Information needs among patients with chronic obstructive pulmonary disease at their first hospital admission: priorities and correlates

Su-Er Guo, Chiung-Yu Huang and Hsin-Tien Hsu

Aims and objectives. To better understand chronic obstructive pulmonary disease patients’ informational needs and associated factors using the Predisposing, Reinforcing and Enabling Causes in Educational Diagnosis and Evaluation model.

Background. Despite the increase in the incidence of chronic obstructive pulmonary disease, little research has been carried out on the information needs from a patient perspective.

Design. A cross-sectional, correlational design was used.

Methods. A convenience sample of 107 subjects was recruited from four Taiwanese hospitals. Multiple regression analyses were conducted to identify the total informational needs and related factors.

Results. Major findings were that (1) patients’ top informational need was daily care, and (2) variables associated with the total information needs were younger age, greater health internal locus of control, less dyspnoea severity and greater social support.

Conclusions. Patients’ perceived chronic obstructive pulmonary disease informational needs are not congruent with the information received from healthcare professionals.

Relevance to clinical practice. Healthcare professionals need to be sensitive to the fact that treatment-related information was not the top priority of patients with chronic obstructive pulmonary disease. Healthcare professionals also need to target the special subpopulation of chronic obstructive pulmonary disease patients with greater total informational need to maximise educational impact.

Key words: chronic disease, health education, health locus of control, health needs, lung disease, patient perspective, patient teaching, self-care, self-management, social support

Accepted for publication: 5 February 2013

Introduction
Chronic obstructive pulmonary disease (COPD) is a persistent and progressive illness for which no cure has yet been found. It is the fourth leading cause of death in North America and will be expected to become the fifth leading cause of death by year 2030 (Mathers & Loncar 2006, Sin et al. 2006, Global Initiative for Chronic Obstructive Lung Disease 2011a). Chronic obstructive pulmonary disease has also been prevalent in Asia, when it was among the top eight leading causes of death in Taiwan in 2009 (Taiwan Society of Pulmonary & Critical Care Medicine 2012).
As cigarette smoking is increasingly popular among younger age groups, COPD will likely continue to be a common disease around the world (Global Initiative for Chronic Obstructive Pulmonary Disease 2011b). However, despite the growing rate of COPD mortality, little research has considered the type of information this patient population actually desires.

Background
Increasing the ability of patients to recognise and manage their illness using patient education is not only a healthcare priority but also a crucial part of effective management of chronic conditions such as COPD. Because current health education is usually formulated and delivered from the viewpoints of the healthcare professionals, it often does not match patients’ education needs or information needs (Suhonen et al. 2005). Furthermore, research into a range of different diseases has generally indicated that healthcare professionals are often incorrect nor accurate in identifying the type and amount of information desired by patients (Timmins 2005, Li et al. 2011). To address these issues, effective patient education must take into account the knowledge and skills that patients want to develop, as well as the self-management subject matter considered as important by healthcare professionals themselves.

Recent consensus statements on the management of COPD have advocated a partnership approach to education that encourages active patient involvement directed at changing patients’ own behaviour to improve their quality of life (Siafakas et al. 1995, Corsello & Tinkelman 2008, UK National Institute for Health & Clinical Excellence 2010). However, while patient participation is recognised as important, it is often not clear whether current education and patient self-management guiding principles actually incorporate patient viewpoints and priorities (Wilson et al. 2007). To know patient’s health-related information needs is a key to plan educational interventions appropriately, yet patient’s perspective on information needs has rarely been assessed. This study attempts to know the gap in understanding COPD patients’ information needs and associated factors using the Predisposing, Reinforcing and Enabling Causes in Educational Diagnosis and Evaluation (PRECEDE) model and identify their information preferences as a guideline for patient education activities.

The PRECEDE model provides a framework for the systematic development and evaluation of health education programs. Within the PRECEDE model, predisposing, enabling and reinforcing factors are classified as antecedents to health behaviours. Predisposing factors include demographic characteristics, knowledge, attitude, beliefs and values. Enabling factors refer to those aspects of the environment or of individuals that help bring about the desired behavioural changes, including availability, accessibility and affordability of healthcare and community resources (Gielen & McDonald 2002). Reinforcing factors refer to any rewards or punishments experienced, or any anticipated consequences of behaviour. These include the attitudes of close relatives and/or healthcare providers supporting the patients, as well as the physical consequences of behaviours (Gielen & McDonald 2002).

Methods
Design
A descriptive cross-sectional correlational design was used to examine the relationships between the predisposing (demographic variables, COPD knowledge, health locus of control), enabling (health resource availability, health status) and reinforcing (social support) factors and patients’ information needs. To obtain a sample size that would provide adequate power to avoid type II error, sample size was determined by power analysis based on multiple linear regression. The target sample size of 109 participants was sufficient to detect a median effect size of 0.15 on the outcomes with a power of 0.80 and an alpha level of 0.05.

A convenience sample of patients was recruited from four local hospitals located in a city in southern Taiwan with a population of approximately 1,873,794 (Tainan City Government 2010). To be eligible for this study, subjects had to be inpatients on their first admission to hospital for a diagnosis of COPD; 40 years of age or older; able to speak Mandarin or Taiwanese; and without other diseases that could influence lung function, including pulmonary tuberculosis, lung cancer and congestive heart disease. One hundred and twelve patients were deemed eligible for the study and agreed to participate; five of these patients dropped out for a variety of reasons, including inability to participate due to illness and family problems. The participants in this study had a mean age of 70.3 years (SD = 7.7) and were primarily men (81.1%), married (76.4%), retired (75.5%) and have moderate severity of dyspnoea (2.7 ± 1.0) based on Medical Research Council Dyspnea Scale. About half had six years of education or less (47.2%), and the majority were living with their families (94.3%). All patients recruited for this study were ethnic Chinese (no aboriginal persons or other ethnicities).
Data collection

The patients were referred to the study by physicians at the four hospitals, and all those meeting the inclusion criteria were invited to participate. Prior to participant enrolment, written consent was obtained from all participants in accordance with procedures approved by the Institutional Human Subjects Review Boards of the four hospitals. Patient data, including information needs and three sets of PRECEDE factors, were collected by interview, three to six days after admission to hospital.

Measures

The COPD Information Needs Scale

Information needs were determined using the COPD Information Needs Scale, a 35-item scale related to the disease of interest (symptoms distress, treatments, disease progression, exercise, nutrition, side effects of treatments, etc.) and developed by the authors of this study. Several sources contributed to the scale’s design, including (1) a literature review, and (2) the clinical experience of an interdisciplinary pulmonary team. The content validity was judged by four pulmonary nurse experts and two respiratory specialists. Six experts evaluated all the scales for their content relevance and appropriateness, rating each item as follows: 1 = not very proper, 2 = not proper, 3 = fair but needs minor revisions, 4 = proper and suitable for inclusion and 5 = very proper and needs to be included. The Content Validity Index (CVI) of the scale was 0.95; this was calculated by dividing the number of items that received a rating greater than three by the total number of items. The factor analysis produced five domains: knowing the disease, respiratory therapy, daily care, oxygen therapy and medication. Each domain was scored on a 5-point scale to measure the extent of information needs, using the following response options: ‘strongly not needed’, ‘not needed’, ‘natural’, ‘needed’ and ‘strongly needed’. The possible range of each subscale is listed in Table 1. The total perceived informational need was calculated as the grand mean of all the domains. This scale had good test–retest reliability (r = 0.83), as well as excellent internal consistency (Cronbach’s alpha = 0.90–0.95). Patients were also asked whether they had received information about any of the information needs items and if so, from whom (healthcare professionals, friends and/or family members) and whether they feel satisfied about these information needs items.

COPD Knowledge Scale

We developed a 25-item scale to assess the patients’ knowledge regarding COPD, respiratory symptoms, treatments, side effects of treatments and daily care. Responses were coded as follows: ‘Correct’ responses were coded as ‘1’, and both ‘Incorrect’ and ‘I don’t know’ responses were coded as ‘0’. The possible scores ranged from 0–25, where higher scores indicate better knowledge of COPD. The scale had good internal consistency (Kuder–Richardson 20 = 0.80), and face and content validity was judged to be good (CVI = 0.92) by a panel of three pulmonary nurse experts and two respiratory specialists. Some items within the instruments were revised according to the experts’ suggestions.

The Multidimensional Health Locus of Control Scale

The Multidimensional Health Locus of Control (MHLC) Scale, developed by Wallston et al. (1978), is based on constructs generated by Rotter (1954) and Levenson (1973). The MHLC measures the health locus of control construct, which is the extent to which individuals believe their health outcomes are under their own control, under the control of powerful others or the results of chance occurrences. The three subscales are (1) internal health locus of control (IHL, 6 items), (2) external chance locus of control (CHLC, 6 items) and (3) external locus of control by powerful others (PHLC, 6 items). A 6-point Likert format includes responses ranging from 1 (strongly disagree)–6 (strongly agree). The possible scores of each subscale range from 6–36. Scales are scored by summing respective items for a total scale score, and higher scores reflect stronger endorsement of MHLC Scales (Wallston et al. 1978). The MHLC has been shown to have satisfactory internal consistency, acceptable test–retest reliability and good construct validity (Wallston & Wallston 1981). The present study used a Chinese version of the MHLC, developed by Wang et al. (1992), that was shown to have satisfactory internal consistency (Cronbach’s alpha = 0.69–0.81) and acceptable test–retest reliability (r = 0.70–0.83). The Cronbach’s alpha

Table 1 Ranking of information needs (n = 107)

<table>
<thead>
<tr>
<th>Categories</th>
<th>Mean</th>
<th>SD</th>
<th>Items</th>
<th>Actual range/ Possible range</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily care</td>
<td>4.19</td>
<td>0.34</td>
<td>12</td>
<td>3.62–4.70/1.0–5.0</td>
<td>1</td>
</tr>
<tr>
<td>Knowing the disease</td>
<td>3.68</td>
<td>0.36</td>
<td>8</td>
<td>3.32–4.04/1.0–5.0</td>
<td>2</td>
</tr>
<tr>
<td>Respiratory therapy</td>
<td>3.45</td>
<td>0.48</td>
<td>5</td>
<td>2.93–3.89/1.0–5.0</td>
<td>3</td>
</tr>
<tr>
<td>Oxygen therapy</td>
<td>2.81</td>
<td>0.37</td>
<td>6</td>
<td>2.54–3.28/1.0–5.0</td>
<td>4</td>
</tr>
<tr>
<td>Medication</td>
<td>2.36</td>
<td>0.35</td>
<td>4</td>
<td>2.01–2.71/1.0–5.0</td>
<td>5</td>
</tr>
<tr>
<td>Total information needs</td>
<td>3.52</td>
<td>0.39</td>
<td>35</td>
<td>3.30–4.60/1.0–5.0</td>
<td></td>
</tr>
</tbody>
</table>
coefficient of IHLC in this study was 0.82, 0.90 for CHLC, 0.87 for PHLC and 0.88 for the total scale.

The Social Support Questionnaire
Social support is theoretically defined as any activities that help an individual move towards goals (Caplan et al. 1976), including emotional, informational or practical assistance (Thoits 1986). In the current study, social support was measured using the Social Support Questionnaire (SSQ), which was adapted from Cohen et al.'s Interpersonal Support Evaluation List (Guo & Chiou 1997). The SSQ is a 20-item Likert scale that measures four dimensions (emotional, informational, tangible and self-esteem supports) of the frequency of help received from and offered to others. Patients rated how often they had received help during the last month, with a scale that ranged from 0 = never; 3 = very often. The possible scores ranged from 0–60, where higher scores indicate more frequent instances of social support. The Cronbach’s alpha coefficients among the four subscales and the overall scale of the Social Support Questionnaire ranged from 0.82–0.87. The SSQ also has good content validity (CVI = 0.95) (Guo & Chiou 1997). In this study, the Cronbach’s alpha of this scale was 0.86.

Based on the literature and PRECEDE model, several potential confounding variables were measured. Health resource availability refers to the availability of all materials, personnel, facilities, funds, etc. involved in the provision of health care and services (Mosby’s Medical Dictionary 2009). In the current study, the patients were asked whether they received any information about COPD directly from healthcare providers or through other materials (brochures, pamphlets, or media or posters on the wall); these questions used a yes/no answer format. Health status includes disease duration and disease severity. Disease duration was measured by month and reported by the patients themselves. Dyspnoea severity was determined by asking patients to score their dyspnoea level using the Medical Research Council Dyspnea Scale (MRC Dyspnea Scale). The MRC Dyspnea Scale is a simple and valid measure of breathlessness in patients with COPD (Bestall et al. 1999). The Cronbach’s alpha coefficient of MRC Dyspnea Scale in this study was 0.86.

Data analysis

The data were analysed using spss, version 17.0 (SPSS Inc., Chicago, IL, USA). Data were described using mean and standard deviations (SD) for continuous variables or as percentages for categorical data. Stepwise multiple regression analyses were used to determine correlates of information needs. In the first step, univariate regression analyses were used to determine the unadjusted association between the perceived information needs (the overall information needs and each of the information needs) and predisposing factors (demographic variables, COPD knowledge, health locus of control), enabling factors (health resource availability, health status) and reinforcing factors (social support). There was no evidence of multicollinearity except in gender and education, so we used education as the sole variable in the next step. In the second step, only variables (age, education, COPD knowledge, internal health locus of control, severity and social support) that were associated with the perceived information needs (p > 0.25) were included in the final multivariate model. Statistical significance was set at p < 0.05 in the final model.

Results

The mean score of the total information needs was 3.52 (±0.39), which was above the midpoint of the 5-point Likert scale. In terms of the subscales of information needs, daily care had the highest score (4.19 ± 0.34), followed by knowing the disease (3.68 ± 0.36). Respiratory therapy had roughly the same score (3.45 ± 0.48) as knowing the disease but with a larger variation. Oxygen therapy (2.81 ± 0.37) and medication (2.36 ± 0.35) were identified as having the least informational need and had approximately the same magnitude of scores (Table 1).

Most patients reported receiving information from nurses and physicians (52.90 and 34.20%, respectively). However, while a percentage of patients had received some information from healthcare professionals, such information was insufficient to satisfy their needs in the selected areas (t = −3.27, p < 0.05).

The average score on the COPD Knowledge Scale was 9.0 (±3.2) out of 25, which was rather low. There was a lack of health resource availability; roughly only one-quarter (26.2%) of the patients was able to find the resources they felt they needed. A large proportion of the patients (73.8%) reported that they received insufficient information about how to manage their disease. Those who were provided with information on disease management received it mostly from their physicians or nurses. Healthcare brochures and pamphlets did not play a key role in educating the patients.

The total information needs was mainly affected by education level, age, knowledge of COPD, health locus of control, severity of disease and social support in univariate regression analysis (Table 2).
Age, severity of dyspnoea, social support and internal locus of control were the important factors of influence ($F = 8.54, p < 0.001$); 44% of the variance of the total information needs was accounted for by the regression model (see Table 3).

**Discussion**

Our goal was to scrutinise the priority of information needs perceived by participants and to examine what factors influence COPD patients’ needs, to establish appropriate education programs. We found that patients with COPD have the greatest information needs for daily care, knowing the disease and respiratory therapy (the average score ranged from 4.19–3.41). In contrast, the average score of perceived informational need for oxygen therapy and medication was lower, usually below 3.0.

In addition, our study found that the lowest informational need from the patients’ perspective was the need for medication education (Table 1). This is surprising, because the high numbers of medications often prescribed to older adult and geriatric populations present inherent challenges in terms of management and adherence to a complicated medication regime (Elliott 2006). Indeed, Wilson _et al._ (2007) noted that although patients complained about
insufficient medication information, they frequently failed to actively ask for or seek assistance with medications and medication education. Our finding of low perceived medication education needs is in line with these results.

Asian cultural beliefs may have also contributed to patients’ lower perceived medication education needs. In Asian cultures and societies, filial piety is considered a fundamental duty, and younger family members are expected to take care of their sick parents not only in terms of physical and emotional needs, but also in terms of decision-making for the patients (Blackhall et al. 2001, Hsu & Shyu 2003). Thus, several studies have shown that in Asian culture, the responsibility for information seeking and caretaking is often assumed by delegated family members and doctors, rather than by patients themselves (Litwin 1994, Yamamoto & Wallhagen 1997). Keith (1992) has also demonstrated that many Asian patients feel that responsibility for disease management rests with healthcare authority figures such as doctors and nurses, and that their responsibility as patients is to comply with treatment directives. Indeed, several patients in the present study expressed the desire to be told what treatments to undergo or medications to take without any additional disease-related information. However, this issue may need further exploration before it is fully understood.

Additionally, patient’s COPD knowledge was found to be quite low among the population of interest. There are a number of possible reasons for this. As previously noted, almost half of the patients had six years or less of formal education. As a result, the subjects may have been less well informed about COPD or less able to identify and access sources of potential information. Healthcare professionals within the Taiwanese healthcare system may be at least partly responsible for further perpetuating the low disease knowledge state of patients with COPD by limiting the amount of information provided to patients or discouraging requests for additional information, based on the assumption that low educational attainment will prevent certain patients from adequately comprehending or making use of the information. This study also showed that only 26-2% of the patients were notified about their condition. This finding is consistent with the finding of another Taiwanese study that revealed that doctors often do not provide patients with explanations of their disease or treatment (Guo et al. 1995).

Furthermore, at the time of this study, there was a marked dearth of both nurse educators and resources such as brochures, pamphlets and other transportable educational media for patients with COPD to access in doctor’s offices, hospitals and other healthcare centres. These combined factors both result from, and may also perpetuate, widespread cultural attitudes and structures within the Taiwanese healthcare system that severely limit patients’ ability to access or even request information about their disease.

Dyspnoea is also likely to contribute to COPD patients’ perceived information needs. A consistent inverse relationship between disease severity (dyspnoea) and information needs was found after controlling other variables. That is, those patients with lower severity felt a greater need for information, while those who were more severe felt less information need. However, healthcare providers focused their patient education efforts on the more severe patients to the detriment of those whose condition was less severe, and therefore, the more severe patients were the ones who received more information ($t = 2.46, p < 0.05$), even though they did not desire it. This study also found that the patients who had more social support, who were healthier, who were younger and who had greater internal locus of control were more likely to actively seek for knowledge to improve their health; this result was in accordance with the findings of several previous studies (Kennedy et al. 1991, Myers et al. 1994). It seems clear therefore that healthcare professionals need to be more sensitive and to listen more carefully to the patients themselves, and that targeted education and assessment initiatives focusing on the needs of patients with less severe COPD need to be developed.

Certain limitations need to be taken into consideration when interpreting the results of this study. First, the study used convenience sampling with not big enough sample size, which may limit the generalisability of the findings to other populations of patients with COPD. Second, some of the measures only addressed content validity and internal consistency. Even though they are reliable, future research should use more validated methods to confirm their validity, particularly for construct or criterion validity. Nonetheless, the study provides useful information about the perception of information needs and their influence factors among Taiwanese patients who are experiencing their first hospital admission for COPD and can be used as a reference for related research in the future.

Conclusion and relevance to clinical practice

In summary, nearly three-quarters of patients felt they did not receive sufficient information from healthcare providers about how to manage their disease. Moreover, the information needs among patients with COPD in this study appear to be highly correlated with such factors as age, internal locus of control, severity of dyspnoea and social support. These findings underscore the importance of including the patient as a collaborative partner in healthcare education.
processes by addressing his/her individual information needs. This study provides direction to inform educational strategies for the special subpopulation of COPD patients with greater information needs. Furthermore, patients’ perceived information needs and the information they receive from healthcare professionals about their illness may not always be congruent; therefore, to help patients better self-manage their disease, healthcare professionals need to become more sensitive to patients’ perspectives.

We found that the first priority of perceived information needs among patients with COPD is daily care. We suggest that education programmes should address patients’ needs from the patients’ perspective. This could be done by offering individual and group education sessions in which patients are provided with information about how to care for themselves and manage their disease in their daily life. This primary focus would likely induce patient interest, and the healthcare educator could then follow this topic with a discussion about managing other important aspects of COPD that patients may be less interested in, such as oxygen therapy, anatomy and physiology.

Finally, because our finding shows that many patients with COPD had both quite low resources and limited access to transportable educational media about their illness, we also suggest that there is a need for healthcare professionals to provide themselves as resources and to create more educational materials, brochures and teaching videos, which could then be made available to patients. The written materials should be designed to accommodate those with low levels of education and should include visuals such as pictures and diagrams (Decker et al. 2008).

Acknowledgements
The authors thank the contributions of all patients with COPD who participated in this study.

Contributions
Study design: SEG; data collection and analysis: SEG and manuscript preparation: SEG, CYH and HTH.

Conflict of interest
No conflict of interest has been declared by the authors.

References


Levenson H (1973) Multidimensional locus of control in psychiatric patients.

© 2013 John Wiley & Sons Ltd
*Journal of Clinical Nursing*, 23, 1694–1701


The Journal of Clinical Nursing (JCN) is an international, peer reviewed journal that aims to promote a high standard of clinically related scholarship which supports the practice and discipline of nursing.

For further information and full author guidelines, please visit JCN on the Wiley Online Library website: http://wileyonlinelibrary.com/journal/jocn

Reasons to submit your paper to JCN:

High-impact forum: one of the world’s most cited nursing journals, with an impact factor of 1.316 – ranked 21/101 (Nursing (Social Science)) and 25/103 Nursing (Science) in the 2012 Journal Citation Reports® (Thomson Reuters, 2012).

One of the most read nursing journals in the world: over 1.9 million full text accesses in 2011 and accessible in over 8000 libraries worldwide (including over 3500 in developing countries with free or low cost access).

Early View: fully citable online publication ahead of inclusion in an issue.

Fast and easy online submission: online submission at http://mc.manuscriptcentral.com/jcnur.

Positive publishing experience: rapid double-blind peer review with constructive feedback.

Online Open: the option to make your article freely and openly accessible to non-subscribers upon publication in Wiley Online Library, as well as the option to deposit the article in your preferred archive.

© 2013 John Wiley & Sons Ltd
Journal of Clinical Nursing, 23, 1694–1701

Original article

Li PWG, So WKW, Fong DYT, Lui LYY, Lo JCK & Lau SF (2011) The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. Cancer Nursing 34, 49–57.