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ELECTRONIC FEEDBACK MESSAGES FOR HOME SPIROMETRY LUNG TRANSPLANT RECIPIENTS

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Abstract

Background—Lung transplant recipients use a telemedicine device known as the electronic home spirometer to gauge the function of their lungs when they are away from the hospital or clinic setting. Health care providers review transmitted spirometry tests and user's symptom responses to detect early signs of infection and or rejection. Current home spirometry users have questions, concerns, and preferences about spirometry which may influence their daily adherence. A spirometer with two-way electronic messaging has the capability to deliver feedback messages to potentially address these questions and concerns.

Objectives—The purpose of this study was to identify the type of messaging content users prefer to receive and recognize as positively influencing their spirometry usage.

Methods—The study design followed a qualitative approach investigating experiences, perceptions, preferences, and realities of home spirometry. Three focus group sessions were employed to generate opinions and interests about automatic messaging content.

Results—The focus group approach revealed the nature of six categories and five sub categories for feedback messaging content. These include education (general, life style, and infection), goals, timing, technique, monitoring and reminders (time sensitive, positive). Messages were created according to length, feasibility, past experience, and neutrality for electronic implementation.

Conclusions—The narrative content served as primary source of the electronic feedback messages. Actual quotes were used when applicable. It is believed that pertinent automated electronic feedback messages will enhance home spirometry connection, raise confidence in spirometry usage, and influence daily adherence to the spirometry protocol.

The content additionally serves as a foundation for establishing a plan of care individualized to each home spirometry user.

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Introduction

Advanced technology is changing the world of health care. The use of technology has reached such proportions that a new method of health care delivery has evolved: telehealth or telemedicine. This study explores the use of a telemedical device known as the electronic home spirometer and how it can be used to improve the quality of care for the lung transplant patient.

Spirometry is a useful instrument that can measure lung function and gauge the progress of lung transplantation. The spirometer measures elastic recoil of the lungs, large and small airway function, muscular effort, and interdependence between airways and alveoli.¹ Two primary mechanical calculations derived from spirometry include Forced Vital Capacity (FVC), greatest volume of air expelled with forced expiration, and FEV1 or Forced Expiratory Volume in one second. These specific lung measurements, coupled with a lung transplant's clinical symptoms, can assist health care providers in determining the presence of infection and/or rejection.²

Spirometry is a tool that can be used in the clinic office¹ or in the comfort of a patient's home. Finkelstein et al.³ developed an electronic spirometry program to monitor daily pulmonary function tests and lung-related symptoms of the lung transplant recipient while they are away from the hospital and clinic setting. Pulmonary function tests and symptom data are transmitted over the telephone line from the patient's house to a computer center where it is then communicated to health care personnel who analyze and interpret the clinical data. Reliability and validity of the spirometer has been conducted in previous studies.^{4,5} The purpose of the remote spirometry is to detect early presence of infection or rejection of the lung transplant patient.

In an ideal setting, home spirometry users would send their pulmonary testing and symptom responses every day of the week. The spirometry protocol requires the user to perform three daily pulmonary "blows" and answer a range of symptom questions pertaining to breathing, sputum color and amount, cough, wheezing, well being, and clinical events. The idea is that the daily data transmissions will provide a record of each individual's trends. Health care personnel who monitor the trends would then be able to detect any variations such as a decline, increase, or plateau, therefore identifying early signs and symptoms of possible acute rejection or infection.⁶ If there are alarming detections, as a result of the data surveillance, the spirometry nurse contacts the individual's transplant coordinator who then notifies the attending provider for further follow up.

Real life scenarios and past research analyses have demonstrated that daily spirometry transmissions can be a challenge. Telemedicine or telehealth technology can only be effective if the patients use the technology regularly. Reasons for spirometry non-adherence include laziness, unavailable equipment, forgetfulness, time conflict, sick or upset with health status, travel, no benefit seen, and out of habit.⁷ Notably, adherence decreases as post transplant time increases.⁸

Multiple strategies address the obstacle of daily spirometry adherence. These include positive reinforcement, recognized efforts, personal data graphs, support from doctors and coordinators, home spirometry newsletters, birthday cards, and frequent telephone reminders.⁹ Adherence even correlates to participant's interest or commitment to research and focus on their overall health; especially to infection and rejection.⁷

Incorporating patient preferences into the health care delivery method may also influence adherence. Patient preferences are based on their experiences, values, reflection, and cognitive evaluations. Tailoring interventions specific to patient preference will influence treatment selection and clinical decisions.¹⁰ Shared decision making between the patient and health care

provider improves health care quality and empowers and supports patients with their choices.¹¹

One way to address home spirometry users' questions and concerns is to incorporate feedback messages via the home spirometer. This study uses an electronic portable spirometer that supports controlled two-way communication over regular voice grade telephone lines between the patient and the provider (TransViva, 2380 WyCliff, Suite 200, St. Paul MN 55114, USA). In future operation, the home spirometry users will send in their pulmonary data to the computer center and feedback messages will be sent back to the users' spirometer while the telephone connection is in place. Tailored electronic feedback messages sent over the spirometer will serve as means of communication and education. These messages have potential to influence or even change spirometry behavior or lifestyle.¹² It may be more important to create tailored messages for home spirometry to positively influence impressions about home spirometry then choosing randomly from a set of previously determined appropriate messages.¹³

The purpose of this study was to identify the type of feedback messaging content home spirometry users prefer to receive and recognize as positively influencing their spirometry usage. It was postulated that incorporating patient preference in the content of the feedback messages it would improve the quality of the messages and enhance the relevance of the messages. The definitive goal of implementing the automated feedback messages is to enhance the feeling of being connected, raise confidence in spirometry usage, and influence daily adherence to the spirometry protocol.

Methods

Study Design

The study design followed a qualitative approach investigating experiences, perceptions, preferences, and realities of home spirometry. Focus group methods were employed to generate opinions and interests about automatic messaging content. This technique was chosen because it allowed interactive discussion in an intimate, non-threatening environment, and facilitates the expression of ideas.¹⁴

Focus Group Planning

Prior to implementing the first focus group, the research team conducted a two hour pilot session. The pilot session consisted of staff in role play of the focus group. The sessions demonstrated feasibility of the methods, aided in refining of methods, enabled practice and training of new members, revealed target aspects for corrective action, and served as a foundation for choreographing successful "real life" focus group sessions.¹⁵ The pilot confirmed the need for one facilitator, one recorder, and one observer. The research team concluded that the number of members present within each focus group session would be determined by the number of focus group participants. Each focus groups would be limited to eight participants including transplant recipients, transplant candidates, and significant others as long as they were familiar with home spirometry. The mock session also verified the need for a minimal one hour time frame and incorporated logistics of room availability and timing of when focus groups would take place.

Participant Recruitment

After the research plan was approved by the University of Minnesota Institutional Review Board (IRB), the home spirometry research nurses began the recruitment process by conducting an informational presentation at the lung transplant support group meeting. The support group includes lung transplant candidates, recipients, support personnel, and significant others. The social worker who facilitates the support group distributed research flyers at the beginning of

every meeting. Interested participants picked a focus group session convenient to them, provided their telephone number, indicated if they were candidate, recipient, or significant other and returned the flyer to the social worker. Additional flyers were mailed to transplant recipients who had participated in a previous home spirometry study but did not attend the support group.¹⁶ Flyers were also posted in the pulmonary function laboratory located in the transplant clinic. The research nurses then contacted the interested individuals to set up focus group sessions.

Sample

The convenience sample consisted of five lung transplant recipients, two lung transplant candidates and one significant other. The five recipients were male; the two candidates and significant other were female. All participants were attendees of the transplant support group, spoke English, were married, and Caucasian. Age varied from 51 to 64 with the mean age being 58.8. Recipients and the significant other had an average of 2 years of home spirometry experience. The candidates had sporadic exposure to home spirometry, generally through contact with transplant recipients who utilize home spirometry.

Focus Group Procedure

A total of three focus group sessions were held in the same room as the lung transplant support group meetings and were one hour before the support group. Two participants attended the first session, two attended the second session, and four participants attended the third session. Parking tokens were given to all participants as a gesture of appreciation for their participation. The participants were seated at a table face-to-face with other participants and the research team. The participants were then informed that the focus group study was part of a larger research project and that their ideas would support on-going research for home spirometry. The moderator read the verbal consent out loud that stated attendance at the focus group session implied their consent to participate in the study, following the guidelines of the University of Minnesota Institutional Review Board.

The moderator, observer, and recorder changed roles in the conduct of the series of focus groups. The moderator for the focus group asked the participants to respond to the discussion questions. The facilitating questions were: 1. What has been your experience with home spirometry monitoring? 2. What did you like about it? 3. What barriers did you experience and what concerns do you foresee in the future? 4. What kind of feedback would be helpful from the monitoring staff? 5. What examples of feedback messages do you have?

The recorder documented participants answers on a flip chart and categorized them for review at the end of the session. The observer took field notes and monitored the milieu of the focus group session. Each session was audio-taped to ensure accuracy of the data collection process and establish trustworthiness of the data analysis.¹⁴ The dialogue lasted until the discussion became repetitious, which averaged 50–55 minutes. The remaining time allowed the researchers to review and validate the participants' statements and thank them again for their participation. Researchers compared notes and assessments post focus group to form an agreement of what was observed in each session. These activities increase inter-rater reliability.¹⁶

Content Analysis

Initially the researchers met to assess the data content and quickly construct informal patient preferred feedback messages. This was done to facilitate incorporation of the messages into the automated electronic spirometry system. Based on the initial review, it was evident that similar patterns and themes had emerged suggesting three focus group sessions were a sufficient number of sessions.

Following the initial review, the data were analyzed in greater detail. The analysis method used to review the data was consistent with a constant comparative analysis. Data analysis began by transcribing the raw data and looking for patterns and connections between the data. The raw data included field notes, interview flip charts, audiotapes, personal notes about intentions, journaling, dispositions, as well as pilot worksheets and outlines. Audiotapes were transcribed verbatim according to each focus group.¹⁷ Narrative quotes were compared to corresponding records on the flip chart specific to each focus group. This was to confirm the credibility of the findings. The raw data served as audit trails which were subsequent measures for providing data accuracy.¹⁸

Narrative quotes were organized according to the five questions asked during the focus group in a computerized spreadsheet. The responses to these questions were the content of the data analysis. From there, the narrative data was coded, sub coded, and interpreted according to reoccurring themes and patterns.¹⁹ Each focus group resulted in the conclusion of similar emerging themes, validating the believability of the findings. Six categories and five subcategories emerged from the data analysis.

At least three investigators reviewed the focus group data in the initial assessment. Triangulation reduced the possibility of data analysis bias or one sided interpretations because more than one researcher initially assessed the data. One investigator conducted the majority of the data coding and frequently reviewed the findings and data processing with the other investigators.

Results

Category One: Education

The first category was education. There are three subcategories within the education category. The subcategories include general, lifestyle, and infection. In the first subcategory, general education topics include Pulmonary Function Tests (PFT), spirometry definitions, disease information, and medication influence. "I watch my PFT in the machine, they vary." "If the people could help me be smarter, self actuated [that would help]." "I saw somewhere in the lung hand book that says what they all mean FEV1 etc" "it would be good to have someone sit down with you and explain it". "No definitions are on the machine, just a bunch of numbers." "FEV1 is what the doctor looks at." "You can't underestimate how little people know." Others wanted information tailored to their pulmonary disease and how that affects spirometry. "What's a good number for you may not be a good number for me." Education about specific diseases and how they relate to spirometry was another general interest, "alpha versus IPF, emphysema, a lot of this stuff has a genetic glitch." "The data – what does that mean specific to me – his results compared to so and so compared to their diagnosis- alpha versus IPF and emphysema, how does that affect spirometry?" Another thought "it is important to know what drugs might affect the breathing."

The second subcategory of education was lifestyle. Many familiar with home spirometry felt it was important to remind co-lung transplant recipients of the importance of leading healthy lifestyles. "A standard question at clinic is 'are you smoking' I say are you nuts?" Another commented "smoking is beyond noncompliant and drinking, that messes with the stats, and longevity. We found many of the transplants are dying from other things not related to the lung." Participants often referred to their lung transplant handbook which included education information about maintaining a healthy life style. "I can't believe that people have been out six weeks and are out raking leaves." "I can't go in the garden, no plants, animal scratches or bites, no cat litter- it's a lifestyle change."

The third and final subcategory of education was infection. Participants were interested in learning how infection could affect their spirometry. “You see that you are up and down but don’t know where you are at.” “Medications that suppress your immune system changed my response on the machine, they called the coordinator, and then they called me; kind of a sign that it works.” Other participants wanted to know more about infection itself, “anything that you could print out about the different infections and so forth [would be helpful].”

Category Two: Goals

Setting personal goals was a recurring theme when analyzing the data. Participants looked for specific numbers, tailored goals, comparisons, and ways to gauge their home spirometry. “I would be more comfortable to know how to assess for yourself.” “I want some goals set, something like ‘keep your numbers at...’ “I shoot for the highest number.” “How are your numbers at the beginning of the month compared to the end of the month?” “It’s like monitoring my glucose; you get smarter after a while.” “[Provide] enough instruction on your own to know what you are looking for.”

Category Three: Timing

Many participants spoke about timing of their spirometry when speaking about their experiences. This theme surfaced within all three focus groups. “Earlier in the day is better off, less likely to forget, better attitude.” “Depending on your schedule or time of day you will notice a change.” “Monday is so busy, try to do it everyday at same time.” “I do it every day but my schedule changes” “They say keep it consistent.” “I haven’t done it everyday recently, when I had more problems I did it everyday”

Category Four: Technique

Technique was a category of interest with those familiar with home spirometry especially when comparing their home results to the clinic results. “Bob [in 10 clinic] only does two blows.” “If two is good for one why not good enough for the other?” “There are differences, don’t hold nose, don’t inhale at the end.” “You do it three times, it is quite simple, the told me I have a good technique.” “A difference in my results, should I wait between tests or bang, bang, bang?”

Category Five: Monitoring

Participants commented on knowing who was monitoring on the other end of the electronic home spirometer. This theme emerged throughout all focus groups. “If I put a wheeze they check me right away.” “Good if there was someone to talk to, confirm you were doing the test properly.” “No news is good news.” “I feel like I have been paid attention to; that is important not just out in cyber space.” “I think they catch things, they did call when he was not as consistent.” “I got something from the clinic; it shows my attendance is good.” “You might not see so much hand holding, if something is meaningful you will get a call.”

Category Six: Reminders

The participants all familiar with home spirometry commented that reminders would be good feedback messages. This included the subcategory of positive reinforcement like “good job” and “nice work.” One participant stated “it is always nice to hear positive,” “compliments are always good [to hear].” Two other participants said “each day is a milestone when you are a lung transplant.” Participants suggested gentle reminders like “need more results” “continue everyday” and “use spirometer to know you.”

Time sensitive reminders were a second sub category. Participants wanted to know what was happening in the transplant world and what information was pertinent to them at certain points in time. Time sensitive messages might include “there were X numbers of transplants this week,

or thus far” as one participant suggested. “Yeah, Happy Birthday and Happy Lung Transplant Anniversary would be okay with me.” Other time sensitive messages overlapped with educational messages such as tips about the weather, get your flu shot, wear sun screen, or wear a mask in dusty areas.

Once these categories were identified, the research nurses generated a list of example feedback message. Examples are located in Table 1. The narrative content served as primary means of the feedback messages. Actual quotes were used as feedback messages when applicable. Feedback messages were created according to length, feasibility, past experience, and neutrality for electronic implementation. Each message is confined to a specific number of characters due to the limitations imposed by the spirometer display panel. The developed list of feedback messages was informally brought back to the focus group participants. Member checking allowed the participants to confirm and validate their responses therefore supporting the credibility of the study’s results.¹⁸ Initiation of the automatic feedback messaging with the new home spirometry device is currently in process. Evaluation and discussion of the impact of feedback messages is yet to be determined.

Discussion

The purpose of this study was to identify the type of feedback messages home spirometry users would like receive on their electronic home spirometer. The focus group approach revealed the nature of six categories and five sub categories for feedback messaging content. These include education (general, life style, and infection), goals, timing, technique, monitoring and reminders (time sensitive, positive).

The first category, including its subcategories, was education. Most of the participants echoed the need for ongoing education. Particular interest was around spirometry definitions, life style changes, disease specific education, medications, and infection. The education theme is consistent with prior research suggesting lung transplant recipients require reeducation about self care to maintain compliance with the self care regimen.²⁰ This is particularly true as the length of time since transplant increases.

The second category included goals. Focus group participants were interested in setting goals for their home spirometry use. This individualizes spirometry and gives them something to strive for. Tailoring feedback messages about goal setting or goal attainment would assist spirometry users in establishing confidence in their spirometry, give them something to work towards daily, and generate support for daily usage. Matlock et al. implies that when tailored messages were associated with daily identified goals with Dietary Approaches to Stop Hypertension (DASH), participants demonstrated a higher compliance with diet regimens.²¹

The third category of timing was consistent with all those familiar with home spirometry. Participants felt the time of day, duration of time, daily health, time of schedule and activities, were all pertinent and individual specific with spirometry usage. Possible messages about home spirometry and timing, such as incorporating spirometry into your day, plan it when you can, will include users in the planning their daily self care. The lung transplant recipient and their health care provider participated in a shared decision making process about the importance of home spirometry in a self care regimen. Shared decision making enhances patients’ decision making and is usually congruent with their preferences²². Therefore, if the patient decides home spirometry is relevant and feedback messages support the use, the user may be that much more inclined to utilize the spirometer and feel responsible to use it within their specific daily routines.

Technique was another important category for the focus group participants. Many of the participants compared home spirometry technique to the clinic technique. Participants often

questioned if their technique or approach might be correct. Tailored feedback messages about technique would support or reinforce proper technique approaches, offer suggestions to correct technique, and presumably produce better results. Tailored messages about technique might be as successful as tailored messages with a heart failure program and medication adherence.²³ Krueter and Wray found that participants who received tailored weight loss material had more positive thoughts about the materials than those who did not receive tailored information.²⁴ Tailored messages about technique can validate current spirometry user's technique or improve actual results based on alterations in technique.

The fifth category was monitoring. Questions were often raised as to who was receiving their data, whether the electronic information was being reviewed, who should they call, and when could they talk about their spirometry results. Monitoring is a crucial component of home spirometry and is often an area of disconnect when the home spirometry user does not always see or hear from the receiving end on a daily basis. Feedback messages that support monitoring status will address the questions and concerns raised about "the other end" of home spirometry. Freidman et al. compared the effects of an automated telephone counseling and monitoring system on proper blood pressure control. Their findings suggest increased medication adherence and decreased blood pressure because of the increased monitoring and patient awareness.²⁵ Feedback messages about monitoring may also influence spirometry adherence and confidence in the spirometry protocol.

The final category was reminders. Participants felt that it was important to be reminded about doing spirometry, staying positive, and keeping abreast on what was happening in the transplant world. Dijkstra et. al. found computer tailored interventions about smoking cessation, particularly personalized and feedback reminder messages, led to significantly more smoking cessation activity after four months than did their standard information approach.²⁶ Frequent reminders about home spirometry will jog the users memory about home spirometry, assist in redirecting energy towards home spirometry, and essentially lead to increased spirometry adherence.

The findings in this research study such as education, reminders, goal setting, timing, and even technique and monitoring are findings that could be generalized to different patient populations. The diverse sample of eight participants, although small, aided in the understanding of the different perspectives of home spirometry use. The variety of viewpoints challenged any preconceived notions about home spirometry, allowing the researchers to remain open.

Nursing Implication

Clinical implications can be derived from the study's findings. The categories of education, goals, timing, technique, monitoring, and reminders have the potential to fit into a detailed care plan for home spirometry. In the health care world today, there is patient centered care and shared decision making. Incorporating patient preferred categories into a care plan involves the patient in their care and planning of their care. Active involvement of the patient in their care is suggested to influence their health behaviors and participation.²⁷

A nursing care plan has the basic elements of a priority set of diagnoses. It contains communication of what to teach, observe, implement, outcome criteria for evaluation of care, and direct care interventions for patient, family, and nursing.²⁸ A similar approach could be applied to home spirometry users to personalize spirometry care.

Focus group participants discussed the importance of establishing goals, the need to understand home spirometry specific to themselves, their disease, their plan of care, techniques, education, individual routines, and timing. Participants echoed the need to review their trends with

someone. A spirometry care plan would individualize the spirometry protocol for each lung transplant recipient and address each individual's needs.

Spirometry nurses can develop a home spirometry plan of care with each lung transplant recipient. This plan or shared decision making would serve as a contract between spirometry user and the monitoring health care personnel. This outlined plan of care would help the patient to establish a successful routine or pattern to home spirometry. Background decisions can be made such as the amount of blows feasible per week, time of when to perform home spirometry, and selecting an activity to associate with home spirometry. The nurse and the patient can identify barriers and possible solution as to why the participant may not transmit daily. This can be documented on their individualized care plan and reviewed each time the patient comes into clinic.

Secondly, the nurse and the patient can create goals. Based on the patient's current status, he or she should try to transmit daily, if not, then minimally three times a week. The nurse and the patient can determine timing, individual techniques, write out clinical monitoring information such as dates spirometry reports are reviewed, who reviews them, the number to call for questions, meeting times, and when to expect spirometry graphs. The care plan can include education tips, definitions, lifestyle indications, time sensitive reminders and patient specific education regarding his or her health conditions.

Collaboratively, the patient can review the spirometry plan of care with his or her physician. The physician can assist the patient in establishing FEV1 and FVC goal ranges based on the patient's clinical presentation and health status. The physician or nurse can review the medications that would affect or influence spirometry results and document them within their plan of care.

The qualitative data gathered in this study reflects the experiences and realities of daily home spirometry. Incorporating the feedback message categories into a clinical care plan and then contracting with the home spirometry user includes the user in his or her care. The patient is now accountable for his or her contributions to the plan and adherence to the home spirometry protocol. The spirometry care plan can be reviewed at each clinic visit and used as a communication tool.

The 2007 Cochrane Review on adherence suggests that there is lack of evidence in regards to contracting with patients to positively influence adherence.²⁹ However, incorporating the patient's preferred content, such as the findings within this study, the clinical contract may be more appealing to the patient and result in favorable outcomes. Further research is warranted to determine the effects of contracting with patient preferred content with home spirometry users.

The categories generated from the narrative content of the focus groups resulted in patient preferred feedback messages. The content additionally serves as a foundation for establishing a plan of care individual to each home spirometry user. Enhanced personalized care is an end result of this study.

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Table 1**Patient-preferred feedback messages****Education****General**

FEV1: vol. of air exhaled 1 sec.

FVC: max vol. air exhaled after max inhale

Wheezes sound like soft whistles

Lifestyle

Exercise regularly

Get good rest

Please don't smoke

Have you read your transplant handbook?

Infection

Your FEV1 can change with infection

Wash hands to prevent infection

Sputum color can help ID an infection

Prevent infection: Wear a mask

Goals

Your FEV1 goal is...

Shoot for three blows a day

Push to do your best!

How many blows have you done this week?

Monitoring

We review your reports every Friday

The spirometry RN will see you in clinic

We will review your data with you

Call 555-555 to learn more about your testing

Technique

Pause between blows

It is okay to sit for spirometry

Biggest breath right away is best

Don't plug your nose with these blows

Three blows are best. We take the average

Timing

Associate your tests with an activity

Consistency is key!

Plan for spirometry today.

Develop a routine in your day for spirometry

Reminders

Need more data please

Continue every day!

Don't forget to change your mouth pieces.

Remember to do your blows everyday

Positive

Keep it up!

We appreciate your efforts!

Way to go! Thanks for the transmissions

Time Sensitive

Happy Birthday

Happy Transplant Anniversary

Don't forget to get your flu shot

You have transmitted _ times this month