Genetic Counseling in South Africa: Comparison and Analysis of Session Goals between Patients and Genetic Counselors: A Two Part Investigation

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May 2013

Introduction:
Genetic counseling has been a formally recognized profession for approximately four decades, yet a model of practice specific to genetic counseling has only recently been proposed. The Reciprocal Engagement Model (REM) includes 17 goals for genetic counseling practice (McCarthy Veach et al., 2007). The REM goals were validated in two studies of genetic counseling providers in North America (Geiser et al., 2009) and the Middle East (Al Hajj et al., 2010). Such studies provide a starting point for learning about genetic counseling at a transnational level.

The present qualitative research extends the work of Geiser et al. (in preparation) and was the first investigation of the relevance of REM goals in the emerging South African genetic counseling practice. The purpose of this research is to determine the importance of the REM goals and the extent to which they are accomplished in genetic counseling practice in South Africa. The REM goals were examined by interviewing both genetic counseling providers and patients, in Part I and II of the study, respectively. Identifying the goals of South African patients receiving genetic counseling is important for aligning professional and patient objectives for genetic counseling sessions. For individuals affected by or at risk for a genetic condition, having adequate knowledge or access to knowledge about a specific diagnosis, gives them power to respond to their life situation. This study sought to identify salient cultural aspects that may impact a session.

Financial Summary:
Approximately $4,400 of the $10,000 total grant funds were used for plane tickets from Minneapolis to Cape Town, South Africa. Another large portion of the grand funds were used as stipends. Each of the two investigators received $1,275 as a stipend. This amount encompassed 75 hours of work at the standard graduate student salary. This stipend was used for housing and transportation (to and from the University, clinic and schools) while in Cape Town. Additionally, $2,450 was allotted for transcription services, which allowed for 70 hours of transcribing interviews at $35 hourly. The remaining $560 was used for supplies and equipment, including a digital voice and phone recorder, a hard drive to back up data and interviews, and phone and internet fees.

Results:
These investigators gave a presentation while in South Africa to the Medical Genetics Department on the purpose, methods and expectations for the results within each area of this study’s focus. These investigators completed this project in May 2013 as individual Plan B projects and in partial completion of the Master’s Degree of Genetic Counseling through the University of Minnesota. These
investigators plan to combine their individual Plan B thesis projects for publication in the near future. These investigators were invited to present their findings at the National Society of Genetic Counselors AEC in October 2013.

The results obtained from the genetics providers’ perceptions (Part I of the study) were analyzed using the data obtained from the online survey (which identified factors contributing to and hindering the success of a genetic counseling session) and follow-up interviews (which were conducted for further exploration of salient cultural aspects and specific cultural limitations to genetic counseling practice). Respondents’ mean ratings of goal importance and frequency generally are consistent with ratings obtained in prior research on the REM. Content analysis of open-ended survey responses and interview data revealed unique barriers, including: patient preconceived notions/mistrust, cultural differences (e.g., religious beliefs, ethnicity), limited understanding of genetics, conflicting agendas, socio-economic disparities, time and resource limitations, and public health concerns. These findings support the validity of the REM and have implications for genetic counselor training and practice, public understanding, and policy development in South Africa.

The purpose of this study was to contribute to a greater global study and the results will further genetics providers’ understanding of cultural differences and increase awareness of and sensitivity to unique patient perspectives. The results of this study will also contribute to the education of other medical professionals, while increasing the awareness and importance of this unique and specialized profession of genetic counseling. Furthermore, the findings of this project support the use of the REM model for professional preparation of genetic counselors in South Africa. The REM model may also be useful for public education campaigns aimed at increasing awareness of genetic counseling. The findings concerning unique professional and clinical challenges for genetic counselors may help to promote advocacy efforts for further funding of genetic services in South Africa.

In part II of this study, 18 patients were interviewed following a genetic counseling session in order to explore genetic counseling goals and experiences of South African patients and to assess to what degree they reflect the goals and outcomes articulated in the Reciprocal-Engagement Model (REM) of genetic counseling. Results indicated that most patients’ initial goals are consistent with the REM. Each of the 17 REM goals comprising four overarching factors (Understanding and Appreciation, Support and Guidance, Personal Connection, and Patient-Centered Education) were mentioned by at least one participant. Most prevalent were Patient-Centered Education goals. Participants cited many examples of how the genetic counseling provider accomplished these goals. Data also revealed themes concerning family as decision makers and sources of support, religiosity, and beliefs about the causes of genetic conditions, and HIV prevalence that potentially affect the genetic counseling session. The findings provide support for the REM as a valid model to guide genetic counseling practice in South Africa, despite distinct cultural factors.

Future project plans:

This research was in partial completion of the Master’s degree program in Genetic Counseling, which was completed for both investigators May 2013. Furthermore, both investigators were invited to present their own respective findings and contributions to the larger project at the National Society of Genetic Counselors AEC (Annual Educational Conference) October 2013.
These investigators plan to combine the individual aspects of the project for publication in the near future. The purpose of publication would serve as a means to provide education and a resource to genetic/medical professionals highlighting cultural differences and the importance of awareness for and sensitivity to unique patient perspectives. This publication would also serve as support for the use of the REM model for professional preparation of genetics providers in South Africa, and may be useful for public education and promoting advocacy efforts for further funding of genetic services in South Africa.

Plans for future research include extending this project to other countries as a contribution to the larger transnational study. The extent to which the REM goals have international applicability requires further validation studies. Additional work is needed to identify strategies and goals that promote the 17 REM goals. As these strategies and behaviors are articulated, studies should be done to assess their cross-cultural efficacy.