Allocation of Work Activities in a Comprehensive Cancer Genetics Program

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Hereditary cancer programs that provide risk assessment, genetic education, and counseling services are becoming increasingly common. This article describes one possible approach to providing comprehensive cancer genetics care by a credentialed genetics advanced practice nurse. In addition to the description of the program, data from a recently conducted time study are included to provide insight into work allocation of different program components. Findings from the study indicate that about 41% of the time is spent in direct clinical time with patients and families, including initial visit counseling, phone consultation, and follow-up visits. The rest of the time is spent in other indirect care activities, including previsit activities, risk calculation, clinical trials enrollment, correspondence, teaching, and administrative duties. For those developing or expanding a cancer genetics program, considering all activities that will occur and the time allocated to each activity is important.

Background

The Hereditary Cancer Program (HCP) at Saint Louis University (SLU) was initiated in 1999 and is managed by an APN with an advanced practice nurse in genetics (APNG) credential and certification as an Advanced Oncology Certified Nurse® (AOCN®). Other personnel include a medical oncologist who has a collaborative practice agreement with the APN and a business manager who allocates 7% of work effort to provide administrative support.

Since its inception, the HCP has provided services to more than 1,750 families with steady growth, particularly in the previous four fiscal years. During the fiscal year that ended June 2012, the HCP served 293 new and 52 established families, which included 742 counseling sessions (see Tables 1 and 2). Every individual received risk assessment data and recommendations for prevention and screening (418 people). Seventy-eight families were evaluated to participate in a clinical trial to identify a hereditary susceptibility gene and 56 families were enrolled.

A unique feature of the program is that patients may access educational services as often as needed without costs because charitable funding pays for the salary of the APN.

Knowledge of genetics is rapidly changing oncology practice, largely because of the isolation of multiple cancer susceptibility genes and the increasing commercial ability of genetic testing. The National Society of Genetic Counselors (NSGC), 2012) reported that, in 1994, only 10% of genetic counselors specialized in cancer genetics; in 2012, 25% of counselors reported specializing in oncology. In addition, many accreditation agencies are recommending that patients have access to genetic services (American College of Surgeons Commission on Cancer, 2011; National Accreditation Program for Breast Centers, 2011).

The Institute of Medicine ([IOM], 2011), in the landmark publication The Future of Nursing: Leading Change, Advancing Health, emphasized that identifying and developing innovative solutions for delivering coordinated care should be priorities. One of the biggest challenges associated with providing genetics care is to provide coordinated seamless care for the entire family. This article describes one possible approach to providing comprehensive cancer genetics care by an advanced practice nurse (APN)–managed program. Data from a recently conducted time study are included to provide some insight into work allocation to different program components.
funding has been secured to assist those who cannot afford genetic testing but for whom it is appropriate. Families are referred from healthcare providers from SLU, community health-care providers, or are self-referred (see Figure 1). The APN provides educational programs to healthcare providers and the public to increase awareness of hereditary cancer syndromes and availability of services (see Table 3).

Methods

To better understand how time is spent on various activities, a time study was initiated from April 2012 to June 2012, resulting in 13 weeks of data collection. Study methodology is listed in Figure 2. Data on referral patterns, syndrome types, and testing outcomes are collected on an ongoing basis and also are included.

Findings

The activities were broken down into categories (see Table 4). The findings will be discussed by category, followed by a discussion of related findings cited in the literature.

Initial and Follow-Up Visits

Families are routinely scheduled for 90 minutes for the initial visit. The average initial visit lasted 84 minutes (excluding documentation) (see Figure 3). For patients who undergo genetic counseling, adequate and supportive pretest counseling is associated with positive outcomes and fewer complications adjusting to the results of genetic testing (Riley et al., 2012; Twomey, 2011; Weitzel, Blazer, MacDonald, Culver, & Offit, 2011). Although trying to reduce the amount of time for these educational and supportive activities is tempting, they are necessary for the patient to have informed consent (Berliner & Fay, 2007).

Follow-up visits are routinely scheduled for 90 minutes (see Figure 4). The average follow-up visit lasts 74 minutes (range = 42–95 minutes). Shorter visits usually occur with negative test results in the context of a known family mutation. The individual is informed they have population risk, recommendations for prevention and early detection are usually straightforward based on those for the general population, and patients usually are relieved. Longer visit times typically occur when positive results are given because of the complexity of the recommendations for management and the associated emotional reactions to learning one has a genetic predisposition for developing a malignancy. Longer visit times also occur in patients who have complicated family histories or noninformative results and need additional recommendations for screening based on family history or test results. For those considering enrollment in research studies, visits also can be longer to gather additional data, complete forms, and provide education.

Potential benefits from a results disclosure session include allowing the patient and family to begin to assimilate the information in a supportive environment (Riley et al., 2012). During the visit in which the genetic testing specimen is collected, a discussion takes place regarding results disclosure procedures. The policy of the HCP is generally to disclose in person, as it provides a structured plan for providing education on recommended screening modalities and any other education and support as needed. Results disclosure probably takes more time when conducted in person; phone disclosure may take as little as 15 minutes (Doughty Rice, Ruschman, Martin, Manders, & Miller, 2010). Providing patients with a choice on how to receive results might lead to more positive outcomes (Baumanis, Evans, Callanan, & Susswein, 2009). Concerns about phone disclosure include that there may be more difficulty understanding the meaning of the

### TABLE 1. Comparison of Hereditary Cancer Syndromes Seen During Fiscal Year 2012 and Study Period

<table>
<thead>
<tr>
<th>Syndrome</th>
<th>Fiscal Year(^a) (N = 293)</th>
<th>Study Period(^b) (N = 96)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Hereditary breast and ovarian</td>
<td>164</td>
<td>56</td>
</tr>
<tr>
<td>HNPCC</td>
<td>74</td>
<td>26</td>
</tr>
<tr>
<td>Familial adenomatous polyposis</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>MEN2</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Von Hippel-Lindau</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>MEN1</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Neurofibromatosis type 2</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Li-Fraumeni syndrome</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Hereditary melanoma</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Muir Torre syndrome</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Hereditary gastric</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Cowden syndrome</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Neurofibromatosis type 1</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Birt Hogg Dube syndrome</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>HLRCC</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

\(^a\)From July 1, 2011, to June 30, 2012
\(^b\)From April 1, 2012, to June 30, 2012

HLRCC—hereditary leiomyomatosis and renal cell cancer; HNPCC—hereditary nonpolyposis colorectal cancer; MEN1—multiple endocrine neoplasia type 1; MEN2—multiple endocrine neoplasia type 2

Note. Because of rounding, not all percentages total 100.
results regardless of whether they are negative or positive, although some genetics counselors believe that disclosing negative results on the phone is satisfactory (Bradbury et al., 2011; Jenkins et al., 2007) when followed-up by written recommendations and a copy of test results.

**Chart Management**

Documentation of visits and phone conversations can be very time consuming. Chart management also includes scanning and downloading pathology reports and referrals from other providers and filing any information in an electronic folder that is important for the care of the family, such as the pedigree, follow-up correspondence, insurance preauthorization documents, and test results.

The HCP uses a completely electronic system for the family charts developed specifically for the program. Charts are filed by the proband’s name with subfolders for other family members. Information is electronically backed up to a secure server and to a portable hard drive stored in a locked area.

Much controversy exists over the use of electronic medical records (EMR) and the storage of genetic records (Glaser, Henley, Downing, & Brinner, 2008; Hudson, 2011). Certainly healthcare providers need access to genetic testing results, and if the information only includes information about one individual, it can be included in an EMR and such information has certain protections against discrimination provided by the Genetic Information Nondiscrimination Act. What makes charts in programs such as the HCP different is that records and information from other family members often are available, such as a pedigree, pathology reports, or a positive test result of a relative, which are necessary to order the correct test or make accurate risk calculations for the patient being seen. Such information is critical to providing comprehensive care to the family, but placing it in a general EMR would include a breach of confidentiality for other family members.

**Grant Activities**

The HCP provides all counseling and education at no charge, so any individual or family can receive comprehensive genetics education. This requires annual funding for salary support for the APN. The HCP takes this a step further and ensures that any patient who desires testing or could potentially benefit from testing and demonstrates financial need can have the costs of testing covered (which range from about $200–$4,000). Many programs overlook this issue, which requires significant funding. The program has successfully accomplished this for more than 10 years, but it requires an ongoing commitment to grant writing and fundraising, which is primarily completed by the APN. Because most foundations only fund one year at a time, this challenge is ongoing.

Grant activities including finding grants, submitting proposals after receiving appropriate institutional approvals, completing progress reports and final reports, and attending any functions requested by the granting agency. Some agencies have more requirements than others. Grant writing is an activity that many genetics professionals find necessary to help sustain various components of a program (Powell, Hasegawa, & McWalter, 2010).

**Administration**

Administrative activities include attending faculty and staff meetings, cancer committee meetings, and preparing reports. Some administrative activities are Writing Grant Proposals and Supporting the APN. Because the APN is busy conducting patient care and teaching, administrative responsibilities can be overwhelming.

**Exploration on the Go**

The Oncology Nursing Society’s Cancer Genetics Special Interest Group offers you connections to colleagues in this new and growing field. To access, open a barcode scanner on your smartphone, take a photo of the code, and your phone will link automatically. Or, visit [http://cancergenetics.vc.ons.org](http://cancergenetics.vc.ons.org).
for committees. It also includes any meetings with the business manager regarding finances. Work-related e-mail also is included in this category.

Although attendance at meetings can be time consuming, administrators and other members of the team should understand the resources available and productivity in the HCP. Ongoing promotion of the HCP internally is as important as external promotion. Devoting 8% of the time to administrative duties reported in this study is similar to the 7%–10% figure for administration that has been reported by genetics counselors and medical geneticists (McPherson et al., 2008).

Phone Communication With Other Providers

Communicating with other healthcare providers includes providing information about how to access services for a provider, making a first referral, or assisting a provider seeking additional information about a syndrome or recommendation. This also includes peer-to-peer review for insurance denials and appeals that often occur in genetics practice (McPherson et al., 2008).

Correspondence

Patient education includes reinforcement and summarization of information about recommended cancer prevention and early detection maneuvers based on the cancer risk assessment and genetic testing that is accomplished by sending a summary letter to the patient and any identified providers. Tasks to complete this step include writing and printing the letter, making copies, scanning to the medical record, and mailing or faxing the recommendations to the patient and any designated referring healthcare providers.

Letters to patients should include the recommendations, rationale for the recommendation, and known limitations and risks associated with the recommended screening strategies (Plutynski, 2012). The impact of a personal, tailored letter with specific recommendations should not be underestimated and is associated with increased screening participation rates (Ling et al., 2009; Weitzel et al., 2011). Communicating these recommendations to primary care providers is important because, in most cases, the patient will return to these providers for long-term care, therefore reducing the chance of miscommunication. With rare genetic syndromes, this correspondence often is accompanied by supporting literature; however, finding such literature also requires time.

Educational Activities

About 10% of the effort of the APN is spent in providing academic education and other educational programs. Half of this time is spent preparing for and teaching various disciplines, including fellows, residents, and medical, nursing, and allied health students. The other half of the time is spent preparing for and giving lectures in the geographic region served by the HCP. These educational programs and lectures might be to community groups as well as healthcare professionals.

The need for increased professional education regarding genetics is well documented, and the need is projected to continue to increase to promote a healthcare force knowledgeable about basic genomic concepts (Greco, Tinley, & Seibert, 2012; National Coalition for Health Professional Education in Genetics [NCHPEG] 2007; Weitzel et al., 2011). In a study of medical geneticists employed in academic education, direct teaching efforts account for about 13% of effort; for certified genetic counselors, teaching efforts for professionals and the public accounts for about 5% of their efforts (McPherson et al., 2008).
• For two weeks prior to implementing the study, the advanced practice nurse (APN) kept a list of activities completed.
• Activities were categorized into groups.
• The list was made into a Microsoft® Excel® spreadsheet.
• When data collection began, the time was noted when the APN started an activity, and the time was again noted when the activity ended.
• The number of minutes were recorded in the appropriate activity category on the spreadsheet. For example, when a phone call was initiated to clarify information with a patient, the time was noted. When it was completed, the total number of minutes were added in the category of patient consultation. A count of the number of patients who received consultation also was made to later determine how long the average phone consultation takes.
• The time spent on each activity was recorded throughout the day as each activity was completed.
• The data were summarized for each day, then by week, and then for the study.
• Descriptive statistics, including percentages and means, were used to better understand the data.

FIGURE 2. Study Methodology Steps

Other Activities

Risk calculation: Risk calculation accounts for 3% of the APN’s activity. Multiple calculations of risk for developing cancer(s) and the risk of a mutation are made outside of the counseling session. These are also needed for insurance justification. Calculating empiric risks and mutation probabilities is a standard practice in cancer genetics counseling and practice (NCHPEG, 2007; Weitzel et al., 2011).

Clinical trials enrollment: The APN spends about 3% effort identifying, educating about, and enrolling families in studies that seek to benefit genomic science and possibly identify mutations, which might be helpful to the entire family. If a mutation is detected or additional follow-up is required for those enrolled in the trial, the APN completes the task. Clinical trials enrollment has been identified as an important activity in genetics practices (Hudson, 2011; Weitzel et al., 2011).

Professional activities: Professional activities include serving on medical advisory boards and committees for national organizations with tasks such as writing standards and educational programs to enhance genetic competency. The NCHPEG has stated that genetic APNs have a responsibility and expectation to promote leadership to implement and promote organizational and professional policies that promote genetic health (Greco et al., 2012).

Tumor board: The APN participates in various tumor boards as a member of the multidisciplinary team to both identify patients that might benefit from genetics education and to provide education about recommendations for care based on the risk assessment and genetic testing. This participation is an important way to communicate with other healthcare providers and provide comprehensive and coordinated care as recommended by many professional groups (American College of Surgeons Commission on Cancer, 2011; National Comprehensive Cancer Network, 2012).

Literature review: Some families have an unusual constellation of symptoms and diagnoses, and additional research is needed to better understand these syndromes and provide recommendations. This also might include calls or e-mails to national and international experts for additional advice—a common practice in comprehensive cancer genetics programs (McPherson et al., 2008).

Previsit activities: To provide comprehensive care in an efficient manner, the APN often will review family histories, prior test results, and medical records before the visit. For families who travel several hours for an appointment, this can be particularly important because it prevents having them from coming for a visit with important information about the family’s health history. This genetics practice is common and time-consuming and depends on the types of syndromes seen (Berlin & Fay, 2007).

Collaborative practice: APNs must work within the limits of their license, and most have some requirements for ongoing review of the cases with the collaborating physician (usually scheduled every two weeks). If an unusual case or situation arises, the APN discusses it with the collaborating physician promptly so the collaborator is aware and does not wait for the scheduled review. This helps reduce the potential for negative outcomes and liability.

Professional Development

The APN also participates in ongoing continuing education and professional writing outside of the regular workday. The APNG credential (offered by the Genetic Nurse Credentialing Commission [www.geneticnurse.org]) requires a minimum of 50 genetics continuing contact hours every five years for renewal, and the AOCN® (provided through the Oncology Nursing Certification Corporation [www.oncc.org]) requires

<table>
<thead>
<tr>
<th>Activity</th>
<th>%</th>
<th>X (Minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Direct patient care activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial visit</td>
<td>21</td>
<td>84.1 per patient</td>
</tr>
<tr>
<td>Follow-up visit</td>
<td>12</td>
<td>74.2 per patient</td>
</tr>
<tr>
<td>Phone calls with patients</td>
<td>5</td>
<td>12.6 per patient</td>
</tr>
<tr>
<td>Scheduling</td>
<td>3</td>
<td>5.9 per patient</td>
</tr>
<tr>
<td><strong>Indirect patient care and other activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chart management</td>
<td>13</td>
<td>29.9 per patient</td>
</tr>
<tr>
<td>Grant activities</td>
<td>9</td>
<td>1,275 per grant</td>
</tr>
<tr>
<td>Administration</td>
<td>8</td>
<td>–</td>
</tr>
<tr>
<td>Phone consultation with providers</td>
<td>5</td>
<td>14.5 per provider</td>
</tr>
<tr>
<td>Correspondence with patient and providers</td>
<td>4</td>
<td>13.85 per patient</td>
</tr>
<tr>
<td>Risk calculation</td>
<td>3</td>
<td>12.5 per patient</td>
</tr>
<tr>
<td>Outside speaker preparation</td>
<td>3</td>
<td>210 per hour of lecture</td>
</tr>
<tr>
<td>Clinical trials enrollment</td>
<td>3</td>
<td>39.4 per family</td>
</tr>
<tr>
<td>University teaching class preparation</td>
<td>2</td>
<td>311 per hour of lecture</td>
</tr>
<tr>
<td>University teaching</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Speaker (outside presentations)</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Professional activities</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Tumor board</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Previsit chart review and preparation</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Literature review of unusual syndromes</td>
<td>1</td>
<td>47.4 per syndrome</td>
</tr>
<tr>
<td>Collaborative practice</td>
<td>&lt;1</td>
<td>–</td>
</tr>
</tbody>
</table>

*Note. Because of rounding, percentages may not total 100.*
The following activities are generally performed during the initial visit. They center around assessment and education. If genetic testing is not indicated, they are modified.

**Reassure**
- Introduce self to patient and family members and provide a business card and information about funding sources for counseling.
- Discuss purpose of visit and agenda with patient. Assess patient concerns, motivations, and expectations regarding genetic testing.
- Clarify misconceptions about the process or concepts.

**Investigate**
- Construct pedigree (3–4 generations maternal and paternal, current ages, ages at death, ages at diagnoses, and ethnicity) based on information from a family history form and direct patient interview.
- Assess and document pertinent health and medical information (general, surgeries, major illnesses), nonmodifiable cancer risk factors (age at first menarche, menopause), modifiable lifestyle risk factors (tobacco, alcohol use, exercise, diet, exogenous hormone intake), cancer screening history and outcome (mammograms, colonoscopy), family dynamics and support systems (record ethnicity), and responses to negative information.

**Act**
- Perform targeted physical examination to identify features associated with hereditary cancer syndromes as appropriate (head circumference, dermatologic lesions).

**Communicate**
- Discuss factors that limit interpretation and assessment (limited family structure, lack of information).
- Present basic risk information for both developing cancer(s) and risk of having a mutation, if appropriate.
- Discuss principles of cancer genetics in understandable terms.
- Identify and discuss who is the best individual(s) to test (ideally someone diagnosed with cancer).
- Discuss that the alternative to undergoing genetic testing is to decide against genetic testing and the implications of each choice.
- Prioritize order of tests if more than one test or strategy are considered.
- Discuss method of testing (blood, saliva); potential test outcomes (positive, true-negative, uninformative, indeterminate); possible management strategies for each outcome, including prophylactic surgery, chemoprevention, or aggressive surveillance as appropriate; testing costs, turnaround time to results, and insurance coverage issues; possible discrimination issues; psychological, cultural, communication, or ethical issues (coercion); and the responsibility of communicating genetic information to at-risk family members and healthcare providers.
- Offer multiple opportunities to ask questions for clarification.

**Implications for Nurses**

For those developing or expanding a cancer genetics program, consider all of the activities that will occur, including direct clinical time with patients and families as well as previsit activities, risk calculation, clinical trials enrollment, correspondence, teaching, and administrative duties. This study provides some insight for those developing such a program.

The practice of clinical cancer genetics can be time consuming and labor intensive as the current article suggests, and this limits the number of patients and families that can be seen during a typical clinic week. Average actual direct clinical time for an initial visit is 84 minutes, with an average of 74 minutes for a follow-up visit. In the HCP, patients are scheduled every 90 minutes, which means seeing more than five patients in an average day is unrealistic. During the study, the APN had an average of 13 visits per week of direct patient contact, for an average of 23.9 hours per week. In this study, 41% of the time was spent in direct communication with patients, either face-to-face in the clinical setting or by phone. A recent workflow study of genetic counselors and medical geneticists reported that 38% of time was spent in direct patient contact and the rest of the time was spent in nonreimbursable activities that were necessary to provide appropriate genetic care (McPherson et al., 2008).

All of the other activities combined took an average of 28.5 hours per week. Explanations as to why genetics practice is different than other subspecialties include that the focus is on a family usually involving multiple individuals, a record review for the patient and extended family, a review of unusual syndromes, identification of trials, and education for the referring provider who will implement the recommendations for care. Strengths of the study include the prospective design and the detail regarding the activities. Weaknesses include a relatively short time period studied (three months) and the limitation of a single institution with a single APN. In addition, the activities were not witnessed by an outside observer, the study did not capture the time the business manager provided, and the APN might have forgotten to document an activity. Future studies should include larger and more diverse representation of providers, and programs might identify areas within categories where time could be saved, efficiency enhanced, or activities delegated.

**Conclusions**

The activities involved in the initial and follow-up counseling sessions provided to patients and families, as well as other communication with patients and referring providers, are extensive and labor intensive. For those practices that choose to bill for...
counseling services, it may be difficult to achieve adequate financial reimbursement from insurance, particularly for the activities that do not directly involve patient counseling but are time consuming, nonreimbursable, and yet critical to the success of such programs. If an institution chooses not to bill for such services, consideration must be given as to how such services will be provided. Writing grants for salary support to make counseling accessible is feasible, as is obtaining additional funds to assist the uninsured with the costs of testing, but time must be allocated to identify such funding, write the grants, and comply with all requirements for such funding. Consideration of the time and professional effort involved in these activities should be considered when implementing a cancer genetics program.

The author gratefully acknowledges the St. Louis affiliate of Susan G. Komen for the Cure, St. Louis Men's Group Against Cancer, Circle of Hope, St. Louis Blues 14 Fund, and the private donors who have provided generous continued salary support and funds for genetic testing for those who cannot afford it to the Hereditary Cancer Program at Saint Louis University, thus assuring comprehensive cancer genetics care for anyone in the region.

References


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