



Spousal bereavement after fibrotic interstitial lung disease: A qualitative study

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ABSTRACT

Introduction: Fibrotic interstitial lung disease (f-ILD) comprises a group of diseases with lung scarring and reduced life expectancy. The short time from diagnosis to death affects the patients' bereaved spouses, who risk developing prolonged grief. In Denmark palliative care is most often offered to cancer patients.

Aim: We aimed to investigate the experience of spouses of f-ILD patients during the final stages of illness and up to the first year after the patient's death to investigate if palliative care could ease the transition and prevent PGD.

Methods: Our study had a qualitative design triangulating in-depth interviews, field notes, participant diaries and the prolonged grief questionnaire PG-13. We included 20 spouses and applied thematic analysis. Initial coding was performed deductively according to the chronological stages of before, during and after the death of the patient. We subsequently coded inductively within the stages.

Results: During the final days the spouses experienced emotional ambivalence shifting between hope, acceptance and despair. Factors affecting the spouses during the final hours were the timing, location, and process of death. After the patient's death the spouses experienced feelings of grief and optimism as they moved toward a new life on their own.

Conclusions: Some of the factors affecting the spouses and potentially causing prolonged grief might be alleviated by offering palliative/supportive care and advance care planning to f-ILD patients and their family.

1. Introduction

Fibrotic Interstitial Lung Disease (f-ILD) is a heterogeneous group of lung diseases characterized by lung scarring either subsequent to inflammation or by aberrant wound healing responses [1]. The clinical course is variable, but often accompanied by progressive exertional dyspnoea leading to loss of physical function with high morbidity and mortality. Idiopathic pulmonary fibrosis (IPF) is the most common f-ILD with the lowest survival rate. The median survival is 3–5 years and there is no available cure. IPF is an inexorably progressive disease with rapid decline in lung function. The incidence of ILD and IPF is 4.1 and 1.3 respectively per 100,000 inhabitants per year in Denmark [2].

Palliative care is recommended in patients with advanced non-

malignant lung disease, albeit this group is often neglected [3]. Palliative care is an intervention for patients with life threatening disease and their families focusing on improving quality of life [4]. The need for palliative care is increasing due to the world's ageing population, cancer and other non-communicable diseases [4]. In Denmark palliative care is predominantly offered to cancer patients [5], although patients with non-malignant lung disease and a similar symptom burden are equally in need of care [6,7]. In this study we wished to investigate the need for early palliative care for the partner to ease the transition to life alone after the death of the patient. The consequence of not receiving palliative care is yet unknown.

Fibrotic interstitial lung disease puts a burden on the family. As the disease progresses, spouses experience a gradual role shift toward

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family caregiver and start to prepare themselves for a life of loneliness [8,9]. Spousal grief might start months before the loss and continue for years [10]. Grief is the normal response to the loss of a close relative, but a small group of bereaved spouses develop a more complicated reaction to loss described as Prolonged Grief Disorder, PGD [11]. PGD is a condition of intense and persistent grief lasting more than six months after the loss potentially causing impairments in psychological, social and daily functioning [11,12]. Given the poor prognosis of f-ILD and the risk of developing PGD, we aimed to describe the experience of f-ILD patients' spouses during the final stages of illness and up to the first year after the patient's death to investigate if palliative care could ease the transition and prevent PGD.

2. Material and methods

The study had an overall qualitative, explorative, descriptive design triangulating data from interviews, field notes, and participant diaries, supplemented with grief assessment.

2.1. Participants

The participants in our study were spouses or partners of patients that died of f-ILD in 2016–2017. For ease of the narrative we refer to the participants as spouses. The participants were recruited at two specialized pulmonary clinics in 2017 at two university hospitals in the Capital Region of Denmark. One of the clinics was a specialized ILD-centre. Eighteen of our participants were recruited from this centre where patients and family had close contact with specialist ILD physicians and nurses throughout their disease trajectory but received no additional support. Spouses were eligible if the patient had been diagnosed with ICD-10-CM codes: J81-J89 and J678-J679, and they had cohabited the last two years of the patient's life. Pulmonologists identified patients by chart review and potential participants were contacted by the investigators by phone and later in writing. The same member of the research team, a research nurse, contacted each spouse and asked how they were doing and whether they wished to participate in an investigation of their experiences to improve the care for future patients and their family. After verbal consent to participate, a date for the interview was set. We used a convenience sample, as there was a limited number of patients that had died within the timeframe of our study. We included 20 spouses, 19 females and one male. Three invited male spouses declined. We did not pursue their reasons for declining, but one male spouse was upset by our invitation and stated that he found research a waste of time.

2.2. Data collection

Using a Data Collection Package (Informed consent sheet, Participant information, Participant demography, Participant diary, PG-13, and Interview guide) we generated four datasets: Transcribed interviews, field notes, participant diaries and responses to the Prolonged Grief Disorder Questionnaire PG-13 [13]. Interviews constituted the main dataset, Table 1.

2.2.1. Interviews

Individual semi-structured in-depth interviews were conducted by one or two investigators (IE, GK, or DO) at 6–12 months after the patient's death. The interview guide is shown in Appendix 1. The location was as preferred by the participants at home ($n = 17$), in hospital ($n = 2$), or by phone ($n = 1$). We entered the field by recapping the focus of the interview and the ethical principles for participation. Written consent was obtained and permission to record the interview. The first part of the interview packet provided socio-demographic data and the PG-13 questionnaire served as an introduction to the interview. The interview guide consisted of chronological themes informed by the literature [3,9], and our previous study exploring life with IPF [8]. The interview followed the trajectory from two weeks before the patient's death (pre-loss data) and up to a year after (post-loss data). Questions included broad themes about the final days and hours with the patient, professional and family support, experience of grief, and constructing a new life. We included a question of self-reported health: "How do you regard your health on a scale from 1 to 5, where 1 is excellent and 5 is poor?" The interviews were digitally recorded and professionally transcribed verbatim, mean duration was 58 min (range 38–81).

2.2.2. Field notes

After each interview, each interviewer took field notes. Field notes serve several purposes in qualitative research, e.g. to prompt observation, supplement dialogue, document sensory impressions, encourage reflection, and facilitate initial coding [14]. Field notes were used to support the narrative during analysis and were also analysed separately to provide additional information.

2.2.3. Diaries

We asked each participant to compose a short diary, or chronological narrative, describing the two weeks before the patient's death, the experience of the final hours, and the time following, Appendix 2. A short instruction was provided. Diaries have been widely used to help patients and family understand the trajectory after critical illness [15,16] or as an investigative tool providing the family perspective during acute illness [17]. We received two hand-written diaries and nine computerized narratives. Nine participants declined writing a diary.

2.2.4. Grief questionnaire PG-13

During each interview, we surveyed the participants using the Danish version of the PG-13 questionnaire to determine if they suffered prolonged grief. The questionnaire is a 13-item scale assessing grief symptoms according to the criteria for prolonged grief set up by the author of the scale [11]. The PG-13 has been translated into Danish and has previously shown good psychometric properties [18]. We used the questionnaires as a case-by-case assessment of grief to support our data. The PG-13 required the interviews to be conducted at least six months after the patient's death.

Table 1

Matrix of datasets, perspectives and content.

Dataset	Interview Primary dataset	Field notes Supporting dataset	Diaries Supporting dataset	PG-13 Supporting dataset
Perspective	Joint perspective (co-constructed narrative)	Investigator perspective	Participant perspective	Theoretical perspective
Content	Before, during and after patient death: <ul style="list-style-type: none"> • Final days • Final hours • Bereavement • New life 	Immediate impressions and reflections on the: <ul style="list-style-type: none"> • Interview situation • Interview content • Summary 	First person narrative and chronological reflections on the: <ul style="list-style-type: none"> • Illness trajectory • Bereavement experience 	Grief assessment: <ul style="list-style-type: none"> • Normal grief • Risk of prolonged grief • Prolonged grief

Table 2
Spouse demographics.

Spouse ID	Spouse Age*	Spouse gender	Years married	Diary written	Timing of death as expected	Location of death as preferred	Process of death as planned	Self-rated health	PG-score
SP-01	74	F	50	Yes	No	No	No	3	NG
SP-02	47	F	**	Yes	No	Yes	No	1	NG
SP-03	69	F	46	Yes	No	No	No	1	Risk
SP-04	73	F	54	No	No	No	No	1	NG
SP-05	66	F	20	No	No	No	No	2	NG
SP-06	80	F	56	No	Yes	Yes	Yes	3	Risk
SP-07	69	F	40	No	Yes	Yes	Yes	2	NG
SP-08	70	F	**	No	Yes	No	No	2	NG
SP-09	69	M	43	No	Yes	Yes	Yes	1	NG
SP-10	79	F	2***	No	No	Yes	No	2	NG
SP-11	66	F	42	Yes	No	Yes	No	2	Risk
SP-12	51	F	26	Yes	No	No	No	3	NG
SP-13	77	F	54	Yes	Yes	Yes	Yes	4	Risk
SP-14	65	F	28	Yes	Yes	Yes	Yes	2	NG
SP-15	52	F	27	No	No	No	No	3	NG
SP-16	57	F	27	No	Yes	No	Yes	1	NG
SP-17	69	F	45	Yes	Yes	Yes	Yes	1	NG
SP-18	60	F	**	Yes	Yes	Yes	Yes	4	Risk
SP-19	64	F	40	Yes	Yes	Yes	Yes	3	PG
SP-20	71	F	55	Yes	Yes	No	Yes	2	Risk

Spouse age* = at interview. Spouse gender: M = male, F = female.

Years married: calculated from 16 couples, **missing, ***outlier.

PG-score: NG = normal grief, PG = prolonged grief, Risk = PG-score > 25.

2.3. Strategy of analysis

2.3.1. Quantitative data

Demographic data and PG-13 scores were entered into a spreadsheet and analysed using descriptive statistics, [Tables 2 and 3](#).

2.3.2. Qualitative data

Thematic analysis was used to explore the interviews, field notes and participant diaries [19]. The steps of analysis were: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report. From the onset, we generated a deductive coding scheme of chronological stages

of before, during and after the death of the patient. We coded our data inductively within each stage and the research team jointly discussed and decided on the final themes. The research team consisted of three nurses experienced in qualitative research, three pulmonologists with experience of f-ILD, and a psychologist experienced in grief assessment. All members of the research team were highly experienced in their fields. The COREQ guideline (Consolidated criteria for reporting qualitative research) was used to ensure trustworthiness of our study [20]. The qualitative software system NVivo version 11 (QSR International) was used to organize our data and support the process of analysis.

2.4. Ethical considerations

The study was approved by the National Committee on Health Research Ethics (No. 16024776), the Danish Patient Safety Authority (No. 3-3013-1680/1) and the Danish Data Protection Agency. Permission was obtained to use the Danish version of PG-13 from the authors and translators. Participants were encouraged to invite a close family member to the interview for support and were offered a consultation at the pulmonary clinic or with the hospital chaplain after the interview. We informed the participants that data were handled confidentially, were presented anonymously, and that participation was voluntary.

3. Results

3.1. Quantitative data

We included 20 spouses of 20 decedents, [Tables 2 and 3](#). Mean age of spouses (at time of interview): 66 years (range 47–80), mean age of patients (at time of death): 70 (range 54–82), mean time from patient death to interview (not shown in table): 8 months (range 6–10), and mean years of marriage: 41 (range 20–55). Self-reported health of spouses was ‘very good’ with a median of 2 on a Likert scale of 1–5 (1 = excellent; 5 = poor). Two patients died at home, 13 in hospital, three in hospice and two at other location. According to the author’s guidelines of the PG-13 scale, assessment yielded one spouse with prolonged grief and 19 with normal grief, of which six were at risk with a PG-sum score above 25 [13].

Table 3
Patient demographics.

Patient ID	Patient Age*	Patient gender	Location of death	Patient Diagnosis
01	72	M	Hospital	IPF
02	56	M	Hospital	IPF
03	70	M	Other care	Scleroderma related fibrosis
04	79	M	Other care	IPF
05	73	M	Hospice	IPF
06	80	M	Hospital	IPF
07	71	M	Hospital	Unclassifiable lung fibrosis & disseminated cancer
08	75	M	Hospital	Fibrotic cryptogenic organising pneumonia
09	70	F	Home	IPF
10	76	M	Hospital	IPF
11	65	M	Hospice	Scleroderma related fibrosis
12	56	M	Hospital	IPF
13	82	M	Hospital	IPF
14	77	M	Hospice	IPF
15	54	M	Hospital	IPF
16	58	M	Hospital	IPF
17	68	M	Hospital	IPF
18	72	M	Home	Unclassifiable lung fibrosis
19	64	M	Hospital	IPF & lung cancer
20	71	M	Hospital	IPF

Patient age* = at the time of death. Patient gender: M = male, F = female.

Patient diagnosis: IPF = idiopathic pulmonary fibrosis.

Table 4
Chronological stages and themes.

Stage I Before death: the final days	Stage II Dying: the final hours	Stage III After death: bereavement
Emotional ambivalence <ul style="list-style-type: none"> ● State of hope ● State of acceptance ● State of despair Physical surroundings <ul style="list-style-type: none"> ● Home ● Hospital ● Hospice ● Other location 	Timing of death <ul style="list-style-type: none"> ● As expected ● Not as expected Location of death <ul style="list-style-type: none"> ● As preferred ● Not as preferred Process of death <ul style="list-style-type: none"> ● As planned ● Not as planned 	Elements of grief <ul style="list-style-type: none"> ● Boundaries of grief ● Experience of loss ● Experience of guilt ● Experience of regret A new life <ul style="list-style-type: none"> ● Experienced health ● Continuity ● Disruption

3.2. Qualitative data

The qualitative findings are presented according to the chronological stages of the trajectory, Table 4. The main themes and sub-themes are presented in the following text, and direct quotes are presented for illustration and documentation in Tables 5–7. Please note that we do not seek to generalize from our data. We use more general terms to increase the readability of the prose, but only refer to the 20 participants in this study.

3.3. Stage I: before death – the final days

3.3.1. Emotional ambivalence

The spouses experienced emotional ambivalence during the final days. The emotional state of hope was characterized by maintaining optimism and keeping death at bay. This was, perhaps, also a state of denial, where grief was put on hold. The spouse was unprepared if death occurred at this time. The state of acceptance was characterized by facing reality, letting go, and welcoming death. Finally, some spouses faced despair, when the weight of reality fell on them. In some cases the couple acknowledged the situation, and talked about fear of dying, fear of suffocation, and relief when it was finally over. In other cases the spouses were left alone with their uncertainties.

3.3.2. Physical surroundings

The location of the patient during the final days affected the spouse. In some cases, the patient or spouse had expressed a preference for the location of death, e.g. home, hospital, hospice or other. Dying at home had the advantage of extending normal life as long as possible, but many spouses were overwhelmed by the burden. A homecare nurse

could alleviate the burden if the patient preferred to die at home. Most patients died at hospital, where they were brought in with pulmonary exacerbations or other complaints. The patient and family were upset if the patient was taken to an unfamiliar hospital during the final days. In some cases, the patient got a single room to accommodate the family, but not always. Three patients died in ICU and never woke up after intubation. Three patients died at hospice. Two experienced hospices as a pleasant place with competent and friendly staff and time for laughs. One patient was delayed and died shortly after arrival. Several spouses were discouraged that hospice was unable to accommodate the necessary level of oxygen for the patient. Two patients inadvertently died in respite care that was intended as a temporary measure to relieve the spouse, Table 5.

3.4. Stage II: dying – the final hours

3.4.1. Timing of death

The timing of death affected the spouse. If death was expected, the spouse and family had time to prepare and the patient had a chance to say goodbye. If death was unexpected, the spouse was unprepared and death could be chaotic. Sudden death could leave the spouse with unresolved questions, such as: could more have been done to prevent or postpone death? Should I have done more? Many spouses needed to talk to the pulmonologist to ask questions and obtain closure. The spouses wished that someone had told them when death was approaching, so they could have planned better and stayed at the hospital and called the family. Some patients suffered a cardiac arrest followed by unsuccessful cardiopulmonary resuscitation leaving the final parting in chaos.

3.4.2. Location of death

The location of death affected the spouse. The location could be as preferred or not as preferred by the patient. Not all patients had preferences, but it was important that the patient died at the location of choice or at a familiar location. Spouses were distressed if the patient was taken to an unfamiliar or unplanned location to die.

3.4.3. Process of death

The process of death affected the spouse. The final hours could be as planned or not as planned. The ideal process of dying was a comfortable patient with the family present. All patients feared suffocation, which could be alleviated or prevented by medications and comfort measures. If the patient died at home, the spouse could be comforted by a familiar nurse who could take charge, enabling the spouse let go of

Table 5
Stage I Before death: quotes, sub-themes and themes.

Quotes – the final days	Themes
<p>“I don't think I realized how sick my husband was toward the end, and I remained optimistic although we could see that it was unlikely he would be able to get up again.” (Diary SP-01)</p> <p>“It became more and more difficult to maintain faith in his survival ... but the hope kept him alive ... or else he kept his despair from me.” (Interview SP-18)</p> <p>“The doctor went through our options, including a lung transplant. For a second we hoped that there was a way we hadn't thought of, but then the doctor said that this had never really been an option.” (Diary SP-20)</p> <p>“Pulmonary fibrosis, you know, is a sad and severe illness. It's a person that can't breathe, it's terrible to watch.” (Interview SP-18)</p>	Emotional ambivalence <ul style="list-style-type: none"> ● Emotional state of hope ● Emotional state of acceptance ● Emotional state of despair
<p>“I found [dying at home] difficult, because he was very ill and it required a lot of work. I didn't always have the stamina or knowledge of how to manage, so sometimes we barked at each other. When I look back, I should have had help ... so we could have enjoyed each other”. (Diary SP-12)</p> <p>“Then I asked where they would take him, and they said to [an unfamiliar hospital]. No, I said; take him to the hospital where he usually goes.” (Interview SP-20)</p> <p>“Yes, he never woke up ... I was called up and told that he would be on a ventilator ... It was what he wanted. I don't know if he expected to wake up again.” (Interview SP-10)</p> <p>“At a certain point [the patient] said: ‘if the end is just half as good as this, everything is fine’.” (Diary SP-14)</p> <p>“They [hospice] were not honest when they said they had oxygen. We were surprised that we had to bring our own equipment.” (Interview SP-05)</p> <p>“We waited a week for respite care. During this period he hadn't walked, so the leg muscles were non-existent. When he finally got there, he needed help to go to the toilet, but it was too much. When we got him back to bed his heart stopped.” (Diary SP-03)</p>	Physical surroundings <ul style="list-style-type: none"> ● Home ● Hospital ● Hospice ● Other

Table 6
Stage II Dying: quotes, sub-themes and themes.

Quotes – the final hours	Themes
<p>“We were at the right location with our two children and he asked us all to hold hands. He held a speech for us and asked the children take care of me, and he thanked us for our life together. His greatest worry was how I would continue. He told me this several times; we were married for 56 years. It was just so beautiful and grand, I will always remember it.” (Interview SP-06)</p> <p>“But I would have liked to know how bad it was. My daughter and I left at six and were called up very late. It was a shock.” (Diary SP-01)</p> <p>“Afterwards I was surprised and sorry he died so fast. If I had known I wouldn't have gone home to sleep. If they had known at the hospital, I would have liked to know.” (Diary SP-11)</p> <p>“He sat in a chair and was gone ... he was dead. I thought that since he didn't have a pulse, he must have had a cardiac arrest. Then I thought I should hurry and get someone that can do CPR, because we had accepted resuscitation” (Interview SP-02)</p>	<p>Timing of death</p> <ul style="list-style-type: none"> ● As expected ● Not as expected
<p>“And that was the last thing I could give him, it was to let him stay at home. It was his biggest wish and he was grateful that I would help.” (Interview SP-18)</p> <p>“And then they promised that he would go to the usual hospital, but suddenly one morning the nurses said that he wouldn't go there. I actually think he got angry and then he couldn't breathe.” (Interview SP-15)</p>	<p>Location of death</p> <ul style="list-style-type: none"> ● As preferred ● Not as preferred
<p>“The nurse came to our home several times during the day and I slowly understood that this was it ... I called the closest family and we stayed with him all day, supported by the nurse ... He never woke up. We held his hand, talked to him, told him we loved him and that now he could say goodbye. We all felt that he had suffered enough and that he needed peace. My greatest worry was that I couldn't keep my promise to him that he wouldn't suffocate ... he took his last breath at three in the morning, death came peacefully and it comforted us ... I turned off the oxygen, his lifeline, and feared he would gasp for breath and panic. His usual nurse helped us the next day ... It was a good ending.” (Diary SP-18)</p> <p>“I knew he wasn't afraid of dying. He said so, but he was afraid of the process, and worried that he would suffocate.” (Interview SP-12)</p>	<p>Process of death</p> <ul style="list-style-type: none"> ● As planned ● Not as planned

Table 7
Stage III After death: quotes, sub-themes and themes.

Quotes – bereavement	Themes
<p>“The process of grief already started when he got the fatal diagnosis.” (Interview SP-14)</p> <p>“Mentally I prepared for the day when I had to say goodbye. That's what you do, even if you don't want to.” (Interview SP-12)</p> <p>“People ask if I'm over it, but it won't ever be over.” (Interview SP-07)</p> <p>“It's difficult to get over it, but I'm not ... if I should describe it as a sailing voyage, I haven't reached the harbour yet.” (Interview SP-14)</p> <p>“On the dark days I got up, but never got dressed.” (Interview SP-16)</p> <p>“Of course it still comes in waves, and it may come suddenly, after a longer period, and then suddenly uncontrolled weeping, while driving home, and then it's over. But the periods are farther apart.” (Interview SP-12)</p> <p>“Loneliness came in waves, it is difficult to say if I feel sadness or grief” (Interview SP-14)</p> <p>“A part of me is gone. It's true, it's like I lost my right arm.” (Interview SP-12)</p> <p>“I feel the same way, sometimes it is worse ... like being cut in half.” (Interview SP-20)</p> <p>“He should have had a comfortable passing ... what was most important for him was to avoid panic ... but that was just what happened ... I haven't have trouble accepting that he's gone, but I just can't accept the way he died ... why didn't I go and get the nurses? It was my biggest mistake.” (Interview SP-05)</p> <p>“The hardest part has been that I wanted more time with him toward the end. It has bothered me, why wasn't I there as much as I really wanted?” (Interview SP-12)</p>	<p>Elements of grief</p> <ul style="list-style-type: none"> ● Boundaries of grief ● Experience of loss ● Experience of guilt ● Experience of regret
<p>“I'm just hanging in there, I don't have the energy I used to have, not like before he died.” (Interview SP-18) “Physically I felt that I wasn't as strong as before.” (Interview SP-12)</p> <p>“I got a sore throat, an ear infection and pneumonia. I also had a toe infection, it's just crazy.” (Interview SP-08)</p> <p>“I'm more vulnerable, I feel it in many ways ... my memory is worse because of the stress.” (Interview SP-12)</p> <p>“Everything takes time; it's a long and difficult process. I sold our house and moved to a smaller place and try to get my life together again. At least get a life, even if it's a sad one. I'm still supported by our friends and family, but it's the loss that's hard to fill.” (Diary SP-18)</p> <p>“How I feel now? It's okay, I'm finding myself and how things should be.” (Interview SP-08)</p> <p>“Things like adding water to the furnace, typical male things, changing tires on the car and so on. The past few years I have participated in these things because I knew that at some point I would have to do it alone.” (Interview SP-03)</p> <p>“What I missed was some financial counselling. Someone who could give recommendations without interfering with my economy.” (Interview SP-05)</p> <p>“[The spouses] have to learn how to be alone, I think because after having known each other for so many years, like my mom and dad, they have to learn to be alone, and it's a process to learn to fill the time instead of staring into space.” (Interview daughter-19)</p>	<p>A new life</p> <ul style="list-style-type: none"> ● Experienced health ● Continuity ● Disruption

responsibilities, Table 6.

3.5. Stage III: after death – bereavement

3.5.1. Elements of grief

Grief was experienced differently by the spouses and was affected by factors during the illness trajectory. The elements of grief that emerged in our study were the boundaries of grief and the experience of loss, guilt and regret. The process of grief started at the time of diagnosis, when the spouses began to prepare for their pending loss and continued beyond our study. At the time of the interview none of the spouses had ‘gotten over’ their grief, which was described as a void, peaking at the time of death and returning in waves of uncontrollable mood swings and weeping. Several spouses experienced an extreme

sense of loss described as a feeling of their body being severed by grief; they no longer felt whole after many years of marriage. One of the painful elements of grief was the experience of unresolved guilt. One wife continuously reproached herself for her actions around the time of death. Another element of grief was regret, when the spouses felt they should have done things differently. Many spouses were left with unanswered questions and needed more knowledge to obtain closure.

3.5.2. A new life

The spouses suffered in various ways before and after the patient's death. Some experienced more infections and others became more anxious and jumpy the first few months. Many suffered persistent insomnia and other health issues. Even spouses that recovered well stated that their strength had not become the same as before. The spouses

were all in the process of establishing a new life alone, without their partner. Moving on was a process of continuity and disruption. Continuity was the gradual process of taking over household chores and social activities and maintaining daily life. Disruption consisted of finding a new path without the partner. Some spouses had been independently active for years and continued their activities, while others had to find new interests and make some effort to continue on their own. Spouses needed practical help, such as a social worker for financial counselling. Some wanted to meet other people in the same situation for mutual support. Most spouses adapted well as they were supported by their children and grandchildren, friends, family, neighbours, the Elder society, and Red Cross, etc. and got involved in charity work, clubs and sports. Physical activity was popular, such as hiking, swimming, and badminton, but also art shows and travel, [Table 7](#).

4. Discussion

We aimed to investigate the experience of spouses of f-ILD patients during the final stages of illness and up to the first year after the patient's death to investigate if palliative care could ease the transition and prevent PGD. Using interviews, field notes and participant diaries we uncovered factors affecting the spouse during the trajectory. To gauge the spouses' long-term responses, we used the PG-13. The final days were characterized by mood swings and reactions to the physical surroundings, and the final hours were affected by how the patient died. The spouses experienced different elements of grief as they embarked on a new life on their own.

Our main findings were related to the circumstances at the time of death involving timing, location and process. These three potentially modifiable factors were pivotal for the spouses' experience. In our study, the final days and hours appeared to affect the process of grief, taking into consideration the long-lasting marriages behind the couples. A similar study of people with non-malignant respiratory disease found that lack of preparedness for death was one of the main issues for the family carers [3]. Emotional ambivalence affected the needs of the spouses in our study. When they were optimistic they suspended their need for closure and preferred the ambiguity of not knowing when the patient would die. During the emotional state of acceptance, the spouses sought closure by way of unambiguous information from the staff. This is consistent with the definition of closure as a desire for definite knowledge on some issue [21].

The spouses in our study were disappointed if they were not informed by the staff when the patient was terminal. Their demands left a conundrum of what the healthcare professionals should tell the family. Several issues had an impact on the spouses' experiences. The first is related to the uncertain trajectory of end-stage lung fibrosis that makes it difficult to predict exactly when death is imminent [3]. The second is related to the timing of information, where acting prematurely might be construed as brutal, and acting with delay might be perceived as negligent [22]. And finally, the provision of incorrect information might be regarded as unprofessional. Resultantly, the healthcare providers might be hesitant toward anticipating exactly when the family should be present. The issue of pinpointing the time of death is, perhaps, less important if the patient is in the "right location". If the patient is receiving palliative care, some of the responsibility is off the back of the spouse and chances are better for the provision of patient comfort and family presence [4].

It has been shown that early palliative/supportive care (PSC) and advance care planning (ACP) improve outcomes for patients with incurable cancer [22]. Similarly we assume that ACP would support the couples during end-stage lung disease. PSC focuses on improving quality of life for patients with incurable illness and limited life expectancy [23]. Spouses should be included in PSC focusing their emotional needs and ACP to ensure that when the health status of the patient changes the care corresponds to goals and needs of patient and spouse. We have previously identified emotional dyssynchrony during

the earlier stages of the IPF trajectory demonstrating different informational needs in patient and spouse [8]. Reactional dyssynchrony and emotional ambivalence are key concepts when planning the structure of the palliative effort.

Grief started at the time of diagnosis and extended beyond the limits of our study. It was experienced as loss, guilt or regret, partially affected by the circumstances precipitating the patient's death. Grief came in waves that subsided and became less frequent as time passed. At the same time the spouses were trying to move on with continuity and disruption related to their earlier life. The simultaneous loss oriented and restoration-oriented behaviour has been described in the Duel Process Model of Coping with Bereavement [24]. This model predicts good and poor adaptation to stressful life events to better understand how people individually come to terms with bereavement. It is a model of coping with loss, as opposed to the consequences of bereavement. This model provides understanding of adaptive and non-adaptive outcomes and differs from earlier models of sequential phases [24]. We found one out of 20 spouses experienced prolonged grief, which corresponds to other studies [18]. It is also common that grief continues while building a new life.

The elements of grief that emerged in our study included questions of whether spouses should have done more or acted differently toward the end. They expressed that they needed a chance to talk to the physician that usually treated the patient to get answers to some of their questions. They needed closure to resolve some of their grief. They wish to know that the patient did not suffer towards the end or that everything was done. A general concern of the patients was the ever-present fear of suffocation. Suffocation might not be a modifiable factor in itself, but steps should be taken to predict and prevent it. Problems with the provision of palliative care have been described as lack of preparedness for death, lack of consistency in palliative care delivery, and role ambiguity related to the caregiving role [3]. These factors are similar to the uncertainties found in our study.

4.1. Limitations of the study

Qualitative interviews are inherently limited by recall bias, but we attempted to increase the trustworthiness by triangulating our data. The current study was limited by an unbalanced sample including only one male spouse. This gender imbalance can to some extent be explained by the uneven distribution of illness. Also, the female spouses might be more willing to participate in an interview study; only male spouses declined participation. Studies have shown that non-participation is more common in men than women (Markanday et al., 2013). Suggested reasons are time constraints or inability to understand the study. We did not apply gender-specific recruitment strategies, but this could perhaps have strengthened our design. The credibility (internal validity) of our findings was increased by using established methods of research and by triangulating sources, methods and investigators [25]. Transferability (external validity) was increased by the multi-centre design, and dependability (reliability) was increased by redundancy across and within our datasets. Finally, the trustworthiness was increased by the experienced interdisciplinary research team.

5. Conclusions

In conclusion, we recommend palliative/supportive care during the final stages of f-ILD, and IPF in particular. As it is seen in cancer care, advance care planning is important to ensure that the final parting is as peaceful as possible. The location of death should as far as possible be as preferred and permit family presence. Patient and family need to know when the condition is terminal, and measures must be taken to avoid suffocation and alleviate discomfort. Grief support for the family should start early in the trajectory, and after the death the spouse should have access to a final consultation with the treating doctor and nurses to get answers to questions that might have arisen in the final

stage.

Author contributions

Conception and design: IE, GK, SBS, KM, DO. Data acquisition: IE, GK, DO. Data analysis and interpretation: IE, GK, SBS, MBG, KM, DO. Manuscript drafting and revision of critically important intellectual content and final approval of the version to be submitted: IE, GK, SBS, MBG, AB, KM, DO.

Declaration of interest

The authors have no declarations of interest.

Appendix 1. The interview guide

Interview guide

Questions/items related to the time before the patient's death

1. Please tell us how you experienced the last one or two weeks before your husband/wife died.
2. Please describe your responsibilities close the death of your husband/wife and how you coped. Did someone help you?
3. Did you and your family say goodbye the way you had wanted, or did you want things differently?
4. How did you and your family prepare for the loss? (emotionally, pragmatically, financially, housing, car, etc.)

Questions/items related to the time after the patient's death

5. What was most difficult for you after your husband/wife died?
6. How did you feel the first months after your husband/wife died?
7. How have you handled your grief?
8. Has your general health been affected? (physically or psychologically)
9. How would you describe your reaction or symptoms at the time of your husband's/wife's death?
10. Did it help you to stay close to your husband/wife?
11. How would you describe your grief now?
12. How do you experience daily life, evenings, social events or anniversaries?
13. Have you had contact with the healthcare system? Have you needed or received support?
14. Do you have questions, comments or advice for the future?

Appendix 2. The instructions for writing a diary

Instructions for writing a diary

Dear husband or wife after the loss of your spouse to fibrotic lung disease. We invite you to write a short diary of your experiences. You may write about 1–4 pages describing your experience from about a week before the death of your spouse to about two weeks after.

How did you feel?

Did you get the support you needed?

Did you need more help?

From whom?

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