Psychological Characteristics of People with Parkinson’s Disease Who Prematurely Drop Out of Professionally Led Internet Chat Support Groups

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ABSTRACT

Researchers of Internet health interventions have begun to address the problems of high attrition rates. Attrition has been a problem for psychosocial interventions for nearly 50 years. It is ubiquitous no matter what the type of intervention or the modality of delivery. Consistent are the repeated findings that demographic characteristics are the most robust variables. We tested the hypothesis that the greater the fear and apprehension experienced in professionally led Internet support groups, the more likely the participants would not complete the 25-week intervention. The sample consisted of 66 people with Parkinson’s disease; each participant was assigned to one of six chat groups. To assess psychological states, we used PCAD, a text analysis program analyzing each person’s postings during each chat room session. There was a statistically significant difference between those who terminated the group early and those who completed the intervention on the Anxiety-Fear dimension, $F = 2.35$, $(6,63)$, $p = 0.03$. People who dropped out demonstrated higher death and shame anxiety. A number of possible designs for online groups that may reduce premature attrition are discussed.

INTRODUCTION

Internet health intervention researchers have recently begun to address the problems of high attrition rates associated with a wide variety of online health programs. Eysenbach states that in many Internet eHealth trials, especially those with self-help applications, high attrition may be a natural and typical feature. In studies of effectiveness, such attrition rates may underestimate the impact of the intervention on those who continue to participate. He suggests using survival analysis as a corrective measure in online intervention studies. An Internet-based evaluation of a panic disorder self-help program found that only 12 of 1,161 participants (about 1%) completed the entire 12-week program. A similar observation that evaluated a depression program with five modules found that only 97 of 19,607 (0.5%) participants completed all five modules in an “open” setting. Another study evaluated whether people would actually use (and continue to use) an Internet-based communication and disease management program. They found that 26 of 58 participants used it over a period of three months. In a study of 11,969 participants, reports a considerable proportion of dropouts (65%). The picture of attrition is not as bleak in professionally conducted Internet support groups. For example, a study of professionally facilitated breast cancer chat groups reported a dropout rate of 20%. A controlled study of professionally led breast cancer groups reported an attrition rate of 22%.

Attrition, dropout, or premature termination has been a problem for psychosocial interventions for
nearly 50 years. A number of reviews have addressed traditional intervention settings. A meta-analysis that reviewed drug abuse outcome studies reported evidence based on 1,571 cases that participated in either individual counseling, peer group therapy, or family psycho-education. Family therapy frequently had a higher treatment retention rate than did nonfamily therapy modalities. A community epidemiological survey using representative samples of the United States and Ontario interviewed individuals treated for self-described mental health problems in the preceding year. Sociodemographic characteristics associated with treatment attrition included low income, young age, and lack of insurance coverage for mental health treatment (United States only). Attitudes associated with attrition included viewing mental health treatment as relatively ineffective and embarrassing. Respondents who received both medication and talk therapy were less likely to drop out than those who received single-modality treatments. A meta-analysis of 125 psychotherapy attrition studies reported the mean dropout rate was 47%. Dropout rates were unrelated to most of the variables examined. Significant effect sizes were observed for three client-demographic variables: racial status, education, and income. Attrition increased for African Americans (and other minorities), those less educated, and lower income groups.

Collectively, these reviews of diverse types of intervention point to some similar conclusions: large attrition in treatment and the influence of demographic variables on those who remain compared to those who prematurely terminate.

Less frequently studied is the contribution of personality characteristics to attrition. Many attempts at isolating personality traits as predictors have yielded insignificant results. For example, a study of 351 male sex offenders found that Minnesota Multiphasic Personality Inventory (MMPI) scales did not yield a significant F value. In an investigation of client factors influencing group therapy dropouts and those who continued in 155 groups, clients reported that somatic complaints and introversion were weak predictors of attrition. McCallum and Piper examined three variables: psychological mindedness, SCL-90, and problem severity (rated by the participant). Dropouts were less psychologically minded and more psychiatrically disturbed. A study that investigated predictors of attrition in behavioral medicine programs reported that pretreatment expectations (rejection of the treatment rationale) and higher psychopathologies were predictive of early attrition. In a study of patients in time-limited, interpretive individual psychotherapy, pretherapy predictors, which included demographic, diagnostic, and initial psychiatrically disturbance, did not significantly differentiate the two groups. However, scales used to measure therapeutic processes found that dropouts had poorer scores on therapeutic alliance, were less work oriented in therapy, and were less interested in personal exploration.

In summary, the attrition of participants from health intervention is ubiquitous no matter what the type of intervention or the modality of delivery. Consistent are the repeated findings that demographic characteristics of the participant are the most robust variables. Personality characteristics have not produced a comparable consensus on what psychological variables merit study. The lack of consistency across studies and the less-than-stellar methodology makes this area of prediction opaque. It should be noted, however, that the literature cited in our review addresses professionally developed interventions. As noted earlier, much of the Internet work is based on self-help programs. Good data examining dropouts/attrition on non-Internet self-help groups is very limited. See Kelly and Moos for a review of substance abuse groups and attrition.

The present pilot study, using professionally led Internet groups, examined psychological characteristics and attrition of people with Parkinson’s disease. Specifically, we tested the hypothesis that the greater the fear and apprehension people experienced early in the Internet support group, the more likely they would not complete the intervention.

The hypothesis that during the early meetings, groups participants who experience high levels of fear and anxiety will prematurely terminate is based on concepts from the field of group psychotherapy. A diverse array of small groups directed toward personal change, repairs, or growth is fraught with potential for anxiety-induction. Based on a theory initially developed by Whitaker and Lieberman for linking small group theory to psychoanalytic constructs was based on participants’ initial fears and anxieties. Participants in a newly formed group are not sure what may happen next, they know that exceedingly personal topics are often discussed, and interactions among members may evoke highly emotional events. They are faced with a variety of dilemmas basic to the small group setting, such as developing a relationship with the group leader and the other members, disclosing usually private aspects of themselves, and establishing the group's boundaries.

Although no direct study has assessed fear and anxiety as a predictor of premature termination,
there is a considerable conceptual and empirical work that develops procedures in group psychotherapy to reduce participants’ fear and anxiety when initially entering the group setting. In traditional group psychotherapy, a variety of therapist-developed strategies are used to help manage members’ initial fears. Most frequent is the therapist developing a relationship with the group members. For example, in the Rogerian tradition, emphasis is placed on the establishment of supportive relationships; genuineness, positive regard, and empathy are the terms of this framework.

A variety of other strategies have been used in the past, many of which are suitable for online groups and are further elaborated in the discussion section. The following three strategies help to reduce group members’ anxiety.

1. Many therapists structure the group setting to reduce the ambiguity about the therapeutic task so that participants can safely engage in constructive interactions. Dies19 reviewed 51 studies on the use of structure. He reported that 78% of the studies that utilized more structured groups had lower attrition.

2. Another method to reduce participants’ anxiety is to select group members according to criteria designed to ensure a therapeutic group. The most common criterion for composing psychotherapy/support groups is member similarity (e.g., gender, illness, marital status).20 A review of group therapy in the treatment of people with HIV and AIDS21 examined the effect of group composition on the three curative factors (instillation of hope, universality, and group cohesion) of group therapy. Results suggested that support groups homogeneous for stage of illness, risk behaviors, and gender provide members with the greatest benefits through facilitating the three curative factors of group therapy. Other investigators studied groups selected on the basis of personality variables. For example, in a study using measures of extraversion and conscientiousness, they found that extraversion was associated with group performance. Many early studies22,23 examined sensitivity training settings using interpersonal sensitivity as well as fundamental interpersonal relations orientation (FIRIO-B). Overall, these studies reported positive results. Composition studies rely on participant selection based on the view that similar people facing similar predicaments are more likely to rapidly establish bonds with one another and form a more cohesive group. In essence, group homogeneity allows members to see others as sharing certain common character-istics, problems, or concerns, thereby contributing to more rapid group cohesiveness. A more cohesive group is presumed to improve the effectiveness of the group intervention and reduce the fears group members may experience at the onset of the group.

3. A third way to reduce group members’ anxiety is to prepare each participant (using interviews and discussion, group training sessions, relevant reading material, etc.) before he or she joins a group. Bandura’s24 formulation regarding the process of expectation setting and the role of expectations in motivating behavior provides a conceptual framework. The goals of a preparatory procedure are to help participants understand what is expected of each group member; believe with some certainty that they can adequately fulfill such a role; and expect that if they adequately execute the role, the desired therapeutic gains will be realized. Four studies looked at attendance or dropout rates. Garrisons25 found that over the first 6 weeks of therapy clients who experienced “verbal persuasion” preparation showed significantly better attendance than “controls.” Prepared clients had a 22% dropout rate compared with a 67% rate for control subjects. Piper et al. also reported significant positive results (4.3% vs. a 31.3% dropout rate, and 88% vs. a 75% attendance rate). On the other hand, two studies27,28 failed to affect attendance and dropout rates through “vicarious experience” and “verbal persuasion” preparatory procedures.

All of these therapeutic strategies are directed toward creating a safe and risk-taking environment by reducing the anxiety and fear common to members when they first enter a group.

MATERIALS AND METHODS

The sample was composed of people coping with Parkinson’s disease. We chose this population for support groups because patients experience many psychosocial problems stemming from their illness. It has been estimated that 40% to 60% percent of people with Parkinson’s disease suffer from clinically significant depression. Their quality of life is often diminished.

Sixty-six participants, after signing human subjects consent forms, completed baseline questionnaires at the study’s Web site (www.ucsf.edu/pdchat/). They were assigned to one of six professionally led online support groups. Participants received instruction on accessing the Internet and the
online support group before the first group session. They also were invited to go online with the project coordinator to examine and correct problems they may have in using the chat software.

Each group met for 90 minutes weekly for 25 weeks. In addition to the synchronous chat room (real-time online communication), each group site featured a bulletin board where group members could post messages at any time. They used the bulletin board specific to their group for communicating with each other outside of the specified meeting time. To insure privacy, participants received their own log-in name and password. In addition to the support group, three health educational “chats” were scheduled at a time when members could ask an expert questions about Parkinson’s disease.

Prepost outcomes for this sample were previously reported. Significant prepost changes were found for the sample on depression (CESD) and quality of life (PDQ39).

Premature termination was defined as a patient who participated in fewer than 10 meetings. This study compared 26 premature terminators (median number of meetings, 5.5) with 40 continuers, with a median attendance of 14.5 meetings. No significant differences were found on baseline depression, quality of life, and Parkinson’s symptoms between terminators and those who remained in the support groups. Nor were there any differences and age and number of years they suffered from Parkinson’s. We tested the question whether those who prematurely dropped out of the groups were patients’ who experienced greater fear and apprehension.

To assess such psychological states, we used a text analysis program, PCAD 2000,32 to analyze each patient’s postings during each chat room session. PCAD performs content analysis on scales modeled on psychoanalytic theory. The method for measuring the magnitude of various psychological states and traits from the content analysis of verbal behavior has been successfully applied to many different populations. The scales are corrected for the total number of words for each patient’s scores based on clauses, not individual words. Extensive empirical research has established the validity and reliability of these scales, measuring a variety of emotional states, including the anxiety/fear dimension used for the present study. Gottschalk provided a helpful review of the extensive literature.

**Fear-anxiety dimension**

The anxiety dimension is classified into six scales: death, mutilation, separation, guilt, shame, and diffuse or nonspecific anxiety. Fear of death is assessed by those content items dealing directly with death and destruction. Mutilation anxiety is synonymous with castration anxiety, and the descriptive items in the scale pertaining to this subtype of anxiety are derived from clinical psychoanalytic psychology. The concept of separation anxiety and the descriptive items designating what references in speech are to be included under this heading are also derived from psychoanalytic psychology. The descriptive items differentiating shame from guilt anxiety are verbal references to ridicule, inadequacy, embarrassment, humiliation, and exposure of shortcomings or details of a person’s private life; those that distinguish guilt are verbal references to adverse criticism, abuse, condemnation, and moral disapproval, especially based on internalized attitudes or values. Diffuse or nonspecific anxiety is the category of anxiety for which it is impossible to distinguish the type of anxiety or fear that is being verbalized.33 Several studies have addressed the validity and reliability of the PCAD anxiety-fear dimension. One study correlated the State-Trait Anxiety Inventory, the Beck Anxiety Inventory, and the Ulm Affective Dictionary.34 The results show high correlation of the Dresden Anxiety Dictionary with conventionally derived PCAD scores and the Ulm Affective Dictionary. Another study reported adequate reliability for the PCAD anxiety dimension.34 Kordy et al. provided information on the stability of anxiety and hostility dimensions of the PCAD. They reported on the stability across different situations and stability over time. In a study to assess affective reactions to stressful life events by analysis of samples of verbal behavior, all of the anxiety dimension subscales, with the exception of the separation anxiety subscale, had satisfactory reliability.36

The following examples illustrate the coding for the anxiety dimension.

A rather vicious cat to other people; anxiety-mutilation
He bit her tail; anxiety-mutilation
But then he was killed out in front of the house; anxiety-death
One neighbor was afraid of our older cat; anxiety-diffuse
My mother used to lock them out of the house; anxiety-separation
That the baby was going to drop the ashtray; anxiety-separation

**Weights**

The scales were weighted so that the total score on a scale is the combined weighted sums corrected for the number of words. A multivariate analysis with Bonferroni correction was used to analyze the
six scales included in the fear-anxiety dimension. The unit of analysis was a person posting in each meeting.

RESULTS

There was a statistically significant difference between patients who terminated the group early and those who completed the intervention on the anxiety-year dimension ($F = 2.35$, $df = 4,663$, $p = 0.03$ with a Bonferroni correction). Dropouts showed significantly higher scores on the anxiety dimension. Table 1 shows the univariate tests and mean scores. An examination of this table suggests that those who dropped out showed higher death and shame anxiety than those who completed the online group therapy.

DISCUSSION AND CONCLUSIONS

This pilot study supports the hypothesis that participants in professionally facilitated online support groups who experience high levels of anxiety and fear are more likely to prematurely terminate. What are the implications of the findings? In the background for this paper, several standard methods used to contain patients’ initial anxiety in psychotherapeutic groups were briefly reviewed. How will such strategies, structure, composition and preparation, work in online groups? A limited body of empirical research is available.

Structure

In a study of online, professionally directed breast cancer groups, the leaders used a highly structured format and found significant changes in outcomes. Seventy-two women treated for breast cancer were assigned to a 12-week, asynchronous, moderated online support group (Bosom Buddies) or a wait-list control (WLC). Intention-to-treat analyses were used. Each week, the leader introduced a topic for discussion:

1. Introductions and procedures
2. Getting to know you (ask each other questions and learn how to support one another and respond to emotion in postings)
3. Difficult emotions (share difficult emotions and ways of coping with them)
4. Medical teams (share experiences with the medical team and any successes and frustrations)
5. Uncertainty and helplessness (share any feelings of uncertainty and fears, especially about the future)
6. Self- and body images (share how cancer has affected their body image)
7. Romance and sexuality (share feelings about self as a sexual being, changes in sexuality with partners)
8. Family (share how relationships with family are affected)
9. Friends (share how friends and coworkers reacted to diagnosis and how relationships were affected)
10. Fear of recurrence (think about and discuss concerns about recurrence)
11. Meaning of life (reflect on life priorities)
12. Closure (reflect on what the group has meant and say goodbye)

Compared to the WLC group, Bosom Buddies participants reported significantly greater reductions in depressive symptoms as measured by the Center for Epidemiologic Studies Depression

Table 1. Multivariate Analysis of Premature Termination vs. Continuers*

<table>
<thead>
<tr>
<th>Dimension</th>
<th>F</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety-fear</td>
<td>2.35</td>
<td>6163</td>
<td>0.03</td>
</tr>
</tbody>
</table>

Means and univariates of significant tests

<table>
<thead>
<tr>
<th>Scale</th>
<th>Terminate mean</th>
<th>Continue mean</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death anxiety</td>
<td>0.61</td>
<td>0.56</td>
<td>4.17</td>
<td>0</td>
</tr>
<tr>
<td>Mutilation anxiety</td>
<td>0.71</td>
<td>0.68</td>
<td>2.14</td>
<td>0.14</td>
</tr>
<tr>
<td>Separation anxiety</td>
<td>0.74</td>
<td>0.73</td>
<td>0.35</td>
<td>0.55</td>
</tr>
<tr>
<td>Guilt anxiety</td>
<td>0.61</td>
<td>0.62</td>
<td>0.21</td>
<td>0.64</td>
</tr>
<tr>
<td>Shame anxiety</td>
<td>0.92</td>
<td>0.86</td>
<td>3.5</td>
<td>0.1</td>
</tr>
<tr>
<td>Diffuse anxiety</td>
<td>0.65</td>
<td>0.71</td>
<td>2.34</td>
<td>0.13</td>
</tr>
</tbody>
</table>

*Bonferroni corr
Scale (CES-D; effect size = 0.54), posttraumatic stress symptoms as measured by the PTSD Checklist-Civilian scale (PCL-C; effect size = 0.45), and perceived stress levels as measured by Perceived Stress Scale (PSS; effect size = 0.38) from baseline to followup. Furthermore, 53% of Bosom Buddies participants whose depression score indicated significant depression at the baseline (CES-D > 16) were no longer depressed at followup, compared to 29% in the WLC group. The study, unfortunately, does not provide an empirical test of structured and unstructured online support groups. Rather, it points to a successful study demonstrating the use of one type of structure in online groups.

**Composition**

Sixty-six people diagnosed with Parkinson’s disease were assigned to a 20-week, professionally facilitated online support group. Two hypotheses were tested: that homogeneous groups are more cohesive than groups consisting of random members and that participants in homogeneous groups benefit more than do participants in random-member groups. Participants were assigned to one of two group types on the basis of patient similarity. Cohesiveness (behaviors reflecting both commitment and satisfaction from membership) was measured using text analysis by the frequency of three positive constructs: hope, general positive words, and affection when participants referred to their group. The output of the text analysis program is the percentage of recognized words belonging to each category. A repeat measure multivariate analysis with a Bonferroni correction was used to compare the two types of composed cohesion. The between-group variable was type of group; the within-group variables were time and time × type of group interaction. Overall multivariate values are as follows: between-groups: \( F = 2.91, \ df = 3,23, \ p = 0.06, \text{Eta}^2 = 0.275 \); within-groups time: \( F = 4.2, \ df = 3,23, \ p = 0.02, \text{Eta}^2 = 0.36 \); within-group time × type of group interaction: \( F = 3.9, \ df = 3,23, \ p = 0.02, \text{Eta}^2 = 0.34 \). The homogeneously composed groups were significantly more cohesive than the heterogeneous groups. Homogeneous groups showed significantly greater improvement than did the heterogeneous groups. For both depression and Parkinson’s disease symptoms, members of the homogeneous groups improved while those in the heterogeneous groups reported slightly higher depression scores from time 1 to time 2. On the quality of life measure (PDQ39), all participants improved (between-groups: \( F = 3.4, \ df = 3,27, \ p = 0.03, \text{Eta} = 0.28 \); within-group time: \( F = 5.4, \ df = 3,27, \ p = 0.01, \text{Eta} = 0.38 \); within-group time × type of group interaction: \( F = 4.0, \ df = 3,27, \ p = 0.02, \text{Eta} = 0.31 \).

**Preparation**

No empirical studies exist for online support groups using pre–support group preparation. An example of pre-support group preparation can be found on the Wellness Community’s virtual community Web site (www.thewellnesscommunity.org). Prior to registering for an online support group, prospective participants are encouraged to read several documents, including discussions of commitment, punctuality, cancer patients’ psychosocial concerns (loss of hope, unwanted aloneness, and loss of control), participants’ role in the group (particularly in sharing experiences), and confidentiality.

The discussion has attempted to illustrate the strategies that can be used to help participants in online support groups navigate and contain their fears and anxiety when becoming a member. Much critical research still needs to be done. How robust is the relationship between a participant’s anxiety and fears and the preparatory strategies outlined here? Do these strategies actually reduce participants’ fear and anxiety? Which of the three strategies; group structure, pregroup selection, participant preparation, is most effective, in reducing attrition.

The findings from the current study on attrition are difficult to place, in a larger context. Aside from the common demographic characteristics noted in the review of traditional interventions, psychological dimensions are less studied, and the publications reviewed do not point to even a limited consensus of what personality dimensions are important.

This exploratory study began with an expectation that behaviors in the Internet groups that indexed participant fear and anxiety could be relevant to dropping out of a group that asked participants, in a controlled environment, to “talk” about and “listen” to emotionally laden issues associated with a serious disease. The results, albeit of low power, are encouraging. We found that those who dropped out were not different from those who continued on the pretest measures of depression, quality of life levels, and intensity of Parkinson’s disease symptoms. That is, they were not experiencing the onslaught of the disease at a more intense level.

There are a number of limitations to this pilot study. The study represents a convenience sample with unknown representativeness to people with
Parkinson’s disease in general. More serious is that such a sample does not mirror the diversity of Internet health interventions currently available. The small sample size further compromises the study. Finally, studying attrition on the most common form of Internet support, bulletin boards or newsgroups, presents a much more difficult challenge for researchers interested in examining attrition. Many bulletin boards have hundreds of participants and sometimes countless thousands who read messages but do not post. Definitions of attrition in such circumstances constitute a problem that requires solutions. Operationally defining what constitutes attrition has also been a problem in non-Internet interventions. The variety of definitions is a major factor confusing the study of attrition. In most studies, failure to attend a specified number of sessions is the criterion for classifying a person as a dropout. Unfortunately, researchers use different cutoffs, with the consequence that those considered dropouts in one study are viewed as continuers in others.41,42

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