



## REVIEW ARTICLE

# Effectiveness of non-pharmacological nursing interventions to improve the quality of life of patients with idiopathic pulmonary fibrosis: A systematic review

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### Abstract

**Aim:** To evaluate whether non-pharmacological nursing interventions improve the quality of life, including both physical and psychosocial states, for patients with idiopathic pulmonary fibrosis, compared to patients receiving the usual care visit or not receiving routine nursing.

**Methods:** A comprehensive search was conducted of the following electronic databases in English and Japanese: PubMed, MEDLINE, EMBASE, CINAHL, The Cochrane Central Register Controlled Trials (CENTRAL), NPO Japan Medical Abstracts Society's Ichushi – Web database, National Institute of Informatics' Scholarly and Academic Information Navigator (CiNii) database, Grants-in-Aid for Scientific Research (KAKEN) database, and Database of Health Labor Sciences Research Grants. The keywords were as follows: [interstitial lung disease], [interstitial pulmonary fibrosis], [idiopathic pulmonary fibrosis] AND [nurse OR nurses' role OR nursing]. A search method was used based on the eligibility criteria without including words, such as “randomized controlled trial” (RCT). Three categories defined the search parameters: (i) patients with idiopathic pulmonary fibrosis; (ii) non-pharmacological nursing interventions; and (iii) RCT.

**Results:** Three-hundred-and-ninety-four articles were reviewed. Two articles met all the eligibility criteria. The nursing interventions were “disease management program” and “community case conference,” both involving nurse specialists. The quality-of-life scores decreased after 6 weeks of intervention with the disease management program. The quality-of-life scores improved after 4 weeks of intervention with the community case conferences. The risk of bias for these two studies was high.

**Conclusion:** There was limited evidence of non-pharmacological nursing interventions improving the quality of life of patients with idiopathic pulmonary fibrosis.

**Key words:** idiopathic pulmonary fibrosis, non-pharmacology, nursing, quality of life, systematic review.

## INTRODUCTION

Idiopathic pulmonary fibrosis (IPF) is a specific form of chronic, progressive fibrosing interstitial pneumonia of unknown cause that primarily occurs in adults who are >60 years of age (Raghu *et al.*, 2011). It is characterized by progressive worsening of dyspnea and lung function

and is associated with a poor prognosis of ~3 years (Raghu *et al.*). Opioids are recommended to decrease the pain of IPF's breathlessness (Trawinska, Rupe-singhe, & Hart, 2016).

In Japan, from 2009 to 2011, the yearly incidence was estimated to be 10 cases per 100,000 individuals (Natsuizaka *et al.*, 2014). Acute exacerbations are part of the natural progression of IPF (Raghu *et al.*, 2011). Even though the survival rate is worse than that of several types of cancers, there are clinical similarities between IPF and lung cancer and people with IPF are

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often overlooked in terms of novel approaches to treatment (Vancheri, Failla, Crimi, & Raghu, 2010). Therefore, patients with IPF have been reported to suffer from physical and psychosocial burdens, as well as the negative impact on their quality of life (QOL) (Swigris, Gould, & Wilson, 2005). The management of IPF requires a methodical approach, in terms of the implementation of both pharmacological and non-pharmacological intervention strategies. However, Egan (2011) recommended not only symptom relief but also advanced care directives, particularly regarding the use of life-support interventions in palliative care for improving the QOL specifically for patients with IPF because the effectiveness of other medical interventions remains unclear.

According to a qualitative study about Japanese patients' experiences with IPF and dyspnea, the occurrence of dyspnea changed patients' perspective on life and patients explored the meaning of their illness experience (Igai, 2016). The patients with IPF were burdened by dyspnea and cough. As a result of the progressive nature of the disease, life became increasingly difficult, limiting their self-care, daily activities, and work. Their social isolation seemed to increase as their energy decreased. The author recommended support for activities of daily living (ADLs), education about breathing methods, spiritual methods for relieving existential distress, and strategies to avoid social isolation. The IPF treatment guidelines also suggest that specific goals for palliative care should include relief from physical and emotional suffering and the provision of psychological and spiritual support (National Clinical Guideline Centre, 2013).

In a systematic review of non-pharmacological nursing interventions to improve both the symptoms and QOL of patients with interstitial lung disease, including IPF, physical exercise in mainly pulmonary rehabilitation showed moderate evidence of improving the QOL (Bajwah *et al.*, 2013). Moreover, a Cochrane's review (Dowman, Hill, & Holland, 2014) reported that pulmonary rehabilitation (aerobic training, aerobic and resistance training, and unspecified exercise modalities) for interstitial lung disease, including IPF, showed low evidence of improving the QOL. It was thought that the patients with IPF needed clinical nursing specialist interventions regarding symptom relief, psychosocial support, patient education, daily life support, and individualized care coordination. A systematic review of randomized controlled trials (RCTs) on the effectiveness of non-pharmacological nursing interventions for patients with IPF and the impact on their QOL should

provide healthcare providers with high-quality, evidence-based interventions, as well as identify gaps in research.

The aim of this study was to examine whether or not non-pharmacological nursing interventions for patients with IPF improved their QOL: the author reviewed the outcomes of RCTs that included programs to improve both their physical and psychosocial states, compared with patients who received the usual care (routine regular or irregular nursing visits).

## METHODS

### Eligibility criteria

The inclusion criteria for the systematic reviews were RCTs that compared the effects of improving QOL from the perspective of nursing interventions or usual care.

“Non-pharmacological” nursing interventions were defined as the care for symptom relief (e.g. pain, dyspnea), psychosocial support, patient education, daily life support, and individualized care coordination being providing by the care team, including the specialist nurses or nursing care, as inferred from the descriptions of the nursing intervention. “Usual care” was defined as the regular visit and not receiving counseling with nurses on a routine basis in the outpatient ward. The inclusion criteria included English and Japanese materials, specifically RCTs with non-pharmacological nursing interventions from unpublished material, abstracts, and data from RCTs.

The exclusion criteria included: (i) mainly physical exercise in pulmonary rehabilitation; (ii) pulmonary rehabilitation with an unclear or no specified nursing role; (iii) drug and treatment interventions; (iv) animal studies; (v) basic science research; (vi) reviews; (vii) commentaries; (viii) letters to the Editor; and (ix) duplicates.

### Types of outcome measures

Health-related quality of life (HRQOL) was the primary outcome. All measures of HRQOL that were used were considered. The secondary outcome measures included those that examined dyspnea, cough, anxiety, and depression during the intervention or follow-up periods. Mortality documentation also was included.

## Data sources

The studies were identified by using Google search engine for the following electronic databases and were restricted to the English and Japanese languages: PubMed (1976 – August, 2017), Medline (1976 – August, 2017), CINAHL (1982 – August, 2017), the Cochrane Central Register Controlled Trials (CENTRAL) (1976 – August, 2017), Embase (1976 – August, 2017), NPO Japan Medical Abstracts Society's Ichushi – Web database (1976 – August, 2017), National Institute of Informatics' Scholarly and Academic Information Navigator (CiNii) database (1976 – August, 2017), Grants-in-Aid for Scientific Research (KAKEN) database (1991 – August, 2017), and the Database of Health Labor Sciences Research Grants (1998 – August, 2017). The patients with IPF data were requested from the author. The last search was run on December 1, 2017.

## Search strategy

The author used the following combination of MeSH and search terms to search all trial registers and databases: [interstitial lung disease], [interstitial pulmonary fibrosis], [idiopathic pulmonary fibrosis] AND [nurse OR nurses' role OR nursing]. Words, including the control of "RCT" were not included because there were few reports regarding nursing in IPF. The search strategy is shown in Table 1.

To carry out the data collection and assessment, two reviewers independently conducted the eligibility assessment by using the Cochrane Collaboration data collection form (The Cochrane Collaboration, 2013) and PRISMA statement (Moher *et al.*, 2015) in an unblinded standardized manner. When the reviewers disagreed about the study selection, they jointly reviewed the Cochrane Collaboration data collection form and discussed their findings until they resolved their differences and consensus was reached.

The retrieved abstracts underwent primary screening based on the aforementioned eligibility criteria as either "present" or "absent." The abstracts were excluded if the eligibility criteria or exclusion criteria were vaguely or poorly expressed and thus unable to be clearly evaluated at this stage.

Secondary screening entailed a careful reading of the full article, in which the same two reviewers using the Cochrane data collection form and PRISMA documented the type of study design, participants, country of origin, content of the intervention, intervention period, and outcomes. The reviewers also contacted the authors

of the studies about the data that had not been or were unclearly reported. Information was extracted from the included trials on the: (i) participants, including the stage of IPF that was or was not defined, the trial's inclusion criteria, as were able to be read and understood in English or Japanese, and to live with or care for the patient with IPF; and (ii) type of interventions. The nursing interventions were included as: the care of symptom relief, psychosocial support, patient education, daily life support, and individualized care coordination by the specialist nurses. The hypothesized nursing interventions would decrease the symptoms of the patients with IPF and improve the HRQOL of the patients and care partners, compared to the usual care for patients (a regular visit) or no regular nurse counseling. The types of outcome measure were changes in dyspnea, anxiety, depression, and HRQOL.

## Risk of bias assessment within and across studies

In order to ascertain the validity of eligible RCTs, pairs of reviewers working independently by using the Cochrane Collaboration's tool for assessing the risk of bias in the Cochrane handbook (Higgins & Green, 2011) and with adequate reliability, determined and evaluated: random allocation concealment to prevent selection bias, blinding to prevent execution bias, outcome evaluation blinding the data, and missing data due to dropouts for case-decreasing bias. Missing data from the included studies were considered as selective reporting bias.

## Summary measures and synthesis of the results

The primary and secondary outcome measures were calculated by using the statistical analysis in nursing interventions comparing usual care. The risk ratio was evaluated for the two variables of the same evaluation item and the mean difference was evaluated for the continuous variables of the same scale. Heterogeneity was assessed by using  $I^2$  statistics. An  $I^2$  of >40% was considered to be highly heterogeneous. The reliability of the statistics' 95% confidence interval (CI) was calculated.

A subgroup analysis was not conducted. Moreover, the studies did not use similar outcome measurements; therefore, a meta-analysis was not conducted. Registration was not required for this systematic review.

**Table 1** MeSH check words and search strategy

Database	Words
PubMed	<ol style="list-style-type: none"> <li>1. [interstitial lung disease] AND nursing</li> <li>2. [interstitial lung disease] AND nurse's role</li> <li>3. [interstitial lung disease] AND nurses</li> <li>4. [idiopathic pulmonary fibrosis] AND nursing</li> <li>5. [idiopathic pulmonary fibrosis] AND nurse's role</li> <li>6. [idiopathic pulmonary fibrosis] AND nurses</li> </ol>
MEDLINE	<ol style="list-style-type: none"> <li>1. (MH "Lung Diseases, Interstitial/NU")</li> <li>2. "interstitial lung disease AND nurse"</li> <li>3. "idiopathic pulmonary fibrosis AND nurse"</li> <li>4. "idiopathic pulmonary fibrosis AND nursing"</li> <li>5. [MH "Pulmonary Fibrosis"] AND nurse</li> <li>6. [MH "Pulmonary Fibrosis"] AND nursing</li> <li>7. [MH "Pulmonary Fibrosis"] AND nurses' role</li> </ol>
EMBASE	<ol style="list-style-type: none"> <li>1. "interstitial pulmonary fibrosis"/exp. OR "interstitial pulmonary fibrosis" AND ["nursing"/exp. OR nursing]</li> <li>2. "interstitial pulmonary fibrosis"/exp. OR "interstitial pulmonary fibrosis" AND ["nurse"/exp. OR nurse]</li> <li>3. "interstitial pulmonary fibrosis"/exp. OR "interstitial pulmonary fibrosis" AND ["nurse"/exp. OR nurse] AND ["nursing"/exp. OR nursing]</li> <li>4. "idiopathic pulmonary fibrosis"/exp. OR "idiopathic pulmonary fibrosis" AND ("nursing"/exp. OR nursing)</li> <li>5. "idiopathic pulmonary fibrosis"/exp. OR "idiopathic pulmonary fibrosis" AND [ "nursing"/exp. OR nursing] AND ["nurse"/exp. OR nurse]</li> <li>6. "idiopathic pulmonary fibrosis"/exp. OR "idiopathic pulmonary fibrosis" AND ["nurse"/exp. OR nurse]</li> </ol>
CINAHL	<ol style="list-style-type: none"> <li>1. [MH "Lung Diseases, Interstitial/NU"]</li> <li>2. interstitial lung disease AND nurse</li> <li>3. interstitial lung disease AND nursing</li> <li>4. idiopathic pulmonary fibrosis AND nursing</li> <li>5. [MH "Idiopathic Pulmonary Fibrosis/NU"]</li> <li>6. [MH "Pulmonary Fibrosis"] AND nurse</li> <li>7. [MH "Pulmonary Fibrosis"] AND nursing</li> <li>8. [MH "Pulmonary Fibrosis"] AND nurses' role</li> </ol>
The Cochrane Central Register Controlled Trials (CENTRAL)	<ol style="list-style-type: none"> <li>1. interstitial lung disease, nursing publication year from 1976 to 2017</li> <li>2. interstitial lung disease, nurse publication year from 1976 to 2017</li> </ol>
Ichushi – Web database and NPO Japan Medical Abstracts Society's database	<ol style="list-style-type: none"> <li>1. ([肺線維症-特発性/TH or 特発性肺線維症/AL] and [看護/TH or 看護/AL]) and (DT = 1976:2017 and PT = 原著論文) (In Japanese) / ([fibrosis-idiopathic/TH or idiopathic pulmonary fibrosis/AL] and [nursing/TH or nursing/AL]) and (DT = 1976:2017 and PT = original article)</li> <li>2. ([肺疾患-間質性/TH or 間質性肺疾患/AL] and [看護/TH or 看護/AL]) and (DT = 1976:2017 and PT = 原著論文) (In Japanese) / [lung disease–interstitial/TH or interstitial lung disease/AL] and [nursing/TH or nursing/AL] and (DT = 1976:2017 and PT = original article)</li> </ol>
National Institute of Informatics' Scholarly and Academic Information Navigator (CiNii)	<ol style="list-style-type: none"> <li>1. 間質性肺炎 看護 (In Japanese) / interstitial lung disease, nursing</li> <li>2. 特発性肺線維症 看護 (In Japanese) / idiopathic pulmonary fibrosis, nursing</li> </ol>

Table 1 Continued

Grants-in-Aid for Scientific Research (KAKEN) database

1. 間質性肺炎 看護 (In Japanese) / interstitial lung disease, nursing
2. 特発性肺線維症 看護 (In Japanese) / idiopathic pulmonary fibrosis, nursing

Ministry of Health, Labor and Welfare Grants System databases

1. 間質性肺疾患 看護 (In Japanese) / interstitial lung disease, nursing
2. 特発性肺線維症 看護 (In Japanese) / idiopathic pulmonary fibrosis, nursing

AL, All Field; CiNii, National Institute of Informatics' Scholarly and Academic Information Navigator; DT, Date of Publication; exp, explode using narrower Emtree terms; MH, MeSH; PT, Publication Type; TH, Thesaurus.

## RESULTS

### Study selection

The systematic review process is summarized by using the PRISMA flow diagram in Figure 1. The author reviewed a total of 394 articles from PubMed ( $n = 138$ ), Medline ( $n = 14$ ), Embase ( $n = 58$ ), CINAHL ( $n = 36$ ), Cochrane CENTRAL ( $n = 3$ ), Ichushi – Web database ( $n = 77$ ), CiNii ( $n = 58$ ), KAKEN database ( $n = 5$ ), Database of Health Labor Sciences Research Grants ( $n = 4$ ), and a manual search identified one article.

The search identified 394 articles, of which 21 articles were excluded and 370 articles from the primary screening were excluded: qualitative research ( $n = 7$ ), case studies ( $n = 91$ ), drug research ( $n = 6$ ), pulmonary rehabilitation, mainly with exercise therapy ( $n = 7$ ), not nursing care ( $n = 94$ ), letters ( $n = 81$ ), and reviews ( $n = 84$ ). The records that were screened ( $n = 3$ ) were full-text articles. One article from the secondary screening was excluded because it was a retrospective study design that used a pre–post test, as opposed to a RCT. As a result, there were two full-text articles that met the eligibility criteria as systematic reviews: Bajwah *et al.* (2013) and Lindell *et al.* (2010).

### Study characteristics

The study characteristics that were extracted from the included trials (Bajwah *et al.*, 2015; Lindell *et al.*, 2010) are summarized in Table 2.

### Participants

Lindell *et al.* (2010) studied outpatients and their care partners. The participants were randomly assigned to either the intervention group ( $n = 21$ ) or the control group ( $n = 20$ ). The inclusion criteria were: an age of  $\geq 21$  years, the stage and severity of the disease (forced vital capacity [FVC] reflecting moderate (FVC: 55%–70% predicted) or severe (FVC: < 55% predicted) function, and the IPF functional status. In addition, the care partner participants had to be able to read and

understand English and to live with or care for the patient with IPF. The method of diagnosis was not described.

Bajwah *et al.* (2015) studied outpatients and inpatients and their care partners. The patients were randomized to a care group or a waiting list. The inclusion criteria were: end-stage disease, as judged by either high-resolution computed tomography or composite physiologic index scores, and the patients and care partners had to be >18 years of age and possess sufficient mental capacity to comprehend and complete questionnaires in English. The methods of IPF diagnosis were not established.

### Types of interventions

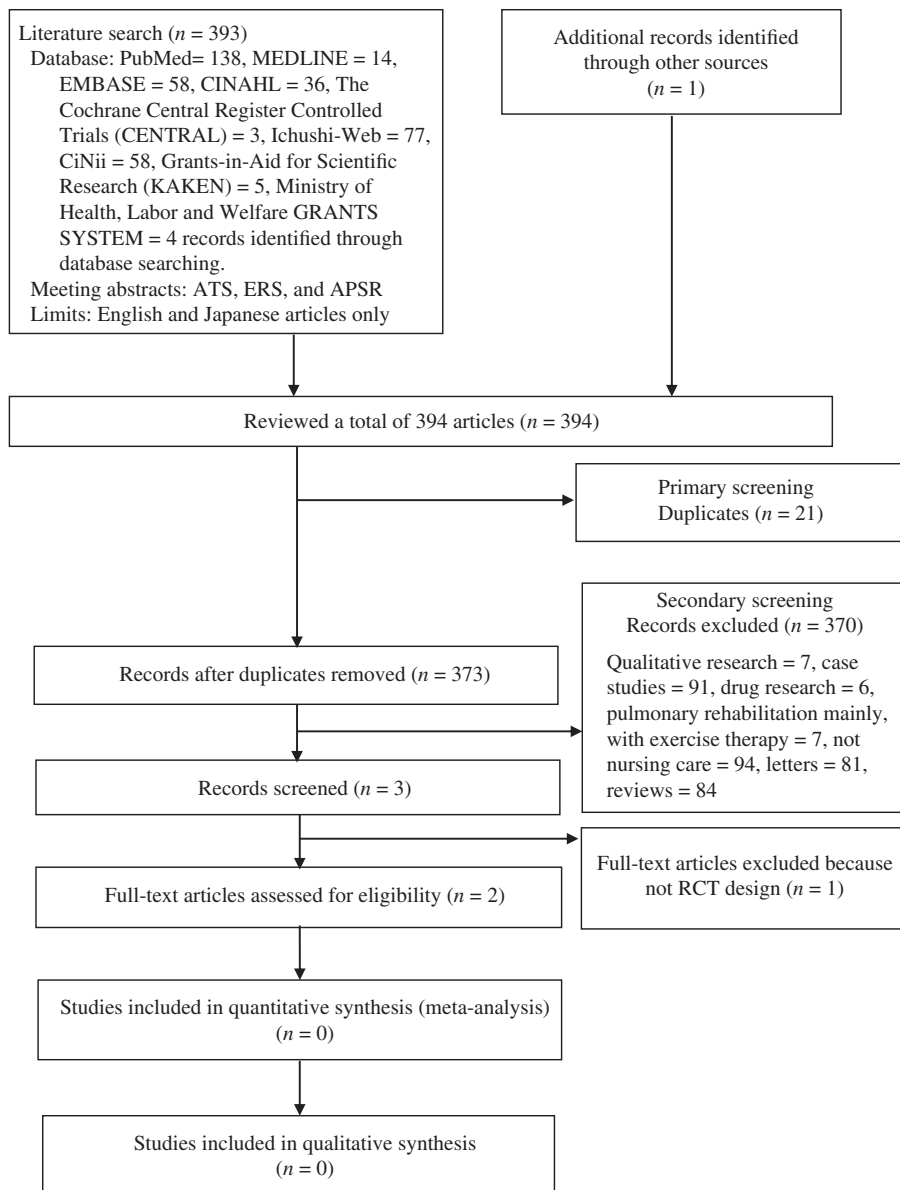
The nursing interventions were extracted from the trials of Bajwah *et al.* (2015) and Lindell *et al.* (2010). They are summarized in Table 3.

#### *Disease management program by the nurse specialist and healthcare providers*

Lindell *et al.* (2010) reported on a disease management program with nursing interventions that was provided by pulmonary and psychiatric clinical nurse specialists and healthcare providers, compared to the usual care. The Program to Reduce Idiopathic Pulmonary Fibrosis Symptoms and Improve Management (PRISIM) (Lindell *et al.*) consisted of six weekly group sessions that were attended by the patients and care partners; each session lasted for 2 h. The nurses, physicians, physical therapists, and nutritionists provided the disease management program for the patients and care partners.

The content of the PRISIM program was developed collaboratively by a pulmonary clinical nurse specialist whose practice involved patients with IPF, the psychiatric clinical nurse specialist with training in cognitive behavioral therapy, and an advanced care planning (ACP) instructor.

The disease management program had six sessions: Session one: “What is IPF and how to live with it?” (a review of the causes, pathophysiology, and treatment of IPF); Session two: “Gaining control of your moods and feelings – You feel the way you think” (basic



**Figure 1** Flow diagram of the review process and trial selection. APSR, Asian Pacific Society of Respiriology; ATS, American Thoracic Society; CiNii, National Institute of Informatics' Scholarly and Academic Information Navigator; ERS, European Respiratory Society; RCT, randomized controlled trial.

principles of cognitive behavior techniques and cognitive distortions); Session three: “Gaining control of your moods and feelings – What can you do about depression?” (concepts of stress and depression and their interrelationships with illness); Session four: “Putting your life in order - What do I do now?” (planning for uncertainty and concerns related to a terminal illness, communicating with clinicians, coping, and planning one’s affairs); Session five: “Living with IPF” (symptom management, energy conservation, oxygen therapy, and the importance of exercise); and Session six: “Wrap-up and review group” (informal discussion and review).

The control group was a clinical care team consisting of a pulmonary clinical nurse specialist and physicians with expertise in the management of IPF who provided the usual care in this study, typically at intervals of every 3–6 months.

#### *Community case conference with nurse specialist coordination*

Bajwah *et al.* (2015) compared a fast-track group of patients who were enrolled in a community case conference that was coordinated by a nurse specialist and

**Table 2** Summary of included studies evaluating the efficacy of the nursing interventions

Nursing intervention	Source	Country of origin	Setting	No. of Participants	Inclusion criteria of the participants	Follow-up (weeks)	Outcome measure
Disease management program	Lindell <i>et al.</i> (2010)	USA	OP	42	≥21 years; FVC: 55–70% and <55%; read and understand English	6	PF, MH, BAI, BDI, PSS, SOBQ
Community case conference	Bajwah <i>et al.</i> (2015)	UK	OP, IP	53	(1) End-stage disease as judged by either high-resolution CT or composite physiologic index scores; >18 years; sufficient mental capacity; read and understand English	4	POS, KBILD, SGRQ, HADS, MRC, D12 Scale

BAI, Beck Anxiety Inventory; BDI, Beck Depression Inventory-II; CT, computed tomography; D12 scale, breathlessness severity; FVC, forced vital capacity; HADS, Hospital Anxiety and Depression Scale; IP, inpatients; KBILD, King's Brief Interstitial Lung Disease questionnaire; MH, "Mental health" in SF-36; MRC, Medical Research Council breathlessness scale; OP, outpatients; PF, "Physical functioning" in MOS-Short Form 36 (SF-36); POS, The Palliative Care Outcome Scale; PSS, Perceived Stress Scale; SF-36, SF-36, Medical Outcomes Study-36-Items Short Form Health Survey; SGRQ, St George's Respiratory Questionnaire; SOBQ, Shortness of Breath Questionnaire.

compared the group with the waiting list group. A case conference model of care (Hospital2Home) also has been used for patients with cancer in the acute oncology setting in the UK.

The patient, their care partner, Hospital2Home nurse, general practitioner, community matron or district nurse, respiratory nurse, and community palliative care nurse (and any other health or social care professional that was involved in their care or was identified as important by the patient) were invited to attend the case conference. The Hospital2Home nurse aimed to resolve any issues by liaising with the relevant community health professionals.

The participants were randomized into the fast-track group or the waiting list group. For the fast-track patients, a Hospital2Home nurse organized a case conference as soon as possible. Bajwah *et al.* (2015) reported that 24% of the fast-track group received the community case conference within 2 weeks. The outcomes were compared with the waiting list group at 4 weeks. The waiting list patients then were referred for the case conference 4 weeks after randomization.

The Hospital2Home intervention included a number of steps that individualized the care for the patient and their care partners. The Hospital2Home nurse telephoned before the case conference. The patient and care partners identified what their current palliative care concerns were and what they hoped to achieve from the case conference. This included identifying whether the patients wished to discuss the sensitive matter of disease

progression and planning for the future. Their concerns were discussed, where appropriate, and end-of-life preferences were discussed. Following the case conference, the Hospital2Home nurse drafted an individualized care plan that then was communicated to the patient and care partners, the interstitial lung disease specialist team, the general practitioner, all the attendees at the case conference, and any other health professional that had been identified by the patient as involved in their care. The Hospital2Home nurse monitored the patient and their care partners with follow-up phone calls and aimed to resolve any issue by liaising with the relevant community health professionals.

### Type of outcome measures

Lindell *et al.* (2010) examined the outcome measures of anxiety, depression, perceived stress, and HRQOL. The Shortness of Breath Questionnaire (SOBQ) was used to assess dyspnea, the MOS-Short Form 36 (SF-36) assessed physical functioning (PF) and mental health (MH). The Beck Anxiety Inventory (BAI), Beck Depression Inventory-II (BDI), and Perceived Stress Scale (PSS), assessed psychological health. The 9 month mortality also was documented.

The outcome measures for Bajwah *et al.* (2015) were the Palliative Care Outcome Scale (POS), King's Brief Interstitial Lung Disease questionnaire, St George's Respiratory Questionnaire, Medical Research Council breathlessness scale, and the Hospital Anxiety and Depression Scale.

**Table 3** Nursing interventions for improving the patients' quality of life

Study	Nursing intervention
Bajwah <i>et al.</i> (2015)	<p>“Hospital2Home” specialist nurse telephoned the patient and care partners before the case conference to:</p> <ul style="list-style-type: none"> <li>• Identify what are their current palliative care concerns?</li> <li>• What the patient and care partners hoping to achieve from the case conference?</li> <li>• Identifying whether the patients wished to discuss the sensitive matter of disease progression and planning for the future; end-of-life preferences were discussed where appropriate</li> </ul> <p>Following the case conference by the Hospital2Home nurse:</p> <ul style="list-style-type: none"> <li>• Draft of an individualized care plan</li> <li>• Communication to the patient and care partners, the ILD specialist team, the general practitioner, and all attendees at the case conference</li> <li>• Follow-up phone calls to the patient and care partners</li> </ul>
Lindell <i>et al.</i> (2010)	<p>To provide by a pulmonary clinical nurse specialist, clinical psychiatrist, and an advanced care planning instructor:</p> <p>Session 1. Review the causes, pathophysiology, and treatment of IPF</p> <p>Session 2. Discuss the basic principles of cognitive behavior techniques and cognitive distortions</p> <p>Session 3. Discuss the concepts of stress and depression and interrelationships with illness</p> <p>Session 4. Address planning for uncertainty and concerns related to terminal illness, communicating with clinicians, coping, and planning for one's affairs</p> <p>Session 5. Discuss symptom management, energy conservation, oxygen therapy, and the importance of exercise</p> <p>Session 6. Involve informal discussion and review</p>

ILD, interstitial lung disease; IPF, idiopathic pulmonary fibrosis.

### Risk of bias, concealment, and randomization

The risk of bias by using the data collection and assessment form (The Cochrane Collaboration, 2013) is summarized in Table 4. There was no description about concealment in the studies of Bajwah *et al.* (2015) or

Lindell *et al.* (2010). The participants were randomized to groups after the completion of the baseline questionnaires. These studies used a permuted block randomization for the assignment of equal numbers of patients to each group. The Lindell *et al.* study was not based on a power calculation for the sample size as it was a RCT that was designed as a feasibility study.

### Results of individual studies

The outcomes of the nursing interventions for improving the QOL of patients with IPF are summarized in Table 5.

#### Disease management program

The MH in the SF-36 was higher in the intervention group than in the control group. The PF in the SF-36 was lower (more negative) in the intervention group than in the control group, which was statistically significant. The BAI, BDI, and PSS were higher in the intervention group than in the control group. The SOBQ was lower in the intervention group than in the control group, but was not significantly different. Mortality 9 months after study entry was 29%.

#### Community case conference

The community case conference improved the palliative symptoms and QOL after 4 weeks. The mean (standard deviation) POS scores at 4 weeks were −5.7 (7.5) for the fast-track group, compared to −0.4 (8.0) for the control group (the mean change difference between the two arms was −5.3 (95% CI: −9.8 to −0.7) using the independent *t*-test ( $P = 0.02$ ); the effect size had a 95% CI of −0.7 (−1.2 to −0.1). The QOL, anxiety, and depression improved in the fast-track group and no participant became worse. Mortality was not reported.

The author was unable to conduct a meta-analysis, as the outcome measurements were not similar in these studies. There also was no subgroup analysis or funnel plot conducted. However, the results were reported for all outcomes measures at all time points. The author did not identify large imbalances of the baseline characteristics.

## DISCUSSION

This systematic review examined two RCTs regarding nursing interventions for patients with IPF. One study was about a disease management program by nurse specialists and healthcare providers and the other was a community case conference that was coordinated by a



**Table 4** Quality measures of the randomized controlled trials (RCTs)

Trial	Concealment of randomization	RCT stopped early	Patients blinded	Healthcare providers blinded	Data collectors blinded	Outcome assessors blinded	Selective reporting
Bajwah <i>et al.</i> (2015)	No	No	No	No	No	No	No
Lindell <i>et al.</i> (2010)	No	No	No	No	No	No	No

**Table 5** Results of nursing intervention outcomes

Nursing intervention	Study	Outcome	Adjusted mean scores		Effect size (95% CI) at 4 weeks
			Intervention	Control	
Community case conference	Bajwah <i>et al.</i> (2015)	HRQOL	–	–	–
		POS	–	–	–0.7 (–1.2 to –0.1)
		KBILD	–	–	0.6 (0.0 to 1.2)
		SGRQ			
		Symptoms	–	–	–0.2 (–0.8 to 0.4)
		Activity	–	–	–0.5 (–1.1 to 0.1)
		Impact	–	–	–1.0 (–1.6 to –0.4)
		Total	–	–	–0.9 (–1.5 to –0.3)
		Psychosocial state			
		HADS	–	–	–
		Anxiety	–	–	–0.6 (–1.1 to 0.0)
		Depression	–	–	–0.7 (–1.3 to –0.1)
		Total score	–	–	–0.7 (–1.2 to –0.1)
		Physical status			
		D12 scale	–	–	–0.3 (–0.9 to 0.3)
		MRC	–	–	–
		Median	–	–	NR
Disease management program	Lindell <i>et al.</i> (2010)	HRQOL			
		PF in SF-36	31.06 ± 4.61*	36.04 ± 4.63	–
		MH in SF-36	55.98 ± 2.71	55.61 ± 2.71	–
		Psychosocial state	–	–	–
		BAI	15.13 ± 6.92	8.56 ± 6.95	–
		BDI	9.71 ± 4.34	9.44 ± 4.35	–
		PSS	19.32 ± 3.64	18.20 ± 3.65	–
		Physical status	–	–	–
		SOBQ	49.51 ± 22.64	49.88 ± 22.64	–
		Mortality	–	–	–
		9 months after study entry (%)	29	NR	–

\* $P < 0.05$ . The values were the mean ± standard deviation. BAI, Beck Anxiety Inventory; BDI, Beck Depression Inventory-II; CI, confidence interval; D12 scale, breathlessness severity; HADS, Hospital Anxiety and Depression Scale; HRQOL, health-related quality of life; KBILD, Kings Brief Interstitial Lung Disease questionnaire; MH, “Mental health” in SF-36; MRC, Medical Research Council breathlessness scale; NR, not reported; PF, “Physical functioning” in MOS-Short Form 36 (SF-36); POS, The Palliative Care Outcome Scale; PSS, Perceived Stress Scale; SGRQ, St George’s Respiratory Questionnaire; SOBQ, Shortness of Breath Questionnaire.

specialist nurse. The RCTs evaluated enough patients for a sufficient duration to allow conclusions to be made about the clinical outcomes, such as acute exacerbation events and mortality.

There was a high risk of bias in both studies for the following conditions: no description about the concealment of randomization; no patient was reported as blinded; healthcare providers' blinding was not reported; no data collector blinding was reported, and no outcome assessor blinding was reported. The following conditions provided a low risk of bias: neither RCT was stopped early and the results were reported for all outcomes at all time points in both studies.

The participants in the disease management program of Lindell *et al.* (2010) showed increased knowledge of the disease, coping skills with depression and anxiety, and end-of-life-discussion. The evidence was not sufficiently robust to determine the comparative effectiveness of the nursing intervention for improving the QOL of the patients with IPF. In both studies, the nursing interventions were conducted in collaboration with multiple professionals. Acceptable evidence from the comparison of the nursing interventions and usual care by members of the clinical care team in the management of IPF, typically at intervals of every 3–6 months (Lindell *et al.*), suggested differences in the physical state during the nursing interventions. The other variables were not significant between the nursing intervention group and the control group. Therefore, the evidence regarding the other outcomes is weak.

The community case conference (Bajwah *et al.*, 2015) managed illness uncertainty by facilitating early discussions about illness progression, improving communication, and addressing end-of-life planning needs. Lee, McLaughlin, and Collard (2011) found that the ACP was an essential component for patients with a progressive illness, such as IPF, and that the focus of care needed to be palliative care. When the nurses became involved from the time of the patients' daily visit, the patients' QOL improved. It was thought that these nursing interventions with physical, social, and psychological aspects contributed to improving the patients' QOL.

In a survey of the impact of declining ADLs for patients with IPF, it has been reported that in addition to the loss of independence of daily behavior by the patients, their role in the family had changed and the psychological influence, such as an increase in the patient's anxiety, was recognized (Schoenheit, Becattelli, & Cohen, 2011). There were 29% of the patients in the intervention group of Lindell *et al.* (2010)

who died within 9 months from the start of the program. There was a possibility that the progression of the disease affected the period of the intervention and decreased the patients' ADLs and their QOL.

Respiratory rehabilitation is a comprehensive concept that requires each healthcare professional's cooperation for the implementation, with exercise therapy as the main axis, relying on the role and leadership of the physical therapists. None of the literature on respiratory rehabilitation clearly described the role of nurses. For this reason, the author focused on the nursing interventions and the role of nurses, such as patient education and coordination.

Therefore, the nursing interventions for improving the QOL of patients with IPF are considered to be potentially effective, not only with ADL education on pulmonary rehabilitation or disease management, but also for the psychological aspects of patients. More RCTs are needed to investigate the nursing interventions for existential pain and individual coordination by the specialist nurse. There were few nursing interventions that were reported for improving the QOL of patients with IPF. Future RCT studies are required to develop effective non-pharmacological nursing interventions for patients with IPF.

### Limitations of the review

The main limitation of this review was the limited number of RCT studies regarding nursing interventions for patients with IPF. Publication bias might account for some of the effect; however, it is more likely related to the disease's relative rarity and short lifespan of the patients with the disease. In addition, one RCT was a feasibility study; thus, the outcomes must be interpreted cautiously. It also was possible that despite efforts to locate all the relevant extant studies, some were missed during the review process. The question remains regarding the inclusion of both randomized and non-randomized studies in the systematic review. A case can be made for including multiple study designs in the future, with the caveat of being sure to give attention to the direction and magnitude of the effects (Peinemann, Tushabe, & Kleijnen, 2013). Finally, the language restriction for the search was, of course, a limitation.

### CONCLUSION

This systematic review showed non-pharmacological nursing interventions for improving the QOL of

patients with IPF. The RCTs of nursing interventions were two: the disease management program by the specialist nurse and healthcare providers and a community case conference that was coordinated by a specialist nurse.

The disease management program that included illness and self-management education for patients resulted in lower QOL scores. The community case conferences included individualized care that was coordinated by nurse specialists and improved the patients' QOL after 4 weeks of intervention. The risk of bias was high in both studies.

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## DISCLOSURE

The author declares no conflict of interest.

## AUTHOR CONTRIBUTIONS

Y. I. contributed to the conception and design of this study, carried out the analysis, drafted the manuscript, and read and approved the final manuscript.

## REFERENCES

- Bajwah, S., Ross, J. R., Peacock, J. L., Higginson, I. J., Wells, A. U., Patel, A. S. *et al.* (2013). Interventions to improve symptoms and quality of life of patients with fibrotic interstitial lung disease: A systematic review of the literature. *Thorax*, 68, 867–879.
- Bajwah, S., Ross, J. R., Wells, A. U., Mohammed, K., Oyebode, C., Birring, S. S. *et al.* (2015). Palliative care for patients with advanced fibrotic lung disease: A randomised controlled phase II and feasibility trial of a community case conference intervention. *Thorax*, 70, 830–839.
- Dowman, L., Hill, C. J. & Holland, A. E. (2014). Pulmonary rehabilitation for interstitial lung disease. *The Cochrane Database of Systematic Reviews*, 10, CD006322.
- Egan, J. J. (2011). Follow-up and nonpharmacological management of the idiopathic pulmonary fibrosis patient. *European Respiratory Review*, 20, 114–117.
- Higgins, J. P. T., Altman, D. G. & Sterne, J. A. C. (2011). *Assessing risk of bias in included studies*. In Higgins, J. P. T., Green, S. (Eds), *Cochrane handbook for systematic reviews of interventions version 5.1.0*. (updated March 2011). The Cochrane Collaboration, 2011. Available from URL: [www.cochrane-handbook.org](http://www.cochrane-handbook.org).
- Igai, Y. (2016). Experience of Japanese patients with idiopathic pulmonary fibrosis who cope with dyspnea. *Journal of Japan Academy of Nursing Science*, 36, 238–246 (in Japanese).
- Lee, J. S., McLaughlin, S. & Collard, H. R. (2011). Comprehensive care of the patient with idiopathic pulmonary fibrosis. *Current Opinion in Pulmonary Medicine*, 17, 348–354.
- Lindell, K. O., Olshansky, E., Song, M., Zullo, T. G., Gibson, K. F., Kaminski, N. *et al.* (2010). Impact of a disease-management program on symptom burden and health-related quality of life in patients with idiopathic pulmonary fibrosis and their care partners. *Heart & Lung*, 39, 304–313.
- Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M. *et al.* (2015). Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. *Systematic Review*, 4, 1.
- National Clinical Guideline Centre (UK). (2013). *Diagnosis and management of suspected idiopathic pulmonary fibrosis. Idiopathic Pulmonary Fibrosis NICE Clinical Guidelines no. 163*. National Clinical Guideline Centre (UK). London: Royal College of Physicians. [Cited 20 Sep 2017] Available from URL: <https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0068972/>
- Natsuizaka, M., Chiba, H., Kuronuma, K., Otsuka, M., Kudo, K., Mori, M. *et al.* (2014). Epidemiologic survey of Japanese patients with idiopathic pulmonary fibrosis and investigation of ethnic differences. *American Journal of Respiratory and Critical Care Medicine*, 190, 773–779.
- Peinemann, F., Tushabe, D. A. & Kleijnen, J. (2013). Using multiple types of studies in systematic reviews of health care interventions – A systematic review. *PLoS One*, 8, e85035.
- Raghu, G., Collard, H. R., Egan, J. J., Martinez, F. J., Behr, J., Brown, K. K. *et al.* (2011). An official ATS/ERS/JRS/ALAT statement: Idiopathic pulmonary fibrosis: Evidence-based guidelines for diagnosis and management. *American Journal of Respiratory and Critical Care Medicine*, 183, 788–824.
- Schoenheit, G., Becattelli, I. & Cohen, A. H. (2011). Living with idiopathic pulmonary fibrosis: An in-depth qualitative survey of European patients. *Chronic Respiratory Disease*, 8, 225–231.
- Swigris, J. J., Gould, M. K. & Wilson, S. R. (2005). Health-related quality of life among patients with idiopathic pulmonary fibrosis. *Chest*, 127, 284–294.
- The Cochrane Collaboration. (2013). The Cochrane public health group data extraction and assessment template. [Cited 1 Dec 2017] Available from URL: [https://ph.cochrane.org/sites/ph.cochrane.org/files/public/uploads/CPHG%20Data%20extraction%20template\\_0.docx](https://ph.cochrane.org/sites/ph.cochrane.org/files/public/uploads/CPHG%20Data%20extraction%20template_0.docx)

- Trawinska, M. A., Rupesinghe, R. D. & Hart, S. P. (2016). Patient considerations and drug selection in the treatment of idiopathic pulmonary fibrosis. *Therapeutics and Clinical Risk Management*, *12*, 563–574.
- Vancheri, C., Failla, M., Crimi, N. & Raghu, G. (2010). Idiopathic pulmonary fibrosis: A disease with similarities and links to cancer biology. *The European Respiratory Journal*, *35*, 496–504.