J Genet Counsel (2015) 24:433–437
DOI 10.1007/s10897-014-9799-z

PROFESSIONAL ISSUES

Genetic Counselors and Health Literacy: The Role of Genetic Counselors in Developing a Web-Based Resource About the Affordable Care Act

Sylvia Mann · Pauline Mui · Jennifer Boomsma · Lianne Hasegawa

Received: 13 February 2014 / Accepted: 19 November 2014 / Published online: 16 December 2014

Abstract The Western States Genetic Services Collaborative (WSGSC) recognized the need for clear and understandable information about the Affordable Care Act (ACA) for families throughout the life course. The genetic counselors working in the WSGSC developed, tested, and implemented a web resource (http://www.westernstatesgenetics.org/ACA_home.htm) to help families navigate information about the ACA tailored to their life situation. The training and experience of genetic counselors provide the skills needed to translate complicated information, like that of the ACA, into formats that the general public can comprehend. The website went public in October 2013, and it has been positively received. The development of this website is a good case study in how genetic counseling skills can be applied to public health education and improving health literacy.

Keywords Genetic counselor · Health literacy · Affordable care act · Website development · Insurance coverage · Public health genetics

Introduction

Traditionally, most genetic counselors work in clinical settings that focus on prenatal, pediatric, and cancer genetics. However, the core competencies in which genetic counselors are trained can be applied across diverse practice settings and can be readily adapted to different genetic counseling roles (Wicklund and Trepanier 2014). This was first documented in 1985 when then-National Society of Genetic Counselors (NSGC) president Luba Djurjinovic appointed an ad hoc committee to determine how genetic counselors had applied their skills to "less traditional" positions (Heimler 1997). The resulting survey revealed that many genetic counselors successfully re-imagined their roles and were performing a range of duties including education, research, and administration. The increasing number of genetic counselors who have chosen to specialize in areas other than prenatal, pediatric, and cancer highlights how genetic counselors continue to redefine and expand their roles (NSGC PSS 2012).

The field of public health is a popular choice for genetic counselors interested in less traditional positions. The past three NSGC Professional Status Surveys show that approximately 7 % of non-clinical respondents report working in public health. Powell et al. (2010) noted that the Accreditation Council of Genetic Counseling's (ACGC) Core Competencies can be easily linked to the "10 Essential Public Health Services" defined by the Public Health Functions Working Group. This enables genetic counselors to easily transition their skill set and knowledge to public health activities.

In particular, genetic counselors can use their skills to educate the public about health issues and to improve health literacy. The third domain that defines the competencies of genetic counselors, Education, highlights the specific skills used by genetic counselors to communicate complex genetic information in an understandable manner (ACGC 2013). As such, public health genetic counselors have the potential to significantly impact the health literacy of the communities in which they serve.

Health Literacy and the Affordable Care Act

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, communicate, and understand basic health information and services needed to make

---

S. Mann (✉) · P. Mui · J. Boomsma · L. Hasegawa
Genomics Section, Hawaii Department of Health, 741 Sunset Avenue, Honolulu, HI 96816, USA
e-mail: sylvia@hawaiigenetics.org

appropriate health decisions" (Institute of Medicine 2004). Health literacy is a significant factor in determining a person's health status. Individuals with low health literacy are less likely to actively participate in health care decision making, and more likely to struggle with health management tasks and navigating the health care system (Martin and Parker 2011). Poor health literacy is a stronger predictor of a person's health than age, income, employment status, education level, and race (Weiss 2007).

Several studies have recently highlighted the importance of health literacy to the success of the Affordable Care Act (ACA) (Weinstein et al. 2013, Martin and Parker 2011). Former Health and Human Services Secretary Kathleen Sebelius has stated, "Health literacy is needed to make health reform a reality" (Boodman 2011). Indeed, the complexity of the ACA and its provisions are well known (Martin and Parker 2011). The dynamic policy environment in which its implementation is occurring makes understanding the ACA more difficult, even for those with high levels of health literacy (Sentell 2012). Many have argued about the importance of health literacy in navigating the insurance exchanges and understanding the benefits of the ACA (Parker 2012, Martin and Parker 2011, Sommers and Mahadevan 2010).

The National Center for Education Statistics estimates that about half (53 %) of currently uninsured adults have poor health literacy skills (2006). The ACA has the potential to extend health insurance to millions of these previously uninsured Americans. However, individuals who could benefit the most from the ACA would likely encounter the greatest difficulties navigating the system to reap those benefits. With our training in education and communication, genetic counselors are able to help translate the complex provisions of the ACA for those most in need of accurate, yet understandable information. A better understanding of ACA provisions would empower those individuals to make informed choices that are best for them and their families.

The Western States Genetic Services Collaborative

The Western States Genetic Services Collaborative (WSGSC) is one of seven Regional Genetics Collaboratives (RCs) funded by the Health Resources and Services Administration (HRSA). The WSGSC includes Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. The goal of the RCs is to use a regional approach to improve access to and provision of genetics and newborn screening services. Since its inception, genetic counselors have played an important role in the WSGSC. Genetic counselors make up the core staff of the WSGSC, including its Project Director.

Recognizing the need for clear information about the ACA, WSGSC genetic counselors developed, tested, and implemented a comprehensive ACA web resource (http://www.westernstatesgenetics.org/ACA_home.htm) within the existing WSGSC website to help educate providers and families about ACA provisions. The development of this website is a good case study in how genetic counseling skills can be applied to public health education and health literacy improvement.

Web Resource Development

The WSGSC ACA web resource was developed in three different stages: 1) Creation of the online content; 2) Evaluation of the draft web resource; and 3) Revision of the web resource based on feedback.

Creation of the Online Content

The format of the WSGSC ACA website was initially inspired by Milton-Bradley's Game of Life^{TM} and HRSA's "Through the Life Course" approach (Fine and Kotelchuck 2010). From the start, it was envisioned that the final web resource would resemble a board game with a circular path containing common life events, such as a pregnancy or losing a job. In the middle of the path would be a town square with buildings including a hospital, a school, and a marketplace. ACA information and resources would then be categorized based on these life events and buildings. By organizing information using ordinary experiences and places, we hoped to make the ACA less abstract and more relatable to everyday life. This is similar to the use of common analogies and examples utilized by genetic counselors in clinical and educational settings.

To create the online content, a review of existing web-based ACA resources was first conducted. The WSGSC's genetic counselors then developed fact sheets specific to each life event and building. Complex concepts had to be explained in an easier to understand manner. For example, for families with health insurance, we used examples of coverage that families may have and whether or not the ACA has any impact on their coverage options. We alsoincluded resources for more specific state information that might also affect them. The readability of the text was evaluated using the Flesch-Kincaid Grade Level. Initially, the fact sheets were written at an 11th grade reading level and were very text-heavy. To improve readability, complex words such as "deductable" and "health insurance mandate" were linked to a pop-up glossary definition which reduced the readability to a 7th grade reading level.

Web Resource Evaluation

Once the web resource was constructed using the draft fact sheets, three 1-hour long focus groups were held to review the site's usability, usefulness, format, and content. Participants included family advocates, genetic counselors, physicians, and staff from state departments of health (Table 1). Consent to participate in the focus groups was implied based on voluntary participation. A genetic counselor trained in focus group facilitation moderated all three groups. A second genetic counselor took notes during the sessions, and the focus group discussions were also digitally recorded.

In the first two focus groups, each participant had a laptop with Internet access. Participants were then asked to: 1) Locate specific types of information (such as a link to the Marketplace for the state of Hawaii) starting from the ACA home page and track the number of clicks used to find this information; 2) Review and comment on the format and graphics of the website; 3) Review and comment on the content of the website; and 4) Comment on the overall usability of the website. In the third focus group with a larger number of participants, we were unable to provide hands-on testing of the website and were limited to projecting the website onto a screen. Participants were asked questions about: 1) format and graphics of the website; and 2) content of the website. Five common suggestions emerged from the three focus groups regardless of hands-on or projected presentation of the website (Table 2). Limitations of this evaluation included participants who may have more experience with health insurance coverage than an average person due to their work with families and children with special health needs.

Web Resource Revision

The web resource was revised using the feedback gained from the focus groups. Initially, the fact sheets were written at an 11th grade reading level and were very text-heavy. Participants pointed out that the content would be difficult for the general public to understand, and would be especially challenging for those with poor health literacy. The WSGSC genetic counselors consequently revised the fact sheets so that information was expressed in different ways, including tables, bullets, and graphics. The content was also rewritten to exclude complex words that were explained in the linked glossary; as a result,the readability was improved to a 7th grade reading level using the Flesch-Kincaid Grade Level..

On the draft website, the town square buildings were named based on their structure. For example, the school building was named "School" and the hospital building was named "Hospital." ACA information related to the purpose of the structures was then linked to the building, for example, the "School" building was linked to the ACA glossary and other resources, and the "Hospital" was linked to information about Accountable Care Organizations. Focus group participants found this to be confusing and suggested that the building titles be changed to simply reflect their content.

Two separate SurveyMonkey surveys were added to the ACA website. The first allows website users to provide additional suggestions for improving the site. The second collects personal stories from users about their experiences with the ACA. It is hoped that responses can be used to better understand and address the needs of individuals with or at risk for genetic conditions that should be covered by the ACA. We do not specify the types of stories users submit, and the survey consists of an open text box and three general demographic questions. There is an option at the end of the survey for individuals to voluntarily provide their names and contact information if they would like to participate in future activities, such as speaking to legislators about the ACA's impact.

Finally, given the significant role social media plays in communicating and sharing information, we added the ability to quickly share the site via Facebook.

Making the Web Resource Public

Once all revisions were made and the web resource was finalized, it was made public on October 24, 2013. The final ACA website contains 12 life event boxes and seven town square buildings (Table 3).

Between October 25, 2013 and January 31, 2014, the website had 534 unique visitors. In the first month, several organizations

Table 1 Number and characteristics of focus group participants

	Number of participants	Type of participant
Focus Group #1	8	Hawaii Department of Health Maternal Child Health Branch Staff including Title V staff
Focus Group #2	8	Hawaii Department of Health Children with Special Health Needs Branch Staff including Title V staff
Focus Group #3	16	Family advocates, genetic counselors, physicians, and state health department staff attending the WSGSC annual in-person meeting

Enacted in 1935 as a part of the Social Security Act, the Federal Title V Maternal and Child Health Program has provided a foundation for ensuring the health of the Nation's mothers, women, children and youth, including children and youth with special health care needs, and their families. The funding was converted to a Block Grant in 1981. States receive annual funding from the Block Grant to carry out the goals of Title V.

Table 2 Common suggestions from the focus group

Suggestions
1. Simplify the fact sheet content.
2. Simplify the town square building titles.
3. Add an online survey for additional suggestions.
4. Add a way for families to share their stories about the ACA.
5. Add ways to share the site via social media.

helped to publicize the web resource, including the Genetic Alliance and the Association of Public Health Laboratories. Visits to the website peaked in November 2013, and decreased during the months of December 2013 and January 2014. Two families have shared their ACA experiences via the ACA web resource, and five users have completed a feedback survey. All of the comments received to date have been positive. We will continue to expand the visibility of the website resource by working with the other Regional Genetics Collaboratives, the National Coordinating Center for the Regional Genetics Collaboratives, the Genetic Alliance, and state Title V programs.

Discussion

Genetic Counselors as Health Educators

Genetic counselors are trained to take complex information and translate and present it so a lay person can understand it. This skill translates well from the clinical genetic counseling setting to developing educational resources in broader settings such as public health.

The ACA is an incredibly complex piece of legislation, with its implementation occurring in an ever-changing landscape of rules and regulations. As such, it is difficult for most people to understand the many details of the ACA, and this is made even harder for those with poor health literacy. The development of the WSGSC's ACA web resource by its genetic counselors is a good example of the application of their training and skills, and supports the ability to translate a genetic counselor's skill set to broader settings such as public health.

Challenges

Creating an ACA website containing information and resources appropriate for the general public, including those with poor health literacy, has been challenging. According to experts, patient educational materials should be written at no higher than a 6th grade reading level (Institute for Healthcare Advancement 2014). Using skills gained from genetic counseling training programs and clinical experience, the WSGSC's genetic counselors were able to write the content of the ACA website so that it reads at a 7th grade reading level on the Flesch-Kincaid Grade Level. Although this is still higher than the recommended 6th grade reading level, it was difficult to reduce the readability lower than this because of necessary words such as "health insurance mandate," "pre-existing condition,"

Table 3 ACA Website life event or building description

Life Event or Building Title	Description of Information
General ACA Info	General information about the ACA
You already have health insurance	Information on grandfathered health plans and the ACA
You move to a new state	State-specific information on the ACA
You are a young adult	How the ACA affects people under 26 years of age
You work for a large business	The ACA and large employers (more than 50 employees)
You do not have insurance	How the ACA affects people without insurance
You start a small business	How the ACA affects small businesses
You are pregnant	The ACA and pregnant women and mothers
Your baby and newborn screening	How the ACA affects newborn screening
You have a child with special needs	How the ACA affects children and youth with special health care needs
You have a chronic condition	How the ACA affects those with chronic conditions
You turn 65 years old	The ACA and Medicare
Health Insurance Marketplace/Exchange building	The health insurance exchange
Medicaid building	The ACA and Medicaid expansion
Accountable Care Organization building	The ACA and accountable care organizations
Essential Health Benefits building	The ACA and essential health benefits
ACA Glossary and Resources building	The ACA glossary and other web resources
ACA Legal Documents building	Legal documents associated with the ACA
How to Report Problems building	Information on how to report problems with insurance carriers

and “tax filing threshold.” To mitigate this, we linked complex words and phrases to a pop-up glossary definition.

As shown by the website statistics, interest in the ACA website was initially high likely due to the publicity provided by larger genetics and public health organizations and to the hype surrounding the opening of the Health Insurance Marketplaces. However, traffic to the website fell sharply during the months of December 2013 and January 2014 despite positive comments received on the website’s feedback survey and positive comments given directly to project staff. This highlights another challenge to the success of the website: How do we ensure that we reach families and providers who can benefit from this web resource? To address this, we will expand efforts to partner with the other Regional Genetics Collaboratives, family advocacy programs such as Family to Family Health Information Centers, Title V agencies, and others to publicize this website through listservs, newsletters, social media, and word-of-mouth. We are also working to increase the relevance of the website on search engines by having more presence on other websites. We will continue to add content to the website so that it remains relevant and current.

However, keeping the ACA web resource up-to-date is another challenge. New interpretations, rulings, and regulations regarding the ACA and its provisions seem to be announced almost weekly. Having personnel track these changes and then reflect them on the website requires both time and money. Using a team approach, in which all WSGSC staff share the task of identifying new and important information, has helped to reduce this burden.

Summary

The WSGSC’s ACA web resource is a successful example of applying the skill set of genetic counselors to translate complex information into a concise and useable source of information for the general public. The ACA has the potential to positively affect millions of Americans, including families with or at risk for genetic disorders. However, these individuals need clear information to help them understand how to best take advantage of these benefits. Genetic counselors can communicate information about the complicated ACA provisions to the general public and especially to those with poor health literacy. Although challenges remain in maintaining the website, it has been shown to be a helpful tool in educating the public about the ACA. The WSGSC genetic counselors will continue to support this web resource long term as legislation and policies change and evolve.

Acknowledgments This work was funded by the Health Resources and Services Administration, Maternal and Child Health Branch, Award Number: U22 MCH03961

Conflict of Interest Statement Sylvia Mann, Pauline Mui, Jennifer Boomsma, and Lianne Hasegawa declare that they have no conflict of interest.

Human Studies and Informed Consent Consent to participate in the focus groups was implied based on voluntary participation.

References

Accreditation Council of Genetic Counseling.(2013). Practiced-based compentancies for genetic counselors. Retrieved February 3, 2014 from: http://gceducation.org/Documents/ACGC%20Core%20Competencies%20Brochure_13-Web-Revised-FINAL.pdf

Boodman, SG. (2011). Helping patients understand their medical treatment. Kaiser Health News. Retrieved on February 5, 2014 from: http://www.kaiserhealthnews.org/stories/2011/march/01/health-literacy-understanding-medical-treatment.aspx.

Fine, A., Kotelchuck, M. (2010). Rethinking MCH: The life course model as an organizing framework. U.S. Department of Health and Human Services Health Resources and Services Administration Maternal andChild Health Bureau. [Internet]. Available from: http://www.hrsa.gov/ourstories/mchb75th/images/rethinkingmch.pdf.

Heimler, A. (1997). An oral history of the National Society of Genetic Counselors. *Journal of Genetic Counseling, 6*(3), 315–336.

Institute for Healthcare Advancement. (2014). What is health literacy? Retrieved on February 6, 2014 from: http://www.iha4health.org/default.aspx/MenuItemID/184/MenuGroup/_Home.htm.

Institute of Medicine. (2004). *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academies Press.

Martin, L. T., Parker, R. M. (2011). Insurance expansion and health literacy. *JAMA, 306*(8), 874–875.

National Center for Education Statistics. (2006). *The health literacy of America’s adults: results from the 2003 National assessment of adult literacy*. Washington, DC: US Department of Education.

National Society of Genetic Counselors.(2012). 2012 Professional status survey complete work environment report. Retrieved February 3, 2014 from: http://nsgc.org/p/cm/ld/fid=68.

Parker, R. M. (2012). Health literate practices can facilitate state health insurance exchange communication. *Journal of Health Communication, 17*, 372–375.

Powell, K. P., Hasegawa, L., & McWalter, K. (2010). Expanding roles: a survey of public health genetic counselors. *Journal of Genetic Counseling, 19*(6), 593–605.

Sentell, T. (2012). Implications for reform: survey of California adults suggests low health literacy predicts likelihood of being uninsured. *Health Affairs, 31*(5), 1039–1048.

Sommers, S.A., Mahadevan, R. (2010). Health Literacy Implications of the Affordable Care Act. Hamilton, NJ: Center for Health Care Strategies. Retrieved on February 4, 2014 from:http://www.iom.edu/~/media/Files/Activity%20Files/PublicHealth/HealthLiteracy/Commissioned-Papers/Health%20Literacy%20Implications%20of%20Health%20Care%20 Reform.pdf.

Weinstein, R. S., Graham, A. R., Erps, K. A., & Lopez, A. M. (2013). Health literacy: the affordable care act ups the ante. *The American Journal of Medicine, 126*(12), 1029–1030.

Weiss, B.D. (2007). Health Literacy and Patient Safety: Health Patients Understand. Retrieved February 4, 2014 from: http://www.amaassn.org/ama1/pub/upload/mm/367/healthlitclinicians.pdf.

Wicklund, C., Trepanier, A. (2014). Adapting genetic counseling training to the genomic era: more an evolution than a revolution. Journal of Genetic Counseling, (2014) Jan 28