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An assessment of the efficacy of cancer genetic counselling using real-time videoconferencing technology (telemedicine) compared to face-to-face consultations

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Abstract

There are few published studies regarding the use of telemedicine in counselling families with a history of cancer. In this study, cancer genetic counselling was evaluated when conducted via telemedicine and compared to face-to-face consultations. Participants were placed into a telemedicine group or a face-to-face group depending on their geographical location. Telemedicine consultations took place using real-time videoconferencing technology ISDN6 digital telephone lines. Sixteen participants were evaluated in the telemedicine compared to 21 in the face-to-face group and all participants were asked to complete both a precounselling and post-counselling questionnaire, which assessed their understanding of cancer genetics, anxiety levels, satisfaction levels, and allowed for personal comments. In both the telemedicine and face-to-face groups, a significant reduction in cancer related anxiety levels and high satisfaction levels were reported. There was a trend towards increased cancer genetic knowledge post genetic counselling in both groups. The results show that telemedicine is a useful alternative by which to provide cancer genetic services when geographical distance is an issue.

Keywords: Telemedicine; Cancer genetic counselling; Satisfaction; Cancer related anxiety

1. Introduction

Due to increased public awareness and technological advances in cancer treatments and genetics, the demand for cancer genetic services is rapidly increasing. Telemedicine provides important access to a valuable service that informs, educates, and listens to patients so that they may make informed decisions regarding their cancer risks, possible treatments, or preventative measures. Telemedicine also promotes continuity of care without the cost and inconveniences of travel. It is commonly thought that there are inequalities in patient care, as specialists are usually located only in urban settings [1]. Therefore, telemedicine can be employed to reduce these possible discrepancies in care.

However, limited information is available regarding the use of telemedicine in cancer genetic services. A pilot study by Gray and colleagues [2] describes a group of eight patients, in which a high level of satisfaction with

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telemedicine genetic services was reported. The general trend demonstrated reduced anxiety and worry, along with increased knowledge of cancer genetics. An additional study by Gattas [3], also reported favourable preliminary results by doctors, genetic counsellors, and patients in relation to the use of telemedicine in clinical genetics.

The regional North East (NE) Thames Cancer Genetics Service, serves a population of 4.5 million individuals, with four cancer networks, and includes many hospitals. Within the population served, it is estimated that 20,000 women are at moderate risk, and another 450 at high risk of developing a hereditary breast cancer. This estimate does not include individuals at risk of developing a hereditary colon cancer, or other familial cancers. Travel is a major limiting factor in the delivery of cancer genetic services, as 2–3 h are needed to travel from London to remote sites. Travel, monetary expense, and time off from work or other activities are also major obstacles to patient participation in cancer genetic services.

Therefore, a telemedicine service was developed to provide cancer genetic services to patients in Southend-on-Sea (Southend), Essex, United Kingdom (UK). Using videoconferencing technology, patients at Southend were connected to a genetic consultant at the Institute of Child Health, London, UK located 100 km away. Since the establishment of the initial program, the network has launched three other remote sites, and patients from all four sites were included in the study.

2. Patients and methods

Individuals who had been referred to the clinical genetics service because of a familial history of breast/ovarian or colon cancer were included in the study. Individuals were excluded if they had previously participated in genetic counselling. The study had full ethical approval.

The real time videoconferencing facilities used a Tandberg 6000 system with 384 kbit/s ISDN transmission to ensure quality of service, bandwidth and security. Pressure zone microphones were used for high quality sound pick-up. The patient-end camera was positioned close to the monitor to assist eye contact and body gestures. There was a facility to simultaneously project PowerPoint slides to graphically illustrate points during the consultation.

The written questionnaires were developed by adapting questions used in other studies [4,5] as well as from the experience and expertise of the genetic health professionals involved in this study. These questions were modified and combined to accommodate the purposes and goals of this study. All participating cancer genetic consultants (2), genetic nurses (3), and genetic counsellors (1) reviewed the final versions of the questionnaire for content and comprehensiveness. Statistical analysis was performed using SPSS (Statistical Package for the Social Services) computer software.

3. Results

Twenty-one patients were eligible to participate in the telemedicine group and 29 patients were eligible to participate in the face-to-face group. Of those, 18 agreed to participate in the telemedicine group, and 21 agreed to participate in the face-to-face group. Out of the 18 telemedicine-patients that agreed to participate, two questionnaires could not be analysed as they were incomplete, leaving 16 participants. The two groups were similar in terms of age, with a median age of 43 in the telemedicine group and a median age of 40 in the face-to-face group. However, the patient population was not similar in terms of education level. While 6.7% of the telemedicine group obtained at least one graduate degree, 38.1% of the face-to-face group obtained at least one graduate degree.

3.1. Knowledge of cancer genetics

The correct answers were either "true" or "false," with each correct answer given 1 point (total of 6 points). Fig. 1 demonstrates a general trend towards learning in the telemedicine group, face-to-face group, and as a combined (telemedicine and face-to-face) group. There were smaller increases in knowledge in the individual groups, while for the combined (telemedicine and face-to-face) group, the cancer genetic knowledge gain was statistically significant ($P = 0.02$).

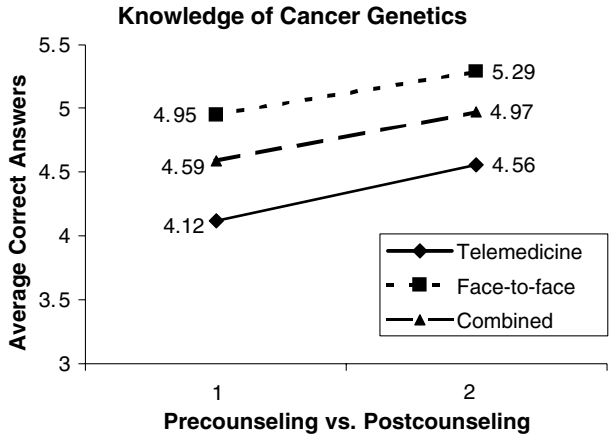

Fig. 1. There was a similar demonstrable increase in knowledge of cancer genetics measured by the number of correct answers in all groups after counselling.

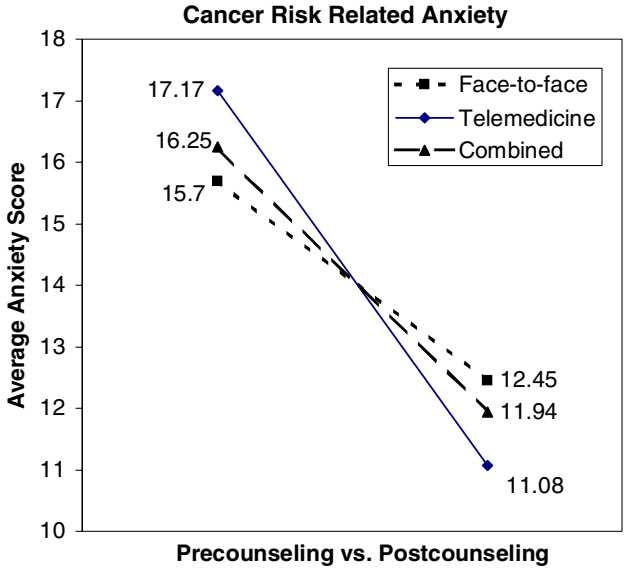

Fig. 2. There was a demonstrable decrease in anxiety in all groups after counselling.

3.2. Anxiety levels

Fig. 2 demonstrates a statistically significant reduction in anxiety levels after cancer genetic counselling in the telemedicine group ($P = 0.00$), face-to-face group ($P = 0.01$), and as a combined (telemedicine and face-to-face) group ($P = 0.00$). The pre-counselling anxiety levels were 17.17 (SD = 4.12), 15.70 (SD = 4.28), and 16.25 (SD = 4.21) for the telemedicine, face-to-face, and combined groups, respectively. The post-counselling anxiety scores were reduced to 11.08 (SD = 3.08), 12.45 (SD = 2.66), 11.94 (SD = 2.86), respectively.

3.3. Satisfaction levels

Table 1 demonstrates the satisfaction level score out of a possible total of 24 points. Although overall satisfaction levels were high, there was statistically significant difference in the mean score representing satisfaction level ($P = 0.08$), as the telemedicine group did have a slightly higher satisfaction level. There was a statistically significant difference ($P = 0.02$) in responses to the question, "I did not feel that my feelings and emotional needs were met," with a mean of 4.00 (SD = 0.00) in the telemedicine group and a mean of 3.35 (SD = 1.09) in the face-to-face group. It appears that the face-to-face group did not feel as satisfied as the telemedicine group in regards to their emotional needs.

3.4. Open-ended questions

An open-ended question was included in the pre-counselling questionnaire: "What do you think is going to happen in the genetic counselling session," as well as in the post-counselling questionnaire: "What else would you like us to know about your genetic counselling session?" There did not appear to be a difference in the expectations and comments between the telemedicine and face-to-face groups, which included discussing the "pros and cons" of testing, helping make an informed decision, and fear and concern for relatives to develop a genetic cancer.

In terms of the post-counselling open-ended question, the responses were generally positive in both the telemedicine and face-to-face groups. One patient in the telemedicine group wrote "Good idea. Saves time and inconvenience for consultant and patient." Another patient wrote: "I found the session very good and feel very relaxed now." Yet another expressed: "I felt it was very informative and sensitively handled." Only one patient in the telemedicine group commented negatively and wrote: "... the videolink [was] a bit difficult to take." Comments from participants in the face-to-face group expressed esteem for the genetic counsellor involved in their care and included: "... she [the genetic counsellor] did make me feel more comfortable and at ease," and "very helpful and informative." One patient wrote, "The session was extremely helpful. Everything was

Table 1
Summary of satisfaction assessment scores[a]

Questions	Telemedicine group ($N = 16$)	Face-to-face group ($N = 21$)	Two-tailed t-test	
	Mean (SD)	Mean (SD)	t	P
I did not feel understood	3.63 (1.02)	3.75 (0.72)	−0.43	0.67
I felt comfortable and at ease	3.75 (0.58)	3.85 (0.67)	−0.47	0.64
I did not feel listened to	4.00 (0.00)	3.80 (0.70)	1.28	0.21
I did not feel that my feelings and emotional needs were met	4.00 (0.00)	3.35 (1.09)	2.67	0.02
My questions/concerns were all answered completely and thoughtfully	3.88 (0.34)	3.60 (0.88)	1.28	0.21
My expectations were met	3.88 (0.34)	3.65 (0.49)	1.62	0.11
Total/24	23.12 (1.36)	22.00 (2.32)	1.82	0.08

[a] Possible answers were strongly agree, agree, disagree, and strongly disagree. All negatively worded questions were recorded, and numerical satisfaction scores were given; with 4 points being the highest satisfaction answer and 1 being the lowest satisfaction answer.

explained and all my questions were answered. "[The genetic counsellor] made me feel very comfortable." The results of the quantitative analysis were supported by the qualitative data extrapolated from the open-ended questions.

4. Discussion

The findings of this study were consistent with those of Gray [2] and Gattas [3]. As this study suggests, there is no significant difference in quality of cancer genetic counselling when it is delivered via telemedicine as compared to face-to-face consultations.

There was a general trend towards increased understanding of cancer genetics. A statistical difference could not be demonstrated as the pre-counselling scores were already high, thereby limiting the possible numerical difference between the two scores. Interestingly, the question answered incorrectly the most often by both groups pertained to understanding that individuals with a known genetic predisposition to breast and ovarian or colon cancer are also at risk to develop other cancers. Responses to this question may have been biased by the patient's gender, as the study consisted of both men and women, but only women are at risk of developing endometrial and ovarian cancers. There was a statistically significant difference in the pre-counselling knowledge of cancer genetics between the telemedicine group and face-to-face group. However, further analyses did not reveal an association between education level and pre-counselling cancer genetic knowledge. It may be that examination of other sociological differences (*i.e.*, heightened community media attention) between the two patient populations would explain this observation.

Both the telemedicine and face-to-face groups demonstrated a statistically significant reduction in anxiety levels after cancer genetic counselling – validating an important (and well supported) function of genetic counselling for individuals at risk of developing a hereditary cancer [5–7]. By effectively reducing the patient's distress and increasing patient understanding of cancer genetics (and genetic testing), patient satisfaction is more likely to be achieved.

Moreover, establishing rapport, creating a positive working relationship, and empathically responding to patients profoundly affects the doctor–patient relationship, the effectiveness of the genetic counselling session and therefore, patient satisfaction. In this study, high satisfaction levels in both the telemedicine and face-to-face settings were reported, and there was no statistical difference between the two mediums. A statistically significant difference was only reported in relation to one question, which addressed the patient's feelings and emotions. Due to the small sample size of this study, it would be presumptuous to assume the reasons the face-to-face group scored less satisfaction for this particular question. However, it is important to note that written feedback expressed high esteem for the genetic counsellor involved in care of the face-to-face group. Slightly lower total satisfaction scores were reported by the participants in the face-to-face group. Although the telemedicine group had higher pre-counselling anxiety levels, they may have benefited further from cancer genetic services than the face-to-face group thereby promoting higher satisfaction levels. Overall, participants appeared satisfied with telemedicine even if it alters the "traditional" genetic counselling session and doctor–patient relationship. Future qualitative analyses may reveal the aspects of telemedicine or cancer genetic counselling that promote high patient satisfaction as well as possible changes to the service that may increase satisfaction.

The purpose of this study was to assess the effectiveness of cancer genetic counselling by telemedicine as compared to face-to-face consultation. Here, we have provided evidence that telemedicine is an adequate medium by which to provide cancer genetic services when geographical distance creates a barrier to care. The findings of this study are encouraging, especially as telemedicine is currently being used to provide cancer genetic services to four remote sites in the NE Thames Cancer Network and to date over 130 families have been seen by the service. We believe the data presented here will provide the impetus to the application of telemedicine in cancer genetic counselling and other medical specialties in the United Kingdom and beyond.

Conflict of interest statement

None declared.

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