Family Risk and related Education and Counselling Needs in Adults with Schizophrenia and their First-Degree relatives

Family, twin, and adoption studies strongly suggest that schizophrenia has heritable components, with heritability estimates of between 60% and 85%. The condition shows evidence of a complex, non-Mendelian pattern of inheritance, involving several different genes. Both rare copy number variants of large effect and common variants of small effect are implicated. Genome-wide significant evidence exists for eight loci of rare copy number variants[3] and 108 common variants of small effect. Currently no genetic test is available to establish, confirm or refine a psychiatric diagnosis of schizophrenia, and family history evaluation is still the most reliable method for predicting risk for schizophrenia. However, in the future, diagnostic, predictive and prenatal testing and preimplantation genetic diagnosis for copy number variants related to schizophrenia are likely to become clinically available. Moreover, work is in progress to determine the clinical utility of genetic testing to predict psychotropic medication response.

Almost no data are available about perceptions of familial risk and attitudes to genetic testing for schizophrenia. This study aims to assess attitudes to diagnostic and predictive genetic, using different risk frames and; causal attributions for schizophrenia, in particular the degree to which a genetic model is endorsed; the impact of these attributions on the perceived stigma of schizophrenia; predictors of psychological distress; attitudes towards childbearing, as well as interest in prenatal testing and preimplantation genetic diagnosis; and information and educational needs in relation to familial risk. The following hypotheses will be tested: interest in genetic testing for schizophrenia risk will be positively associated with (i) certainty imparted by the test; (ii) the extent to which a biological/genetic model for schizophrenia is endorsed; (iii) the perceived preventative potential of genetic testing; and (iv) that intention to pursue genetic testing, should it become available, will be negatively correlated with perceived stigma associated with schizophrenia.

Participation will involve a telephone interview with about 20 participants, which will take about 30 to 60 minutes. The researchers also aim to assess first-degree relatives (mother, father, siblings, children) of participants without a personal diagnosis of schizophrenia.

The results from this study will be used to provide the best possible service for people with schizophrenia and their families. In particular, it will provide the basis for the development of psychoeducational intervention targeted to people with a family history of schizophrenia.

To be eligible, participants need to meet the following criteria:

- Have a diagnosis of schizophrenia
- Are 18 years old and over
- Can speak English proficiently

To be eligible, first-degree relatives need to meet the following criteria:

- Are a first-degree relative (mother, father, child, sibling) of an individual with schizophrenia
- Do not have schizophrenia themselves
- Are 18 years old and over
- Can speak English proficiently

Interviews will be digitally recorded and last between half an hour and one hour. An interview guide will be used. Tapes will be transcribed verbatim and subjected to a rigorous qualitative analysis guided by the thematic analysis framework. The qualitative research computer software package in NVivo will be used to assist with the organizational aspects of analysis. About 10% of the interviews will be recoded by a second coder and any discrepancies between coders will be resolved through discussion to arrive at an agreed upon set of themes and sub themes.