Beginning Genetic Counselors' Comfort Level with Grief and Loss in the Clinical Setting

Master's Thesis
Presented to
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Brandeis University

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Master of Science

By
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ABSTRACT

Beginning Genetic Counselors' Comfort Level with Grief and Loss in the Clinical Setting

A thesis presented to the Genetic Counseling Department

Graduate School of Arts and Sciences
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Waltham, Massachusetts

By Meghan Deeney

Genetic counselors are specialized health professionals who, by nature of their profession, come into contact with patients who are experiencing, or have experienced, some type of loss. As such, it is important that genetic counselors be well prepared to provide emotional support to patients and families who are grieving. The purpose of this study was to determine beginning genetic counselors’ comfort level with issues of grief and loss in the clinical setting. We set out to find what factors, if any, influenced their comfort level in counseling for these personal issues. We recruited clinical genetic counselors with fewer than 6 years of experience from the National Society of Genetic Counselors (NSGC) listserv for participation in a voluntary, anonymous online survey. The survey contained questions related to educational counseling opportunities, personal and professional experiences with issues of loss, and counselors' comfort level with a wide variety of counseling scenarios. Overall, genetic counselors were comfortable with psychosocial counseling scenarios, but were most uncomfortable with scenarios that involved death and dying. Hands-on training including mock counseling sessions, clinical rotations, and community involvement, in addition to on-the-job experience, were
the most helpful factors contributing to counselors' comfort level. Personal experiences and religious beliefs also played a role in how counselors interacted with patients including both positive and negative countertransference. Due to counselors' relative discomfort with more emotionally charged and complex scenarios, in combination with their strong reactions to their own experiences and beliefs, we suggest initiating a formal evaluation of genetic counseling curricula, so that genetic counseling programs can consider how best to incorporate additional training on these topics.
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Introduction

Genetic counselors are specialized health professionals who convey information to patients and their families about the hereditary aspects of disease, provide emotional support in decision making, act as patient advocates, and help families understand the psychological implications of genetic disease (nsgc.org). They have the difficult task of explaining a person’s risk for developing certain genetic and chromosomal conditions, outlining recurrence risks of disease for future children, and perhaps harder still, not being able to provide much needed answers for patients in this ever-changing field. Counselors may also need to deliver potentially difficult news to patients in the form of giving a disease diagnosis, positive test result, or abnormal prenatal ultrasound finding. These and other scenarios can elicit grief and loss reactions by the patient and/or their families. The unique role of a genetic counselor affords these professionals the opportunity to provide a safe and supportive environment in the wake of potentially life-altering events.

If a counselor is not comfortable with the varying reactions of their clients, then the counselor may not be able or willing to explore the beliefs, values, and needs of their patients, or be well equipped and ready to provide the emotional support needed for a successful therapeutic relationship. It is essential that we are meeting our patients' needs, while simultaneously maintaining awareness of our own level of expertise and comfort. Discomfort with scenarios involving grief and loss may also negatively impact the wellbeing of the genetic counselor, which can lead to high levels of emotional distress, or job burnout. Some studies have assessed comfort level with loss in psychology students
and nurses, but there are no such studies that assess the comfort level of genetic counselors.

Of the many different types of losses, death holds a significantly unique place, by virtue of its inevitability and permanence. In 1991, Kirchberg and Neimeyer conducted a study of master’s level psychology students to find out their comfort level with death-related, and non death-related scenarios in counseling. The participants took a twenty minute self-report questionnaire that included fifteen scenarios. Five of the scenarios were related to death, while the remaining ten scenarios involved other psychosocial issues. They found that five out of the eight scenarios that were ranked most uncomfortable were "death-relevant" and dealt with terminal illness, suicide, or bereavement. None of the scenarios that were rated least uncomfortable involved death or loss (Kirchberg and Neimeyer 1991). They suggested that others should continue this type of research in order to better understand underlying reasons for counselors’ discomfort with death issues. Once identified, Kirchberg and Neimeyer (1991) suggested that professional training could be tailored to incorporate relevant coursework, and educational experiences.

Kirchberg, Neimeyer, and James (1998) went on to summarize the research of Terry, Bivens, and Neimeyer (1995), by stating that counselors with little formal training in grief and death, as well as limited contact with clients dealing with these sensitive issues, leads to higher levels of counselor discomfort with grief and loss. In a 1998 follow-up study, Kirchberg, Neimeyer, and James further explored the mental-health professional's comfort level with death and bereavement. The authors also sought to determine counselors' level of empathy towards clients facing loss, and how counselors'
personal feelings towards death determined their response to clients. Their results echoed their previous findings that beginning counselors had a higher level of discomfort with counseling scenarios involving death and loss. Although the overall empathy score was low among beginning counselors, the authors were surprised to discover that counselors showed more empathy towards clients facing death and loss than to clients dealing with other scenarios. Furthermore, counselors who had a higher level of "death fear" were more distressed by scenarios involving loss, while counselors who were "saturated" with scenarios involving death during the study were less empathic to clients. These results suggest that a counselor's exposure to scenarios involving death and loss, as well as his or her personal reactions to death, had an impact on how counselors respond to clients.

More recently, Engler et al. (2004) surmised that education and training can affect the comfort levels of nurses. They conducted a study that surveyed nurses who worked with families of critically ill or dying infants in a neonatal intensive care unit (NICU) to find out their view of bereavement and end-of-life issues (Engler, Cusson et al. 2004). Engler and colleagues studied four points:

1. The comfort level of neonatal registered nurses (RNs) and advanced practice nurses (APNs) with bereavement issues;

2. The roles of neonatal RNs and APNs within the context of the bereaved families;

3. The factors influencing the nurses’ involvement in the care of ill or dying infants; and

4. How education or professional roles influence these issues (Engler, Cusson et al. 2004).
They found that RNs and APNs were comfortable supporting families of infants in the NICU. However, they found that nurses who had more experience, more bereavement and end-of-life education, worked with a bereavement/end-of-life protocol in the NICU, and who saw more critically ill infants, were more comfortable with bereavement and end-of-life care (Engler, Cusson et al. 2004). The researchers in this study suggested that nursing curricula should incorporate more bereavement and end-of-life content. We used several aspects of Engler’s research as a model for our study, as there are many parallels between nurses in the NICU setting and genetic counselors in the clinical setting.

Our study was meant to address the extent to which genetic counselors felt comfortable with grief and loss issues in the genetic counseling setting, as well as to identify the underlying reasons for their comfort or discomfort; mainly regarding genetic counseling training programs and personal experiences. We also sought to identify additional supports that we can offer to genetic counseling students and beginning counselors that may enhance counselors' level of comfort.

Methods

Sampling

We used an anonymous online survey¹ to collect information regarding genetic counselors’ comfort level with a variety of counseling scenarios so that we could identify areas where counselors felt more or less comfortable. We also asked counselors to rate their perception of the availability of learning opportunities in their genetic counseling program, their opinion on the importance of including various counseling topics in

¹ Refer to Appendix A for complete survey
counselor training, as well as participants' level of involvement with counseling scenarios in the workplace. These questions were meant to assist us in identifying any external factors that may have influenced counselors' comfort level.

We submitted a proposal to the Brandeis Institutional Review Board (IRB) on November 6, 2008, and received a status of exempt from the IRB on November 24, 2008. A member of the genetic counseling program faculty posted a recruitment notice on the National Society of Genetic Counselors (NSGC) general listserv three times between January 24, 2009 and February 5, 2009. The notice included a link to "surveymonkey.com," an online survey tool.

Our inclusion criteria was such that only board eligible or board certified genetic counselors with professional clinical experience who graduated from a genetic counseling program between May, 2003 and May, 2008, could participate. We excluded counselors who had more than 6 years of genetic counseling experience in an attempt to control for perceived comfort due to length of time spent in the profession. We also excluded those who had a graduate or post-graduate degree or certification in social work, psychology, psychological counseling, or thanatology2 so that our questions would be solely based on genetic counseling training, and not training in other related fields. Our study did not require us to obtain informed consent from eligible participants, as there was minimal risk to the individuals. However, we provided participants with the contact information of a Certified Thanatologist (CT) and instructed them to contact her if they felt any unsettling emotions as a result of taking the survey.

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2 The study of death and dying
**Design of the Survey**

We piloted the survey using five master’s level genetic counseling students from Brandeis University. It took an average of approximately 25 minutes for each of the students to complete the survey. The survey included our own definitions of loss, grief, and sudden grief reaction, quantitative and qualitative questions, and a demographics section. The quantitative questions were presented in five distinct Likert scales: comfort level; opportunities for learning; opportunities for practice; level of involvement; and level of importance. We asked qualitative questions at the end of each comfort level page, and ended the survey with three open-ended questions related to the impact of training, personal experiences with loss, and religious beliefs. Our intent was to design each section of the survey with the goal of ultimately pinpointing any correlation between counselors’ comfort level with sensitive issues in counseling, and their graduate training experiences, professional experiences, or life experiences.

**Data Analysis**

After the completion of gathering data, we analyzed our results using Statistical Package for the Social Sciences (SPSS) software. We removed any participants from our data set who did not complete a majority of the survey questions. We then used descriptive statistics to obtain the mean rating for each distinct question, as well as the overall mean, in all quantitative sections. We manually identified trends between the highest and lowest rated questions, and used the comments at the end of each Comfort Level section to identify themes. Our study utilized correlation analysis to compare the mean responses in the Comfort Level section with the mean responses of all other
sections, as well as several of the demographics questions. Lastly, we manually identified trends in responses to the open-ended questions.

**Results**

Of the 153 people who initiated the survey, 34 did not meet the inclusion criteria, and another 18 did not answer a significant portion of the questions. We therefore had 101 completed surveys. Not all participants answered every single question, so N may be less than 101 for any given response. N may also be greater than 101 for some sections where participants were able to provide more than one open-ended comment.

**Quantitative Data: Genetic Counselors' Comfort Level**

The Comfort Level section of the survey was designed to find out how comfortable counselors were with different genetic counseling scenarios, most of which were related to grief, loss, and death. The survey was set up such that the more common and less complex counseling scenarios were listed first, and increasingly became more emotionally charged and less common. We used a Likert scale for all 43 scenarios, where 1=very uncomfortable, and 5=very comfortable. The average comfort level score for all scenarios combined was 3.53. No scenario had an average score of less than 2.

Table 1 shows the top 5 scenarios that ranked highest in terms of comfort level. These scenarios are relatively common, and less complex, genetic counseling scenarios. The standard deviation for these scenarios is relatively small, and the majority of responses clustered tightly around the mean. We saw a slight drop in mean in the next 5 most comfortable scenarios, which consisted of counseling scenarios that involve more

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3 Refer to Appendix A, pages 50-53, for the complete list of counseling scenarios
emotion (Table 2). Also of note, these scenarios had higher standard deviation, and thus had much more variation in response.

<table>
<thead>
<tr>
<th>Genetic Counseling Scenario</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Std Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking a pedigree</td>
<td>101</td>
<td>3</td>
<td>5</td>
<td>4.91</td>
<td>0.32</td>
</tr>
<tr>
<td>Giving negative results (patient does not have the mutation, condition, etc.)</td>
<td>101</td>
<td>4</td>
<td>5</td>
<td>4.88</td>
<td>0.33</td>
</tr>
<tr>
<td>Explaining the genetics of different conditions</td>
<td>101</td>
<td>4</td>
<td>5</td>
<td>4.83</td>
<td>0.38</td>
</tr>
<tr>
<td>Counseling a patient who is advanced maternal age</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.69</td>
<td>0.63</td>
</tr>
<tr>
<td>Giving positive results (patient has the mutation, condition, etc.)</td>
<td>101</td>
<td>3</td>
<td>5</td>
<td>4.51</td>
<td>0.58</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Genetic Counseling Scenario</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Std Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving uninformative/ambiguous results</td>
<td>101</td>
<td>1</td>
<td>5</td>
<td>4.18</td>
<td>0.78</td>
</tr>
<tr>
<td>Verbally acknowledging the emotions of the patient and their family members</td>
<td>100</td>
<td>3</td>
<td>5</td>
<td>4.18</td>
<td>0.69</td>
</tr>
<tr>
<td>Exploring how a patient feels about a given diagnosis</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.15</td>
<td>0.78</td>
</tr>
<tr>
<td>Giving a diagnosis</td>
<td>101</td>
<td>1</td>
<td>5</td>
<td>4.09</td>
<td>0.81</td>
</tr>
<tr>
<td>Sitting with a patient who is crying during the counseling session</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.07</td>
<td>0.9</td>
</tr>
</tbody>
</table>

The lowest scoring scenarios on the Comfort Scale can be viewed in Table 3. These scenarios were considered less common in genetic counseling, were more complex, and dealt heavily with death and dying.
Table 3: Lowest scoring scenarios on the Comfort Level scale, in decreasing order of comfort

<table>
<thead>
<tr>
<th>Genetic Counseling Scenario</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Std Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploring a patient's feelings surrounding death and dying</td>
<td>101</td>
<td>1</td>
<td>5</td>
<td>2.92</td>
<td>1.06</td>
</tr>
<tr>
<td>Being in the presence of a family following a termination via labor induction</td>
<td>98</td>
<td>1</td>
<td>5</td>
<td>2.86</td>
<td>1.18</td>
</tr>
<tr>
<td>Exploring religious views of death and dying for patients of a different religion than your own</td>
<td>100</td>
<td>1</td>
<td>5</td>
<td>2.84</td>
<td>1.08</td>
</tr>
<tr>
<td>Leading/co-leading a support group</td>
<td>96</td>
<td>1</td>
<td>5</td>
<td>2.79</td>
<td>1.2</td>
</tr>
<tr>
<td>Contacting families on an anniversary of your patient's death</td>
<td>98</td>
<td>1</td>
<td>5</td>
<td>2.78</td>
<td>1.15</td>
</tr>
<tr>
<td>Being in the presence of a family as their baby/child is dying, or has died</td>
<td>99</td>
<td>1</td>
<td>5</td>
<td>2.76</td>
<td>1.25</td>
</tr>
<tr>
<td>Discussing funeral arrangements</td>
<td>99</td>
<td>1</td>
<td>5</td>
<td>2.75</td>
<td>1.199</td>
</tr>
<tr>
<td>Being in the presence of a family as their family member (your patient) is dying, or has died</td>
<td>98</td>
<td>1</td>
<td>5</td>
<td>2.73</td>
<td>1.17</td>
</tr>
<tr>
<td>Displaying your own emotions (tearing, crying) during a counseling session</td>
<td>100</td>
<td>1</td>
<td>5</td>
<td>2.72</td>
<td>1.09</td>
</tr>
<tr>
<td>Discussing the &quot;danger&quot; signs (suicide ideation, harm to self or others) with a grieving patient</td>
<td>100</td>
<td>1</td>
<td>5</td>
<td>2.67</td>
<td>1.1</td>
</tr>
<tr>
<td>Contacting families on the anniversary of a pregnancy termination (or on the due date)</td>
<td>98</td>
<td>1</td>
<td>5</td>
<td>2.63</td>
<td>1.21</td>
</tr>
</tbody>
</table>

Qualitative Responses: Comments on Counselors’ Perception of Comfort Level

We wanted to better qualify the reasons for why counselors chose “very comfortable,” or "very uncomfortable," for any given scenario⁴. In an effort to make our respondents pause and reflect on their answers, we asked participant's to elaborate on the reasons for their comfort after every 10 or 12 counseling scenarios.

⁴ Refer to all responses in Appendix B, pages 57-75
We found 6 main themes from the 200 comments related to reasons for counselors' *increased* level of comfort (Figure 1). Participants often commented on more than one factor. Professional experiences, counseling training, counselors' personality and natural ability to communicate and work with people, life experiences, and supportive co-workers were all reasons for counselors' comfort. Many participants also noted the difference in comfort level between emotionally charged scenarios, and scenarios where there is minimal emotional involvement.

The majority of our responses (N=149) indicated that experience and repetition lead to higher comfort level with certain genetic counseling scenarios.

*Experience.* *Doing these thing[s] is all very uncomfortable in the beginning of training when you haven't interacted with patients very much. As you learn and see more patients, it becomes more comfortable.*

We received 105 responses regarding reasons for counselors' *decreased* level of comfort. Again, our respondents often mentioned more than one reason for their discomfort. The responses include 7 major themes (Figure 2). The majority of

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5 N is greater than number of participants as there were four different opportunities to respond. Thus, some participants may have multiple responses.
participants (N=56) said that a lack of experience led to their discomfort with a particular counseling scenario. Many counselors said that some scenarios were not the role of a genetic counselor, and felt that they were inappropriate, or crossed professional boundaries.

_I don't feel comfortable touching patients. Only in a few situations have I ever touched a patient who was grieving. I don't often feel it's appropriate. I never feel it is appropriate to display my own emotions during the session. It has nothing to do with comfort level, it just shouldn't be done._

**Figure 2: Reasons Attributed to Counselors' Discomfort (By Number of Times Mentioned)**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of Experience</td>
<td>15</td>
</tr>
<tr>
<td>Not Counselors' Role/Shouldn't be Done</td>
<td>14</td>
</tr>
<tr>
<td>Inappropriate/Crosses Boundaries</td>
<td>10</td>
</tr>
<tr>
<td>More Emotional Scenario</td>
<td>10</td>
</tr>
<tr>
<td>Unsure of Pt. Reaction/Benefit to Patient</td>
<td>9</td>
</tr>
<tr>
<td>Lack of Training</td>
<td>7</td>
</tr>
<tr>
<td>Personal Experiences/Beliefs</td>
<td>56</td>
</tr>
</tbody>
</table>

**Opportunities for Learning and Practice**

Obtaining information regarding participants' comfort level with psychosocial counseling scenarios was a main focus of our survey, but not our only goal. We also wanted to be able to correlate comfort level with certain aspects of the genetic counselor's training education and experiences. In an attempt to quantify this, we asked counselors to rate the opportunity and availability of courses and training that was provided to them during their two year master’s level genetic counseling program.
We first asked participants to rate various counseling topics on a Likert scale, where 1=not enough information and 5=too much information. We obtained the average score for each counseling topic (Table 4).

We then asked genetic counselors in our study to rate how much exposure they had to various counseling scenarios as part of their clinical genetic counseling internships. They were given a Likert scale, where 1=not enough exposure, and 5=too

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Refer to Opportunities for Learning scale, Appendix A, page 47
much exposure\textsuperscript{7}. We asked participants to base their answers on what they were able to do, rather than observe. We obtained the average score for each topic (Table 5).

<table>
<thead>
<tr>
<th>Counseling Opportunity</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Std Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving normal (negative) results to patients/families</td>
<td>100</td>
<td>1</td>
<td>5</td>
<td>3.55</td>
<td>0.72</td>
</tr>
<tr>
<td>Giving bad news during role plays, mocks, etc.</td>
<td>101</td>
<td>1</td>
<td>5</td>
<td>3.25</td>
<td>0.83</td>
</tr>
<tr>
<td>Giving support to patients/families faced with difficult/unexpected news</td>
<td>101</td>
<td>1</td>
<td>4</td>
<td>2.73</td>
<td>0.85</td>
</tr>
<tr>
<td>Giving abnormal (positive) results or difficult/unexpected news to patients/families</td>
<td>101</td>
<td>1</td>
<td>5</td>
<td>2.54</td>
<td>0.96</td>
</tr>
<tr>
<td>Giving ambiguous information/results to patients/families</td>
<td>101</td>
<td>1</td>
<td>4</td>
<td>2.52</td>
<td>0.88</td>
</tr>
<tr>
<td>Opportunities to attend workshops/conferences related to death, dying, and bereavement</td>
<td>101</td>
<td>1</td>
<td>5</td>
<td>2.12</td>
<td>0.98</td>
</tr>
</tbody>
</table>

It is important to take note that, in our comparison of these tables to comfort level, we found that comfort level showed moderate positive correlations with how much information counselors’ received about grief counseling topics during graduate school (Opportunities for Learning) (r=.37, p <.001). Comfort level showed moderate positive correlations with counselors’ opportunities to practice or encounter genetic counseling skills/situations as part of their two year master’s level genetic counseling program (Opportunities for Practice) (r=.27, p<.01). These correlation results show that genetic counseling training has at least some effect on counselor comfort level.

**Level of Involvement**

We hypothesized that current level of involvement with grief and loss in the clinical setting would have an effect on counselors' comfort level. We attempted to assess this probable correlation by asking participants to rate how often they encountered

\textsuperscript{7} Refer to Opportunities for Practice scale, Appendix A, page 48
different scenarios during their current or most recent area of clinical practice. Again, we evaluated this using a Likert scale, where 1 = the counselor has never encountered the given scenario in a counseling session and 5 = the counselor encounters the given situation in every single session. We obtained the average involvement score for each topic. Table 6 shows the scenarios that counselors encountered most often during their practice, and Table 7 shows the scenarios that counselors encountered least often during their practice.

<table>
<thead>
<tr>
<th>Genetic Counseling Scenario</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Std Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explore a patient’s feelings/emotional state during a counseling session</td>
<td>94</td>
<td>2</td>
<td>5</td>
<td>3.72</td>
<td>0.9</td>
</tr>
<tr>
<td>Give negative results (patient does not have the mutation, condition, etc.)</td>
<td>94</td>
<td>1</td>
<td>5</td>
<td>3.69</td>
<td>0.62</td>
</tr>
<tr>
<td>See a patient/family with a family history that puts them at risk for a life-altering, life threatening, or life limiting condition</td>
<td>93</td>
<td>1</td>
<td>5</td>
<td>3.06</td>
<td>0.95</td>
</tr>
<tr>
<td>See a patient/family immediately after they have received a diagnosis that would elicit a grief reaction</td>
<td>94</td>
<td>2</td>
<td>5</td>
<td>3.05</td>
<td>0.72</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 7: Level of Involvement: Scenarios encountered least often by genetic counselors, in decreasing order</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic Counseling Scenario</td>
</tr>
<tr>
<td>See a patient/family who is confronting an impending loss and/or death</td>
</tr>
<tr>
<td>See a patient whose emotional reaction makes you feel uncomfortable</td>
</tr>
<tr>
<td>Discuss the option of adoption following an abnormal prenatal diagnosis</td>
</tr>
<tr>
<td>Explore the option of limitation of interventions as presented by the primary care team</td>
</tr>
<tr>
<td>Explore the option of palliative care as presented by the primary care team</td>
</tr>
</tbody>
</table>

Refer to Level of Involvement Scale, Appendix A, page 54, for the complete list of counseling scenarios.
Our comparison of Level of Involvement data to comfort level showed that there was a moderate, positive correlation to how often counselors’ encountered grief related genetic counseling scenarios in their current or most recent counseling sessions, and how comfortable they were ($r=.33$, $p<.001$). Although not overwhelmingly significant, these results do show that there is a trend between experience and comfort.

**Level of Importance**

Our final quantitative section was meant to give support to our claim that grief related counseling is just as important, if not more important, as learning the hard facts about genetics. Although understanding genetic mechanisms was ranked most important, the psychosocial topics were all highly important to our participants (mean=4.21). For this Level of Importance section, we used a Likert scale, where 1=not at all important, and 5=very important. We obtained the average score for each topic (Table 8). These results showed that, indeed, grief and loss are important to genetic counselors in terms of counseling training.

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9 Refer to Skills Assessment scale (known as Level of Involvement in this paper), Appendix A, page 49
Table 8: Level of Importance: Counseling topics listed in order of importance, in decreasing order

<table>
<thead>
<tr>
<th>Counseling Topic</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Std Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding the underlying genetic mechanisms for various conditions</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.74</td>
<td>0.56</td>
</tr>
<tr>
<td>Learning how to prepare yourself for the emotional reactions for your patients and their family members</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.41</td>
<td>0.74</td>
</tr>
<tr>
<td>Learning how to care for yourself in order to reduce your risk of compassion fatigue and/or job burnout</td>
<td>101</td>
<td>1</td>
<td>5</td>
<td>4.34</td>
<td>0.89</td>
</tr>
<tr>
<td>Learning about grief, death, and dying</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.23</td>
<td>0.73</td>
</tr>
<tr>
<td>Understanding various behaviors displayed by patients who are faced with grief and loss</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.22</td>
<td>0.74</td>
</tr>
<tr>
<td>Recognizing and understanding your own comfort level with death and dying</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>4.1</td>
<td>0.82</td>
</tr>
<tr>
<td>Recognizing and understanding how you own personal loss history affects the way you counsel and support patients/families</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>3.98</td>
<td>0.91</td>
</tr>
<tr>
<td>Introducing or maintaining a formal curriculum for genetic counselors regarding grief and loss</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>3.97</td>
<td>0.81</td>
</tr>
<tr>
<td>Recognizing and understanding your own beliefs surrounding death and dying</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>3.93</td>
<td>0.89</td>
</tr>
<tr>
<td>Learning about multicultural issues and rituals surrounding grief and loss</td>
<td>101</td>
<td>2</td>
<td>5</td>
<td>3.89</td>
<td>0.79</td>
</tr>
</tbody>
</table>

Demographics

Although we expected to find that comfort level was associated with factors such as counselors’ age, year of graduation, years of clinical experience, and area of clinical practice; we did not find significant correlations between comfort level and demographics of our study participants. Comfort level showed small to moderate positive correlations with years as a genetic counselor ($r=.20$, $p<.05$), and years of clinical genetic counseling experience ($r=.22$, $p<.05$). We did find that the counselors who marked that they
simultaneously worked in both cancer and pediatrics had significantly higher comfort scores (mean=3.81) than all other participants (mean=3.49), t(99)=-2.04, p<.05.

**Personal Experiences and Beliefs**

The personal experience section consisted of three open-ended questions that were designed to elicit more in-depth information regarding genetic counselors’ opinions of their graduate training, personal experiences with grief and loss, and how counselors’ culture or religion impacts the way they interact with grieving or bereaved clients\(^{10}\). In order to identify trends in our numerous responses, we placed each response into a specific category used a manual ranking system. The categories and some of the more profound responses are outlined in the remainder of this section.

**Open-Ended 1: Grief and Bereavement Training**

We asked counselors to describe any graduate training experiences that they found particularly helpful in preparing them to work with patients and families facing grief and loss, and we looked for common themes among the 54 comments we received. We identified 6 main themes regarding helpful training practices: role plays; classes and readings; outside lectures from professionals in the field; community involvement, including volunteer work and support groups; post-training professional work experiences or other outside training; and clinical rotations/clinical supervisors. The breakdown of responses can be seen in Figure 3. Many respondents noted the utility of more than one of these training practices, so values total more than N=54.

\(^{10}\) Refer to all open-ended responses in Appendix C, pages 76-87
Although classes and readings were the most common themes, the combination of training that occurred outside of the traditional classroom setting, i.e. dynamic training, outweighed the utility of classroom experience (Figure 4).

We observed that classroom experience was mentioned most often by the participants (N=24).

*My training program offered a class on death and dying. It touched on a lot of issues including cultural issues, how to write a sympathy note, and even grief on the loss of a pet.*
Approximately 15 participants mentioned that their graduate clinical rotation experience was an effective way to prepare them to work with grieving families.

*My internships were very helpful in preparing for me to work with patients and families facing grief and loss. I feel like it is really important to try and be a part of as much as you can in an internship as a student, so that you can become more and more comfortable dealing with patients in crisis.*

Thirteen counselors’ noted that role playing was a good way to prepare for difficult counseling issues.

*Role Plays - I know they can be scary in grad school - but it is so great to be able to practice these sessions in a safe environment - plus you get to pool on your advisors most memorable cases (at least that is how our role plays were) - which you are unlikely to encounter during your limited grad school experience*

Nine participants’ commented that volunteer work, experience with support groups, and other community involvement, was beneficial.

*I volunteered at an AIDS/HIV hospice home and met many people - men mainly - who had over the last 20 years or so lost lovers, friends, family members to the virus and now they themselves were facing and learning to deal with their own mortality. It was a wonderful, aching, beautiful, frustrating (because not much could be changed) experience.*

Still, some counselors (N=8) recognized that they were more prepared to handle patients dealing with grief and loss as they gained more experience in their current practice.

*I feel that most of "training" in working with patients facing grief and loss occurred on the job as I actually saw patients. I do not think I was well prepared for dealing with immediate reactions of grief in grad school at all. Perhaps, to a small extent in Pediatrics clinic.*

**Open-Ended 2: Personal Experiences with Grief and Loss**

We intuited that counselors’ own personal experiences with grief and loss would have some effect on how they interacted with their patients who may be facing similar situations, and asked counselors to elaborate on this. We identified 3 main themes among
the 50 comments we received: counselors had personal experiences with loss that either positively or negatively impacted their counseling; counselors did not have significant personal experiences; and counselors' personal experiences had no perceived effect on how they reacted to grieving patients (Figure 5).

Figure 5: Counselors' Responses on How Personal Experience with Grief and Loss Influence Counseling

![Pie chart showing responses: 67% of counselors believed personal experiences influence counseling, 29% believed lack of personal experience influence counseling, 4% believed personal experiences have no influence on counseling.]

The overwhelming majority of responses showed that counselors' perceived their personal experiences with loss as a way to be more empathic and understanding towards their clients. However, many counselors' experiences were very remarkable, and often showed a blurring between their experience and their patients' experience.

“My father is a pathologist and because I had an interest in medicine, I helped him with many autopsies. One of them was a 6 month fetus who died in utero. He was perfectly formed except when we opened him up and his stomach was littered with ulcers. But I will never forget that he could fit inside my hand and I couldn't finish the autopsy. So when I am with patients who either have a pending IUFD or termination procedure or it just happened, I remember him and even though I never met his parents, I see them in my own patients and know how real that grief can be.

Some who had experienced loss said that their personal experiences with grief have helped them to identify and understand their own grieving process.

“I've experienced the loss of several friends over the years at very young ages (12, 19, 27), which taught me a lot about my own grief process. All of this provides me with tools to help families. As well as allows me to admit that I don't know how they feel but that I can be there to listen or cry with them.
Others remarked that their personal experiences negatively affected their counseling.

*I know I am more distant with some patients whose stories produce feelings of grief within [me] due to similar personal experiences.*

Still others mentioned that they had had either little or no personal experiences with grief or loss, which they thought was unhelpful.

*I do not have a lot of personal experience with grief and loss - the only close family members who have passed away died when I was young and I don't really remember. I think this makes me a bit more uncomfortable with patients dealing with their own loss.*

Other counselors did not think that their personal experiences influenced (or should influence) the way they interact with patients.

*I am very lucky as I have lost few people so close to me...I think my inexperience, at this point in my career, is a good thing as I can remain attended to the patient as opposed to being reminded of my own grief.*

**Open-Ended 3: Religion & Culture**

We asked counselors to describe how their cultural belief system and/or their religious affiliation influenced the way they counsel patients and families facing grief and loss. Again, we noted three major themes of the 42 comments we received: counselors' had a religious affiliation, but did believe it influenced their counseling; counselors' had a religious affiliation and thought that it enhanced their ability to counsel; and counselors' did not identify strongly with a particular religious affiliation (Figure 6).
Many of the participants said that they did not let religious or cultural affiliation affect the way that they counsel patients, regardless of their particular belief system.

*I consider myself a religious person, but I try to keep my religion away from counseling session unless my patients indicate to me that they also share those beliefs. In any situation, I try to let my patients dictate how much religion/cultural beliefs are going to play a role in their grief processes.*

Other counselors said that their belief system helps them to be more comfortable with their clients, as well as being more open to the patients’ ideas and responses.

*My background (cultural/religious/belief system) gives me one view or lens on the situation. I always remind myself that people may view the exact same situation very differently. There is no wrong or right way, just different ways. And even though I may not understand another’s way of grieving, I want to mindful of their feelings and experiences.*

Those who did not strongly identify with a particular religion did not seem to think that their lack of beliefs was a factor in their ability to counsel patients experiencing loss.

*I am not religious and I don't believe in heaven or hell. But I recognize these beliefs as an important part of the coping process for many patients. I let the patient make indications of the importance of these things and then encourage these beliefs as part of their coping.*
Discussion

A large part of a genetic counselor's role in the clinical setting is to provide supportive counseling to patients and their families (nsgc.org). Due to the inherent nature of the profession and the intensive training involved we were not surprised to discover that, overall, genetic counselors who participated in our study were mostly comfortable with psychosocial counseling scenarios, including those related to grief and loss. However, despite counselors' general level of comfort we discovered that there were distinct differences between the scenarios that counselors were most comfortable with, versus those where comfort levels were diminished. Most notably, they were most uncomfortable with counseling scenarios that involved death and dying. These results were similar to those of Kirchberg and Neimeyer (1991) who concluded that psychology counseling students were most uncomfortable with scenarios involving “death, suicide, and loss.” We surmise the underlying reason for counselors' discomfort with death and dying may stem from the notion that in our society the words "death" and "dying" have negative connotations, and can certainly generate negative emotions. As one counselor in our survey noted...

...I would think it would be a rare person who would be "comfortable" as a patient or child is dying.

We agree that there may always be a general discomfort with many of these sensitive issues. However, this natural increased discomfort with death and loss should encourage additional training, resources, and discussion for genetic counselors who will encounter clients dealing with a significant loss or death; hallmark issues in genetic counseling. But on the contrary we observed in our study that exploring one's own
personal loss history, discussing personal attitudes towards death and dying, and opportunities to attend death, dying, and bereavement workshops, scored lowest in terms of learning opportunities for genetic counseling students. We believe that these observations point to the need for more extensive counselor training regarding death and loss.

The need for additional training surrounding issues of death and dying was made even more apparent by the fact that topics involving death and loss were very important to genetic counselors in our study (Level of Importance scale). However, perhaps the most striking evidence that we found to support the need for more grief and bereavement training were the sheer number of insightful comments from counselors describing with openness and honesty how their personal experiences with grief and loss, as well as their religious views, influenced the way that they counseled patients. From counselors' responses to these questions we were able to identify three groups: counselors whose personal experiences with loss, and/or religious beliefs affected the way they counseled patients; counselors whose lack of personal experiences with loss/and or religion influenced their counseling; and counselors who described having specific personal and or religious beliefs, but did not believe this impacted their counseling.

Personal experiences with loss were often viewed by our participants as being a source of increased empathy and understanding of their patients' feelings, although some of these comments hinted that there was some overlap between the counselors' situation and their patients'.

*I can recognize how grief can feel all-encompassing and lead to feelings of hopelessness (that you will never "move on") but through personal experience, know that time will heal*
and most people with proper guidance and support will emerge from grief in one piece, even if changed by the experience.

Those who revealed that they did not have personal experiences with loss were often worried that they weren't able to relate as well to their patients, while some saw their lack of familiarity as a benefit, because they were able to keep distance between themselves and their patients.

I have not had a lot of loss in my life. I've only had two family members pass away (grandma due to old age and an aunt to cancer). I have not had other major "loss" situations either (i.e. my parents have not gotten a divorce, etc.). So, if anything, I feel like my lack of grief and loss makes it more difficult for me to be empathetic for patients with loss situations.

I do not have any major experiences in my life so I think that helps me to not act in the, "this is what I went through so this is what they will experience," attitude.

A fair number of counselors who identified with a religion often felt that they were better able to understand their patients and provide them with more comprehensive care, yet others felt that their beliefs hindered understanding.

I am a member of the dominant culture in my practice area, which makes it easier to understand the reactions of a majority of patients. I have a religious affiliation, but have a pretty good understanding of other religions' views from my training. I might say something like, "Now he is in a better place," or "His suffering is over," but would not bring up religion overtly.

I come from a white Canadian agnostic background. This will affect how I counsel. I work in a very multicultural city, which was traditionally Catholic, so my background more often than not clashes with my patients. I am less likely to discuss religion as a support system with a patient unless they bring it up first.

Some counselors felt that their beliefs did not, or should not, influence a counseling session, so they did not bring their beliefs to the forefront of a counseling
session. Still others who did not identify strongly with a particular religion were aware that they should be sensitive to others' belief systems.

This may help in my own personal resilience, but I do not believe it colors the time with my clients. It would be inappropriate for me to overlay my affiliations/beliefs onto their session.

I am not religious and I don't believe in heaven or hell. But I recognize these beliefs as an important part of the coping process for many patients. I let the patient make indications of the importance of these things and then encourage these beliefs as part of their coping.

Countertransference was the major explicit theme or undertone among these responses. We noted that counselors experiences and beliefs, or lack thereof, may lead to countertransference reactions as many counselors mentioned that their personal experiences influenced the way that they interact with, or at least think about, their patients.

I know I am more distant with some patients whose stories produce feelings of grief within [me] due to similar personal experiences.

What we found even more intriguing was that many counselors did not seem to be aware that they were describing countertransference and some had misidentified this concept altogether.

I have lost several family members to cancer- as have my patients. I think it enables me to relate better to the fear/anxiety that individuals with a family history of cancer face. It also enables me to better understand the need for answers (i.e. test results) that can arise in these situations.

Counselors' responses to these questions were extremely thought-provoking and we sensed their desire to continue these discussions, especially regarding the blurred line that often forms between ones' personal and professional experiences. From these
responses and reactions, we recognize the need for increased awareness and discussion surrounding personal experiences, views, and beliefs of genetic counseling students and beginning genetic counselors. We believe that countertransference may or may not be helpful, and may even be harmful to either the patient or the counselor. Therefore there should be a focus in genetic counseling training on how to cope with personal experiences so that counselors can recognize their own countertransference. Recognition of countertransference allows the counselor to see the potential impact on the dynamics of a counseling session (Djurdjinovic 1998). It was surprising that despite our observations that personal reflection and exploration of their own loss history was important in genetic counseling training, the opportunities for this were given the lowest relative scores by the genetic counselors in our study. This is further evidence that genetic counseling programs should incorporate more time for students to explore their personal beliefs and attitudes towards grief and loss.

Our study suggested that the increased availability of learning and practice opportunities for students in graduate school had a greater impact on comfort level than demographics alone i.e. age, area of clinical practice, year of graduation from a genetic counseling program. We also noted that counselors' comfort level increased as their level of involvement with grief and loss in their professional careers increased, not an unexpected finding albeit reassuring to observe.

Counselors attributed their feelings of comfort with counseling scenarios to professional experiences, counseling training, counselors' personality and natural ability to communicate and work with people, life experiences, supportive co-workers, and relative lack of emotion of these scenarios. Not surprisingly, many scenarios that ranked
highest in terms of comfort level were ones that were more scientifically based, and more commonplace in the genetic counseling setting, i.e. explaining the genetics of different conditions, or giving positive results. Counselors credited their discomfort with highly emotional scenarios to a lack of experience and training, as well as the inappropriateness of counseling scenarios to the typical work of genetic counselors, i.e. touching a grieving patient; scenarios that they did not feel are part of a genetic counselor's role, i.e. discussing funeral arrangements; emotionally laden topics; lack of training; question of benefit to patients, i.e. calling patients on anniversaries of deaths or terminations; and personal experiences and beliefs.

We were intrigued that while the majority of counselors discussed that counseling experience played a major role in counselors' comfort level with grief and loss, we only found a small to moderate correlation between comfort level and years of clinical genetic counseling experience. However, as we discovered from our data, a counselor's level of involvement to grief and loss scenarios did have some impact on comfort level. This information points to the fact that experience and exposure to difficult cases has more of an impact on comfort level than just the number of years a counselor spends in the field. It is also important to note that our overall study results showed that although counseling experience is certainly beneficial it is not the only factor that plays a role in counselor comfort level.

Analysis of our data led us to the conclusion that a formal grief and bereavement curriculum would benefit genetic counselors in terms of increasing their comfort level and awareness of grief and loss issues in counseling. Although classroom experience proved to be very helpful for genetic counselors, more dynamic training, which included
role playing, clinical rotations, guest lecturers, volunteer work, and community involvement, was most useful in preparing counselors to work with patients facing grief and loss. We found that counselors seemed to have very positive feelings regarding the training that they had during graduate school. However, the efficacy of current bereavement training should be studied further. Also, based on participants' comments and reactions to the grief related scenarios in this study, there is a need for students to be involved in discussions surrounding professional boundaries in counseling, appropriate versus inappropriate counseling techniques, the many roles of a genetic counselor, especially in terms of grief counseling, and personal beliefs and experiences surrounding loss.

As for calling patients a year later [after a death or termination], I just don't know how that would be helpful. What if they are not wanting to remember—what if it is still too painful and they are just trying to get through the day and then they receive a phone call from someone they met maybe twice or three times? It would feel like I was intruding.

**Future Research**

Future research should focus on the structure, content, efficacy, and availability, of current bereavement curricula in genetic counseling programs, with the ultimate goal of establishing a formal, standardized curriculum. We recognize that there is already an overwhelming amount of information that needs to be covered in a two year training program, and training and discussions of psychosocial issues may need to continue long past graduation. Thus, it would be beneficial to ascertain how many counselors continue their grief and bereavement training after graduate school, as well as the methods of training that are most utilized. Many counselors in our study noted that on-the-job experience increased comfort level with patients dealing with loss, which suggests that learning about bereavement and loss issues should be continued throughout the
professional life of a genetic counselor. The benefit of post-graduate training, specifically supervision, has been addressed by Kennedy (2000). However, further research would be needed to assess the availability of supervision, and other post-graduate training methods. Also, nursing, social work, and psychological counseling program curricula should be examined to determine the best methods of grief training, as these methods may have significance in the genetic counseling world.

It was clear from the open-ended responses that countertransference played a role in genetic counselors' work; thus we should ensure that counselors fully understand this concept. Since our study only grazed the surface of the complex interaction between counselors' personal experiences and comfort level, future research should focus on further assessing how experiences, beliefs, and attitudes can influence counseling style, especially in terms of grief and loss.

**Limitations**

There are limitations to this study that made it difficult to fully and accurately interpret all of our data, starting with the fact that we did not ask enough questions regarding participant demographics, i.e. geographical counseling region, or genetic counseling program attended. The genetic counseling Professional Status Survey (PSS) does not poll data in a way that is feasible to compare our respondents to the genetic counseling community as a whole, so we cannot say that our participants represent the distribution of counselors in the professional society of genetic counselors. It would have been helpful to have counselors' answer all demographics questions in an open-ended format, so that we could tailor their answers to fit the categories of the PSS.
The Likert scales in our survey were all on a scale of 1 to 5. However, these numbers had very different meanings depending on the section of the survey. For example, in the Opportunities for Learning/Practice scales, a value of 5 meant "too much information/exposure," which implied a somewhat negative connotation in answering at either end of the scale; for these questions, an average value of 2.5 implied "just right."

However, in the Level of Importance scale, a value of "5" meant "very important," indicating that a 5 is the most positive answer. The differences of values between these scales may have led to confusion among participants, and incorrect interpretation of some questions. In the future, Likert scales should be written so that the extreme values are relatively consistent throughout the survey.

We recognize that the length of our survey was a limitation with which we struggled throughout the creation process. We felt that the counseling scenarios listed in the Comfort section were all unique and important; therefore, it was difficult to decide which scenarios to include in the final survey, and which to take out. During the analysis of our data, we realized that the overwhelming amount of scenarios made it difficult to correlate counselors' qualitative Comfort responses to a specific counseling situation. Also, the counseling scenarios listed in the Comfort section did not exactly match the scenarios listed in any other section of the survey, making it hard to find significant correlations between sections. With more time and more intense discussion, we could have created a shorter survey of 15-20 counseling scenarios, which may have been easier for participants' to handle.

Probably the most significant limitation of this study is that we cannot accurately interpret individual participants' perceptions of what it means to be "comfortable," or
"uncomfortable," in the context of counseling situations. We did not define comfort in the survey. Therefore, participants' responded to questions using their own understanding and interpretation of what it means to be "comfortable." Moreover, we cannot determine whether a participants' level of comfort positively or negatively impacts their counseling practice in any way, if at all, so it is hard to make the assumption that a lower level of comfort is "bad," and a higher level of comfort is "good." For example, it is likely, based on some participants' comments, that at least a few counselors' believe that some level of discomfort is necessary, and even beneficial, because the alternative may lead to a counselor becoming emotionally disconnected from their grieving patients.

Conclusion

We set out to find whether or not beginning genetic counselors were comfortable with the psychosocial aspects of genetic counseling; specifically situations that deal with grief and loss. We found that genetic counselors were comfortable with many counseling scenarios that dealt with grief and loss, but there were clear patterns and themes that emerged from counselors' responses, in regards to factors that contributed to their level of comfort. Mainly, genetic counselors were most uncomfortable with scenarios involving death and dying, and they often questioned the helpfulness of certain counseling techniques, such as discussing funeral arrangements, or showing one's own emotions during a session. These observations highlight the need for in-depth discussion, training, and practice surrounding these topics.

We also observed that personal experiences with loss have a subtle, but major, influence on how counselors felt about, and counseled, their grieving patients. This observation is even more striking when compared to the fact that the opportunities to
learn about and discuss these personal views were limited in counselor training. At this time, we suggest that current counseling courses be evaluated to determine where, and how, we can incorporate training for counselors so that they are better able to handle their patients' reactions and beliefs, as well their own countertransference and limitations, in the context of grief and loss, which can be so prevalent in this field.
References


Appendix A

<table>
<thead>
<tr>
<th>Beginning Genetic Counselors’ Comfort Level with Grief and Loss in</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
</tr>
<tr>
<td>Dear Genetic Counselor,</td>
</tr>
<tr>
<td>Thank you for agreeing to take part in this survey. The purpose of this research study is to identify your experiences and attitudes about grief and loss in the genetic counseling setting. The survey questions will address the following subjects:</td>
</tr>
<tr>
<td>o Your genetic counseling education</td>
</tr>
<tr>
<td>o Your clinical experiences</td>
</tr>
<tr>
<td>o Your comfort level with genetic counselling scenarios</td>
</tr>
<tr>
<td>o Your personal experiences with grief and loss</td>
</tr>
<tr>
<td>The answers that you provide will remain confidential and anonymous. The procedures that I have in place to ensure confidentiality have been approved by the Brandeis Human Subjects Review Board.</td>
</tr>
<tr>
<td>This survey contains questions that are sensitive in nature. It is important to know that your participation in this survey is completely voluntary. You may choose to skip any questions or stop taking the survey at any time. If you feel any unsettling emotions as a result of taking this survey, you can feel free to contact Emily Lazar, MS, CT, by phone at (617) 667-6573, or by e-mail, <a href="mailto:elazar@griefweavers.com">elazar@griefweavers.com</a>.</td>
</tr>
<tr>
<td>If you have any questions regarding this survey, you may contact me by phone at (978) 408-8295, or by e-mail, <a href="mailto:mdeesey@brandeis.edu">mdeesey@brandeis.edu</a>.</td>
</tr>
<tr>
<td>Kind Regards,</td>
</tr>
<tr>
<td>Meghan Deesey</td>
</tr>
</tbody>
</table>

| 35 |
### Beginning Genetic Counselors’ Comfort Level with Grief and Loss in

<table>
<thead>
<tr>
<th>Definitions (As they pertain to this survey):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss: The disappearance of something valued, desired or cherished. This can include (but is not limited to): life altering, life threatening, or life-limiting news, a new diagnosis, a shift in perception, progress, or prognosis in relation to a chronic condition, a change in an individual’s sense of self, identity, self esteem, or sense of possibility/potential, a shift in family dynamics, roles, participation, or expectation, the realization of death, or impending death, pregnancy termination, miscarriage, etc.</td>
</tr>
<tr>
<td>Grief: A person’s displayed emotions, reactions, or response to loss. This can include (but is not limited to): sadness, anger, guilt, blame, or hostility.</td>
</tr>
<tr>
<td>Sudden Grief Reaction: The psychological or physical reactions of a person who has experienced a loss with little or no warning, or little or no time to prepare.</td>
</tr>
</tbody>
</table>
## Graduation Information

What year did you graduate from your genetic counseling program?

- [ ] Before 2003
- [ ] 2003
- [ ] 2004
- [ ] 2005
- [ ] 2006
- [ ] 2007
- [ ] After 2007
<table>
<thead>
<tr>
<th>Certification/Eligibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Are you board certified/board eligible?</td>
</tr>
<tr>
<td>○ Yes</td>
</tr>
<tr>
<td>○ No</td>
</tr>
</tbody>
</table>
### Experience as a Genetic Counselor

*Approximately how many years have you been a practicing genetic counselor?*

- [ ] Less than 1
- [ ] 1 to 1.5
- [ ] 2 to 2.5
- [ ] 3 to 3.5
- [ ] 4 to 4.5
- [ ] 5
- [ ] More than 5
Beginning Genetic Counselors’ Comfort Level with Grief and Loss in Clinical Experience as a Genetic Counselor

How many years have you been a practicing genetic counselor in a clinical setting?

- I have never worked in a clinical setting
- Less than one year
- 1 to 1.5
- 2 to 2.5
- 3 to 3.5
- 4 to 4.5
- 5
- More than 5
<table>
<thead>
<tr>
<th>Other Education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Do you have a degree or certification in thanatology?</strong></td>
</tr>
<tr>
<td>☐ Yes</td>
</tr>
<tr>
<td>☐ No</td>
</tr>
</tbody>
</table>
### Other Education

* Do you have a post-graduate degree in psychology?
  - [ ] Yes
  - [ ] No
### Current Clinical Setting

**What is your current (or most recent) area of clinical practice (prenatal, neurogenetics, cancer, etc.)?**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

**In your current (or most recent) clinical position, do you work full-time (35+ hours) or part-time (less than 35 hours)?**

- [ ] Part-time
- [ ] Full-time
<table>
<thead>
<tr>
<th>Current Counseling Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approximately how many hours a week do you spend counseling patients (face-to-face or phone contact)?</td>
</tr>
</tbody>
</table>
### Beginning Genetic Counselors’ Comfort Level with Grief and Loss in

#### Demographics

**How old are you? (years)**

**Are you**
- [ ] Male
- [ ] Female

**What is your ethnicity?**

- [ ] Caucasian
- [ ] African American
- [ ] Hispanic
- [ ] Asian
- [ ] Other (please specify)

**Do you have a religious affiliation?**

- [ ] Yes
- [ ] No
<table>
<thead>
<tr>
<th>Religious Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please specify (Catholic, Jewish, etc.)</td>
</tr>
</tbody>
</table>
### Beginning Genetic Counselors’ Comfort Level with Grief and Loss in Genetic Counseling Education: Opportunities for Learning

Think about the courses that you took as part of your two-year master’s level genetic counseling program. Please use the following scale to rate the amount of information you received pertaining to each topic listed below.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Not enough</th>
<th>Could have used more</th>
<th>Just right</th>
<th>A bit too much</th>
<th>Too much</th>
</tr>
</thead>
<tbody>
<tr>
<td>The basics of grief and loss</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Sudden grief reaction</td>
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<td></td>
</tr>
<tr>
<td>Coping strategies of patients faced with bad, or unexpected, news</td>
<td></td>
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</tr>
<tr>
<td>Strategies on how to handle patients’ grief reactions (anger, disbelief, blame, etc)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Strategies on how to deal with patients’ physical symptoms associated with sudden grief reaction (crying, yelling, hyperventilation, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding grief and loss reactions as they pertain to different developmental stages (early childhood, adolescence, elderly, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Various cultural or religious views on death and dying</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Various rituals surrounding death and dying</td>
<td></td>
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<td></td>
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<tr>
<td>Strategies for counselor self-care</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Discussing your personal attitudes towards death and dying</td>
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<td></td>
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</tr>
<tr>
<td>Exploring your own personal loss history and the influence it may have on the way you counsel patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal time for processing difficult cases</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Beginning Genetic Counselors’ Comfort Level with Grief and Loss in Genetic Counseling Education: Opportunities for Practice

Think about the opportunities you had to practice genetic counseling as part of your two-year master’s level genetic counseling program. Please use the scale below to rate how much exposure you had to the following genetic counseling situations as part of your genetic counseling program. You should answer questions based on what you were able to do, rather than observe.

<table>
<thead>
<tr>
<th>Situation</th>
<th>Not enough</th>
<th>Could have used more</th>
<th>Just right</th>
<th>A bit too much</th>
<th>Too much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving abnormal (positive) results or difficult/unexpected news to patients/families</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Giving ambiguous results to patients/families</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Giving normal (negative) results to patients/families</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Giving support to patients/families faced with difficult/unexpected news</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Giving bad news during role play, mock, etc.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Opportunities to attend workshops/conferences related to death, illness, and bereavement</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
### Genetic Counseling Education: Skills Assessment

Below is a list of genetic counseling related topics. Please use the given scale to rate how important you think each topic is in terms of genetic counseling education and training.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Not at all important</th>
<th>Somewhat unimportant</th>
<th>Somewhat important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding the underlying genetic mechanisms for various conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning about grief, death, and dying in genetic counseling</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Introducing or maintaining a formal curriculum regarding grief and loss for genetic counselors</td>
<td></td>
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</tr>
<tr>
<td>Learning about multicultural issues and rituals surrounding grief and loss</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Understanding various behaviors displayed by patients who are faced with grief and loss</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Recognizing and understanding your own comfort level with death and dying</td>
<td></td>
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</tr>
<tr>
<td>Recognizing and understanding your own beliefs surrounding death and dying</td>
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<tr>
<td>Recognizing and understanding how your own personal loss history affects the way you counsel and support patients and families</td>
<td></td>
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<tr>
<td>Learning how to prepare yourself for the emotional reactions of your patients and their family members</td>
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<tr>
<td>Learning how to care for yourself in order to reduce your risk of compassion fatigue and/or job burnout</td>
<td></td>
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</tr>
</tbody>
</table>
### Beginning Genetic Counselors’ Comfort Level with Grief and Loss in Counseling

#### Counselor Comfort Level (Page 1 of 4)

Using the scale below, please rate your comfort level with the following counseling scenarios in your current (or most recent) clinical practice.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>very uncomfortable</th>
<th>uncomfortable</th>
<th>comfortable</th>
<th>very comfortable</th>
<th>I have never encountered this scenario before counseling (in person or by phone)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking a pedigree</td>
<td></td>
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<tr>
<td>Explaining the genetics of different conditions</td>
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<tr>
<td>Counseling a patient who is advanced maternal age</td>
<td></td>
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</tr>
<tr>
<td>Giving positive test results (patient has the mutation, condition, etc.)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giving negative test results (patient does not have the mutation, condition, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giving ambiguous test results</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Giving a diagnosis</td>
<td></td>
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</tr>
<tr>
<td>Exploring how a patient feels about a given diagnosis</td>
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</tr>
<tr>
<td>Exploring issues that may evoke sadness</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Sitting with a patient who is crying during the counseling session</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploring a patient's coping strategies after they have been told difficult/unexpected news</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For the above situations which you answered with a "4" (very comfortable), to what do you attribute this?

For the above situations which you answered with a "1" (very uncomfortable), to what do you attribute this?
### Beginning Genetic Counselors' Comfort Level with Grief and Loss in Counseling (Page 2 of 4)

Using the scale below, please rate your comfort level with the following counseling scenarios in your current (or most recent) clinical practice.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>very uncomfortable</th>
<th>uncomfortable</th>
<th>comfortable</th>
<th>very comfortable</th>
<th>I have never encountered this scenario in my counseling (in person or by phone)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploring a patient's support systems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting in silence with a patient who is grieving</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Verbally acknowledging the emotions of the patient and their family members</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Appropriately touching grieving patients as a way of showing your care and concern</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Displaying your own emotions (crying, telling) during a counseling session</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussing the &quot;danger&quot; signs (suicide ideation, harm to self or others) with a grieving patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing support for grieving patients who are of the same culture as your own</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing support for grieving patients who are of a different culture than your own</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploring a patient's feelings surrounding death and dying</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For the above situations which you answered with a "4" (very comfortable), to what do you attribute this?

For the above situations which you answered with a "1" (very uncomfortable), to what do you attribute this?
### Using the scale below, please rate your comfort level with the following counseling scenarios in your current (or most recent) clinical practice.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Very Uncomfortable</th>
<th>Uncomfortable</th>
<th>Comfortable</th>
<th>Very Comfortable</th>
<th>I have never encountered this scenario outside counseling (in person or by phone)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploring religious views of death and dying for patients of a religion similar to your own</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Exploring religious views of death and dying for patients of a different religion than your own</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Discussing pre-termination arrangements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Discussing post-termination arrangements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Discussing funeral arrangements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Contacting families on the anniversary of a pregnancy termination (or on the due date)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Contacting families soon after a termination has occurred</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Contacting families on anniversaries of known patient deaths</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Contacting families soon after the death of a family member</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Supporting a patient and exploring feelings of a patient/family following a recent diagnosis of a chronic illness</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Supporting a patient and exploring feelings of a patient/family following a recent diagnosis of a terminal illness</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

For the above situations which you answered with a "4" (very comfortable), to what do you attribute this?

For the above situations which you answered with a "1" (very uncomfortable), to what do you attribute this?
### Using the scale below, please rate your comfort level with the following counseling scenarios in your current (or most recent) clinical practice.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>very uncomfortable</th>
<th>uncomfortable</th>
<th>comfortable</th>
<th>very comfortable</th>
<th>I have never encountered this scenario even counseling (in person or by phone)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploring a patient’s (or their family member’s) feelings following the news that their unborn child will not survive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploring a patient’s (or their family member’s) feelings following the diagnosis of their child’s chronic illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploring a patient’s (or their family member’s) feelings following the diagnosis of their child’s terminal illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploring a patient’s feelings about their own cancer diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploring a client’s feelings about their immediate family member’s cancer diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being in the presence of a family following a termination via labor induction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being in the presence of a family as their baby/child is dying, or has died</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being in the presence of a family as their family member (your patient) is dying, or has died</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leading/post-leading a support group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For the above situations which you answered with a "4" (very comfortable), to what do you attribute this?

For the above situations which you answered with a "1" (very uncomfortable), to what do you attribute this?
### Beginning Genetic Counselors’ Comfort Level with Grief and Loss in Clinical Experience: Level of Involvement

In your current (or most recent) clinical genetic counseling role, how often do you (or did you) encounter each given scenario?

<table>
<thead>
<tr>
<th>Scenario</th>
<th>I have never, or rarely even encountered this situation before</th>
<th>Less than half of my cases involve this situation</th>
<th>More than half of my cases involve this situation</th>
<th>This situation occurs in almost every single session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give negative test results (patient does not have the mutation, condition, etc.)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Give positive test results (patient does have the mutation, condition, etc.)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Explore a patient’s feelings/emotional state during a counseling session</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Discuss the options of termination following an abnormal prenatal diagnosis</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Discuss the options of continuing a pregnancy following an abnormal prenatal diagnosis</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Discuss the options of adoption following an abnormal prenatal diagnosis</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>See a patient who has a family history of cancer</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>See a patient/family immediately after they have received a diagnosis that would elicit a grief reaction</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>See a patient/family member who has suffered a recent loss</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>See patients who have just received positive test results</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>See patients whose family member has just received a positive test result</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>See patients whose unborn child has been given a diagnosis that is not compatible with life</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>See a patient whose emotional reaction makes you feel uncomfortable</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>See a patient/family member who displays emotions in your office associated with a grief reaction (tears, anger, shock, blame, etc.)</td>
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<tr>
<td>Personal Experience</td>
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<tr>
<td>Please describe any experiences from your training that you found particularly helpful in preparing you to work with patients/families facing grief and loss.</td>
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<tr>
<td>Please describe how your own personal experiences with grief and loss impacts the way you counsel patients/families.</td>
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<tr>
<td>Please describe how your religious affiliation influences the way you counsel patients/families facing grief and loss.</td>
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</table>
Thank You

Thank you so much for participating in this survey. If you have any questions regarding this survey, please e-mail me at mdeesney@brandeis.edu.
Appendix B

Reasons for Comfort

Displaying 1 - 95 of 95 responses

1. Repetition
   Fri, 2/13/09 8:15 AM

2. These situations are more frequent, routine, and for which I have received better training or are overall "easier" and less complex situations in general.
   Wed, 2/11/09 8:47 PM

3. We are what we are. We shouldn't try to go too far beyond what we are. We are information givers and support, but we are not psychologists.
   Fri, 2/6/09 8:15 AM

4. training/experience
   Thu, 2/5/09 11:37 PM

5. Experience
   Thu, 2/5/09 3:23 PM

6. Experience
   Thu, 2/5/09 8:08 AM

7. Time to have had been in practice. Also, the ones that I feel most comfortable with are those that are mostly "teaching" aspects of our job. I do feel less comfortable (not uncomfortable) with the psychosocial aspects.
   Thu, 2/5/09 7:46 AM

8. Practice
   Thu, 2/5/09 7:45 AM

9. experience
   Thu, 2/5/09 7:19 AM

10. My thorough graduate training program and my ability to establish patient rapport.
    Thu, 2/5/09 6:41 AM

11. These are situations that I find myself in on almost a daily basis, so I'm very used to them. I also think that these situations are less emotionally charged than some of the others.
    Mon, 2/2/09 1:01 PM

12. My training and experience. As an HD counselor, I give results often.
    Mon, 2/2/09 7:07 AM

13. My experience as a genetic counseling student, my current work experience, and life experiences.
    Thu, 1/29/09 2:38 PM

14. Repetition, firm belief that I am helping them in some way even if it is very small, strong desire to want to help, personal comfort level with being around people who are in tough situations
    Thu, 1/29/09 8:34 AM

15. More training and experience - more straightforward and less emotion involved
    Thu, 1/29/09 8:26 AM

16. doing it over and over
    Thu, 1/29/09 7:46 AM

17. Having basic people skills, experience with these situations
    Thu, 1/29/09 7:08 AM

18. Independent of client emotions, minimal variables involved
    Thu, 1/29/09 1:41 AM
19. My background training in human genetics, the current patient population I see and a supportive geneticist at my workplace

20. These are things I do almost on a daily basis

21. Excellent clinical rotations with amazing counselors who were encouraging and supportive while I was learning and made me confident so that when I went out on my own I had faith in my abilities. Now I have had a lot of practice after doing prenatal and now pediatrics with a focus on neuromuscular conditions where we do a lot of giving bad news

22. Experience. Doing these thing is all very uncomfortable in the beginning of training when you haven’t interacted with patients very much. As you learn and see more patients, it becomes more comfortable.

23. training, experience

24. Formal training and life experiences

25. on-the-job (rather than in grad school) experience

26. Practice and learning from sessions that did not go as smoothly as they could have.

27. Repetition and experience

28. Experience

29. experience

30. I became more comfortable with these situation as a practicing genetic counselor

31. familiarity, experience, relatively emotionally neutral

32. Some happen in every counseling scenario Most happen daily

33. I have been in practice for three years and had good preparation in school.

34. Experience

35. lots of practice/experience

36. Experience with a wide variety of patients

37. Becoming comfortable with these things during graduate school.

38. Experience and self analysis

39. received a great deal of psychosocial training in my graduate program as well as having a lot of experience counseling friends and family in addition to previous counseling experience; also personally am an open person who is comfortable with expressing and dealing with people expressing emotion

40. I am a 2008 graduate. I attribute my high level of comfort to graduate school training in a wide variety of settings. The diversity of cases as well as diverse populations has prepared me for a
broad spectrum of cases. I also attribute my comfort to the confidence my co-workers put in me. They are confident that I am a good counselor, thus making me confident.

41. experience and a natural comfort level before entering the field

42. experience

43. Preparation, practice, looking forward to giving people good news.

44. I am very comfortable with these scenarios because I have gained experience in this particular areas.

45. Because I was not prepared enough to handle these situations by my program training alone, after two years in practice I attended and became certified in RTS Bereavement Care. I’m a certified instructor now and have many more tools to help my patients through the grief process.

46. experience

47. Practicing doing these things, because even though we talked about them often in our coursework and did numerous role plays, every person reacts so differently to difficult news, so I become more and more comfortable with each one I do.

48. Experience

49. Do it every day

50. Personal experience. Professional experience.

51. I attribute the 5s to the most practice as a student and something that is done at every patient session as a practicing genetic counselor. I think the familiarity of taking a pedigree and explaining different genetic conditions helps me feel most comfortable.

52. my training and the ability to be able to sit with a patient and spend extra time with them if they need it - doctors don’t always have that luxury and it enables a closer relationship with a patient, which in turn allows them to open up more and us as counselors better understand their verbal and non-verbal cues.

53. Do this very often on an almost daily basis

54. experience--the more patient contact you have, the more opportunity you have to interact with patients in different scenarios

55. Experience

56. practice and getting used to giving bad news and mangaging patients reactions

57. training in school, and colleagues i work with now. even though i am not in school, I am lucky to have great role models in the counselors at my institution.

58. My graduate education and professional experiences, in addition to my compassion for my patients.

59. I think that these things are what I had the most training/experience with in school.
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<tbody>
<tr>
<td><strong>60.</strong> Experience</td>
<td>Mon, 1/26/09 10:10 AM</td>
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<tr>
<td><strong>61.</strong> For the situations that I have a &quot;5&quot;, these are comfortable situations because of the number of times the situations arise--these have become &quot;routine&quot;.</td>
<td>Mon, 1/26/09 10:00 AM</td>
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<tr>
<td><strong>62.</strong> Having experience with these situations in both genetic counseling training and working in a clinical setting</td>
<td>Mon, 1/26/09 9:51 AM</td>
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<td><strong>63.</strong> Practice...experience helps with these situations/skills.</td>
<td>Mon, 1/26/09 9:44 AM</td>
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<td><strong>64.</strong> My graduate training and personal skill development. I was good at helping others cope with emotional situations prior to grad school; my skills were honed during my graduate training and subsequent positions.</td>
<td>Mon, 1/26/09 9:34 AM</td>
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<tr>
<td><strong>65.</strong> Experience! Being in a clinical setting, I give results and explain genetics on a daily basis.</td>
<td>Mon, 1/26/09 9:18 AM</td>
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<tr>
<td><strong>66.</strong> Solid training and an empathetic personality, training in bereavement</td>
<td>Mon, 1/26/09 9:09 AM</td>
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<tr>
<td><strong>67.</strong> Lots of experice with taking pedigrees</td>
<td>Mon, 1/26/09 9:08 AM</td>
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<td><strong>68.</strong> Lots of experience with this in a pediatric setting.</td>
<td>Mon, 1/26/09 9:02 AM</td>
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<td><strong>69.</strong> Education in school and regular practice in the workplace.</td>
<td>Mon, 1/26/09 8:48 AM</td>
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<td><strong>70.</strong> Little emotion involved with these steps of a counseling process.</td>
<td>Mon, 1/26/09 8:27 AM</td>
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<td><strong>71.</strong> Experience with the scenario.</td>
<td>Mon, 1/26/09 8:13 AM</td>
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<tr>
<td><strong>72.</strong> The various clinical rotations and the number of patients that I interacted with during those rotations.</td>
<td>Mon, 1/26/09 8:12 AM</td>
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<tr>
<td><strong>73.</strong> For basic skill (pedigree, explaining genetics, AMA) comfort is due to a lot of practice. For exploring patient feelings and sitting with a crying patient, I think I have a natural comfort of working with people in tough situations. I don't &quot;freak out&quot; when a patient is crying and I am comfortable talking about emotions with a patient.</td>
<td>Mon, 1/26/09 8:09 AM</td>
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<td><strong>74.</strong> Good training and experience</td>
<td>Mon, 1/26/09 7:55 AM</td>
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<td><strong>75.</strong> experience</td>
<td>Mon, 1/26/09 7:52 AM</td>
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<tr>
<td><strong>76.</strong> Training and experience</td>
<td>Mon, 1/26/09 7:52 AM</td>
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<tr>
<td><strong>77.</strong> Lots of clinical experience and good training.</td>
<td>Mon, 1/26/09 7:51 AM</td>
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<td><strong>78.</strong> more experience as those are the most common tasks i perform</td>
<td>Mon, 1/26/09 7:50 AM</td>
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<td><strong>79.</strong> Good training in graduate school + lots of experience since graduating.</td>
<td>Mon, 1/26/09 7:37 AM</td>
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<td><strong>80.</strong> experience</td>
<td>Mon, 1/26/09 7:09 AM</td>
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<tr>
<td><strong>81.</strong> Very thorough clinical training in which I saw lots of cases.</td>
<td>Mon, 1/26/09 6:51 AM</td>
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<td><strong>82.</strong> Experience, both professional and personal.</td>
<td>Mon, 1/26/09 6:11 AM</td>
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<tr>
<td>83. My education and both personal and professional experiences.</td>
<td>Mon, 1/26/09 5:55 AM</td>
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<tr>
<td>84. Lots of practice in graduate school and in my current workplace.</td>
<td>Sun, 1/25/09 7:53 PM</td>
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<tr>
<td>85. I attribute this to experiences I have had before, during and after grad school. I feel some classes contributed to the set of skills I have with exploring people's feelings and/or coping mechanisms; however, the most helpful with my comfort level has always been true situations.</td>
<td>Sun, 1/25/09 6:26 PM</td>
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<tr>
<td>86. experience of being with patients in those situations have made me much more comfortable dealing with patients who are experiencing grief over a loss. also, for many of these patients, we are the first people they speak to once they get their abnormal test results, diagnosis, etc, and i have found that just being present with the patient helps them cope.</td>
<td>Sun, 1/25/09 5:51 PM</td>
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<tr>
<td>87. Practice, training, simplicity</td>
<td>Sun, 1/25/09 3:37 PM</td>
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<tr>
<td>88. Experience during training and clinical practice</td>
<td>Sun, 1/25/09 7:52 AM</td>
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<td>89. I do OK, but still dread it when it happens</td>
<td>Sat, 1/24/09 11:19 AM</td>
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<tr>
<td>90. Having a lot of experience doing it makes me more comfortable doing it.</td>
<td>Sat, 1/24/09 9:58 AM</td>
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<td>91. The items to which I replied a 5 (which I am assuming you meant to type as opposed to 4) are more “fact giving” and information taking parts of the session. As I am new in my career, I am still in the developmental stage of my psychosocial skills and hope to become very comfortable in the coming years.</td>
<td>Sat, 1/24/09 8:02 AM</td>
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<tr>
<td>92. my training was the foundation, but my clinical experience is what makes me very comfortable</td>
<td>Sat, 1/24/09 7:41 AM</td>
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<tr>
<td>93. repetition, both in the classroom and the clinical setting</td>
<td>Fri, 1/23/09 10:53 PM</td>
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<tr>
<td>94. Practice and many opportunities to experience those situations.</td>
<td>Fri, 1/23/09 10:53 PM</td>
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<tr>
<td>95. Previous experience (unrelated to genetic counselling) dealing with grief, loss and crisis.</td>
<td>Fri, 1/23/09 3:39 PM</td>
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</tbody>
</table>
4. Grief is universal just as contendedness and joy; I believe that being with a person when they are grieving is a gift to them if they allow it and it is an honor to help when they do.

5. The ones I am comfortable with are the ones I have more experience with, are more familiar to me, and are less emotionally-charged.

6. Wanting to help the patient

7. Again training program an clinical practice

8. Life experiences and clinical rotations

9. experience - it is generally to the patient's (and my) benefit

10. It is my natural reaction to being with a grieving person.

11. Very common occurrences

12. experience

13. I've always been able to do this, even as a student....

14. Used to doing this in everyday life as much as job life

15. My training was excellent in these areas.

16. I feel these issues can be more clear-cut

17. Experience

18. experience

19. growing up with extremely diverse and multicultural friends, exposure to different cultures, customs, and a background in philosophy of religion...also we reviewed a lot of religion, psychosocial assessment tools in my grad training school

20. Experience and natural instinct

21. experience

22. experience through clinical work and role-play in grad school

23. After over 5 years of being in clinics with multiple anomalies per day and weekly losses, you get comfortable with doing the “dirty” work of prenatal genetic counseling. If you can’t find the tools to help yourself get comfortable and can’t adapt, you may have to switch to a different area of genetic counseling in my opinion.

24. Again, we talked about these situations often in school, but I think some of these things just come naturally to me (sitting in silence if someone is crying). It just feels like the right thing to do in that situation. I was very fearful of showing emotion or tearing up during a session, but then it happened once and I realized it wasn't such a bad thing, it really is just the sincerest form of empathy, and as long as you're not sitting there bawling your eyes out, I think the patient understands this is not easy for us either.
25. experience

26. n/a - but for my 4's it was comfort level with experience

27. Personal experience, professional experience.

28. I feel it has always been easier for me to identify emotions than to address the emotions. I am comfortable verbally acknowledging the emotion but am uncomfortable feeling as thought I'm "prying" into a patients emotions.

29. I was trained (outside of grad school) in grief techniques and dealing with personal vs. patient grief

30. experience, becoming comfortable with my own counseling style

31. counseling skills class, personality.

32. My training

33. It seems like an 'easy' question to ask without usually evoking many difficult emotions

34. Experience

35. Experience in training and in the clinical setting has demonstrated that silence during the initial time a patient is grieving can help them with processing grief.

36. My graduate program had a strong psychosocial component and explored all of these issues. As mentioned previously, my graduate training honed prior skills and raised my awareness of my limitations.

37. experience

38. Again lots of experience

39. I am very comfortable with silence in general. I also think that personal experience with grief and the warmth of a quiet presence helps me to truly relate to the patient in that moment.

40. Experience with the scenario

41. There is less anxiety/complication in discussing sensitive issues if the patient has the same belief system as me

42. lots of clinical experience and good training

43. I used to volunteer at a suicide/crisis hotline

44. n/a

45. My education and both personal and professional experiences.

46. na

47. They seem easy/straightforward
48. I don't know  Sat, 1/24/09 11:20 AM
49. More familiarity with doing it.  Sat, 1/24/09 9:59 AM
50. I have learned that if you sit long enough in silence as they take their time, they tend to have something important to say afterward. This was a skill emphasized during our training.  Sat, 1/24/09 8:05 AM
51. I'm just being myself.  Fri, 1/23/09 10:55 PM
52. extra grief counseling training I received before I went to grad school for genetic counseling  Fri, 1/23/09 10:38 PM

1. These are situations I deal with often and through experience, have become more comfortable with and confident in my ability to handle well.  Wed, 2/11/09 8:51 PM
2. We are not termination counselors. We wouldn't even have a job in our state if our jobs were termination. Our jobs are information. I think a follow up phone call is wonderful, but we also need to be careful not to overstep our bounds.  Fri, 2/6/09 8:20 AM
3. In these situations I feel like I'm giving out more factual information than emotional information, so it's a much more comfortable situation for me  Mon, 2/2/09 1:07 PM
4. The ones I am comfortable with are the ones I have more experience with, are more familiar to me, and are less emotionally-charged.  Thu, 1/29/09 8:31 AM
5. Training, clinical practice as a student and a gc  Wed, 1/28/09 11:06 AM
6. Clinical experience and life experience  Tue, 1/27/09 7:16 PM
7. i have done this and think it's a good way to show support  Tue, 1/27/09 2:24 PM
8. Common occurence  Tue, 1/27/09 1:21 PM
9. experience  Tue, 1/27/09 12:52 PM
10. These are things I do regularly  Tue, 1/27/09 10:30 AM
11. experience/practice  Tue, 1/27/09 9:57 AM
12. Experience  Tue, 1/27/09 9:48 AM
13. my level of experience handling terminations has made me comfortable, was level comfortable with my first one  Tue, 1/27/09 9:01 AM
14. There were a few books we read in our training program that helped with this. And, it just so happened that in my first eight  Tue, 1/27/09 6:59 AM
weeks on rotation I had seven abnormal cases. But, for the most part RTS training is what has really prepared me and made me comfortable with helping families, co-workers, and myself through the grief process.

15. I'm not sure, but I think it's part of my personality to check up on people and see how they are doing after a difficult situation. Tue, 1/27/09 6:55 AM

16. experience Tue, 1/27/09 6:49 AM

17. I feel that these are welcome and appreciated contacts, and these actions have been well received in the past Tue, 1/27/09 6:48 AM

18. I specifically work in a pedi hem/onc department. While I was not very comfortable in the beginning exploring a patient/family's feelings following the diagnosis of a terminal or chronic illness, it it definitely the case of "practice makes progress" and I feel very comfortable discussing these things now. Mon, 1/26/09 2:17 PM

19. Having had a child of my own Mon, 1/26/09 1:00 PM

20. on the job experience Mon, 1/26/09 11:49 AM

21. Experience with this situation Mon, 1/26/09 10:43 AM

22. Experience Mon, 1/26/09 10:14 AM

23. Being more familiar with the situations based on clinical experience Mon, 1/26/09 10:13 AM

24. See previous answers Mon, 1/26/09 9:37 AM

25. Bereavement training done following grad school Mon, 1/26/09 9:11 AM

26. Again, we do this all the time in pediatrics Mon, 1/26/09 9:04 AM

27. I have never had the opportunity to work with a family with regard to a termination, other than to present it as an option and brief discussion. I have not yet reached an anniversary of a patient death, although I will have one coming up soon. I expect that, due to the rapport I was able to develop, that this will be a comfortable call for me to make. Mon, 1/26/09 8:57 AM

28. I do those things on a regular basis Mon, 1/26/09 7:53 AM

29. clinical experience and training Mon, 1/26/09 7:53 AM

30. Multiple experiences with situation since graduating. Mon, 1/26/09 7:43 AM

31. My education and both personal and professional experiences. Mon, 1/26/09 5:57 AM

32. na Sun, 1/25/09 7:57 PM

33. I have had a lot of experience with these situations, and over time, I have become very comfortable with discussing these things with patients. Plus, if I don't discuss these things, who would, and who would be helping these patients through such a trying time in their life. Sun, 1/25/09 5:56 PM

34. N/A, although I am very comfortable contacting patients on anniversaries, but unfortunately, I do not do that often since I am Sun, 1/25/09 3:53 PM
so busy.

35. Experience and practice

36. Experience.

37. Doint it more often makes me more comfortable.

38. did not answer with a '4'

Displaying 1 - 30 of 30 responses

<table>
<thead>
<tr>
<th>Comment Text</th>
<th>Response Date</th>
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<tbody>
<tr>
<td>1. I do this on a regular basis in the MDA clinic</td>
<td>Thu, 2/5/09 7:48 AM</td>
</tr>
<tr>
<td>2. Lots of experience with psychosocial counseling and a graduate training that emphasized the same.</td>
<td>Thu, 2/5/09 6:46 AM</td>
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<tr>
<td>3. I have not found myself in most of these situations as I counsel in only a prenatal setting, so it is hard for me to determine what my comfort level might be in those situations since I have not experienced them.</td>
<td>Mon, 2/2/09 1:09 PM</td>
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<td>4. I think personally, it is a bit easier relatively to discuss how other families have changed or not changed in similar situations - many patients ask me about how other families would do/did/had done etc. They want to know that they are proceeding similarly and are not &quot;crazy.&quot; I think those situations are more instructive rather than ambiguous and definitive such as death of a patient is.</td>
<td>Thu, 1/29/09 8:41 AM</td>
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<tr>
<td>5. The ones I am comfortable with are the ones I have more experience with, are more familiar to me, and are less emotionally-charged.</td>
<td>Thu, 1/29/09 8:33 AM</td>
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<td>6. Part of my responsibilities as a genetic counselor</td>
<td>Thu, 1/29/09 7:11 AM</td>
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<tr>
<td>7. Volunteer experience before genetic counseling formal training</td>
<td>Tue, 1/27/09 7:17 PM</td>
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<tr>
<td>8. Personal experience with chronic illness.</td>
<td>Tue, 1/27/09 2:16 PM</td>
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<tr>
<td>9. experience</td>
<td>Tue, 1/27/09 12:53 PM</td>
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<tr>
<td>10. I attribute this to experience I’ve had within my job</td>
<td>Tue, 1/27/09 12:34 PM</td>
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<tr>
<td>11. Experience</td>
<td>Tue, 1/27/09 10:32 AM</td>
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<tr>
<td>12. practice/experience</td>
<td>Tue, 1/27/09 9:58 AM</td>
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<tr>
<td>13. Experience</td>
<td>Tue, 1/27/09 9:48 AM</td>
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<tr>
<td>14. Experience given my clinical setting</td>
<td>Tue, 1/27/09 8:17 AM</td>
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</table>
15. Experience - and also for me dealing with cancer or adult conditions is a little easier than prenatal or pediatric devastating news - I think the level of unknowns with prenatal make it particularly difficult to counsel. I am not any less compassionate with the adults, it is just a different counseling scenario that I find easier emotionally.

16. We co-lead some support groups in school, so I would be comfortable doing this now.

17. Same answer as previous set of questions - "practice makes progress"

18. Experience

19. Experience

20. This is something I deal with quite often

21. This is part of being a good genetic counselor.

22. Experience leading a monthly support group

23. Experience in these situations.

24. clinical experience and training

25. Very strong cancer genetics rotation in my clinical training.

26. My education and both personal and professional experiences.

27. sorry, this is getting too long and I have other things to do...best of luck on your project


29. Experience

30. did not answer with a '4'

Reasons for Discomfort

Displaying 1 - 24 of 24 responses

<table>
<thead>
<tr>
<th>Comment Text</th>
<th>Response Date</th>
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<tbody>
<tr>
<td>1. N/A</td>
<td>Thu, 2/5/09 6:41 AM</td>
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<tr>
<td>2. I didn't answer &quot;very uncomfortable&quot; to any, but for the ones where I answered a &quot;2&quot;, I think I attribute this to the fact that these are situations that I am not encountered with on a very frequent basis.</td>
<td>Mon, 2/2/09 1:01 PM</td>
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</table>
I also feel that I’m always more uncomfortable in situations where I don’t exactly know what reaction to expect from my patients. It’s very difficult to prepare for those types of situations.

3. The ones I rated lower are the more emotional scenarios and the scenarios that I have not experienced as often.

Thu, 1/29/09 8:26 AM

4. I don’t do these often enough to feel very comfortable

Wed, 1/28/09 12:34 PM

5. I feel as I am not qualified to make a clinical diagnosis

Tue, 1/27/09 1:19 PM

6. n/a

Tue, 1/27/09 12:49 PM

7. I didn’t answer 1, but I answered 2, I don’t work directly with a physician so my discomfort with giving is diagnosis is mostly role based.

Tue, 1/27/09 10:28 AM

8. not as much practice/experience

Tue, 1/27/09 9:54 AM

9. N/A

Tue, 1/27/09 9:37 AM

10. If I felt that I was very uncomfortable with any of these situations, I’d be taking a class or finding a way to become more comfortable, so I didn’t feel that I was very uncomfortable with any of them at this time.

Tue, 1/27/09 6:52 AM

11. n/a

Tue, 1/27/09 6:41 AM

12. Never felt that I was properly trained to do these things

Tue, 1/27/09 6:27 AM

13. I attribute being uncomfortable with giving uninformative results to not being able to provide an answer to patients. I am uncomfortable giving a diagnosis because where I trained diagnoses were given my physicians and followed discussion of diagnoses with the counselors.

Mon, 1/26/09 10:00 AM

14. I have never felt as comfortable with the psychosocial aspect of counseling as I do with the educational aspect. When faced with a difficult emotional situation, I don’t feel confident in my ability to handle it, although I feel I have handled tough situations well enough in the past.

Mon, 1/26/09 8:27 AM

15. N/A

Mon, 1/26/09 8:12 AM

16. none

Mon, 1/26/09 8:09 AM

17. N/A

Mon, 1/26/09 7:52 AM

18. n/a

Mon, 1/26/09 7:51 AM

19. n/a

Mon, 1/26/09 7:09 AM

20. N/A

Mon, 1/26/09 6:51 AM

21. na

Sun, 1/25/09 7:53 PM

22. N/A. I gave 2 for giving a diagnosis because I do not feel that is in my scope of practice

Sun, 1/25/09 3:37 PM

23. n/a

Sat, 1/24/09 8:02 AM
<table>
<thead>
<tr>
<th>Comment Text</th>
<th>Response Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I think crying during a session is often inappropriate as it may take the focus away from the patient; the others I do not feel very competent or experienced in.</td>
<td>Wed, 2/11/09 8:49 PM</td>
</tr>
<tr>
<td>2. We have some role in these situations, but we need to know our scope of practice. We need to refer people on in some of these situations. As a male, there is too big a risk to be sued if we touch people, so we have to be careful about touching.</td>
<td>Fri, 2/6/09 8:17 AM</td>
</tr>
<tr>
<td>3. I don't feel comfortable touching patients. Only in a few situations have I ever touched a patient who was grieving. I don't often feel it's appropriate. I never feel it is appropriate to display my own emotions during the session. It has nothing to do with comfort level, it just shouldn't be done.</td>
<td>Thu, 2/5/09 7:49 AM</td>
</tr>
<tr>
<td>4. N/A</td>
<td>Thu, 2/5/09 6:43 AM</td>
</tr>
<tr>
<td>5. Providing support for individuals of a different culture can sometimes be difficult, because I don't always know what it is that they expect of me and I don't want to overstep my bounds or make them more uncomfortable than they already are.</td>
<td>Mon, 2/2/09 1:04 PM</td>
</tr>
<tr>
<td>6. The ones I am less comfortable with are the ones I have less experience with, are less familiar to me, and are more emotionally-charged.</td>
<td>Thu, 1/29/09 8:29 AM</td>
</tr>
<tr>
<td>7. Feeling that displaying my own emotions during a counseling session would not be in the patient's best interest.</td>
<td>Thu, 1/29/09 7:10 AM</td>
</tr>
<tr>
<td>8. i am not familiar with these signs</td>
<td>Tue, 1/27/09 2:22 PM</td>
</tr>
<tr>
<td>9. My patients are mostly female and, being male, I do not touch them to avoid a situation where they feel I am making sexual advances. The only time I touch them is to shake hands and, if needed, perform CPR.</td>
<td>Tue, 1/27/09 1:13 PM</td>
</tr>
<tr>
<td>10. I don't feel I should tear up in front of patients. I do tend to worry regarding patients who have danger signs and usually refer them to a mental health/family counselor</td>
<td>Tue, 1/27/09 12:32 PM</td>
</tr>
<tr>
<td>11. Lost parent to suicide so don't like discussing</td>
<td>Tue, 1/27/09 11:07 AM</td>
</tr>
<tr>
<td>12. Letting myself become emotionally vulnerable can make it very difficult for me to cope with repeated grief/death experiences</td>
<td>Tue, 1/27/09 10:19 AM</td>
</tr>
<tr>
<td>13. I don't think it's appropriate to show my own emotions during a session. However, it is possible to show sincere empathy without emotion. I also feel that in today's society as well as among many cultures, touching is inappropriate.</td>
<td>Tue, 1/27/09 9:15 AM</td>
</tr>
<tr>
<td>14. Lack of experience and knowledge about how to broach the topic</td>
<td>Tue, 1/27/09 8:13 AM</td>
</tr>
</tbody>
</table>
15. I almost clicked 1 for some of the situations in which we would explore death/dying with someone of another religion or culture. This is not easy for me to do, but we had a lot of multicultural training in our coursework, so I at least feel like I have some framework for this.

16. discomfort with the topic and how to approach it, determining receptiveness of patient to discuss

17. Don't feel that I have enough training to do this properly

18. As a man, I would not want my attempt at "appropriately touching" to be misunderstood.

19. I'm not sure when I should be discussing "danger" signs and with who. If it's the patient I'm concerned about, I feel as though addressing the warning signs with family members are more appropriate but they are not always easy to reach or available.

20. Uncomfortable topics with evoke more emotional responses which I have not yet had that much experience with

21. Lack of experience outside of mock clinicals during training

22. While, I did not answer "1," the situation where I answered "2" comes from being unsure with how displaying my own emotions might cause conflict or distract from the patient's own expression of grief.

23. Just need more experience and I will be more comfortable.

24. I don't know if I have ever touched a patient, or maybe I have done it once. To be honest, I think I the worry that the patient would feel that I have invaded their space outweighs my sense that an appropriate touch would be comforting to them. I may find this easier as I have more experience, but at this point, I can't see myself doing it.

25. I feel nervous opening a dialogue that could make a delicate situation even more uncomfortable. I worry about the patient's reaction to my questions.

26. I think there are many other ways of saying "I care, I support you" rather than touching a patient

27. I do not think it is appropriate to cry infront of the patient. I think the counselor is to support them and if the counselor is crying it makes the patient feel worse.

28. death is a very hard topic to discuss especially in the context of someone's religion and beliefs

29. n/a

30. I think "touching" can be tricky territory as not everyone would welcome that and some may even be offended. I also have never been one who feels it is appropriate to cry in front of a patient. I don't think that would be comforting to see.

31. n/a

32. na

33. I think it is inappropriate to cry in front of patients as it takes the attention of them and places it on you. You are supposed to be
supporting the patient, and if you are crying, the patient may feel like they need to support you. I am not religious, have never had any formal training in any religion and do not believe in God, so it is always a struggle for me to explore religious views with patients, as I really have no experience to draw upon. I would almost feel like a fraud if I tried to explore things of a religious nature with a patient.

34. I answered a 2 for touching because I am always concerned about crossing professional boundaries with touching and I never know which patients would be comfortable with it and who wouldn't. When I do touch, I always ask first.

35. Did not receive training in this area

36. Lack of training. I believe that at this point I would try to involve a psychologist who has the appropriate training for this - I do not feel qualified.

37. Did not answer any with a '1'

<table>
<thead>
<tr>
<th>Comment Text</th>
<th>Response Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>The ones I listed as &quot;1&quot; aren't things that I am relevant in my prenatal counseling position.</td>
<td>Thu, 2/5/09 8:13 AM</td>
</tr>
<tr>
<td>Contacting families on the anniversary of one's death or following the death of the patient is just not something that I do. First, I would not keep records to alert me to the situation and rarely have time to do so. I have only on one occasion actually had a patient herself die during pregnancy. In prenatal, I just wouldn't be in a position to have many patients who themselves pass away.</td>
<td>Thu, 2/5/09 7:52 AM</td>
</tr>
<tr>
<td>For a few of those scenarios, I don't believe they are appropriate - such as discussing funeral arrangements - that is not a part of our job. If the patient mentions funeral arrangements, I would ask about the plans but I would not be involved with them. As for calling patients a year later, I just don't know how that would be helpful. What if they are not wanting to remember - what if it is still too painful and they are just trying to get through the day and then they receive a phone call from someone they met maybe twice or three times? It would feel like I was intruding.</td>
<td>Thu, 1/29/09 8:38 AM</td>
</tr>
<tr>
<td>The ones I am uncomfortable with are the ones I have less experience with, are less familiar to me, and are more emotionally-charged.</td>
<td>Thu, 1/29/09 8:31 AM</td>
</tr>
<tr>
<td>I do not work in a prenatal clinic</td>
<td>Wed, 1/28/09 9:18 PM</td>
</tr>
<tr>
<td>Inexperience with those situations</td>
<td>Wed, 1/28/09 8:47 AM</td>
</tr>
<tr>
<td>I have no knowledge of the process of planning a funeral</td>
<td>Tue, 1/27/09 2:24 PM</td>
</tr>
<tr>
<td>Have not run into this situation</td>
<td>Tue, 1/27/09 1:21 PM</td>
</tr>
</tbody>
</table>
9. lack of experience and knowledge (i.e., not working in a prenatal setting, so don't have a wealth of experience speaking with patients about or physically being present during termination procedures).

Tue, 1/27/09 12:52 PM

10. I don't do prenatal and there was not a n/a choice

Tue, 1/27/09 11:09 AM

11. I do not practice pre-natal and haven't since I graduated...

Tue, 1/27/09 10:30 AM

12. lack of experience and not routinely done

Tue, 1/27/09 8:12 AM

13. No matter how much training you have or how many times you have to do something, some things just don't come easy and will always feel a little uncomfortable.

Tue, 1/27/09 6:59 AM

14. n/a

Tue, 1/27/09 6:48 AM

15. I work in prenatal genetics so I don't typically have patients that have a terminal illness or die

Tue, 1/27/09 6:30 AM

16. Many of the questions I responded 1 to are questions related to the prenatal setting- which I have not been in for 2.5 years.

Mon, 1/26/09 4:24 PM

17. Not enough experience

Mon, 1/26/09 1:57 PM

18. I have not been in this situation before, as I am currently practicing cancer counseling and doing research. I also did not have a chance to talk about pre- and post- termination issues in much detail during clinical rotations during training.

Mon, 1/26/09 12:59 PM

19. I do not believe this is the role of a genetic counselor in many situations because it is very personal and may invoke unnecessary sadness for the patient, and possibly is inappropriate.

Mon, 1/26/09 11:50 AM

20. my own insecurities and worry i'll be bothering my patients.

Mon, 1/26/09 11:49 AM

21. Lack of experience with this situation

Mon, 1/26/09 10:43 AM

22. lack of experience or haven't had such a situation.

Mon, 1/26/09 10:14 AM

23. Again, lack of experiencing that situation in training or clinical situations

Mon, 1/26/09 10:04 AM

24. My personal faith makes counseling for termination difficult, therefore I choose not to pursue employment with a hospital requiring counseling for particular scenarios.

Mon, 1/26/09 9:37 AM

25. personal beliefs

Mon, 1/26/09 9:21 AM

26. I dont work in a prenatal setting, mostly because I do not believe in pro-choice.

Mon, 1/26/09 9:04 AM

27. Most of these are beyond the scope of my experience. When I see a patient with terminal cancer for cancer counseling, I don't often focus on their outcome, we tend to focus on their family. When it comes down to it, I think I'm a big coward about digging into their feelings about their illness.

Mon, 1/26/09 8:33 AM

28. for many of the "2", I haven't been in that field since my graduation

Mon, 1/26/09 8:15 AM

29. This is not something I have had experience with

Mon, 1/26/09 8:14 AM
30. lack of training and experience  
Mon, 1/26/09 7:57 AM

31. Not in the prenatal setting so not a lot of experience so not comfortable  
Mon, 1/26/09 7:54 AM

32. I have never done those things  
Mon, 1/26/09 7:53 AM

33. n/a  
Mon, 1/26/09 7:53 AM

34. No experience with a difficult/uncomfortable situation.  
Mon, 1/26/09 7:43 AM

35. I only have limited prenatal experience (grad school) and therefore don't feel comfortable with many of the above-mentioned scenarios due to lack of experience.  
Sun, 1/25/09 7:57 PM

36. Funeral arrangements seem out of my scope of expertise. The others for which I said, "3" are less comfortable to be for legal concerns and for sensitivity to the family reasons.  
Sun, 1/25/09 3:53 PM

37. Little or no experience - I work in adult cancer counseling, therefore do not work with families making prenatal decisions, etc  
Sun, 1/25/09 7:57 AM

38. I don't feel it's the GC's place to set up funeral arrangements.  
Sat, 1/24/09 11:22 AM

39. did not answer with a '1'  
Fri, 1/23/09 10:57 PM

40. Again, the "1"s are things that are not relevant to my job or I haven't done  
Thu, 2/5/09 8:14 AM

41. The ones I am uncomfortable with are the ones I less experience with, are less familiar to me, and are more emotionally-charged.  
Thu, 1/29/09 8:33 AM

42. Some of these are things that I have never encountered in my career so far, such as being present when a patient dies  
Wed, 1/28/09 12:38 PM

43. i have never done any of these things  
Tue, 1/27/09 2:25 PM

44. No experience with this.  
Tue, 1/27/09 2:16 PM

45. I have not been faced with this situation and would imagine it would be quite difficult  
Tue, 1/27/09 1:23 PM

46. I do not have much experience in pediatrics, especially with terminal diagnoses. Due to my lack of experience, I would feel unprepared and anxious presenting such information and support.  
Tue, 1/27/09 8:25 AM

47. Lack of experience  
Tue, 1/27/09 8:17 AM

48. These situations are not what I'm familiar with and it has been too long since I've been in school to feel comfortable with them. Also, my personal family history of cancer makes those situations very difficult because it hits too close to my own situation. This is why I  
Tue, 1/27/09 7:02 AM

49.  
50. responses per page

Displaying 1 - 29 of 29 responses  
<< Prev  Next >>  Jump To: 1  Go >>
only do prenatal counseling.

10. In some ways, I'm not sure it's my place to be with the family while their child/family member is dying. It seems like a very personal thing, and I would gladly be there if someone asked me to, but I think it's a situation that should be kept very intimate.

Tue, 1/27/09 6:57 AM

11. lack of experience

Tue, 1/27/09 6:51 AM

12. Many of these questions relate to the pediatric/prenatal settings-which I am not involved in. I have not been in the presence of a family as their loved one is dying, but would feel very out of place in that scenario- would feel as though I'm intruding on something very personal.

Mon, 1/26/09 4:26 PM

13. Not done often enough - do not work with adults or pediatrics

Mon, 1/26/09 1:58 PM

14. Not something I would be interested in.

Mon, 1/26/09 1:05 PM

15. Have not been exposed to that situation before.

Mon, 1/26/09 1:01 PM

16. Again, this seems like a personal and private matter, and genetic counseling may be inappropriate at that time.

Mon, 1/26/09 11:51 AM

17. Lack of experience with these situations and the difficulty in knowing how to deal with the emotions evoked by them (my own and the patient/family members)

Mon, 1/26/09 10:44 AM

18. Lack of experience or exposure to such situations.

Mon, 1/26/09 10:16 AM

19. No experience in this

Mon, 1/26/09 9:12 AM

20. My father died of cancer so I don't practice cancer genetics and stay as far away from these situations as possible. They bring up many emotions for me.

Mon, 1/26/09 9:05 AM

21. I have never lead a support group.

Mon, 1/26/09 9:00 AM

22. again, due to lack of experience, I would be uncomfortable

Mon, 1/26/09 7:55 AM

23. n/a

Mon, 1/26/09 7:54 AM

24. never had that experience

Mon, 1/26/09 7:54 AM

25. These would be very difficult situations for me to be a part of. I would feel very out of control of my own emotions and would therefore not feel equipped to be supportive of the family.

Mon, 1/26/09 7:47 AM

26. I have not been in this situation, and I would think it would be a rare person who would be "comfortable" as a patient or child is dying.

Mon, 1/26/09 6:15 AM

27. No training or experience in this area.

Sun, 1/25/09 8:00 AM

28. I don't feel it would be my place to be with the family as their baby dies. Possibly if they had no other family, friends or support, I could provide that role, but I think I would be uncomfortable with someone outside of my circle watching the worst experience of my life.

Sat, 1/24/09 8:09 AM

29. did not answer with a '1'

Fri, 1/23/09 10:58 PM
## Appendix C

### Open-ended 1 (Most Helpful Training Experiences)

<table>
<thead>
<tr>
<th>Comment Text</th>
<th>Response Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel that most of &quot;training&quot; in working with patients facing grief and loss occurred on the job as I actually saw patients. I do not think I was well prepared for dealing with immediate reactions of grief in grad school at all. Perhaps, to a small extent in Pediatrics clinic.</td>
<td>Wed, 2/11/09 8:57 PM</td>
</tr>
<tr>
<td>2. Lots of role playing as well as rotations where cases focused on being the primary counselor for patients dealing with grief and loss.</td>
<td>Thu, 2/5/09 6:53 AM</td>
</tr>
<tr>
<td>3. Learning about grief processes and death and dying in some of our psych and counseling classes was helpful. I wish I could have had more hands on experiences in my clinical settings, though. I was able to sit in on some sessiong where bad news was being given, but when I was finally counseling on my own, I never encountered any abnormal results. That wasn't because I was kept away from those situations, they just didn't happen very often.</td>
<td>Mon, 2/2/09 1:21 PM</td>
</tr>
<tr>
<td>4. One thing that really stands out for me, aside from role plays and course lectures on the topic, is when the palliative care team from our children's hospital came to speak to us about grief, loss, and the palliative care process. It was such a great lecture and I learned so much about the services that are available, that it took some of the pressure off of me to be that sole support. I knew that there were other people in the hospital who could help.</td>
<td>Thu, 1/29/09 2:48 PM</td>
</tr>
<tr>
<td>5. I volunteered at an AIDS/HIV hospice home and met many people - men mainly - who had over the last 20 years or so lost lovers, friends, family members to the virus and now they themselves were facing and learning to deal with their own mortality. It was a wonderful, aching, beautiful, frustrating (because not much could be changed) experience.</td>
<td>Thu, 1/29/09 8:48 AM</td>
</tr>
<tr>
<td>6. Meeting families who had lost their child but expressed how important and meaningful the child was to their lives.</td>
<td>Thu, 1/29/09 8:39 AM</td>
</tr>
<tr>
<td>7. A heavy psychosocial focus supported with theory and practice in counseling for loss, grief, coping and adaptation. I will always think about professional supervision as having played a significant role in my professional development as a genetic counselor working with patients/families experiencing loss/grief.</td>
<td>Thu, 1/29/09 1:54 AM</td>
</tr>
<tr>
<td>8. Role plays in front of class be director, luck of the caseload that gave me opportunities to give bad news, undergraduate classwork in sociology and death and dying. Experience prior to grad school being involved with giving diagnoses</td>
<td>Wed, 1/28/09 11:16 AM</td>
</tr>
<tr>
<td>9. Formal presentation in class by greif/loss counselor whow orks with prenatal/postnatal patients</td>
<td>Tue, 1/27/09 7:23 PM</td>
</tr>
<tr>
<td>10. Class focused on counseling issues/situations</td>
<td>Tue, 1/27/09 1:25 PM</td>
</tr>
</tbody>
</table>
11. role plays; watching video of seasoned genetic counselors Tue, 1/27/09 12:55 PM

12. We have a person in our department whose son passed away from CF, and I ahve since met with several of their family members for carrier testing. I was also very close with a family whose son passed away from SMA and I spend the few months of his life between his doagnosis and death learning about the different ways they coped with this loss. Tue, 1/27/09 12:36 PM

13. a course: Faith Cultures Spirituality and Healing in Health Care Tue, 1/27/09 10:40 AM

14. placements in prenatal settings and cancer settings were most helpful on a practical level. coursework (readings, role palyaing, etc) can help in school, but i think the best preparation is clinical placements/experience Tue, 1/27/09 10:06 AM

15. Role playing, talking with families who have experienced losses, reading Jon Weil's book Tue, 1/27/09 9:53 AM

16. role plays and discussing key phrases that are helpful...having a class taught by a counseling psychologist was very helpful Tue, 1/27/09 9:05 AM

17. I have found that just talking to patients who have experienced grief and loss helps prepare the next patient for similar feelings. I have gained great rapport with a couple families that have opened up about the feelings and experiences and they have equipped me with knowledge that you will never gain from a book or article. I also feel that talking to me is helpful for them, because they can help future patients by sharing their experiences with me. Tue, 1/27/09 8:30 AM

18. Observing and co-counseling in situations where bad news is delivered. Tue, 1/27/09 8:23 AM

19. RTS training (post graduation from training program) Tue, 1/27/09 7:39 AM

20. Role Plays - I know they can be scary in grad school - but it is so great to be able to practice these sessions in a safe environment - plus you get to pool on your advisors most memorable cases (at least that is how our role plays were) - which you are unlikely to encounter during your limited grad school experience Tue, 1/27/09 7:24 AM

21. We co-lead a grief support group, which really helped me see the different ways in which individual's grieve. Tue, 1/27/09 7:01 AM

22. We had mock patient sessions in how to give bad news. The "patients" were actors who were trained to respond to the bad news in various ways making it a more real situation. This was then video taped and we critqued our response and discussed ways we could improve that response. Mon, 1/26/09 4:32 PM

23. -specific classes on death/dying/grief and religious implications of our field -being lead counselor giving back results - positive and negative -being told to take a few minutes for myself before entering the room of a brca positive patient who I knew was going to be emotional Mon, 1/26/09 2:24 PM

24. We did a lot in grad school with empathizing with different cultures and their beliefs, though not much time was spent on specific cultural beliefs. Mon, 1/26/09 2:02 PM

25. role plays Mon, 1/26/09 1:47 PM

26. It was helpful to think of my own past experiences during a class. Also going through difficult sessions and discussing afterwards with the genetic counselor. Role playing. Mon, 1/26/09 1:08 PM
27. I was able to observe Angelwatch (our local perinatal hospice) cases and meet with families. As part of our training we had to co-facilitate a bereavement support group for individuals who had lost a spouse/child. Mon, 1/26/09 11:54 AM

28. Role plays Classes by very experienced genetic counselors and social workers Mon, 1/26/09 10:48 AM

29. Lecture from a Grief counselor, lectures from genetic counselors associated with the program and their experience with grief reactions, experiences in rotation with patients grief, discussing experiences on rotation helped by reflecting back on some grief reactions that I wasn't able to associate with grief at the moment it was occurring (such as anger in a counseling session) Mon, 1/26/09 10:27 AM

30. Learning about different cultures, though I think my program spent way too much time on this instead of actually dealing with the grief. Mon, 1/26/09 10:21 AM

31. Role plays of "tough" situations Reading literature on grief (minimal, but still helpful). Mon, 1/26/09 9:34 AM

32. Counseling course on grief and loss which explored our own personal experiences and feelings. Mon, 1/26/09 9:25 AM

33. In graduate school I had the opportunity to take a class on death and dying. This class was invaluable to me, and I wish that it were a required course for all genetic counseling students. I had a few patients during my training that also stand out in my mind - one mother who's baby had Zellweger syndrome, a family from Saudi Arabia with PGA1, and my first positive BRCA1 session. I think the supervisors in those cases really gave me the freedom to get to know my patients and to explore the experience with them. Mon, 1/26/09 9:19 AM

34. RTS Bereavement training and coordinator training Mon, 1/26/09 9:13 AM

35. Practice makes perfect. The more experience I have giving difficult results, the more comfortable I feel. Every new patient and every new reaction helps me feel better prepared to deal with the next patient. Mon, 1/26/09 8:42 AM

36. My training program offered a class on death and dying. It touched on a lot of issues including cultural issues, how to write a sympathy note, and even grief on the loss of a pet. Mon, 1/26/09 8:34 AM

37. Volunteered with a bereavement support group for children Mon, 1/26/09 8:24 AM

38. N/A Mon, 1/26/09 8:17 AM

39. Formal discussions with supervisors or classmates surrounding these cases. Projects on different cultures' views on grief and loss. Mon, 1/26/09 8:07 AM

40. Being allowed to participate in or at least observe counseling sessions involving grief and loss. Mon, 1/26/09 8:02 AM

41. volunteering with a support group, lectures specifically geared at these topics Mon, 1/26/09 7:57 AM

42. different grief seminars Mon, 1/26/09 7:57 AM

43. Semester long course in the rehab counseling department on "counseling grief and loss" - activities to assess your own thoughts and attitudes, education about common responses and coping strategies Mon, 1/26/09 7:22 AM
44. There was a reading (can't remember exactly what it was) we did about miscarriages and stillbirth and how it can trigger profound feelings of loss. Mon, 1/26/09 7:03 AM

45. I took a semester-long course on Counseling in Grief and Loss that spent a lot of time focusing on our own personal experiences and how they may shape our interactions with patients. Mon, 1/26/09 6:20 AM

46. My graduate training was invaluable due to the experiences I participated with, workshops we had, and resources available to me. I had great supervisors who pushed me to emotional places that may not have been comfortable at the time, but prepared me for the real world challenges of this profession. Additionally, I attend a grief and loss workshop each month in my current position which adds to my perspective and understanding. Mon, 1/26/09 6:05 AM

47. I did an independent rotation for 3 weeks where I worked in a hospice setting, a place where I had a background as a volunteer. I'm very interested in grief work and would like to pursue more education in this area in the future. In my grad program, training was sporadic with lectures and with small group discussion. Sun, 1/25/09 8:06 PM

48. The supervised clinical experience. A social work class on death and dying. Working on a presentation regarding palliative care for neonates with terminal conditions. Sun, 1/25/09 6:39 PM

49. My internships were very helpful in preparing for me to work with patients and families facing grief and loss. I feel like it is really important to try and be a part of as much as you can in an internship as a student, so that you can become more and more comfortable dealing with patients in crisis. Sun, 1/25/09 6:13 PM

50. Bad news role plays, understanding the stages of grief, and understanding what actions are helpful to most people while grieving Sun, 1/25/09 3:56 PM

51. My classmates and I had the opportunity to attend a camp for children with Fanconi Anemia, which included group support for the parents and for the affected children/siblings. Hearing from them was invaluable. Sun, 1/25/09 8:06 AM

52. The multi-cultural classes we had helped me learn a lot Sat, 1/24/09 11:25 AM

53. Role plays. Sat, 1/24/09 10:05 AM

54. I feel that my clinical rotations were by far the best experiences I had. We were not limited to the types of sessions we could be involved in and reporting numerous abnormal amnio findings, positive mutations and explaining autopsies were great learning opportunities. We had a few classes/discussions with regards to grief, but I feel that it is an ongoing learning process post-graduation - the best way to counsel parents in grief. Sat, 1/24/09 8:17 AM

55. excellent rotations where I gave "bad news" (BRCA positive, pediatric chrom deletion, and prenatal dx of Klinefelter) Fri, 1/23/09 10:44 PM
Open-ended 2 (Personal Experiences)

Displaying 1 - 50 of 50 responses

<table>
<thead>
<tr>
<th>Comment Text</th>
<th>Response Date</th>
</tr>
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<tbody>
<tr>
<td>1. I can recognize how grief can feel all-encompassing and lead to feelings of hopelessness (that you will never &quot;move on&quot;) but through personal experience, know that time will heal and most people with proper guidance and support will emerge from grief in one piece, even if changed by the experience.</td>
<td>Wed, 2/11/09 8:57 PM</td>
</tr>
<tr>
<td>2. I believe that the only thing one can often control in a given situation is how one reacts to that situation. I try to help families by realizing what is and isn't under their control and explore their feelings about this.</td>
<td>Thu, 2/5/09 6:53 AM</td>
</tr>
<tr>
<td>3. I have had my own recent experiences with loss of a couple of close relatives (one from complications associated with a genetic condition) that I feel make me more empathic regarding how individuals process those experiences. I learned a lot by just thinking about the different ways that each of my family members experienced and processed the same losses as me. So, I think that makes me more open to the fact that individuals are going to have their own personal reactions to grief and loss and that all of those different reactions are normal and expected.</td>
<td>Mon, 2/2/09 1:21 PM</td>
</tr>
<tr>
<td>4. The more grief and loss that I experience, either in my personal life or through working with families, the more broad my understanding becomes. I have seen and experienced such a range of emotions related to death and dying that I am now able to understand what others may be feeling.</td>
<td>Thu, 1/29/09 2:48 PM</td>
</tr>
<tr>
<td>5. My father is a pathologist and because I had an interest in medicine, I helped him with many autopsies. One of them was a 6 month fetus who died in utero. He was perfectly formed except when we opened him up and his stomach was littered with ulcers. But I will never forget that he could fit inside my hand and I couldn't finish the autopsy. So when I am with patients who either have a pending IUFD or termination procedure or it just happened, I remember him and even though I never met his parents, I see them in my own patients and know how real that grief can be.</td>
<td>Thu, 1/29/09 8:48 AM</td>
</tr>
<tr>
<td>6. Having a diagnosis of a genetic disease myself helps me to realize the potential feelings towards daily life, having children, etc.</td>
<td>Thu, 1/29/09 8:39 AM</td>
</tr>
<tr>
<td>7. They provide me with the context to genuinely empathize with my clients. Also, they help me identify my own responses and keep them separate from the assessments and support of my clients.</td>
<td>Thu, 1/29/09 1:54 AM</td>
</tr>
<tr>
<td>8. I do not have any major experiences in my life so I think that helps me to not act in the &quot;this is what I went through so this is what they will experience&quot; attitude.</td>
<td>Wed, 1/28/09 11:16 AM</td>
</tr>
<tr>
<td>9. Due to my age and life experiences, I have dealt with both sudden death and death due to chronic illness, and probably feel more comfortable with those situations than the average-age counselor.</td>
<td>Tue, 1/27/09 7:23 PM</td>
</tr>
<tr>
<td>10. My grandmother lived with us from when I was 4 until she died when I was 22. The fact that her doctors were open and honest about her illness and what we could expect made her death more understandable and therefore easier to experience.</td>
<td>Tue, 1/27/09 2:28 PM</td>
</tr>
</tbody>
</table>
11. Loss of parent Infertility  Tue, 1/27/09 11:12 AM

12. I find myself more able to understand their process.  Tue, 1/27/09 10:40 AM

13. I (thankfully) do not have too much personal experience with grief and loss, but I try to base my counseling on empathy for what a person would want or need in the particular situation  Tue, 1/27/09 10:06 AM

14. It allows me to better relate to how they may be feeling. Even within the same family, different members grieve differently. I have seen this with my own family.  Tue, 1/27/09 9:53 AM

15. I have limited experience with grief and loss and perhaps that helps me to remain sympathetic but not have countertransference reactions  Tue, 1/27/09 9:05 AM

16. I have not experienced a major loss or hard grieving period in my life, which I believe helps and harms my counseling. I do not have similar experiences to draw from when my patients are hurting. On the other hand, I do not have to be concerned as much about countertransference.  Tue, 1/27/09 8:30 AM

17. Easier to put myself in someone's shoes if I think back to when I heard about an unexpected death or diagnosis in my own family.  Tue, 1/27/09 8:23 AM

18. Unfortunately, they nicknamed me the "black cloud" while I was in my genetiv counseling program. Bad news seemed to follow me and I had to deal with several new and different situations. When I left grad school, my first job was at an institution where we saw abnormalities every day. Plus, I've experienced the loss of several friends over the years at very young ages (12, 19, 27), which taught me a lot about my own grief process. All of this provides me with tools to help families. As well as allows me to admit that I don't know how they feel but that I can be there to listen or cry with them.  Tue, 1/27/09 7:39 AM

19. I have had losses of every kind in my life, I think that is why I am very comfortable with other people's difficult losses. Also, I know that we all experience this feeling in some way at some point in our lives, and I think that ties us together in a way.  Tue, 1/27/09 7:01 AM

20. I have lost several family members to cancer- as have my patients. I think it enables me to relate better to the fear/anxiety that individuals with a family history of cancer face. It also enables me to better understand the need for answers (i.e. test results) that can arise in these situations.  Mon, 1/26/09 4:32 PM

21. I lost my father at a young age, and use this knowledge to try to empathize with people who are dealing with life altering news. I do acknowledge, however, that losing a father is very different from losing a child or an infant.  Mon, 1/26/09 2:02 PM

22. better able to anticipate feelings they have or will have  Mon, 1/26/09 1:47 PM

23. Since my experience with grief and loss is fairly limited, I assume I cannot fully understand what they are going through.  Mon, 1/26/09 1:08 PM

24. I have more empathy and sympathy (in appropriate cases) for loss and issues surrounding death/dying/grief.  Mon, 1/26/09 11:54 AM

25. Having lost my mother as a teenager to cancer, I think makes me more empathetic to those who are around my age who lost or are losing a parent to cancer. I think there is just an underlying sense of understanding that comes across with those patients that may not be there with other types of patient I see.  Mon, 1/26/09 10:48 AM
26. My experience with my own grief and loss and my family has helped me to be aware that individuals express grief and react to loss differently. It helps me be aware of this and be open to allowing patients to express their grief or better recognize if they are not grieving appropriately.

27. Been through some of the same issues as my patients. I'm adopted, so know & always offer this option.

28. I have experienced significant grief several times as an adult and have used my experiences to become a better counselor. Understanding the grief process is essential.

29. I have little personal experience with grief and loss, so I try to make sure that I put myself in their shoes to get a better sense of what they may be feeling.

30. My boyfriend died in a motorcycle crash not long after I graduated from my program, and before I defended my thesis. I'm sure you can imagine that this experience greatly influenced my understanding of shock, acute grief reactions, and moving forward with life and career after a significant loss. There are things that I would never have even thought to my patients before he died that I am comfortable talking about now. For example, I am much more likely to talk about God or heaven with a patient. Having received condolences, I know which words comforted me most, and were the most meaningful, and do my best to use similar phrases and ideas with my patients who are grieving. I am better able to anticipate grief reactions and to help patients prepare for them. I also know the value of the follow-up call - a person in grief can sometimes feel forgotten once their friends or family have moved on, or has reached their maximum ability to support the griever.

31. I have a very difficult time when children are involved in the process in some way. That is the main reason I know I can't do prenatal counseling. It is challenging enough for me when I have a young mother with terminal cancer or a newly diagnosed patient who has to terminate a pregnancy in order to undergo treatment. Losing a child or not being there for my child is not something I have experienced, but it is one of my biggest fears. Controlling my emotions in those situations is difficult. If I make it through the session, I have to find another way to let those feelings out when I am alone. I have yet to find the best way to do that.

32. I have not had a lot of loss in my life. I've only had two family members pass away (grandma due to old age and an aunt to cancer). I have not had other major "loss" situations either (ie. my parents have not gotten a divorce, etc.) So, if anything, I feel like my lack of grief and loss makes it more difficult for me to be empathetic for patients with loss situations.

33. This last year I have experienced loss and grief on more than one occasion. Those experiences have reminded me of the variety of emotions that can occur with a loss. I think it has renewed my insight into loss and I have tried to be more patient and not try to rush through that discussion with my patient.

34. N/A

35. I recently lost a loved one and have had immediate family members affected by cancer. I think it allows me to empathize with these families more easily.

36. I do not have a lot of personal experience with grief and loss - the only close family members who have passed away died when I
was young and I don't really remember. I think this makes me a bit more uncomfortable with patients dealing with their own loss.

37. I think that having lost a close relative, I can relate on some level to patients who have also suffered a loss. Mon, 1/26/09 7:57 AM

38. I am able to put my feelings aside for the most part during a grief counseling session. Mon, 1/26/09 7:57 AM

39. Thankfully, my own experiences with loss are limited and I think this helps me to have a certain distance or separation from my patients reactions. Mon, 1/26/09 7:22 AM

40. I have had minimal experiences of loss so sometimes I find it hard to empathize with my patients who are experiencing loss or have experienced loss in the past. Mon, 1/26/09 7:03 AM

41. My experiences with losing my mother at a young age to breast cancer and going through a miscarriage have helped me to empathize with my patients, knowing that the grief never goes away. Mon, 1/26/09 6:20 AM

42. Having experienced personal loss, while it may not be the same type of loss as my clients, allows me additional perspective to these emotions and a comfort in accompanying my client through stages of uncertainty and grief. Mon, 1/26/09 6:05 AM

43. I have lost loved ones and have had loved ones diagnosed with cancer. I don't know what it feels like personally to have a known genetic diagnosis in a family. I think that loss in general adds a certain level of sensitivity to a counseling session - just as I think being a mother would make me a better counselor in prenatal or pediatric clinical settings. Personal experience with grief isn't required for a good counselor but it certainly can't hurt unless it is debilitating. Sun, 1/25/09 8:06 PM

44. I know I am more distant with some patients who's stories produce feelings of grief within myself due to similar personal experiences. Sun, 1/25/09 6:39 PM

45. I, fortunately, have not had many personal experiences of loss of someone or something close to me. What helps me with my patients is that the vast majority of them have never been through the situation they are currently experiencing, and if I can help guide them through it as a familiar face and person they can turn to, then I feel like I have helped them in the most basic way. Sun, 1/25/09 6:13 PM

46. I find the opposite is true: that my training affects how I deal with grief and loss in my personal life. Sun, 1/25/09 3:56 PM

47. Knowing family members who have had or died of cancer helps me understand some of the issues surrounding a terminal illness. Sun, 1/25/09 8:06 AM

48. It has helped me feel comfortable in the presence of persons while they're actively grieving. Sat, 1/24/09 11:25 AM

49. I am very lucky as I have lost few people so close to me that I am experiencing the same level of grief as my patients. I think my inexperience, at this point in my career, is a good thing as I can remain attended to the patient as opposed to being reminded of my own grief. Sat, 1/24/09 8:17 AM

50. I had excellent grief counseling training 2 years before I started grad school, and had one year experience doing grief counseling and sitting with bereaved family members. I myself have not had many significant losses besides grandparents death. Fri, 1/23/09 10:44 PM
### Open-ended 3 (Religious Beliefs)

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<table>
<thead>
<tr>
<th>Comment Text</th>
<th>Response Date</th>
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<tbody>
<tr>
<td>1. N/a</td>
<td>Wed, 2/11/09 8:57 PM</td>
</tr>
<tr>
<td>2. I was raised catholic but don't practice and lack a strong cultural identity. However, I have a background in international studies and an interest in other cultures and religions. I try to help families identify their own belief systems and use that to help them cope with a given situation.</td>
<td>Thu, 2/5/09 6:53 AM</td>
</tr>
<tr>
<td>3. I consider myself a religious person, but I try to keep my religion away from counseling session unless my patients indicate to me that they also share those beliefs. In any situation, I try to let my patients dictate how much religion/cultural beliefs are going to play a role in their grief processes.</td>
<td>Mon, 2/2/09 1:21 PM</td>
</tr>
<tr>
<td>4. I work in a community that is overall quite religious. My having a religious affiliation allows me to feel comfortable asking about their own beliefs and further exploring that with them.</td>
<td>Thu, 1/29/09 2:48 PM</td>
</tr>
<tr>
<td>5. I am agnostic but I was raised Lutheran. But being agnostic I believe is helpful as when I am meeting with patients who repeatedly mention how strong their faith is or how God will decide, I can be more open to exploring those ideas. I can try to be as nonjudgemental as I can.</td>
<td>Thu, 1/29/09 8:48 AM</td>
</tr>
<tr>
<td>6. I believe things happen for a reason and that we are all part of something much bigger than us, which allows me to be hopeful when working with families.</td>
<td>Thu, 1/29/09 8:39 AM</td>
</tr>
<tr>
<td>7. I can comfortably acknowledge and support the role of patient's faith or religion in their decision-making process and when they hear difficult news or results.</td>
<td>Tue, 1/27/09 7:23 PM</td>
</tr>
<tr>
<td>8. Practice in strongly religious/spiritual area of the country so patients bring up God often. I am also strongly spiritual/religious so feel comfortable discussing patients' beliefs with them</td>
<td>Tue, 1/27/09 11:12 AM</td>
</tr>
<tr>
<td>9. Being a Christian I believe in a better life after death, this is often comforting to my patients who believe in an afterlife, however it is hard to help those who have no belief in afterlife.</td>
<td>Tue, 1/27/09 10:40 AM</td>
</tr>
<tr>
<td>10. n/a</td>
<td>Tue, 1/27/09 10:06 AM</td>
</tr>
<tr>
<td>11. It allows me to connect with those who have strong religious faith. It also helps me cope with my own feelings and stresses in difficult situations.</td>
<td>Tue, 1/27/09 9:53 AM</td>
</tr>
<tr>
<td>12. history of diversity is extremely helpful, my best friend had arranged marriage and many friends have varying beliefs on religion, termination, origin of birth defects, role of science, etc.</td>
<td>Tue, 1/27/09 9:05 AM</td>
</tr>
<tr>
<td>13. I have spiritual beliefs but I do not regularly practice religion and am not part of organized religion. I feel this allows me to connect</td>
<td>Tue, 1/27/09 8:30 AM</td>
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</table>
with patients who have faith, but I feel limited at times with patients
who have a very strong bond with their faith and regularly attend
organized religion practices.

14. Regardless of my own spiritual beliefs I try to understand where
the patient is coming from their own belief system to understand
how that is helping them cope through the situation. Tue, 1/27/09 8:23 AM

15. To me, everyone’s religious beliefs are different. I’m christian but
several of my christian friends believe differently than I do. So, for
my patients I ask how I can best help them, do they want me to
call a minister, preacher, chaplain, etc. Is there anything special
that they need. Would they like to pray, etc. Tue, 1/27/09 7:39 AM

16. This is a little hard - I am a religious person, but quite liberal - and
living in the south the average person here is a much more
conservative religious person - and I am very comfortable in
supporting patients who have used their faith to already make a
decision (prenatal in particular, and my experience is that people
use their faith to guide them in BOTH deciding to continue or
terminate) however, it can be a little tricky when they are in the
decision making process and want to discuss religion in their
counseling - as I want to be supportive of this very important part
of their decision making process, but I am very careful in the
questions and comments that I use to direct the conversation (as I
do not want to say something to make them feel I am not someone
they can talk to about their religious feelings related to the
diagnosis). So, this can be tricky. Like everything else, listening
and allowing them to explore their feelings in a supportive and
non-judgemental environment is key. I am supportive of their
beliefs (whatever they may be), but try to avoid allowing any of my
own to come into the conversation. Tue, 1/27/09 7:24 AM

17. It really doesn't. Tue, 1/27/09 7:01 AM

18. I don't have strong religious tendencies. I believe that everyone
has a different belief system (whether cultural/religious) that
makes them unique (myself included) so it's best to treat everyone
as unique. Mon, 1/26/09 4:32 PM

19. -I am religious which helps me personally deal with patients and
my personal emotions in situations -I work in a very religious area
of the country, so patients/families find comfort in learning that I'm
religious - this doesn't come out in every session, just when
appropriate Mon, 1/26/09 2:24 PM

20. I try not to let my personal beliefs alter the way I counsel. Having
been through a loss, I understand that every reaction is different,
and no reaction is 'wrong' Mon, 1/26/09 2:02 PM

21. it doesn't Mon, 1/26/09 1:47 PM

22. Having a positive view of death (a place of peace and oneness
with God) as part of my religion affects how I think families deal
with death, and therefore how I interact with them. Mon, 1/26/09 1:08 PM

23. As a Christian, I believe in the afterlife and have more of a sense
of peace about loss/death than some. I try to use this calmness in
my voice and demeanor during our sessions. Mon, 1/26/09 11:54 AM

24. My religious affiliation and belief system helps me to accept loss
and helps with grief. I think this helps me be open to patients or
help them explore their support systems and dealing with grief.
This also helps to be open to patients with different
cultural/religious/belief systems by recognizing that their particular
belief system may be helpful to them in dealing with loss.

25. I'm not that religious. So if anything, I have always been aware of other religions as I am part of a minority. Otherwise I don't think my slight religious background makes much difference. Mon, 1/26/09 10:21 AM

26. My faith helps me counsel my families, especially those who express a connection with a particular faith. I keep my personal beliefs to myself, but it helps to have an understanding of multiple faith traditions and how faith impacts the grief response. Mon, 1/26/09 9:42 AM

27. Being a Christian has influenced me in many ways...I am not sure if it causes me to counsel families differently; however, I believe that I often feel deep compassion for my patients. Additionally, my faith leads me to give each patient the benefit of the doubt in a given situation. Mon, 1/26/09 9:34 AM

28. I am Jewish, and the tradition that resonates with me the most about grief is the tradition of 'sitting shiva'. Forgive me if you are already aware of this custom, but it is expected for the grieving family to literally sit for a week and allow the family and friends to support them in their grief. The griever does not cook, clean, or make any arrangements. S/he is visited and taken care of throughout this period. I think sitting shiva allows the griever time to process, and to be shown love and support. Shiva only lasts a week, however, which encourages the griever to regain control, which is necessary to move forward. Mon, 1/26/09 9:19 AM

29. I am not religious and I don't believe in heaven or hell. But I recognize these beliefs as an important part of the coping process for many patients. I let the patient make indications of the importance of these things and then encourage these beliefs as part of their coping. Mon, 1/26/09 8:42 AM

30. I try to follow their lead and mirror the terms they use. If they refer to a god, then I will talk to them about the god, etc. I don't think my being agnostic influences the way I counsel for the good or bad. Mon, 1/26/09 8:34 AM

31. My background (cultural/religious/belief system) gives me one view or lens on the situation. I always remind myself that people may view the exact same situation very differently. There is no wrong or right way, just different ways. And even though I may not understand another's way of grieving, I want to mindful of their feelings and experiences. Mon, 1/26/09 8:24 AM

32. N/A Mon, 1/26/09 8:17 AM

33. I am a member of the dominant culture in my practice area, which makes it easier to understand the reactions of a majority of patients. I have a religious affiliation, but have a pretty good understanding of other religions' views from my training. I might say something like, "Now he is in a better place" or "His suffering is over" but would not bring up religion overtly. Mon, 1/26/09 8:07 AM

34. I don't think my own beliefs affect the way I counsel patients. Mon, 1/26/09 8:02 AM

35. they don't really play into how i counsel patients Mon, 1/26/09 7:57 AM

36. I don't believe they do Mon, 1/26/09 7:57 AM

37. most of my patients are of the same religious background as i am, so i think that we are "on the same page" in many cases, this is a very religiously conservative area, so i have found myself often cautioning against belief in miraculous healings but trying to use Mon, 1/26/09 7:22 AM
38. Coming from a Western culture, it is sometimes hard for me to understand the beliefs about loss and illness that other cultures have, as well as the way they cope with grief.

39. My belief in God and heaven allow me to relate to patients who have similar beliefs, but do not prevent me from working with patients who have different belief systems.

40. This may help in my own personal resilience, but I do not believe it colors the time with my clients. It would be inappropriate for me to overlay my affiliations/beliefs onto their session.

41. I honestly don't think it makes a big difference. Or at least it hasn't in my practice. If someone mentions faith or their beliefs I support them in that and encourage them to use all possible support systems which certainly includes faith and beliefs.

42. I try to keep my beliefs of loss separate from my patient's for two reasons, first, my beliefs tend to be much different than many of my patients', and second, what is important is my patient's beliefs and cultural/religious affiliations, and how I can help them and support them in that context.

43. I am unwilling to tell people that my prayers are with them; instead, I say that my thoughts are with them or that I am thinking about them.

44. They don't

45. I come from a white Canadian agnostic background. This will affect how I counsel. I work in a very multicultural city, which was traditionally Catholic, so my background more often than not clashes with my patients. I am less likely to discuss religion as a support system with a patient unless they bring it up first.