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Newsletters and adherence to a weekly home spirometry program after lung transplant

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Abstract

Context—Newsletters are a common intervention for patients in clinical trials. However, it is not clear whether newsletters are associated with increased adherence to the health regimen, and if so, which aspects of the newsletter are reported as most helpful to patients.

Objective—To examine the association between patients' ratings of worthwhileness of a quarterly newsletter and adherence with a home spirometry regimen.

Design—Patients ($n = 48$) were in a research-based spirometry program after lung transplant and had received at least 1 newsletter; 24 (50%) returned completed surveys via postal mail.

Main Outcome Measures—Adherence for forced vital pulmonary function tests for respondents versus nonrespondents, number of weeks they were adherent, ratings they gave the newsletter, and which components of the newsletters were helpful to the respondents.

Results—Respondents had more forced vital capacity pulmonary function tests ("blows") overall, blew more times weekly, and blew more consistently from week to week than did nonrespondents. Although it was not statistically significant, a mild correlation was found between the number of weeks that the respondents were adherent and their ratings of the newsletter ($r = 0.36$, $P = .08$). Most respondents reported that newsletter length was "about right," and 86% reported that newsletters helped encourage regular spirometer use, maintain interest in the study, educate about general health, and alert readers to seasonal health risks.

Implications for Practice—High ratings for newsletters used to encourage participation among adults in our home spirometry study were associated with higher adherence.

Nonadherence to health care and clinical research regimens is a barrier both to optimal health outcomes for patients and high-quality research.¹ Sending newsletters to patients and research participants as a part of patients' follow-up care is common practice in health care and clinical research. Newsletters are generally convenient, inexpensive, and easy to produce.²

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Researchers closely monitor time and money to simplify and streamline care, yet little research has been done on the effects of newsletters on patient care outcomes or rates of adherence to therapeutic regimens. Many articles mention newsletters as an adjunctive intervention, but our review of the literature indicates that fewer articles have been published that focused on the use of newsletters as a tool for increasing education or adherence among patients. Those articles included newsletters as education tools for diseases such as cancer,³ hypertension,⁴ heart failure,⁵ diabetes mellitus,⁶ and Alzheimer disease.⁷ Newsletters were also tools for psychological or behavioral effects: to increase adherence to antidepressant (sertraline) regimen,⁸ promote psychological well-being after divorce,⁹ encourage follow-up care for mammograms,^{10,11} increase motivation to perform physical activity,¹² nutrition,^{13–19} enhance parenting techniques,^{20–29} alter adolescents' behavior regarding sex and use of drugs,³⁰ and even facilitate health-related political activism.³¹

In previous studies of adherence to medical regimens, few data were collected on why newsletters had been helpful. Ryan et al³² noted that for breast health and mammograms, patients who received individually tailored newsletters as follow-up to interviews did not have significantly different outcomes from patients who received generic follow-up newsletters. For newsletters focused on parenting, it was common for respondents to save the newsletters^{22–24} and use them as a reference.^{22,24} Riley et al²³ found that 70% reported that someone else in the house (ie, other than the intended recipient) read the parenting newsletters. Similarly, Dickinson and Cudaback²⁴ found that 83% of respondents shared the newsletters with others. Information about patients' preferred length or frequency of newsletter is lacking in the literature, although Ruud et al¹⁷ noted that young adults preferred bright colors, short length, and easy reading level.

Home Spirometry Program After Lung Transplant

Finkelstein and colleagues^{33–35} designed and studied a system for home monitoring of pulmonary functioning after lung transplantation for more than a decade. As part of a larger home spirometry research study, lung transplant recipients at the University of Minnesota are asked to use a home spirometer (Trans-Viva Home Spirometer, Minneapolis, Minnesota) daily to generate clinical data about their pulmonary function. These data are stored in the spirometer and transmitted via modem to a data center and are subsequently reviewed weekly by research nurses. Negative deviation from the subject's recent (ie, 2-week) norm generates an alert to the clinical nurse coordinators in the transplant center based on clinical indices. The home monitoring data are used by nurse coordinators and pulmonologists to identify subjects who may be in the earliest detectable stages of bronchopulmonary events and differentiate them from subjects who are stable or making improvements. The clinical team (ie, not the research team) subsequently decides how the alert should affect the subject's clinical management. Subjects who show no detectable negative changes in pulmonary status continue with their usual care and home monitoring. As part of this larger study, subjects also received a quarterly newsletter entitled "Lungs in Focus" prepared by members of the Nurse Triage Home Spirometry Research Team. The value of the newsletter to patients and its potential role in enhancing study adherence was unknown: therefore, we decided to survey our subjects to address this knowledge gap.

Purpose

This newsletter survey study sought to ascertain the association between subjects' ratings of how worthwhile the newsletter was and their adherence to the home spirometry protocol. The protocol requested daily "blows" and specified a minimum of 1 blow per week. For the purposes of this investigation, worthwhileness attempted to quantify the perceived value of the newsletter. The feedback from the survey was used in 2 ways: to make improvements to the research team's current newsletter and to expand the evidence base for incorporating newsletters in other biomedical research trials and patient education.

Methods

Statistical Design

A descriptive correlational research design was used to examine the relationship between subjects' ratings of the worthwhileness of the quarterly newsletter(s) and rates of adherence to the weekly home spirometry program using the nonparametric Spearman correlation. Descriptive data examined specific features of the newsletter. Qualitative data were gathered via free text areas to provide subjects with a nonstructured area to express their opinions. A Student *t* test was used to investigate the difference in the home spirometry adherence distributions for respondents and nonrespondents.

Subjects and Setting

This study is part of a larger study that examined informatics-based nursing triage in home spirometry (pulmonary function tests of forced vital capacity) after lung transplantation. All subjects had received at least 1 edition of a quarterly newsletter produced by investigators in the informatics-based triage study. Subjects were 48 adults (21 women, 27 men) who had received either single-lung ($n = 41$) or bilateral single-lung ($n=7$) transplants at the University of Minnesota Medical Center–Fairview in Minneapolis between October 2005 and August 2008. The mean (SD) age of subjects was 57.75 (10.12) years. At the beginning of the study in March 2009, the mean length of time that subjects had been in the larger study was 25.5 months. For the purposes of this newsletter study, survey data were collected from March 2009 through May 2009.

All subjects in the home monitoring study had provided informed written consent, following the guidelines of the University of Minnesota's institutional review board for their spirometry results to be examined. Subjects in the newsletter survey were informed in writing that returning the newsletter survey implied consent to use their survey responses and correlate them with their weekly spirometry tests over the 12-week continuous span. The newsletter survey was approved independently from the larger study by the University of Minnesota's institutional review board.

Newsletter Survey Design

We were interested in what features of the newsletter subjects perceived as helpful and what could be improved. In addition, based on a review of the literature,^{21–23} the survey asked whether the home spirometry subjects saved the newsletters or shared them with anyone

else. The primary investigator of the newsletter study developed the survey with input from the informatics-based nursing triage investigation team. The 10-question, 1-page survey (see Figure) was sent via postal mail to all eligible subjects. It included Likert-type scale ratings, yes/no questions, “check all that apply” sections, and free text areas. A rating scale from 1 to 10 (1 = low, 10 = high) was used to assess subjects’ ratings of worthwhileness of the quarterly newsletter. Investigators agreed about the face validity of the survey; however, no reliability or validity measures were evaluated. The Flesch-Kincaid Reading Level for the newsletter survey was 7.0, indicating the estimated number of years of education in the US school system required to understand the text.

Procedure

Home Spirometry Testing—All subjects had received individualized education for using the home spirometer and were being followed up by the nursing triage research team. For the purposes of this sub-study, adherence was defined as at least 1 blow (ie, use of spirometer) per week. However, subjects could use their spirometer as often as they liked to check their vital lung capacity and were encouraged to do so daily if possible. The spirometry data were transmitted from the spirometer to the research center via a modem and traditional telephone line. Subjects were considered to have an excused absence from using the spirometer if they were on vacation, were in the hospital, or had an equipment malfunction and were therefore unable to use the equipment. These excused weeks were noted but were not counted as episodes of nonadherence to the program.

Newsletter Survey—The survey, research information sheet, and a preaddressed return envelope were sent to the subjects’ postal addresses. The survey was estimated to take approximately 15 minutes to complete. Subjects were asked to answer every question and return the survey in the preaddressed envelope. The return due date was at least 3 weeks after anticipated delivery date by the US Postal Service to the subjects’ homes by using regular post. After the first wave of responses, a second letter was sent to nonrespondents with the same contents and the addition of a handwritten note encouraging the subject to use this survey as an opportunity to share their opinions of the newsletter. Surveys were precoded to identify subjects for the purpose of linking survey data with adherence data.

Results

Response Rate

Of the 48 surveys sent out, 3 subjects returned blank surveys stating that they had never received a newsletter. Twenty-four completed surveys were returned, yielding a usable response rate of 50%. For the purposes of generalization, spirometer data from subjects returning nonusable surveys were included in the “nonrespondent” category.

Survey Responses

General Newsletter Helpfulness—Most respondents (83%) indicated that they “always” or “usually” read the quarterly newsletter. Approximately the same proportion stated that they found the newsletter “somewhat helpful” or “very helpful” in 5 areas: (1) in general, (2) for encouraging subjects to take care of their health, (3) maintaining interest in

the study, (4) updating them about the status of the study, and (5) encouraging them to use their spirometers regularly. Five respondents found the newsletter “extremely helpful” in at least 1 of these areas, with emphasis on encouraging patient self care and encouraging regular use of the spirometer.

Sharing, Saving, and Interests—Respondents varied on sharing the newsletter with other people (yes=58%, no = 42%). Most respondents (71%) did not save the newsletters. In response to the question, “What about the Newsletter is helpful or interesting to you?” 92% of respondents indicated that education about maintaining their health after transplant was interesting. Most respondents (83%) liked the seasonal health information, 63% liked information about the health care providers and research team, 50% liked the testimonials of other research participants and the humor sections, and 42% liked the tips on using the home spirometer.

Qualitative Feedback—Free text responses indicated that subjects appreciated when the newsletter reinforced information from previous newsletters, provided updates about the overall study, and made subjects feel as though the researchers cared about them as people. One subject noted that although the newsletter was informative and had a good layout, they preferred the personal contact of a telephone call from the care managers. When asked what other information they would like to see included in the newsletter, many respondents stated that they wanted more information about changes in seasonal spirometry results and what had been learned thus far in the study. Subjects also noted that they would like more information in 2 areas: (1) how to manage posttransplant health while traveling and (2) posttransplant recipients’ health limitations (with a focus on possible decreases in energy level) to promote family communication and understanding of the recipients’ conditions. Several respondents stated that they would like information on other lung transplant programs in the Midwest and information on the other subjects in the study.

Length, Frequency, and Sources of Information—Most respondents (87.5%) felt that the length (1 page, front and back) and frequency (about every 3 months) of the newsletter was “just right.” The other 12.5% stated that the length was “too short” and the frequency was “too few.” When asked about what other sources of information they used about lung transplant, breathing exercises, or health, respondents indicated health care providers (67%), Web sites (58%), support groups (46%), books (21%), the American Lung Association (17%), physical therapy (4%), the Coalition for Pulmonary Fibrosis (4%), and television (4%). Although family members were listed as another potential source of information, no respondents indicated that they used their family members in that way.

Worthwhileness—The mean response for question no. 10, “How worthwhile is the ‘Lungs in Focus’ Newsletter to you?” was 7.2, with equal modes at 5, 6, 7, and 9. The anchors for this item ranged from 1 (low worthwhileness) to 10 (high worthwhileness).

Adherence for Survey Respondents and Nonrespondents

Data were examined by using a Student *t* test to determine whether the participants who returned a completed survey differed from those who did not at baseline. Respondents with

usable data ($n = 24$) were adherent for more weeks (mean, 10.25; SD, 3.78) than were nonrespondents ($n=24$, mean, 5; SD, 4.46). This difference was statistically significant ($P < .001$).

Adherence and Worthwhileness

A Spearman correlation was used to quantify the relationship between respondents' worthwhileness rating of a newsletter and their mean number of forced vital capacity blows recorded by the spirometer per week (excluding the excused weeks). The relationship between worthwhileness and the percentage of weeks the subject was adherent to the home spirometry program (1 blow per week) correlated mildly ($r = 0.36$, $P = .08$) with increased worthwhileness of the newsletter, but did not reach the level of statistical significance.

Discussion

The baseline adherence rates of the survey respondents and the nonrespondents differed significantly, even when excused absences such as vacations, hospitalizations, and equipment malfunction are allowed for. For respondents, the percentage of weeks adherent to the protocol was mildly correlated with higher ratings of the newsletter, but the correlation was not statistically significant. This result indicates that positive ratings of the newsletter were correlated with increased use of the spirometer.

Many respondents shared their newsletters with others. However, unlike in previous studies,^{22–24} recipients were not saving newsletters for future reference. The length (1 page, front and back) and frequency (quarterly, or approximately every 3 months) were rated as “just right” by the majority of respondents. This result implies that newsletters do not have to be very lengthy or distributed at higher frequencies (ie, monthly) to meet subjects' expectations. Similarly, our results suggest that quarterly newsletters may be satisfactory for promoting protocol adherence. However, our correlational data are insufficient to make causal inferences regarding the effect of the newsletter on adherence.

Many respondents wanted more information about other subjects and other lung transplant programs. Such information presumably enhances subjects' sense of being connected to the overall study and to each other while providing them with reassurance about their clinical program. Whereas providing such information in newsletters presents some issues (ie, preserving participants' rights to privacy and confidentiality), these issues can be addressed by securing an individual's permission before including personal information.

Another aspect of interest is the cost of producing the newsletter. In our instance, approximately 30 hours (over multiple weeks and revisions) is spent creating and formatting each edition of the newsletter. Cost for supplies (printing paper, ink, stamps, envelopes) was estimated at \$65 per edition. The creators of the newsletter are supported financially by a grant and do not represent an outside cost. Given this relatively small cost and the potential for benefit to the subjects, newsletters appear to be an important addition to the research and health care regimen.

Limitations

A limitation of this study is the small sample size. It suggests the possibility of nonresponse bias (respondents vs nonrespondents) that may affect estimates of satisfaction with the newsletter and the correlation of the newsletter satisfaction with adherence. Although not tested explicitly, our process for developing the survey provided some face validity for the survey; we did not assess reliability. In this study, protocol-adherent subjects appeared to find the newsletter worthwhile, but it is not clear how much newsletters motivated subjects who were not already adherent. It would be interesting to know more about these relationships. For example, future studies could be focused on nonadherent subjects regarding their opinions of what (if anything) could make the newsletter more valuable to them, whether a different format would be easier to use (ie, e-mail newsletter rather than postal mail), or whether the newsletter was too technical, simplified, or impersonal. It is not known what personality variables or other factors may influence either adherence to a home spirometry protocol or responsiveness to newsletters.

Conclusions

Our subjects' responses suggest that it is reasonable to conclude that the newsletter was generally perceived as valuable and could possibly promote protocol adherence. The relatively small expense and effort inherent in creating and disseminating newsletters is likewise a worthwhile investment in promoting the success of the research endeavor. It appears prudent for clinical trials to continue including newsletters as part of their overall adherence-enhancing strategies.

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HOME SPIROMETRY "LUNGS IN FOCUS" NEWSLETTER SURVEY

DIRECTIONS: This survey is being conducted to help us understand the role of newsletters in clinical research. It should take about 15 minutes to complete. Please answer every question and return it in the pre-addressed envelope by April 21, 2009.

1) How often do you read the "Lungs in Focus" Newsletter? ☐ Always ☐ Usually ☐ Sometimes ☐ Never

2) How helpful is the Newsletter information in:

	Not at all helpful	Somewhat helpful	Very helpful	Extremely helpful
a. General?				
b. Encouraging you to take care of your health?				
c. Maintaining your interest in the study?				
d. Updating you about the status of the study?				
e. Encouraging you to use the spirometer regularly?				

3) Do you share the Newsletters with other people? ☐ Yes ☐ No

4) Do you save the "Lungs in Focus" Newsletters? ☐ Yes ☐ No

5) What about the Newsletter is helpful or interesting to you? (Check all that apply)

☐ Education about maintaining your health after transplant

☐ Tips on doing home spirometry

☐ Information about the healthcare providers/research team

☐ Seasonal health information

☐ Testimonials of other research participants

☐ Jokes/fun sections

☐ Other (please describe): _____

6) What other information would you like included in "Lungs in Focus"? _____

7) In general, the length of the 2-page Newsletter is: ☐ Too short ☐ About right ☐ Too long

8) The frequency (about every 3 months) of the Newsletter is: ☐ Too few ☐ About right ☐ Too frequent

9) Which other sources of information do you use about lung transplant, breathing exercises, or your health?

☐ Websites ☐ Family members ☐ Support groups ☐ Health care providers ☐ Books

☐ American Lung Association ☐ Other (specify): _____

10) How worthwhile is the "Lungs in Focus" Newsletter to you? (1 = low, 10 = high; Please circle one number)

1 2 3 4 5 6 7 8 9 10

Any other comments: _____

Thank you for your time!

Figure.

Home spirometry "Lungs in Focus" Newsletter survey.