The relationship between religious expression and outcomes in online support groups: A partial replication

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1. Introduction

The Internet holds the promise of increasing access to health care and reducing health care disparities. In particular, the Internet has the potential to reduce barriers that many people with a variety of physical and mental illness face trying to obtain psychosocial support group services. Results from a 2005 Harris poll indicated that 74%, or approximately 117 million Americans, have gone online for health information (Harris Poll, 2005). Research sponsored by the Pew Internet & American Life Project (Pew Internet & American Life Project, 2003) has shown that many Americans use the Internet to provide and receive support and information. For example, more than half (54%) of Internet users, or about 63 million Americans, have visited a Web site that provides online support group services. Results from a 2005 Harris poll indicated that 74%, or approximately 117 million Americans, have gone online for health information (Harris Poll, 2005). Research sponsored by the Pew Internet & American Life Project (Pew Internet & American Life Project, 2003) has shown that many Americans use the Internet to provide and receive support and information. For example, more than half (54%) of Internet users, or about 63 million Americans, have visited a Web site that provides online support groups (OSG) for people interested in a specific medical condition or personal situation (Fox & Fallows, 2002). Further, when asked whether they visited an OSG yesterday, 1.6 million responded in the affirmative. The magnitude of the availability of online support groups can perhaps be demonstrated by those hosted by one Web portal, Yahoo, that enables 32,401 support groups for health/illness problems.

The number and quality of studies evaluating the effectiveness of Web-based support settings have grown over the past several years although, to date, definitive studies are not available. In contrast, there have been dozens of randomized controlled trials (RCTs) designed to test the efficacy of various face-to-face psychosocial interventions for cancer patients, including face-to-face education and support groups (Lepore & Coyne, 2006). The evidence on the efficacy of these interventions has been debated (Andrykowski & Manne, 2006; Coyne, Lepore, & Palmer, 2006; Lepore & Coyne, 2006; Manne & Andrykowski, 2006), but the results from recent large-scale and carefully controlled trials suggest that persons with cancer who have high needs (e.g. elevated distress, low psychological or social coping resources, low levels of education) do appear to benefit from psycho-educational and supportive interventions (Goodwin et al., 2001; Helgeson, Cohen, Schulz, & Yasko, 2000; Helgeson, Lepore, & Eton, 2006; Lepore, Helgeson, Eton, & Schulz, 2003; Nezu, Nezu, Feligoe, McClure, & Houts, 2003).

Despite the widespread use of OSGs by people with cancer, there have been very few studies, especially RCTs, on the efficacy of OSGs in improving cancer patients’ quality of life and level of...
depression. In one review, (Klemm et al., 2003) identified 10 non-controlled, descriptive research studies on computer-mediated cancer support groups. Nine of the 10 studies concluded that OSGs help people to cope more effectively, but none of them used randomization to groups or a control group. Similarly, Eysenbach and colleagues (Eysenbach et al., 2004) conducted a comprehensive, systematic review of online, peer-led OSGs that included efficacy data and found thirty eight studies. Because the reviewed OSG interventions typically had less than optimum research designs, and small non-representative samples, Eysenbach et al. (2004) concluded that there was no robust evidence on the health benefits of OSGs. They called for more research on the efficacy of OSGs, on which conditions and for whom they are effective, and on how to improve the effectiveness of delivering OSGs.

More recently a handful of investigators have turned their attention to online processes in the support group. A variety of group processes and participant experiences have been studied that link events in the interaction with outcomes. Most of those selected for study have been borrowed from traditional small group research and/or group psychotherapy. Studies of OSG’s have tested the hypotheses that groups characterized as having (a) higher “cohesiveness,” (Lieberman, Winzelberg, Golant, & DiMinno, 2005) (b) more norm-regulated behaviors, (Lieberman, Golant, & Altman, 2004) and (c) greater agreement between participants and leaders show more improvement than participants in groups low on these characteristics (Lieberman & Golant, 2002); (d) group participants who express higher rates of fear and anger will obtain more benefit from their participation than participants lower on these measures (Lieberman & Goldstein, 2005a,b); (e) group members who express higher levels of perceived social support. H6: Writing a higher percentage of religion words will be associated with higher levels of emotional well-being, health self-efficacy, and positive reframing.

Using Pennebaker’s LIWC text analysis software program (Pennebaker & Francis, 1999) seven hypotheses were examined; H1: Writing a higher percentage of religion words will be associated with fewer breast cancer-related concerns. H2: Writing a higher percentage of religion words will be associated with lower levels of negative emotions. H3: Writing a higher percentage of religion words will be associated with higher levels of emotional well-being. H4: Writing a higher percentage of religion words will be associated with higher levels of health self-efficacy. H5: Writing a higher percentage of religion words will be associated with higher levels of perceived social support. H6: Writing a higher percentage of religion words will be associated with higher levels of functional well-being. H7: Writing a higher percentage of religion words will be associated with higher levels of positive reframing.

The goal of this study is to replicate their findings of the impact of religious expression in asynchronous online groups using the same text analysis procedures and many of the same outcome measures. Specifically, we will test the central hypothesis that the percentage of religious words written by members of online breast cancer support groups will be associated with improvement in psychological outcomes.

2. Methods

For this study, five online breast groups from our previous work (Lieberman & Goldstein, 2005a,b) were available for review. This sample consisted of five peer-led asynchronous groups available on the Web to all interested members. Ninety-one participants from these groups completed baseline and 6 months post-measures. On average they posted 471 messages (sd = 259) over 6 months. See Table 1 for participant and group demographics. Messages were analyzed using the LIWC software. The study was approved by the UCSF’s Human Subject committee.

This uncontrolled study evaluated the impact of peer-led BC online support groups on women’s level of distress and quality of life (i.e., depression, psychosocial well-being, and post-traumatic growth. One hundred and fourteen participants were recruited, 91 completed the measures at baseline and 6 months later (follow-up). All five peer groups had a large active membership which provided for new members to experience high levels of similarity with a subgroup of similar women that usually responded within a day to the new member. These groups appear to remain relatively stable over time in total membership; they are ongoing systems that, despite some turnover, manage to keep a core of active members that provide continuity. The core members share views that provide a framework of how to cope with the disease, involving the notion of fighting and actively combating the disease. In addition, they encourage lurking which permits new members to both learn the culture of the group and make a decision about participating.

3. Measures

In addition to demographic data, participants completed the following measures at baseline and post-treatment.

\textit{The center for epidemiological study depression scale} (CES-D), (Radloff, 1977). The CES-D is a 20 item Likert self-report scale

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<tr>
<th>Ethnicity</th>
<th>CHESS</th>
<th>Current</th>
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<tbody>
<tr>
<td>Caucasian</td>
<td>72%</td>
<td>100%</td>
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<tr>
<td>African-American</td>
<td>25%</td>
<td>0%</td>
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<tr>
<td>Hispanic</td>
<td>1%</td>
<td>0%</td>
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<tr>
<td>Asian</td>
<td>1%</td>
<td>0%</td>
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<tr>
<td>Native American Indian</td>
<td>1%</td>
<td>0%</td>
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<tr>
<td>Percent religious Expression</td>
<td>59%</td>
<td>82%</td>
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Table 1: Demographics; CHESS study, current study.
developed to measure depression in the general population. The CES-D shows high internal consistency (α = .85) in the general population, and good reliability after 6 months (α = .54).

Functional assessment of cancer therapy-breast (FACT-B). (Cella, Tulsky, & Gray, 1993). The FACT-B is a multidimensional quality of life questionnaire developed for BC patients that assesses psychosocial well-being. It is the same primary measure used in the Shaw study. It consists of the FACT-G, a measure designed for any cancer patient, and a BC Subscale. The scales used in this replication study are Physical well-being, Social well-being, Functional well-being and breast cancer concerns. Internal reliability (r = .88) (Brady et al., 1997). Measures used in the Shaw study included the subscales of the FACT-B.

spiritual beliefs. We used two items from The PTGI (Tedeschi & Calhoun, 1996) to assess spirituality. Respondents were asked to indicate for each of the statements below the degree to which this change occurred in their lives as a result of having cancer, using the following scale: (1) None; (2) A lot; (3) A great deal; (4) A complete change; (5) A complete change. The items are: (1) I feel better about my cancer experience; (2) I have better health. The internal reliability of the scale was found to be high (α = .78). The frequency of religious expression was entered first, followed, in Step 2, by education level, marital status, number of posts, and spirituality scores. In Step 3, the LIWC count of religious expression, Breast Cancer Concerns, showed that a higher frequency of religious expression increased the likelihood of better outcomes. The one outcome variable associated with religious expression, Breast Cancer Concerns, showed that a higher frequency was associated with more concerns at time 2.

6. Discussion

Overall, the results did not support the hypotheses that a positive relationship exists between the frequency of religious expression and positive outcome in the OSGs we studied. These findings are in sharp contrast to those reported by Shaw et al. Although it is

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Linear regressions; religious expression and outcomes.</th>
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<tr>
<td></td>
<td>CESD</td>
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<td>Step 1</td>
<td></td>
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<tr>
<td>Baseline score</td>
<td>Incremental R²</td>
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<td>Std. Beta</td>
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<td>Step 2</td>
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<tr>
<td>Incremental R²</td>
<td>.1</td>
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<tr>
<td>Std. Beta</td>
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<tr>
<td>Education</td>
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<tr>
<td>Marital status</td>
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<td>Number posts</td>
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<tr>
<td>Spirituality</td>
<td></td>
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<tr>
<td>Step 3</td>
<td></td>
</tr>
<tr>
<td>Incremental R²</td>
<td>.04</td>
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<td>religious expression</td>
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*P < .001.  **P = .01.  ***P = .05.
unclear why these findings are so different, a number of differences exist between the groups examined by Shaw and our own groups. A number of substantive differences were found in the (1) amount of spiritual expression and (2) participant demographics. (3) Frequency of active participation. (4) Perhaps of greatest importance, the differences in the percentage of religious expression differed among the samples. The average percentage of religious expression in the Shaw study was 0.82% compared to 0.59% in our sample. It is unclear if participant demographic variables or group norms contributed to the differences in religious expression.

There is an increasing interest in the role and importance of religion/spirituality in the context of health, illness and health care practice. The prevalence of religious coping generally depends on the source of stress or sample characteristics, and situational factors (e.g., type of illness, time since diagnosis, stage of illness, remission status and treatment). By and large, studies examining religious coping in medically ill patients have found that between 34% and 86% have reported using religious/spiritual cognition and activities in coping with their illness.

Two recent literature reviews provide some instructive information on the role of religion in coping with cancer. In the first review, Ingela et al. (2006) presented studies examining the potential beneficial or harmful effects of religious/spiritual coping in helping mitigate the effects of cancer. Seventeen papers met their inclusion criteria of which seven found some evidence for the beneficial effect of religious coping, but one of these also found religious coping to be detrimental in a sub-sample of their population. A further three studies found religious coping to be harmful and seven found non-significant results. The authors concluded that many studies suffered from serious methodological problems, especially in the manner in which religious coping was conceptualized and measured. They further suggested that the studies also failed to control for possible influential variables such as stage of illness and perceived social support. Due to these limitations in design, the authors concluded that no firm conclusions about the possible beneficial or harmful effects of religious coping with cancer could be made.

A second review (Michael, Paige, Mcdonal, & Stephaniea, 2005) summarized what is known about the role of spirituality and religion in dealing with cancer. The authors concluded that, despite the broad interest in spirituality and religion as it relates to health, little is known about the role it plays in coping with cancer. This is true when both disease outcome and adjustment are considered. Studies examining the role of spirituality and religion’s impact on quality of life and adjustment are decidedly mixed. In addition, there is an increasing interest in the role of spirituality and religion as it relates to health, illness and health care practice. The prevalence of religious coping generally depends on the source of stress or sample characteristics, and situational factors (e.g., type of illness, time since diagnosis, stage of illness, remission status and treatment). By and large, studies examining religious coping in medically ill patients have found that between 34% and 86% have reported using religious/spiritual cognition and activities in coping with their illness.

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It is also possible that some threshold for religious expression is required for it to have an impact. Furthermore, Shaw noted anecdotal evidence that many of the CHSS participants have a high religious orientation. Participant demographics of all three varied a great deal. Although the ethnic differences between the studies are clear, the Shaw analysis reported that ethnicity did not contribute to the relationship between frequency of religious expression and measures of change. The studies differed markedly in educational levels. However, the effects of marital status and education, as shown in Table 2 does not appear, overall, to affect the relationship between religious expression and outcomes. There is one exception; the measure of functional well-being does show a significant effect of education. Finally, as discussed, the reviews of studies examining the role of religion in health outcomes found equivocal results on the benefits of religious expression.

There are a number of limitations in the study that warrant caution in interpreting the results. Most salient is the accuracy of the LIWC software in identifying religious themes. It is acknowledged that counting words is a crude procedure at best. Despite being the most widely used text analysis program for measuring psychological dimension there are significant concerns about the ability of LIWC and any discourse analysis software to analyze linguistic information in complex communications. In our previous research, we found the concurrent validity between human and LIWC ratings to range from r = 0.12 to r = 0.53. Of equal concern, it is unclear if the participants’ written expression of religiosity accurately reflected their personal religious beliefs (i.e., that the LIWC scores are a useful proxy for religiosity). It is also unclear, as noted by Shaw, if the group as a whole is influenced by individual expressions of religiosity.

Much more research is needed both on the role of religious beliefs and the expression of these beliefs in cancer support groups before clinicians should encourage such expression to patients coping with a cancer diagnosis. The first step should be to validate the utility of text analysis programs to adequately capture religious expression as it is quite possible that these crude measures miscalculate religious expression in a number of ways. Secondly, researchers need to determine the relationship between religious beliefs and religious expression in support groups.

Web-based support groups have the potential to meet some of the unmet psycho-social and information needs for people coping with a cancer diagnosis. Both needs have been shown to be associated with positive quality of life outcomes in cancer patients (Helgeson & Cohen, 1996). As noted in the introduction, the dramatic increase in the number of Web-based support groups for people with cancer along with increased access to the Internet, in general, holds the promise that cancer patients from all backgrounds and locales will be able to access Web-based services. These groups are a cost-effective means for providing support and disseminating timely information and it opens the possibility for faster more transparent communication between patients, caregivers, and healthcare professionals. As research continues, the results of current and future evaluations of Web-based support groups will offer providers of both professionally-facilitated and unmoderated Web-based support groups guidance on how to design these groups to maximize their effectiveness and how to help patients make the best use of these forums.

References


