Preferences regarding targeted education and risk assessment in people with a family history of major depressive disorder

Running Head: Preferences regarding targeted education

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Abstract

Genetic testing for susceptibility to major depressive disorder (MDD) is not available for clinical use at present. Given this, family history remains the best predictor for development of MDD, and family-history-based risk assessment and information about familial aspects of MDD may be useful to clients at increased risk for MDD attending for genetic counseling. This study uses a mixed-methods design to assess the information needs and preferences of people at increased familial risk for MDD. Telephone interviews were conducted with 23 individuals, who had at least one first-degree relative with MDD and were recruited through advertisements placed on depression education websites. The most preferred way to access depression information was via the internet (87% of participants), although this preference may have been due to the internet-based recruitment method. The second most preferred dissemination strategy (56%) was face-to-face delivery through a health professional, including genetic counselors. Individuals reported a need for information about etiology and development of MDD, reproductive decision-making, early detection of symptoms and risk-reducing strategies. Nearly all participants expressed an interest in risk assessment. The present study found evidence of a high level of interest for information targeted to people at increased familial risk for MDD. Genetic counselors are likely to be called upon increasingly to provide supportive counseling to assist clients at increased familial risk in interpreting and contextualizing such information once it becomes available.

KEY WORDS: Major depression; family history; attitudes; education; genetic counseling; risk assessment
Introduction

Having a family history of depression is the strongest known risk factor for the development of depression (Sullivan et al. 2000). Family, twin, and adoption studies demonstrate that both major depressive disorder (MDD) and bipolar disorder (BD) have heritable components (Merikangas et al. 2002), with heritability estimates of 40% for MDD (Kendler and Prescott 1999; Sullivan et al. 2000) and 80% for BD (Kieseppa et al. 2004; McGuffin et al. 2003). Individuals suffering from MDD experience significant psychological and often physical impairment, frequently causing marital, occupational and substance abuse problems, and the over-utilization of health services (American Psychiatric Association 2000). In the 2008 World Health Report, MDD is listed as the leading cause of years lost to disability (World Health Organisation 2008), which has led to calls for comprehensive and coordinated attempts internationally for intervention at a societal level (World Health Organisation 2012). These sorts of calls have been reflected in attempts to understand the genetic etiology of the disorder, potentially as a basis for future predictive genetic testing (should it become available) and for early intervention. A meta-analysis conducted using data from five familial aggregate studies revealed a strong association between MDD status of probands and the development of MDD in first degree relatives (Sullivan et al. 2000). The importance of genetic factors in such familial transmission is demonstrated in a review of twin and adoption studies by the same authors, which showed high concordance rates in diagnoses between relatives even when shared familial environments were accounted for or removed (Sullivan et al. 2000). Odds ratios calculated in aggregation studies commonly report that individuals with one first degree relative affected with MDD are between two and three times more likely to develop MDD compared with people without a first degree relative (Lieb et al. 2002; Steinhausen et al. 2009; Sullivan et al. 2000), a risk which is further elevated for individuals
with two or more affected first degree relatives (Lieb et al. 2002; Sullivan et al. 2000).

Despite the evidence for a genetic contribution to MDD as well as other psychiatric disorders, including bipolar disorder and schizophrenia (e.g. Gottesman et al. 2010), much of the genetic variance in psychiatric disorders has yet to be accounted for. Shyn et al. (2011) conducted a meta-analysis of three Genome Wide Association Studies (GWAS) across individuals with and without MDD, finding that despite there being no genome-wide significant association, there was evidence for modest associations between multiple single nucleotide polymorphisms (SNPs) and MDD development. However, the failure of any SNPs to reach genome wide significance in multiple GWAS studies (e.g. Cross-Disorder Group of the Psychiatric Genomics Consortium et al. 2013; Lewis et al. 2010; Shyn et al. 2011; Sullivan et al. 2009) indicates that multiple genetic polymorphisms may interact with environmental factors, and more research utilizing larger samples is required. Rare structural variants are also thought to be relevant in a small minority of cases of some psychiatric disorders although their exact contribution is yet to be determined (International Schizophrenia Consortium 2008).

It has been argued that the construct of “risk” refers to both the objective numerical probability for certain outcomes as well as the broader concept of “risk,” which includes severity of the outcome and effects on individuals’ subjective perception of the numerical probability. In this article we will, however, use the term “risk” in its narrow sense as referring to the numerical probability of developing MDD, consistent with the widespread use of the term in the academic literature.

Genetic testing for psychiatric disorders is currently not available in public health settings due to the lack of analytically and clinically valid genetic testing (Mitchell et al. 2010; Wilde et al. 2010). Although genetic testing is currently premature, the provision of risk information based on epidemiological data to individuals with a family history of
depression remains an important goal. In the absence of an analytically or clinically valid genetic test, family history has been advocated as a surrogate for assessment of risk of developing genetically transmitted disorders (Yoon et al. 2002). It has been suggested that such risk assessment allows for the identification of individuals at high risk of developing MDD and therefore most likely to benefit from implementation of risk-reducing strategies (Wilde et al. 2012). As community awareness of the heritability of MDD increases, genetic counselors may be called upon increasingly to provide risk assessments (Feret et al. 2011).

The development of education targeted to those who are at an elevated risk of developing depression or experiencing future episodes owing to a family history of MDD, offers an important opportunity to reduce the incidence and/or severity of depression. Whilst there are targeted resources for people with a family history of other conditions with a substantial heritable component (e.g. Wakefield et al. 2008) to date limited progress has been made in developing such resources for people with psychiatric disorders, despite evidence of considerable unmet informational needs in these populations (Barney et al. 2011). Nor are any data available on the content and format preferences for targeted education for people at increased familial risk for MDD that could be used to inform the development of educational interventions and the best-practice provision of supportive strategies, including genetic counseling.

Research exploring the potential risks and benefits of providing information concerning familial risk for psychiatric disorders typically yields mixed findings of the perceived clinical and personal utility of risk assessment. For example, Laegsgaard, Kristensen and Mors (2009) conducted a survey of participants who had volunteered for genetic research and found that some individuals were concerned that psychiatric genetic research would pose difficult choices (39%), could cause discrimination of at-risk individuals (50%) and may bring on the psychiatric disorder in question (37%). Despite this, 58% of the
sample suggested that they would feel more prepared to deal with the disorder if they knew that they were predisposed towards developing it. Austin, Smith and Honer (2006) found that many individuals at increased risk for psychotic disorders overestimate their personal risk, and that such overestimation was associated with being less likely to want children. The benefits of risk assessment could therefore include helping individuals accurately view their likelihood of developing MDD, as well as aid them in procuring information about how risk can be reduced using behavioral strategies to prevent unwarranted life impact.

However, the potential benefits of providing individuals with information regarding their familial risk of MDD may be limited by the well-documented disparity between an individual’s intention to adopt health behaviors and actual adoption (e.g. Sniehotta 2009), as well as the reduced salience of a probabilistic risk estimate compared with a more instructive genetic test result. While a growing body of literature is available on at-risk individuals’ attitudes to genetic testing for depression risk (e.g. Meiser et al. 2008; Meiser et al. 2005; Trippitelli et al. 1998), virtually no data are available exploring preferences for receiving risk estimates based on family history. Accordingly, using a mixed-methods design, the present study aims to assess the preferences of individuals with a family history of MDD towards receiving risk assessment, as well as for the content, format and delivery of education targeted to people at increased familial risk. The consistency of these preferences across demographic variables including gender, age and severity of family history was also explored. The knowledge gained from this study will be an important step to inform the development of targeted educational strategies, which could be used in conjunction with genetic counseling.

Methods
Participants

Participants were recruited over a two-year period through advertisements placed on the depression literacy websites Black Dog Institute (http://www.blackdoginstitute.org.au), beyondblue (http://www.beyondblue.org.au) and Depressionet (http://depressionet.org.au). Eligibility criteria were being 18 years or older and having at least one first-degree relative diagnosed with MDD. Ethical approval for this study was provided through the relevant Institutional Review Board (Human Research Ethics Committee, University of New South Wales, Australia). All participants provided informed consent after the nature of their participation had been fully explained to them.

Procedures

Telephone interviews were conducted and digitally recorded by AW and ZC. A mixed-methods design was used for the study. Specifically, in the first part of the interview, a structured interview schedule with predominantly closed-ended questions was used to obtain quantitative information about: the most relevant and useful content about depression and the preferred format for delivery, and interest in receiving an individualized risk estimate and the preferred format for its delivery. A quantitative approach was used for this component because of the focused nature of the research aims, namely identifying the preferred content and format of targeted education to provide the basis for the subsequent development of an educational intervention. In the second part of the interview, a qualitative approach using open-ended questions and probes as appropriate was employed to explore participants’ perceived advantages and limitations of receiving an individualized risk estimate and targeted education; given this is an unexplored area, a qualitative approach was deemed most suited to explore the range of participant views, as opposed to quantifying the extent to which such views are held.
Procedures - quantitative component

All participants completed a short demographic questionnaire, including items eliciting age, sex, highest level of education, language spoken at home and occupation. Participants were also screened for personal and family history of MDD using a modified list of questions from the Family History Screen (Weissman et al. 2000), and the Mini-International Neuropsychiatric Interview (Sheehan et al. 1998) was used as a brief symptom measure for current depression symptomatology.

Scheuner, Wang, Raffel, Larabell and Rotter (1997) developed general guidelines for the assessment of risk for developing physical chronic diseases, based on the strength of family history. Their approach was advocated by Yoon et al. (2002) as it takes into account the age of onset, the number of relatives affected, as well as their degree of closeness to the individual. According to this classification system, “high-risk” individuals have at least one of the following: early-onset disease in a first-degree relative; two affected first-degree relatives; one first-degree relative with late or unknown disease onset and an affected second-degree relative with early-onset disease from the same lineage; two second-degree maternal and/or paternal relatives with at least one having early-onset of disease; three or more affected maternal and/or paternal relatives; or presence of a “moderate risk” family history on both sides of the pedigree. “Moderate risk” is defined by having one first-degree relative with late or unknown onset of disease, or two second-degree relatives from the same lineage with late or unknown disease onset. For the purposes of its current use, the authors classified early-onset development as earlier than 25 years of age (Zubenko et al. 2002). Written notes and digital recordings of interviews were used to prepare a quantitative summary of responses collected in the structured component of the interview.
Procedures - qualitative component

An interview guide was developed with open-ended questions on the basis of a review of the relevant literature and expert opinion, which included a list of structured prompts, which were used if participants were unable to answer a question or unsure of its meaning. Wording and sequence of questions was left open to the interviewer. The qualitative part of the telephone interview was transcribed.

The conceptual framework of Miles and Huberman was chosen to guide data collection and analysis (Miles and Huberman 1994). Analysis included continuous development and amendment of codes reflective of the themes uncovered during exploration of the transcripts. ZC coded initial transcripts until coding saturation was achieved. ZC then trained AW and KBS in the coding scheme and the group informally coded and discussed ten percent of the transcripts until a consensus was achieved. Another 10% of the transcripts were then formally coded to ensure inter-coder reliability and upon the completion of cross-coding, a level of 0.91 consensus was calculated using percent agreement, indicating a high level of inter-coding agreement. Analysis of the coded transcripts was carried out by VQ. The software package QSR Nvivo 9 (Qualitative Solutions and Research, Doncaster, Victoria, Australia) was used to analyze the coded transcripts for prominent themes, enabling the comparison of participants with different demographics.

Results

Results - quantitative component

Participation rate and demographics

Twenty-six people participated in the current study; however three participants were subsequently excluded from the analysis due to absence of family history of MDD. Therefore the interviews of 23 eligible people (20 female, 3 male) were included in the analyses. The
mean age was 36 (SD=11.6); range 23-64 years. Eleven participants had one or more children, whilst 12 had no children. Twenty-one (91%) participants also revealed a personal history of MDD. There were more participants with a strong family history of MDD (n=17, 74%) than a moderate family history (n=6, 26%). Demographic, disease and family history characteristics of participants are presented in Table 1. In the following, for responses to closed-ended questions asked of all participants, frequencies and percentages are reported, whereas frequencies only are reported for responses to open-ended questions.

[Insert Table 1 about here]

**Resources previously accessed by participants**

Participants were asked which sources of information about depression they had used previously, with prompts including leaflets and websites. Web-based resources, such as the beyondblue and Black Dog Institute websites, were the most frequently accessed resources prior to this study (n=15, 65%). Other common sources of information about MDD were via communication with a general practitioner (n=5, 22%) and through books on MDD (n=4, 17%). Five (22%) participants reported not having accessed information about MDD prior to this study.

**Preferred content of information**

**Risk reduction and early intervention**

When asked how they would use information about personal risk and disease development, 17 (74%) felt that educational resources should provide information as to how to reduce the likelihood of depression occurring both for themselves and their family. Two participants mentioned that such information would have had a major impact on their lives if it had been
provided while they were pre-symptomatic, in that it might have led to early detection, if not prevention, of depression.

Related to this, 20 (87%) participants felt that information in regards to early signs and symptoms of depression would be helpful. Two participants also thought that information on early signs and symptoms was important in relation to recurrence of depression.

Understanding of the disorder and its etiology

During the interview, participants were asked whether they would prefer scientific information that explained ideas such as the genetic basis for depression or more general information that described depression in lay terms, although participants were able to select both. There was a slight preference for information that was based on scientific discoveries and understanding (n=18, 78%) rather than general information about depression (n=15, 65%), however many participants described being comfortable with both forms of information.

Participants were asked if they would be interested in information that described known environmental risk factors for depression as well as information on how the environment might affect their depression risk. Seventeen (74%) participants expressed interest in information about currently known environmental risk factors such as stress and lifestyle factors, while 11 reported interest in information about the interaction between environment and depression development.

Twenty-one (91%) participants acknowledged the importance of information about MDD, including its etiology, for people who have not been affected with MDD but have a familial history of the disorder. However, given that most participants were affected with MDD, they tended to be ambivalent towards receiving such information themselves, with
five stating that it was either too late or that they had already gained sufficient knowledge through self-initiated research efforts.

*Heritability of major depressive disorder and reproductive decision-making*

Participants were asked if they would be interested in educational materials concerning the likelihood of offspring developing MDD based on family history. Nineteen expressed an interest in gaining risk information related to reproductive decision-making, with an even mix between those who did ($n=11, 58\%$) and those who did not have children ($n=8, 42\%$), although no significance testing for differences was performed to due to the limited sample size. Four participants reported that knowledge of an increased genetic risk might reduce the likelihood that they would have children, or had already done so, with these views as likely to be held by those with a moderate family history (two) and those with a strong family history (two). Seven of the 11 participants with children ($64\%$) suggested that information regarding reproductive decision-making would be important knowledge to discuss with their children. Two participants also suggested that information on the risks of developing postnatal depression in women at increased familial risk was required.

*Preferences for format and delivery of education*

Participants were asked which formats for information delivery would be feasible and preferred; prompts included booklets, face-to-face delivery through a health professional, web-based delivery as well as CD and DVDs. Participants were able to select multiple formats as well as offer spontaneous opinions. Twenty ($87\%$) participants expressed an interest in a web-based information resource. Five participants showed interest in this format due to its ease of access and the ability to undertake self-initiated research without the need to go through a third party.
Although web-based information delivery was the most preferred format, 13 (56%) participants also expressed interest in face-to-face delivery. Ten participants expressed a desire to have face-to-face communication with a health practitioner in conjunction with web-based information. It was argued that face-to-face methods of delivery through a health professional would facilitate greater understanding and communication. Participants were asked which health professional they would wish to consult, and if no specific type of practitioner was mentioned spontaneously, they were provided with prompts, including GP, psychiatrist, genetic counselor and psychologist. Psychiatrists were the most frequently preferred \( \left( n = 14, 61\% \right) \) for communication. General practitioners were second most preferred \( \left( n = 10, 43\% \right) \), followed by psychologists \( \left( n = 8, 35\% \right) \). Responses to the genetic counselor prompt showed that several individuals held misconceptions including that genetic counselors were too hard to access, were not trained in mental health, or were responsible only for the provision of genetic test results. Due to this, only 5 (22%) participants agreed they would consult a genetic counselor after prompting, with those demonstrating confusion over the role of genetic counsellors stating that they would not. The preferred type of health professional did not appear to differ between participants who were classified as having a moderate or strong family history of MDD. The least preferred formats were CDs and DVDs \( \left( n = 4, 17\% \right) \) due to their perceived inaccessibility and inconvenience.

**Preferences for the format and delivery of risk estimates**

The questions eliciting preferred risk value formats included the following three risk presentation formats as prompts: single percentage (e.g. 30% lifetime risk), percentage range (e.g. 20% to 40% lifetime risk) and population risk comparison (e.g. lower than average risk). Participants were asked for each option whether this would be a preferred format for them. Twenty-two (96%) participants indicated that they would be interested in receiving an
estimate of their risk of developing MDD. The single percentage risk figure was the most preferred \((n=16, 70\%)\) format, closely followed by a percentage range \((n=15, 65\%)\). However, after further questioning, it seemed that preferences for a single estimate were largely based on the misconception that single percentage figures represent more precise estimates. A population risk comparison was the least preferred format \((n=9, 39\%)\), with four participants believing this format to be a less valid method for communicating risk due to its lack of detail.

**Results - Qualitative component**

Throughout this report quotations are denoted according to participants’ sex \([M= male; F= female]\), parity \([NC= no children; C= one or more children]\), age and strength of family history \([MH= moderate family history, SH= strong family history]\).

**Perceived advantages and disadvantages of receiving individualized risk estimates**

Participants were asked to consider the advantages and limitations of receiving a family-history-based risk estimate, both for themselves and their family members. It was explained that such a risk estimate would be based on the probability of developing the disorder, rather than be based on a genetic marker for depression, and that risk estimates varied greatly and were inherently uncertain. The majority of participants felt that there could be both positive and negative ramifications of receiving such an estimate, but largely reported that the benefits could outweigh the risks if delivered properly. It is important to note that due to the majority of participants having personal experience of depression, some responses concerning advantages and disadvantages were retrospective in nature.

**Perceived advantages of determining individualized risk estimates**
Twenty-two (96%) participants interviewed detailed benefits of determining personal risk of MDD based on one’s family history of depression. Themes included the potential for the risk estimates to increase awareness and hope for offspring, to provide an opportunity for early intervention and to reduce stigma associated with the disorder.

**Awareness and the opportunity for early intervention**

The most commonly cited benefit of receiving a personal risk estimate was that it would increase awareness about the disorder, which could then present the opportunity for individuals to implement early intervention strategies. Most participants thought that this would be helpful in reducing the likelihood of depression developing: “For me I think I would have sought assistance as a teenager if I had had that knowledge then” [F, C, SH, 32 years]. However, many also felt that this would be of help continuously throughout living with the disorder: “Again, looking out for warning signs … just being able to catch like an early episode” [F, NC, SH, 27 years]. Two participants also mentioned the potential use of this awareness towards motivating behavioral change: “If I had something showing me what my risk was, I might take it a bit more seriously than I do now even though I know I’m at risk because I’ve had depression” [F, C, SH, 29 years].

**Increased hope for offspring**

The second most frequently mentioned benefit of receiving a risk estimate was that it potentially reduced the occurrence of depression in offspring, and this was cited as frequently by participants with children as by those without. The importance of understanding the risk of offspring developing depression was centered on the idea that knowledge concerning predisposition empowered individuals to make behavioral changes. This was mentioned both in early detection and normalizing their offspring’s experiences, and in focussing on
parenting aided by this increased awareness, “Because understanding how … the way that I behave when I'm depressed may have an impact on whether my children develop depression, as well as the genes behind it” [F, C, SH, 34]. This hope was also expressed by one participant in terms of providing research for future generations that could eventually be used to understand and prevent the disease in different ways.

Reduced stigma

There was some indication that being given a risk estimate might also reduce personal stigmatization associated with the disorder: “People say ‘Oh, you sleep so much,’ or ‘Oh, just cheer up, just get a grip on yourself,’ and it’s not nice hearing that all the time, so it would be nice to know that it’s in the family” [F, NC, SH, 33 years]. Another participant expressed the view that: “The family plays such a large role, such a key role, you know, and getting them to understand that – you know, that you’re not weak or, you know, that it’s not disappointing, it’s a case of, you know, accepting and understanding” [F, NC, SH, 32 years].

Perceived disadvantages of determining individualized risk estimates

Fatalistic thinking

More than half the sample reported that fatalistic thinking and rumination about a high-risk estimate would be a disadvantage of receiving this information. There was a perception by many that this thinking could itself lead to the development of the disorder, rather than making it less likely to occur: “That’s the end for me, I’ve sort of, I’ve got a predisposition to this, and [if] it’s this much percent then yeah, it’s like a self-fulfilling prophecy” [F, C, SH, 43 years]. The potential for risk estimates to make depressive episodes feel more permanent and evidence of a stable, rather than a situational, predisposition was also mentioned by three participants: “If you do have a strong family risk of it going down the line and you were
yourself depressed, I think there is some risk in that, you know, it could make you feel like it's inevitable” [F, C, SH, 34 years]. This view was also noted more frequently in participants with a strong family history compared with those with a moderate family history.

Reliability and validity concerns

Several participants reported concerns about the validity of an individualized risk estimate, given that the genetic transmission of psychiatric disorders is still relatively poorly understood: “It’s not black and white and everything in your genes ... you might be prone to it, but it’s not necessarily that you’ve got to be depressed” [F, NC, SH, 33 years]; and “If it’s misleading, if it’s not reliable, so it’s, I think…it can make things worse, yeah.” [F, NC, MH, 21 years].

Two participants also mentioned that they would fear undue discrimination as a result of receiving a risk estimate: “There’s a tendency that you know when people know these things about you that it becomes a lens through which they interpret everything” [M, NC, SH, 36 years]; and “Unless the numbers got into the hands of someone that I didn't want to see them” [F, NC, MH, 23 years].

When questioned directly about reliability and validity, most still felt that the possibility of being identified as being at increased risk but never developing the disorder was an acceptable disadvantage of receiving a risk estimate: “You’ve got a risk calculator there that says you might be 65% heading towards depression but never get it, well then that’s a bonus if you don’t end up getting it, but at least you are aware, and you can look out for the signs just in case” [F, C, SH, 47 years].

Discussion
Risk reduction and early intervention are important goals for mental health research and are pivotal in reducing the health burden of psychiatric illness. In the absence of genome wide significant associations, family-history-based risk assessment is an important strategy to identify individuals who are at an increased risk for developing MDD or for experiencing future episodes for those individuals who have already experienced MDD. This study is the first to provide detailed data on the informational needs and preferences of individuals at increased familial risk, which can be used to maximize the benefits of genetic counseling to such individuals.

**Preferred information format and communication method**

The most frequently accessed resources by participants prior to the study were websites designed to provide depression information, and this was also the preferred avenue for the provision of family-history-based information. This preference was attributed to ease of access of online interventions and the anonymity they provided. As the current sample was recruited using advertisements placed on websites designed to provide information related to depression, it should be kept in mind that this may have prevented those who prefer printed resources or face-to-face delivery from being adequately sampled. Notwithstanding the fact that the sample includes exclusively internet users, the results indicate that those who use the internet to access mental health information perceive it to be a useful and trustworthy source of such information. Studies that have suggested that the internet is not a trusted resource concerning these issues (e.g. Powell and Clarke 2006) have typically used population-based samples rather than those with a personal experience of the disorder, and the present results suggest that these individuals may view the internet as a way of receiving accurate and anonymous information that can be accessed rapidly.
Jorm, Christensen and Griffiths (2005) found that residents in Australian states with a high exposure to the national Australian depression literacy initiative from 1995 to 2004 showed moderately greater recognition of depression, significantly greater acceptance of the efficacy of treatments for depression, and a significant increase in depression literacy at a national level. Based on these results and those of the current study, it would appear that the internet presents an important, potentially cost-effective and clinically utilizable method of providing education to individuals at increased risk of developing depression or experiencing depression recurrence. Online education could be used in conjunction with, and to supplement, genetic counseling, to enable genetic counselors to focus on providing supportive counseling to clients to assist them in interpreting and contextualizing the information. There is increasing evidence that it is the supportive counseling, rather than the educational, component of genetic counseling that is of most value to clients and leads to the highest satisfaction ratings (Austin 2010; Meiser et al. 2008; Ellington et al. 2006). However, these preferences ascertained in our study would need to be assessed in a more broadly recruited sample of people with family history of depression, rather than relying solely on participants recruited through the internet, before it can be concluded that online interventions will be acceptable to the majority of people at increased risk based on family history.

Participants indicated that the face-to-face delivery of information was their second most preferred method of receiving targeted information, with psychiatrists being the most favored type of health professional. Zhou et al. (2012) compared attitudes towards communicating psychiatric genetic risk information between clinical geneticists, genetic counselors and psychiatrists. Despite nearly all respondents agreeing that it was their role to discuss this information with patients, only 52% felt that they were competent to undertake this discussion (Zhou et al. 2012). The current findings suggest that as more is understood
concerning predisposition towards developing psychiatric disorders, it will be increasingly important that health professionals (including genetic counselors) receive adequate training in order to be able to effectively answer questions and deliver information to those at increased risk. Participants also seemed to hold several misconceptions about the role of genetic counselors, which suggests that educational resources targeted to those at increased risk based on family history should include a description of the role of genetic counselors and information on how to access genetic counselors.

**Interest in information about MDD heritability in the context of reproductive decision-making**

The present study found evidence for high levels of interest in receiving education related to reproductive decision-making. Reproductive decision-making is an important focus of educational interventions for psychiatric disorders, as it can allow individuals to regain a sense of control over their disorder, as well as make difficult decisions concerning the risks of passing on their illness (Frets et al. 1990). A previous study on attitudes towards childbearing in individuals with multiple cases of bipolar disorder in the family found that 35% of participants were reluctant to have children (Meiser et al. 2007). Bipolar I and II disorders have higher levels of familial transmission than MDD (Bienvenu et al. 2011) and are more likely to be characterized by a chronic, unremitting course requiring continual pharmacological and psychological intervention (Judd et al. 2005). It seems that the lower heritability of MDD and the wider range of treatment options for MDD impacts the way individuals view their hereditary risk in relation to childbearing, as few participants reported that their history of MDD or a hypothetical high-risk estimate would influence their decision to have children, although this was not explicitly asked during this study.
It should be noted that interest in information related to reproductive decision-making was not restricted to the likelihood of passing on MDD, but also pertained to information on the risk of developing postnatal depression, as well as screening and early intervention for offspring. Educational resources designed for those planning a family with a history of MDD in the family should make sure to take this into account.

**Interest in receiving information targeted to people with a family history**

Both participants with moderate and strong family histories expressed an interest in receiving information targeted towards their hereditary risk. This interest was for information concerning both strategies for risk reduction and early intervention, as well as information to increase understanding of the disorder and its etiology. Preferences for information concerning risk reduction and intervention were largely retrospective in nature as many participants had already developed MDD, but results indicate that these individuals felt that this information would have helped them if it had been provided when they were still asymptomatic. Barrera, Torres and Munoz (2007) conducted a review of randomized controlled trials designed to prevent the onset of MDD and found that interventions using cognitive behavioral and interpersonal therapy were effective in reducing development of the disorder. They also noted that interventions targeted at specific at-risk groups were more effective than those aiming to intervene universally. A range of self-help, complementary treatments and other strategies to reduce the risk of depression are also available; many of these do not have proven efficacy (see Form et al. 2002 for a review). It should therefore be an important goal of educational resources targeted towards those with a family history of affective disorders to provide an opportunity for individuals to learn about, and appraise, various options for the prevention and treatment of MDD.
In regards to information pertaining to the development and etiology of depression, participants expressed interest in obtaining information about genetic and environmental risk factors, provided in both scientific and lay terms. This suggests that individuals felt that having a holistic understanding of their disorder was important. Some participants with a strong family history of MDD as well as personal history of the disorder expressed disinterest towards this information, due to a perception that it was too late, or that they had already gained knowledge through their own experiences with depression. Although this suggests that it is important for interventions for individuals with a family history of MDD to be implemented before symptoms develop, it may be that having up-to-date information, particularly regarding new treatments or approaches, would be of benefit to individuals who have already experienced the disorder. In support of this view, a study of Asian women in the UK in primary practice supports the provision of education about MDD (focusing on risk factors, signs and symptoms and treatment) early in the disorder, in that it shows that delivery of such education is beneficial even for those already experiencing symptoms (Jacob et al. 2002).

**Interest in individualized risk estimates based on family history and preferred format of risk estimates**

All but one participant expressed an interest in receiving an individualized risk estimate based on their family history. It is unknown to what extent such interest will translate into actual uptake. However we are currently embarking on a study to develop and evaluate online education for people with a family history of depression, which will yield data on actual uptake of provision of risk estimates. A single percentage was cited as the most preferred format for delivery of a risk estimate of developing MDD, due to its perceived accuracy and its ability to initiate change in behavior. However, it appeared that this stated
preference was based on misconceptions, in that many individuals voiced impressions that a single number would be more informative. It was clear from responses to this question that considerable education as to the meaning and interpretation of probabilistic estimates would have to accompany provision of a risk estimate to prevent misconceptions from occurring. Once again these findings underscore the importance of genetic counseling to assist clients to correctly interpret information about familial risk accessed through the internet and other sources, including probability estimates (Austin 2010).

This study showed that participants with a family history of depression were apprehensive that risk estimates may lead to fatalistic thinking and rumination, and therefore potentially worsen their current condition or trigger a first depressive episode. It is possible that the perspectives of individuals who have not developed MDD themselves may be different, as the possibility of risk estimates causing depression was largely retrospective, given most participants had already experienced MDD. Rumination over the symptoms and causes of depression in individuals with MDD has been found to be associated with increased depressive symptomology, potentially mediating the relationship between negative coping styles and depression (Lo et al. 2008).

These findings suggest that genetic counseling plays a potentially important role in contextualizing risk estimates and normalizing concerns to help prevent rumination and fatalistic thinking. Many of the concerns about the reliability and validity of a risk assessment in participants also regarded the lack of concession towards environmental factors that provision of a risk estimate entailed. In particular, these findings suggest that clients are likely to benefit if provision of risk estimates and information about the interaction between genetic predisposition with behavioral and environmental risk factors are provided in the context of supportive counseling. Findings demonstrate many participants viewed a risk estimate as having the potential to prevent the onset of depression through behavioral change
and vigilance; however, many also believed that it could also lead to premature development of the disorder through fatalistic thinking. These diverging views demonstrate that it is important that risk information be provided in a way that facilitates positive change.

**Study limitations and future research goals**

The shortcomings of this study should be mentioned before drawing conclusion from its findings. Participants were recruited entirely through internet-based depression resources, suggesting that there may have been a self-selection bias in that individuals who were comfortable with technology and received mental health information through the internet were oversampled. Consequently, this study is limited to the perspectives and opinions of a sample that may not represent the preferences of individuals with a family history of MDD more widely. Ascertainment bias is also suggested by the large number of individuals who had a personal history of MDD as well as having a family history, and the perspectives and needs of individuals who are not symptomatic may be different. Although individuals with high familial risk who have experienced MDD in the past are at an increased risk of recurrence, the informational needs of individuals who have no personal history of depression may differ systematically. The sample was also comprised mostly of women and those with a high familial risk, which made comparisons across gender and risk groups difficult. A larger quantitative study may be of use in verifying the informational needs and preferences of these individuals, as well as determining how these may differ across demographic variables. Such a study should employ a method of recruitment that is less likely to give rise to ascertainment bias (e.g. recruitment of a consecutive sample of patients, or through advertisement in print media).

**Conclusion**
The current study indicates that there is strong interest in targeted education for people with a family history of MDD, suggesting there would be a strong demand for such education once it becomes available, and that genetic counselors may play an important role in offering access to such education and potentially using it to supplement genetic counseling. Findings suggest that the internet would be a viable avenue through which this information could be disseminated, although this may just be for individuals who are already comfortable accessing health information through the internet. This, as well as many individuals reporting that discussion with a health professional would also be important, indicate that genetic counselors should be involved in delivering and facilitating access to interventions to this target group. Targeted resources should be made available to individuals early in life and include information related to the etiology and development of the disorder, reproductive decision-making, detecting signs and symptoms, early intervention strategies, and provision of risk estimates based on the severity of family history. From the present study, it seems that the provision of this information may increase quality of life and decrease disease burden for individuals with a family history and/or personal history of MDD.

Acknowledgements

We are very grateful to the people who participated in this study and so generously shared their views. This study was supported by National Health and Medical Research Council (NHMRC) Program Grant and the Fellowship Enhancement Scheme, Faculty of Medicine, University of New South Wales. Associate Professor Bettina Meiser is supported by a Career Development Award Level 2 from the National Health and Medical Research Council of Australia.

Informed consent
All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.
**Conflict of interest**

Authors Veronica Quinn, Author Bettina Meiser, Author Alex Wilde, Author Zoe Cousins, Author Kristine Barlow-Stewart, Author Philip B. Mitchell and Author Peter R. Schofield declare they have no conflict of interest.
References


Table I: Demographic Characteristics of the Sample (N=23)

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Female</td>
<td>20 (87%)</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 (48%)</td>
</tr>
<tr>
<td>No</td>
<td>12 (52%)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>25-34</td>
<td>9 (39%)</td>
</tr>
<tr>
<td>35-44</td>
<td>5 (22%)</td>
</tr>
<tr>
<td>45-54</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>55-64</td>
<td>2 (9%)</td>
</tr>
<tr>
<td><strong>Highest Education Completed</strong></td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>13 (56%)</td>
</tr>
<tr>
<td>High School</td>
<td>5 (22%)</td>
</tr>
<tr>
<td>TAFE or diploma</td>
<td>5 (22%)</td>
</tr>
<tr>
<td><strong>Strength of family historya</strong></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>17 (74%)</td>
</tr>
<tr>
<td>Strong</td>
<td>6 (26%)</td>
</tr>
<tr>
<td><strong>Number of affected FDRs &amp; SDRs with depression</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>2</td>
<td>7 (30%)</td>
</tr>
<tr>
<td>3</td>
<td>6 (26%)</td>
</tr>
<tr>
<td>4</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>5</td>
<td>3 (13%)</td>
</tr>
<tr>
<td><strong>Number of affected FDRs &amp; SDRs with early onset of depression</strong></td>
<td></td>
</tr>
<tr>
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<td></td>
</tr>
<tr>
<td>1 - 2</td>
<td>10 (44%)</td>
</tr>
<tr>
<td>3 - 4</td>
<td>10 (44%)</td>
</tr>
<tr>
<td></td>
<td>3 (13%)</td>
</tr>
<tr>
<td><strong>Number of affected FDRs &amp; SDRs with recurrent depression</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
</tr>
<tr>
<td>1 - 2</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>3 - 4</td>
<td>12 (52%)</td>
</tr>
<tr>
<td></td>
<td>7 (30%)</td>
</tr>
<tr>
<td><strong>Personal experience of depression</strong></td>
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</tr>
<tr>
<td>Affected</td>
<td>21 (91%)</td>
</tr>
<tr>
<td>Unaffected</td>
<td>2 (9%)</td>
</tr>
</tbody>
</table>

FDR=First degree relative; SDR=second-degree relative; *Based on Scheuner et al. (1997)