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Delivery of Internet-based cancer genetic counselling services to patients' homes: a feasibility study

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Summary

We examined the feasibility of home videoconferencing for providing cancer genetic education and risk information to people at-risk. Adults with possible hereditary colon or breast-ovarian cancer syndromes were offered Internet-based counselling. Participants were sent webcams and software to install on their home PCs. They watched a pre-recorded educational video and then took part in a live counselling session with a genetic counsellor. 31 participants took part in Internet counselling sessions. Satisfaction with counselling was high in all domains studied, including technical (mean 4.3 on scale from 1–5), education (mean 4.7), communication (mean 4.8), psychosocial (mean 4.1), and overall (mean 4.2). Qualitative data identified technical aspects that could be improved. All participants reported that they would recommend Internet-based counselling to others. Internet-based genetic counselling is feasible and associated with a high level of satisfaction among participants.

Introduction

Cancer risk assessment and genetic counselling is a standard part of the evaluation of people suspected of having inherited cancer susceptibility syndromes, such as Lynch syndrome and hereditary breast and ovarian cancer syndromes. A formal counselling process is commonly recommended because of the ethical, legal and social implications associated with genetic testing.[1]

The demand for genetic counselling services is increasing as genetic information becomes integrated into oncology and mainstream medical practice.[2,3] Furthermore, direct-to-consumer marketing of genetic tests [4] and increased access to information has raised awareness, interest and demand for genetic testing by the public. As a result, the number of genetic tests ordered is rising.[5] Unfortunately, clinical genetics expertise is not widely available, particularly in rural areas.[6–7]

Genetic counselling via telemedicine, also known as telegenetics, is a way of providing genetic services to those who do not have access to a genetic health care professional.[8,9] Several pilot studies have been reported in which genetic information was relayed from specialists at large regional hospitals to smaller, remote healthcare facilities.[10,11] In general, these studies reported high levels of patient satisfaction related to convenience and comfort with the sessions. The telemedicine interventions were viewed as a successful

alternative to usual genetics care. However, they were not conducted in the participant's own home and required travel to a location equipped for videoconferencing. Furthermore, they did not involve more than a single remote site per consultation, and thus did not permit participation of multiple family members simultaneously. Group counselling sessions may help overcome the constraints of conventional one to one genetic counselling.[12]

We have developed a counselling system using Internet-based videoconferencing. This permits multiple family members to participate in a group counselling session from convenient locations such as their homes. The purpose of the present study was to test the feasibility of this approach for providing cancer genetic education and risk information to people at-risk.

Methods

Participants were at least 18 years old, and were appropriate for evaluation for hereditary colorectal or breast and ovarian cancer syndromes. Participants were those at increased risk due to a personal or family history of cancer, including people affected and unaffected by cancer. Participants were offered an individual counselling session and the inclusion of family members was at the discretion of the proband. Eligibility criteria included access to a suitable PC and a broadband Internet connection. Participants were also required to have an email address and to be able to load software and connect hardware to their computer. If a participant wished to take part in a family session but did not meet the technology requirements, he or she was allowed to come to the Fox Chase Cancer Center (FCCC) to participate in the session as long as at least one member of the family participated remotely. A maximum of four remote sites per session was permitted to maintain video quality.

Participants were recruited between August 2005 and December 2007 through referrals from genetic counsellors and as part of the intake process for the Gastrointestinal Tumor Risk Assessment Program and the Family Risk Assessment Program at the FCCC. Potential participants were sent an information letter and were contacted by the study coordinator one week later. The study was approved by the appropriate ethics committee.

Procedures

After receipt of written consent, participants were mailed video equipment, which included a USB-based web camera and the videoconferencing software (Polycom ViaVideo II). The unit used during the session at the FCCC was capable of supporting up to four simultaneous connections (Polycom ViewStation VSX server). The software originally sent to participants was upgraded to Polycom PVX 6.02 in January 2008 in response to changes in the Fox Chase network infrastructure as well as difficulties in the original software's ability to function with Windows XP and Vista operating systems.

Participants were provided with written instructions for installation of the web camera and software. Instructions were written at an 8th-grade reading level and were accompanied by computer screenshots. All study participants were given installation and dialling instructions. A connectivity test was initially undertaken by each participant by dialling into a predefined meeting room on the bridge with auto-answer to ensure proper installation of the software. Then, at the time of the meeting, the participant dialled into the videoconference unit used for the sessions. Technical support was provided by telephone as required.

Counselling session

During the online counselling session, participants were shown a 20-min pre-recorded educational video. The educational presentation reviewed basic information about colorectal

or breast/ovarian cancer, including risk factors, genetic aetiology of respective hereditary cancer syndromes, and screening/prevention measures. Immediately after the educational presentation, participants were connected to the genetic counsellor. During the counselling session, each person was able to see and hear all the other participants, including the genetic counsellor. The counselling session included a review of the family history and a risk assessment based on the family history of cancers. A pedigree (genealogy) was shown to participants as part of the cancer risk counselling session. Genetic testing was offered if indicated based on the risk assessment. The sessions lasted for approximately one hour. The videoconferencing traffic was encrypted to the AES (Advanced Encryption Standard).

Outcome measures

Participants were asked to complete a post-session survey (on paper or by telephone), within 72 hours of completion of the live counselling session. The five survey domains were: technical feasibility, education and information, communication, psychosocial and summary. Items were scored using a 5-point Likert scale (1=strongly disagree to 5=strongly agree). Participants who were present at the FCCC for the online session were not asked to complete the questions on technical feasibility that were relevant to remote participation.

Technical feasibility—Eight items assessed the technical aspects of the study such as ease of installation of camera and software, audio and visual clarity, and staff support from the FCCC (Cronbach's $\alpha=0.67$).

Education and information—Six items assessed perceived understanding of the information in the educational video and benefits received from the genetic counselling session. Participants were asked if the session was helpful, interesting and informative (Cronbach's $\alpha=0.76$).

Communication—Five items assessed the perceived communication and relationship between the participant, genetic counsellor and/or family members (if present) (Cronbach's $\alpha=0.89$).

Psychosocial—Three items assessed the comfort of the proband during the counselling session (Cronbach's $\alpha=0.49$).

Summary—Eight items assessed participants' overall satisfaction with the genetic counselling session and their preference for having the session in person or via the Internet.

In addition to the above, three open-ended questions were asked: "What would have made the session better for you?"; "What was the best aspect of this counselling session for you?"; "What was the worst aspect of this counselling session for you?" The responses were categorized and tabulated.

Statistics

Descriptive statistics and Cronbach's alpha were calculated using a standard package (SPSS 12.0). Means were computed for each survey item. Reverse scoring was applied where appropriate in summary scores.

Results

A total of 31 subjects completed the study including 18 probands and 13 family members (see Table 1). There were 19 sessions altogether: eight family sessions (proband and at least one family member) and 11 individual (proband only) sessions. Twenty-six participants

(84%) were counselled from a remote location while five participants were counselled at the FCCC (16%).

Technical evaluation

In general, participants were satisfied with the technical aspects of the study (mean summary score 4.3, SD=0.6). They felt that the instructions for installing the software and the web camera were easy to understand (mean score 4.5, SD=0.6) and the computer software and camera were easy to install (mean score 4.4, SD=1.0). The participants also felt that they had enough knowledge of computers to complete the tasks required (mean score 4.2, SD=1.3). Participants were generally satisfied with the quality of the sound (mean score 4.2, SD=1.4), video (mean score 4.1, SD=1.3) and projected documents (mean score 3.8, SD=1.3).

Although participants rated the technical aspects of the study as adequate, analysis of the qualitative data and technical notes taken during each session indicated that most participants experienced some technical problems either before or during the session (Table 2). Firewall difficulties, Network Address Translation (NAT) problems, anti-virus and anti-spyware problems, video problems and intermittent loss of connectivity with a wireless connection were technical problems that arose during the study.

Counselling session evaluation

Regarding the education and information aspect of the study, participants were highly satisfied (mean summary score 4.7, SD=0.4). Participants felt that the live counselling session was informative (mean score 4.8, SD=0.4) and the information was presented at a level that was understandable to everyone involved (mean score 4.7, SD =0.6). During the session, participants learned about their risk for cancer (mean score 4.7, SD=0.5) and felt that they received sufficient information about genetic testing (mean score 4.7, SD=0.5).

Participants also commented on the high quality of communication during the session and were satisfied with the overall communication aspects of the study (mean summary score 4.8, SD=0.4). Participants felt that the counsellor was able to communicate with them (mean score 4.9, SD=0.4), build an adequate relationship with them (mean score 4.8, SD=0.4) and helped them feel at ease during the session (mean score 4.8, SD=0.6). In addition, participants felt that the genetic counsellor gave them sufficient time during the session to absorb the information being presented (mean score 4.8, SD=0.4), and understood the participants' concerns (mean score 4.8, SD=0.4). Overall, participants were satisfied with the psychosocial aspects of the counselling sessions (mean summary score 4.1, SD=0.8). Most participants (87%) agreed with the statement, "I felt relaxed and at ease talking through the computer screen" (mean score 4.3, SD=0.9). However, 22% of the participants either somewhat or strongly agreed that they felt uncomfortable knowing that everybody could see them on the computer screen (mean score 2.2, SD=1.3) and almost 10% agreed that "the session felt impersonal to me" (mean score 1.7, SD=1.1).

Responses to the summary items indicated that participants were highly satisfied with the session (mean summary score 4.2, SD=0.4) (Table 3). All participants agreed with the statement, "I would recommend this type of session to others," (mean score 4.7, SD=0.5). However, 29% also agreed that they would have "preferred to have this session in-person" (mean score 2.8, SD=1.4). When asked to identify the best aspect of the session, 12 participants identified education, while 10 participants cited risk assessment and screening recommendations (Table 2).

Discussion

The present study demonstrates that Internet-based counselling is feasible and there is a high level of participant satisfaction. Overall, participants reported that the technical aspects (video, sound, graphics) were satisfactory, although most participants experienced one or more technical problems. Nonetheless, the participants generally expressed a high level of satisfaction with communication over the Internet. Thus, in-person cancer genetic counselling may not be the only method of establishing successful rapport with patients. Previous telegenetic studies involving cancer genetics have taken place in the UK and patients travelled to remote sites for teleconferencing,[8,13,14] rather than communicating with the provider from their own home. These studies also reported a high level of satisfaction with the telegenetic service. Other telegenetic studies have been performed with similar levels of overall satisfaction but did not specifically address cancer genetics [10,15] or did not use detailed measures to assess the counselling process. Another study, based in Australia, used remote hospitals as opposed to the patient's home for Internet connection to genetic providers. The outcome measures used in the present study were primarily centred on general satisfaction and technical ease, but did not assess the counselling process itself. [11] Previous work has found, as we did, that Internet cancer risk education and counselling is well received by participants who are at high-risk of developing colorectal or breast and ovarian cancers.[8,13]

The present study was limited by its small sample size and the findings may not be generalizable to the general population. As in other studies of genetic counselling, minority populations were under-represented in our sample.[16] In addition, use of the technique requires a high-speed Internet connection, which may limit potential dissemination. Although Internet access has previously been a barrier to this type of service, recent reports show that the overall penetration of the Internet is increasing. For example, in 2008, 55% of Americans had a broadband connection at home, in comparison with 47% in 2007.[17,18] The study identified certain technical matters that need to be improved in future studies. In addition, it highlighted the need for technical support that can be accessed from the patient's home.

Although participants generally felt relaxed and at ease when talking through the computer screen during the session, some expressed discomfort about knowing that everybody could see them on the computer screen. In addition, many participants (29%) reported that they would have preferred to have counselling in-person. Future research is needed to identify methods to improve the technical aspects of Internet-based communication, and also to identify the personal characteristics that are associated with a preference for in-person vs. Internet-based genetic counselling. Additional research is also needed to determine which components of the genetic counselling encounter are most critical. For example, what is the additional value of video over audio counselling alone (i.e. by telephone).

We suspect that some of the technical problems encountered in the present study were the result of bandwidth limitations enforced by Internet service providers, although we could not verify this. The effect on telehealth applications of bandwidth limitation practices by Internet service providers may be an area that warrants further study.

The present results support further exploration of Internet-based alternatives to in-person counselling, as a method of overcoming access barriers. In addition, these data suggest that patients may not need to leave their own homes to receive specialized information from a qualified professional. Unlike physician visits, which necessitate physical examination, cancer genetic counselling sessions involve only the flow of information, which makes home-based Internet counselling well suited for genetics. Overall, the participants were

satisfied with the genetic counselling session, learned about their cancer risk and how to reduce it by screening and prevention strategies. Although troubleshooting of technical problems was required, it is likely that continued advances in low cost consumer Internet audio and video technology, along with a variety of new web-based services will occur. Many professional organizations including the American College of Medical Genetics and the National Society of Genetic counsellors recommend that genetic professionals be involved in the interpretation of the results of genetic testing. Home videoconferencing may help to bridge the gap between the increasing demand for counselling services and the limited genetic counsellor workforce.

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References

1. Eng C, Hampel H, de la Chapelle A. Genetic testing for cancer predisposition. *Annu Rev Med.* 2001; 52:371–400. [PubMed: 11160785]
2. Collins FS. Shattuck lecture--medical and societal consequences of the Human Genome Project. *N Engl J Med.* 1999; 341:28–37. [PubMed: 10387940]
3. Myers MF, Chang MH, Jorgensen C, Whitworth W, Kassim S, Litch JA, et al. Genetic testing for susceptibility to breast and ovarian cancer: evaluating the impact of a direct-to-consumer marketing campaign on physicians' knowledge and practices. *Genet Med.* 2006; 8:361–370. [PubMed: 16778598]
4. Lowery JT, Byers T, Axell L, Ku L, Jacobellis J. The impact of direct-to-consumer marketing of cancer genetic testing on women according to their genetic risk. *Genet Med.* 2008; 10:888–894. [PubMed: 19092441]
5. Wideroff L, Vadaparampil ST, Greene MH, Taplin S, Olson L, Freedman AN. Hereditary breast/ovarian and colorectal cancer genetics knowledge in a national sample of US physicians. *J Med Genet.* 2005; 42:749–755. [PubMed: 15784723]
6. Smith, M.; Freigoval, M.; Parrot, S. National Society of Genetic Counselors, Inc. Professional Status Survey 2008. [Internet]. Available from: www.nsgc.org.
7. Gray RE, James P, Manthorne BA, Gould J, Fitch MI. A consultation with Canadian rural women with breast cancer. *Health Exp.* 2004; 7:40–50.
8. Coelho JJ, Arnold A, Nayler J, Tischkowitz M, MacKay J. An assessment of efficacy of cancer genetic counseling using real-time videoconferencing technology (telemedicine) compared to face-to-face consultations. *European Journal of Cancer.* 2005; 41:2257–2261. [PubMed: 16176873]
9. Mitchell JA, Demiris G. Telegenetics: the next phase in the provision of genetics services? *Genet Med.* 2005; 7:1–2. [PubMed: 15654221]
10. Lea DH, Johnson JL, Ellingwood S, Allan W, Patel A, Smith R. Telegenetics in Maine: Successful clinical and educational service delivery model developed from a 3-year pilot project. *Genet Med.* 2005; 7:21–27. [PubMed: 15654224]
11. Gattas MR, MacMillan JC, Meinecke I, Loane M, Wootton R. Telemedicine and clinical genetics: establishing a successful service. *J Telemed Telecare.* 2001; 7 Suppl 2:68–70. [PubMed: 11747665]
12. Calzone KA, Prindiville SA, Jourkiv O, Jenkins J, DeCarvalho M, Wallerstedt DB, et al. Randomized comparison of group versus individual genetic education and counseling for familial breast and/or ovarian cancer. *J Clin Oncol.* 2005; 23:3455–3464. [PubMed: 15908654]
13. Gray J, Brain K, Iredale R, Alderman J, France E, Hughes H. A pilot study of telegenetics. *J Telemed Telecare.* 2000; 6:245–247. [PubMed: 11027129]
14. Mackay J, Taylor A. Moving genetics into clinical cancer care: examples from BRCA gene testing and telemedicine. *Breast.* 2006; 15 Suppl 2:S65–S70. [PubMed: 17382866]

15. Abrams DJ, Geier MR. A comparison of patient satisfaction with telehealth and onsite consultations: a pilot study for prenatal genetic counseling. *J Genet Couns*. 2006; 15:199–205. [PubMed: 16779676]
16. Hall MJ, Olopade OI. Disparities in genetic testing: thinking outside the box. *J Clin Oncol*. 2006; 24(14):2197–2203. [PubMed: 16682739]
17. Horrigan, JB. Home broadband adoption 2008. [Internet]. 2008. [updated 2008; cited 2008 May]; Available from: www.pewinternet.org.
18. Horrigan, J.; Murray, K. Home broadband adoption in rural america. [Internet]. 2006. [updated 2006; cited 2006 April 20]; Available from: www.pewinternet.org.

Table 1Participant demographics ($n=31$). The median age was 47 years (range 21–71)

	n	%
Sex		
Male	11	36
Female	20	65
Race		
White	31	100
Cancer risk		
Colon	16	52
Breast/Ovarian	15	48
Participants		
Probands	18	58
Family members	13	42

Table 2

Qualitative data

What would have made this session better for you?	Number of instances	Number of people
Nothing		11
Did not answer		7
Technical problems		14
a. Audio	3	
b. Internet connectivity	1	
c. Web-camera quality and installation	5	
d. Readability of documents on the screen	5	
e. Other computer problems	4	
Educational video content		2
Environment (extraneous household distractions)		1
Additional participants (my doctor, other family members)		3
What was the best aspect of this counseling session for you?		
Did not answer		3
Ability to have session at home		4
Ability to have family members present		6
The education, risk assessment, and screening recommendations		22
Live audio and video		7
Pedigree document projection		1
Educational video		1
Relieved worries		3
What was the worst aspect of this counseling experience for you?		
Nothing		10
Did not answer		6
Technical Problems		15
a. Audio	5	
b. Web-cameras	5	
c. Readability of documents on screen	1	
d. Computer requirements	2	
e. Hardware installation	3	
Length of educational video		1
Learning about my increased cancer risk		6

Table 3

Evaluation of Internet risk assessment summary data

Question	Strongly Agree No (%)	Some what Agree No (%)	Neither Agree nor Disagree No (%)	Somewhat Disagree No (%)	Strongly Disagree No (%)	Missing	Mean (SD)
1. "I did not feel my privacy was invaded"	25 (81)	5 (16)	1 (3)				4.77 (1)
2. "My perception of cancer risk was changed due to this session"	9 (29)	8 (26)	9 (29)	2 (7)	1 (3)	2 (7)	3.76 (1)
3. "This session helped me to understand how to reduce my cancer risk by screening and prevention strategies"	16 (52)	13 (42)	1 (3)			1 (3)	4.50 (1)
4. "If other sessions were needed I would participate through the computer"	25 (81)	5 (16)	1 (3)				4.77 (1)
5. "I would recommend this type of session to others"	22 (71)	9 (29)					4.71 (1)
6. "I would have preferred to have this session in person" (Reverse score)	4 (13)	5 (16)	10 (32)	3 (10)	8 (26)	1 (3)	2.80 (1)
7. "After the session I knew what steps to take in the future to lower my risk of cancer"	17 (55)	11 (36)	2 (7)			1 (3)	4.50 (1)
8. "The computer session made me less anxious about my cancer risk"	4 (13)	12 (39)	10 (32)	1 (3)	2 (7)	2 (7)	3.52 (1)
						<i>Grand mean</i>	<i>4.2</i>