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THE ROLE OF INSIGHTFUL DISCLOSURE IN OUTCOMES FOR WOMEN IN PEER-DIRECTED BREAST CANCER GROUPS: A REPLICATION STUDY

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ABSTRACT

This study was stimulated by the recent publication (Health Commun 2006;19(2):133–142) who reported the effects of insightful disclosure on outcomes in ‘peer-led internet breast cancer support groups. The present study attempted to replicate their hypotheses using the same methods for coding insightful disclosure as well as parallel outcome measures. Four hypotheses are tested; writing a higher percentage of insightful disclosure words will be associated with: (1) fewer BC concerns; (2) reduction in the emotional distress; (3) better physical health; and (4) few functional limitations. New members to BC bulletin boards (BB) were recruited through BB postings and/or e-mails. We asked them to fill out questionnaires measuring depression and quality of life, when they joined the BB, and again six months later. Two questionnaires (CESD and FACTB [Functional Well being, Physical well being, and Breast cancer Concerns]) were administered and repeated six months later. For two of the four outcome measures (Functional Well being and Breast Cancer Concerns), insightful disclosure played a crucial and significant role, the other two showed a trend toward significance (CESD and Physical well being). The three control variables, stages, years of cancer and level of participation all had effects on the outcomes, varying with the type of outcome measure. The findings, in this study, support Shaw et al. hypotheses. In their study, only one outcome measure, reduction of emotional distress was significant.

INTRODUCTION

This study was stimulated by the recent publication [1] who reported the effects of insightful disclosure on outcomes in peer-led internet breast cancer support groups. The present study attempted to replicate their hypotheses using the same methods for coding insightful disclosure as well as parallel outcome measures. Shaw et al. viewed the key questions as whether the act of making sense out of one's traumatic experience can help to reduce the ruminative thoughts associated with illness. They expected that a higher percentage of insightful disclosure words written within an online support group will result in fewer breast cancer (BC) concerns (worries about body image, side effects, and sexuality). Four hypotheses were tested. Writing a higher percentage of insightful disclosure words will be associated with: (1) fewer BC concerns; (2) reduction in the emotional distress; (3) lower levels of negative emotions; and (4) improved emotional well-being. The goal of the current study is to test their hypotheses. In the present study, the underlying theory is based on Lepore's [2] social-cognitive processing model of emotional adjustment to cancer. His model argues that cognitive integration of the challenging aspects of cancer, including diagnosis, treatment, and future health risks, occurs through mental processes of assimilation (reappraising events to fit preconceptions) or accommodation (changing mental models to fit information inherent in a traumatic event). Through assimilation and accommodation processes, people with cancer interpret their illness in personally meaningful terms, integrate threatening and confusing aspects of the disease into a coherent conceptual framework, and achieve intellectual or emotional resolution. In essence, they engage in an active process of confronting, contemplating, and re-evaluating aversive, trauma-related stimuli in a manner that facilitates emotional adaptation.

The Internet holds the promise of increasing access to health care to all Americans and reducing health-care disparities. Of the estimated current 165 million internet users in the US, approximately fifteen million have visited online support groups [3]. Further, when asked whether they visited an online support group yesterday, approximately 1.6 million responded in the affirmative. In recent years, there has been growing evidence that online groups are effective. A meta-analysis of studies concluded that online cancer support groups helped people cope more effectively their disease [4]. They reported an overall effect size of 0.42 (range 0.15–0.69). Peer-led groups are the fastest growing Internet resource for people with cancer yet only a handful of studies across diseases have evaluated the effectiveness of such groups. Eysenbach [5] examined 38 studies of health-related online community interventions, but found that only six of these evaluated ‘pure’ peer-to-peer communities. Most of the studies included other treatment arms, combined interventions, or incorporated professional intervention. He concluded that insufficient data are available to assess the efficacy of these online communities. Klemm et al. [6] in a recent review reported on nine OSG studies.

These studies, along with our own study [7] provide some evidence that these peer-led groups are effective. Studies of processes linked to outcomes in peer online cancer groups are rare. Lieberman and Goldstein [8] using text analysis methods reported that in five BC peer online groups participants who expressed more anger predicted higher quality of life and lower depression, while the expression of fear and anxiety predicted lower quality of life and higher depression. Another study [9] used a self-report questionnaire, Helpful Group Experiences (HGE). Five dimensions were assessed: support; disclosure; existential; cognitive; and altruism. Overall, follow-up changes were significant, with moderate to strong effect sizes. The overall regression for depression (CESD) was highly significant, post traumatic growth (PTGI) showed a trend and quality of life (FACTB) was not significant. Members who reported that cognitive experiences were very important, showed at time two lower depressions, while those who viewed existential experiences as important, showed higher depression. The only HGE linked to PTGI was a report of frequent altruistic experiences.

Evidence of the role of both emotional expression and insightful disclosure can be found in the work of Pennebaker and his colleagues. Particularly relevant to the current study is Pennebaker, Mayne, and Francis’s study [12] that analyzed disclosure essays and found that there were specific linguistic factors that reliably predicted improved physical health outcome. They found that a higher percentage of insightful disclosure words; terms associated with learning or understanding (e.g. realize, see, understand, and know) were strongly associated with improved health.

METHODS

New members to BC bulletin boards (BB) were recruited through BB postings and/or e-mails. We asked them to fill out four questionnaires that measured depression, reaction to traumatic events, pain, and quality of life, when they joined the BB and again six months later. Bulletin board selection We searched the Internet for BC BB’s. The search yielded more than 100 results. Four criteria were used to choose acceptable boards. (1) The boards chosen all had more than 20 postings a day, and most averaged considerably more, ensuring an active community. (2) Provided emotional support (those that provided primarily medical information were excluded).

(3) Had an archive which enabled the confirmation that people joining the study were in fact new members. (4) Gave us permission to recruit participants.

PROCEDURE

Moderators of boards were asked their preference for us to recruit members. An agreed upon message was drafted inviting new members to participate in 'a study of BC BBs.' The study web site described the human subjects' consent. Because names or identifying information was not requested (participants used their BB pseudonym), UCFS's Committee on Human Research Participants did not require a signed consent form. Participants were informed that joining the study was voluntary, and the study required them to complete four online questionnaires (in this replication study, only two were used) upon joining the study and again six months later. Those interested were directed to fill out the questionnaires. After filling out the questionnaires on the study website, the initial posting by each participant was located to ensure that the participant was a new member (one who had joined the board less than eight weeks before participating in the study). This criterion was used in order to ensure that new members had an opportunity to read the e-mail study invitation. Participants received an e-mail thanking them for their interest and informing them that they would receive a follow-up e-mail in six months asking them to fill out a similar set of questionnaires. After six months, an e-mail was sent reminding them about the study and asking them to return the study web site to fill out the final set of questionnaires.

MEASURES

Two of the four questionnaires that paralleled the Shaw study were used for this replication. The Center for Epidemiological Study Depression Scale (CES-D) The CES-D [10] is a 20-item, Likert self-report scale developed to measure depression in the general population. The CES-D shows high internal consistency, alpha $\frac{1}{4}$ 0:85 in the general population, and good reliability after six months $r = 0:54$:

Functional Assessment of Cancer Therapy-Breast (FACT-B) The FACT-B is a multidimensional quality of life questionnaire developed for BC patients [11]. It consists of the FACT-G, a quality of life measure for any cancer patient, and a Breast Cancer Subscale. Three scales of the six scales from the FACTB were used to assess outcomes in this study, Functional Well Being (FB), Physical Well Being (PFB) and Breast Cancer Concerns (BCC). The correlations at time 1 among these were PB FB $\frac{1}{4}$ 0:18; PB BCC $\frac{1}{4}$ 0:45; FB BCC $\frac{1}{4}$ 0:70: These three account for the majority of variances in the measure. Furthermore, there is a moderately high correlation between emotional distress (a scale not used in this study) and the CESD depression measure.

Computer-based text analysis [The Linguistic Inquiry and Word Count (LIWC) [12] procedure was utilized to examine the hypothesis that the manner in which cancer patients write about their illness and its treatment contributes to positive outcomes in cancer support groups. The dictionary provides a method called LIWC for studying the various emotional, cognitive, structural, and process components present in written speech. This study used one cognitive scale, insight disclosure based on 116 words (e.g. aware, know, realize, think, and understand). This procedure has been extensively utilized in studies examining the beneficial effects of writing about traumatic life events.

The study sample of 77 women drew from six BC BBs were mostly married (75%). Their mean

age was 45.1 (SD 8.4) ranging from 29 to 65. There was a well-educated group, 16% college graduates, 21% professional or graduate school, and the remainder stated that they had some college. All were Caucasian, 60% were currently working. Cancer stages were: stages I 1/436%; II 1/434%; III 1/423%; and IV 1/47%. Before they began participating in the newsgroup, 80% lurked, Table 1. Linear regressions; hypothesis test typically one or two weeks reading the post before posting themselves. A little more than 30% had some form of professional psychotherapy to address their problems associated with the cancer. They were all heavy users of the internet: 12% had been in chat rooms; 45% in other BBs; and all used the internet for information about their cancer. Four linear regressions were calculated for the outcome dimensions: depression (CESD); functional well being (FB); physical well being (PFB); and BCCs. The LWIC insightful disclosure dimension (scored as percentage of total words) was used in a three step regression: at step 1, the time 1 score of the outcome measure was entered; at step 2, control variable (BC stage, number of months since cancer diagnosis and frequency of participation (number of weeks)) over the six months were entered. All three could potentially impact the outcome variables used. At step three, the insightful disclosure dimension was entered. Prior to computing the regressions, education and age were tested for their relationship to insightful disclosure, education ($r = 0.07$; age $r = 0.00$). Results Table 1 shows the results of this analysis. For all the four outcome measures, insightful disclosure played a role. Two of the regressions were significant, functional well being and BCCs. Both depression and physical well being showed a significant trend. The three control variables, stages, years of cancer, and level of participation all had effects on the outcomes, varying with the type of outcome measure.

The findings in this replication study support the hypothesis proposed by Shaw et al. [1]. The differences in the relative power of this study compared to the findings reported in the Shaw et al. study is examined in the discussion section. Steps R squared change F change d.f. Significance F 1. CESD1 0.25 29.3 172 0.2. Stage, participation, years cancer 0.04 1.51 369 0.25 3. Insightful disclosure 0.03 3.03 168 0.08 1. Physical well being 0.15 12.2 169 0.001 2. Stage, participation, years cancer 0.13 4.01 366 0.01 3. Insightful disclosure 0.04 3.48 165 0.06 1. Functional well being 0.02 1.55 169 0.21 2. Stage, participation, years cancer 0.06 1.51 366 0.22 3. Insightful disclosure 0.05 4.1 165 0.05 1. Breast cancer concerns 0.03 1.78 169 0.19 2. Stage, participation, years cancer 0.21 5.96 266 0.001 3. Insightful disclosure 0.07 6.52 165 0.01

DISCUSSION

The positive results linking insightful disclosure to outcomes using a rather simple measure, counting the number of insightful disclosure words used by BC women in asynchronous support groups is encouraging. The role of cognitive factors in a wide variety of tradition (face-to-face) therapeutic and support groups have been well documented.

The finding that some similar process plays a role in online groups suggests that the models developed over many years to study psychotherapy and support groups have relevance for the newer setting provided by the Internet. In comparison to the results of the Shaw et al. study of support groups which found that only the outcome measure, and emotional distress, our positive findings are more extensive. Their study found that neither BCCs nor physical well being was significantly impacted by insightful disclosure. The samples and setting are of course different, although CHESS (Comprehensive Health Enhancement Support System) groups are not

professionally facilitated and thus resemble the peer groups we studied, the groups occur within a professional environment. Our sample was a more educated group, but we did find no relationship between educational level and frequency of insightful disclosure words, a strategy not available to the women in the CHESS study. The studies also differed in the ethnic composition, the CHESS study that had a representation of 26% minority members. This study was 100% Caucasian. A previous publication of the CHESS group [13] reported that minority BC women used the support group differently than did Caucasian women. The former was more likely to emphasize the instrumental knowledge about their illness and treatment, but white women focused much more on their daily lives and their feelings. Another possible explanation for these differences is the recruitment and entry procedures used by the BB's we studied. In a previous publication [14] we provided findings supporting the hypothesis that participants select the particular groups that best fits their needs. All the online groups encouraged 'lurking', reading the postings before joining. We found that 74% lurked, half of them for about a week, the other half from two to eight weeks and 48% shopped for the 'right fit' by trying out other internet BC groups. Perhaps the match between participant and group enhanced the effectiveness of the group and led to our findings about insightful disclosure, a strategy not available to the women in the CHESS study.

There are some limitations to our analysis that one should consider. Our results, while suggestive, are correlational by nature. Therefore, it is impossible to say whether the frequency of insightful disclosure words is a cause of the changes or is simply a manifestation of such changes. Nonetheless, our results are buttressed by the finding that insightful disclosure was not associated with time 1 scores, showing that the final regressions were not an artifact of baseline scores. Another major limitation in this paper is the lack of a control group and randomization. Unfortunately, due to the nature of peer-led BBs, randomization is near impossible. The culture of such groups emphasizes that all are welcome. Furthermore, since the study was voluntary, it is unclear how the experiences of those that chose not to participate differed.

Table I. Linear regressions; hypothesis test

Steps	R squared change Significance	F change	d.f	P.
I. CESDI	0.25	29.3	172	0
2. Stage, participation, years cancer	0.04	.51	369	0.25
3. Insightful disclosure	0.03	3.03	168	0.08
I. Physical well being	0.15	12.2	169	0.001
2. Stage, participation, years cancer	0.13	4.01	366	0.01
3. Insightful disclosure	0.04	3.48	165	0.06
II. Functional well being	0.02	.55	169	0.21
2. Stage, participation, years cancer	0.06	1.51	366	0.22
3. Insightful disclosure	0.05	4.1	165	0.05
III. Breast cancer concerns	0.03	1.78	169	0.19
2. Stage, participation, years cancer	0.21	5.96	266	0.001
3. Insightful disclosure	0.07	6.52	165	0.01

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