

Impact of Unselected Population Panel Genetic Testing and Ovarian Cancer Risk Stratification on Emotional Wellbeing and Health: a Qualitative Study

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BACKGROUND

Algorithms for predicting ovarian-cancer (OC) risk, have been developed and validated in the ‘Predicting–Risk-of-Ovarian-Malignancy-Improved-Screening and Early-detection’ (PROMISE) programme. This enables population stratification for OC-risk prediction, screening and prevention.

We present results of a qualitative-study exploring range of attitudes, experiences and impact on emotional wellbeing, lifestyle and health following unselected panel-genetic-testing (PGT) and OC-risk stratification in unselected women ≥ 18 years ascertained through primary care networks in the PROMISE Feasibility-Study (ISRCTN 54246466). This is the first qualitative-study in unselected general-population women undergoing PGT.

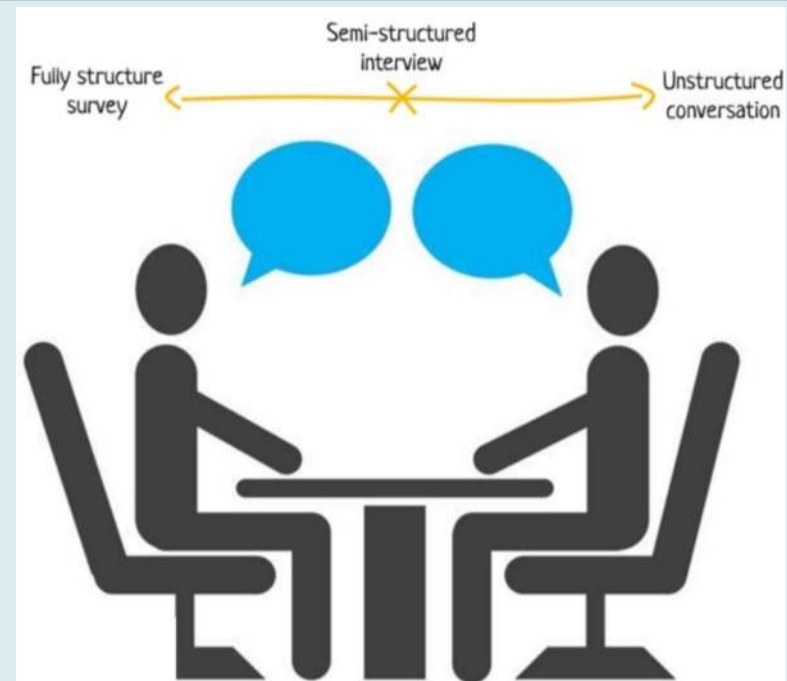
METHODOLOGY

In-depth semi-structured 1:1 interviews were conducted using a pre-developed topic-guide (development informed by literature review and expert consultation) until informational saturation reached. Wording and sequencing of questions were left open with probes used to elicit additional information. All interviews were audio recorded and transcribed verbatim. Questions were fine-tuned during a pilot-interview. Transcripts were analysed using an inductive theoretical framework and data managed using NVIVO-v12.

RESULTS

10/103 individuals who underwent unselected-population-based-PGT/OC-risk-stratification as part of the PROMISE Feasibility-Study were interviewed. Table-1 summarises participant characteristics.

Our data identified eight interconnected-themes: health behavioural choices; interest; counselling; decision making; facilitators/barriers determining acceptability; effect of results on health/wellbeing; results communication; satisfaction. All interviewees reported high levels of satisfaction with their decision and would advise others to undergo the same. 7/10 had decided to undergo PGT/risk-stratification prior to any counselling. There was the feeling that a negative PGT/low-risk-category may result in a false sense of security leading to individuals potentially ignoring future OC symptoms. Most important facilitators were ease of testing, learning about children’s risk, desire to maintain health/prevent disease. Barriers included change in family dynamics, insurance, stigmatization, personality traits associated with stress/worry. Table-2 showcases representative quotes from the interviews.



ID	Quotes
05	“... health is priority over everything because if I don’t have my health, there is no point me working or anything else...”
02	“I thought great, this must be a good thing, surely it’s better to know?”
01	“I think I’d probably already decided that I was keen to do it but obviously it’s useful to have the full information...”
03	“I’d say it can potentially save your life”
04	“They’ve said it’s low risk and then one day in 10 years’ time, I could wake up and have all the signs of it [ovarian cancer] but ignore it ...”
08	“I’d rather be aware of what I’m predisposed to than not. Not that I would let it interfere with my day-to-day life but it’s more the fact that if I knew I had a predisposition then it would make me consider my lifestyle choices and change them to a beneficial way ...”
09	“...I know there’s been some controversy about having genetic tests done, in case it affects insurance premiums etc. and again, being discriminated against in future employment, in case it’s something you’re asked to readily provide”

Table-2: Interviewee quotes

CONCLUSION

Population based genetic testing for OC-risk prediction in general population women is associated with high acceptability and satisfaction. The facilitators and barriers observed are largely similar to those reported with genetic-testing seen in high-risk cancer clinics and unselected testing in the Jewish population.

ID	Age (years)	Ethnicity	Employed	Parity	OC PGT results	Lifetime risk of OC (%)	Number of relatives with OC	Number of relatives with other cancers	Length of time from receiving results and interview (days)
01	47	Caucasian	No	3	Negative	2.7	1 FDR	4	117
02	44	South-East Asian	Yes	1	Negative	0.7	0	0	117
03	60	Jewish	Yes	2	Negative	1.2	0	1	120
04	57	Caucasian	Yes	2	Negative	1.5	1 FDR	1	113
05	51	Caucasian	Yes	2	Negative	0.6	0	0	110
06	36	Caucasian	Yes	1	BRCA1 positive	42.0	1 SDR	1	90
07	69	Caucasian	No	2	Negative	1.2	0	4	110
08	37	Caucasian	No	3	Negative	1.0	0	2	116
09	33	South-East Asian	Yes	0	Negative	1.9	0	1	115
10	85	Caucasian	No	0	Negative	0.6	0	4	95

Table-1: Baseline characteristics of interviewees

FDR – first degree relative, SDR – second degree relative