Risk communication in genetic counselling: exploring uptake and perception of recurrence numbers, and their impact on patient outcomes

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Conflict of Interest

Authors AI, EM, and JA are/have had involvement in the delivery of the service from which data were drawn for this study. All authors declare no commercial conflict of interest.

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ABSTRACT

Providing recurrence numbers is often considered a fundamental component of genetic counselling. We sought to fill knowledge gaps regarding how often patients actively seek recurrence numbers, and how they impact patient outcomes. We conducted a retrospective chart review at a clinic where patients routinely complete the Genetic Counselling Outcomes Scale [GCOS, measuring empowerment] pre (T1)/post (T2)-appointment. Using ANCOVA we evaluated the effect on T2 GCOS score of: a) receiving recurrence numbers, and b) patient perception of recurrence numbers. Recurrence numbers were a primary indication for 134/300 patients (45%). After counselling about etiology and risk-reducing strategies, 116 patients (39%) opted to receive recurrence numbers, with most (n=64, 55%) perceiving the number to be lower than expected. There was no difference in T2 GCOS scores between those who: a) received recurrence numbers vs. those who did not, or b) perceived the number to be lower than expected vs. those with other perceptions. However, a subset of patients who did not receive recurrence numbers had larger increases in GCOS scores. Our data provide impetus to question the assumption that recurrence numbers should be routinely provided in genetic counselling, and demonstrate that in naturalistic practice optimal patient outcomes are not contingent on receipt of recurrence numbers.

Keywords: risk communication, recurrence risks, risk estimates, empiric risks, genetic counselling, psychiatric illness

INTRODUCTION

Risk communication is considered such an integral component to genetic counselling that the concepts of genetic counselling and risk communication are sometimes conflated, even within the medical community. Risk communication often includes the provision of numerical probabilities for illness recurrence amongst relatives of an affected individual (recurrence numbers). Although the definition of the process of genetic counselling has evolved over time, from a focus on "risk of occurrence of a genetic disorder in a family"[1] to encompass a broader definition of "helping families to adapt to the medical, psychological and familial implications of the genetic contribution to disease"[2], there is still a tendency to see the provision of recurrence numbers as a necessary component of genetic counselling[3]. Despite implicit assumptions that patients seeking or being referred to genetic counselling are motivated by a desire to know recurrence numbers, there are limited substantiating data on this topic[4].

Studies have examined patients' naturally pre-existing estimations of numerical probabilities for disease recurrence, and explored how objective probabilistic information affects their perceptions[5,6,7,8]. However, despite increasing recognition of the importance of research focused on the impact of clinical genetics services on patient outcomes, there have been limited studies on how risk communication and perception impacts patient outcomes of genetic counselling.

Therefore, in the context of a psychiatric genetic counselling clinic, we sought to investigate how often recurrence numbers constitute a primary indication for referral, and how often patients ultimately choose to receive these numbers. We also aimed to explore how receiving recurrence numbers influenced patient outcomes by testing the hypotheses that greater

increases in empowerment after genetic counselling would be observed amongst patients who: 1) received recurrence numbers during their genetic counselling appointment (as compared to those who did not) (hypothesis 1), and 2) perceived the recurrence numbers to be lower than anticipated (as compared to patients who had other perceptions of the number they received) (hypothesis 2).

MATERIALS AND METHODS

Though this study was conduced in the context of naturalistic clinical practice, rather than as an intervention study, we have opted to use the reporting standards for genetic counseling research as outlined by Hooker et al [9] (see supplemental material for checklist).

Clinical Context

We conducted a retrospective chart review study using data from a specialist psychiatric genetic counselling clinic (The Adapt Clinic) based in Vancouver, BC, where two board certified counselors provide services to people with a personal or family history of a psychiatric disorder (structure, content, and mode of delivery of sessions is described in Inglis *et al.* 2015)[4]. Clinic patients routinely complete the Genetic Counselling Outcomes Scale (GCOS, see below) as a clinical assessment/contracting tool at the beginning of their genetic counselling session (T1), and complete it again via phone administration by the genetic counselor at one-month follow-up (T2).

Previous research conducted in this clinic has demonstrated higher levels of patient empowerment and self-efficacy following the genetic counselling appointment[4,10].

In the psychiatric genetic counselling context, there are no interventions, referrals or

procedures that are contingent on patient knowledge of recurrence numbers, and thus their disclosure can be driven by patient preference. Our clinical experience reveals that after counselling about: the complex etiology of psychiatric illness; general discussion of how we all have some genetic vulnerability to mental illness, but that generally individual genetic variants are neither necessary or sufficient for psychiatric illness; and strategies for protecting mental health/reducing risk, patients may decide to not receive recurrence numbers. Therefore, routine clinical practice honors this experience, and (as described in Inglis *et al*. 2017)[11] the counselor contracts with patients about desire for numbers both before and after a fulsome discussion of these other issues. Given that there are no clinical guidelines suggesting the use of genetic testing to estimate probability of psychiatric illness onset (outside of the context of a known or suspected genetic syndrome), when recurrence numbers are requested, they are typically generated based on empiric data and analysis of a detailed, three generation psychiatric family history (as described by Austin *et al.* 2008)[12], and provided in the form of absolute risks/frequencies in the context of population rates.

Data collection

All patient data, including: demographic information, primary indication(s) for the appointment (e.g. provision of recurrence numbers, counselling about etiology of mental illness as indicated on referral/by patient at initial contracting), whether a recurrence number was provided, and for whom (e.g. self, children, or other relative), patient perception of the recurrence number (e.g. higher, lower, the same as expected, or did not know what to expect, as documented by the counselor after the in-session discussion), and questionnaire (GCOS data), were collected from clinic databases and review of the patient chart.

Study data were collected and managed using REDCap electronic data capture tools hosted at BC Children's and Women's Hospital[13]. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. The study was approved by the BC Children's and Women's Hospital Research Ethics Board (H17-00254).

Inclusion criteria

All patients seen between 1 February 2012 (the clinic's inception) and 28 February 2017, who had completed the GCOS at both T1 and T2, and who had complete demographic/referral data were included in the study.

Instrument

Genetic Counselling Outcomes Scale (GCOS) is a 24 item, 7-point Likert scale-based questionnaire that measures empowerment[14], defined as "a set of beliefs that enable a person from a family affected by a genetic condition to feel that they have some control over and hope for the future"[15]. The score of this scale can range from 24-168 and higher scores indicating higher levels of empowerment. The GCOS was developed and validated for use in clinical genetics settings and has high internal consistency ($\alpha = 0.87$) and test-retest reliability ($r = 0.86$)[14]. GCOS scores were calculated according to instrument-specific instructions.

Study groups

To test hypothesis 1, regarding whether or not changes in empowerment (as measured by GCOS scores) arising from genetic counselling were related to receiving a recurrence number, we first divided our cohort into two groups representing patients who a) received, and b) did not receive recurrence numbers. Then, for a secondary sub-analysis, these groups were subdivided as followed: 1) patients whose primary indication included recurrence numbers, who ultimately decided to actually receive them ("Yes to Yes" (Y/Y)), 2) patients whose primary indication did not include recurrence numbers, but who received them after expressing desire for them during the course of the appointment ("No to Yes" (N/Y)), 3) patients whose primary indication included recurrence numbers, but who ultimately decided they did not want to receive them ("Yes to No"(Y/N)), and 4) patients whose primary indication did not include recurrence numbers, and who did not receive them ("No to No" (N/N)).

To test hypothesis 2, regarding the relationship between patients' perceptions of recurrence numbers and change in level of empowerment (as measured by GCOS score), we divided our cohort into two groups: 1) those who perceived the number they received to be lower than expected, and 2) those who had other perceptions of the recurrence number they received.

Analyses

We applied descriptive statistics to the demographic data and the research questions about how often recurrence numbers constitute a primary indication, and how often patients ultimately choose to receive these numbers.

To test differences in patient outcomes between groups who did, and did not receive recurrence numbers, we used analysis of the covariance (ANCOVA) on post-appointment (T2) GCOS scores, using baseline (T1) scores as the covariate. We used the same approach to test

differences in patient outcomes between the group who perceived recurrence numbers to be lower than anticipated, and the group that included patients with all other perceptions of the number they were given. Where appropriate, significant findings were further explored with Tukey Post Hoc tests, and analysis of variance (ANOVA). To contextualize data, paired sample t-tests, and standard multiple regression were used to explore the relationship of patient age and T2 GCOS scores.

Statistical significance was assumed at $p<0.01$ after Bonferroni correction. Partial eta-squared (η^2) was used to estimate effect size, with η^2values of 0.01, 0.06, and 0.138 corresponding to small, medium, and large effect sizes, respectively[16]. All analyses were performed using IBM SPSS Statistics Version 23 (IBM Corp., Armonk, N.Y., USA). Prior to performing any of the above analyses, preliminary assessments ensured that there were no violations in assumptions of normality, linearity, and homogeneity of variances. Power calculation revealed that detecting moderate effect sizes (which can be used to approximate clinically meaningful change[17]) would require a sample of N=115 to achieve 80% power.

RESULTS

Recurrence numbers: frequency of indication and uptake

In total, 300 patients met our inclusion criteria (demographic data are shown in Table 1).

<<Insert Table 1 about here>>

Recurrence numbers constituted a referral indication for 134 patients (45%), making it the second most common indication for the appointment (See Table 2).

<<Insert Table 2 about here>>

Ultimately, recurrence numbers were received by 116 patients (39%), with 54 patients' (18%) decisions about receiving recurrence numbers differing from the initial indication for the appointment (see Figure 1).

<<Insert Figure 1 about here>>

Effect of receiving recurrence numbers on empowerment

There were no significant differences in T2 GCOS scores between those who did and those who did not receive recurrence numbers after controlling for T1 score ($F(1,297)=2.016$, $p=0.157$, small effect size ($\eta^2 = 0.007$)).

In our secondary analysis, we repeated the ANCOVA using four study groups (Y/Y, N/Y, Y/N, N/N, as described above) and this analysis showed a statistically significant difference between the T2 GCOS scores after controlling for T1 scores ($F(3,295)=4.89$, $p=0.002$, large effect size ($\eta^2=0.47$)). A Tukey HSD post hoc analysis revealed a statistically significant difference between Y/N and N/N groups; with the Y/N group having a greater increase in GCOS scores compared to the N/N group ($p=0.002$). None of the other comparisons between groups were statistically different ($p>0.01$). There was no significant difference between baseline (T1) GCOS scores between all four groups ($p>0.01$).

Impact of perception of recurrence numbers on empowerment

When recurrence numbers were provided, the majority of the patients perceived the number that they received as being lower than expected (Table 3). After controlling for T1

GCOS score, there were no significant differences in T2 GCOS scores between those individuals who perceived the number as lower than expected, and those who had other perceptions (i.e. higher, the same as expected, or did not know what to expect) of the recurrence number ($p=0.796$, $F(1,113)=0.067$, small effect size, $\eta^2=0.001$).

<<Insert Table 3 about here>>

As a secondary strategy, we repeated the analysis with four groups (representing each of the different perceptions individually: higher, the same as expected, or did not know what to expect, see Table 3), and found no statistically significant differences between any of the groups (all $p>0.01$).

Contextual data

A total of 627 patients were seen at the Adapt Clinic within the study time frame. Of these, 311 (50%) completed the GCOS at both T1 and T2. An additional 11 patients were excluded due to incomplete demographic or referral information.

There were statistically significant increases in GCOS scores from T1 to T2 for those who: did receive numbers, did not receive recurrence numbers (both $p<0.001$, see Figure 2), perceived the recurrence number received to be lower than expected, or had other perceptions of the number they received (both $p<0.001$, see Table 3). As well, there were statistically significant increases in GCOS scores for the sample as a whole (average T1 GCOS score = 111.44, average T2 GCOS score = 126.85 ($p<0.001$,$\eta^2 = 0.663$, large effect size).

<<Insert Figure 2 about here>>

Demographic characteristics were similar to each other between study groupings, aside from age, which was significantly different between those who received and those who did not receive numbers (see Table 1). Despite this, standard multiple regression revealed no significant relationship between age and T2 GCOS scores (age accounted for 0.47% of the variance of T2 GCOS score (p-0.235)). The largest predictor of T2 scores was T1 scores, which accounted for 49.6% of the variance ($p<0.005$). The decision to receive recurrence numbers or not accounted for 1.3% of the variance of T2 GCOS scores and was not statistically significant ($p=0.049$).

DISCUSSION

We present the first data regarding how often patients request recurrence numbers, and how receiving numbers impacts patient outcomes in a psychiatric genetic counselling context. In this study population, discussion of recurrence numbers constituted the second most common indication for genetic counselling[18]. In an earlier study in this same clinic, discussion of recurrence numbers was the most common indication for genetic counselling, this suggests that reasons for referral are evolving [4].

Importantly, after counselling regarding the complex etiology of psychiatric disorders, and risk reduction strategies, fewer than half of all patients receiving psychiatric genetic counselling opted to discuss specific recurrence numbers, with nearly 1 in 5 patients (18%) ultimately making a decision about this that differed from the initial indication for referral and/or desire expressed during initial contracting. This highlights the dynamic nature of the process of contracting to develop a shared understanding of goals and topics for the session – rather than being a discrete task that is accomplished at the beginning of the genetic counselling session, it

may be important to revisit assumptions and desires about session content as it unfolds and evolves to ensure a patient-centred focus.

Given the assumptions about the integral nature of risk communication to the genetic counselling encounter, we hypothesized that the provision of recurrence numbers would associate with greater increases in patient empowerment. However, our data supported no such relationship. Even when patients perceived recurrence numbers to be high – all patients, including those who did and those who did not receive recurrence numbers - demonstrated large increases in GCOS scores. One possible explanation for this observation is that providing recurrence numbers may not be as fundamentally important to genetic counselling as originally speculated – at least from the perspective of patient reported outcomes – the increased empowerment observed after genetic counselling is unrelated to the provision of recurrence numbers, or to the patients' perceptions of the number provided. Indeed, even patients who perceived the recurrence numbers that they received to be higher than expected demonstrated significant increases in empowerment.

We found significantly greater increases in empowerment after genetic counselling among those who decided to not receive recurrence numbers despite it being an initial indication for the appointment (Y/N), compared to those for whom recurrence numbers were not a primary indication, and did not receive them (N/N). Given the current study design, we are unable to determine the direction of causality of this effect, so it is possible either that: 1), the Y/N group's ultimate decision to not receive recurrence numbers arose from feeling empowered by the discussion of genetic etiology, risk reduction strategies and psychotherapeutic support to the extent that they no longer felt the need for recurrence numbers, or alternatively, 2) perhaps the patient's process of decision-making was validated and respected by the genetic counsellor,

which lead to increased empowerment. However, the likelihood of this being the direction of the effect is undermined by the fact that the N/Y group also went through a similar process, in that their ultimate decision differed from the indication for their appointment, but the increase in empowerment observed for this group was not significantly different. It is possible that the Y/N group constitutes a subpopulation of patients who stand to benefit disproportionately from genetic counselling – this is potentially an important issue that warrants further study, especially given the fact that our group sizes for N/Y and Y/N groups were relatively small.

Limitations

This was a naturalistic study based on a convenience sample, and so was influenced by the same factors that shape the population served by the clinic. As a result, our study population was enriched for women and individuals of European background. Our findings may not be generalizable beyond the psychiatric genetic counselling population – though this is an issue worthy of future study. Although our overall sample size was relatively large, we had smaller sample sizes for some of our subgroups. The unequal sample sizes when analyzing the four groups in the secondary analyses may have underestimated the possibility of a type 1 error.

Our sample size places the current study among the largest ever conducted to explore the impact of genetic counseling on patient outcomes[19], and provided good power to detect differences between groups of moderate effect size (that can be used to approximate differences of clinically significant magnitude). Post hoc calculations using *observed* (very small) effect sizes revealed that a sample size of N=1550 would be required for adequate power to detect effects of receiving recurrence numbers and perception of recurrence numbers on patient empowerment. A reasonable interpretation of this is that: 1) provision of recurrence numbers and

2) perception of numbers have effects on patient outcomes that are so small as to render the effects of these variables on the outcome of interest clinically meaningless.

It is possible that the groups of patients in whom we tested our hypotheses are different in some way that confounds hypothesis interpretation. However, the groups were demographically similar, with the exception of age amongst those who did and did not ultimately receive a recurrence number – with those receiving numbers being younger (likely reflecting the patients who were family planning and wanted to discuss recurrence numbers in a preconception setting). Given that the regression model showed no impact of age on the overall prediction of T2 GCOS scores, this difference in age had no impact on difference in change in empowerment between the groups studied.

Conclusion

This is the first study of which we are aware to examine the effects of recurrence numbers on patient outcomes of genetic counselling. Our data challenge the notions that recurrence numbers should be routinely provided in genetic counselling, and demonstrate that optimal patient outcomes are not contingent on receipt of recurrence numbers, at least in a psychiatric setting. Future studies in other contexts where provision of recurrence numbers is driven by patient preference only would be valuable. Our data also support previous findings of the important positive patient outcomes of psychiatric genetic counselling[4,10], and add to the growing body of work on genetic counselling outcomes, which will inform future evidence-based practice in clinical genetics.

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Table 1. Participant demographics

Characteristic	All patients (N=300)	Recurrence number (groups for hypothesis 1)			Perception of number (groups for hypothesis 2)		
		Received recurrence number (n=116)	Did not receive recurrence number (n=184)	p value	Lower than expected (n=64)	Other perception of number‡ (n=52)	p value
Age (mean, years (SD))	41.7(12.8)	35.3(9.5)	45.7(12.8)	<0.001 †	33.9(8.4)	37.1(10.4)	0.074
Female n (%)	239 (80)	94 (81)	145 (79)	0.447	51 (80)	44 (85)	0.331
European n (%)	221 (74)	83 (72)	138 (75)	0.654	45 (70)	38 (73)	0.527
Personal history of mental illness n (%)	242 (81)	90 (78)	152 (82)	0.669	47 (74)	42 (66)	0.181

Legend: †) Standardized multiple regression showed that age did not have a significant impact on GCOS T2 scores (p=0.235). ‡) Other perceptions included: the recurrence number being higher than expected, the same as expected, as well as those who did not know what to expect.

Table 2. Indications for referral and receipt of recurrence numbers

Initial indication for referral/initial interest expressed in contracting	**Number/proportion of patients with initial indication** **n (%)**	**Ultimate, post-counselling decision about receiving recurrence numbers**	
		Received recurrence numbers n (% of those with initial indication)	**Did not receive recurrence number** n (% of those with initial indication)
To understand causes of mental illness n (%)	186 (62)	60 (32)	126 (68)
To learn ways to protect mental health n (%)	86 (29)	18 (21)	68 (79)
To learn chance of illness recurrence n (%)	134 (44)	98 (73)	36 (27)
Self	15 (11)	12 (80)	3 (20)
Child	118 (88)	90 (76)	28(24)
Other relative†	13 (9)	4 (30)	9 (70)
Other indications‡	44 (15)	19 (43)	25 (57)

Legend: Some patients had more than one initial indication for their appointment, and some patients wanted to discuss numbers for more than one relative type. †) Recurrence numbers are typically not provided, even if patients request them, for individuals other than self or children (see Ryan *et al.* 2015)[20] ‡) This category included: unsure/other for 23 patients (8%), pregnancy

related concerns (e.g. teratogen exposures) 18 patients (6%) and 3 patients (1%) wanted to discuss genetic testing.

Table 3. Receipt and perceptions of recurrence number in relation to GCOS score

Group	% (n)	Mean T1 Score (SD)	Mean T2 Score (SD)	Mean change T2-T1 (SD)
Receipt of recurrence numbers in relation to GCOS score (n=300)				
Received numbers	39 (116)	115.1 (16.4)	131.1 (15.5)	15.4 (15.1)
Yes/Yes[A]	33 (98)	114.4 (16.2)	130.4 (15.9)	15.1 (15.3)
No/Yes[B]	6 (18)	109.1 (17.3)	131.2 (16.0)	22.6 (12.0)
Did not receive numbers	61 (184)	111.3 (17.9)	126.3 (18.4)	15.4 (16.5)
Yes/No[C]	12 (36)	119.1 (17.4)	135.3 (12.7)	16.8 (14.4)
No/No[D]	49 (148)	111.7 (18.1)	125.2 (18.8)	13.7 (17.0)
Patient perception of recurrence number in relation to GCOS score (n=116)				
Lower than expected	55 (64)	113.9 (16.2)	130.6 (15.2)	16.7 (11.7)
Other perceptions*	45 (52)	116.6 (16.7)	131.8 (16.0)	15.2 (12.6)
Higher than expected	14 (16)	114.4 (17.6)	128.8 (19.8)	14.3 (15.8)
Same as expected	25 (29)	117.3 (17.8)	134.1 (15.2)	16.7 (11.7)
Unsure what to expect	6 (7)	118.5 (11.1)	126.5 (8.0)	11.0 (13.7)

[A] patients whose primary indication included recurrence numbers, who ultimately decided to actually receive them

[B] patients whose primary indication did not include recurrence numbers, but who received them after expressing desire for them during the course of the appointment

[C] patients whose primary indication included recurrence numbers, but who ultimately decided they did not want to receive them

[D] patients whose primary indication did not include recurrence numbers, and who did not receive them

*** aggregate data from the higher than expected, same as expected, and unsure what to expect perception groups**

Figure 1. Patients' interest in recurrence numbers at different time-points across the genetic counselling process.

Legend: Patient interest in recurrence numbers, as timepoints across the genetic counselling process, including at: a) initial contracting (i.e. indication for referral and/or interest expressed by the patient during initial, general contracting, which occurs routinely at the outset of the session), and b) during risk communication specific contracting (which occurs routinely after counselling about etiology).

Figure 2. GCOS scores at T1 (before genetic counselling) and T2 (1 month post genetic counselling) for patients who did and did not receive recurrence numbers.

Legend: The Y-axis scale reflects the range of possible scores. Scores increased significantly for both groups between T1 and T2 ($p<0.001$; $p<0.001$). After controlling for T1 score, there was no difference in T2 GCOS score between groups who did and did not receive numbers ($p=0.157$). GCOS; Genetic Counselling Outcomes Scale.