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ORIGINAL ARTICLE

End-of-life trajectory of coping and self-care of patients with idiopathic pulmonary fibrosis: A meta-synthesis using meta-ethnography

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Abstract

Aim: This study aimed to extract patient narratives regarding the end-of-life trajectory of their self-care and coping experiences as patients with idiopathic pulmonary fibrosis and to use meta-ethnography to discover common metaphors of their experience in order to inform the development of nursing interventions.

Methods: A comprehensive search of qualitative research using electronic databases, in English and Japanese, regarding patients with IPF, identified four articles. The meta-ethnography approach followed seven steps, which provided a synthesis of the phenomena from both comparative and cumulative analyses of the qualitative data.

Results: Seven key concepts and metaphors were synthesized: (i) an extended period before obtaining a diagnosis ("*Waiting for the other shoe to drop*"); (ii) suffering as the pathway of illness ("*Gloom and doom*"); (iii) the burden of the symptoms and loss of independence ("*Staggering under the load*"); (iv) acceptance and living with the restrictions of home oxygen therapy ("*A double-edged sword*"); (v) changes in the family role ("*All in the same boat*"); (vi) existential suffering ("*Dead-end streets and rays of hope*"); and (vii) challenges to maintain independent living ("*Making the best of it*"). Reciprocal, refutational, and line-of-argument modes of synthesis revealed the relationships of the metaphors. Meta-ethnography provided a mechanism for a cumulative knowledge base for necessary nursing interventions.

Conclusions: The critical nursing interventions were: the relief of symptoms, particularly dyspnea and cough; coordinating lifestyle changes; providing psychological support for living with an illness beginning from the time of diagnosis; and carefully starting the end-of-life discussions with patients and families.

INTRODUCTION

Idiopathic pulmonary fibrosis (IPF) is not strictly speaking a malignant lung disease, as it is not a cancer, but as it has a poor prognosis and is often compared to a malignant or cancerous disease, it is usually regarded as a "progressive" lung disease with a poor prognosis. The survival prognosis is shorter, from 2–7 years (Duck *et al.*, 2015; Raghu, 2011; Rajala *et al.*, 2016). Idiopathic pulmonary fibrosis tends to have a shorter prognosis than other malignant diseases (Vancheri, Failla, Crimi, & Raghu, 2010) and has a history of both diagnostic and prognostic uncertainty because of its complex presentation. Although the disease trajectory is difficult to predict, a hallmark is the deterioration of forced vital capacity. The IPF trajectory pattern is varied. Some patients can progress slowly and attain a somewhat stable course, yet other patients can rapidly decline. Patients, despite being stable for extended periods of time, can manifest an acute exacerbation. It is the annual incidence of acute exacerbations of idiopathic pulmonary fibrosis (AE-IPF) that is typically

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Duck et al. (2015), Igai (2016), Overgaard et al. (2016), and Schoenheit, Becattelli, & Cohen (2011) were the studies that were included in the meta-synthesis.

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reported at 5–15% and the short-term mortality of AE-IPF is ~50% (Ryerson, Cottin, Brown, & Collard, 2015). In addition, for the older male who smokes, the risk of developing lung cancer along with IPF is higher. Lung cancer combined with IPF is significantly higher with emphysema, compared with fibrosis only (Antoniou, Tomassetti, Tsitoura, & Vancheri, 2015). As evidence-based IPF treatment has not been fully established, the long-term progress is doubtful even with anti-fibrotic drugs, such as pirfenidone and nintedanib (Canestaro, Forrester, Raghu, Ho, & Devine, 2016).

The daily living activities of patients with IPF become gradually limited due to coughing and dyspnea at the time of exertion. Several studies indicated that the quality of life (QOL) for patients with IPF tends to be low. Nishiyama *et al.* (2005) reported that dyspnea was the greatest factor that decreases the QOL. A qualitative study of patients with IPF and coping with dyspnea described additional narratives of patients expressing existential suffering, such as questioning the meaning of living with spiritual pain, psychological distress, and symptoms that are associated with the progression of IPF. These symptoms caused physical and additional psychological and emotional burdens, all of which degraded their QOL (Igai, 2016).

The palliation of symptoms is a specific treatment goal for IPF (Gilbert & Smith, 2009). The joint statement of the American Thoracic Society, European Respiratory Society, Japanese Respiratory Society, Latin American Thoracic Association (Raghu *et al.*, 2011) and the IPF guidelines in the UK (National Clinical Guideline Centre (UK), 2013) urge the use of psychosocial therapy in addition to symptomatic relief. However, there was no nursing intervention, as such, included.

In the review of the literature on the effectiveness of nursing as a non-pharmacological therapy for improving the QOL of patients with IPF, the nursing research was limited and no research was found with high-level evidence. There were very few intervention studies on nursing care. However, there were several informative qualitative studies that involved the narratives of patients with IPF who were living at home regarding the experiences of their self-care and coping (Duck *et al.*, 2015; Igai, 2016; Schoenheit, Becattelli, and Cohen 2011). These studies revealed the phenomena experienced by patients. When the prognosis of patients with IPF is uncertain, it is necessary to understand the phenomena of patients' self-care and coping experiences with IPF. That understanding is important in order to consider nursing interventions that contribute to improving or to maintaining patients' QOL. According to the descriptions in the qualitative studies about patients with IPF, common phenomena existed in the experiences of patients with IPF. Therefore, it was decided to interpret the phenomena by using a meta-synthesis in order to understand the experiences that are common across patients' narratives about living with IPF.

Thus, the aim of the research was to conduct a meta-synthesis of patients' narratives regarding their self-care and coping experiences with IPF, from waiting for the initial diagnosis to facing the realities of their diminishing health, the results of which might lead to the discovery of new findings in order to inform nursing interventions that are closely related to, and are aligned with, patients' experiences.

METHODS

Search method

A comprehensive search was conducted of the following electronic databases, in English and Japanese, from 1976 to 2016: PubMed, MEDLINE, EMBASE, CINAHL, Ichushi-Web by NPO Japan Medical Abstracts Society database, Scholarly and Academic Information Navigator (CiNii) by National Institute of Informatics database, Grants-in-Aid for Scientific Research (KAKEN) database, and Database of Health Labor Sciences Research Grant. The combination of MESH and key words that were used were as follows: [interstitial pulmonary fibrosis], [idiopathic pulmonary fibrosis] AND [nurse OR nurses role OR nursing]. To search for publications other than journal articles, a Web search was conducted by using the author's name from prior research publications. Information on the Internet was similarly obtained by using the search engine "Google." The search date was 3 October, 2016 and the search string was accessed on 3 October, 2016.

Eligibility criteria

The eligibility criteria included qualitative research of patients with IPF, in English or Japanese. The exclusion criteria included quantitative studies, studies of no living experience at home, drug and education interventions, and the study of care needs.

Research screening method

For the retrieved documents, their primary screening was conducted to satisfy the eligibility criteria, based on

the article title and abstract. Research was not included if it did not clearly meet the eligibility criteria. In the secondary screening, after the full article was carefully read, items about the patient narratives regarding their self-care and coping experiences with IPF, discipline, year, participants, country of origin of the medical facility, data analysis, research design, aim, sample size, age, and research period were documented. A grid was used to organize these data. Rigor was enhanced through careful documentation of each study and following the research protocol.

Analysis

Meta-ethnography is a type of meta-synthesis that provides for a comparative and cumulative approach to provide generalizations of individual qualitative studies (Barnett-Page & Thomas, 2009). It defines the theories, grand narratives, generalizations, or interpretive translations that are produced from the integration or comparison of findings from qualitative studies (Sandelowski, Docherty & Emden, 1997). Researchers analogize and interpret the data that are obtained from individual participants of common qualitative research and then they reinterpret the data. Noblit and Hare (1988) developed the meta-ethnography process for synthesizing qualitative studies.

To analyze the findings, the following seven steps from the meta-ethnography approach of Noblit and Hare (1988) were used to find new meanings: (i) make a decision on the phenomenon of study; (ii) make a decision on what qualitative studies will be included in the synthesis; (iii) read the qualitative studies; (iv) determine how the qualitative studies are related to each other; (v) the key concepts of the qualitative studies then are translated into one another to evolve overarching metaphors; (vi) synthesize the translations, making a whole that is more than what the individual parts imply; and (vii) express the results by means of the written word. First, the concepts in this study were synthesized. Then, the concepts were examined on a deeper level for their implied meanings. Metaphors were developed as a second-order synthesis in order to express the implied or implicit meanings.

A meta-synthesis using the meta-ethnography of Noblit and Hare (1988) provides three possibilities for integration: reciprocal, refutation, and line of argument. The process of reciprocal translation as synthesis is facilitated by the emerging conclusions that relate the questions of the reviewed studies to each other, yielding metaphors. This type of synthesis requires that the studies can be "added" together, based on the assumption that the researched studies are about similar topics. When the assumption of similarity is not valid, a different approach (refutation) is needed. Refutational synthesis treats the refutation itself as part of the interpretation to be synthesized. This synthesis "takes into account" the implied relationship between the competing explanations and the implied refutation is analyzed substantively and subsequently incorporated into the synthesis. The line-of-argument synthesis is about inference and the construction of an interpretation. Whereas, the reciprocal synthesis finds commonalities and the refutational synthesis finds differences, the line-of-argument synthesis finds similarity at a higher level of abstraction. It is essentially a process of clinical inference and grounded theorizing by an inference; it also may serve to reveal what is hidden in individual studies (Barnett-Page & Thomas, 2009; Noblit & Hare).

Rigor of the study

Although the individual studies reveal the patients' stated experience, the meta-synthesis reveals the researchers' viewpoint in the translation (Noblit & Hare, 1988). Systematically following the steps for synthesis provided rigor.

Ethical considerations

All the study's participants from the reviewed studies had provided informed consent. All the research that is included in this meta-synthesis had received ethical approval.

RESULTS

Search results

In the study, 394 articles were extracted: 138 (PubMed), 14 (MEDLINE), 58 (EMBASE), 36 (CINAHL), three (Cochrane CENTRAL), 77 (Ichushi-Web), 58 (Scholarly and CiNii), five (KAKEN), four (Database of Health Labor Sciences Research Grant), and one (manual search). An overview of the included studies was made based on the eligibility criteria. There were four articles that met all the eligibility criteria and that were about patients' narratives regarding their self-care and coping experiences with IPF.

Characteristics of the extracted literature

The medical institutions within which the four studies took place were situated in the following three

countries: Japan (Igai, 2016), UK (Duck *et al*., 2015; Schoenheit *et al*., 2011), and Denmark (Overgaard *et al*., 2016). The remaining characteristics of these studies are listed in Table 1.

Key concepts and metaphors

The seven key concepts that were synthesized initially are as follows: (i) an extended period before obtaining a diagnosis; (ii) suffering as the pathway of illness; (iii) the burden of the symptoms and loss of independence; (iv) acceptance and living with the restrictions of home oxygen therapy; (v); changes in the family role; (vi) existential suffering; and (vii) challenges to maintain independent living. The reciprocal translation was used in order to arrive at a deeper meaning. This process yielded seven metaphors: (i) "*Waiting for the other shoe to drop*"; (ii) "*Gloom and doom*"; (iii) "*Staggering under the burden*"; (iv) "*A double-edged sword*"; (v) "*All in the same boat*"; (vi) "*Dead-end streets and rays of hope*"; and (vii) "*Making the best of it.*"

These metaphors represent the patients' narratives regarding their self-care and coping experiences with IPF. The key concepts of the experience of patients with IPF that were expressed were aligned with the metaphors, as follows: (i) an extended period before obtaining a diagnosis ("*Waiting for the other shoe to drop*"); (ii) suffering as the pathway of illness ("*Gloom and doom*"); (iii) the burden of symptoms and loss of independence ("*Staggering under the load*"); (iv) acceptance and living with the restrictions of home oxygen therapy ("*Double-edged sword*"); (v) changes in the family role ("*All in the same boat*"); (vi) existential suffering ("*Dead-end streets and rays of hope*"); and (vii) challenges to maintain independent living ("*Making the best of it*"). Each metaphor is discussed next in more detail and the results of the patient narratives regarding their self-care and coping experiences with IPF are shown in Table 2.

"Waiting for the other shoe to drop" (an extended period waiting for a diagnosis)

The patients were aware that physically they had come far from their usual normal state, especially when symptoms were triggered by their actions. For example, they became acutely aware of their body's reaction as different from usual when they experienced shortness of breath and coughing when climbing stairs (Duck *et al*., 2015; Igai, 2016). Initially, the patients consulted their family doctor, but they found that a diagnosis could not be made. They underwent medical treatment with the diagnosis of chronic respiratory diseases, such as chronic obstructive respiratory disease (COPD) and asthma (Duck *et al*.; Overgaard *et al*., 2016). However, because the symptoms did not improve, a family doctor introduced them to a respiratory hospital, where they were finally diagnosed with idiopathic pulmonary fibrosis (Duck *et al*.; Igai). During the period of waiting for a diagnosis, the patients looked back on their past coping behaviors and physicians' treatments with feelings of stress, anger, and regret (Duck *et al*.; Schoenheit *et al*., 2011). Duck *et al*. reported that patients found it was the nurse who seemed to best understand their suffering.

"Gloom and doom" (suffering as the pathway of illness)

Idiopathic pulmonary fibrosis is a type of idiopathic interstitial pneumonia. The patients received explanations of the medical condition from the physician, but it is a very complicated disease and difficult to understand. In some cases, the physician showed little capacity to present the disease process in layman's terms and in a way that the patient could grasp. There is no established cure for IPF and the prognosis is poor with a shortened life span. The physician explained that it was a disease where one might die suddenly due to an acute exacerbation (Igai, 2016; Overgaard *et al*., 2016; Schoenheit *et al*., 2011).

The patients who received an explanation of the condition assumed that home oxygen therapy was needed in the future; furthermore, they realized there was a limit to the time that they could live. They became very conscious of their impending death.

The patients urged their family to provide for nursing care in the future and to have their family become independent from them, as they would not be able to feed them in the future (Igai, 2016; Overgaard *et al*., 2016; Schoenheit *et al*., 2011). As IPF is a disease that is not known by the public, the patients felt it was difficult to gain understanding or empathy from others (Igai; Schoenheit *et al*.).

"Staggering under the load" (the burden of the symptoms and loss of independence)

The characteristic symptoms of IPF of cough and dyspnea made it difficult for the patients to live independently and freely. The patients talked about the activities of daily living that were impossible to carry out due to their severe symptoms (Duck *et al*., 2015; Igai, 2016; Schoenheit *et al*., 2011). In addition, the

Table 1 Characteristics of the qualitative studies that were included in the meta-synthesis

	Schoenheit, G., Becattelli, I., & Cohen, A. H. (2011)	Duck, A., Spencer, L. G., Bailey, S., Leonard, C., Ormes, J., & Caress, A. (2015)	Overgaard, D., Kaldan, G., Marsaa, K., Nielsen, T. L., Shaker, S. B., & Egerod, I. (2016)	Igai (2016)
Discipline	Medical, pharmacological	Nursing	Medical, nursing	Nursing
Research period	2004	2007	2014	2011
Country	France, Germany, Italy, Spain, UK	UK	Denmark	Japan
Data analysis	Analyzed the raw data in a collaborative process	Framework analysis (Ritchie & Spencer, 1994)	The National Center for Social Research Framework	Content analysis
Research design	Qualitative study	Qualitative study	Qualitative descriptive study	Qualitative description study for factor search
Aim	To generate in-depth insights regarding the patient's journey, including symptoms, triggers to seeking medical care, referral patterns, initial diagnoses, follow-up, and current disease management	To understand the perceptions, needs, and experiences of patients with idiopathic pulmonary fibrosis	To increase knowledge of life with idiopathic pulmonary fibrosis in patients and family caregivers	To describe the experiences of Japanese patients with idiopathic pulmonary fibrosis who cope with dyspnea
Sample size	45	17	25	14
Age	67 (median)	67 (median)	71.1 (median)	71.2 ± 8.9 (average)
Sex	22 Male (49%), 23 female (51%)	7 Male (41%), 10 female (59%)	15 Male (60%), 10 female (40%)	13 Male (93%), 1 female (7%)
Participants	Patients with a physician-confirmed diagnosis of idiopathic pulmonary fibrosis	Patients with the multidisciplinary team's idiopathic pulmonary fibrosis diagnosis	Idiopathic pulmonary fibrosis patients >40 years who were diagnosed according to international guidelines; family caregivers were individuals >18 years who had the same access to information as the patient	Stable outpatients or hospitalized patients with a physician-confirmed diagnosis of idiopathic pulmonary fibrosis, >40 years old, and Borg scale score of ≥1 at the time of exertion
Characteristics	Home oxygen therapy: Continuous: 18 (40%) Non-continuous: 7 (16%) None: 20 (44%) Family history of idiopathic pulmonary fibrosis: Confirmed: 1 (2%) Suspected: 5 (11%) Smoking history: Ex-smoker: 34 (76%) Never smoked: 11 (24%)	Home oxygen therapy: Continuous: 10 Ambulatory: 2 None: 5 Family history of idiopathic pulmonary fibrosis: Confirmed: 3 (18%) Smoking history: Ex- or current smokers: 10 Never smoked: 7 Lung transplant waiting list: 3 patients	Home oxygen therapy: Continuous: 7 Pack-years: 33.4 (median) Smoking history: Ex-smokers: 20 Never smoked: 5 %FVC†: 83.1 (median) Treatment with pirfenidone: 15 patients	Home oxygen therapy: Continuous: 8 Non-continuous: 4 Pack-years: 47 (median) Smoking history: Ever smoked: 13 Never smoked: 1 %FVC†: 66.6 (median) Participants living with family members: 11 patients

†FVC, forced vital capacity (<80% indicates obstruction).

Table 2 Metaphors related to the patients' narratives regarding their self-care and coping experiences with idiopathic pulmonary fibrosis

Metaphor	Schoenheit, G., Becattelli, I., & Cohen, A. H. (2011)	Duck, A., Spencer, L. G., Bailey, S., Leonard, C., Ormes, J., & Caress, A. (2015)	Overgaard, D., Kaldan, G., Marsaa, K., Nielsen, T. L., Shaker, S. B., & Egerod, I. (2016)	Igai (2016)
(i) "Waiting for the other shoe to drop" (an extended period before obtaining a diagnosis)	"I think all GPs should have a recording of the lungs of a person with pulmonary fibrosis and if they hear that noise, they should send you to the chest clinic as the first port of call. My GP hadn't even listened to my lungs before sending me to the heart clinic and I'm breathless. Come on""I do think that it was badly handled, actually""I was angry and upset, it took over 2 years to get a diagnosis and I felt none of the doctors cared"	"It started with a cough ... I was getting a bit breathless going upstairs being typical" "It's nothing more than stress and anxiety" "I came in and saw the nurse and she knew more and understood more about my complaint than anyone I'd seen prior ... it gives you confidence ..." "Some kind of fibrosis ... so I just kept going to the clinic and they did lung function ... which ... at the time ... were quite low ... then he decided to refer me to Dr. X's clinic and then we found out that I was too bad for the trial"	"It started about 5 years ago, but I didn't realize that something was terribly wrong. It just came gradually. I was diagnosed with something "fibrotic" and was told that I probably had untreated asthma"	"I went for my usual walk. However, I felt stuffy despite walking slowly and a short way""Whether I ran, stopped, or walked, there was nothing wrong. But, that day I felt stuffy. So I realized that my body is strange""The first change began when my cough started. I went to the hospital several times to cough, but I could not understand the cause""So it may have been wrong but I left it for a while.""Finally, my family doctor referred me to the respiratory hospital. Then, I got a diagnosis and started to treat it, but rather than treatment, it is treatment to suppress progress"
(ii) "Gloom and doom"(suffering as the pathway of illness)	"I was told in the most blunt way, really, 'you've got this illness and there's no cure' and they didn't tell me anything about it""The doctors themselves give the impression that they don't really understand"The pulmonologist told me I wouldn't understand anything if he explained what fibrosis is. I know that I didn't go to university but I believe that if he explained		"They said that I would die from it ... yes, it was on the phone, where (he) called and said that he had bad news and that it would be hard to handle""I was called up by the specialist at the clinic, it was almost like there was already a coffin next to me""We had a disagreement ... our children were home for dinner and I said that this will be the last time I serve them, next time	"I was prepared to know that home oxygen therapy would be necessary either way. I did not anticipate it would be necessary so suddenly"All the family watched TV commercials. 'Is my father's disease the same as in the commercial now?' all the family said (the patient's finger was pointing.) It was a worse illness than on TV""I have been examined for about

Table 2 Continued

Metaphor	Schoenheit, G., Becattelli, I., & Cohen, A. H. (2011)	Duck, A., Spencer, L. G., Bailey, S., Leonard, C., Ormes, J., & Caress, A. (2015)	Overgaard, D., Kaldan, G., Marsaa, K., Nielsen, T. L., Shaker, S. B., & Egerod, I. (2016)	Igai (2016)
	things, I might be able to remember some details. I have the feeling it would help me to know more about the condition" "Nobody actually sat me down at any time and said 'You have pulmonary fibrosis. It is this and this is what's going to happen,' it was just kind of like assumed that I knew. and so me being fairly quiet at the time and naïve, I didn't sit down and ask "Well, what's that then?'" "If I had cancer. people would empathize more"		they have to bring their food. I said that I would need help in the future"	5 years. They found a shadow in the lungs in 5 years. I do not know if it is a cancer shadow, but they found a shadow on the lungs about 2 times" "The sickness is getting worse day by day. After a month, my condition is quite different from what it was six months ago" "I do not know the cause of this illness. Therefore, I received an explanation that there is no treatment method and no medicine"
(iii) "Staggering under the load" (the burden of the symptoms and loss of independence)	"You're not free, cannot laugh, or cry fully because if you do, you won't be able to breathe, even with oxygen – that is terrible and upsetting. Also being tied to oxygen makes you feel like you're stuck inside the cage"	"... you are in this together, its not me ... it's not Christine ... we are in this together ... like going up and down the stairs ... and I say to Christine 'When you come down, will you bring me so and so?'" "When I go upstairs and sometimes I walk up, no trouble ...cough very little ... other times I walk up, start coughing, and then I've really got to go to the toilet and if I don't go to the toilet, well ... sometimes I wet myself" When I shave, I put my shaving cream on, I've	"I get out of breath, I can't do the things I used to. She has taken over mowing the lawn"	"Actually, I can run with portable oxygen, but I cannot run" "Regional activities must be refused. I do not want to refuse, but I cannot avoid doing it"

Table 2 Continued

Metaphor	Schoenheit, G., Becattelli, I., & Cohen, A. H. (2011)	Duck, A., Spencer, L. G., Bailey, S., Leonard, C., Ormes, J., & Caress, A. (2015)	Overgaard, D., Kaldan, G., Marsaa, K., Nielsen, T. L., Shaker, S. B., & Egerod, I. (2016)	Igai (2016)
		got to take the oxygen off, and I know it doesn't take long ... but I can't wait to get the oxygen back on ... (I am) thinking about getting an electric shaver 'cause I can just lie down and use itOver 30 years, we've been playing cards, alternate weeks, playing poker and that's stopped 'cause she can't concentrate when we're playing		
(iv) A doubleedged sword'" (acceptance and living with the restrictions of home oxygen therapy)		"With the oxygen on at least I can get around, not as fast as normally, but I can get around ... and I don't seem to cough as much""I couldn't sit here this long talking to you without oxygen""... sometimes, I think ...Do people think I am lazy ...because they will say, 'You look so well'"... cause I've been so active you see, I used to go out and do 40 miles (on the bike) before I went to work, then I used to go out and do the same at night ...and I've rode across the country in 3 days and 216 miles in 12 h ..."	"I cannot pull myself together, this is what's most exasperating"	"(Oxygen inhalation) in the presence of family and friends, there is no resistance at all""I am concerned about how others see me. I do not mind at the hospital""I do not like going out so much because how I look with the portable oxygen is not attractive""I am very angry. I cannot move freely because I have a cannula. I cannot go anywhere. I think that it is inconvenient. I must move with portable oxygen always""Because I move quickly, during rehabilitation, PT said 'Please walk slowly' "I understand it but I have such a habit of walking fast"

Table 2 Continued

Metaphor	Schoenheit, G., Becattelli, I., & Cohen, A. H. (2011)	Duck, A., Spencer, L. G., Bailey, S., Leonard, C., Ormes, J., & Caress, A. (2015)	Overgaard, D., Kaldan, G., Marsaa, K., Nielsen, T. L., Shaker, S. B., & Egerod, I. (2016)	Igai (2016)
(v) "'All in the same boat" (changes in the family role)		"I've always been active, garden, DIY, you know I'd do anything around the house. I mean, there was a little job there yesterday and I had to get Christine to (do it) .... I sort of direct operations now, but physically do it, NO"	"I said that I would need help in the future. Then, there was silence and our oldest daughter said that she refused – that made me very sad and my other daughter didn't say anything"	"It is most heartbreaking for me to get families to take care and to trouble family members" "I am feeling burden, though my family comes to be caring about my illness" "I am an impossible parent, but my child will do it instead"
(vi) "'Dead-end streets and rays of hope'" (existential suffering)	"Google and up came this site, saying 'life expectancy 2–5 years' and I thought 'Oh my goodness!'"	"I just couldn't come to term(s) with it ... I was getting panic attacks ... two or three times a week ..." "... there were people there that had (had) it 7 years who were on oxygen and looked really poorly ... I started picking up on it ... it came out in conversations and I was twigging away there thinking, 'Gosh, I'm at the beginning' ... and I thought I was getting near the end" "It's his only chance, really, unless there is something else"	"In the beginning, I felt terrible. When will I die and how? It has been awful and I have been sad ... I felt own space and to balance their grief and optimism" "I have it oxygen on all the time, I can't do without it. At first, I was told that I only had to use it 16 h a day, but then it went quickly ... I got used to it ... or I got worse"	"I am spending a fulfilling day" "Because I only have difficulty breathing when I move, I live happily now" "There is no way to return to the original life, so I have to live in this state" "I wonder what I am living for. There is nothing useful for society. Also, it will not help the family"
(vii) "Making the best of it" (challenges to maintainindependent living)	"I had to fight for my pension in court. The federal Pension Plan Agency for Employees said 'You are just too lazy for working. You are 42 and probably not ill at all'"	"So it's getting around I think is the big change ... actually doing jobs ... you've got to think before you do anything, if you want to ... just nip into the shops, you've gotta think 'Have I enough liquid oxygen? Have I filled the bottle? Have I		"I measured the charge in SpO_2 value when I walked at how fast. I measured the SpO_2 value with various actions. I tried it on purpose, how fast, and time you can walk with the change of SpO_2 to the minimum on a slope, and

Table 2 Continued

Metaphor	Schoenheit, G., Becattelli, I., & Cohen, A. H. (2011)	Duck, A., Spencer, L. G., Bailey, S., Leonard, C., Ormes, J., & Caress, A. (2015)	Overgaard, D., Kaldan, G., Marsaa, K., Nielsen, T. L., Shaker, S. B., & Egerod, I. (2016)	Igai (2016)
		done this? Have I done that?'"		whether it is similar for the stairs"
		"Look at yourself in the mirror. I stopped wearing makeup and wore my oldest clothes in order to be taken seriously"		"Walk slowly. I try not to make a very harsh move"

DIY, do-it-yourself; FVC, forced vital capacity; GP, general practitioner; PT, physical therapist; SpO_2, peripheral capillary oxygen saturation.

patients described the loss of smaller and more detailed movements and the impact of that on their living and social activities (Duck *et al.*; Igai; Overgaard *et al.*).

"A double-edged sword" (acceptance and living with the restrictions of home oxygen therapy)

Initially, the patients used home oxygen therapy only at the time of exertion in order to reduce the feeling of dyspnea; for example, at the time of exercise, but then they needed to use it for 24 h per day. Home oxygen therapy allowed the patients to resume an independent life, but it also brought about restraints because of the entanglement of oxygen tubes and limitation of the range of movement. On the one hand, the patients had tolerated home oxygen therapy because it allowed them to live independently, but on the other hand, the patients were suffering because of how they appeared with portable oxygen; others stared at them and they felt stigmatized (Duck *et al.*, 2015; Igai, 2016). A common response was for patients to become angry with themselves. Even after rehabilitation, they were not able to resume their normal level of exertion. They reflected back to the time when they were able to have a normal active life and attempted to establish a sense of equanimity (Igai; Overgaard *et al.*, 2016).

"All in the same boat" (changes in the family role)

The fact that the patients could not move by themselves due to the progression of their disease changed their roles and relationships within their family. Therefore, the family members also were affected by the patient's condition. The patients suffered from the changes, realizing they were imposing a burden on their family, as well as experiencing that some family members might fail to provide the needed support (Duck *et al.*, 2015; Igai, 2016; Overgaard *et al.*, 2016).

"Dead-end streets and rays of hope" (existential suffering)

At the time when the patients were diagnosed with IPF, they were told of the illness conditions: the prognosis of this disease is poor and life expectancy is short; and there is no treatment. The breathlessness becomes a heavy burden with the progression of the disease and, due to an acute exacerbation, the participants were astonished to hear that there was a possibility of death. As they began to realize that there was no way out of the disease, they worked to manage their feelings of fear and despair (Igai, 2016; Schoenheit *et al.*, 2011).

However, it was not easy to manage such strong feelings. Indicators of existential suffering, as identified by Bates (2016), began to emerge, such as a loss of purpose and connectedness to others, wondering about the dying process, struggles about their sense of self, loss of hope, and loss of autonomy.

The patients asked themselves, "What do I have to live for?" They suffered from panic attacks and the awareness of their impending death (Duck *et al*., 2015; Igai, 2016; Overgaard *et al*., 2016). In order to reduce the uncertainty of their declining health, some patients gauged the amount of oxygen use as an indicator of their condition (Igai; Overgaard *et al*.). In such a situation, the patients still hoped for some treatment and at the same time grappled with how to make their lives meaningful, given their deteriorating condition.

"Making the best of it" (challenges to maintain independent living)

The patients gradually became unable to move due to the heavy burden of their symptoms, but in order to continue living independently for a long period of time, one patient devised an action to avoid fluctuations of percutaneous oxygen saturation and to carefully plan when to go out. Getting economic support when they were unable to work was another burden. They made various attempts to find ways to live as independently as possible. They had a great desire to live without disturbing others (*Duck et al*., 2015; Igai, 2016; Schoenheit *et al*., 2011).

DISCUSSION

Seven metaphors that were obtained from four qualitative studies of patients' narrative about their experiences regarding their self-care and coping experiences with IPF were consistently reported in at least two studies. Among the synthesized metaphors, three were found in all four studies: (i) "*Waiting for the other shoe to drop*" (an extended period before obtaining a diagnosis); (iii) "*Staggering under the load*" (the burden of the symptoms and loss of independence); and (vi) "*Dead-end streets and rays of hope*" (existential suffering). These metaphors are thought to be particularly important concepts in the future when developing nursing interventions for patients living with IPF.

Relationships among the synthesized qualitative studies and metaphors as reciprocal translation

Step six of the analytic process, "Synthesize the translations, making a whole that is more than the individual parts imply," requires an explanation of how the seven metaphors from the four integrated studies were mutually related.

(i)"Waiting for the other shoe to drop" (an extended period before obtaining a diagnosis).

In the four qualitative studies, although the patients noticed physical abnormalities, it took a long time to be introduced to a respiratory specialty hospital and to have an accurate diagnosis. Even during the diagnosis, the patients experienced stress and anxiety; then after having a diagnosis, they had various other distressing emotions, such as their anger toward the physicians about the extended time for referral and diagnosis. In the report of Schoenheit *et al*. (2011), 58% of the patients waited for >1 year for a diagnosis and more than three physicians examined them until an accurate diagnosis was provided. Once the patients gained entry into the respiratory specialty hospital, they encountered a whole team of specialty physicians that was dedicated to diagnoses and treatment. Some patients might have found that unsettling, thereby failing to understand the value of it. Comparing the local hospitals and specialized respiratory institutions, the respondents who received treatment at a specialized respiratory facility were satisfied with their care; unfortunately, there are not many specialized respiratory facilities, with a potential disadvantage for patients who then experienced more stress and became angry.

(ii) "Gloom and doom" (suffering as the pathway of illness)

This was reported in three qualitative studies. Being diagnosed with IPF shook the patients to their core. They faced the fact that there was a limited time for them to live. They suffered over the uncertainty of their own life and the future life of their family. Three qualitative studies were published in academic journals after 2011, but the actual survey time of two articles was before 2011. For this reason, researched experiences prior to 2011, before the approval of the therapeutic drugs, pirfenidone or nintedanib, also were included. Even so, it was difficult to ameliorate the symptoms and

improve the prognosis with the current therapeutic agents.

The environment surrounding the patients has not notably improved. Ahmadi *et al.* (2016) reported that the course of interstitial lung disease in patients, including those with IPF requiring home oxygen therapy, led to a survival rate of about 8.5 months after the initiation of home oxygen therapy. These researchers, in comparing lung cancer to IPF, found that with IPF there were more sudden occurrences of exacerbations and death was more unexpected, the outcome prediction was more difficult, and the quality of end-of-life care was lower, compared to those who died of lung cancer as there were fewer end-of-life discussions, more unrelieved breathlessness, pain, and anxiety.

Patients with IPF were considered to suffer more disadvantages in the medical system, compared to patients with lung cancer, and their poor prognosis gave them very little hope. Therefore, research is necessary to determine if their comfort could be improved by providing end-of-life care from the time of diagnosis.

(iii) "Staggering under the load" (the burden of the symptoms and loss of independence)

Thiswas reported in three qualitative studies. The patients noted losses in four main areas: respiratory function, daily activities and freedom, family role, and social role. This disease is difficult to manage and generally the symptoms do not improve.Patients live face-to-face with the deterioration of symptoms, so in addition to the physical burden, the psychological and emotional burdens are also great. De Vries, Kessels, and Drent (2001) found that health-related QOL was inhibited with regard to the level of physical health and independence because the loss of independence of daily behaviors becomes a life that is dependent on others. Health-related QOL is thought to affect both the physical and psychological aspects of patients. In the systematic review of health-related QOL, Swigris, Gould, and Wilson (2005) reported that the deterioration of QOL cannot be explained only by the quality of breathing and lung function. During the course of IPF, the patients were experiencing unrelenting losses, which were thought to lead to a decline in the QOL. Sgalla *et al.* (2015) reported that because IPF symptoms are difficult to manage, effective care for psychological aspects is required.

(iv) "A double-edged sword" (the acceptance and living with restrictions of home oxygen therapy)

Thiswas reported in three qualitative studies. In a report of patients with COPD resulting in chronic respiratory failure, home oxygen therapy was one treatment that brought shame and stigma to the patients (Katsenos & Constantopoulos, 2011). In addition, it was reported that the oxygen tube and portable oxygen tank were clear indications of suffering and identified to others that the patients were sick persons (Earnest, 2002).

Yet, home oxygen therapy for IPF patients decreased hypoxia and allowed the patients to maintain an independent life. Even though home oxygen therapy placed some limits on the lives of patients, they could still maintain more of an independent life. Although the patients with IPF felt the restrictions on their life from home oxygen therapy, they also began to accept it.

(vi) "Dead-end streets and rays of hope" (existential suffering)

This was reported in all four qualitative studies. In this malignant disease, dyspnea was regarded as a factor that hindered patients' will to live, and in addition to palliative care for dyspnea symptoms, the patients were receiving care for existential pain. Boston, Bruce, and Schreiber (2011) conducted a systematic review of existential suffering in palliative care and found 64 papers with 56 different definitions. Both Bates (2016) and Boston *et al.* noted that healthcare workers were still not sure how to define existential suffering. Therefore, for this study, it was assumed that when the participants talked about the meaning of living, it was an indication of some aspect of their *existential suffering*. Murata *et al.* (2006) supported this assumption in their consensus study of psycho-existential suffering. They assumed that psycho-existential suffering was caused by the loss of the essential components that make up the core of a person and what it means to be human: the loss of relationships (with others), loss of autonomy (independence, control over the future, continuity of self), and loss of having a future.

Dyspnea is regarded as the main factor that decreases the QOL in IPF. There is a possibility that the existential suffering of IPF is amplified with dyspnea. Rajala *et al.* (2016) pointed out that patients with IPF have anxiety and depression and that their symptoms are not systematically documented in patient records. The psychosocial problems of patients with IPF will be overlooked unless the healthcare providers intentionally

notice and then empathically explore patient's' thoughts and feelings. Also, the patients understood that there is no cure for IPF; however, they expressed the hope there might be a new treatment. The patients with IPF were focused on striving to maintain a stable disease state and delay disease progression (Duck *et al*., 2015). For the patients with IPF, it seemed that hope for living existed at the core of their thoughts.

Although most patients were considering their prognosis as rather hopeless, they still considered the possibilities of respiratory rehabilitation, lung transplant, and registration for clinical trials, all of which gave them hope for living. However, in Japan, lung transplantation was not yet a common treatment. Patients with IPF were less likely to have hope, although some patients were more hopeful than others. In addition, the patients lived in an environment where it was difficult to find hope for living, so it was important to seek a stable emotional environment. Halpin, Seamark, and Seamark (2009) described the necessity of coping for patients with IPF; therefore, care that supports emotional adaptation is necessary.

(vii) "Making the best of it" (challenges to maintain independent living)

This was synthesized by integrating concepts from three qualitative research studies. The patients were unable to work due to IPF and were searching for social resources to sustain economic independence and to devise lifestyle behaviors to live independently. The patients were able to raise their self-esteem by devising ideas to enhance their lives while coexisting with their illness. In order to acquire ease of breathing while moving about, the patients used respiratory rehabilitation, with exercise therapy as the principal component.

Holland *et al*. (2015) reported that patients with IPF had specific educational needs that were not met by current respiratory rehabilitation. It is important for healthcare providers to assist patients so that patients can think and decide on their own.

Relationship between the qualitative studies to be synthesized and the metaphors as refutational translation

Refutation was used where the similarity of the phenomenon did not emerge. There was one metaphor that was synthesized as a result of integrating three qualitative studies.

(v) "All in the same boat" (changes in the family role)

As IPF is frequently found in the elderly, in addition to disease progression, the overall decline in function of daily life that is related to aging and the ensuing care needs must be acknowledged at some point. In the three studies, the family roles changed as a result of losing independence due to the progress of the disease; thus, roles shifted. However, in addition to the changes in family roles, only in the Japanese study was there a narrative regarding a concern about a decline in self-worth, including withholding feelings and thoughts from families, and is considered to be refuted in the metaphor. This was probably influenced by differences in the ethnic culture and way of thinking; for example, not wanting to be a burden.

Jo, Randhawa, Corte, and Moodley (2016) stated that IPF is a devastating disorder and includes many elderly patients, so it is necessary to pay attention to the complexities of multidrug therapy and end-of-life care. As for patients' management of drugs and management of home oxygen therapy, it is necessary for family members to assist at any point and would include families supporting patients' feelings and providing material and economic aid.

Line-of-argument, rather than a reciprocal or refutational translation, between the qualitative studies to be synthesized and the metaphors

Among the seven metaphors that were synthesized from the narratives and that were reported in all four studies were three that represented a line of argument: (i) "*Waiting for the other shoe to drop*" (an extended period before obtaining a diagnosis); (iii) "*Staggering under the load*" (the burden of the symptoms and loss of independence); and (vi) "*Dead-end streets and rays of hope*" (existential suffering).

These three metaphors indicated that the patients' self-care and coping experiences represented a chronological and thus sequential order. Therefore, unlike the interpretation of reciprocal or refutational relationships, it was thought that they best explained a line of argument. The patients had an emotional reaction, such as anger, when (i) "*Waiting for the other shoe to drop*" and then, following the progress of the disease, patients experienced (iii) "*Staggering under the load*" and distress related to the course of the disease. Then, as the implications of their disease became more pronounced, the patients moved into a state of (vi) "*Dead-end streets and rays of hope*." Hashimoto and Kanda (2011)

described the experiences of patients with advanced lung cancer suffering from dyspnea during the treatment period. Six experiences were identified: "difficulties performing assigned activities," "aspirations for self-stability," "self-isolation," "threat of an uncertain future," "decline in self-concept," and "loss of life support." However, patients with advanced lung cancer did not have acute exacerbations, as did IPF patients, and could receive specialist nursing or palliative care. Moreover, Ahmadi *et al.* (2016) reported that patients with interstitial lung disease received poorer access to specialist end-of-life care services and experienced more breathlessness than patients with cancer. Therefore, this sequence suggests that patients experienced repeated distress from several incidents occurring over the passage of time.

This meta-analysis revealed important patient information for nursing care. First is the multidimensional nature of the patients' illness experience and second, related to that, is the finding that patients go through phases or stages over time. Therefore, it is important not only to assess the phase but also to support patients' physically, psychologically, emotionally, and spiritually as they move through the phases.

As this study clarified patients' obscured experiential trajectory of living with IPF, future studies could expand or deepen the understanding of the trajectory, as well as examine specific nursing care for supporting the end-of-life trajectory and improve the QOL. Given the poor prognosis for this population, palliative care should be introduced as early as possible. Research about the knowledge, attitudes, and practices of introducing palliative care by healthcare providers for patients with IPF could provide valuable information for developing targeted educational programs. Therefore, future research for nurses should aim to develop care that enhances the physical, emotional, psychological, and spiritual status of patients with IPF.

Limitations of the study

This research was a meta-synthesis of qualitative research and it was influenced by the intention and perspective of the researcher. Therefore, the extracted and synthesized results are only one of the possibilities for the interpretation of the phenomenon.

CONCLUSION

This was a meta-synthesis of four qualitative research studies on patient narratives regarding their self-care and coping experiences with IPF. Seven metaphors were synthesized from key concepts by using meta-ethnography.

In addition to responding to the relief of symptoms, particularly breathlessness and cough, and coordinating lifestyle changes, it is important to provide nursing interventions for psychological and emotional support for living with the illness at the beginning at the time of diagnosis and to carefully start the end-of-life discussions with patients and their family sooner rather than later.

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DISCLOSURE

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