Impact of the physical environment on patient outcomes of genetic counseling: an exploratory study

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Running head: Impact of environment on genetic counseling outcomes

Abstract

The psychology literature shows that the physical space in which counseling sessions are conducted influences outcomes of the interaction. However, this phenomenon has not been quantitatively explored in genetic counseling (GC). Through retrospective review of naturalistic data from a psychiatric GC clinic (where patient outcomes are routinely tracked from pre- to 1 month post-appointment using the Genetic Counseling Outcome Scale (GCOS, empowerment) and the Illness Management Self Efficacy scale (IMSES)), we tested the hypotheses that patients seen in comfortably furnished counseling (C) rooms would have greater increases in a) empowerment and b) self-efficacy after GC than patients seen in medically oriented (M) rooms. We matched each patient with complete GCOS and/or IMSES who was seen in a C room between Feb 2012-Dec 2017 to four M room controls where possible. We used T tests to compare change in outcome scale scores between groups. There were no significant differences in change in scores between patients seen in M- type (GCOS n=84, IMSES n=56) and C-type rooms (GCOS n=22, IMSES n=18) ($p=0.241$, $d=0.26$, and $p=0.602$, $d=0.14$, respectively). The effect sizes we demonstrate allow estimation of sample size calculations for the design of future prospective studies.

Keywords: patient outcomes, clinical genetics, psychiatric disorder, mental illness, empowerment, self efficacy, physical environment

Introduction

The importance of evidence-based practice has been recognized by the genetic counseling profession (Cragun & Zierhut, 2018; Hooker, Babu, Myers, Zierhut, & McAllister, 2017) and a growing body of literature regarding patient outcomes of genetic counseling is amassing (Madlensky et al., 2017). At present, however, most of the published studies examining patient outcomes compare genetic counseling to other interventions, or no intervention (Madlensky et al., 2017) and there remains a relative gap in our knowledge regarding how different variables *within* the genetic counseling appointment influence patient outcomes.

Only recently have studies started exploring some of these variables, with a focus on how fundamental components of the genetic counseling process – e.g. mode of collection of family history information (Slomp, Morris, Inglis, Lehman, & Austin, 2018) , provision of numeric probabilities for illness recurrence in relatives (Borle, Morris, Inglis, & Austin, 2018) - influence patient outcomes. There are many other facets of genetic counseling that may influence patient outcomes that have yet to be investigated. Exploring these issues is crucial to allow the genetic counseling profession to make evidence based decisions to optimize the process of service delivery for the improvement of patient outcomes.

One facet of the genetic counseling encounter that may influence patient outcomes is the physical characteristics of the space in which a counseling session is conducted. Indeed, numerous studies have suggested that the physical environment in non-genetic counseling contexts can influence patient/client outcomes (Chaikin, Derlega, & Miller, 1976; Dijkstra, Pieterse, & Pruyn, 2006; Gifford, 1988; Maslow & Mintz, 1956; Mintz, 1956; Pearson, 2012; Pressly & Heesacker, 2001). However, to our knowledge, only one small qualitative study to date has explored this concept in the context of genetic counseling (Phelps et al., 2008). The

authors concluded: "the results suggest that making efforts to provide a less clinical environment for genetic counseling may have benefits for all." (Phelps et al., 2008, pg 404).

The aim of this current study was to test the hypothesis that as compared to patients counseled in a medically oriented (M-type) room, patients counseled in a more comfortably furnished counseling (C-type) room would have greater increases in empowerment and self efficacy after genetic counseling.

Materials and Methods

We conducted a matched cohort study using data gathered from a retrospective review of ~1000 clinical charts of patients who received genetic counseling at a specialist psychiatric genetic counseling clinic in Vancouver BC. Though the study was not conducted as a prospective intervention study, but rather used data from naturalistic clinical practice, we nevertheless opted to use the reporting standards for genetic counseling research (Hooker et al., 2017)(see supplemental material for checklist) (Hooker et al., 2017).

Clinical Context

Appointments in the psychiatric genetic counseling clinic (covered by the publicly funded healthcare system) are provided by one of two board certified genetic counselors, (trained by the same supervisor (JA) to provide psychiatric genetic counseling) and both of whom typically conducted appointments in an M-type room, with C-type rooms (see description below) used by both counselors as available. As part of routine practice, all patients complete validated questionnaires (the Genetic Counseling Outcome Scale – GCOS, and Illness Management Self Efficacy Scale – IMSES, both described below) as clinical assessment tools both at the

beginning of their ~90 minute genetic counseling encounter (as a contracting tool) (T1) and via telephone during a ~30 minute call (counselor administration) approximately one month later (T2). The genetic counseling provided aligns with the Reciprocal Engagement Model (Veach, Bartels, & Leroy, 2007) and is psychotherapeutically oriented, with attention paid to issues around guilt, fear, blame, and stigma that patients attach to explanations for cause of illness. Visual aids are used to help patients make coherent meaning of how genes and environment work together to precipitate mental illness. Genetic testing – if indicated (e.g. for 22q Deletion Syndrome) – is facilitated in a separate visit with an MD, subsequent to the genetic counseling appointment and follow up. When patients wish to receive information about numerical chances for illness recurrence for themselves or their children (Borle et al., 2018), these are derived based on empirical data and family history (Austin et al., 2008) and provided in the form of absolute risks/frequencies in the context of population rates. Clinical data including GCOS and IMSES, demographic data, and type of room the patient was seen in are recorded in a clinical database. Previous research conducted in this clinic demonstrates significant increases in patient reported empowerment and self-efficacy after genetic counseling (Borle et al., 2018; Inglis, Koehn, McGillivray, Stewart, & Austin, 2015; Slomp et al., 2018).

Descriptions of counseling environments

The classification of rooms as M-type or C-type was a consensus-based process involving all authors, and based on overall gestalt of the physical space.

M-type rooms

The two M-type rooms were both located within the Provincial Medical Genetics Program, at BC Women's Hospital. These rooms have natural light but also involve hard floors

and chairs, a round table (of working height), medical equipment and sometimes an examination bed, and no art-work (see Figure 1 panels A and B.)

C-type rooms

The two C-type rooms used in the study were located within the medical genetics department at Vancouver Island Hospital (Figure 1, panel C) and within the Richmond Child and Adolescent Program, BC (Figure 1, panel D). The Victoria room had no natural light, but contained soft comfy chairs, art-work, a rug, and a low, coffee-type table. The Richmond room had natural light, soft chairs and a sofa (not shown), art-work, carpeted floors, and a low, coffee-type table. Neither of the C-type rooms contained medical equipment (e.g. examination bed).

<<Insert Figure 1 here>>

Procedures

Charts of patients who were seen in the clinic between 1 February 2012 and 31 December 2017 who: had in-person appointments, were English speaking, and had completed the GCOS and/or IMSES both at the beginning of their appointment (T1) and one month following their appointment (T2) were reviewed for potential inclusion. As there were far fewer patients in the data set that were counseled in a C-type room, all of these patients were included in the study. We then used matching, a pseudo-randomization technique (that aims to control for variables that are known to be correlated with the outcomes but that are not of direct interest to the study) (Stuart, 2010) to match each patient counseled in a C-type room with four patients counseled in an M-type room. Matching was based on the following criteria (listed in terms of priority from most critical to least critical): patients' mental illness history status (i.e. personal or family

history, and the patient's primary diagnosis if applicable), sex, and age. For all patient charts included in the analysis, data were abstracted regarding: demographic variables, the type of space the patients were seen in (i.e. C-type or M-type room), and GCOS and IMSES scores.

Study data were collected and managed using REDCap (Research Electronic Data Capture) tools hosted at BC Children's and Women's Hospital. REDCap 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 (Harris et al., 2008). The study was approved by the BC Children's and Women's Hospital Research Ethics Board (H17-02109).

Instrumentation

The GCOS is a validated, 24-item instrument that measures empowerment (McAllister, Wood, Dunn, Shiloh, & Todd, 2011). Each item is rated on a 7-point anchored Likert scale (1= strongly disagree, 7 = strongly agree). Scores range from 24 to 168 with higher scores indicating higher levels of empowerment. All patients (regardless of whether they had a personal and/or family history of psychiatric illness) attending the psychiatric genetic counseling clinic completed the GCOS whenever possible.

The IMSES is a 9-item, self-report questionnaire that measures self-efficacy related to illness management (that is, confidence to manage one's own illness), adapted from the Chronic Disease Self-Efficacy Scales (using the manage disease general subscale) (Lorig, Stewart, Ritter, González, & al, 1996). Each item is rated on a 10-point anchored Likert scale (1 = not at all confident and 10 = completely confident), and mean scores are calculated with higher scores

indicate higher levels of self-efficacy. Only patients who had a personal history of psychiatric illness completed the IMSES.

Data Analyses

We applied descriptive statistics to the demographic data. Based on instructions on use of the GCOS, patients who left more than five items blank on the GCOS were excluded from analysis, and data were imputed for those with fewer missing items. For the IMSES, mean item scores were used after excluding patients who left more than 2 items blank. For both scales, change scores were calculated (by subtracting T1 score from the T2 score), and checked for normality of distribution and equal variance assumptions. Hypotheses were tested by comparing these change scores between the two study groups using independent sample T tests (using IBM SPSS Statistics Version 23, IBM Corp., Armonk, N.Y., USA). A significance threshold (α) of $p < 0.025$ was applied (to allow for two tests at a nominal overall significance level of 0.05).

Given that there were no pre-existing data in the context of genetic counseling from which to estimate the size of the effect of C-type rooms versus M-type rooms on GCOS and IMSES scores, and therefore no data on which to base a power calculation, we used our convenience sample, and conducted post hoc power calculations (to help interpret the veracity of our results) using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007).

Results

We identified 22 patients seen in a C-type room that met all inclusion criteria. We successfully matched 18/22 C-type patients each with 4 M-type patients, while the 4 remaining C-type patients only had 3 M-type patients available (total M-type patient matches n=84), to

generate a total sample size for analysis of N=106. Of the C-type patients, 20/22 individuals had a personal history of mental illness, 18 of which had complete IMSES data. The remaining 2/22 C-type patients were parents of an individual with a personal history of mental illness and therefore did not complete the IMSES. Some of the M-type patient matches for these 18 C-type patients did not have complete IMSES data resulting in a total sample size for IMSES analysis of N=74. Demographic data for patients who were included in the study are shown in Table 1.

<<Insert table 1 about here>>

Overall (using combined data from all 106 charts for GCOS, and 74 charts for IMSES), average scale scores increased significantly from T1 to T2 for the GCOS (t = -13.861, $p <$ 0.0001, d = 1.35), and for IMSES (t = -3.458, p = 0.001 d = 0.37).

Effect of counseling environment on change in GCOS scores

There was no significant difference in baseline mean GCOS scores between groups counseled in C-type and M-type rooms (t = -0.038, p = 0.971). Assumptions about normality of distribution and equal variances of GCOS change score data were met. Though there was an almost 4-point difference in mean GCOS change scores between patients seen in C-type and M-type rooms, with the C-type room patients having the larger increase (see Table 2), the difference was not statistically significant (t = 1.179, p = 0.241, d = 0.26), see Figure 2.

<<Insert Table 2 about here >>

<<Insert Figure 2 about here>>

Effect of counseling environment on change in IMSES scores

There was no significant difference in baseline mean IMSES scores between groups counseled in C-type and M-type rooms ($t = 0.048$, $p = 0.875$). Assumptions about normality of distribution and equal variance of IMSES change score data were met. Mean IMSES scores of C-type room patients increased by 0.15 additional points compared to M-type room patients (see Table 2), but again this difference was not statistically significant ($t = 0.524$, $p = 0.602$, $d = 0.14$), see Figure 3.

<<Insert Figure 3>>

Power

Given the observed effect sizes, post hoc power calculations revealed that our sample was under-powered (19% power for the hypothesis regarding the GCOS score, and 7% power for the hypothesis regarding IMSES), and therefore vulnerable to type 2 error (failing to reject a false null hypothesis). Using our observed effect sizes, a sample of n=728 for GCOS, and n=2506 for IMSES would be required to achieve adequate (80%) power to detect a significant difference between groups in future studies.

Discussion

This is the first quantitative study of which we are aware to explore the effects of the physical environment on patient reported outcomes of genetic counseling. Though change in

GCOS and IMSES scores appeared to be larger for the C-type room group, the difference was not statistically significant.

No prior research has quantitatively examined whether physical environment influences patient outcomes in the context of genetic counseling. Findings of a qualitative study suggested that a non-medical environment for receiving cancer genetic counseling was perceived positively by patients (Phelps et al., 2008) and while our data did not find significant differences or large effects of the C-type rooms on patient outcomes, it is possible that there are other outcomes (other than empowerment and self-efficacy) and patient benefits not captured in our study. Other research findings in other domains (Chaikin et al., 1976; Dijkstra et al., 2006; Gifford, 1988; Maslow & Mintz, 1956; Mintz, 1956; Pearson, 2012; Pressly & Heesacker, 2001) have identified increases in self-disclosure, positive impressions of the counselor, feelings of comfort, and relaxation when counseling sessions were held in more spaces analogous to our C-type rooms (Gifford, 1988; Pressly & Heesacker, 2001). Conversely, sessions held in spaces broadly analogous to our M-type rooms have been shown to increase hostility and negative perceptions among clients (Mintz, 1956). While we did not measure parameters such as these in our study, it seems plausible, given that the counseling process is dependent on patients feeling comfortable and engaged, that these types of variables may influence other types of genetic counseling outcomes, in addition to the small effects we observed in the outcome measures in our study.

Study Limitations

Given that there was no pre-existing data from which to estimate required sample size to achieve adequate power, we used an exploratory approach with a convenience sample. Thus, our sample size was limited by the number of patients who - in the context of naturalistic clinical

practice - had been seen in the C-type rooms, and was underpowered. However, this exploratory work has provided us with data to estimate the sample size for future work that would allow this question to be addressed more definitively. Given that we do not yet understand how effect size relates to clinical impact in the context of these two scales, further research into the clinical significance of changes in GCOS and IMSES scores is also needed.

The optimal study design to address the question of whether physical environment influences patient outcomes of genetic counseling would involve true randomization of patients to C-type or M-type rooms. Though this was not possible in the context of the current study, the pseudo-randomization matching technique we applied was used to control for variables other than counseling setting as much as possible (Stuart, 2010).

The rooms of different types were not constructed or designed purposefully for the study, but rather were spaces that were used as part of naturalistic clinical practice, and as such their classification into C and M types was a subjective process based on overall gestalt. For example, though both of the M type rooms had natural light, all authors agreed they still felt very much medically oriented in the overall impression they generated.

The study was conducted in the context of a specialist psychiatric genetic counseling clinic, and the group studied was enriched for those who were English speaking, women, and/or of European ancestry. As such, the findings may not be generalizable to other areas of practice or to different demographic groups.

Practice Implications

This study shows that overall patients benefit significantly from psychiatric genetic counseling and with a large effect, regardless of the setting in which the counseling is performed.

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Research Recommendations

Further research into the clinical implications of changes in empowerment and self-efficacy scores would allow for better interpretation of the clinical significance of the small effect of the counseling environment on patient outcomes observed in our study. Given the potential importance of this small effect in our findings, a larger prospective study using purpose designed spaces and involving patients attending genetic counseling appointments for a diverse range of conditions may be worthwhile.

Authorship Contributions

EM contributed to data collection, analyses, and manuscript preparation. JB contributed to data analyses and manuscript preparation. AI contributed to data collection and manuscript preparation. JA contributed to study design, data analyses and manuscript preparation.

Acknowledgements

Conflict of Interest

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Figure Legends

Figure 1: M-type and C-type rooms
Legend: M-type rooms are shown in panels A and B, C-type rooms are shown in panels C and D.

Figure 2. GCOS scores prior to GC (T1) and 1 month post-GC (T2) for patients counseled in C-type and M-type rooms.

Figure 3. IMSES scores prior to GC (T1) and 1 month post-GC (T2) for patients counseled in C-type and M-type rooms.

Table 1. Demographics

	Total patients (*N* = 106)	Patients seen in M-type room (*n*=84)	Patients seen in C-type room (*n* = 22)
Age [mean (SD)]			
Mean (years)	42.2 (13.3)	42.4 (12.97)	40.8 (14.73)
Sex [% (n)]			
Female	69.8 (74)	70.2 (59)	68.2 (15)
Male	30.2 (32)	29.8 (25)	31.8 (7)
Indication for Counseling [% (n)]			
Personal experience with mental illness	90.6 (96)	90.5 (76)	90.9 (20)
Depression	76.0 (73)	76.3 (58)	75.0 (15)
Bipolar disorder	10.4 (10)	10.5 (8)	10.0 (2)
Anxiety	13.5 (13)	13.1 (10)	15 (3)
Parent of Affected Individual	9.4 (10)	9.5 (8)	9.1 (2)

Table 2. GCOS & IMSES scores

GCOS Scores mean (SD)	Total patients (N = 106)	Patients seen in M-type room (n=84)	Patients seen in C-type room (n = 22)
T1	110.33 (17.91)	110.36 (17.74)	110.20 (18.98)
T2	127.42 (19.03)	126.71 (19.98)	130.2 (14.93)
Mean change (T2-T1)_	17.09 (12.69)	16.3 (11.81)	19.9 (15.62)
IMSES Scores [mean (SD)]	Total patients (N = 74)	Patients seen in M-type room (n=56)	Patients seen in C-type room (n =18)
T1	7.30 (1.41)	7.28 (1.43)	7.34 (1.36)
T2	7.73 (1.41)	7.68 (1.37)	7.89 (1.57)
Mean change (T2-T1)	0.43 (1.08)	0.40 (1.08)	0.55 (1.08)