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Research Article
Published: 26 Jan, 2018

Journal of Psychiatry and Behavioral Health Forecast

Mechanisms Linked to Positive Outcomes in Online Professionally Led Breast Cancer Groups: A Replication Study in a Randomized Study

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Abstract

Two perspectives underlie all theories of therapy/support/self help groups: group conditions that enable participants to work effectively in the group, and mechanisms associated with a participant's positive changes. Group conditions include constructs such as cohesiveness, group climate, amount of structure and focus, as well as aspects of the relationship between participants and the leader. Mechanisms include a variety of experiences and behaviors associated with positive change such as self disclosure, insight, information, expression of emotions.

This study explores mechanisms of change, helpful group experiences, also frequently referred to as curative factors. Our question is embedded in the view that the processes in online groups, whether professionally led or peer facilitated, can, in part, be understood by applying the constructs developed over many years in studies of small groups such as group therapy, support groups and self help settings. Studies of these constructs, helpful group experiences or curative factors, has been based on the testimony of participants to the question, "what events or experiences in the group were helpful to you"?

Keywords: Mechanism of positive change; Helpful group experiences; Depression; Change mechanisms; Online support groups; Professional leaders

Introduction

Prior to the present study, our research group published three studies of Helpful Group Experiences (HGE) of both on line and in person support groups. In the first study [1] we asked, do HGE's relate to patient improvement, if so, which specific mechanisms. We also asked the role of the group leader in effecting patients' choice of specific HGE's. Studied were 109 women with breast cancer. They all were participants in face-to-face professionally led support groups. The leaders were from The Wellness Community (TWC). A series of linear regressions, one for each of the dependent variables, Physical Problems, Social Well Being, Patients Relationship with Their Physician, Positive Emotions, Functional Behaviors [2,3] and Depression [4]. Two of the five dimensions used to assess helpful group experiences were linked to beneficial outcomes. Group participants who emphasize the importance of cognitive experiences are more likely to benefit from their experience. The second significant finding was that participants who highly rated the belief system of TWC, essentially a cognitive proscription on how to get well, e.g. developing a new attitude toward life, improved more. In addition, we found that a correlation between the members of the groups and the professional facilitators' perceptions of the HGE items was r=.66, a statistically significant correlation. This finding underscores the general principal that all therapeutic systems, either implicitly or explicitly, provide patients with a map of what they must do in order to benefit from the group's help and that the leader is the central carrier of this belief system [5].

In another study [6] we examined five breast cancer bulletin boards. One hundred and fourteen women were recruited from these bulletin boards. Positive change was assessed by three measures, quality of life (FACT-B) [3], depression (CESD) [4] and the Post traumatic Growth Inventory (PTGI) [7]. Helpful group experiences were assessed by five dimensions; Support, Disclosure, Existential, Cognitive-information, and Altruism. The overall regression for the CESD was highly significant, the one examining the PTGI showed a trend and the FACT-B scales were not significant. Members who reported that cognitive experiences were very important, showed at time 2, lower depression

OPEN ACCESS

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Received Date: *22 Sep 2017*
Accepted Date: *15 Jan 2018*
Published Date: *26 Jan 2018*

Citation: *Lieberman M, Lepore SJ. Mechanisms Linked to Positive Outcomes in Online Professionally Led Breast Cancer Groups: A Replication Study in a Randomized Study. J Psychiatry Behav Health Forecast. 2018; 1(1): 1001.*

ISSN 2643-802X

Table 1: Demographics.

Variable	N=183
Age	52.3 (7.7)
Race Caucasian	174 (96%)
Education	
HS graduate	93 (51%)
College graduate	90 ((49%)
Employed	126 (69%)
Married	156 (85%)
Cancer stage	
1	101 (55%)
2	82 (45%)

(CESD) scores, while those who viewed existential experiences as important, showed at time 2, higher depression scores. The only HGE positively linked to PTGI was high ratings of altruistic experiences.

Our last study was of in person professionally led breast cancer support groups leader style and HGE [8]. This study tested the effects of leader behaviors on outcomes in 269 cancer patients in professionally led in person support groups. Both the direct effect and a mediation hypothesis, HGE were examined. The leader model specifies five dimensions: evoke stimulate, executive management, meaning attribution, uses of self, and support caring. This model was developed by Lieberman, Yalom and Miles [9]. Patients were drawn from The Wellness Community, a national organization that provides services to cancer patients [9]. Outcomes included quality of life (FACT-B) and depression (CESD).

A multivariate analysis of variance testing outcomes resulted in an overall significant effect (p=.01). There was a substantial relationship between HGE dimensions and outcomes, Group participants who emphasize the importance of cognitive experiences are more likely to benefit from their experience. In this study both the cognitive dimension (Getting honest feedback from others, Gaining insight about myself, Getting new understandings or explanations, Getting direct advice, suggestions, or education, Gaining access to important information) as well as internalizing the belief system of TWC, essentially a cognitive prescription on how to get well (Learning that I am responsible for how I cope with my life, Developing a new attitude toward life, Learning to become a partner with my physician, Discussing ways that I can become a patient and take responsibility for life, Discussing ways that I can participate in my fight for recovery, Becoming hopeful) were crucial. In a linear regressions analysis, leaders perceived as high on meaning attribution and management structure, the group members showed significantly lower depression, fewer physical problems, higher well-being, and better functioning. In a test of the mediation hypothesis, leader behaviors associated with outcomes were substantially mediated through helpful group experiences. and when the leader variables were added to the equation, they contributed little power to positive outcomes.

Background

Our work is embedded in a long history of previous group therapy studies. Beginning with Corsini and Rosenberg's 1955 publication [10] psychotherapy researchers for more than 60 years have studied and theorized about the transactions associated with patient/participant benefit in small face to face groups. A useful review and evaluation in the general literature on therapeutic factors studies prior to 1981 can be found in Bloch's paper [11].

Despite the long history of interest in patient reports of helpful experience only a handful of studies examine their link to outcomes. Yalom [9] studied a sample of 20 group therapy patients. Factors valued by these patients were behavioral feedback, catharsis and family re-enactment. Lieberman, Yalom and Miles [10] in a randomized study of 12 encounter groups found that high learners emphasized cognitive factors. Steinfeld and Mabli [13] studied prisoners and drug abusers, using Yalom's Q sort. They reported that insight was the most important factor. Women participating in Conscious Raising groups reduced depression emphasized interpersonal learning self-understanding, catharsis and the instillation of hope [10].

Methods

The study

This study set out to explore HGEs on depression-anxiety (HADS) and a scale based on three dimensions from the FACT-B, physical health, functional and BC concerns in professionally conducted internet support groups in 184 women with breast cancer. The women were selected from the BC registry in Pennsylvania. Women selected were all high in distress (HADS >8). Outcomes were assessed using the pre post scores for depression-anxiety (HADS) and the FACT-B.

The data used were derived from our study that tested the helper therapy principal [10]. Based on the helper therapy principle, in the parent study it was hypothesized that the addition of structured helping opportunities and coaching on how to help others online compared to a randomized controls of support groups absent the special input, will increase the psychological benefits of a standard online group. The study was a two-armed randomized controlled trial with pretest and post test. Non-metastatic breast cancer survivors, were randomized to either a standard facilitated online group or to a prosocial facilitated online group, which combined online exchanges of support with structured helping opportunities (belonging, breast cancer outreach) and coaching on how best to give support to others. Measures were administrated approximately one month before and after the interventions. Age-stratified block randomization (< 51 vs. 51 + years) was used to assign women to condition and ensure that age is balanced across treatment arms. In total 12 groups of 15 women each met the criteria and began participation in the support groups.

Measures of helpful experiences

The Helpful Group Experience Questionnaire used in this study was first developed for the Encounter study [9] and modified for use with a variety of Self Help groups [11]. This is 25 item questionnaire, six point scales from zero being not applicable to five one of the most important.

Support: "Getting support and encouragement";"making contact with someone who I could call on for help"; "belonging to and being accepted by the support group"; "developing new friendships" (alpha = .57).

Disclosure: "Talking about fears of death"; "discussing sexual concerns"; "expressing my true feelings"; "discussing long-term, unremitting stress"; discussing unwanted aloneness, loss of control, and loss of hope" (alpha = .67).

Existential: "Owning up to maladjustment when it seems important"; "deepening my spiritual life"; "confronting difficult

problems and fears" (alpha=.66).

Cognitive–information: "Getting honest feedback from others"; "gaining insight about myself"; "getting new understandings or explanations"; "getting direct advice, suggestions, or education"; "gaining access to important information" (alpha=.68).

Altruism: "Helping others"; "Being a friend to a woman who developed cancer"; Reaching out to others who are hurting"; "Opportunities to give emotional support and encouragement"; Opportunities to offer advice, suggestions, or education to group members"; Opportunities to offer a different perspective"; Opportunities to offer empathy or compassion" (alpha = .91).

Measures of outcomes

HADS-This scale has an established reliability and validity, which has been used extensively and validated with breast cancer and other cancer patient populations

Two multivariate linear regressions with Bonferroni corrections were used, step 1, the time 1 score of the HADS, step 2, the experimental condition (prosocial vs standard), step 3 the five HGE scales. Similarly, the composite FACT-B outcome was analyzed.

Results

Table 1 shows the demographic characteristics of the sample.

The two three step regression is shown in Table 2.

As can be seen in Table 1, the sample studied was relatively homogenous. In the initial published study of this data set, we compared the experimental vs. the control groups, none of the central demographic variables were statistically significant. We also tested whether differences among the 12 groups in the relationship of HGE to any linkage to HADS. Non were statistically significant. In Table 2, the overall significant test of the central hypothesis shows borderline significance. Our examination of the five dimensions showed that two scales were of interest, Altruism and Disclosure. The more important the women saw disclosure the higher their post group (time 2) anxiety-depression. Surprisingly, Altruism showed the opposite, women who valued Altruism showed lower HADS at time 2.

Table 2a: Overall regressions HGE and HADS.

Steps	HADS
1 time 1 score	p = .01
2 prosocial vs controls	p = .05
HGE	p = .01

Table 2b: HGE Dimensions and Hads.

HGE	B	t	P
Support	-.09	-.56	NS
Cognitive	.17	1.0	NS
Existential	-.10	-.68	NS
Altruism	-.33	-2.5	.01
Disclosure	.25	1.8	.07

Discussion

As in previous support group studies described at the onset of the paper, participants experiences in the groups setting (HGE) are linked to outcomes. Unlike previous study, we found no effect of the different groups with different leaders (Lieberman) nor of the experimental design (helping instructions vs control support groups). This may be because all the leaders shared a common ideology and training. Furthermore they were guided by a manual specifically developed for the study as well as weekly supervision by highly experienced professionals from The Cancer Community. However, similar to our previous studies on other online support groups, the particular HGE dimensions found significantly associated with positive outcomes have some similarity (altruism), but also show some difference. This observation echoes our review of group psychotherapy studies.

What follows are speculations on why the lack of commonality in the relationship between HGE and positive outcomes. The helping process in a group setting occurs in a complex social microcosm. The groups create a special society with its own defined boundaries and rules of conduct that distinguishes them from the remainder of society. Such helping groups, however, are not totally isolated from the larger society with its cultural prescriptions and proscriptions about what problems to rise in the support are legitimate. In one of our previously cited studies we found that group members entered small helping groups with a set of expectations what the group will be like and what kinds of things will help them. Other influences on helpful experiences stem from the group's leader. We found that positive change was linked to the similarity of the participant's view of helpful group experiences and that of the leader. In previous studies we have also found that the disease or problem that is being addressed by the group influences the perception of what was helpful. In a large-scale study Lieberman and Borman studied several thousand members of a variety of self-help groups (widows, parents whose children have died, patient who had open-heart surgery, mothers of twins, and first-time mothers) [16]. In addition for this study of the aforementioned self-help groups we added data from 1700 women who participated in the women's consciousness-raising groups [14], group psychotherapy patients, and participants in encounter groups [9]. We found that the particular issues that the group was organized to address influenced participants view of what experiences were helpful to them. This was best illustrated by members of the self-help group that addressed parents who experienced the death of a child (Compassionate Friends). They saw altruism, helping others as one of the most important experiences they found helpful. The members of Compassionate Friends rated altruism 74% of the time as very important in helping them. No other group we studied shared this perspective on altruism. However, altruism in the present study is significantly related to better outcomes. An examination of other group HGE's suggested a unique set, clearly the nature of the problem influences participants view of what experiences are helpful.

Investigators studying mechanisms in small helping groups are faced with challenge. Positive influences of HGE are clear, but many other factors impact on the specific mechanism linked to positive change. Clearly, more complex models are needed.

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