Institution: University of Plymouth

Unit of Assessment:UoA4

Title of case study: Improving the treatment of respiratory disease through psychological intervention.

1. Summary of the impact

Chronic Obstructive Pulmonary Disease (COPD) affects 6% of the world's population [1]. Two assessment tools have been developed to help clinicians manage COPD; one as a measure of severity to guide clinical management, and the other to be used by clinicians either as a pre-interview assessment of information needs or for assessing the quality of educational initiatives. These measures are used by clinicians (e.g., doctors, physiotherapists, respiratory nurses) in the UK and other countries such as Japan, Canada and The Netherlands in medical settings that include hospitals, specialist respiratory clinics, and community medicine (General Practice). Beneficiaries include the medical community as well as patients, whose quality of life is improved as a result. There is also research evidence of potential for healthcare cost savings through lowered hospitalisation rates.

2. Underpinning research

Research into the psychology of respiratory medicine has been carried at Plymouth since the late 1980s (Michael Hyland was the first respiratory psychologist in the UK, and appointed professor of health psychology in 1996) within the broader remit of the active health psychology group within the School. Rupert Jones, a GP with a fractional appointment as a research fellow at the Medical School at Plymouth since 2003, has a special interest in respiratory disease, and has collaborated with Michael Hyland since 2000.The research programme has involved the development of assessment tools to assist clinical management and outcome.

In chronic obstructive pulmonary disease (COPD) two factors are critical for the key outcomes of quality of life, morbidity, mortality, and healthcare consumption. These factors are: (1) decisions made by the doctor (including medications and rehabilitation) and (2) self-management by the patient (decisions concerning smoking, exercise, diet, and self-management of acute exacerbations). We have developed psychometrically useful assessment tools to assist both processes.

(1) Clinical management of COPD differs with the progression of the disease, and therefore requires a measure of disease severity to guide management. Assessment of disease severity in COPD requires multi-component measures to reflect the several components of the disease. Although multi-component measures of severity existed we were aware that they are difficult to use in clinical practice, in particular because some of the components are not routinely measured. We therefore developed the DOSE index based on routinely taken measures, and which could therefore be used more widely in clinical practice. We showed it had superior predictive power compared with other indices (Jones et al., 2009, 2010). The DOSE index was specifically designed to guide management, unlike other indices, which assess severity only. We developed the DOSE index by examining data held by several respiratory research groups in the UK, the Netherlands, and Japan in 2008, and examined outcome in relation to the different possible predictors. Michael Hyland was responsible for selecting the combination of parameters that make up the index by finding an algorithm that was predictive of several outcomes (Jones et al., 2009). The data collection for derivation was done by Jones, and the data for validation came from the other authors. Rupert Jones and Michael Hyland took the primary role in writing the paper as indicated by author position (first and last). The work was funded by an unrestricted grant from Boeringher Ingelheim.

(2) Without the understanding of what is wrong and how to manage the condition, patients are unable to take appropriate steps to improve lifestyle and improve self-care. The initial idea of the Lung Information Needs Questionnaire (LINQ) came from qualitative research with COPD patients into adherence, (Jones, Hyland, Hanney & Erwin, 2004). We found that (in contrast to asthma) intentional adherence was good, but, unexpectedly, there was poor understanding by patients of their disease and its management. We felt we needed to do something to remedy this situation and so the LINQ was therefore designed to help clinicians identify and rectify these information needs. The LINQ was developed by focus groups led by Michael Hyland (Hyland, Jones & Hanney, 2006) who identified information needs, and devised the wording of the scale by using patients to select the wording of the items. This then led to quantitative evaluation in the UK (Hyland, Jones & Hanney, 2006; Jones et al., 2008) and Japan (Wakabayashi et al., 2011), which

showed that that the LINQ can be used to evaluate educational initiatives, and that the resulting better care (and education) leads to reduced information needs as well as to reduced numbers of hospitalisations during the intervention. This research showed that compared to a usual-treatment control group who showed no change in rate of hospitalisation from baseline to 6 months, the LINQ intervention group reduced hospitalisation rates from 0.17 at baseline (9 hospitalisations from the sample of 52), to zero hospitalisations during the 6 months of the active intervention.

3. References to the research

Jones, R. C., Donaldson, G. C., Chavannes, N. H., Kida, K., Dickson-Spillmann, M., Harding, S., Wedzicha, J. A., Price, D., & Hyland, M. E. (2009). Derivation and Validation of a Composite Index of Severity in Chronic Obstructive Pulmonary Disease: The DOSE Index. American *Journal of Respiratory and Critical Care Medicine,* 180, 1189-1195. http://www.atsjournals.org/doi/full/10.1164/rccm.200902-0271OC
Citations: 81 Impact factor: 11.08 (2011). Journal ranked 1/50 for IF and 1/50 for Eigenfactor in 'Respiratory System' (JCR)

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Jones R.C., Hyland M.E., Hanney K., & Erwin J. (2004) A qualitative study of compliance with medication and lifestyle modification in Chronic Obstructive Pulmonary Disease (COPD). *Primary Care Respiratory Journal*, 13, 149-54. https://www.thepcrj.org/journ/vol13/13_3_149_154.pdf
Citations: 32. Impact factor: 2.2. Journal ranked 38/50 for IF and 38/50 for Eigenfactor in 'Respiratory System' (JCR)

Hyland M.E., Jones R.C.M., & Hanney K.E. (2006) The Lung Information Needs Questionnaire: Development, preliminary validation and findings. *Respiratory Medicine,* 100, 1807-1816. http://www.sciencedirect.com/science/article/pii/S0954611106000497
Citations: 26. Impact factor: 2.6. Journal ranked 24/50 for IF and 25/50 for Eigenfactor in 'Respiratory System' (JCR)

Jones R.C.M., Wang X., Harding S., Bott J., & Hyland M.E. (2008) Educational impact of pulmonary rehabilitation: the Lung Information Needs Questionnaire. *Respiratory Medicine,* 102, 1439-1445. http://www.sciencedirect.com/science/article/pii/S0954611108001674
Citations: 6. Impact factor: 2.6. Journal ranked 24/50 for IF and 25/50 for Eigenfactor in 'Respiratory System' (JCR)

Wakabayashi R., Motegi T., Yamada K., Ishii T., Jones R.C., Hyland M.E., Gemma A., & Kida K. (2011) Efficient Integrated Education For Older Patients With Chronic Obstructive Pulmonary Disease Using The Lung Information Needs Questionnaire. *Geriatrics and Gerontology International,* 11, 422–430. http://onlinelibrary.wiley.com/doi/10.1111/j.1447-0594.2011.00696.x/full
Citations: 5. Impact factor 2.2. Journal ranked 27/46 for IF and 30/46 for eigenfactor in 'Geriatrics and Gerontology' (JCR)

Jones, R. Hyland. M.E. and Hanney, K.E. (2002-2003) A qualitative study of concordance in COPD. £62500 awarded by Boeringher Ingelheim.

4. Details of the impact

The DOSE index

Treatment decisions for COPD depend crucially on an accurate prediction of the future progression of the disease, and treatment guidelines recommend physicians to assess disease severity. Of the several multi-system indicators available, both the DOSE and the BODE are significant predictors of mortality [2] but the DOSE index is simpler and cheaper to use compared with the BODE index. The BODE index is the most commonly cited index of severity in research studies, but is virtually never used in primary and secondary care. A 2012 analysis of 14610 records on the OPC database of patients with a diagnosis of COPD revealed no case for which there was a complete BODE score [3]. This is because the BODE requires trained staff to conduct

a six minute walk test along a 30 metre corridor, with total administration time of at least twice that time (>12 minutes). In contrast the DOSE index consists of 4 items which according to NICE recommendation should be part of the routine assessment of patients in all settings (NICE CG 101), and so for many patients incurs no additional costs for assessment. The same 2012 analysis of the 2012 OPC database revealed that around half of COPD patients (7,228 of 14,610) had a valid DOSE index properly recorded. If the indicators for the DOSE are not collected (i.e., about 50% of this sample) then guidelines are not being followed. The DOSE index and associated management recommendations can be automatically computed from routinely collected data by data analysis systems such as the OPC COPD reporting service (http://www.optimumpatientcare.org/), and the Health Intelligence risk stratification service (http://www.health-intelligence.com/population-based-risk-stratification.html). This means that the NHS staff require no extra work to obtain the DOSE score other than that required by following the NICE guidelines. By calculating a DOSE score they are thereby able to identify patients in need of intensive management.

The DOSE index has been widely adopted internationally and has led to changes in recommended guidance worldwide in terms of assessing disease severity. The following guidelines or organisations recommend the use of the DOSE: (a) The Global initiative for Chronic Obstructive Lung Disease (GOLD) 2011 guidelines, which are the most influential in the world, recommend the DOSE for assessing disease severity [1]. (b) 'Diagnosis and management of COPD in primary care: A guide for those working in primary care' (Primary Care Respiratory Society, Third Edition, 2010) [4] (c) IMPRESS guidelines (an organisation that links the British Thoracic Society with the Primary Care respiratory society) [5] and (d) the COPD exchange educational website with >7,500 registered members in 2012 recommends the DOSE index in routine clinical care [6]. A UK company used by NHS commissioners (Health Intelligence) uses the DOSE index to stratify risk for people with COPD, and thereby determine treatment selection. The DOSE index is also used by a patient management organisation, Optimal Patient Care, which has been providing assessments using the DOSE index on 7000 patients annually over the last three years [3]. The results are returned to doctors and patients, and the scores are used to assess disease severity and guide treatment recommendations. The National COPD audit is a Department of Health initiative similar to the diabetes and cancer audits. The audit is currently being developed with first data collection due in late 2013. It aims to include nearly all 800,000 patients in primary care with a registered diagnosis of COPD. One of the key items being used to assess disease severity and progression is the DOSE index [7].

The DOSE index is used as part of a COPD management template which has been developed by the Primary Care Respiratory Society in conjunction with Almirall (a pharmaceutical company) and the Department of Health. The template is currently in beta-testing with 1,000 practices per year scheduled to receive it over the next 3 years [7]. The template is being used in primary care to assess disease severity and to estimate future risk of progression and complications. The template provides management decision support based on the DOSE index and other data.

The LINQ

The LINQ has achieved the following changes to clinical practice: It provides a convenient way of helping clinicians identify patients' information needs prior to the clinical interview so that the clinician can focus on the topics where the patient has information needs. Our research shows that its use improves patient education as well as anxiety. When used in an integrated education package, it has been shown to significantly reduce rate of hospitalisation, with patients being less breathless and having improved daily living activities (Wakabayashi et al., 2011). Its use has also been extended to other respiratory diseases [8].

The LINQ is currently used in specialist respiratory units, pulmonary rehabilitation programmes and in primary care both in the UK and worldwide. Its use is recommended in various guidelines, including Impress [5] and the COPD Exchange [6] which has approximately 500 registered users. The scale has been translated into 11 languages [9]. In Japan, the LINQ is currently used in 26 institutions where it is used in patient care by 9 physicians, 7 nurses, 4 physiotherapists, 1 pharmacist, 5 university nursing departments [10], and a LINQ book has been written on the information that should be provided to patients [11]. In Canada its use is reflected in the development of a scoring template by a Canadian physician that is now available on the LINQ website, hosted by Plymouth University [8]. Its use across different countries is reflected in the number of hits on the website: 200,000 between December 2011 and January 2013, and the

number of downloads of translations of the questionnaire in different countries during the same time: English = 582; Japanese = 315; Italian = 314; Chinese = 243; Dutch = 240; Bulgarian = 227; Spanish = 221; Finnish = 201; German = 201. In many cases a single download is then used for several assessments.

The research has informed national guidelines through the involvement of Hyland and Jones on key committees. Prof Hyland has acted as a member of the Outcome Assessment and Pulmonary Rehabilitation subcommittees of The National Strategy for COPD and the International Primary Care Respiratory Group where his research informed the production of guidelines on practice with a set of recommendations for patient management on the care of adults with difficult to manage asthma: http://www.theipcrg.org/download/attachments/1901269/Difficult+to+Manage+asthma+deskop+helper.pdf?version=1&modificationDate=1335729880000.) Dr Jones has served on the Global emPOWER international education initiative for COPD editorial board (used in meetings involving 36,000 primary clinicians in 28 countries), COPD exchange editorial committee (producing a national COPD web based resource with over 7,500 registered users), the British Thoracic Society review group producing Home Oxygen guidelines for Adults and Home Oxygen guidelines for Children, and served on the Main Implementation committee of National Strategy for COPD.

5. Sources to corroborate the impact

[1] Global Strategy for the Diagnosis, Management and Prevention of COPD, Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2011 (Page 17)
[2] Oga T, Tsukino M, Hajiro T, Ikeda A, Nishimura K. (2011) Predictive properties of different multidimensional staging systems in patients with chronic obstructive pulmonary disease. *International Journal of Chronic Obstructive Pulmonary Disease,* 6, 521-526.
[3] Professor David Price, Director of Optimal Patient Care (OPC): http://www.optimumpatientcare.org/.
www.goldcopd.org/guidelines-global-strategy-for-diagnosis-management.html
[4] Diagnosis and management of COPD in primary care : A guide for those working in primary care (pages 14-15 for LINQ and 6-7 for DOSE)
www.pcrs-uk.org/resources/copd_guidelinebooklet_final.pdf
[5] Impress
www.impressresp.com/index.php?option=com_docman&task=doc_view&gid=41&Itemid=82
[6] COPD exchange. www.copdexchange.co.uk/landing/
[7] Rolink, M, W, van den Haak-Rogen, S, Pieters, W, Schermer, T, van den Bernt, L (2013) Using the DOSE index to predict changes in health status of chronic obstructive pulmonary disease patients with COPD: A prospective cohort study. Primary Care Respiratory Journal, 22(2), 169-174.
[8] Fowler, R. P., et al. (2011) S29 Assessing the educational impact of pulmonary rehabilitation in non-COPD patients using the lung information needs questionnaire. Thorax 66.Suppl 4: A16-A16.
[9] The LINQ website: www.linq.org.uk
Note this website is a repository of information about the scale and the place where clinicians can download it. This is maintained and hosted by Plymouth University. It can also be accessed from the website of the Plymouth Respiratory Psychology Partnership at www.prpp.org.uk
[10] Kozui Kida, MD, Ph.D. Dept. of Pulmonary Medicine, Infection, and Oncology, Respiratory Care Clinic, Nippon Medical School, Tokyo, Japan will provide written evidence upon request.
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