EFFECTS OF GENETIC COUNSELORS’ PERSONAL GRIEF AND LOSS EXPERIENCES ON CLINICAL PRACTICE

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Genetic Counseling Program

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ABSTRACT

Effects of Genetic Counselors’ Personal Grief and Loss Experiences on Clinical Practice

A thesis presented to the Biology Department
and Genetic Counseling Program

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Genetic counselors are in a unique position in that they explain medical genetics and testing while guiding a decision-making process that can deal with very serious, often life-changing issues. Scientific information is given while psychosocial support is provided to patients that are often experiencing very strong emotions. The purpose of this qualitative study was to explore how genetic counselors’ personal grief and loss experiences affect the genetic counseling process, especially in a clinical setting. We interviewed eight board-certified genetic counselors with a personal grief or loss experience in the New England area with least five years experience. Face-to-face, in-depth interviews were conducted using a semi-structured guide covering three main topics: discussion of personal grief or loss experience, effect of experience on overall counseling, and case discussion. The audiotapes of the interviews were transcribed verbatim, and themes were identified and coded using ATLAS.ti software. Results showed major themes of 1) change, 2) separation of personal and professional lives, 3) identification of countertransference, and 4) consequences of countertransference. Subthemes under the theme of change included changes in beliefs and attitudes, in
understanding patient experiences, and in patient encounters. Subthemes under the theme of separation of personal and professional lives included the necessity of this separation, and the burden of knowledge from being a genetic counselor. Identification of countertransference had subthemes that included case identification, triggers, and indicators. The consequences of countertransference in this study included the subthemes of self-disclosure and burnout. The results of our qualitative, exploratory study bring to light the necessity of understanding how personal experiences interact with the professional realm, especially in genetic counseling. The importance of professional support to examine and accept countertransference is highlighted. Future studies may include exploring the patient perspective on genetic counselor self-disclosure or an investigation of empathy and psychosocial counseling techniques in genetic counseling.

**KEYWORDS:** Genetic Counseling – Grief – Countertransference – Self-disclosure – Burnout
## Table of Contents

Acknowledgements........................................................................................................ ii  
Abstract .......................................................................................................................... iii  
Table of Contents .......................................................................................................... v  
Introduction ...................................................................................................................... 1  
Methods ........................................................................................................................... 6  
Results .............................................................................................................................. 9  
Table 1 ................................................................................................................................. 11  
Discussion .......................................................................................................................... 40  
Conclusion .......................................................................................................................... 48  
References ......................................................................................................................... 50  
Appendix A: Recruitment Notice ....................................................................................... 51  
Appendix B: Informed Consent Form ................................................................................ 52  
Appendix C: Eligibility Screening Tool ............................................................................ 54  
Appendix D: Interview Guide ........................................................................................... 55
**INTRODUCTION**

Genetic counselors are in a unique position in that they explain medical genetics and testing while guiding a decision-making process that can deal with very serious, often life-changing issues. The educational, information-giving component of genetic counseling can be presented in a way that emphasizes empowerment, decency, thoughtfulness, and positive reinforcement to give patients hope and encouragement, help them deal effectively with their situations, and improve patient self-esteem. Genetic counseling is more than a process or communication; there is “non-quantifiable truth” in the human interactions that occur (Abrams & Kessler, 2002). The interactions that occur in genetic counseling sessions are not strictly quantitative; more than just information is exchanged during the session. Exploration of feelings regarding test results, risk numbers and implications for the patients’ future are shaped by the life experiences of both the counselor and patient, whether consciously or unconsciously.

Empathy is thought to be a necessary skill in genetic counseling, and is defined as the ability to mentally put oneself in a patient’s place and understand their experiences, while also communicating that understanding to the patient (McCarthy Veach, et al., 2003). Expressing empathy is a way to comfort the patient, and giving comfort in times of suffering is an integral part of genetic counseling. Patients are often experiencing very strong emotions such as apprehension, fear, anger, guilt, sadness or grief, and when a genetic counselor expresses their understanding of these strong emotions, the origin of this understanding may be due to a personal experience. It is important to remember that
the subject matter in genetic counseling is intimate and can hit “close to home,” and emotional reactions, or countertransference, in genetic counseling could be far more intense than in other counseling professions (Kessler, 1999).

In the genetic counseling process, countertransference has been defined as the “conscious and unconscious emotions, fantasies, behaviors, perceptions and psychological defenses that the genetic counselor experiences as a response to any aspect of the genetic counseling situation” (Weil, 2010, p. 176). Countertransference is inevitable, as all genetic counselors have previous life experiences that shape them and in turn influence their interactions with patients. Countertransference can occur as a reaction to emotions the patient directs towards the counselor (McCarthy Veach, et al., 2003) or in response to the patient’s story (Djurdjinovic, 1998).

In the focus on grief and loss, experiences with vulnerabilities throughout life continuously shape beliefs and attitudes about loss, suffering and death, and can profoundly affect the counselor’s responses to similar issues that occur during a genetic counseling session. While a lifetime of experiences can gradually shape the counselor, Weil states that “personal or family difficulties that occur while the genetic counselor is working have an immediate impact” (2010, p. 180). These contemporary losses, especially those that mirror the situations that occur for patients in genetic counseling, can interfere with the counselor’s ability to maintain emotional distance. When the counselor is in the midst of experiencing the strong emotions and defense mechanisms associated with the grief process, they can have difficulty separating the patient’s experience from their own. In this way major life events can shape the genetic counselor’s response to various aspects of their work immediately and over time.
Countertransferential reactions can be more complicated if a patient’s emotional responses or defenses remind the counselor of themselves or someone they know, and interactions can become more complex if the counselor and patient mutually escalate use of similar defenses. However, almost any characteristic of a session or patient can contribute to a countertransference reaction in the counselor. Likewise, it is important to remember that any challenging counseling situation can trigger countertransference simply based on emotional intensity (Weil, 2010).

Indicators of countertransference can include behaviors such as giving too much advice to the patient, having unusually strong feelings towards the patient or a particular session, or avoidance of the patient’s feelings. The consequences of countertransference are varied, and can range from emotional withdrawal due to uncomfortable emotions, to over-involvement, indicated by inappropriate attempts at nurturance or directive counseling. Moreover, a countertransferential reaction in the counselor may take the focus off of the client and place it on the counselor’s situation, experiences, and life (McCarthy Veach, et al., 2003). Other issues can include inadequate exploration of the patient’s circumstances and limitation of the counselor’s assessment of the patient. A breakdown of appropriate boundaries can occur if the patient has characteristics that trigger a nurturing reaction or feelings of professional inadequacy in the counselor (Weil, 2010). The counselor may become more directive to guide the patient to think or act as they did in their perceived parallel situation, and self-disclosure may occur.

The issue of self-disclosure in genetic counseling is a complex one, and the literature on self-disclosure in genetic counseling is limited at the time of this study. Genetic counselors with a painful personal experience tend to self-disclose when a patient
implies that the counselor cannot understand their suffering. Overall, the genetic counseling community believes that self-disclosure is inappropriate and should not occur in a genetic counseling session (Kessler, 1992) and many training programs teach that self-disclosure should be avoided. Weil recommends that self-disclosure be used carefully and sparingly, with attention to possible countertransference triggers such as “frustration that the patient is not emotionally engaged, the wish to be more helpful than is possible, the need to share unresolved issues or pain with someone who is perceived to be empathic and receptive due to shared circumstances, or an attempt to ‘buy’ friendship or to console patient rage after giving bad news” (2010, p. 188). Previous research by Thomas et al. explored self-disclosure practices and opinions of genetic counselors who had personally received some form of genetic services. Their study revealed that counselors felt it was difficult to assess the effectiveness of self-disclosure in achieving goals such as “providing the patient with honest answers, connecting with them, providing honest viewpoints, and validating and normalizing their feelings or decisions,” and it was universally acknowledged by the counselors in their study that self-disclosure should be used judiciously (2006, p. 174).

Strong countertransference reactions to different cases or patient circumstances can impact the genetic counselor in a variety of ways. The genetic counselor’s mood in their personal life can be impacted, as can the quality of psychosocial counseling given to other patients. If the impact of these feelings continues unabated, the counselor’s emotional responses may be dulled and professional burnout can occur (Weil, 2010). In a study by Upidi et al., genetic counselor burnout was the greatest predictor of compassion fatigue. Compassion fatigue was defined as feeling overwhelmed by patients’ suffering
and eventually feeling drained of empathy. This description is similar to that of professional burnout, but the differences between compassion fatigue and burnout lie in the onset as well as the causes. Burnout is a gradual process and results in the counselor being too worn down to make positive changes, and can be caused by work conditions. Compassion fatigue is usually more sudden and can be caused by a deep, personal grieving over patients’ misfortunes (2008).

Addressing countertransference and its consequences is not always easy, as the genetic counselor’s experiences that trigger the countertransference may be painful to remember. In addition, the feelings and actions associated with the countertransference reaction may not correspond to the counselor’s self-image. In having the self-awareness to explore countertransference and accept it as a normal part of clinical practice, the genetic counselor can interpret his or her emotions and use that information accordingly during the session (Weil, 2010). The purpose of this study was to assess the effects of genetic counselors’ personal grief and loss experiences and the effects of the presence of countertransference on clinical practice.
METHODS

RECRUITMENT

The Brandeis University Institutional Review Board approved this study design. We conducted semi-structured, qualitative face-to-face interviews with genetic counselors to examine their personal experiences with grief and loss and discuss the effects of these experiences on clinical practice. We recruited participants by emailing a recruitment notice (see Appendix A) to the National Society of Genetic Counselors (NSGC) listserv. The recruitment notice was posted for approximately two weeks, during which time eight counselors responded by email to express interest in the study. These counselors were contacted and a short eligibility screening tool (see Appendix C) administered by telephone confirmed that all eight respondents were eligible for study participation. Eligible participants were board certified genetic counselors in the New England area with a personal grief or loss experience and at least five years of clinical genetic counseling experience. After eligibility was confirmed, an interview was scheduled at the participants’ convenience and an informed consent form (see Appendix B) was mailed to them. We offered study participants a gift card as a gesture of our appreciation for their time and contribution.

DESIGN OF INTERVIEW QUESTIONS

We designed a semi-structured interview guide with open-ended interview questions (see Appendix D). The interview guide attempted to gather information from three broad categories: nature and description of the genetic counselor’s personal
grief/loss experience, effect the counselor perceives this experience to have had on their clinical practice, and reflection on a specific case in which the counselor had strong feelings towards a patient or situation. Question design stemmed from the authors’ clinical experiences and knowledge of literature related to genetic counselors’ personal grief and loss experiences.

**Data Collection**

Before proceeding with interviews, we obtained informed consent from participants (see Appendix D). We interviewed study participants for approximately 30 to 60 minutes and each interview was audiotaped. To protect participant confidentiality we did not mention participant names during interviews and audiotapes, interview notes and study files were labeled with identification numbers rather than participant names. A semi-structured approach allowed the interviewee to respond freely and without interruption. We kept our responses and the order of questions flexible, which allowed interviewee and interviewer to explore ideas and themes as they arose. Questions were adapted to account for original thoughts expressed by the interviewee, although the overall interview content remained consistent.

**Data Analysis**

A confidential transcriptionist transcribed the audiotaped interviews. We imported transcripts into the qualitative analysis software Atlas.ti (Version 5.0) for thematic analysis to manage and organize the coded data and support research using the codes. We used codes (referred to as elements in Results) to identify and group sections of text that represent a similar view, practice or experience that we viewed as significant. Some general ideas concerning genetic counseling, grief and loss, and countertransference were
utilized for coding. Broad grounded coding was also used, which involved putting aside presuppositions and developing codes in an inductive manner as topics emerged from the data. Broad coding of the data by the principal investigator led to focused grouping of codes, where each group represented a theme. Themes are broad topics that study participants frequently spoke of or emphasized. After completing transcript analyses, we selected themes and codes that were representative of study participants’ most prominent and significant views and experiences.
RESULTS

DEMOGRAPHICS AND EXPERIENCES

We recruited eight genetic counselors as study participants, hereafter referred to as counselors. The eight eligible counselors are all in the New England area and all are female. Half of the counselors currently work in a prenatal setting, two work in research and two no longer work in a clinical setting. All of the counselors had experience working in another setting such as pediatrics, adult genetics, or preconception counseling. Years of clinical experience ranged from seven to 20 years with a median of eight years clinical experience. Years since being certified by the American Board of Genetic Counseling ranged from three to 15 years, with a median of 6.5 years since board certification.

Personal grief or loss experiences were varied and included: non-specific incorporation of various deaths and illnesses into everyday life, fetal anomaly that resolved during pregnancy, elective termination due to a fetal anomaly, late-term fetal demise, neonatal death, and death of a parent from cancer. The time that passed since loss ranged from two to 15 years, with a median of four years since the experience.
THEMES

The eight interviews provide a richness of data and breadth of information concerning the lived experience of the genetic counselor and the impact of personal grief and loss experiences on clinical practice. In this study, we chose to focus on the effect of the counselors’ grief and loss experience, its impact on the counselor, and its consequences. We analyzed eight transcripts and identified themes that related to these issues. The themes are:

1. Change due to experiences
2. Separation of personal and professional life
3. Identification of countertransference
4. Consequences of countertransference

Each theme is comprised of specific elements (referred to as codes in Methods) representing a specific idea disclosed by counselors, which the corresponding theme encompasses. We sorted these broad themes into subthemes, as displayed in Table 3. For each theme and subtheme, we summarize counselors’ comments and present illustrative quotes from counselors’ responses.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes due to grief/loss experience</td>
<td>Beliefs and attitudes</td>
</tr>
<tr>
<td></td>
<td>Understanding of patient experiences</td>
</tr>
<tr>
<td></td>
<td>Change in patient encounters</td>
</tr>
<tr>
<td>Separation of personal and professional life</td>
<td>Necessary to separate</td>
</tr>
<tr>
<td></td>
<td>Burden of knowledge</td>
</tr>
<tr>
<td>Identification of countertransference</td>
<td>Case identification</td>
</tr>
<tr>
<td></td>
<td>Triggers</td>
</tr>
<tr>
<td></td>
<td>Indicators</td>
</tr>
<tr>
<td>Consequences of countertransference</td>
<td>Self-disclosure</td>
</tr>
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<td></td>
<td>Burnout</td>
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Table 1. The corresponding sub-themes categorized under the themes: Change due to experiences, Separation of personal and professional life, Identification of countertransference, and Consequences of countertransference.
THEME: CHANGES DUE TO GRIEF/LOSS EXPERIENCE

All the counselors acknowledged that they were changed by their personal experience with grief and loss. These changes included their personal attitudes and beliefs and how they saw the world, differences in perceived understanding of patient experiences, and changes in patient encounters and counseling style.

Subtheme: Change in beliefs and attitudes

Counselors described a change in their overall outlook on life and the world after their personal grief and loss experience. One counselor stated, “I’ll never be able to be quite as happy, because I’ve had that sort of taint to my life.” Similarly, another counselor compared her optimistic outlook before her experience to her life after the loss:

Definitely felt that feeling of invincibility beforehand. I wasn’t jaded at that point in time. I had a very positive outlook and felt very positive. Just happier. I was a happier person I think overall, and it took me a long time to get that back, after everything happened... I’m still not back to baseline, what I was before. I don’t think [I ever will be].

There was a common feeling of vulnerability among the counselors, as one counselor stated, “I think it does give me a perspective on how precious life is, and those kinds of bigger issues; people don’t realize how much can happen.” The counselors spoke of changing various aspects of their lives due to this new perspective, including adopting a more attentive parenting style, working part-time instead of full-time to spend more time raising children, or eliminating people that weren’t “quality” from everyday life. This fresh understanding of the transience of life affected interactions with others, and one counselor seemed frustrated:
If I was talking to somebody about how they ‘just want to make sure the baby’s healthy’…that’s a good approach, but there are a lot of other things that happen…it’s nice to still know that people are out there that are optimists and see a pregnancy test and that means a baby. For me it really doesn’t. There’s a lot that can happen. It’s a mine field.

Other counselors described this understanding of the frailty of life as giving them a renewed compassion for humanity. After loss, these changes in personal outlook led one counselor to “appreciate all the stuff that people might be going through, that you [might have] assumed they’re not before.” One counselor described her changed outlook in broader terms when she stated, “We are not who we were two years ago, and we are not who we are two years from now. We have to go with what we know now, and our values and beliefs now.”

Subtheme: Change in understanding of patient experience

All the counselors believed they had a better patient connection or an increased understanding of their patients’ life experiences after their personal grief or loss experience. Counselors spoke of being able to “put myself in their shoes in a way that I never could before” and relating to patients on a more personal level:

“I feel like I can relate a little bit better…because you have been there before, you just have a better understanding of what they are really they’re going through instead of trying to understand what they’re really going through.”

“Everybody still says that, “You couldn’t have done anything.” As a genetic counselor, I would say the same thing to my patients, but [as a patient] I didn’t believe it. And I’m sure a lot of my patients feel that way, too. And that was a valuable lesson for me to learn.”

This sense of understanding encompassed broad life experiences, such as pregnancy. One counselor described her feelings in giving bad news in a prenatal setting:
It’s a really significant moment in somebody’s life, and changes their perspective on many, many things…pregnancy will never be the same for them. The way they look at the world…[I have] even more of an appreciation being able to be there during probably one of the most, if not the most important moment – even if it’s not the happiest moment.

The counselors also described more specific patient experiences that they felt they understood more fully after their personal grief or loss experience. These experiences included having a baby with a birth defect, elective termination, and fears in a subsequent pregnancy after a loss. One counselor described a greater understanding of the concept that is taught in genetic counseling programs of loss of the “normal” child:

I do think so much of our field does have to do with grief and loss, because we learn in school a birth of a baby with multiple congenital anomalies is the loss of a normal baby. They’ve lost their Harvard graduate. They’ve lost their baseball player. So if you can even fathom loss, you can fathom what’s going on, but to live through it, it helps.

Regarding arranging elective termination:

And I knew a little bit about everything, you know, everything that we’ve done for our patients before, but you learn how much you don’t know when you go through it, the process.

Regarding neonatal loss:

I think infant loss is very different than miscarriage loss, it’s different. The underlying tenets are a lot of the same things. The grief is a lot of the same things. But the circumstances really make it feel very different. My experience matched some people but not other people.

That actually did open my eyes up to how women [feel] who had losses in their second pregnancy. I was nervous with [my first], but not really for any reason. And then this time I was paranoid about everything.”
Overall, counselors described the change in their perception of patient experiences and counseling style as a reflection of the personal change due to their personal experience.

I think that’s the whole thing about being a counselor. Every single life event makes you a different counselor, a different person. And I tell people that, too, now. This is one of my new favorite things to say to patients. “Every place you have been up until this point is shaping your decision, and this decision is going to shape any decision you make in the future, too.”

Subtheme: Change in patient encounters

Seven of eight counselors mentioned that their experience positively affected the way they interacted with and counseled patients. Of the counselors who implied a positive change in their counseling, one said:

I think any grief experience is going to change your background, and how you interact with people...Every experience leaves a mark on you and you take from that experience for the next time you’re faced with it. You are reminded ‘how did I handle that situation?’ or ‘what issues came up?’

One element of the counselors’ change in counseling was an increase in use of psychosocial counseling techniques due to an increased comfort level and understanding of grief and loss emotions. Several counselors described being more comfortable with silence in a genetic counseling session to give patients a chance to talk about their emotions.
I feel like it’s made me more emotional in my counseling, which is I think a good thing overall because I’m not. I was more scientific when I went to genetic counseling school and I was a little, I don’t know, if I was aloof in my counseling, but I was more businesslike in my counseling. Now I’m a little more comfortable, and I feel like if a patient comes in and they don’t want to talk about the scientific stuff and they want to talk about the emotional stuff, I feel more confident that I can do that. And I can talk to them and be more empathetic to them without mocking them, making them feel bad or being disingenuous.

In addition to an increased comfort with psychosocial counseling, one counselor also described her awareness of the variety of emotions among people due to a grief or loss experience:

I try really hard never to impose my feelings on patients. You also learn that in graduate school that you shouldn’t -- but it’s even more apparent to me now, after I went through a support group for a little bit, seeing how people handle things very differently. I give examples of a lot of different situations that other people have been through, and try to normalize it.

Many of the counselors also identified specific counseling issues in which they changed what they said to patients as part of their standard counseling practice. One counselor mentioned understanding the loss of a “normal” pregnancy – even with normal test results:

That’s when I grasped the concept of losing a normal pregnancy, so I do talk to patients about that. Even when patients have abnormal screening and they have an amniocentesis and it’s normal, or they have an ultrasound and it’s normal. I say to them “We’ve taken something away from your pregnancy. And you’re never going to get back to where you were the day before you heard these results. But our goal is to get you as close as possible.” That’s my new thing to say to them, and I feel like that’s the best we can do.
She also described her reaction to patients with a first trimester loss, and how her patients seem to appreciate this increased understanding.

I used to think, when miscarriages happened at eleven weeks, I think I said the same thing that most people say. “It’s a good thing it was early.” But when it was eleven weeks and I was thinking if I was going to miscarry or if it was going to be a termination, I was like, “I’ve already invested eleven weeks. This is eleven weeks.” So I definitely say to patients now, when they have a loss, they will say “It was only nine weeks.” I’ll be like, “But that was still nine weeks.” And they’re like “Yeah. People really don’t get that.” And I’m like “Yeah.”

Regarding recurrence risks, one counselor described how she chose her words more carefully after her loss. She found that her outlook on giving recurrence risks was changed and she believed that the most important thing to give the patient was hope:

I was an empathic genetic counselor before. It wasn’t like I didn’t have empathy before. I did…But I think it gave me a little more perspective on the things we say to cover ourselves medically and legally to patients when things happen. We’re always saying, our default, if we don’t know what caused it, is that there could be up to a 25% recurrence risk. And that’s what we say a lot. I hate that. I hate that phrase so much…I didn’t hate it before. I used to say it all the time to people on the phone. I didn’t even really think that much about it. And you know, most of the time there isn’t a 25% recurrence risk. Most the time there’s little to no recurrence risk, in many cases. We know of most of the syndromes where there is a clear cut, big recurrence risk…I do think that as a genetic counselor I was a little bit less callous about quoting those recurrence risks after that. I’m just a lot more sensitive about how important it is to have hope, because when something goes wrong again, it doesn’t make any difference what you told them prior to that.

One counselor described giving patients hope in a different way:
I feel like I do a better job... I try not to ever say ‘I’m sorry’ to someone. I try to tell them something that might be useful to them or point them in a direction that might give them information, even if I don’t have any information that is going to cure them, but something that might make them feel empowered... because that’s a little bit helpful to get from someplace, especially when they’re pinning all their hopes that we’re going to tell them something awesome. I think that’s something I do differently now than I used to do.

Another common change mentioned was an increase in comfort with emotional counseling sessions, as well as showing emotion in the presence of the patient. Feeling intimidated in emotional sessions was identified as a fear while training and prior to their personal grief or loss experience. While it was still something difficult to face after a grief or loss experience, there was an increased comfort with the patients’ emotions and with the counselors’ own emotions.

As previously mentioned, seven of the eight counselors felt their experience had positive effects on their counseling. The remaining counselor acknowledged that her grief and loss affected the way she counseled, and she left clinical practice shortly after her personal experience. Her experience changed her patient encounters in more extreme ways. She said she “wasn’t as emotionally available.” Before she left clinical practice, she once refused to counsel a patient. Although the change due to her personal experience seems much more profound, it is also worth noting that she left clinical practice at the point when she felt the quality of her counseling was compromised.

One counselor poignantly described the unavoidable reality of loss and grief:

Loss is part of life. Grief is part of life. Everyone’s always going to have something to grieve over. And it shouldn’t be something that we sweep under the rug. It should be something that we talk about. That we allow, and that we shouldn’t be afraid of.
THEME: SEPARATION OF PERSONAL AND PROFESSIONAL LIFE

Most of the counselors described the importance of separation of their personal and professional lives. One counselor questioned “how do personal losses or hard situations really interface with your counseling experience? I think we all struggle with that.” Some counselors found the division of the two more difficult, while others described a conscious, careful and successful effort to keep them separate. Another element in the separation of the personal and professional life is the way the scientific and medical knowledge of genetic counselors interfaces with the personal life in times of medical crisis.

Subtheme: Necessary to separate personal and professional life

One counselor spoke of the struggle to separate her emotions from the cases she saw:

I could compartmentalize for a while, and then after a couple of months of doing that it’s like it wasn’t working so well for me anymore. I think I just, I couldn’t tell if I was bringing home my patients’ problems or if I was just thinking about my own problems, and they were kind of like melding into my patients’ problems.

The same counselor described her reactions when she was no longer able to “compartmentalize” as “I think I need to get out of this for a while because it’s too much bleeding over in both directions and things.” Another counselor illustrated her awareness of this separation as “I’m always trying to be careful about ‘this is my personal, this is my professional hat.’” One counselor, who expressed a rage towards the pregnant people she saw on the street after her loss felt she was successfully able to separate her personal feelings from her professional life while in the clinic due to the “helping” nature of genetic counseling:
I came back to work, and in my mind the patients that I was working with I didn’t feel that hatred towards that I just saw random people on the street. I think because I was helping them…the patients we see are also having problems.

However, it was not only professional experiences that affected the counselors’ personal feelings. One counselor described the rush of memories that accompany the time of year when she experienced her loss, and states “my mind goes back to that, and that might be a bad day for me then…I just try to tell myself that doesn’t make me a bad counselor. I just have to know my capabilities.”

*Subtheme: Burden of professional knowledge in personal life*

Most of the counselors described the effect of their professional knowledge on their lives, especially if their grief or loss experience was related to the field of genetic counseling. Some of them described a general feeling of the burden of this knowledge, and depicted it as an “occupational hazard, because you see a lot of really rare things. So [they] seem more common than they really are.” The general consensus was that genetic counselors “know too much.” One counselor expressed:

> My clinical jobs have really scarred me personally for years. And when I look at – I get really emotional – just how grateful I am to have such a normal child after what we see as genetic counselors, and to have had such an unremarkable pregnancy.

Several of the counselors also portrayed their medical knowledge as a burden during the time of their personal experience. One counselor seemed to regret not using her knowledge to ask questions while receiving care:
I really didn’t want to look into things too deeply. I just wanted to take his word for it. And I think a lot of genetic counselors have the habit – any medical professional has the habit of trying to look into things and read into things and it’s not their area of expertise, so let the experts do it. That was my mantra.

Another counselor felt the burden of educating those around her while also being a patient having a difficult personal experience. She describes feeling misunderstood and frustrated:

Your natural loss or spontaneous loss is not the same as my potential diagnosis of a major abnormality...that was hard when people didn’t quite get it. And I’m not sure if people who are not as knowledgeable feel the same way, because I think they could be like “Well, it is kind of similar to a miscarriage.” I did feel a big burden with having to be the educator.

Although the role of educator felt very burdensome, this same counselor described the knowledge itself as beneficial to her in hindsight:

But I think having that knowledge helped with just dealing with it. I don’t think that too much knowledge was scary, because someone would have given it to me anyway, and I would have only remembered 30% of it, and then I would have been at a loss. So I think I’m a better counselor because of it, and I was a better patient because I was a genetic counselor.
**Theme: Identification of Countertransference**

In reflecting on specific cases in which the counselors had strong feelings towards a patient or situation, countertransference was a common theme. The type of patient or case that may trigger a countertransference reaction seemed to be easily identified by the counselors. One counselor said:

“I’m very anxious in situations where there is loss. I can feel a visceral reaction come on. So physically that’s a reaction, and emotionally I guess, too. I can almost feel an anxiety reaction where I get cold – it starts in my head and goes right down to my toes when I have to talk about certain things.”

**Subtheme: Case identification**

About half the counselors identified specific cases in which they experienced strong emotions. The majority of cases described by the counselors were related or similar in some way to their own personal grief and loss experience. Common elements of similarity included patient characteristics, patient experience and circumstances, and patient reaction or decision-making process. One counselor identified a patient with a life situation and personal characteristics similar to her own:

I remember I was working with a patient and I completely – I think it’s called transference, or countertransference, I don’t remember, I’m sorry. She was my age. She grew up in the same area as I did. She loved yoga. She was pregnant with her first child, and said, “I just want an amniocentesis for reassurance on this baby.” We started talking, and she’s like, “Oh, I played volleyball in high school.” I said “Me, too! Where did you go to high school?” Turned out we competed against each other. And I was taking her family history and she said, “My mom has this really rare condition.” And I was like, “Oh my God. My mother has the same thing…”

22
This was the only counselor to use the term ‘countertransference’ in the interview. The similarities in the cases that counselors identified were sometimes coincidental, such as the same birthday:

We noticed that there was lack of fluid and the baby was a little bit smaller, and I had this gut feeling – this is exactly [like my daughter],” And she actually ended up being admitted for bed rest and same thing, her baby was delivered on [my daughter’s] birthday...There’s just the similarities there really struck me, so that emotionally...but in that situation, that is another situation where my history, I did discuss with them, and she appreciated it. Just to talk to me about the fact that I did go on and have another pregnancy – she was actually ready to talk about it. I wasn’t ready to talk about that. I’m like “I don’t want another baby. I wanted her.” But she was already...

However, the similarities weren’t always mirrored in such a strikingly similar patient situation; they also encompassed the patient experience. One counselor described her experience since leaving clinical practice, and said:

It’s really interesting to be on the other end of the phone with one of these doctors who is looking for the results and is really upset that it takes over a week to finish the testing. His patient’s medical management is being based on these decisions and to hear them say, “You just work in a lab and you don’t understand what this family is going through waiting for these results.” And it is sometimes challenging to bite my tongue and say, you know, what I think in my head is, “I know better than you think I do.” I try something a little more diplomatic and tell them that every single person whose patient, whose specimen, we are testing are waiting for results for those exact same reasons. And I try to not personalize it, but that’s what I think in my head. “I’ve been on the other end of the phone waiting for those results. I know exactly what you’re talking about. Trust me, I get it.”

Counselors also described feeling strongly about their patients’ decisions, usually in the midst of their own grief or loss experience. One counselor described a case with a
situation similar to her own, as well as a decision-making process that was comparable to her own, that all occurred in the same time period:

When I was going through this whole crisis, I had a patient who presented to us because she had a pregnancy that was diagnosed with Turner syndrome by amniocentesis at an outside doctor’s office, which should not happen, and then she came to see us. She had been told a lot of wrong information from her doctor. And she met with me, and she was like “This is not what my doctor told me about Turner syndrome, or my future pregnancy risks.” So she struggled, we struggled, over what to do, and she ended up continuing the pregnancy. In my mind, the “right” thing to do, eventually. That’s maybe why I like her so much…I had gone through what I had gone through, and I think I desperately wanted to tell her that I was pregnant and that I would have chosen the same route. That’s what made me think I would continue [my] pregnancy, and I think I would follow in her footsteps, and I know it’s a hard path, because I’m seeing her do it, but I really felt like that was going to be my [path]. And I so desperately wanted to tell her that, and disclose that I, too, had a pregnancy complication, and I kind of got what she had gone through. But I didn’t. Which is probably a good thing."

Subtheme: Countertransference triggers

Counselors identified personal triggers that could cause a countertransference reaction. Often the strongest reactions occurred during or soon after their personal experience. On the day she found out the information that would lead to her experience of loss, one counselor described how her mind flashed to her career, and the feelings she believed she have towards her patients in light of her own decision-making process:

I thought “I cannot be a genetic counselor anymore. This is the end of my career.” Because I thought, “How can I be non-directive? How can I be normal for patients who have the same diagnosis? I mean, what if the baby has a syndrome? And what if I terminate a pregnancy? And how will that make…I can’t counsel unbiased. Every time a patient continues a pregnancy, how is that going to make me feel? Or if I continue a pregnancy, how am I going to feel when patients terminate?” I thought “I can’t do this.”
Counselors’ recalled that strong emotional reactions were more likely to occur during their personal experience. Several counselors described being more prone to tears:

If my mom was having a particularly tough time, or if I was having a particularly tough time with what was going on with her, and I saw a patient who had [a poor diagnosis], if I was in a particularly emotionally tough spot that day I was more likely to cry with her. And that isn’t something I did very often before. I don’t want to say that it’s not appropriate, it’s rarely appropriate I guess I would say. Or in my opinion I didn’t feel like it was appropriate for me to. And there were at least few cases on tough days where that I cried and I was only partly crying for the patient.

One counselor recognized that emotional reactions during a session have become less intense as more time passes since her experience, but still remembered crying with patients:

I think soon after I was more prone to tears. I would cry with people in a session, and they thought I was crying for them, and part of it was for me, too. I mean, it was for them, because I was really feeling how raw it is at the time when they get their diagnosis. Now it’s pretty rare that I do that.

Multiple counselors described a countertransference reaction to cases with similar circumstances to those of their own grief and loss experience. “Anytime someone comes in and there’s low fluid and poor growth, it triggers a response in me.” Another counselor said, “I certainly know when there’s something that’s very similar to ours, there’s a stillbirth, and it’s late-term. A few of them have come through with the same physician that I’ve seen, so it’s almost an identical picture. Those are the ones that I am most anxious beforehand.” Several counselors that had experienced pregnancy complications described a strong reaction when thinking about pregnancy. One counselor asked herself, “How was I possibly going to be able to do the job that I did or see pregnant women ever again? How could I possibly look at anybody and think that things would work out?”
Another counselor describes feeling surrounded by healthy pregnancies, in sharp contrast to her own experience: “All of a sudden everybody gets to have a healthy baby except for me. I felt that way for a while. It was hard to be in the prenatal practice. When I had my second child, I felt that it could work out for me too. That really helped.” A number of counselors described the difficulties of working as a prenatal counselor after having a grief or loss experience in their own pregnancy. One counselor spoke of feeling unknowingly judged by the patients:

It was hard for me when I had to talk about like amniocentesis, and the results would come back at 18 weeks and then depending on the results, then people would make comments like, ”You can have a termination at 18 weeks? Oh my God, that’s horrible! I would never do that.” And some of that it was hard not to take personally.

Countertransference also occurred in response to patients’ frustrations:

Someone at one point in one of those sessions said to me, “All the miscarriages and then this loss,” - she’d had a bad history too - “the next time I get pregnant I’m going to shout it from the rooftop.” And I think that struck a chord with me. I had spent so much time hiding the pregnancy and people didn’t even know I was pregnant, and then I went through this loss.

And in response to having to tell a patient they have reached the end of their options:

I think that it was the thought that we couldn’t do anything else for them made me feel more upset, because it’s hard when someone says, “That’s it. You just have to go on.” So I think that was the hardest thing…she knows how hard it is and difficult it is and for me to be like, “I’m sorry, I can’t do anything else for you.” I thought that was the hardest part because I had just been through that same thing when they said to us about there being no treatments; there’s nothing we can do.

Countertransference also occurred in response to a patient’s positive outcome, such as in the counselor who was reminded of her neonatal loss in a little girl who survived similar
circumstances: “I remember one time I made a comment to a little girl who was born almost as premature as [my child], and she was fine and healthy, no problems. And I was like ‘Do you know you’re a miracle?’”

Patients’ experiences also caused feelings of disbelief and anger in the counselors, and triggered a countertransference reaction as they reflected on the seeming excessive or undeserved experiences they and their patients had to endure. One counselor exclaimed, “How much crap are we supposed to deal with? You know, hello, where are you? Where’s the logic in the world and where’s the fairness of any of this?…[My patient] wanted a family, and we did too.” Another counselor said “This can’t happen. This isn’t going to happen to me, and this can’t be happening to her. I cannot – I don’t know how to do this.” This same counselor seemed aware of her countertransference reaction and the possibility of projective identification, as she described herself as “projecting so much of myself onto this. I just couldn’t do it, and I couldn’t, I couldn’t because I was like, ‘No! That doesn’t happen.’”

Subtheme: Indicators of countertransference

Indicators of countertransference include behaviors such as giving too much advice to the patient, having unusually strong feelings towards the patient or a particular session, avoidance of the patient’s feelings, or even verbal clues from the patient to the counselor. Some of the counselors identified these elements of countertransference indicators in their practice, including feeling extremely pleased with the way a session went, especially after self-disclosing; feeling frustrated at a patient who could not make up her mind because “she had choices and my family didn’t,” self-identifying as
emotionally unavailable, and in one case, refusing to see a patient. One counselor described a frustration with patients, especially in cases that seemed minor to her:

> When people are freaking out about echogenic focus I feel like saying…“You’re freaking about echogenic focus. Are you kidding me?” Or the AMA woman who was 35 and she’d have an amniocentesis right away, or she’d have a normal screening and she’d have an amniocentesis. I’m like “You don’t even know.”

Another element that encompassed indicators of countertransference was the feeling that the counselor was able to anticipate patient wants and needs after their grief or loss experience. Approximately half the counselors mentioned this idea, one stating, “They do need to know that I came out the other side. Still here, had more kids. The survivor part of it I think is what a lot of patients want.” The element of anticipating patients’ needs pertained to both logistical and procedural concerns, as well as emotional needs, as demonstrated by one counselor’s statements regarding her elective termination: “For patients who are taking a route similar to mine, I feel much more prepared at helping them understand what’s to come in their future. I wish somebody would have been there to tell me more about that…” and “I can tell my patients, ‘Some people might feel this or this. Or if you do feel anything unusual, speak to a counselor about it, because it might not be that unusual.’”
Theme: Consequences of Countertransference

Subtheme: Self-disclosure

Seven of the eight counselors mentioned self-disclosure in the interviews. Most counselors felt self-disclosure could be a helpful tool in a difficult counseling session, although several of them acknowledged that it is a complex issue. Counselors reported a variety of factors when choosing whether or not to share their personal experiences with a patient. Some factors mentioned by the counselors as reasons for self-disclosure included: a patient saying no one could understand their experience, a strong connection or good rapport with the patient, a gut feeling that self-disclosure was appropriate, or a desire to help the patient.

Several counselors mentioned self-disclosing when a patient seemed convinced no one could understand their experience. One counselor described it as “a judgment of [whether] they say anything…that I wouldn’t…understand what they’re going through. ‘How could you possibly know what I’m going through?’” One counselor recounted:

The very first time I [self-disclosed] was there was a young girl who had a loss very similar to mine, and she was carrying around a picture…and talking about it. And she started saying “I don’t think anyone can understand.” And I finally just said to her, “I think there are people who can understand.” And she was kind of aggressive. And so I said “I’ve had a similar loss.” And it totally switched the tone of the counseling and she was much more receptive.”

Another counselor self-disclosed in a similar situation:
Right when she said “Nobody else knows what I’m going through,” she was going off on a rant for five minutes. I said “Actually, I’ve been almost identical thing to you…I know where you’re at. I don’t know exactly what you’re going through, but I’m sure we share some of the same feelings and opinions.” And she just shut up at that point. Totally didn’t know what to say…She just went from being this very angry person to just being a little more calm and talking to me like most clients do with a little bit more respect, and I felt like it was a turning point for her as a patient.

Counselors also mentioned having a certain intuition that self-disclosure was appropriate, and one counselor described, “I usually just sort of feel it out. If it seems like the right thing to do, then I do. I can’t really put a formula on when it feels like the right thing to do or not.” Another counselor described it as “a gut feeling, and some people have that gut and some don’t. So if you’re somebody who hasn’t ever been naturally that good with social interactions, maybe you shouldn’t be a genetic counselor.” One counselor also mentioned her comfort level self-disclosing to a patient with whom she felt they had a strong connection, stating, “I wouldn’t [self-disclose] regularly. I would certainly only do it when I knew, when you got that sense from someone that it was okay. ‘This is the sort of person where I could probably bring this in.’” In relating an instance when she chose to self-disclose, she said, “I knew just because of the rapport I had with this patient, I could just go there with her.”

One counselor mentioned self-disclosing to help the patient by giving them hope. She described the type of patient she might disclose to as “feeling hopeless” and her self-disclosure as coming from “not really knowing how else to help them and wanting so terribly to help the patient…I wanted to give them that hope…so I think that’s where my heart was in it, with wanting to share with them.” When describing a case in which she self-disclosed, she recalled telling the patient:
It will get easier. It will get better. And I’m not just telling you that. I’m telling you that because I’ve been through it before and I have now met a lot of other people through support programs who have been through it before.

Another counselor felt that after she shared her experience, the patient “appreciated it...just to talk to me about the fact that I did go on and have another pregnancy. She was actually ready to talk about it.” Another counselor mentioned self-disclosing with the hope that the patient may be more likely to seek support through a similar outlet:

I was trying to really look at who do I share it with and who do I not share it with, and why do I choose one or the other? And I think sometimes [I self-disclose] if I sense that people would get support from a group if they knew it was supportive to me.

Most of the counselors reported positive experiences after disclosing aspects of their grief or loss experience to patients. One counselor said, “I can almost get more satisfaction about being able to help others, and you can modify what you do share or what you don’t share, or how you bring in your personal experiences and when you put them aside.” She asserted that “I don’t ever feel like [self-disclosure] was looked at negatively. I think it only added a positive aspect to that counseling session.” This counselor described counseling a patient with a strikingly similar life experience, and a sort of loss they shared:

And we talked a lot, and offered each other support, almost, about our own sort of struggles and issues. So I know it’s not a grief example, but it’s a perfect example of where a barrier, I think was, “Oh, I’ve got to talk with this girl about it.” Perhaps it was selfish. It wasn’t why she was there...I was with her I think, for two hours. We had the nicest experience in a genetic counseling session.

Another counselor emphasized, “I think that self-disclosure is really okay at certain times. I think it’s appropriate at certain times. I believed this before we went through this
and I believe it even more now.” However, she did mention using caution in disclosing, saying “there is a time and a place to not self-disclose and there is a time and a place where self-disclosure can be really helpful – as long as you don’t make it about you.” She stated:

I did self-disclose a couple of times...and I think it’s okay to say, “You’re not alone. Just so you know, I went through a loss as well and I can only imagine what you’re going through.” And you make it be about the patient again. But I think shedding a tear, just showing that you care and that you know something, but that you’re not owning their experience [is okay]. Because everybody has their own. I think it’s actually really, really helpful and powerful.

Another counselor described her inner conflict when she first disclosed to a patient that she had a similar experience, and her positive feelings afterward:

I think I was probably almost sweating when I was sitting in the chair...“Do I tell her? Don’t I tell her? Do I tell her? Is this going to turn out absolutely horribly?” Because it could have. In my mind, I was worried that she was going to yell at me, “This is about me. Why are you telling me about your medical history? I don’t want to hear that.” I was very, very nervous before telling her. And then I left the session actually really happy that I did. I felt like in this case, it was a good counseling technique because it did get her just to calm down and see the big picture a little bit, that this had happened to other people and they can get through it, and she wasn’t the only one who suffered.

Similarly, one counselor described caution in self-disclosing, and the positive outcome on the rare occasion when she did self-disclose:

I’m always really careful about not trying to let out personal information, but sometimes, I mean, it’s very rare, but sometimes something comes up where I do talk about “I’ve had a loss too.” And to get someone to open – who really breaks down.

In describing the session when she self-disclosed:
I said to them, “We’re not supposed to do this, but yesterday was…it happened to me, three years ago on this day.” And the husband then just started talking. He was dead silent before, but after he talked, and talked, and talked and [his wife] was like, “It’s the first time I saw him talk.”

Another counselor reported self-disclosing twice, and stated “they always talk in genetic counseling programs when to disclose or not to disclose. One time it backfired, and the other time it was fantastic. So I’m still on the fence with if I’ll ever do it again.”

Most of the counselors had a positive outlook on self-disclosure, but one counselor felt that it was inappropriate. She described a patient that had similar loss and wanting “so desperately wanted to tell her that, and disclose that I, too, had a pregnancy complication, and I kind of got what she had gone through. But I didn’t, which is probably a good thing.” However, she described the importance of boundaries when she stated “No, my role is a genetic counselor…That’s not okay. It’s not appropriate…I felt that friendship with her, and I felt like we could bond over our similar struggles. But no…”

Several of the other counselors also mentioned boundaries in regards to self-disclosure. One counselor said “When you experience your own reactions to…loss and things like that, I think that can play a role, and so the boundaries sometimes come down.” She described that even if she did not disclose, she would often allude to her personal experience or an inside understanding:

Instead of saying ‘I’m so sorry for your loss,’ I might say “I’m so sorry for your loss. I can appreciate how hard that is.” It’s my boundary problem. And it’s another way to connect with a patient…I think in some cases, it is an advantage. And I think in other cases it can be problematic.

The importance of boundaries was a common element among the interviews. One counselor describes “wanting to say ‘I’ve been there too,’ really wanting to connect with
them on that level, and that’s not appropriate a lot of the time…but that’s where I feel like my experience can be really helpful to somebody, if I can navigate the right boundaries.” Another counselor described feeling slightly conflicted and noted the need to use caution regarding self-disclosure:

I’ll think “Will I disclose to this patient? Will I not disclose to this patient?” And I usually end up not, now. But it’s hard during those sessions, because there are also a lot of my own thoughts going on about my experience. So I have to work to stay focused on the patient, and try to see things from their point of view and their situation, and remember that it’s unique from mine.

Counselors reported other feelings associated with self-disclosure. Two counselors mentioned feeling relief after self-disclosing, related to anxiety and the chance to talk about their experiences. One counselor had feelings of guilt, explaining that she had not disclosed since the most recent instance:

I had justified [self-disclosure], thinking…it changes the session and helped a little bit, but really who am I to judge that?...I felt like I used it to help, but at the same time...the guilt’s not eating me up, but I walk away and I’m like “Should I really have done that?” And you can’t go back and change it, but to move forward what would I do? And actually since that time I have not told anyone.

Subtheme: Burnout

Several of the counselors mentioned experiencing burnout as a result of their personal grief or loss experience in clinical practice. One counselor stated:

I don’t know if that makes me a better genetic counselor or not. I think in some ways it probably did, because I really connected with patients. But in some ways, I think it was detrimental to me as well, because I was giving of myself, and that leads to burnout…“Can I really do this again tomorrow?”
Counselors recognized burnout by their lack of emotional availability to their patients, as one counselor came to the realization that “I was doing a disservice to my patients because I wasn’t anywhere near as emotionally available to them as they deserved.”

Another counselor noticed “some cases where I wasn’t able to be as in-depth as I wanted to be, so the session was shorter, and I leave thinking ‘I wish I wouldn’t have seen this patient, because one of my colleagues probably would have done a better job.’”

Other counselors spoke of being unable to counsel while in the midst of their grief or loss experience. One counselor took time off during her crisis and did not see patients during the following month at work. Another counselor recognized while she was going through the most difficult time in her personal life, she was in the right place professionally:

> It definitely was helpful being here in a non-clinical position at the end. My coworkers knew what was going on and I didn’t need to explain things to people. I didn’t need to be “up” or “on” if I was not having a day where I felt like that. This type of career afforded me that kind of emotional flexibility that seeing patients definitely wouldn’t.

Some of the counselors even mentioned that they felt the need to switch positions after their grief or loss experience. One counselor said that the transition from a prenatal to a research position was exactly what she needed after a pregnancy in which she lost a baby.

Another counselor recalled her realization that,

> If I have to start farming out my work to other people, I can’t do my job anymore. And frankly, I don’t think that would have lasted very long. I’m a pretty strong person and I really feel that I could have pulled it together and done whatever I needed to do, but [it was] time for me to take care of me.

She also recognized the point at which her clinical position was no longer the place for her, as she could sense that “it’s [not] a good fit for my patients anymore.”
One counselor was very straightforward with the level of burnout she reached as a result of her loss, and the emotional toll it took on her. She described her realization:

The work was getting more hectic and demanding and I only had so much energy to split between the various priorities, and I tried for a long time to be “everything for everybody”…I pulled it off for a while but…I started to realize that things needed to change, and I just continued to try to meet all of those responsibilities. I think that I started meeting some of those responsibilities less well on an emotional level. And while I certainly had some patients who managed to break through and get exactly what they needed from me, a lot of the rest of them got, and especially the more routine cases, got surface me.

She describes that she did “reach a point where the presenting and explaining of the information was really all that I was capable of. And I was exhausted all the time…”

She remembered a moment of clarity when she was beginning to seriously consider leaving clinical practice:

I actually had a call from a counselor at a clinical lab with an affected prenatal result. And the counselor called and said, “Okay, this patient’s fetus has X diagnosis and we’re sending you the report. Have a good afternoon.” And I thought “Wow, now I need to call the family. Her job is done and mine is just starting.” And I think that was when I first realized that there was a way to do this job and not have to be involved with breaking the bad news and supporting the family through the tough decisions.

She knew beyond doubt that it was time for her to “get out now” when she “started comparing my grief and my stress to that of my patients as if it was a contest like, ‘Your problems aren’t as bad as my problems.’” She decided to stay within the field of genetic counseling but to leave clinical practice altogether. She stated, “even though the issue with my mom is resolved in that she passed away, even though that’s no longer an issue, I still don’t have it in me to see patients.” She asserted, with great self-awareness, that:
I don’t think I’ll ever go back. I remember when I was in college and first looking into this as a career and there were people who had been doing this for 25, 30 years. I wonder how some of these people do it. I wonder if they just have a never-ending capacity for compassion, or whether they somehow manage not to get emotionally invested in their patients. Like if they’re better able to detach than I ever was. I don’t know what the trick is. But because I don’t know the trick, I know that even without a personal stressor that I would again reach burnout at some point. And when you’re doing fine, it’s a fine job, but if you start to reach burnout, for me at least, it was a long, exhausting, stressful, hard, hard road. It just, it wore me out in every possible way. So I know that if I went back to clinical practice I would have that to look forward to. And I’ve done it once and I didn’t love it, that part of it, and I don’t really want to go through that again…the reward didn’t outweigh ultimately the cost for me personally.
OTHER THEMES AND SUBTHEMES

The richness of data gathered in these interviews presented us with some subthemes that we noted but chose not to address further at this time. The subthemes include counselors’ reactions to their own grief or loss experience, the idea of becoming a “better” genetic counselor as a result of their grief or loss experience, the influence of motherhood on clinical practice, and sources of support in the professional setting.

In describing their feelings and reactions to their personal grief and loss experiences, the counselors spoke of healing by passage of time, the feeling of vulnerability, wanting and needing hope, readjusting and finding a sense of normalcy in their life, and being grateful for other things in their lives that they had previously taken for granted.

The majority of the counselors mentioned the idea of being a “better” genetic counselor due to their grief or loss experience. Several counselors expressed frustration when colleagues or friends would tell them their experience would make them more empathic, and therefore a better genetic counselor. Although some of the counselors were unsure whether or not they felt they were a better counselor after their experience, several of them did believe they were now a better counselor, a better patient, and even a better person.

The majority of counselors with children mentioned the effect of motherhood on their clinical practice, especially in regards to prenatal genetic counseling. Counselors revealed that they had a greater understanding of pregnancy issues, and felt that after having children they counseled differently in a prenatal setting. Most of these counselors felt they were unable to work in a prenatal setting until they were done having children.
Another common element was the support of colleagues. Most of the counselors named their colleagues, whether a boss, co-worker, or peer supervision group, as their principal source of support regarding professional and occasionally personal issues. They described seeking support for a variety of reasons including to discuss sessions in which they had a strong emotional reaction, to talk about feelings regarding self-disclosure, and even to help deal with their personal grief or loss experience.
**Discussion**

We interviewed eight genetic counselors to explore the effects of their personal grief and loss experiences on clinical practice. The themes we found included personal and professional changes, separation of personal and professional lives, and issues related to countertransference. In these interviews we gained a wealth of information and insight into the counselors’ inner thoughts and lives and the broad range of effects a personal grief or loss experience can have on clinical practice.

It is essential for genetic counselors to integrate their professional and personal lives, as no one is exempt from suffering. All the counselors in our study felt they had been changed fundamentally by their experience. They had an increased awareness of their own vulnerability, and of the fragility of life. When counselors experience problems similar to those of their patients, it not only changes them as individuals, it affects the character of their work (Kessler, 1992). Counselors had a changed outlook regarding common patient issues in genetic counseling such as prenatal decision-making, disclosure of test results, and disease diagnosis. This changed outlook altered the way counselors interacted with patients in complicated and intangible ways. As best we can discern, all the counselors in our study felt a deeper understanding of patient experiences with difficult decision-making, grief, and loss experiences. In specific situations, it is notable that several of the counselors said they changed how they counseled patients with experiences similar to their own due to this increased understanding. However, as with the genetic counselor, each patient has a unique lived experience. Counselors must
carefully examine this perceived increase in empathy, including its origin and the resulting professional changes, and remain open to exploring the patient’s experience as it belongs to the patient and not as it pertains to the counselor.

Most of the counselors had spoken with medical professionals during their experience, and some had undergone genetic counseling themselves. They remembered both what they found helpful and what they found frustrating in their interactions with medical professionals, and used this information to change their counseling accordingly. A study by Peters et al. provided empiric data on whether genetic counselors had received genetic counseling, and if so, the reported impact on clinical practice. Most of the genetic counselors in their study that had received genetic counseling reported that it affected their clinical practice in a variety of positive ways, including greater empathy, understanding, connection, and rapport with patients (2004). The counselors in our study reported similar effects on their clinical practice as well as a greater comfort with emotions surrounding grief and loss.

Several of the counselors mentioned being more comfortable with silence to give the patient room to talk about the intense feelings associated with grief or loss, and increased comfort with a session where the patient wanted to focus mainly on these feelings. One counselor specifically mentioned feeling intimidated during her training by the intense emotions associated with loss; she may have become more comfortable with using psychosocial counseling approaches in the presence of grief and loss emotions after experiencing these feelings herself. Other counselors specifically emphasized that they were empathic before their experience. Undoubtedly there are other factors that affect a counselor’s perception of her own empathy, including comfort with strong emotions prior
to the personal grief or loss experience, training in psychosocial counseling techniques, extent of clinical experience, and other personal experiences. In losing some of the fear of these emotions, this perceived increase in empathy could be seen as an increased comfort with grief and loss emotions, and counselors could be more comfortable with psychosocial counseling techniques that would otherwise be intimidating to attempt in the presence of these strong emotions. The scientific knowledge base necessary in genetic counseling can be a crutch for counselors who feel anxious in emotionally charged situations. Not all counselors will have a devastating personal grief or loss experience, but at some point in every counselor’s career, they will be at the side of a patient experiencing intense suffering and grief. Genetic counseling programs should work to find the balance between clinical knowledge and the importance of becoming adept in using psychosocial counseling techniques, especially during intensely emotional sessions.

Although most of the counselors in our study reported positive changes in their counseling after their grief or loss experience, the effects of personal experience in the professional life carry over beyond the face-to-face patient interaction. Counselors who described being strongly affected by a case while in the midst of their personal grief seemed to link their own decisions, emotions, and grief experience to those of their patients. This issue of identification with the patient can lead to the complications in the session, and it has been suggested that genetic counselors should suppress these feelings of identification to allow for greater empathy during a session (Kessler, 1992). However, suppression of feelings is not as easy as simply deciding to do so, and the unconscious elements of countertransference can affect counselors in their personal lives as well. Almost all the counselors mentioned the concept of burnout. Some counselors took a
short-term break from counseling or a reduction of clinical duties in their career during or after their experience. In a more extreme case, one counselor reached her breaking point, left clinical practice altogether and stated that she would never return. The striking experience of this counselor in our study was her experience with burnout and her stated inability to give empathy; all she felt she was capable of giving her patients was information. The experience she described fit the characterization of burnout, but also had considerable overlap with compassion fatigue. This counselor stated her aspirations and goals when she was a new genetic counselor – and was self-aware enough to recognize that while dealing with her own grief, she was not accomplishing these goals.

The largest predictor of compassion fatigue was delivering bad news (Udipi, et al., 2008) and a turning point for this counselor was the realization that she could stay within the field of genetic counseling while avoiding involvement with giving patients bad news. Countertransferential reactions after a personal grief or loss experience can cause burnout, and in this case the counselor was aware of feeling burned out and left clinical practice. This level of self-awareness was unique among the counselors we interviewed, and her decision to leave clinical practice could be a reflection of her utilization of countertransference to the utmost benefit to herself and her patients. It seemed this counselor was still in the midst of her emotions, and we speculate that perhaps her outlook will change as time passes and she works through the grief process, however, she seemed confident in her future outside of the clinic. Perhaps this experience brought her to the limits of her capacity for empathy and compassion, and she was frightened by what she found there – she was not the type of counselor she wanted to become, and there was no going back. Regardless of the complexities of her career decisions in light of her
personal experience, she seemed to have a deep desire to stay in touch with her emotional responses and to truly understand them.

An interesting subtheme that emerged was self-disclosure as a consequence of countertransference. The term “self-disclosure” was not used by the interviewer and the issue of self-disclosure was not explicitly addressed in other ways, however, the majority of the counselors mentioned it, often in connection with a case in which they felt strong emotions. Most of the counselors felt that self-disclosure contributed positively to a genetic counseling session when it was used with a careful eye as to what part of their story would be helpful to the patient, and seemed quite satisfied with the use of self-disclosure. As the paradigm of the genetic counseling process shifts away from non-directiveness and towards a shared decision-making process, the counselors seemed to view self-disclosure as a tool to benefit the patient – but one to be used cautiously, if at all. The counselors felt that self-disclosure to a patient with similar circumstances can be used to express empathy and understanding. In addition, counselors tended to self-disclose when a patient was inconsolable, in order to provide empathy and hope.

Regarding the counselors who felt that their self-disclosure caused a dramatic change in patient attitude or a turning point in the session – there is the possibility that the patient was truly comforted by the counselors’ self-disclosure. But perhaps the act of self-disclosure made the patient uncomfortable; perhaps the patients felt intimidated by the counselors’ loss; or perhaps they were later distressed not only by their own experiences but by the description of the counselors’ experience as well. Without investigating the patients’ true feelings regarding self-disclosure, there is no way of knowing why the tone of the session changed. Although the counselors reported positive results with self-
disclosure, it is important to remember that self-disclosure may be seen as beneficial by some counselors simply because they have only had positive experiences with its usage thus far, and from their point of view.

However, one of the counselors felt strongly that there was no place for self-disclosure in genetic counseling – in her eyes it was always inappropriate. She had felt the desire to share her experience with patients, but had never self-disclosed. The fact that there was only one counselor that disagreed with usage of self-disclosure is troubling, as there is a paucity of literature on genetic counselor self-disclosure – especially the effects of self-disclosure on patients in a genetic counseling setting. Several of the counselors could not identify how and when they decided to self-disclose and described it as due to good rapport with a patient, or as a gut feeling or an instinct. While this may be true, the fact remains that counselors most often self-disclosed in a session in which they were feeling strong emotions, or countertransference, usually triggered by similarities in the patients’ stories to the counselors’ own personal grief experience. In taking a personal and often unconscious emotional process such as countertransference and trying to make room for it in a genetic counseling session, who can judge or blame the counselors for trying to use self-disclosure as a tool to help their patients? They came through the other side of loss and often immeasurable grief. To see a patient facing similar pain would inspire in many counselors the human urge to use their changed outlook to ease the patients’ pain in the best way they could think of – by using self-disclosure as a tool to let patients know they are not alone and that they will endure. As countertransference is a largely unconscious process, the true role of self-disclosure as a helpful counseling tool
must be examined carefully, and further research is warranted as to the patient perspective on genetic counselor self-disclosure.

This is an exploratory, qualitative study that provides a better understanding of countertransference and the effects of a counselor’s personal grief and loss experiences on clinical practice. Grief and loss are a part of life, and the counselors in this study allowed us a glimpse into their inner selves and the thought processes related to the complicated experience of incorporating their personal lives into clinical practice. This was a small pilot study and our data and discussion cannot be generalized, but this study can provide guidance in assessing the possibility of undertaking a more extensive study related to genetic counselors’ personal grief and loss experiences or on the effects of genetic counselor self-disclosure on patients.

Regarding recall bias as a limitation in this study, the psychological processes involved in responding to a grief or loss experience are inevitable – this is the counselor’s story. As time passes, it is human nature to write and rewrite “our” story. In this study, the changes in memory of the event and the associated emotions may be thought of as an inevitable psychological response to the original event as the counselor is reminded of it in the course of their clinical practice. A related issue is the social desirability experienced while answering questions of a very personal nature. The uncomfortable feelings associated with countertransference may have resulted in the counselor feeling self-conscious and perhaps uncomfortable with being truly honest about the emotions evoked by a certain case. In our study we gained a richness of data from self-aware counselors who seemed as straightforward as possible in their recollections. In sampling counselors with five or more years of experience, they had many clinical experiences on
which to reflect, as well as considerable self-awareness to allow for rich descriptions of their experiences.
CONCLUSION

Genetic counselors were interviewed regarding their personal grief or loss experience and its potential effects on clinical practice. Some themes that emerged included personal and professional changes, separation of personal and professional lives, identification of countertransference, and self-disclosure and burnout as consequences of countertransference. This study is important because it begins to delve into the largely unexplored, but important, territory regarding the effect of genetic counselors’ personal grief and loss experiences on their clinical practice. These experiences affect patient interactions, especially those with a patient whose suffering reminds the counselor of their own. Genetic counselors’ personal grief and loss experiences affect clinical practice in undeniable but also extremely complex ways, and in acknowledging these interactions we can begin to find ways to integrate them into clinical practice.

If a counselor with a personal grief or loss experience is to remain in clinical practice, the question remains: When and how is it acceptable to use a countertransference reaction in a session? Are counselors using self-disclosure in a self-seeking manner, under the guise of “helping the patient” to open up, feel less alone, or see that there is hope for the future? It is difficult to assess the impact of attempting to use countertransference in a genetic counseling session. This highlights the need for peer supervision groups and other professional supports, where counselors can draw awareness to countertransference reactions in an atmosphere of acceptance.
Further research is warranted as to the patient perspective on genetic counselor self-disclosure, and gaining insight on this may clarify possible benefits of self-disclosure. In addition, an exploration of empathy and its relationship with psychosocial counseling techniques in genetic counseling could provide information to training programs regarding comfort with grief and loss emotions.

As one counselor articulated: “Loss is part of life. Grief is part of life. Everyone’s always going to have something to grieve over. And it shouldn’t be something that we sweep under the rug. It should be something that we talk about. That we allow, and that we shouldn’t be afraid of.” This pilot study takes steps in a direction that will allow genetic counselors to reconcile their inner selves with their outer lives and find peace, including in the clinical setting.
References


ARE YOU A GENETIC COUNSELOR WITH A PERSONAL GRIEF OR LOSS EXPERIENCE?

I am a graduate student in the genetic counseling program at Brandeis University. I am seeking volunteers to participate in a qualitative research project. The goal of this study is to explore the influence of genetic counselors’ personal experiences with grief and loss on their clinical practice.

ELIGIBILITY REQUIREMENTS:

- Genetic counselors with a personal grief or loss experience
- Genetic counselors in New England
- Board certified genetic counselors
- Genetic counselors with at least 5 years experience

Following a brief phone or email questionnaire to assess eligibility, participation involves one face-to-face audiotaped interview that will last approximately 45 minutes to an hour. I hope to have all interviews completed by March 1, 2010.

Identifying information will be kept strictly confidential during the study and will be destroyed upon completion of the study. Identifying details will be changed to protect the privacy of the participants. To show appreciation for time contributed, all participants will receive a $25 Visa gift card upon completion of the interview.

If you are interested in participating in this study or would like more information, please email me at dbienski@brandeis.edu by February 1, 2010.

Thank you for your consideration!

Denise Bienski, Master’s Candidate
Genetic Counseling Program
Brandeis University
Informed consent to participate in a research study

Please take a moment to read the following consent agreement:

This is a research study exploring genetic counselors’ personal experiences with grief and loss. Your responses to the interview questions will be used to understand genetic counselors’ personal experiences with grief and loss and the effect on their clinical practice. The results of this study may be used to develop ideas for future research projects.

If you agree to participate, you will be contacted by telephone or email to verify eligibility and arrange an interview time and location at your convenience. The interview will last approximately 45 minutes to an hour and will be audiotaped, transcribed, and studied. Your identifying information such as name, work address and home address, telephone number(s), and email address will be kept strictly confidential during the study and will be destroyed upon completion of the study. If you are quoted or referred to in any written or oral reports of the study, you will be assigned a pseudonym. Identifying details will be changed to protect your privacy. You will never be referred to by your real name or any other identifying or demographic information in any written or oral reports based on your interview.

This study is voluntary and you are under no obligation to participate. You may discontinue your participation at any time and for any reason until the time the study is complete. You will receive a $25 Visa gift card upon completion of the interview as a gesture of appreciation for your time and contribution.

If you have any questions regarding this study, please contact the Primary Investigator, Janet Rosenfield, by email at jmrosenfield@mac.com.

You may also contact the Student Researcher, Denise Bienski, at 214-502-8060 or by email at dbienski@brandeis.edu.
If you have experienced emotional distress as a result of participating in this study, Dr. Annette Kennedy, a licensed psychologist who has extensive experience with genetic counseling, is available for assistance at 781-674-9990.

If you have questions regarding your rights as a research subject, please contact the Brandeis University Institutional Review Board at 781-736-8133 or by email at irb@brandeis.edu.

Please initial here to indicate your willingness to be audiotaped. 

__________________

Please sign below to indicate your willingness to participate in this study under these conditions.

__________________________________________________              _______________
Participant’s Signature                                      Date

__________________________________________________
Participant’s Name (Please Print)

__________________________________________________              _______________
Student Researcher’s Signature                              Date
Name:
Location:
Phone number:

1. How long have you been a genetic counselor?
2. When were you board certified?
3. Briefly describe your current (and past, if applicable) position, including length of time spent at each.

[It sounds like you meet the eligibility criteria, and I’d like to meet with you.]

4. Regarding your personal loss experience, when can you describe what happened in just one or two sentences?
APPENDIX D

INTERVIEW GUIDE

Below is a general guide that we will use to lead our individual interviews. We may modify this guide as needed.

Participant Name:
Date:
Time:
Location:

I. Introduction and Background

1. Conduct the informed consent process and discuss confidentiality.
2. Let the participant know they can take a break or terminate the interview at any time, for any reason.
3. Explain the presence and purpose of recording equipment and note-taking.
   a. I’m going to record the audio of our interview to make sure I don’t miss anything. The interview will be transcribed by a confidential transcription service, and your name will not be associated with it. Any potentially identifying information that might come up as we talk will be deleted from the transcript before data entry.
4. Give the participant a brief protocol summary and general overview of the interview process.
   a. The aim of this study is to learn more about how genetic counselors’ personal experiences with grief and loss may affect their clinical practice before, during and after interactions with patients. Do you have any questions before we begin the interview?

II. Discussion of history of personal grief/loss experience

1. I know we spoke briefly on the phone about your work history as a genetic counselor. Can you tell me more about your professional experiences?
2. We briefly discussed your experience of _________ on the phone. Can you tell me more about it?
3. When did this happen?
4. Where are you now with it? How have your feelings changed or evolved since it happened?

5. It sounds like it was a very ________ experience. How have you taken care of yourself since that happened?

III. Effect of Personal Experience on Overall Counseling

1. As you think about the experience now, do you feel there are ways in which it has affected your genetic counseling, in the past and at present? How so?

2. Describe a situation in counseling sessions that you feel differently about since your own personal experience. To what extent do these thoughts or feelings stay with you after a session?

3. In what ways, if any, has your counseling changed in these situations?

IV. Case Discussion

1. Is there a specific case that comes to mind in which you can recall having had strong emotions before, during, or after the counseling session? Tell me about the case.

2. What do you remember feeling about their circumstances?

3. What was your reaction to your patient(s)?

4. How did you feel about your reaction?

5. How did you deal with your emotions?

6. Do you have someone to talk to or a way to take care of yourself when this happens? Has this been helpful? Do you wish there were other supports available in your work setting?

V. Closing comments

1. Thank the participant.

2. Ask them how the interview experience was for them.

3. Remind them that Dr. Annette Kennedy is a resource if they experience emotional distress after the interview.


5. Offer to send a copy of the abstract to the participant when the study is complete.

VI. Issue Compensation