



# Beyond standard care?—idiopathic pulmonary fibrosis patients' perception of care coordinators

Lars Hagemeyer<sup>1,2</sup>, Winfried Randerath<sup>1,2</sup>

<sup>1</sup>Institute of Pneumology, University of Cologne, Solingen, Germany; <sup>2</sup>Hospital Bethanien Solingen, Clinic of Pneumology and Allergology, Center for Sleep Medicine and Respiratory Care, Solingen, Germany

*Correspondence to:* Lars Hagemeyer, MD. Hospital Bethanien Solingen, Clinic for Pneumology and Allergology, Center of Sleep Medicine and Respiratory Care, Aufderhöherstraße 169-175, 42699 Solingen, Germany. Email: lars.hagemeyer@klinik-bethanien.de.

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## Idiopathic pulmonary fibrosis (IPF)

IPF has been defined as specific form of chronic, progressive, fibrosing interstitial pneumonitis of unknown cause, occurring primarily in older adults and being limited to the lungs (1). Lung transplantation is the only curative therapeutic approach. Pirfenidone and Nintedanib are the only approved pharmaceutical therapies in IPF. However, both antifibrotics only could demonstrate a reduction of the lung function decline over time, thereby slowing down disease progression (2,3).

Due to the irreversibility of the progressive fibrotic processes and the limited availability of highly effective medical treatment, disease monitoring remains an essential part of the clinical care in IPF (4). Thereby, the physician is responsible for patient education, monitoring drug adherence, documentation and treatment of drug-induced side effects, screening and treatment of relevant comorbidities, evaluation for lung transplantation, early implementation of palliative care and supportive therapies (e.g., oxygen therapy).

Although considered a relatively rare disease, the costs associated with IPF specific medical care are high and disproportionate to the incidence and prevalence (5). A major issue to be addressed is personal and time resource.

Physician assistants and care coordinators have been implemented in different medical specialties to relieve workload from the physicians as well as to further develop

and improve individualized therapy concepts.

This editorial will focus on the potential role of care coordinators in the treatment of IPF patients as it has been analyzed by Nathan Hambly *et al.* in their article “A cross-sectional evaluation of the idiopathic pulmonary fibrosis patient satisfaction and quality of life with a care coordinator” (6).

## Care coordinators

Physician assistants and care coordinators have become essential in routine clinical work in the face of shortages of medical staff and low financial resources. The education of care coordinators may be attractive for many health care facilities as it may result in a substantial reduction in workload for the physicians. With specific training, the care coordinators may even become experts in their specific field of qualification. A structured education program may enable care coordinators to be trained in such a way that they are able to perform parts of the routine clinical work in patients independently, albeit under close supervision of the responsible physician. Patients may appreciate the continuity of care, the empathetic surveillance, the competence, the high flexibility and reliability of scheduled visits. These professions have long been well established in numerous medical fields (e.g. general medicine, cardiology, oncology, orthopedy, urology, dental medicine) with a still growing need (7). Halter *et al.* analyzed 16 observational

studies from specialty care facilities (emergency medicine, traumatology/orthopedy, acute internal medicine and dental medicine). It could be shown that the integration of specialized physician assistants reduced waiting periods, medical care time and costs with constant readmission rates and good acceptance by peers and patients. In the field of internal medicine the patient outcome was shown to be not associated with the fact whether physicians or physician assistants performed defined processes (8).

### Assessment of patient satisfaction and quality of life in IPF

Regaining and preserving quality of life, providing comfort to the patients represent the main aims in the guidance of supportive therapy (9,10).

Symptoms and health related quality of life (HRQL) may be assessed through open ended questions and the use of questionnaires. There are different instruments to assess dyspnea severity and to quantify longitudinal changes like the University of California San Diego Shortness of Breath Questionnaire, the Medical Research Council dyspnea scale or the Borg scale. The Chronic Respiratory Questionnaire and the St George Respiratory Questionnaire may represent the most commonly used disease specific measurement tools to assess HRQL in patients with chronic respiratory disease, however both tools are time-consuming in clinical practice and were originally validated in patients with obstructive airway disease (11,12). Focusing on interstitial lung disease (ILD), the King's Brief Interstitial Lung Disease (K-BILD) questionnaire is a brief, validated 15-item, ILD-specific HRQL questionnaire that is predominantly used in clinical trials (13). Other HRQL questionnaires have been recently validated in ILD (14).

Measuring patient experience and satisfaction may be an attractive strategy for improving medical care. There are several instruments to assess the patient satisfaction with medical care which have been originally validated in IPF, in oncologic or other chronic diseases (15).

### Trial overview

To determine the effect of a care coordinator on IPF patient satisfaction and quality of life Hambly *et al.* analyzed 40 IPF patients with either low coordinator use (LCU, n=20) or high coordinator use (HCU, n=20). The modified FAMCARE and IPF Care UK Patient Support Program

surveys were used to assess patient satisfaction, the Living with Idiopathic Pulmonary Fibrosis (L-IPF) questionnaire was applied to determine HRQL (15-17). Calculation models and staff surveys were applied to estimate costs and patient management requirements.

Applying the IPF Care UK Patient Support Program survey, the authors found at the HCU facility an increased patient satisfaction with their current care compared to that at the prior institution ( $P<0.05$ ). In contrast, at the LCU facility they did not detect differences in patient satisfaction. According to the FAMCARE survey the patient satisfaction with overall care, physician care and coordinator care was very good (>94%) in both cohorts (HCU and LCU), detected differences were not significant. The high overall patient satisfaction may reflect the high level of patient care and experience of a specialized tertiary care hospital. No significant differences in HRQL were found according to the L-IPF survey.

The surveys as well as received testimonials showed that the patients felt that the coordinator had a relevant impact on confidence and disease control. Interestingly the coordinator was estimated to alleviate about 30% of a physician's IPF-related workload, with one model calculation leading to an estimated annual saving of costs of about \$137,212.00.

In this single site, cross-sectional study patients were recruited from two different clinics. The patient characteristics did not show significant differences between both groups. Only the mean time from diagnosis differed significantly ( $1.4\pm 0.7$  vs.  $3.7\pm 2.7$  years,  $P<0.05$ ). This means that the LCU cohort may contain more recently diagnosed patients and the HCU cohort may contain patients with longer established diagnosis. The authors discuss that this may be a limitation of the study as the two cohorts differ not only in the variable of coordinator use. In this way, it remains unclear whether differences between the cohorts may be caused by factors other than the extent of coordinator use. It has to be discussed whether patients with longer established diagnosis per se have had more visits, more disease education and are more experienced with disease management. This may be a substantial contributing factor to higher patient satisfaction.

However, the study shows that coordinator use may allow an alleviation of physician's IPF-related work with substantial saving of costs but without loss of quality in terms of patient satisfaction and HRQL.

### Clinical implications and future directions

In times of understaffing and rising costs, care coordinators represent a worthwhile adjunct to overall health care management.

Several aspects have been learned from previous pilot projects. The use of coordinators not only potentially relieves the workload of physicians, but also that of nursing staff and secretaries. These aspects have to be considered when cost-saving calculations are applied, thus making reliable estimations more challenging.

The full role of care coordinators has to be further determined. Future studies should quantify the extent to which each defined professional group is supported and which resources are freed up as a consequence. Additional service may be provided by care coordinators. However, this will not result in cost saving but probably in an improved quality of medical care and overall patient satisfaction.

Cost-saving calculations are of high interest but are likely to vary across countries and continents, due to differing health care systems and reimbursement conditions.

Compared to routine clinical work, care coordinators' work may be for the large part performed "on -top". This may be less relevant in a tertiary care hospital but may be of high relevance in less specialized facilities. Future studies need to analyze patient satisfaction, quality of life and cost-saving, explicitly for these institutions. It may be hypothesized that this approach will bring significant clinically relevant differences in patient satisfaction and quality of life.

Future studies could analyze the longitudinal effect of IPF care coordinators on patient outcome and therapy adherence (hospital admissions, acute exacerbations, discontinuation rate of antifibrotic drug use, exercise tolerance, vaccination rate, prescription rate of anxiolytic/antidepressive medications, etc.). A standardized coordinator training program may allow the implementation of a large comprehensive network of comparably well-educated IPF care coordinators.

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