Telephone Genetic Counseling

A Comparison of Telephone and In Person Genetic Counseling from the Genetic Counselor's Perspective

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NSGC Service Delivery Models (SDM)

In Person SDM (IPGC)
• Reflects the historical model of providing service in healthcare
• In person at healthcare facility or private office
• Previously referred to as ‘face-to-face’

Telephone SDM (TGC)
• Considered a model of service delivery when parallels traditional in person SDM
• Entire session by telephone
• Patient being counseled for new indication

TGC Current Research

• Vast majority of literature focusing on patient outcomes
  • Many studies were focused on solely providing results for BRCA1/2 testing by telephone, not conducting a full session
  • Similar patient outcomes between the 2 SDMs: patient satisfaction, retained knowledge, anxiety, and psychological well-being
  • Some patients were found to prefer TGC, when given a choice between IPGC & TGC
  • Sutphen et al. (2010) found that some patients would not have pursued GC had it not been available via telephone
  • None focused strictly on telephone genetic counseling from the provider’s perspective
Why is further research needed?

- Many studies providing evidence that TGC is effective from the patient’s perspective, but lacking from the GC perspective
- Field of genetic counseling is expanding
  - Trend of insurance companies covering the cost (some requiring before genetic testing) of genetic counseling
  - The general population is becoming more aware of genetics and the availability of genetic testing, creating a higher demand for genetic services
  - Little to no GCs in rural areas of the country
- Need for different ways for patients to receive genetic counseling services to meet the demand
- How do counselors tailor their counseling to be effective by telephone without having a patient physically present?
- Will this have implications for training?

Study Aims

**Overall Goal:** Compare and contrast genetic counseling performed through the telephone SDM with counseling performed using the in person SDM.

- Establish if telephone GCs perform standard genetic counseling tasks differently in TGC compared to IPGC
- If differences, what are they and why do they exist?
- Identify areas where new skills may be needed by GCs to perform TGC effectively

Study Methods

- Created novel online survey using standard genetic counseling tasks as defined by the ABGC Practice Analysis to compare how GCs perform in person and telephone counseling
  - Inclusion/Exclusion criteria: Participants must have performed TGC according to the NSGC SDMTF definition
  - Listed tasks in ABGC Practice Analysis to be compared in their use in TGC & IPGC using a Likert-like scale and open ended questions
  - Open ended question asking about GCs needing to be taught additional skills during training for TGC
  - Demographics questions: time spent counseling (IPGC & TGC), years of experience (overall, IPGC, & TGC), NSGC region, circumstances under which IPGC has been performed (i.e. training only), patient indication counseled for (TGC), and practice setting (IPGC & TGC)
- Pilot review with 3 GCs performing telephone counseling
- Final survey was sent to NSGC and ABGC directories
Results - Demographics

- 113 consented and met inclusion criteria
- Time spent counseling (N=66)
  - IPGC mean 47.18 min.
  - TGC mean 37.90 min.
  - Difference found to be statistically significant (p<0.001)
- Years Experience (N=66)
  - IPGC mean 10.04 years
  - Median 8.00 years
  - 3 participants only had IPGC experience during training
  - TGC mean 4.85 years
  - Median 2.00 years
- Two most common patient indications in TGC (N=65)*
  - Reproductive (46.15%)
  - Cancer (43.08%)
- Two most common practice settings in each SDM (N=63)*
  - IPGC
    - University Medical Center (44.44%)
    - Private Hospital/Medical Facility (33.33%)
  - TGC
    - Diagnostic Lab-Commercial (30.16%)
    - University Medical Center (26.98%)
- Two most common NSGC regions of practice (N=60)
  - Region 2 (38.33%)
  - Region 4 (21.67%)
  - Overrepresentation of these regions compared to NSGC Professional Status Survey

*Participants could select more than one answer.

Results - Differences Identified, Quantitative

- Tasks were determined different if the ‘different’ category received 25% or more of participant responses
- 13 (14.8%) of the 88 tasks inquired about were determined to be ‘different’
- Tasks that were identified to be most different:
  - Contracting
    - ‘Establishing rapport through verbal & nonverbal interactions’ (60.2%, N=63)
    - ‘Establish rapport through interpreters’ (50%, N=66)
  - Psychosocial Assessment
    - ‘Recognizing factors affecting counseling interaction’ (47.8%, N=67)
    - ‘Assessing client/family emotions, support, etc.’ (40.9%, N=66)
    - ‘Assessing client psychosocial needs and recognizing the need for referral’ (38.8%, N=67)
  - Testing Options
    - ‘Facilitating genetic testing’ (40.9%, N=66)
  - Inheritance/Risk Counseling
    - ‘Educating clients about basic genetic concepts’ (35.4%, N=73)
Qualitative Data Analysis

• Themes were identified and defined by all authors for the open ended responses
• Answers were then coded by 2 out of 3 of the authors

Results - Differences Identified & Why They Exist, Qualitative

• Nonverbal
  • Found to be the key difference in many of the Practice Analysis tasks due to not being physically present with the patient
  • Have to rely more heavily on verbal cues, such as tone of voice and rate of speech
  • Impacts their ability to build rapport, assess understanding, and make psychosocial assessments during TGC
  • “At the beginning of the conversation I usually explain to the patient that since we are not in the same room I cannot read their non-verbal cues and need them to speak up if they have questions or get confused. I am almost never this blunt during in-person discussions. I also ask the patients counseled by phone more often during the session if they have questions or if “everything makes sense so far” to assess if I have retained their attention and understanding.” (Respondent #155)

• Additional Visual Information
  • Again, found to be a difference due to the lack of being physically present during TGC
  • Difficulty presenting complex information without visual aids
  • Have to modify the way questions are asked about ethnicity (i.e. could not assume ethnicity and ask, “Would you consider yourself to be...?”)
  • Not being able to observe family dynamics
  • Inability to visualize dysmorphic & other physical features to create a differential
  • “...communication is more difficult without being able to use diagrams to explain biological and genetic concepts, so that I can show (i.e. transmission of mutations, hypertrophic heart) and where patient can point out parts of the concepts not understood...” (Respondent #32)
Results - Differences Identified & Why They Exist, Qualitative

- **Logistics**
  - Differences resulting from being in different geographical locations and the counselor not being familiar with local resources for the patient
  - Coordinating genetic testing, billing, and obtaining medical records
  - Making referrals to local healthcare providers & local support/other resources to create a management plan for the patient
  - "Referrals and resources are harder when dealing with an expansive geographical network. My patients can be anywhere in the world so I do not know of supports and other providers in many of these areas." (Respondent #34)

Results - Additional Skills for TGC

- 53.8% (35/65) respondents felt GCs should be taught additional skills to be effective in TGC (close ended question)
- Themes developed from open ended question asking participants to elaborate on additional skills:
  - No new skills specifically
  - More exposure to/practice with TGC SDM in training
  - More training on performing psychosocial assessment and building rapport for TGC SDM (i.e. doing this with only verbs)
  - More training on explaining concepts without the use of visual aids
  - Most of responses fell into the theme of 'no new skills specifically'

Additional Skills for Training

- "Yes, there is a lack of graduate training for telephone counseling... Students need to learn to respond to verbal queues only and to not use visual aids when counseling." (Respondent #146)
- "Additional training in psychosocial techniques to elicit more verbal engagement is useful for phone GC." (#42)
- "... and train students to develop verbal analogies for genetic concepts rather than just utilizing images." (#87)
- "More in-depth education on non-verbal cues is important for telephone consultation, such as intonation and silences, is necessary. Many of the cues we are taught in our graduate programs are physical cues, such as facial expression and body position/language." (#148)
Discussion/Summary

• Most ABGC Practice Analysis tasks were identified as being performed in a similar fashion in TGC and IPGC.
• Most differences fell into tasks pertaining to assessing patient understanding and emotion, representing the main finding from the quantitative Likert data.
• The main finding from the qualitative data was the absence of nonverbal communication in TGC compared to IPGC.
• Not necessarily new skills needed, but modifying GC core skills to be effective in TGC.
• Potential impact on the GC field: From the data collected in this study, we would recommend altering training of genetic counseling students to incorporate exposure to the TGC SDM, as well as adding lessons and practice on counseling without visual aids or nonverbals from the patient.

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Conflict of Interest Disclosures

In relation to this presentation, I declare that there are no conflicts of interest.

Thank you!
Any questions?