



Mental Illness in the Family: Investigating the sibling experience

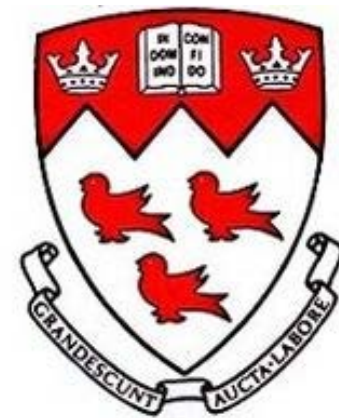
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Overview

- ◆ Key Messages
- ◆ Background
- ◆ Rationale
- ◆ Objectives
- ◆ Methods
- ◆ Preliminary results
- ◆ Expected contributions

Key Messages

- ◆ Master's Thesis exploring the sibling experience of mental health
- ◆ Work in progress, presenting methods and general approach
- ◆ This work aims to gain an improved understanding of the well sibling experience
- ◆ Results will contribute information and tools to a larger module
- ◆ Development of key messages for health and educational professionals

Background

HealthTalkOnline

- People access the internet for health information, but is this information reliable?
- University of Oxford has developed www.healthtalkonline.org and www.youthtalkonline.org , where people can access reliable information about experiences of health and illness
- These websites feature a collection of people's personal accounts about health and illness for over 80 different topics

Background

HealthExperiences Project

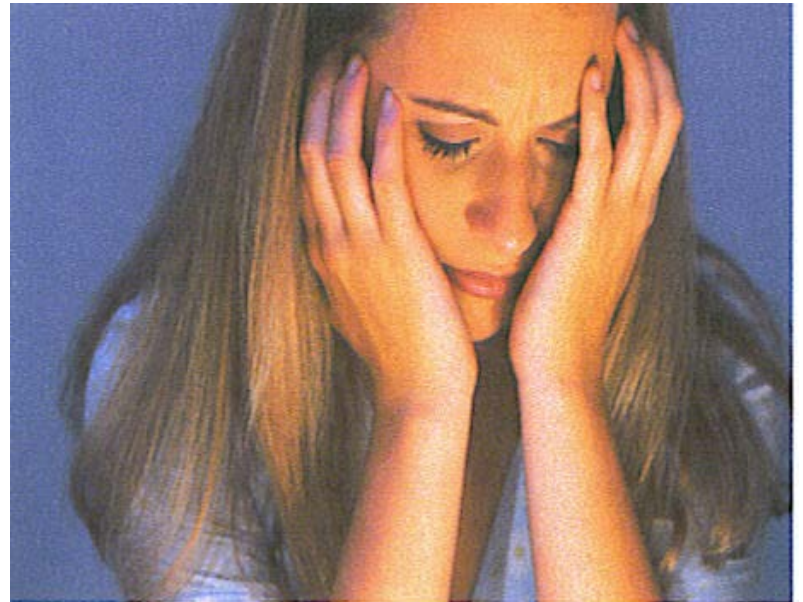
- ◆ St. Mary's Hospital and McGill University have undertaken a Canadian initiative which will produce a site similar to that of the UK
- ◆ The first module was conducted on family caregiving for adults with chronic physical illness
- ◆ The next modules will focus on mental health and breast cancer

Rationale

- Very little known about the sibling experience in general
- Patient experiences have been shown to be at the core of patient-centered care
- Uncertainty of the extent to which siblings are at risk for mental health conditions themselves
- To contribute background work to the HealthExperiences mental health module
- To contribute tools for health and educational professionals

Research Objectives

- From their personal perspective, to what extent are young adults affected by their ill sibling's chronic mental health impairment?



Methods

- Review of Evidence:
 - Literature Review
 - Secondary Analysis of published health experiences narratives (web-based)
- Primary Data Collection using 2-3 focus groups with young adults



Methods

Review of Evidence

- ◆ Literature review using major databases [PubMed, MEDLINE, PsycINFO, with articles restricted to 1995-present]
- ◆ Web search for grey literature from major knowledge organizations
- ◆ Secondary analysis of “Having a sibling on the autism spectrum” module

Methods

Primary Data Collection

- ◆ 2-3 Focus Groups (5-6 participants each):
 - ◆ 1st group- to identify key issues and form interview guide
 - ◆ 2nd group- exploring the well sibling perspective and experiences
 - ◆ Possible 3rd group or individual interviews
- ◆ Narrative approach, semi-structured questions
- ◆ Data analysis using qualitative thematic narrative analysis (NVivo10)



Preliminary Results from Existing Literature

- ◆ 20% of Canadians will personally experience a mental illness in their lifetime (CMHA, 2013)
- ◆ Current research is focused on caregiver experiences and neglects the sibling experience
- ◆ Conflicting results suggest both negative and positive effects
- ◆ Although contributions are recognized, siblings experiences of how their sibling's illness affects them are not well established
- ◆ Given the lack of research of the sibling experience, recognition of problems and support interventions for siblings are lacking
- ◆ Health and educational professionals could likely benefit from an improved understanding of the unique needs and experiences of well siblings

Secondary Analysis

- ◆ From HTO module “having a sibling on the autism spectrum”
 - ◆ 14 siblings aged 17-54
 - ◆ Published February 2011
- ◆ **“Some of the time we were treading on egg shells”**
- ◆ Well siblings speak about adjusting their schedules and needs to fit their ill sibling’s requirements
- ◆ Family life is “all on [the ill sibling’s] terms” and this can create barriers within the family

Secondary Analysis

- Well siblings talked about the close relationship they shared with their ill sibling
- Most siblings spoke about taking some responsibility for their ill sibling and helping their parents
- Many siblings felt neglected in terms of support and found existing support groups somewhat ineffective



Benefits of Research

- **“It is important for young people to have the opportunity to talk to other people that have similar experiences”**
- There is some evidence that narrative construction has been shown to be therapeutic (Carlick & Biley, 2004)
- Focus groups will allow for validation of shared feelings

Expected Contributions

- ◆ Enhanced understanding of siblings experiences and unique needs for support
- ◆ This work will contribute to the development of the mental health module for HealthExperiences
- ◆ Key messages for healthcare and educational professionals and policy makers

Thank You!!

Questions?

- ◆ Recruitment strategies
- ◆ Guidance with focus groups and screening of participants
- ◆ Web-based health experience literature

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