.

Respondent#46: After my son was diagnosed, I had virtually nothing to do with my religious faith or community. I just couldn't believe this was happening. I got no support from our then religious leader. However, when we got a new religious leader who was phenomenal in his ability to provide support, somehow I went back to my religion. This was one of the best things I ever did.

Respondent # 54: I am not religious at all now. But I am spiritual. I am more connected to God and understand more than religion taught.

Study Limitations

Though we are able to draw some conclusions from our study, it is limited by sample size and bias. The information we gathered may not be representative of all parents whose children died of a progressive neurological disorder. Our time constriction and available resources limited us to literate, English-speaking parents with internet access. Recruitment through disease advocacy organizations may have focused our sample on parents who are connected with support services, as opposed to those who may be isolated. Due to the data collection tool being an online anonymous survey, the sample population is skewed by self-selection. Our participants were almost exclusively white, predominantly female, and heavily coupled. Additionally, many variables pertaining to the child's illness did not represent an even distribution. For example, about 70% of families had been affected by a disorder with onset in infancy, so some of our statistics regarding illness and death time points may be influenced by this overrepresentation. That said, our study shed light on the experiences of parents bereaved by genetic neurological disease that raise important issues to explore further, with these families as well as others not represented in this preliminary sample.

CONCLUSIONS

The participants in our study reported experiences that included both extreme difficulty and positive change. Experiences did not appear to vary according to type of illness, or demographics of the parent. Only a small minority of our sample met clinical criteria for prolonged grief disorder. Those that did tended to have parented a child with an infantile onset condition and experienced the loss more recently. These four also tended to reflect on the medical care of their affected child during their illness and death with dissatisfaction. The majority of our participants firmly stated that they would make the same care choices and voiced the importance of support in this. Though most participants in our study did not meet criteria for prolonged grief disorder, many remarked that they experienced some symptoms such as difficulty connecting with other people who had not experienced similar loss and lack of motivation for certain activities.

Overall, our study participants demonstrated a modest amount of posttraumatic growth. The wide range and lack of correlation with other variables indicate that this is a very individualized experience and it cannot be assumed that all bereaved parents will experience positive changes as a result of their child's death. The highest scores overall were in the "appreciation of life" subfactor, which was reflected in many open-ended responses. Many parents described an impetus to live a fuller life, both in terms of health and happiness as well as giving back to others. The next highest scores were in the "personal strength" subfactor, which garnered few, but conflicted responses. Some parents in our study appear to feel uncomfortable being praised for their personal strength, feeling that they only did what they had to do.

Overall, many relationships in the lives of our study participants did not change for the better or the worse. Those that did tended to be of a very close and personal nature. Relationships with other children tended to improve and to be a source of comfort and support for the parents in our study. Relationships with partners and/or child's other parents improved, worsened, and stayed the same. Parents whose relationships worsened frequently mentioned difficulty in supporting each other's grief. Greater faith and spirituality was also reported by many parents, but just as often not, or worsened. Changes in relationships did not seem to correlate with any measures of participant demographics or child's illness. Again, these results demonstrate the individualized experience of each parent.

Research Recommendations

Our study raised many questions that we would like to explore further. Using an in-depth, qualitative interview, we would like to further examine our participants' unique individual experiences on topics including sources of support, moments of surprise and disappointment, particulars of strengthened and weakened beliefs and factors affecting posttraumatic growth. The results of this study would also be enhanced if extended to a greater audience, perhaps using different recruitment methods to capture a more varied experience. Additionally, a longitudinal study surveying parents at several time points before and after their loss could increase understanding of how their lives change over time.

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Appendix A: Recruitment Notice



Study of Grief Two Years and More Later

ONLINE SURVEY

Private and Anonymous



[Click here to take survey](#)

Results of the survey will be shared in the June issue of Lifeline Online.

Are you a parent mourning the loss of your son or daughter two or more years ago to Tay-Sachs, Sandhoff, GM-1, Canavan or related disease?

Elizabeth Williams is a graduate student in the Genetic Counseling Program at Brandeis University and seeking volunteers to participate in a survey-based research project. The goal of her study is to explore the long-term effects on parents of the death of their child from a genetic, neurological condition such as Tay-Sachs or other allied disease. It is her hope that the results of her project can be used by medical and counseling professionals to better help families faced with these diagnoses.

Participation is open to adults who:

- Are at least 18 years old,
- Are English speaking
- Have parented, biologically or otherwise, a child who died of a genetic, neurodegenerative disease (diagnosed clinically or by genetic testing).
- We are currently seeking participants who experienced this loss 2 or more years ago.

Participation is voluntary and anonymous. Participants are asked to take an approximately 30 minute online survey which includes personal questions about themselves, their child, their child's death, and the ways their life has changed since then. No identifying details will be collected. You may discontinue at any time, or stop and return at a later date.

Stay Connected



national tay-tachs & allied diseases association

[\(617\) 277-4463](tel:(617)277-4463) |

(800) 90-NTSAD

2001 beacon street, suite 204, boston, ma

01235

www.ntsad.org

Appendix B: Study Instrument

NTSAD Survey Tool, using Qualtrics software (www.qualtrics.com). Please visit a web preview to see proper formatting at:

https://new.qualtrics.com/SE/?SID=SV_41O39mnrFgyDCg5&Preview=Survey&BrandID=brandeis

Thank you for visiting our survey page. We are conducting this study as part of my master's thesis in genetic counseling at Brandeis University.

An integral part of genetic counseling is discussing new diagnoses with families and helping them to picture what their future may be like. This study is designed to gather information about the long-term effects on parents after the death of their child to a genetic, neurodegenerative condition. Research shows that compared with the death of a parent or spouse, loss of a child has the most intense and varied grief response, but there is little research done to understand the experience of losing a child to a rare genetic condition. Clinicians have found that it is the families themselves who are the true experts. While your participation may provide no direct benefit to you, it is our hope that with a better understanding of your experience, we may be able to help families at an earlier point in this difficult process.

This survey contains questions about your experiences through your child's illness and death, and your life as it is today. Your participation is voluntary, and it is completely anonymous.

Our criteria for participation in this study are: You must be English-speaking, 18 years of age or older, and have parented a child who died of a genetic, neurodegenerative disease (diagnosed clinically or by genetic testing) 2 or more years ago.

This survey will take approximately 30 minutes. It consists of multiple choice and open-ended questions. The questions will cover basic information about you, your family structure, the circumstances of your child's illness and death and your experience throughout. The survey concludes with evaluation tools used to measure grief and growth and space to provide advice to other families and any final thoughts.

You may skip any questions you do not wish to answer and you may exit at any time. You may leave the survey and return at a later time if you like. No identifying information will be collected. Data stored electronically will be password protected. Printed material will be stored in a locked cabinet at the genetic counseling program facility at Brandeis University, where it will remain for 3-5 years. Following this, material will be destroyed via shredding. The study findings may be published and will be made available through the National Tay-Sachs & Allied Disease Association.

If you prefer to take this survey in paper format, please email emwill@brandeis.edu with the subject line "GC Parent Survey" and include an address to which the survey can be mailed. An addressed, stamped envelope will be provided for survey return. Your contact information will be stored separately from your responses and not linked in any way.

Participation in this study does not involve more than minimal risk (i.e., the level of risk encountered in everyday life). However, if you experience any distress as a result of this survey, please discontinue it. A counselor is available to speak with you by phone or email, should you

need any emotional support during or after this survey. Please contact Dita Obler, CGC at dita.obler.cgc@gmail.com.

If you have questions about your rights as a research subject please contact the Brandeis Institutional Review Board at irb@brandeis.edu or 781-736-8133. If you have any questions about this research project in particular, please contact emwill@brandeis.edu.

Click below to indicate your consent to the above conditions.

Yes, I consent.

No, I do not consent. (Survey will be exited)

If No, I do not consent. Is Selected, Then Skip To End of Survey

Section 1: Demographic Information

The following questions will tell us a bit about our participants. Feel free to skip any questions that you prefer not to answer or feel are not applicable.

What is your gender?

- Male
- Female
- Other

What year were you born? (drop-down menu)

- Prior to 1940
- 1940
- 1941
- 1942
- 1943
- 1944
- 1945
- 1946
- 1947
- 1948
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- 1992
- 1993
- 1994
- 1995
- 1996

How would you describe your current relationship status?

- Single
- Divorced
- In a relationship
- Married
- Other

How would you describe your racial identity? (you may check more than one)

- Black or African American
- White
- Asian
- American Indian or Alaska native
- Hawaiian native or Pacific Islander
- Other _____

Are you Hispanic or Latino/a?

- Yes
- No

What is your highest education level?

- Some elementary/middle/high school
- High school graduate
- Some college
- Associate's or other 2-year degree
- Bachelor's or other 4-year degree
- Master's degree
- Professional degree (MD, DVM, JD, etc)
- Doctoral degree (PhD, EdD)

Section 2. Child's illness and death

We would like to gather some information about your child, and the circumstances of your child's illness and death. Feel free to be as brief or as detailed as you like, and skip any questions that you do not wish to answer.

If you have lost more than one child to a genetic, neurodegenerative condition, please answer the questions in reference to your eldest child. Feel free to use the textboxes if you would like to share any additional information about your other children.

What year was your deceased son or daughter born? (drop-down menu)

- 2013
- 2012
- 2011
- 2010
- 2009
- 2008
- 2007
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- 2005
- 2004
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- 1957
- 1956
- 1955
- 1954
- 1953
- 1952
- 1951
- 1950
- Prior to 1950

What was your relationship with your son or daughter?

- Biological child
- Stepchild
- Adopted child
- Other _____

What age was your son or daughter when you began noticing symptoms of his or her illness?
(drop-down menu)

- under 6 months
- 6 months to a year
- 1
- 2
- 3
- 4
- 5
- 6
- 7
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- 50

What was the ultimate diagnosis, if any, given for your child's condition?

How old was your child when you learned of his or her diagnosis? (drop-down menu)

- 6 months or less
- 6 months - 1 year
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
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How old was your son or daughter when he or she died? (drop-down menu)

- 6 months or less
- 6 months - 1 year
- 1
- 2
- 3
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- 40

Do you have any other children besides your deceased child? (you may check more than one)

- No
- Yes, I had a child or children after my deceased child's birth.
- Yes, I had a child or children before my deceased child's birth.

Answer If Have you had any other children besides your deceased child? (you may check more than one)

Yes, I had a child or children before my deceased child's birth. Is Selected

Were your previous children biological or adopted? How many? (you may check more than one)

- I had a biological child or children prior to my deceased child's birth. (Fill in number of children in blank) _____
- I adopted a child or children before my deceased child's birth. (Fill in number of children in blank) _____

Answer If Have you had any other children besides your deceased child? (you may check more than one)

Yes, I had a child or children after my deceased child's birth. Is Selected

Were your subsequent children biological or adopted? Did you have them before or after your child was diagnosed? How many? (you may check more than one)

- Yes, I had a biological child or children after this child, before he or she was diagnosed. (Fill in number of children in blank) _____
- Yes, I adopted a child or children after this child, before he or she was diagnosed. (Fill in number of children in blank) _____
- Yes, I had a biological child or children after this child, after he or she was diagnosed. (Fill in number of children in blank) _____
- Yes, I adopted a child or children after this child, after he or she was diagnosed. (Fill in number of children in blank) _____

What was your experience with death prior to the loss of your child? Please check any you feel are relevant. The textboxes are optional, for any extra details you may wish to provide.

- Death of a parent _____
- Death of a sibling _____
- Death of a close friend _____
- Death of another child _____
- Other _____
- Other _____

Please use this space to provide us any other details about your family structure that you feel are relevant. (e.g. assisted reproduction, non-traditional or blended family structure, etc.)

The following questions are about your experience throughout your child's illness and death. For the following, again, please feel free to be as brief or as descriptive as you like. There are no wrong answers, and you may skip any you do not wish to answer.

A philosophy of care is a framework of care goals and values to make choices for your child and family. These “philosophies of care” occur along a spectrum from comfort care only to minimal medical procedures to use of extensive medical equipment, invasive procedures, etc.

Would you say that you had a "philosophy of care" for your child?

- Yes
- Maybe
- No
- Not sure

Answer If “philosophy of care” No Is Not Selected

If you feel that you did employ a "philosophy of care", please move the sliding bar to where you feel your decisions fell in this spectrum.

Space is provided below for more details.

If you are using a screen reader, such as JAWS, please feel free to use the space in the next question to describe your philosophy of care.

Degree of medical intervention:

Comfort care only

All life-extending interventions offered

|.....|.....|

Answer If “philosophy of care” No Is Not Selected

Please use this space to elaborate on the question above. We are interested in decisions such as whether to place a feeding tube or not, use of BiPAP, trach, other surgical procedures, drug choices, pain management, etc.

Answer If “philosophy of care” No Is Not Selected

Did your philosophy of care change over the course of your child's illness? If so, why?

Answer If “philosophy of care” No Is Not Selected

Looking back, would you make the same philosophy of care choices? Why or why not?

Who did you consult, if anyone, in making decisions regarding the medical care of your child?

	Heavily consulted	Moderately consulted	Somewhat consulted	Did not consult	Does not apply
Your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your child's other parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your spouse/partner (if different than above)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your siblings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your extended family/in-laws	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your spiritual community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other parents of children with life-limiting disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your child's healthcare team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic support, such as grief counselor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other professional support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please use this space to provide any additional details that you would like to share with us about medical care decision-making for your child.

How satisfied were you with your child's healthcare team...

	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied	Not applicable
During your child's initial diagnosis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After their diagnosis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During their end-of-life period?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At the time of your child's death?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After your child's death?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please share any specific examples related to your answers to the above questions. (ie: a time you were very satisfied with a healthcare provider, or something you wish had been done differently)

Did you seek information and/or support from an allied health professional in the care of your child?

	Yes, and it was helpful.	Yes, and it was not helpful.	No
Genetic counselor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grief counselor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bereavement counselor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative care professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other counselor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A coping resource can be defined as a factor that can be drawn upon to deal with the impact of a life-changing experience.

Were any of the following potential coping resources helpful to you? Please check all that apply.

	A source of support during my child's illness	A source of support during my child's end-of-life period	A source of support after my child died	A source of support currently	Never a source of support	Not applicable
Your child's other parent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your spouse/partner (if different than above)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your extended family, in-laws	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your personal spiritual beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your religious community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your disease support community (ie NTSAD)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online community or social media	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Therapeutic counselor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your financial resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your emotional strength	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your work community or colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your hobbies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please use this space to share with us any additional information about your coping resources.

How, if at all, did your child's death affect important relationships in your life?

	Relationship is better	Relationship is about the same	Relationship is different, but neither better nor worse	Relationship is worse	Not applicable
Relationship with your child's other parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your spouse/partner (if different than above)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your parents/siblings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your work community / colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your faith	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationship with your spiritual community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please use this space to share any additional information about the impact of your child's death on important relationships in your life.

What, if anything, have you done or are you doing to memorialize your child's life? What made you select this particular activity/event/object/place?

Many parents find that meaning-making can be an important part of the experience of their child's illness and death. If this is true for you, please tell us more.

Section 3: Psychometric Inventories of Grief and Growth

The following are two evaluation tools developed by psychology professionals to measure the effects of a profound loss. The first is designed to measure prolonged grief, and the second is designed to measure personal growth.

Of course, these scales are unable to encompass your unique, personal experience, so please feel free to use the space provided to elaborate on any question, add comments, explain your answer further, or provide any additional information to help us understand.

In the past month, how often have you...

	Not at all	At least once	At least once a week	At least once a day	Several times a day
Felt yourself longing or yearning for your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had intense feelings of emotional pain, sorrow or pangs of grief related to the lost relationship with your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to avoid reminders that your child is gone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Felt stunned, shocked or dazed by your loss?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For each item, please indicate how you currently feel.

	Not at all	Slightly	Somewhat	Quite a bit	Overwhelmingly
Do you feel confused about your role in life or feel like you don't know who you are (i.e., feeling that a part of yourself has died)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have trouble accepting the loss of your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is it hard for you to trust others since your child died?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you feel bitter over your child's death?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you feel that moving on (e.g. making new friends, pursuing new interests) would be difficult for you now?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you feel emotionally numb since your child's death?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you feel that life is unfulfilling, empty, or meaningless since the death of your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Are you experiencing a significant reduction in social, occupational, or other important areas of function (e.g., domestic responsibilities)?

Yes

No

Please use this space to comment further on any of the above statements.

Indicate how much you agree or disagree with the following statements as of today. There are no right or wrong answers to any of the questions.

	I did not experience this change	I experienced this change to a very small degree.	I experienced this change to a small degree.	I experienced this change to a moderate degree.	I experienced this change to a great degree.	I experienced this change to a very great degree.
I have changed my priorities about what is important in life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a greater appreciation for the value of my own life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to do better things with my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a better understanding of spiritual matters.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a greater sense of closeness with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I established a new path for my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know better that I can handle difficulties.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a stronger religious faith.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I discovered that I'm stronger than I thought I was.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I learned a great deal about how wonderful people are.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Reflecting on your answers to the above questions overall, would you say that you feel like that....

- 25% of the time or less
- 26-50% of the time
- 51-75% of the time
- 76-100% of the time

Please use this space to comment further on any of the above statements.

If you wish, please describe other ways your life has changed since the death of your child.

Is there anything you would want other parents whose children are diagnosed with a life-limiting illness to know?

This concludes the survey. Thank you for your time and for sharing your experiences with us.

If you would like to discuss the content of this survey further, please contact Elizabeth Williams at emwill@brandeis.edu.

If you would like to speak with a professional counselor, please contact Dita Obler, CGC at dita.obler.cgc@gmail.com.

Please click the forward arrows to submit your responses.

Appendix D: Permission Letters

Permission to use prolonged grief inventory (PG-13):

Prigerson, Holly G, Ph.D. <Holly_Prigerson@dfci.harvard.edu>

Sat, Nov 23, 2013
at 4:23 PM

To: Elizabeth Williams <emwill@brandeis.edu>

Dear Elizabeth, It sounds like you've given a lot of thought to your study. The latest ("best of") version of the ICG-R is our PG-13 -- to assess what we call Prolonged Grief Disorder (will be in ICD-11 under that name).

Please feel free to use the attached for your purpose.

Best of luck to you.

Holly Prigerson

Holly G. Prigerson, PhD
Director, Center for Psychosocial Epidemiology and Outcomes Research
Dana-Farber Cancer Institute
Professor of Psychiatry
Harvard Medical School
1134 Dana Building, 450 Brookline Avenue Boston, MA 01225
p:[617-632-2369](tel:617-632-2369); cell:[617-459-3304](tel:617-459-3304);e:holly_prigerson@dfci.harvard.edu

Permission to use posttraumatic growth inventory (PTGI):

Posttraumatic Growth <PosttraumaticGrowth@uncc.edu>

Mon, Dec 2, 2013
at 1:00 PM

To: Elizabeth Williams <emwill@brandeis.edu>

Ms. Williams,

As requested, a copy of the PTGI-SF is attached for use in your research. We would ask that, once your study is complete, that you send us a copy of your findings.

Best wishes,

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