

Implementing a digital platform to support family communication about hereditary cancer risks

Monica Aceti^{1,2}, Vasiliki Baroutsou¹, Andrea Kaiser-Grolimund^{1,3}, Carla Pedrazzani^{1,4}, Marion Rudaz¹, Nicole Burki⁵, Pierre Chappuis^{6,7}, Rossella Graffeo-Galbiati⁸, Christian Monnerat⁹, Manuela Rabaglio¹⁰, Sue Kim¹¹, Maria Caiata-Zufferey^{4*}, Maria C. Katapodi^{1*} and the CASCADE Consortium

¹Department of Clinical Research, Faculty of Medicine, University of Basel, Switzerland; ²Institute of Sociological Research, University of Geneva, Geneva, Switzerland; ³Swiss Tropical- and Public Health Institute, University of Basel, Basel, Switzerland; ⁴Department of Business Economics, Health and Social Care, University of Applied Sciences and Arts of Southern Switzerland, Manno, Switzerland; ⁵Women's Clinic and Gynecological Oncology, University Hospital Basel, University of Basel, Basel, Switzerland; ⁶Unit of Oncogenetics and Cancer Prevention, Division of Oncology, Geneva University Hospitals, Geneva, Switzerland; ⁷Division of Genetic Medicine, Geneva University Hospitals, University of Geneva, Geneva, Switzerland; ⁸Institute of Oncology (IOSI) and Breast Unit (CSSI) of Southern Switzerland, Bellinzona, Switzerland; ⁹Oncology Department of the Jura Hospital, D  l  mont, Switzerland; ¹⁰University Clinic for Medical Oncology, Inselspital Bern, Bern, Switzerland; ¹¹College of Nursing, Yonsei University, Seoul, Korea.

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Background

In Hereditary Breast and Ovarian Cancer (HBOC), active coping and communication of genetic risk among families are essential for engaging with cascade genetic testing, surveillance, and prevention. According to Swiss and Korean laws, individuals identified with a pathogenic variant have the sole responsibility to share information about test results to relatives. However, empirical evidence shows that up to 50% of blood relatives of known HBOC cases are unaware of potential benefits of genetic testing, raising the question of barriers and facilitators in family communication about genetic risk of cancer. Interventions that support 'open' communication and increase genetic literacy among HBOC-harboring families through disclosure of genetic test results can reduce mutation carriers' psychological distress and provide relatives with accurate and credible information about cascade genetic testing. Web-based-enabled genetic education can explain the benefits and drawbacks of genetic testing to blood relatives of HBOC cases. The Family Gene Toolkit is a web-based intervention designed to enhance active coping and open communication among blood relatives of HBOC-harboring families.

Specific aim

Explore HBOC cases' experiences, needs, wishes and opinions in order to develop a digital platform that is based on linguistic and cultural adaptation of the Family Gene Toolkit, and is designed to support communication around cancer genetic predisposition among family members who are at different moments of their life trajectory.

Ascertain mutation carriers and family desires and ideas to increase the relevance of the platform and the concrete and varied needs of HBOC cases and blood relatives.

Expected outcome

Understanding communication issues and coping challenges related to hereditary cancer will be useful to 1) increase our knowledge on how to address family communication in genetic services and how to enhance coping around HBOC risk 2) develop a digital platform to support family communication and coping around genetic cancer risk tailored to mutation carriers' and blood relatives' needs.

Method

A qualitative and comparative study is currently being conducted in Switzerland and Korea. Face-to-face, online focus groups and in-depth interviews are presently ongoing with a diversified sample of HBOC mutation carriers (male/female, affected/not affected with cancer) in three linguistic regions of Switzerland and in Korea (N= 60). Interviews are video and/or audio recorded, transcribed and inductively analyzed by a multilingual and interdisciplinary qualitative researchers' team, exploring potential cultural interpretations, risk perceptions, way of coping, lay theories and personal reasons (not) to communicate genetic test results to blood relatives. Identifying new data through a bottom-up approach i.e. an in-depth, comprehensive, inductive and sensitive method is intended to better understand needs linked to contextualized and grounded way of thinking and acting.

Results

Preliminary results of the bottom-up approach suggest the need to build an digital platform centered around HBOC and designed to provide reliable, comprehensible, clear and visual information, with the possibility of access to the latest scientific knowledge and/or medical discoveries about the syndrome. Participants would welcome the opportunity to interact with health professionals and/or other mutation carriers, such as by having access to testimonials from other cases.

The ongoing study is expected to better illuminate the context of family communication and coping by further exploring culturally framed influences and addressing the different communication challenges that may arise based on gender, health status, life trajectory of the mutation carrier and/or the blood relative, or based on the structural and contextual effects of different healthcare systems in genetic counseling. These broad and in-depth analyses will sustain the development of a tailored and interactive digital health platform.