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‘We are pretty sure we can never say never’: exploring how risk and uncertainty communication impacts care in public genetic counselling consultations in South Africa

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Abstract

Introduction
Risk and uncertainty are inherently part of genetic counselling (GC) due to the complex nature of the information conveyed. Despite an emphasis on communication within the GC profession little is understood about the process of GC communication in everyday practice, particularly within socio-cultural diverse settings. The study aims to explore how risk is communicated and how uncertainty is managed during public-based South African GC consultations and how these processes impact patient care.

Methods
This qualitative interactional study includes 18 video-recorded patient-genetic specialist consultations, 12 genetic specialist interviews, and researcher field notes collected from genetics clinics at 3 tertiary public hospitals in Cape Town, South Africa. The study utilises a blended interactional analysis approach that draws on principles of conversation analysis and theme-orientated discourse analysis. Thematic analysis and content analysis are utilised for talk-extrinsic data. All data has been triangulated.

Results
Several interactional features are noted to create tension in the communication of risk and management of uncertainty in a local context. The volume and complexity of risk information and formats, together with universal and personal uncertainty are difficult to address in GC consultations. Contextual factors such as limited patient engagement, challenges in gathering patient information, literacy barriers and language mismatches, as well as differing risk perceptions create further interactional uncertainties that must be managed. Findings suggest that engaging with risk and uncertainty topics in GC whilst attempting to achieve GC’s goals of establishing and prioritising patient agendas, tailoring information according to a patient’s needs, ensuring complete disclosure of risk information and maintaining a neutral stance create complex interactional spaces. Findings in this study suggest that the activities and communication approaches currently used within these complex interactional spaces may be hindering, rather than promoting patient care.

Conclusion
GC risk communication is more complex in reality than what is suggested in theory. The study highlights that some of the goals of GC are not being met in a South African context and existing guidelines create additional interactional uncertainties and tensions. The findings of this study call for the reconsideration of current GC risk communication practice in South Africa. Current practice suggests a heavy teaching focused GC model. More attention is needed on the counselling model of GC which focuses on a patient’s concerns and needs. Greater symmetry with the counselling GC model will assist in developing a care relationship within

local GC practice that pays attention to tailoring risk information and managing uncertainty in GC consultations. Collectively, this approach may promote contextually attuned South-African based GC guidelines that may assist in achieving positive patient outcomes, and assist local genetic specialists navigate the complexity of practice in a socio-cultural diverse setting. The study adds to the growing literature demonstrating the value of interactional qualitative research within healthcare. The findings are important for South African and international GC training and practice, as well as other healthcare areas where risk is conveyed,

Key Words: Risk, Uncertainty, Care, Genetic Counselling, Communication, Interactional Research, Socio-cultural diversity, South Africa