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Descriptive and numeric estimation of risk for psychotic disorders among affected individuals and relatives: Implications for clinical practice

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Abstract

Studies show that individuals with psychotic illnesses and their families want information about psychosis risks for other relatives. However, deriving accurate numeric probabilities for psychosis risk is challenging, and people have difficulty interpreting probabilistic information, thus some have suggested that clinicians should use risk descriptors, such as ‘moderate’ or ‘quite high’, rather than numbers. Little is known about how individuals with psychosis and their family members use quantitative and qualitative descriptors of risk in the specific context of chance for an individual to develop psychosis. We explored numeric and descriptive estimations of psychosis risk among individuals with psychotic disorders and unaffected first-degree relatives. In an online survey, respondents numerically and descriptively estimated risk for an individual to develop psychosis in scenarios where they had: A) no affected family members; and B) an affected sibling. 219 affected individuals and 211 first-degree relatives participated. Affected individuals estimated significantly higher risks than relatives. Participants attributed all descriptors between “very low” and “very high” to probabilities of 1%, 10%, 25% and 50%+. For a given numeric probability, different risk descriptors were attributed in different scenarios. Clinically, brief interventions around risk (using either probabilities or descriptors alone) are vulnerable to miscommunication and potentially profoundly negative consequences –interventions around risk are best suited to in-depth discussion.

Keywords

risk perception; genetic counseling; probability; recurrence risks; schizophrenia; schizoaffective disorder; bipolar disorder; family members; psychosis; psychotic disorders

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1. Introduction

Psychosis can occur in the context of psychiatric conditions like bipolar disorder, schizophrenia and schizoaffective disorder; which cumulatively affect about 3% of the population. These are complex disorders, for which observed clinical heterogeneity is thought to reflect considerable etiological heterogeneity. However, in broad terms, evidence to date supports the idea that usually these illnesses arise as a result of both genetic and environmental vulnerability factors.

Previous research has demonstrated that individuals with psychotic illnesses and their families are interested in knowing about the chances for other family members to be affected (DeLisi and Bertisch, 2006; Lyus, 2007). Further, in the absence of consultation about risks for children to be affected with psychotic illnesses, unaffected relatives of individuals with psychosis make their own estimations of what probabilities for children to be affected might be. Although these estimations are often inaccurate, they inform important life decisions, e.g. whether or not to have children. More specifically, increasing overestimation of probability correlates with increasing likelihood of choosing not to have children (Austin et al., 2006).

Studies have shown that psychiatrists feel that it is their responsibility to engage in communication about risks for other family members to develop psychotic disorders with patients and their patients' families, but that many feel under-prepared to adequately tackle this topic (Finn et al., 2005; Hoop et al., 2008). Indeed, both assessing the level of risk and communicating about it are challenging.

The gold-standard for assessing risk for psychotic disorders among family members of affected individuals is founded on documenting a detailed psychiatric family history and using this in conjunction with empiric recurrence-risk data. However, while finding empiric risk data for a first-degree family member of an individual with schizophrenia to develop schizophrenia is straightforward (Austin et al., 2006), empiric risk data do not exist for some more complex family histories that are encountered clinically. For example, there are no empiric risk data for someone who has three affected cousins, an affected uncle, and an affected sibling. Assessing risk for psychotic illness in relatives is further complicated by two other factors: 1) different source studies for empiric data tend to generate slightly different numeric probabilities, and 2) empiric data represent probabilities for individuals to develop illness, which are influenced by complex sets of variables (including individual, family, genetic, and environmental factors). The cumulative effect of these factors is that, when assessing risk, deriving a single discrete numeric probability for an individual to develop psychotic illness is rarely possible or adequate (Austin and Peay, 2006; Austin et al., 2008). Instead, probability empiric data should ideally be presented in the context of confidence intervals, and discussion of how they can be personalized according to aspects of the presenting individual's family history.

In terms of communication about risk, there is evidence that numeracy levels in the general population are low (Reyna et al., 2009) and numeric probabilities - even discrete single numbers - are problematic for laypersons to interpret (Brun and Teigen, 1988). Furthermore,

perception of risk is not solely dependent on accurate understanding of numeric probability. Perception of risk certainly incorporates understanding of numeric probability, but other contextual factors (such as perceptions of severity of outcome to which the numeric probability applies) are also critical (Patt and Schrag, 2003; Austin, 2010).

Given that both assessment of, and communication about, risk are so challenging, it can be tempting for clinicians to use qualitative risk descriptors, (e.g. “quite high” or “very low”) rather than numeric probabilities. Indeed, due to concerns around interpretability of numeric probabilities for laypersons, some authors have even suggested that using risk descriptors might be preferable (Crowson et al., 2007; Smerecnik et al., 2009). On the other hand however, risk descriptors such as “likely” are interpreted by different individuals to imply a huge range of probabilities (Weber, 1994; Bjorvatn et al., 2007). For example, Bjorvatn et al.. (2007) found that different individuals attributed the descriptor “likely” to numeric probabilities of 30–90% and “possibly” to probabilities of 5–95% (Bjorvatn et al., 2007). Indeed, it seems clear that descriptors of risk in general are typically both used and interpreted when used by others as incorporating more than numeric probability alone (Weber, 1994), and that contextual factors are of critical importance in influencing how numeric probabilities are described (Michie et al., 2005; Sivell et al., 2008); (Patt and Schrag, 2003). Given the inter-individual subjectivity and importance of context in how meaning is attached to both numeric probabilities and descriptors of risk, both are ambiguous as linguistic devices (Nessa, 1995; Noveck and Reboul 2008). Effective communication in the face of such ambiguity requires what linguists refer to as “pragmatic competence” (Ifantidou, 2010), which is the ability to understand how another attaches meaning to an ambiguous word or phrase, given a specific context. However, although psychiatrists are often called on to discuss risk for psychosis with patients and their families, little is known about how individuals with psychosis and their family members use quantitative and qualitative descriptors of risk in the specific context of chance for an individual to develop psychosis – this is a barrier both to psychiatrists attaining pragmatic competence in this area, and to effective communication about risk for psychosis.

We conducted an online survey to investigate pragmatic linkages between estimations of numeric probability and risk descriptors in the specific context of risk for psychosis in a cohort of individuals with psychotic disorders and unaffected first-degree relatives, in an effort to inform the development of pragmatic competence among clinicians who engage in communication about risk for psychosis.

2. Methods

2.1 Participants and Procedure

Responses to an on-line survey, housed on a psychosis support/information website (www.psychosissucks.ca), were collected from October 1, 2003 – October 9, 2006. We adopted a passive recruitment strategy whereby any visitor to the website had the option to complete the survey. Individuals were eligible if they reported either having (a) schizophrenia, bipolar disorder, schizoaffective disorder, or another disorder involving psychosis, or (b) a first-degree family member with one of these illnesses. No identifying

information was collected, and consent was implied by completion of the survey. This study was approved by the Fraser Health Institutional Review Board.

2.2 Survey instrument

Participants were asked to evaluate risk for psychosis in two scenarios.

> Scenario A: "What do you think is the chance for a person who has no family members with psychosis to develop psychosis themselves?" [General population risk for psychosis]
>
> Scenario B: "What do you think is the chance for someone who has a brother or sister with psychosis to develop psychosis themselves?" [First-degree relative risk for psychosis]

In each scenario, participants were asked to evaluate risk numerically (by selecting from the following options: ~1%, ~10%, ~25%, ~50%, ~100%, "don't know", and "other"). They were then asked how they would qualitatively describe the number that they had selected (by responding to the prompt: "Do you think this chance is:" and selecting from the following options: "very low", "quite low", "moderate", "quite high", and "very high"). In addition, we collected demographic data.

2.3 Data analysis

All survey responses were manually inspected in an effort to ensure the integrity of the data. Participants who stated that they had an affected family member *and* a psychotic illness themselves were categorized as affected in all analyses. We first explored numeric probability responses descriptively. The "correct" response in Scenario A was defined as ~1% and in Scenario B was ~10%. Non-parametric Pearson chi-square tests were used to compare frequencies of numeric probabilities given by affected individuals to those given by unaffected relatives within each scenario. We then explored the relationship between numeric probability and risk descriptor responses descriptively. Very few participants selected the 100% option ($n = 11$), so we collapsed this category together with the 50% to make a new category "50%+". Non-parametric chi-square tests were used to compare frequencies of qualitative risk descriptors attributed to 10% and 25% between Scenarios A and B. For these analyses, 'very low' and 'quite low' were collapsed into a single category, 'low'; similarly 'very high' and 'quite high' were collapsed into 'high'. Inadequate cell sizes prohibited a similar approach for 1% and 50%+ categories. As we conducted four chi-square tests, we set $\alpha < 0.001$ (for a conservative Bonferroni correction yielding $\beta = 0.0125$).

3. Results

3.1 Response

Surveys were submitted by 882 individuals over the 36 months it was available online (~25 per month). The website main page receives around 1,800 unique visits per month. Thus, ~1% of website visitors per month chose to complete the survey. Of the 882 individuals who completed the survey, 430 were study-eligible affected individuals ($n = 219$) or first-degree

family members (n = 211). The excluded surveys were completed by health care professionals, spouses, etc.

3.2 Demographics

The majority of participants were Caucasian (n = 345, 88%) and female (n = 315, 78%). Participants were diverse in terms of education level (128 (32%) completed high school, 67 (17%) had an additional skilled qualification, 130 (32%) had an undergraduate degree, and 78 (19%) had post graduate education) and age (96 (24%) were under 25, 255 (63%) were 25 – 50, and 51 (13%) were over 50). A range of psychiatric diagnoses (self or relative) was represented in the sample (157 (37%) bipolar disorder, 163 (39%) schizophrenia, 45 (11%) schizoaffective disorder, and 53 (13%) other psychosis) (See Table 1).

3.3 Numeric probability based estimates of risk

The most frequent numeric risk estimate selected in each scenario was the “correct” option (mode for Scenario A was the response ~1% with 151 responses, and mode for Scenario B was the response ~10% with 124 responses).

Affected individuals were more likely to choose higher numeric risk estimates than were relatives for both scenarios (Scenario A: $\chi^2 = 22.07$, df = 3, $p < 0.0001$; Scenario B: $\chi^2 = 20.24$, df = 3, $p < 0.0001$)(See Table 2 for frequency tables).

3.4 Attribution of qualitative risk descriptors to numeric probabilities

The most common risk descriptor selected was ‘moderate’. The full range of qualitative descriptors was applied to each numeric probability category (1%, 10%, 25%, and 50%+). Three individuals described 1% as ‘very high’, and one described 100% as ‘very low’. However, overall, as the numeric probability increased, risk descriptors towards the ‘very high’ end of the range were used more frequently and towards the ‘very low’ end of the range were used less frequently (See Table 3).

Additionally, many individuals attributed the same qualitative descriptor to different numeric probabilities, or ascribed different descriptors to the same numeric probability, in response to the two scenarios. For example, one participant used ‘quite high’ to describe both 1% in Scenario A, and 25% in Scenario B. Another described 50% as ‘moderate’ in Scenario A, but ‘quite high’ in Scenario B. In comparing the qualitative descriptors applied to a specific numeric probability between the two scenarios, we found that descriptors closer to ‘very high’ tended to be used more frequently in Scenario B than Scenario A (See Table 3). The risk descriptor category ‘high’ was used significantly more frequently to describe 25% in Scenario B as compared to Scenario A ($\chi^2 = 16.8$, df = 2, $p < 0.0001$). There was no significant difference between the frequencies of risk descriptor responses attributed to the numeric risk estimate of 10% in Scenario A compared to Scenario B ($\chi^2 = 5.85$, df = 2, $p = 0.054$).

4. Discussion

This is the only study to have explored pragmatic linkages between numeric and qualitative estimations of risk in the specific context of chance for psychotic illness in a cohort of affected individuals and family members. Although we demonstrated a correlation between numeric risk estimates and qualitative descriptors in the anticipated direction, consistent with studies conducted in other clinical contexts (Bjorvatn et al., 2007) and empirical research in cognitive psychology (Wertz, 1986), we found that the full range of qualitative descriptors were applied to each probability category. This is consistent with the literature propounding that qualitative risk descriptors are used to communicate more than simple numeric probability in other contexts (Austin, 2010).

This finding has direct relevance to clinical practice in psychiatry: as a result of the fact that people have difficulty understanding numeric probabilities, clinicians often to prefer to use descriptors when communicating about risk (Brun and Teigen, 1988), and some have suggested this approach to risk communication in clinical settings (Crowson et al., 2007; Smerecnik et al., 2009). However, among individuals with psychosis and their family members, there is huge inter-individual heterogeneity in terms of the meaning attached to descriptors of risk in the specific context of the chance for psychosis, and thus, we cannot predict which patients might consider a 1% chance for psychosis to be very high or 100% to be very low. Furthermore, there is evidence that clinicians and patients attribute qualitative risk descriptors to numeric probabilities for medical conditions differently (Wertz, 1986). For example, a psychiatrist could tell an individual with schizophrenia that their chance to have an affected child is “quite low” (which, to them, may be a proxy for a numeric probability of 10%), but the patient could interpret this as meaning numeric probabilities ranging from 1% to 50%. The data presented here, as well as results from previous research, suggest that using descriptors of risk alone has the potential to result in miscommunications between clinician and patient that could potentially have profound consequences (e.g. differences between how patient and clinician apply descriptors to numeric probabilities could contribute to patients’ decisions not to have children, or failure to initiate timely treatment for a relative displaying early symptoms of psychiatric illness).

4.1 Relationships between qualitative descriptors of risk and numeric probability

Risk descriptors attributed to the same numeric probability often differed between the two scenarios (see Table 3). Specifically, as compared to the descriptors of risk applied to Scenario A (estimating the risk for an individual who had no affected family members), there was a tendency for participants to attribute descriptors indicating higher risk to the same numeric probability in Scenario B (estimating the risk for an individual who has an affected sibling) – this difference was statistically significant for the 25% numeric probability category. A similar phenomenon has previously been described in studies of non-clinical cohorts (Windschitl and Weber, 1999) and, in brief, is thought to reflect the idea that risk perception is influenced by contextual factors related to the outcome with which the numeric probability is associated (for a thorough discussion of the nature of these contextual factors, please see Windschitl and Weber, 1999). In this study for example, participants seemed to be intuitively aware that the chance for psychosis would be higher for someone

with an affected relative (Scenario B), and applied a different qualitative descriptor even if they ascribed the same numeric probability estimate. One potential implication of this is that it may be helpful for clinicians to raise their patients' conscious awareness of their implicit risk related beliefs, and assist them in considering how these beliefs might influence their interpretation of risk.

The results from Scenario B in this study are consistent with our clinical experience and previous research: many affected individuals and family members overestimate the numeric probabilities for family members of affected individuals to develop psychosis (Meiser et al.. 2007)(Quaid, 2001)). Therefore, it is reasonable for a clinician to anticipate reactions of relief from patients to whom they provide lower-than-anticipated numeric probabilities for relatives' chances to develop psychosis. However, because risk descriptors are ambiguous linguistic devices, and do not map directly and reliably onto numeric probabilities (e.g. an individual may attribute the descriptor "quite high" to probabilities of both 10% and 25% for a relative to develop psychosis), a patient may still feel that the risk is for example, "quite high", even if the numeric probability is less than anticipated.

4.2 Risk perception differences between affected individuals and relatives

For both scenarios, affected individuals estimated significantly higher numeric probabilities than did unaffected relatives. Research in non-medical disciplines indicates that perception of risk is influenced by perceptions of the nature of the outcome, with more "severe" outcomes being described as of higher risk (Patt and Schrag, 2003). So, one potential explanation for our finding is that affected individuals estimated higher numeric probabilities because their personal experience of illness resulted in a perception that the potential outcome (a relative developing psychosis) was more severe. Clinically, then, it would be important for those engaged in risk communication to uncover and address patients' perceptions of severity of the potential outcome.

Essentially, a patient's perception of risk for a child to develop a psychotic disorder (and the language used to describe it) is a complex construct that incorporates far more than simple numeric probabilities. Thus, a clinical communication process aimed at altering risk perceptions that focuses heavily on numeric probabilities alone or risk descriptors alone is likely to be ineffectual (Austin, 2010). Fundamentally, it would seem appropriate to only use risk descriptors: a) together with appropriate qualifiers (e.g. when I say "high risk", to me that means that a particular outcome is more likely to happen than not, so the probability is more than 50%), and b) together with numeric probability ranges (and confidence intervals), so as to avoid potentially significant miscommunication with patients. The clinician who wishes to help their patient grapple with these issues at a deeper level could consider a risk communication strategy that incorporates exploring: 1) their patient's existing estimates of numeric probability for a child to develop a psychotic illness, as well as 2) how their patient would describe the risk, 3) the factors that have contributed to this perception (for example, the presence of multiple additional affected family members), and 4) their patient's perceptions of illness severity, *before* attempting to provide any new information (Skirton and Eiser, 2003). Further, *after* the delivery of information about chances for children to be affected, the clinician could encourage the patient to reflect on the information in light of

their previous perceptions, and its effect on their perceptions, such that unanticipated reactions can be addressed (Phelps et al., 2007).

It is likely that the most effective strategies clinicians can use to address risk perception for psychosis will – like the approach suggested here – acknowledge and address the inherent complexity involved. However, there is a need for future studies that empirically investigate the effect of this kind of risk communication.

4.3 Strengths & Limitations

In this study, we used a web-based survey, and did not select and invite specific individuals to participate, but allowed anyone visiting the website on which the survey was hosted to complete it. This approach offers an advantage over convenience sampling of participants already involved in, for example, genetic studies of psychosis, because such samples are biased towards individuals with many family members with psychosis and rarely include the perspective of families in which only one member is affected. However, the drawback to this approach is the lack of diversity in the sample in terms of ethnicity and sex (with the majority of our sample being Caucasian and female), thus limiting external validity and preventing generalization of results to those of different ethnic backgrounds. Additionally, our use of a passive recruitment strategy likely explains the small proportion of website visitors who chose to complete the survey. The survey was structured such that participants were presented with a scenario to which they were first asked to assign a numeric probability and then a qualitative descriptor to describe that probability. It is conceivable that the order of these questions could influence participants' responses. Furthermore, it is possible that participants responded to the qualitative and quantitative items differently. Specifically, perhaps the quantitative item was approached as a "knowledge" question, whereas the qualitative item was considered somewhat independently as seeking a more visceral response. Finally, the numeric probabilities that were given as response options restricted the majority of answers to those categories and so more nuanced probability estimates were not obtained.

Conclusion

For individuals with psychotic illnesses and their family members, the perception of risk for children to develop psychosis can be a determining factor in the decision of whether or not to have children (Austin et al., 2008). For clinician engaged in risk communication, providing only a single discrete numeric probability or a risk descriptor for an individual to develop psychotic illness is both inadequate and undesirable, and the clinician should seek to provide a risk range within the context of a detailed discussion of probability, confidence intervals, and a broader composite risk perception, including exploration of the patient's perception of context and severity of the potential outcome.

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Table 1

Summary of demographic information

	Affected Individuals (*n*=219)			Relatives (*n*=211)		
	Number	**Missing data**	**%**	**Number**	**Missing data**	**%**
Sex	206	13		198	13	
Female	151		73.3	164		82.8
Male	55		26.7	34		17.2
Ethnicity	201	18		193	18	
Caucasian	176		87.6	169		87.6
Asian	6		3	6		3.1
African American	4		2	1		0.5
First Nation	4		2	0		0
Other[a]	11		5.5	17		8.8
Age	204	15		198	13	
Under 25	72		35.3	24		12.1
25 – 50	123		60.3	132		66.7
Over 50	9		4.4	42		21.2
Education	204	15		199	12	
High school	82		40.2	46		23.1
Other skilled qualification	26		12.7	41		20.6
Undergraduate degree	69		33.8	61		30.7
Postgraduate education	27		13.2	51		25.6
Psychiatric diagnosis (self or relative)	219	0		211	0	
Bipolar disorder	108		49.3	49		23.2
Schizophrenia	41		18.7	122		57.8
Schizoaffective disorder	27		12.3	18		8.5
Psychosis	36		16.5	20		9.5
Disorder with psychosis[b]	7		3.2	2		1.0

Note. Percentages are based on non-missing data.

[a]Other ethnicities included Hispanic, Mixed, and “Canadian”.

[b] Disorders with psychosis included schizophreniform disorder, reports of hallucinations and delusions without a specific diagnosis, depression with psychosis, or reports of both diagnoses of schizophrenia and bipolar disorder

Table 2

Frequencies of numeric risks attributed to Scenario A and Scenario B by affected individuals and their relatives.

	Numeric Risks *n* (%)				No numeric risk provided *n*
	1%	**10%**	**25%**	**50%+**	
Scenario A					
Affected Individuals	**57 (35)**	46 (28)	30 (18)	31 (19)	55
Relatives	**94 (59)**	38 (24)	13 (8)	15 (9)	51
Scenario B					
Affected Individuals	13 (7)	**49 (27)**	50 (28)	67 (38)	40
Relatives	18 (10)	**75 (44)**	48 (28)	30 (18)	40

Note. "Correct" responses for each scenario are shown in bold text. In each cell in which percentages are presented, these exclude missing data.

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Table 3

Distribution of Risk Descriptors Applied to the Same Absolute Number: Comparison Between Scenario A and Scenario B, stratified by affected individuals and relatives

	Scenario A			Scenario B		
	Frequency of Response			Frequency of Response		
	Total	Affected Individuals	Relatives	Total	Affected Individuals	Relatives
1% risk estimate						
Very low	65	19	46	9	4	5
Quite low	49	19	30	11	4	7
Moderate	26	14	12	10	4	6
Quite high	7	3	4	0	0	0
Very high	3	1	2	0	0	0
10% risk estimate						
Very low	10	7	3	2	1	1
Quite low	30	12	18	37	15	22
Moderate	28	15	13	56	24	32
Quite high	9	7	2	18	3	15
Very high	5	3	2	9	5	4
25% risk estimate						
Very low	1	1	0	0	0	0
Quite low	9	6	3	6	3	3
Moderate	25	17	8	45	22	23
Quite high	5	5	0	30	16	14
Very high	1	0	1	14	6	8
50%+ risk estimate						
Very low	1	1	0	0	0	0
Quite low	2	1	1	2	2	0
Moderate	29	18	11	35	26	9
Quite high	8	6	2	39	27	12
Very high	6	5	1	20	12	8

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