Helping those that are Underinsured:

What are Genetic Counselors doing to help their patients get \textit{BRCA1/2} testing covered?

Master’s Thesis

Presented to

The Faculty of the Graduate School of Arts and Sciences
Brandeis University
Genetic Counseling Program
Barbara Lerner, Advisor

In Partial Fulfillment of the Requirements for Master’s Degree

by
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Acknowledgments

I would like to express my gratitude to my committee members Barbara Lerner, Michele Gabree and Karleen Habin, for their support, time and valuable expertise. Many thanks to Liz Cross who helped me to navigate through my data analysis. To Judith Tsipis, Gretchen Schneider, Beth Rosen Sheidley and Missy Goldberg for their amazing support. I would also like to thank my friends, family and classmates for all of their love and encouragement.
Abstract

Helping those that are Underinsured: What are Genetic Counselors doing to help their patients get BRCA1/2 testing covered?

A thesis presented to the Genetic Counseling Program
Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

By Lindsay Kipnis

According to the U.S. Preventative Services Task Force (USPSTF, 2005), anyone with a personal or significant family history of breast or ovarian cancer should be offered BRCA1/2 testing. Patients who are underinsured (i.e. who have a health insurance policy that does not cover enough of the test’s cost, thus making it unaffordable) may be unable to follow through with these recommendations. However, underinsured patients may be eligible for funding from charitable resources such as the Cancer Resource Foundation Inc. The purpose of this study was to explore cancer genetic counselors’ knowledge regarding financial assistance programs for underinsured patients seeking genetic testing, and to assess the frequency with which they refer patients to such programs. We recruited cancer genetic counselors based in the United States through an NSGC e-blast for participation in an anonymous, online survey. Of the 178 genetic counselors who responded, nearly all (99%) reported that they assist patients in obtaining insurance coverage for BRCA1/2 genetic testing. Participants reported that between December 2011
and December 2012, an average of 11% of their patients canceled their testing due to insurance coverage. Of those patients, the majority (~60%) canceled because they were underinsured. Many of the participants reported using the Cancer Resource Foundation Inc. (43%) or a hospital grant/fund (33%) to assist patients with payment for testing. The participants reported encountering two major problems when trying to obtain funding. First, in many instances the patients did not provide the required documentation for the application. Second, counselors cited funding limitations, including regional variability in the availability of funds and insufficient funding to cover all patients. With the implementation of the Affordable Care Act, *BRCA1/2* testing will now become a preventative care service, which will hopefully allow for more patients to be able to proceed with testing.

Keywords: *BRCA1/2*; genetic testing; funding sources; underinsured; genetic counselors
# TABLE OF CONTENTS

Introduction ..................................................................................................................1

Methods .......................................................................................................................6

Results .........................................................................................................................8

  Sample Characteristics...............................................................................................8

  Insurance Issues .......................................................................................................9

  Funding Sources ......................................................................................................12

Discussion ..................................................................................................................16

  Financial Counselors ...............................................................................................17

  Changes with the ACA ............................................................................................18

  Limitations ..............................................................................................................19

Conclusion ..................................................................................................................20

References ..................................................................................................................21

Appendices ................................................................................................................24

  Appendix A. Recruitment Notice .............................................................................24

  Appendix B. Survey ..................................................................................................25
List of Tables

Table 1. Demographic characteristics of study participants…………………………9

Table 2. Funding Sources Used…………………………………………………………13

Table 3. Top 5 Most Difficult Aspects in Obtaining Funding……………………………14
List of Figures

Figure 1. On a monthly average over the past 12 months, what percentage of your patients canceled their BRCA tests due to insurance reimbursement? .................. 10

Figure 2. Patients unwilling/unable to pay the co-pay or deductible .................. 11

Figure 3. On a monthly average over the last 12 months, how many hours have you spent working on insurance issues? ................................................................. 12
Acknowledgments

I would like to express my gratitude to my committee members Barbara Lerner, Michele Gabree and Karleen Habin, for their support, time and valuable expertise. Many thanks to Liz Cross who helped me to navigate through my data analysis. To Judith Tsipis, Gretchen Schneider, Beth Rosen Sheidley and Missy Goldberg for their amazing support. I would also like to thank my friends, family and classmates for all of their love and encouragement.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Methods</td>
<td>6</td>
</tr>
<tr>
<td>Results</td>
<td>8</td>
</tr>
<tr>
<td>Sample Characteristics</td>
<td>8</td>
</tr>
<tr>
<td>Insurance Issues</td>
<td>9</td>
</tr>
<tr>
<td>Funding Sources</td>
<td>12</td>
</tr>
<tr>
<td>Discussion</td>
<td>16</td>
</tr>
<tr>
<td>Financial Counselors</td>
<td>17</td>
</tr>
<tr>
<td>Changes with the ACA</td>
<td>18</td>
</tr>
<tr>
<td>Limitations</td>
<td>19</td>
</tr>
<tr>
<td>Conclusion</td>
<td>20</td>
</tr>
<tr>
<td>References</td>
<td>21</td>
</tr>
<tr>
<td>Appendices</td>
<td>24</td>
</tr>
<tr>
<td>Appendix A. Recruitment Notice</td>
<td>24</td>
</tr>
<tr>
<td>Appendix B. Survey</td>
<td>25</td>
</tr>
</tbody>
</table>
List of Tables

Table 1. Demographic characteristics of study participants………………………………9
Table 2. Funding Sources Used……………………………………………………………………13
Table 3. Top 5 Most Difficult Aspects in Obtaining Funding…………………………14
List of Figures

Figure 1. On a monthly average over the past 12 months, what percentage of your patients canceled their BRCA tests due to insurance reimbursement? ..........................10

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