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Original Article

Early palliative care program in idiopathic pulmonary fibrosis patients favors at-home and hospice deaths, reduces unplanned medical visits, and prolongs survival: A pilot study☆,☆☆

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ABSTRACT

Background: Idiopathic Pulmonary Fibrosis (IPF) is a lethal disease; most patients die in hospitals because palliative care (PC) is not wildly and early available. We aimed to determine the impact of an early PC program in IPF patients on place of death, emergency department (ED) admission, unplanned medical visits and survival before and after its implementation at our clinic.

Methods: IPF patients from our ILD clinic who died between January 1st, 2018 and December 31th, 2023 were included in the analysis. Primary outcomes were location of death, number of ED access and unplanned medical visits; secondary outcomes was survival from diagnosis.

Results: A total of 46 decedents between 2018 and 2023 were analysed: (median age 71,5 ± 5,5 years, 89 % male): 26 died before the implementation of the early PC program and 20 after. Through χ^2 test, location of death resulted significantly different in the two groups, showing the capacity of early PC to favor at home or in hospice death ($p = 0,02$); similarly, the number of unplanned visits was significantly lower ($p = 0,03$). Finally, survival was significantly lower in patients not receiving the early PC program ($p = 0,01$).

Conclusion: The availability of an early PC program since the diagnosis significantly reduced both the death rate in hospital settings, favoring dying in hospice or at home, and the number of unplanned medical visits. Furthermore, IPF patients receiving early PC showed a longer survival than those who did not.

Introduction

Idiopathic Pulmonary Fibrosis (IPF) is a relentlessly progressive fibrotic interstitial lung disease (ILD) with an unfavourable prognosis[1]. The median survival is 3 to 5 years form the time of diagnosis, but two antifibrotic agents, namely Nintedanib and Pirfenidone, have been shown to slow the decline of lung function (without any significant impact on quality-of-life (QoL)) [1,2]. IPF manifests as an unpredictable trajectory, wherein certain individuals undergo prolonged phases of gradual and progressive deterioration, while others are prone to acute exacerbations [1]; consequently, healthcare providers, patients, and caregivers frequently struggle to discern the variable nature of the disease's progression, leading to elevated levels of stress and anxiety [3]. As the disease relentlessly advances, individuals affected by IPF often encounter challenges in recognizing the fluctuating course of the condition.

Abbreviations: ATS, American Thoracic Society; DLCO, Diffusing capacity of the Lungs for Carbon Monoxide; ED, Emergency Department; ePC, early Palliative Care; ERS, European Respiratory Society; FEV1, Forced Expiratory Volume in 1 second; FVC, Forced Vital Capacity; ICU, Intensive Care Unit; ILD, Interstitial Lung Disease; IPF, Idiopathic Pulmonary Fibrosis; IQR, InterQuartile Range; QoL, Quality-of-Life; PC, Palliative Care; SD, Standard Deviation.

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Consequently, IPF patients and their caregivers experience stress, worsening dyspnoea, impaired QoL, and inadequate "preparation" for end-of-life care planning [4]. In this respect most patients express a preference for dying at home, but the majority die in hospitals, including intensive care units (ICUs) [5], partly because many caregivers assume that end-of-life symptoms are managed more effectively in acute settings.

Therefore, patients with IPF constitute a discernible minority group that qualifies for early consideration and referral to palliative care [5,6]. Early palliative care (ePC) programs targeting IPF patients is limited, but it has been shown that it may improve dyspnoea and QoL [7], and therefore theoretically met wish of the patient to die at home. Unfortunately, it is widely acknowledged that the majority of IPF patients do not receive palliative care throughout their illness or even in their final moments [5], despite recent guidelines advocating for a palliative care approach to ben considered whenever patients and their informal caregivers have physical, psychological, social, or spiritual/existential unmet needs [8].

In this before-and-after observational study we explored as primary outcomes the impact of our ePC program on the location of death and on the number of unplanned clinic visits and emergency department (ED) access, in a group of IPF patients. Secondary outcome was survival from diagnosis.

Materials and methods

Early palliative care model

In January 2018 our academic Interstitial Lung Disease (ILD) clinic at IRCCS Azienda Ospedaliero-Universitaria Sant'Orsola, Bologna, Italy, started a Palliative Care program for IPF patient with end-stage disease only when deemed appropriate by the attending physician or if specifically requested by the patients. This approach basically consisted of periodic hospital consultation every 4 months with the PC team, with the sole objective of addressing symptoms. In January 2021, we implemented an ePC program for all IPF patients at the time of diagnosis, with one of the objectives being to respect the patients' wishes regarding their preferred location of death, following the indications of the official ATS statement, in which authors declare that palliative care should be concurrent with curative, restorative and life-prolonging care [9]. Since the implementation of the ePC program in our clinic, upon receiving a diagnosis of IPF, patients undergo a formal consultation with the Palliative Care (PC) team simultaneously, which includes dedicated pulmonologists, palliative care physicians, psychologists, and nursing staff. In our setting, the team assumes responsibility for patient care, aiming to ensure dignity throughout the entire course of the illness. Particularly, the team addressed several topics including evaluation of patient's understanding of their illness and prognosis and establishing goals of care. At the time of first access to our outpatient's clinic all the PC team was involved. Specifically, at the beginning the team introduced themselves and explained in plane words the meaning of PC and how it can support the patient during her/his "journey" with the disease. The specific components were eventually triggered on demand for specific issue (i.e. pain management, psychological distress, onset of new symptoms, solving problems at home). Medical therapy, such as anxiolytic and antidepressant medications, low-dose opioids, cough suppressant and oxygen titration, was also initiated or changed to ameliorate the symptoms' management. Patients were also allocated in a rehabilitation program consisting of breathing and motor exercises, if feasible. Pulmonary rehabilitation programs provided to patients with ILD typically include a period of 3 to 4 weeks of daily incremental exercise training session [10]. The discussion about the preferred location of death was addressed by the PC team during the time course of the disease, according to the judgment of the PC, once the clinical conditions were worsening and re-evaluated periodically. The PC team is involved in the assessment and management of physical, spiritual, and social symptoms, as well as facilitating awareness and acceptance, not only during the scheduled hospital visit, but also through periodic telephone monitoring, outpatient visits, and home consultations. PC hospital visits occurred whenever a patient visited the ILD clinic, whereas outpatient visits were scheduled monthly, and periodic telephone monitoring was conducted weekly. Home consultations were planned as needed and could also be daily depending on the clinical situation. Additionally, the PC team ensures continuity of care during the transition between different care settings by collaborating with various professionals involved in the care process. PC team is available 24/7 [11]: a dedicated telephone line was provided to each patient, and a physician specialised either in PC or oncology was on call 24/7 and available to answer to the patient's need. A specialised nurse oversaw scheduling the periodic phone call during the daytime.

Study design

IPF patients living within one hundred kilometres from our ILD clinic who died between January 1st, 2018 and December 31th, 2023 were included in the analysis assessing the place of death and the number of unplanned clinic visits and ED admissions. If admitted to hospitals, decisions regarding hospital settings, locations and treatments were totally in charge of the ED and wards physicians and were not influenced by the PC team. Of note, less of 1 % of the Italian population officially signed advanced healthcare directives. In our setting, unplanned clinic visits are usually requested by general practitioners; on the other hand, general practitioners were periodically updated about the clinical and psychological situation of their patients.

Patients were categorised into two groups basing on the watershed date of January 1st, 2021, which corresponds to the introduction of ePC program. Therefore, the two groups consist of those who died between 01/01/2018 and 31/12/2020, and those who died between 01/01/2021 and 31/12/2023. Only patients deceased for reasons linked to their respiratory disease were analysed. Lung transplant recipients and decedents while on transplant list were excluded because of different managements and level of care.

Data sources

Data were extracted retrospectively for IPF patients' who received care at our academic ILD clinic at IRCCS Azienda Ospedaliero-Universitaria Sant'Orsola, Bologna, Italy between January 1st, 2018 and December 31th, 2023. Ethics approval for the review of the data was received by our local ethical committee (Ethical Committee 462/2023/Oss/AOUBo). Written informed consent from the patients to prospectively analysed the collected data, while still alive, were obtained from two different studies (Ethical Committee number 120/2016/0/Sper till September 2020 and 249.2018 Oss from November 2020 on). The ILD clinic conducts an annual evaluation of around 100 new patients with ILD, including approximately 30 new diagnoses with IPF, referred from various regional and national locations. Patient demographic data including age, gender, age at diagnosis, comorbidities (assessed through Charlson Comorbidity Index [12]), treatments, follow-up duration, number of unplanned clinic visits, number of ED access', functional data, and date and location of death were extracted from the electronic medical records.

Statistical analysis

Means ± standard deviations (SD), medians and interquartile range ([IQR]), and frequency and percentages were used as appropriate. The Fisher's test was utilized to analyse categorical variables. Parametric variables with a normal distribution were assessed using the Student's *t*-test, while those with a non-normal distribution were evaluated using the non-parametric Mann-Whitney U test. Any p-values lower than 0.05 were considered to have statistical significance. To explore associations

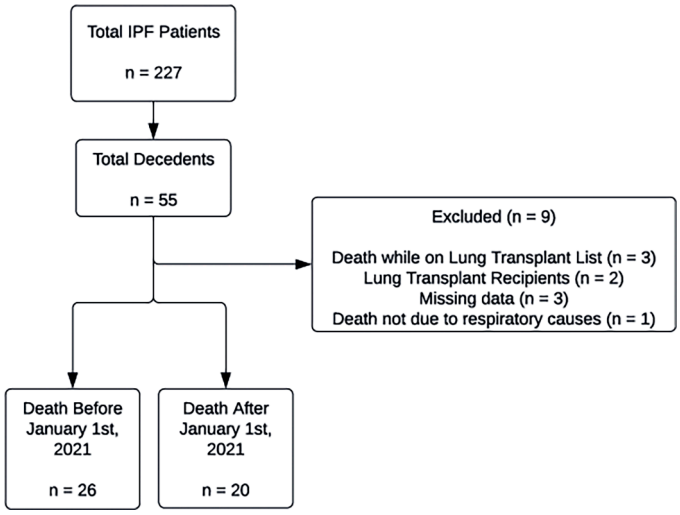

Fig. 1. Flow chart.

Table 1
Patients' characteristics.

	Total (n = 46)	Death Before January 1st, 2021 (n = 26)	Death After January 1st, 2021 (n = 20)	p-value
Age at diagnosis, mean ± SD (range), y	71,5 ± 5,5 (53–82)	70,6 ± 6,2 (53–82)	72,7 ± 4,5 (66–81)	0,10
Age at death, mean ± SD (range), y	74,9 ± 5,8 (57–84)	73,3 ± 6,0 (57–83)	76,9 ± 5,1 (66–84)	0,02
Male sex, n (%)	42 (89 %)	24 (92 %)	18 (86 %)	0,64
Antifibrotic treatment, n (%)	40 (84,8 %)	23 (88,5 %)	16 (80 %)	0,68
If antifibrotic treatment, Nintedanib, n (%)	23 (50 %)	11 (47,8 %)	12 (60 %)	0,10
Charlson Comorbidity Index, median [IQR], points	4 [3–5]	4 [3–5]	4 [3–6]	0,70

Data shown are number (%), mean ± SD, or median [IQR].

between the introduction of ePC and location of death, χ^2 was used. Differences in cumulative incidence for the clinical groups examined were analysed with the Log-Rank test and Kaplan-Meier curves were drafted accordingly. Any p-values lower than 0.05 were considered to have statistical significance. Statistical analysis was performed using the software environment GraphPad Prism version 8.0.1.

Results

Demographic and clinical characteristics

At the beginning of the study on December 31th, 2017, 70 patients were already under the care of our ILD clinic; over the subsequent 6-year study period, from January 1st, 2018 to December 31th, 2023, an additional 157 patients received a diagnosis of IPF, based on the international clinical practice guidelines [1,13]. During the study interval, a total of 55 patients died: 31 before January 1st, 2021 and 24 after that date. After excluding lung transplant recipients (n = 2) and patients died while on lung transplant list (n = 3), those with incomplete data (n = 3), and patients who did not die due to respiratory illness (n = 1), location of death was determined for 46 patients. The flow chart of analysed patients is reported in Fig. 1. A total of 46 patients was analysed, and their characteristics are showed in Table 1. Patients were predominantly male (n = 42, 89 %) and the median age at the diagnosis was 71,5 ± 5,5 years. An antifibrotic treatment was initiated in most patients (n = 40, 84,8 %) with half receiving nintedanib (n = 23, 50 %), without significant differences between the two groups. Furthermore, patients who died before and after the introduction of ePC exhibited similar comorbidities (Charlson Comorbidity Index, median 4 [3–5], p = 0,70) and

Table 2
Functional Status.

	Total (n = 46)	Death Before January 1st, 2021 (n = 26)	Death After January 1st, 2021 (n = 20)	p-value
FVC at diagnosis, median [IQR], L	2,5 [2,1–3,3]	2,4 [1,7–3,2]	2,8 [2,4–3,3]	0,85
FVC at diagnosis, median [IQR], %	78 [68–96,5]	77 [65–92]	90 [74,2–96,7]	0,63
FEV1 at diagnosis, median [IQR], L	2,2 [1,9–2,8]	2,2 [1,5–2,7]	2,2 [2,1–2,8]	0,59
FEV1 at diagnosis, median [IQR], %	89 [75–102]	81 [72–99]	94 [81,2–105]	0,57
Tiffeneau Index at diagnosis, median [IQR], %	85 [77–89]	85 [77–89]	85 [84–89]	0,92
DLCO at diagnosis, median [IQR], %	52 [40,5–58,5]	46 [41–61]	53 [41–55,7]	0,84
Last FVC before death, median [IQR], L	2,1 [1,5–2,7]	1,7 [1,2–2,5]	2,4 [1,8–2,7]	0,73
Last FVC before death, median [IQR],%	62 [50,5–79]	58 [47–79]	68 [60,2–81,2]	0,06
Last FEV1 before death, median [IQR], L	1,9 [1,2–2,3]	1,5 [1,1–2,2]	2,0 [1,5–2,3]	0,60
Last FEV1 before death, median [IQR],%	70 [57,5–90]	65 [49–84]	79 [65,2–90,5]	0,05
Last Tiffeneau Index before death, median [IQR],%	86 [79,5–88,5]	86 [79–91]	84 [80,2–87,7]	0,42
Last DLCO before death, median [IQR],%	30 [25–34]	31 [26–34]	29,5 [23,5–34]	0,55

Data shown are median [IQR]. *Abbreviations*: FVC = Forced Vital Capacity; FEV1 = Forced expiratory volume in 1 second. DLCO = Diffusing capacity of the Lung for Carbon Monoxide.

Table 3
Chronic treatment for dyspnoea.

	Total (n = 46)	Death Before January 1st, 2021 (n = 26)	Death After January 1st, 2021 (n = 20)	p-value
Patients receiving morphine, n (%)	21 (46 %)	3 (11,5 %)	18 (90 %)	< 0,001
Patients receiving opioid other than morphine, n (%)	4 (8,7 %)	2 (7,8 %)	2 (10 %)	1
Patients receiving oxygen therapy, n (%)	42 (91 %)	21 (81 %)	20 (100 %)	0,06
Patients receiving high-flow nasal therapy, n (%)	8 (17 %)	2 (7,8 %)	6 (30 %)	0,06
Patients receiving non-invasive ventilation, n (%)	3 (6,5 %)	2 (7,8 %)	1 (5 %)	1

Data shown are number (%).

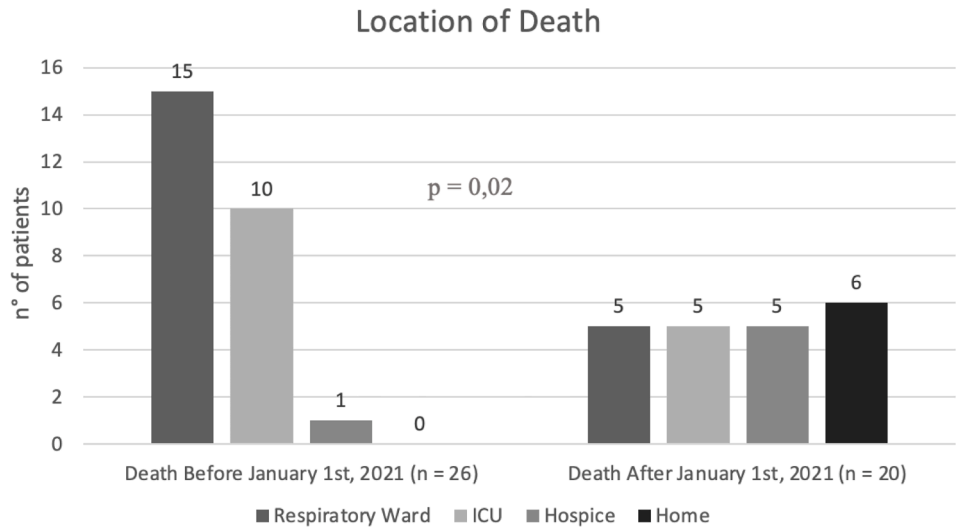

Fig. 2. Location of Death.
Abbreviations: ICU = Intensive Care Unit.

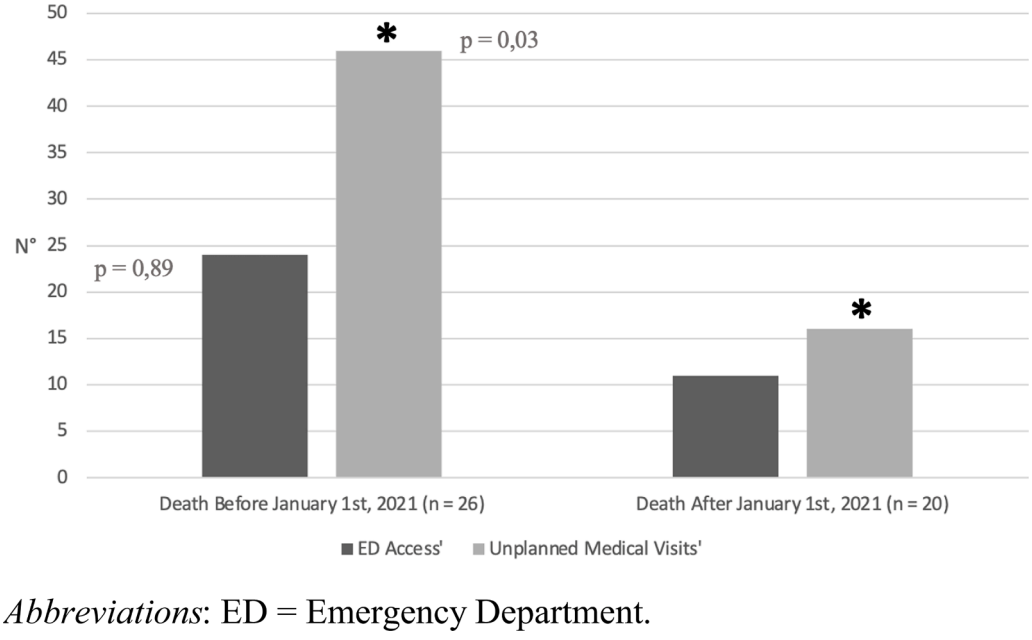

Fig. 3. Use of Medical Resources.
Abbreviations: ED = Emergency Department.

pulmonary function tests results, both at the time of diagnosis and at the last spirometry and diffusing capacity of the lungs for carbon monoxide (DLCO) assessments (Table 2). Conversely, patients who died after the implementation of the ePC program were significantly older (mean age 73,3 ± 6,0 years vs 76,9 ± 5,1 years, $p = 0,02$). Table 3 reports different treatments established in the disease course to address dyspnoea: patients who died after the implementation of the ePC program were significantly more prone to receive morphine to treat dyspnoea rather than patients died before the implementation ($n = 18$ (90 %) vs $n = 3$ (11,5 %), $p < 0,001$), whereas no significant differences were observed regarding other opioids, oxygen therapy, high-flow nasal therapy and non-invasive ventilation.

Location of death and use of medical resources

The number of patients who were included in the palliative care program was significantly different before and after the implantation of the ePC, since starting from January 1st, 2021 all IPF patients were referred to the program ($n = 5/26$, 19,2 % vs $n = 20/20$, 100 %, $p < 0,001$). During the course of the disease, all patients under the PC program received opioids to relieve dyspnoea ($n = 25$, 100 %). Approximately half of the 46 decedents died within a respiratory ward ($n = 20$, 42,5 %) while an additional 31,9 % ($n = 15$) deceased in ICUs. Concurrently, death rates at home and in hospice were both 12,8 % ($n = 6$). Notably, upon scrutinizing disparities pre- and post-implementation of the ePC program, a significant reduction in hospital deaths, encompassing both ICUs and respiratory wards ($n = 5$, 23,8 % each), was

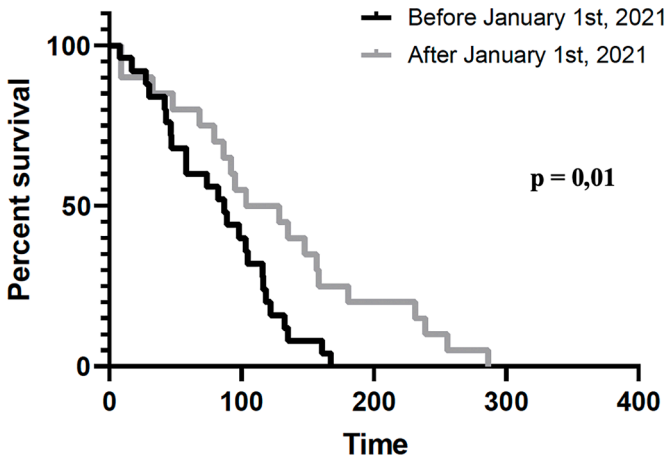

Fig. 4. Duration of survival from diagnosis to death.

observed. Conversely, there was a proclivity towards fatalities occurring in hospice ($n = 5$, 23,8 %) or at home ($n = 6$, 28,6 %) after the introduction of the ePC initiative ($p = 0,02$). These findings are delineated in Fig. 2. Similarly, after the refinement of the ePC program, there was a significant decrease in unplanned medical visits ($n = 42$ vs $n = 16$, $p = 0,03$). A comparable trend was not observed regarding ED access ($n = 24$ vs. $n = 11$, $p = 0,89$) (Fig. 3). Opioid or other sedative treatments were administered in a minority of patients deceasing in a respiratory ward or in ICUs ($n = 24/35$), whereas all patients who died at home or in hospice received a treatment with opioid or sedative drugs ($n = 12/12$, $p = 0,04$).

Time from diagnosis to death

The median survival from diagnosis was 95,2 months (IQR, 48,1–135,1 months). An analysis of trajectories of time elapsed from diagnosis to death, conducted through the Log-Rank test, revealed that, despite receiving less aggressive end-of-life care, patients who died after the introduction of the ePC program experienced significantly longer survival compared to those who died before January 1st, 2021(median survival from diagnosis to death 86,8 vs 115,9 months, $p = 0,01$) (Fig. 4).

Discussion

This study shows the effect of an ePC approach when it is provided throughout the continuum of care for IPF patients. Early integration of palliative care with standard IPF treatment can improve the likelihood of experiencing a home or hospice death under ePC, compared to those not in the ePC group, where most individuals died within a hospital setting. This finding in our study encompasses, on a larger scale, the pre-post Canadian investigation by Kalluri et al. [14]: our study, the first one performed to our knowledge in Europe, expands the findings of Kalluri et al. [14], since our ePC team is available 24/7 and eventually ready to provide direct home assistance, while this was not the case of the former investigation. This approach has been shown to significantly reduce both emergency department admissions and emergency medical services interventions [11].

The implementation of less aggressive end-of-life care did not adversely impact overall survival. Instead, patients who received early palliative care, in comparison to those solely receiving standard care, demonstrated enhanced survival outcomes. A similar effect has been already demonstrated in a randomized trial, in patients with metastatic non-small-cell lung cancer [15], and we believe that this concept can be extrapolated to our field. In fact, our study is not the first one to demonstrate that ePC can effectively impact the survival of IPF patients: two recent retrospective studies came to a similar conclusion [16,17]. We hypothesize that improvements in depression, anxiety and QoL – achievable through an ePC – could contribute to the observed survival benefit [7].

As a matter of fact, the American Thoracic Society/European Respiratory Society (ATS/ERS) guidelines on IPF management recommend PCs as an adjunct to disease-focused care and should be addressed already during outpatient visits in all patients, both as advance directives of care and as end-of-life issues [1]. Despite this statement, the access to palliative care programs is still an unmet need in IPF patients [18], and PC is still conspicuously inaccessible to many patients with IPF compared to oncological diseases [19]. Our hypothesis posits that the introduction of an ePC program for all patients newly diagnosed with IPF could improve QoL, meet some of the needs IPF patients and families have, and ultimately may contribute to the observed survival benefit and reduced number of unplanned medical visits. In our experience, patients and caregivers tend to be more receptive and insightful regarding the prognosis, the end-of-life decisions, and the choice of death location when respiratory and psychological symptoms are mild or absent and when the burden of the disease is still low [20]. This can be achieved only if palliative care is introduced early in the natural history of the disease [21].

Our study has several limitations. First, this is a single centre retrospective study and may not generalize to other areas; indeed, very few (if any) of the Respiratory Units in our Country have a structured palliative care program for IPF patients, so that even psychological support is not usually provided, if not as inpatients and in the end-of-life moments. This may be different in other geographical locations [5,16,17,22], and is the reason why a multicentre approach was not feasible. Second, we had a relatively small sample size: a larger and longer trial is necessary to confirm our findings, but this pilot study could help in calculate sample size for further larger multicentre studies. Lastly, this is not a randomised controlled trial, as other similar studies [16,17]: we believe that, given the evidence available about the effect of ePC in improving QoL [7], reducing symptoms burden [1] and caring for patients in their end-of-life moments [16,17], it would not be ethical to design a randomised controlled study with a placebo arm without access to an ePC program [7].

Conclusion

In conclusion, our study demonstrates that the application of an early palliative care program in an IPF patient's cohort enables a significant reduction in the number of deaths in hospital wards and ICUs and facilitates achieving a dignified death at home or in hospice care.

References

[1] Raghu G, Remy-Jardin M, Richeldi L, et al. Idiopathic pulmonary fibrosis (an Update) and progressive pulmonary fibrosis in adults: an official ATS/ERS/JRS/ALAT clinical practice guideline. Am J Respir Crit Care Med 2022;205(9):e18–47. https://doi.org/10.1164/rccm.202202-0399ST.
[2] Graney BA, Lee JS. Impact of novel antifibrotic therapy on patient outcomes in idiopathic pulmonary fibrosis: patient selection and perspectives. Patient Relat Outcome Meas 2018;9:321–8. https://doi.org/10.2147/PROM.S144425.
[3] Bajwah S, Higginson IJ, Ross JR, et al. The palliative care needs for fibrotic interstitial lung disease: a qualitative study of patients, informal caregivers and health professionals. Palliat Med 2013;27(9):869–76. https://doi.org/10.1177/0269216313497226.
[4] Bajwah S, Higginson IJ, Ross JR, et al. The palliative care needs for fibrotic interstitial lung disease: a qualitative study of patients, informal caregivers and health professionals. Palliat Med 2013;27(9):869–76. https://doi.org/10.1177/0269216313497226. +.
[5] Lindell KO, Liang Z, Hoffman LA, et al. Palliative care and location of death in decedents with idiopathic pulmonary fibrosis. Chest 2015;147(2):423–9. https://doi.org/10.1378/chest.14-1127.
[6] Lindell KO, Olshansky E, Song MK, et al. Impact of a disease-management program on symptom burden and health- related quality of life in patients with idiopathic pulmonary fi brosis and their care partners. Heart Lung 2010;39(4):304–13.
[7] Bassi I, Guerrieri A, Carpano M, et al. Feasibility and efficacy of a multidisciplinary palliative approach in patients with advanced interstitial lung disease. A pilot randomised controlled trial. Pulmonol 2021. https://doi.org/10.1016/j.pulmoe.2021.11.004. S2531-0437(21)00223-3.

[8] Janssen DJA, Bajwah S, Boon MH, Coleman C, Currow DC, Devillers A, Vandendungen C, Ekström M, Flewett R, Greenley S, Guldin MB, Jácome C, Johnson MJ, Kurita GP, Maddocks M, Marques A, Pinnock H, Simon ST, Tonia T, Marsaa K. European Respiratory Society clinical practice guideline: palliative care for people with COPD or interstitial lung disease. Eur Respir J 2023;62(2): 2202014. https://doi.org/10.1183/13993003.02014-2022.

[9] Lanken PN, Terry PB, Delisser HM, Fahy BF, Hansen-Flaschen J, Heffner JE, Levy M, Mularski RA, Osborne ML, Prendergast TJ, Rocker G, Sibbald WJ, Wilfond B, Yankaskas JR. ATS End-of-Life Care Task Force. An official american thoracic society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. Am J Respir Crit Care Med 2008;177(8): 912–27. https://doi.org/10.1164/rccm.200605-587ST.

[10] Dowman L, Hill CJ, May A, Holland AE. Pulmonary rehabilitation for interstitial lung disease. Cochrane Database Syst Rev 2021;2(2):CD006322. https://doi.org/10.1002/14651858.CD006322.pub4.

[11] Valenti D, Gamberini L, Allegri D, et al. Effects of 24/7 palliative care consultation availability on the use of emergency department and emergency medical services resources from non-oncological patients: a before-and-after observational cohort study. BMJ Support Palliat Care 2023. https://doi.org/10.1136/spcare-2023-004412. spcare-2023-004412.

[12] Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis 1987;40(5):373–83. https://doi.org/10.1016/0021-9681(87)90171-8.

[13] Raghu G, Remy-Jardin M, Myers JL, Richeldi L, Ryerson CJ, Lederer DJ, Behr J, Cottin V, Danoff SK, Morell F, Flaherty KR, Wells A, Martinez FJ, Azuma A, Bice TJ, Bouros D, Brown KK, Collard HR, Duggal A, Galvin L, Inoue Y, Jenkins RG, Johkoh T, Kazerooni EA, Kitaichi M, Knight SL, Mansour G, Nicholson AG, Pipavath SNJ, Buendía-Roldán I, Selman M, Travis WD, Walsh S, Wilson KC, American Thoracic Society, European Respiratory Society, Japanese Respiratory Society, and Latin American Thoracic Society. Diagnosis of idiopathic pulmonary fibrosis. an official ATS/ERS/JRS/ALAT clinical practice guideline. Am J Respir Crit Care Med 2018;198(5):e44–68. https://doi.org/10.1164/rccm.201807-1255ST.

[14] Kalluri M, Claveria F, Ainsley E, et al. Beyond idiopathic pulmonary fibrosis diagnosis: multidisciplinary care with an early integrated palliative approach is associated with a decrease in acute care utilization and hospital deaths. J Pain Symptom Manage 2018;55(2):420–6. https://doi.org/10.1016/j.jpainsymman.2017.10.016.

[15] Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010;363(8):733–42. https://doi.org/10.1056/NEJMoa1000678.

[16] Chai GT, Neo HY, Abisheganaden J, Hum AYM. Impact of palliative care in end-of-life of fibrotic interstitial lung disease patients. Am J Hosp Palliat Care 2022;39 (12):1443–51. https://doi.org/10.1177/10499091221083575.

[17] Lu-Song J, Bakal JA, Younus S, Moran-Mendoza O, Harle I, Morales M, Rippon N, Barratt SL, Adamali H, Kalluri M. The impact of integrated palliative care on survival in idiopathic pulmonary fibrosis: a retrospective multicenter comparison. Am J Hosp Palliat Care 2023:10499091231194722. https://doi.org/10.1177/10499091231194722.

[18] Bonella F, Wijsenbeek M, Molina-Molina M, Duck A, Mele R, Geissler K, Wuyts W. European IPF patient charter: unmet needs and a call to action for healthcare policymakers. Eur Respir J 2016;47(2):597–606. https://doi.org/10.1183/13993003.01204-2015.

[19] Kreuter M, Bendstrup E, Russell AM, Bajwah S, Lindell K, Adir Y, Brown CE, Calligaro G, Cassidy N, Corte TJ, Geissler K, Hassan AA, Johannson KA, Kairalla R, Kolb M, Kondoh Y, Quadrelli S, Swigris J, Udwadia Z, Wells A, Wijsenbeek M. Palliative care in interstitial lung disease: living well. Lancet Respir Med 2017;5 (12):968–80. https://doi.org/10.1016/S2213-2600(17)30383-1.

[20] Kalluri M, Orenstein S, Archibald N, Pooler C. Advance care planning needs in idiopathic pulmonary fibrosis: a qualitative study. Am J Hosp Palliat Care 2022;39 (6):641–51. https://doi.org/10.1177/10499091211041724.

[21] Micco A, Carpentieri E, Di Sorbo A, Chetta A, Del Donno M. Palliative care and end of life management in patients with idiopathic pulmonary fibrosis. Multidiscip Respir Med 2023;18:896. https://doi.org/10.4081/mrm.2023.896.

[22] Higginson IJ, Bausewein C, Reilly CC, Gao W, Gysels M, Dzingina M, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. Lancet Respir Med 2014;2(12):979–87. https://doi.org/10.1016/S2213-2600(14)70226-7.