Original Article

A cross-sectional evaluation of the idiopathic pulmonary fibrosis patient satisfaction and quality of life with a care coordinator

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Background: Canadian and international guidelines recommend specialized, multidisciplinary teams for the treatment of patients with idiopathic pulmonary fibrosis (IPF). The objective of this cross-sectional clinical study was to investigate the effect of a care coordinator on IPF patient satisfaction and quality of life.

Methods: Forty IPF patients were enrolled from the practices of two physicians (n=20/physician), with either low (LCU) or high-coordinator use (HCU). Patient satisfaction was measured with modified FAMCARE and IPF Care UK Patient Support Program (UK-CARE) surveys. Health related quality of life (HRQoL) was assessed with the living with IPF impacts (L-IPFi) survey. An economic model assessed the impact of the coordinator; staff surveys informed patient management requirements, and costs were derived from published literature.

Results: Patient satisfaction was similar between the clinics; a trend (P=0.1) towards increased satisfaction among HCU patients was observed. Patients in the HCU clinic reported increased satisfaction (P<0.05) with their current care compared with care prior to joining the tertiary-care clinic, while LCU patients did not. IPF patient HRQoL did not differ between clinics. The coordinator was estimated to alleviate approximately 30% of a physician's IPF-related work load, and to facilitate the care of more patients per physician. Modelled estimates suggest the coordinator lead to annual cost-savings of $137,212.

Conclusions: Reliance upon a coordinator during routine management of IPF patients may improve patient satisfaction, spare physician time and lead to annual cost-savings. Future studies should examine the impact of a coordinator on healthcare resource utilization.

Keywords: Idiopathic pulmonary fibrosis (IPF); satisfaction; quality of life

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Introduction

Access to specialized multidisciplinary teams is recommended by international guidelines as best-treatment for idiopathic pulmonary fibrosis (IPF), an incurable progressive fibrotic lung disease with poor prognosis (1-3). Optimal IPF patient management may include access to a dedicated team of allied health care providers, including a care coordinator, that understands the benefits and potential adverse effects of anti-fibrotic therapy and multifaceted symptomatic management of patients. Specialized care teams have proven effective in the management of complex disease states including stroke, musculoskeletal

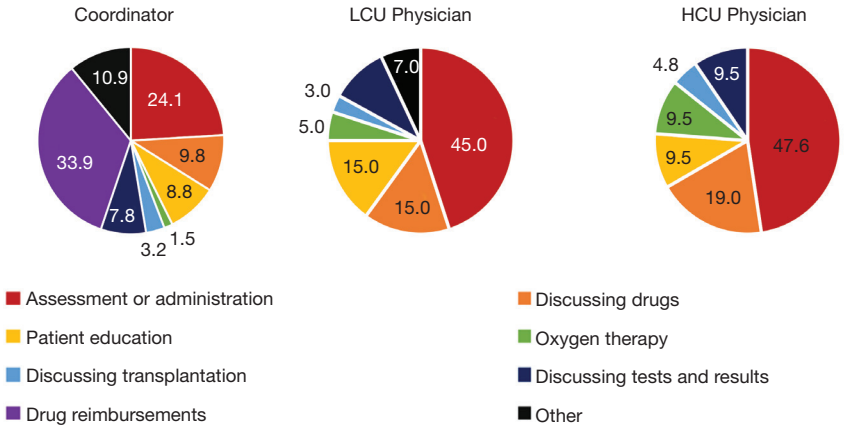

Figure 1 Distribution of tasks related to IPF patient care at the FIRH. Average percentage of time that the coordinator and physician within the LCU and HCU clinic devote to each responsibility of patient care. Percentages were derived from the total time spent on each task estimated by the coordinator and physicians divided by the total time spent on IPF patients each week. The coordinator was found to spend 35.5 h per week on providing care to IPF patients within both the LCU and HCU clinic. The physician within the LCU clinic spent 8 h providing care to IPF patients while the physician within the HCU clinic spent 10 h.

disorders, and cancer metastasis (4-6). These teams have been associated with improvements in prognosis, patient independence and satisfaction. Patient satisfaction has been identified as a key outcome in effective IPF patient-centered care (2).

To our knowledge, although considered important for care, the impact of interprofessional care teams on patient satisfaction and health related quality of life (HRQoL) has not been formally evaluated in a Canadian IPF population (7). Within an interprofessional team, a coordinator can impact many aspects of care; for example, activities assisted by the coordinator at the Firestone Institute for Respiratory Health (FIRH) are presented (*Figure 1*). A coordinator is similar to a specialist IPF nurse (2,3) with additional responsibilities including indirect (e.g., drug reimbursement applications) and palliative care, and research coordination. An IPF care coordinator has the potential to improve treatment compliance through early recognition and management of drug related adverse events by providing education, support and empowerment to IPF patients (8,9). Evidence describing the patient and physician support provided by a coordinator is limited. The primary objective of this cross-sectional study was to evaluate the impact of a coordinator on IPF patient satisfaction and HRQoL. The secondary objective was to assess the economic impact of including a coordinator in the management of IPF patients at the FIRH.

Methods

Study design & participants

This single-site, cross-sectional study recruited 40 IPF patients attending interstitial lung disease (ILD) clinics at the FIRH at St. Joseph's Healthcare (Hamilton, Ontario, Canada) between November 2017 and September 2018. Twenty patients were recruited from the practice of a physician with high coordinator use (HCU) and twenty patients from a physician with low coordinator use (LCU). In the HCU clinic, the coordinator was involved with patient management, education, treatment, research and administration, while the coordinator only assisted with treatment related tasks in the LCU clinic. Differentiation between the LCU and HCU clinics was based upon established clinical practices in each clinic and physician preference. The same coordinator attended both the LCU and HCU clinics. Inclusion criteria for the study were the diagnosis of IPF at least six months previously, and attendance to the FIRH ILD clinic. Exclusion criteria were patient age (<18) and lack of ability to communicate with study staff.

Patient reported outcomes

Patient satisfaction was assessed through the modified FAMCARE-13 (FAMCARE) survey (10) and the modified IPF Care UK Patient Support Program (UK-CARE)

Table 1 Patient characteristics

Characteristic	Full cohort (n=40)	LCU clinic (n=20)	HCU clinic (n=20)
Age, yr ± SD	73.7±6.0	74.3±6.4	73.0±5.7
Male gender, no. [%]	33 [83]	18 [90]	15 [75]
Ever smokers, no. [%]	32 [80]	15 [75]	17 [85]
Time since diagnosis, year ± SD	2.5±2.2	1.4±0.7*	3.7±2.7*
Biopsy confirmed, %	10%	10%	10%
Lung function			
FVC, mean % predicted ± SD	69.8±17.7	73.7±20.4	66.0±14.1
FEV_1, mean % predicted ± SD	78.0±19.1	81.9±21.9	74.1±15.4
D_{LCO}, mean % predicted ± SD	39.7±12.7	42.7±12.5	36.7±12.6
GAP score, mean ± SD	4.7±1.1	4.5±1.1	4.9±1.2
SpO_2, mean ± SD	96.1±2.0	96.6±1.8	95.6±2.1
Patient management, no. [%]			
Use of supplemental oxygen	18 [45]	6 [30]	12 [60]
Current treatment			
Pirfenidone	19 [48]	9 [45]	10 [50]
Nintedanib	19 [48]	9 [45]	10 [50]
No treatment	2 [5]	2 [10]	0 [0]

*, differed significantly between cohorts (P<0.05; two-sided t-test). LCU, low-coordinator use; HCU, high-coordinator use; FVC, forced vital capacity; FEV_1, forced expiratory volume in 1-second; D_{LCO}, diffusion capacity of the lung for carbon monoxide; SpO_2, oxygen saturation of the peripheral blood.

survey (2). The UK-CARE survey was developed to assess the satisfaction of IPF patients with care provided by an IPF patient support program (9), while the FAMCARE questionnaire was designed to assess patient satisfaction in terminal cancer patients, and was thus deemed appropriate for the IPF population due to similar prognosis and risk of adverse events related to therapeutic intervention. To our knowledge, neither survey has been formally validated in IPF patients nor had a minimal clinically important difference estimated. Patient responses to the living with IPF impacts (L-IPFi) survey (11) were collected to assess HRQoL. Administered surveys are presented in *Figures S1-S3*. Surveys were completed immediately after regularly scheduled clinic visits. Voluntary patient testimonials regarding the coordinator role were also collected.

Other data collected

Patient demographics and baseline characteristics were collected from medical records, including patient: gender, age, age at diagnosis, primary IPF physician, date and method of diagnosis, current IPF drug treatment (pirfenidone or nintedanib), pulmonary function, smoking status (never, former or current), and supplemental oxygen (*Table 1*). The intent of this study was not to collect adverse event information.

Data on the number of ILD clinics held per month, number of IPF patients seen per month, staff present within each clinic (administrators, residents, nurses and other staff), distribution of responsibilities and the frequency, duration and topic of patient-contact outside the clinic were collected via staff surveys (of the physicians and coordinator). Finally, the coordinator logged time, in 15-min increments, for five-day to detail time spent on research activities, clinical assessments, physician support, patient related administrative tasks, and patient education and management.

Table 2 Inputs and costs

Variable	World with coordinator		World without coordinator	
	Coordinator	Physicians	Coordinator	Physicians
Base-case scenario				
IPF visits per month[1]	56		56	
Percent of total care h provided[1]	61	39	0	100
Monthly h caring for IPF patients[1]	111	72	0	183
Annual h caring for IPF patients[2,3]	1,332	864	0	2,196
Annual staff salaries, $	60,000	338,726[4]	0	338,726
Proportion of staff salary dedicated to IPF care[5], $	41,625	116,002	0	294,839
Canada-wide scenario				
Number of IPF patients in Canada[6]	6,573		6,573	
Annual hours caring for IPF patients[7]	39,310	25,133	0	64,443
Annual staffing cost for IPF care[4,7], $	1,228,436	3,374,349	0	8,652,176

[1], study data from FIRH. Note that the coordinator spends an additional 7.75 h per week caring for IPF patients from another physician's clinic, however patients from that clinic were not included in the study. The hours shown reflect the time required for 56 IPF patient-visits per month. The percent of total care contributed by the coordinator and physician, was calculated from the estimates of time spent with patients derived from the coordinator time log and physician surveys; [2], it was assumed all hours of care currently provided by the coordinator would be transferred to the physicians (i.e., no reduction in total care); [3], assuming 48 work weeks per year; [4], derived from a recent national estimate of physician salaries in Canada (12); [5], calculated by multiplying the annual salary of each staff member by the estimated time spent caring for IPF patients (direct and indirect); [6], calculated from the incidence of IPF, 18.7 per 100,000 people (14), and the estimated Canadian population (15); [7], FIRH treatment characteristics (3.27 h per IPF-visit, three visits per year, established physician/coordinator care split) assumed representative of Canada. IPF, idiopathic pulmonary fibrosis; FIRH, Firestone Institute for Respiratory Health.

Statistical analyses

Study oversight, data entry, electronic database management and statistical analyses were performed by Cornerstone Research Group. Data are presented as mean ± SD or standard error of the mean (SEM), and/or median (range). Based upon published IPF patient satisfaction (2), this study had a power of 0.82 (α=0.05) to detect a difference in patient satisfaction as a result of the coordinator. Significance was assessed using the Mann-Whitney U test, at a threshold of $P \leq 0.05$, and a Bonferroni correction was applied to account for repeated testing.

Economic analysis

The economic model compared the cost of providing care to IPF patients in a world with the coordinator (i.e., the current scenario) versus a world without the coordinator (i.e., care provided only by physicians). Costs were estimated by calculating the proportion of coordinator and specialist physician salary attributable to the management of IPF patients. Therefore, these analyses assumed that physicians were salaried rather than fee-for-service. IPF patient management costs were estimated by multiplying the total time spent on IPF patients by the physicians and coordinator at the FIRH by their respective estimated annual salaries. It was assumed that all hours that the coordinator spends caring for patients would be transferred to physicians in the world-without the coordinator. Scenario analyses were performed to test the impact of less care in the world-without the coordinator.

Estimates of total time spent on IPF patients by the physicians and coordinator were derived from staff questionnaires. The annual salary of the coordinator was informed by the research site, and the average annual salary for a specialist physician was derived from recent Canadian surveys (12,13). Model inputs are presented in *Table 2*. A one-way sensitivity analysis was performed by varying key inputs by ±20% and scenario analyses were performed to investigate alternative inputs (*Table 2*).

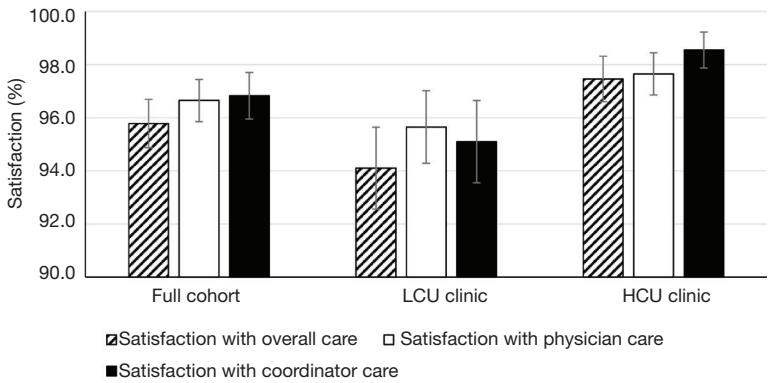

Figure 2 FAMCARE assessed patient satisfaction. Responses to the FAMCARE survey were summed to generate scores representative of: overall percent satisfaction scores (questions 1–18), percent satisfaction with physician care (questions 1, 3, 8, 10, 16) and percent satisfaction with coordinator care (questions 2, 4, 9, 11, 17). Data are presented as mean ± standard error for the full cohort (n=40), low-coordinator use (LCU) clinic (n=20), and the high-coordinator use (HCU) clinic (n=20).

Ethics approval

The trial was conducted in accordance with the Declaration of Helsinki and the Harmonized Tripartite Guideline for Good Clinical Practice from the International Conference on Harmonization. This study was reviewed and approved by the Hamilton Integrated Research Ethics Board (approval #3524) and the Hoffmann-La Roche global review committee. All patients enrolled completed the informed consent form. This cross-sectional study did not affect the current or future provision of care to patients that participated.

Results

Patient characteristics

Forty-one IPF patients were screened and 40 enrolled; there were no patient exclusions or drop-outs. Patient characteristics are presented in *Table 1*. Most patients were males (83%) with a history of smoking (80%). Patients in the LCU clinic had a significantly shorter duration of disease at the time of enrollment, compared with HCU clinic patients; otherwise, patient characteristics were evenly distributed between the two clinics. Thirty-eight patients (95%) were receiving anti-fibrotic therapy, with pirfenidone and nintedanib used equivalently.

Patient reported outcomes—satisfaction

We assessed IPF patient satisfaction using the FAMCARE and UK-CARE surveys. The FAMCARE scale was developed to measure patient satisfaction with palliative care and has been validated in palliative oncology populations (10,16,17). Patients in both clinics were highly satisfied with their overall care, care provided by the physician and care provided by the coordinator, as assessed by the FAMCARE survey (*Figure 2*). Patients reported over 95% satisfaction with their care, and no difference between clinics was noted with the FAMCARE survey. In contrast, HCU clinic patients assessed with the UK-CARE survey reported a significant increase in satisfaction with current care compared to care before joining the IPF clinic, including increased feelings of control of disease, expectations of treatment and confidence in disease management (*Table 3*). Patients in the LCU clinic did not report a significant change in any parameter assessed by the UK-CARE survey. A trend (P=0.1) towards increased mean total satisfaction in the HCU clinic, compared to the LCU clinic was noted.

Patient testimonials

Patients voluntarily commented on their satisfaction via anonymous testimonials. Seventeen testimonials were received and reviewed for core message(s). Sixteen testimonials were positive; representative testimonials are presented in *Table 4*. The most common message described by patients was increased availability to care. Consistent with responses to the FAMCARE and UK-CARE surveys, testimonials reflected a positive impact of the coordinator on confidence and disease control.

Table 3 Patient satisfaction assessed by the IPF Care UK Patient Support Program survey

Cohort	Question	Patient responses		
		Previous care	Current care	P
Full (n=39)	I feel in control of my condition	4.9±2.8; 4.5 [1–10]	8.1±2.2; 9 [2–10]	<0.001
	I know what to expect from my treatment	5.3±3.0; 5 [1–10]	8.7±1.6; 10 [5–10]	<0.001
	I feel confident about how my disease is being managed	5.9±3.2; 5 [1–10]	9.3±1.1; 10 [5–10]	<0.001
LCU clinic (n=19)	I feel in control of my condition	4.9±2.6; 5 [1–10]	7.2±2.3; 7 [2–10]	NS; >0.005
	I know what to expect from my treatment	5.8±2.9; 6 [1–10]	8.3±1.6; 8 [5–10]	NS; >0.005
	I feel confident about how my disease is being managed	6.3±3.2; 6 [1–10]	8.9±1.0; 9 [7–10]	NS; > 0.010
HCU clinic (n=20)	I feel in control of my condition	4.8±3.1; 4 [1–10]	8.9±1.8; 9.5 [3–10]	0.001
	I know what to expect from my treatment	4.8±3.1; 4 [1–10]	9.2±1.6; 10 [5–10]	<0.001
	I feel confident about how my disease is being managed	5.4±3.3; 4 [1–10]	9.6±1.1; 10 [5–10]	<0.001

Patient responses are presented as mean ± SD; median [range]. Mean change in total satisfaction, by clinic: 7.4±7.8; 6 (–2 to 27) in LCU clinic, 12.4±9.4; 14 [–2 to 26] in HCU clinic; P=0.1. Patients were asked to rate their satisfaction with their medical treatment before joining an IPF clinic ('previous care') and now, as a result of the IPF care team/coordinator ('current care'), using a 10-point scale. The total change in satisfaction was calculated by subtracting the sum of past satisfaction from the sum of current satisfaction (a total possible change of ±27). Significance was assessed at P<0.005 using the Mann-Whitney U test, based upon a Bonferroni correction for completion of 10 tests. LCU, low-coordinator use; HCU, high-coordinator use; NS, not significant.

Patient reported outcomes—HRQoL

The impact of the coordinator on IPF patient HRQoL was assessed using the L-IPFi questionnaire, which was developed through IPF patient- and FDA-guided revision of the validated survey, "A Tool to Assess Quality of life in IPF" (11). The total impacts score was calculated as described elsewhere (11). All patients completed the L-IPFi questionnaire and reported a reduction in HRQoL related to their IPF; no statistical difference in HRQoL between the clinics was observed, with LCU clinic patients and HCU clinic patients having a mean impacts score of 47.1 (±SD of 16.6) and 39.6 (±SD of 15.6), respectively (*Figure S4*). That HCU clinic patients reported a numerically lower HRQoL than LCU clinic patients may be related to the increased time since diagnoses of the HCU clinic patients.

Economic analysis

To facilitate the economic analysis, patient and physician support provided by the coordinator and the proportion of specialist physician time devoted to IPF patient management were quantified. Time commitments and responsibilities of the coordinator and physicians are presented in *Figures 1*,*S5*,*S6*. At the FIRH, IPF patients received an average of 3.27 h of care (per patient visit) with the coordinator providing approximately 67% of the care in the HCU clinic and 33% in the LCU clinic. While time per patient was similar between clinics, the HCU clinic had nearly three times as many IPF patient visits (40 *vs.* 16 per month). Analysis of time-log data revealed the coordinator to spend 35.5 h per week caring for IPF patients (*Table S1*), with a ratio of approximately 2.5 h in the HCU clinic per 1 h in the LCU clinic.

In the (current) world with the coordinator, the total physician and coordinator cost to manage IPF patients was estimated to be $157,627. Provision of the same level of care without a coordinator was estimated to cost $294,839, thus the coordinator role may result in annual cost-savings of $137,212 (*Table 5*). As physician salary may not increase linearly with time spent with patients, an alternative analysis was performed to assess the total hours of care lost, if the coordinator role was eliminated but physicians could spend no additional time with patients. This analysis estimated that the removal of the coordinator would lead to the loss of 1,022 h of care, which is approximately 313 IPF patient visits at the FIRH. Sensitivity analyses were performed by

Table 4 Patient testimonials

Theme (No. comments)	Testimonial
Availability (8/17)	"…[the coordinator] was well informed and she made sure that I was aware of any potential side effects and if I experienced any, she was always readily available."
Comfort and Confidence (4/17)	"I am a new IPF patient and being able to call someone and get answers to my questions immediately has been a comfort. You don't feel so alone and the thoughtful, caring person on the other end of the phone was always able to allay my fears and answer my questions."
Coordination (6/17)	"I am grateful that she has been available by phone (when possible) to help resolve any medical emergencies I have experienced and arrange for the doctor's prescriptions to be sent to my pharmacy or to organize an appointment with my respirologist if needed."
Education (5/17)	"The coordinator was professional, knowledgeable, and explained in detail what to expect. I was constantly asked if I clearly understood which provided me with a high degree of reassurance."
Efficiency (4/17)	"I know the amazing IPF physicians would not be as efficient or as effective without [the coordinator]'s coordination. I think the IPF team is an example of "team work" at its best. It makes me think that a lot of services provided at our hospitals would be more effective, efficient and cost effective if they operated such teams."
Other (4/17)	"The coordinator works with the drug supplier and my own drug plan company to ensure continuity of drug supply for my IPF treatment. I believe these functions are very important in dealing with my disease."
Non-positive testimonial (1/17)	"I met twice with my coordinator, the last time in September 2017. There has been no contact since then. I was not provided with a requisition for bloodwork."

Testimonials were allowed to support multiple themes & testimonials were provided anonymously, therefore comments may have been made by patients in either the LCU or HCU clinic. LCU, low-coordinator use; HCU, high-coordinator use.

varying the physician or coordinator salary, or the estimated division of labour by ±20% (*Table 5*). Physician salary was the driver of the model. Inclusion of the coordinator remained cost-saving in all sensitivity analyses.

Scenario analyses were performed to estimate the impact of implementing coordinators throughout Canada, and the size of a community IPF clinic necessary to warrant a coordinator. Parameterizing the model with the estimated total number of IPF patients in Canada (*Table 4*) suggests that employment of coordinators to assist specialist management of IPF patients, in the same capacity as seen at the FIRH, may result in annual cost-savings of $4,049,391 in Canada. Parameterizing the Canada-wide analysis with a published estimate of specialist time commitments (13) that could be supported by a coordinator (31%) resulted in annual cost savings of $2,055,099 in Canada. Finally, using FIRH time estimates, a community care clinic was estimated to require 294 IPF patient visits (per year) to offset the cost of one coordinator.

Interpretation

The objective of the study was to evaluate the impact of a care coordinator on IPF patient satisfaction and HRQoL. Overall, patients recruited into the LCU and HCU cohorts were well aligned, aside from the longer duration of disease in the HCU clinic. Patient satisfaction was assessed using the FAMCARE and UK-CARE surveys. As assessed by the FAMCARE survey, all patients reported high levels of satisfaction, that did not differ between clinics. Elsewhere, the FAMCARE survey has identified a correlation between patient satisfaction and the level of communication with health-care providers (17), which may indicate that the level of patient care provided at the FIRH (approximately 3.3 h per patient visit, including both the initial visit and subsequent responsibilities and care needs occurring prior to the next visit, as outlined in *Figure 1*) is appropriate for these patients.

Among HCU clinic patients, the UK-CARE survey showed a tendency towards greater satisfaction, and a significant increase in satisfaction when comparing care before and after joining the IPF clinic. Previous studies using the UK-CARE survey, in British and Austrian IPF patients, found a 6.1-point mean increase in satisfaction after joining the care program, which was slightly less than the benefit found here (2). Increased patient satisfaction may be related to greater access to care providers; as evidenced by testimonials and research in other disease areas (9,18,19).

Table 5 Model results

Parameter	Estimated FIRH Staff Costs ($)	Value tested	Cost savings ($)
Annual cost of IPF patient care provided by			
Coordinator	41,625	–	
Physicians	116,002		
Total costs			
IPF patient care (world with coordinator)	157,627	–	–
IPF patient care (world without coordinator)	294,839	–	–
Net budget impact			
Annual cost-savings with the IPF coordinator	137,212	–	–
Cost-savings per IPF visit	204	–	–
Sensitivity analyses			
Physician salary (–20%)	–	$270,981.30	101,445
Physician salary (+20%)	–	$406,471.94	172,979
Coordinator salary (–20%)	–	$48,000.00	145,537
Coordinator salary (+20%)	–	$72,000.00	128,887
Coordinator's support to physician (–20%)	–	49%	109,769
Coordinator's support to physician (+20%)	–	73%	164,654

Costs presented are the estimated cost of staff (coordinator and physician) required to care for the IPF population at the FIRH clinic. The coordinator and physician costs represent the proportion of salary from each staff member estimated to be required to care for the IPF patient volume at the FIRH. Cost savings represent the estimated savings at the level of the FIRH (i.e., considering the salary of physicians and the coordinator). FIRH, Firestone Institute for Respiratory Health; IPF, idiopathic pulmonary fibrosis.

That HCU clinic patients reported elevated satisfaction as a result of current care (compared with care received prior to the IPF clinic) and indistinguishable total care time required is of particular interest, given the longer duration since diagnosis of patients within the HCU clinic. The difference in time since diagnosis suggests that the HCU clinic may predominantly consist of prevalent patients with established disease, while the LCU clinic may contain relatively more recently diagnosed incident patients. Together, these data highlight that a coordinator can contribute to care of IPF patients at each stage of disease. Future investigations into the role of the coordinator should focus on patient healthcare resource use and longitudinal degradation of satisfaction/HRQoL, to enable assessment of the role of the coordinator during the transition from incident to later stages of disease.

HRQoL of IPF patients did not differ between the LCU or HCU clinic, indicating that shifting some responsibility of care from a physician to a coordinator may not compromise patient HRQoL. Similar results have been found in diabetes (20) and eczema (19). Interestingly, an IPF patient assistance program at the University of Pittsburgh Medical Center was associated with a decrease in patient reported HRQoL, which prompted the conclusion that benefits of the coordinator may not be adequately captured by standard HRQoL instruments (21). Future efforts to quantify the impact of a coordinator on IPF patient health should focus on aspects of patient health, such as hospitalization rates, emergency room visits and exacerbation rates.

This study demonstrates the considerable time-commitment required for the provision of care to IPF patients. At the FIRH, the coordinator was estimated to allow for an additional 313 IPF patient visits per year. Our analyses suggest that inclusion of a coordinator in the routine management of IPF patients may result in cost-savings to institutions and potentially the Canadian healthcare system.

Limitations of the study

As patients with positive feelings toward the coordinator may have been more likely to enrol, this study was at risk of selection bias. To mitigate this risk, an impartial research coordinator screened and enrolled patients. Population differences may exist, as the two clinics differed in ways other than coordinator usage (e.g., the HCU clinic was larger and contained patients with a longer time since diagnosis), and patient comorbidity data were not collected. As this study focused on the practice of two physicians, it is plausible that physician specific factors may have contributed to study results. Finally, the study was performed at a tertiary care center with a single coordinator and sufficient IPF expertise to optimize use of the coordinator. Results may not be generalizable to smaller centers, with less expertise or patient volume. A multi-site, national study to assess the impact of a coordinator across Canada could help resolve these limitations.

The economic assessment focused on the budget impact of staffing costs, time saved, and patients seen. The model does not capture potential reductions in healthcare resource utilization or improved compliance resulting from the coordinator (22-24). Additionally, Canada-wide analyses assumed that IPF patients received optimal care, without accounting for geographical challenges.

Conclusions

In summary, we have demonstrated that inclusion of a care coordinator in the routine management of IPF patients can enhance patient satisfaction. Further, the transfer of care from the specialist physician to the coordinator was found to spare physician time without reducing patient HRQoL. Through reduction of physician time-commitments, the coordinator role was estimated to reduce the staff costs of managing IPF patients and increase the number of patients that a physician can manage. Future studies should investigate the effect of the coordinator on healthcare resource use and anti-fibrotic drug compliance.

Acknowledgments

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Footnote

Conflicts of Interest: Daniel Grima, Daniel Moldaver and Margaret Ainslie-Garcia are employees of Cornerstone Research Group. Diana Fung, Czerysh Cabalteja and Patricia DeMarco are employees of Hoffmann-La Roche. Hoffmann-La Roche contracted Cornerstone Research Group to oversee and analyze the conduct of this study. Gerard Cox has received personal fees from Boston Scientific. Nathan Hambly has received honoraria and awarded grants from Actelion, Bayer, Boehringer Ingelheim, Novartis, and Roche. Martin Kolb has received honoraria, awarded grants or consulting fees from Roche, Boehringer Ingelheim, GSK, Gilead, Actelion, Respivert, Alkermes, Pharmaxis, Prometic, Indalo and Third Pole. The other authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The trial was conducted in accordance with the Declaration of Helsinki and the Harmonized Tripartite Guideline for Good Clinical Practice from the International Conference on Harmonization. This study was reviewed and approved by the Hamilton Integrated Research Ethics Board (approval #3524) and the Hoffmann-La Roche global review committee. All patients enrolled completed the informed consent form.

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Supplementary

MODIFIED FAMCARE QUESTIONNAIRE

Instructions. ***Think about the care that you and your family has received. Please answer the questions below indicating how satisfied you are with the care received: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), very dissatisfied (VD). Please check the column under the letters that best match your experience. For questions you think do not apply to you, please select not applicable (N/A)***

	How Satisfied are you with the Following	VS	S	U	D	VD	N/A
1	Doctor's attention to patient's description of symptoms						
2	Coordinator's attention to patient's description of symptoms						
3	Availability of the doctor to the patient						
4	Availability of the coordinator to the patient						
5	Time required to make diagnosis						
6	Information given about the patients diagnosis						
7	Information provided about the patient's prognosis						
8	The way family is included by the doctor in treatment and care decisions						
9	The way family is included by the coordinator in treatment and care decisions						
10	Answers from the doctor						
11	Answers from the coordinator						
12	Information given about how to manage the patients shortness of breath/cough						
13	The speed with which symptoms are treated by the doctor						
14	The speed with which the coordinator responds to symptoms						
14	Information given about the patient's tests						
16	The way tests and treatments are followed up by the doctor						
17	The way tests and treatments are followed up by the coordinator						
18	The impact of the coordinator on your quality of life						

Figure S1 Modified FAMCARE questionnaire

Instructions: Please circle the number or check the box that you feel is the most accurate response, 1 being lowest and 10 being highest.

1. Thinking back before you joined the IPF Clinic please rate the following:									
a) I feel in control of my condition									
1	2	3	4	5	6	7	8	9	10
b) I know what to expect from my treatment									
1	2	3	4	5	6	7	8	9	10
c) I feel confident about how my disease is being managed									
1	2	3	4	5	6	7	8	9	10
2. How would you rate the following now, as a result of the IPF Care Team/Coordinator:									
a) I feel in control of my condition									
1	2	3	4	5	6	7	8	9	10
b) I know what to expect from my treatment									
1	2	3	4	5	6	7	8	9	10
c) I feel confident about how my disease is being managed									
1	2	3	4	5	6	7	8	9	10
3. Thinking about the things that you have discussed with the IPF Clinical Coordinator are these:									
☐ The same as topics discussed at clinic visits									
☐ Similar to topics discussed at clinic visits, but with some differences									
☐ Different to topics discussed at clinic visits, with minimal overlap between the two									
☐ Very different to topics discussed at clinic visits									
4. Based on your experience, how important is it that the IPF Clinical Care Coordinator is a qualified allied health care provider (1 = not important 10 = essential):									
1	2	3	4	5	6	7	8	9	10
5. Do you agree with the following statement 'I have stayed on treatment longer than I would have without the support of the IPF Clinical Coordinator' (1 = not at all, 10 = completely):									
1	2	3	4	5	6	7	8	9	10

Figure S2 Modified IPF Care UK Patient Support Program survey

Instructions for Completing the Living with IPF (L-IPF) Impacts Module

The goal of this questionnaire is to determine how Idiopathic Pulmonary Fibrosis affects your quality of life.

Quality of life refers to your perceptions of your overall position in life in relation to:

- your goals and expectations
- your standards and values
- your concerns and judgments

Among other things, quality of life encompasses:

- your physical health (conditions/diseases, symptoms, therapies)
- your psychological state (outlook, emotional well-being)
- your level of independence
- the relationships you have with pertinent features of your environment

Reflect on your life: has Idiopathic Pulmonary Fibrosis affected your quality of life? **As you respond to the items, reflect on your physical health, how you have been functioning, your psychological state, how you have been feeling, your level of independence, what you have done, and where you have gone over the last 7 days.**

Items 1-16: For these items, reflect on the **last 7 days** as you consider where you are on the scale between the two statements.

On average, over the last 7 days...

1. **How much did shortness of breath prevent you from doing things you wanted to do?**

Not at all 0 1 2 3 4 Extremely

2. **How much did fear of becoming too short of breath limit your physical exertion?**

Not at all 0 1 2 3 4 Extremely

3. **How was your stamina when you exerted physically?**

Extremely poor 0 1 2 3 4 Excellent

4. **How frustrated were you by the time it took you to complete a physical activity?**

Not at all 0 1 2 3 4 Extremely

5. **How frustrated were you by the speed it took you to complete a physical activity?**

Not at all 0 1 2 3 4 Extremely

6. **How frustrated were you by your need to rest during or after completing a physical activity?**

Not at all 0 1 2 3 4 Extremely

7. **How much did coughing embarrass you?**

Not at all 0 1 2 3 4 Extremely

8. **How much did coughing frustrate you?**

Not at all 0 1 2 3 4 Extremely

On average, over the last 7 days...

9. **How much did coughing interrupt your conversations (in person or on the phone)?**

Never 0 1 2 3 4 All of the time

10. **How frightening was your coughing to you?**

Not at all 0 1 2 3 4 Extremely

11. **How much was your cough a problem for you?**

Not at all 0 1 2 3 4 Extremely

12. **How much hassle or inconvenience has IPF caused you in your day-to-day life?**

None 0 1 2 3 4 A lot

13. **How much did you have to rest in the middle of doing a simple chore inside the house?**

Not at all 0 1 2 3 4 A lot

14. **How much did you have to pace yourself to make it through the day?**

Not at all 0 1 2 3 4 A lot

15. **How much did it take to get yourself ready to leave the house?**

Very little time 0 1 2 3 4 Extremely long time

16. **How much were you forced to depend on other people to do things for you?**

Not at all 0 1 2 3 4 A lot

Only five more...

For Items 17-19: Think broadly about your shortness of breath, cough and energy level over the last 7 days. Have these symptoms affected how you have felt physically? Psychologically? Have they disrupted your life? Or limited you in terms of what you would like to do or how you would like to do it? Now, please respond to Items 17-19.

On average, over the last 7 days...

17. **How has shortness of breath affected your quality of life?**

Made my quality of life extremely poor 0 1 2 3 4 No negative effect

18. **How much has your cough affected your quality of life?**

Made my quality of life extremely poor 0 1 2 3 4 No negative effect

19. **How much has your energy level affected your quality of life?**

Made my quality of life extremely poor 0 1 2 3 4 No negative effect

For these last two Items: Think broadly again about whether Idiopathic Pulmonary Fibrosis has affected you and your quality of life over the last 7 days. **Reflect on your symptoms and other aspects of your physical health, how you have been functioning, your psychological state, how you have been feeling, your level of independence, what you have done, and where you have gone over the last 7 days.**

On average, over the last 7 days...

20. **How have you felt in terms of physical health?**

Extremely poor 0 1 2 3 4 Excellent

21. **How has your quality of life been?**

Extremely poor 0 1 2 3 4 Excellent

The end.

Thank you for taking the time to complete the L-IPF Impacts Module.

Figure S3 Living with idiopathic pulmonary fibrosis impacts survey

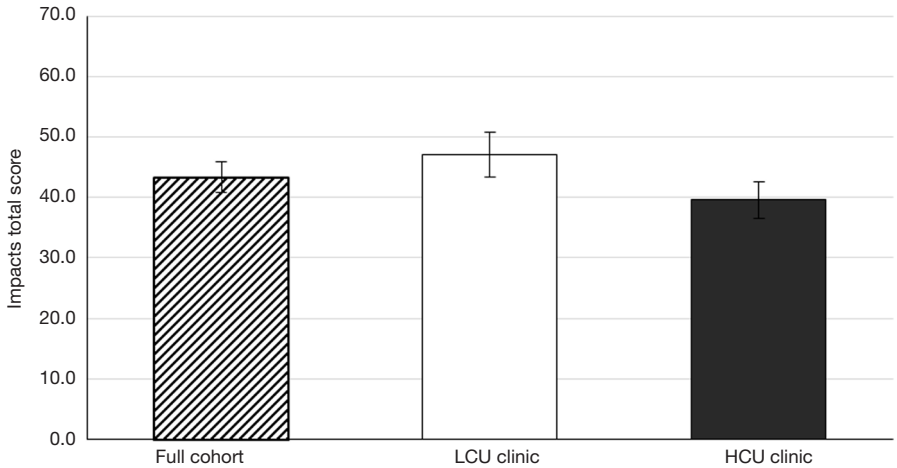

Figure S4 Patient reported HRQoL. Patient HRQoL data are the mean ± standard error impacts total score, calculated from the L-IPFi questionnaire as described by Graney et al. (11), 2017 for the low-coordinator use clinic (n=20) and high-coordinator use clinic (n=20); the full cohort shows the average response of both cohorts (n=40). A greater number represents a poorer QoL. HRQoL, health related quality of life; L-IPFi, living with IPF impacts; IPF, idiopathic pulmonary fibrosis.

IPF Patient Topics Discussed During Calls and E-Mails	Healthcare team member		
	ILD Coordinator	LCU Physician	HCU Physician
a) Clinical assessments	Yes	Yes	Yes
b) Explaining the IPF diagnosis	Yes	Yes	Yes
c) Managing IPF symptoms	Yes	Yes	Yes
d) Discussing tests and test results	Yes	Yes	Yes
e) IPF patient education	Yes	Yes	Yes
f) Transplantation related activities	Yes	Yes	Yes
g) Pulmonary rehabilitation activities	Yes	Yes	Yes
h) Other IPF related activities (eg, hospitalization	Yes	Yes	Yes
i) Anti-fibrotic drug usage	Yes	Yes	Yes
j) General drug usage	Yes	Yes	Yes
k) Drug reimbursement	Yes	Yes	Yes
l) Oxygen therapy	Yes	Yes	Yes
m) Research activities	Yes	Yes	Yes

Figure S5 Topics IPF patients discuss with each member of the IPF healthcare team. Results presented here are self-report by each member of the healthcare team. IPF, idiopathic pulmonary fibrosis; LCU, low-coordinator use; HCU, high-coordinator use.

Tasks	Average daily time (hours ± SD; median [range])		
Total IPF patient related activities	7.01 ± 1.5; 6.75 [5.25 – 8.25]		
Patient contact outside of visits (email/call)	0.95 ± 0.80; 0.75 [0.00 – 2.00]		
Clinical visits	2.05 ± 2.40; 1.00 [0.00 – 5.00]		
Research visits	0.40 ± 0.55; 0.00 [0.00 – 1.00]		
Other (administration)	3.50 ± 0.90; 3.50 [2.25 – 4.75]		
Total Non-IPF related activities	1.15 ± 1.18; 1.25 [0.00 – 2.75]		
Activities	**ILD Coordinator time spent* (%) on each activity**	**Estimated time spent* (%) on each activity by physician**	
		LCU	**HCU**
Patient assessments & related administrative tasks[1]	24.1	45.0	47.6
Discussion of anti-fibrotic drug usage[2]	9.8	15.0	19.0
Patient education[3]	8.8	15.0	9.5
Oxygen therapy	1.5	5.0	9.5
Transplantation (all aspects)	3.2	3.0	4.8
Discussing tests and test results	7.8	10.0	9.5
Drug reimbursement applications	33.9	0.0	0.0
Other IPF related activities (ie, hospitalization)	10.9	7.0	0.0

*, time spent for the ILD coordinator was quantified through averaging the time-spent on each activity over the course of 5-working days. Each physician estimated their time spent on each activity as part of a physician survey.
1, the coordinator was involved in patient assessments and administrative tasks but was not involved in treatment decisions. Related tasks include managing IPF symptoms, research assessment and administration, and indirect patient support.
2, drug discussion includes the extended-access program and general drug therapies.
3, patient education also includes the initial explanation of the IPF diagnosis.

Figure S6 Role of the ILD clinical care and research coordinator. ILD, interstitial lung disease; ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis; LCU, low-coordinator use; HCU, high-coordinator use.

Table S1 Summary of time spent by the ILD clinical care and research coordinator over one week, by task and clinic

Activity	LCU clinic[a]	HCU clinic[a]	Other clinic[a]	Total by activity
Call/Email [%]	1.88 [21]	1.63 [7]	1.25 [15]	4.75 [12]
In clinic [%]	0.00 [0]	6.25 [27]	4.00 [47]	10.25 [25]
Research tasks [%]	1.50 [17]	0.50 [2]	0.00 [0]	2.00 [5]
Outside clinic tasks[b] [%]	5.63 [63]	9.38 [41]	2.50 [29]	18.50[c] [45]
Non-IPF [%]	0.00 [0]	5.00 [22]	0.75 [29]	5.75 [14]
Total by clinic	9.00	22.75	8.50	41.25[c]

[a], data are presented as the time (h) spent per activity and the percent of time spent on that activity in that clinic; [b], the full list of 'Outside Clinic Tasks' completed by the coordinator are described in Figure S6. Briefly, time was most commonly spent on drug reimbursement requests, patient charting, pulmonary rehabilitation and follow-up on transplant/hospitalizations. [c], this includes 1 h of time in a meeting for IPF, not specific to any physician. ILD, interstitial lung disease; LCU, low-coordinator use; HCU, high-coordinator use; IPF, idiopathic pulmonary fibrosis.