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Eating and drinking experience in patients with idiopathic pulmonary fibrosis: a qualitative study

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ABSTRACT

Objective To explore eating and drinking experiences of patients with idiopathic pulmonary fibrosis (IPF), the impact of any changes associated with their diagnosis and any coping mechanisms developed by patients.

Setting Pulmonary fibrosis support groups around the UK and the regional Interstitial Lung Diseases Clinic, Newcastle upon Tyne.

Participants 15 patients with IPF (9 men, 6 women), median age 71 years, range (54–92) years, were interviewed. Inclusion criteria included competent adults (over the age of 18 years) with a secure diagnosis of IPF as defined by international consensus guidelines. Patients were required to have sufficient English language competence to consent and participate in an interview. Exclusion criteria were a history of other lung diseases, a history of pre-existing swallowing problem of other causes that may be associated with dysphagia and individuals with significant communication or other memory difficulties that render them unable to participate in an interview.

Design A qualitative study based on semistructured interviews used purpose sampling conducted between February 2021 and November 2021. Interviews were conducted via video videoconferencing call platform or telephone call, transcribed and data coded and analysed using a reflexive thematic analysis.

Results Three main themes were identified, along with several subthemes, which were: (1) Eating, as such, is no longer a pleasure. This theme mainly focused on the physical and sensory changes associated with eating and drinking and their effects and the subsequent emotional and social impact of these changes; (2) It is something that happens naturally and just try and get on with it. This theme centred on the self-determined strategies employed to manage changes to eating and drinking; and (3) What is normal. This theme focused on patients seeking information to better understand the changes in their eating and drinking and the patients' beliefs about what has changed their eating and drinking.

Conclusions To our knowledge, this is the first study to report on IPF patients' lived experience of eating and drinking changes associated with their diagnosis. Findings demonstrate that some patients have substantial struggles and challenges with eating and drinking, affecting them physically, emotionally and socially. There is a need to provide better patient information for this area and further study.

STRENGTH AND LIMITATIONS OF THIS STUDY

⇒ The sample was diverse regarding age, gender and living status. The patients involved were from various locations in the UK.
⇒ The severity of idiopathic pulmonary fibrosis could not be formally recorded due to the recruitment method via pulmonary support groups, however the researcher was able to gain an understanding of the disease's severity through patients' perceived symptoms.
⇒ Due to the pandemic, the interviews were conducted remotely, potentially excluding individuals without the required equipment or skills.

INTRODUCTION

Idiopathic pulmonary fibrosis (IPF) is a chronic and progressive interstitial lung disease characterised by unknown causes. It is primarily defined by the progressive scarring and fibrosis of lung tissue, leading to irreversible loss of pulmonary function.[1] Typical symptoms of IPF include chronic exertional dyspnoea and a persistent dry cough.[2] Risk factors for IPF include older age, male sex, genetic susceptibility, lung microbiome dysregulation and a history of cigarette smoking.[3]

IPF is the most common type of fibrotic interstitial lung disease. In the UK, its estimated incidence is between 5.3 and 7.3 cases per 100 000 individuals per year, while in the USA, rates range from 31.1 to 93.7 cases per 100 000.[4] The mortality rates associated with IPF have been increasing over time. In the UK, the rates rose from 4.6 cases per 100 000 individuals per year in 2001 to 9.4 cases per 100 000 individuals per year in 2011, while in the USA, a similar increasing trend was observed between 2000 and 2010, with rates escalating from 4.4 to 5.3 cases per 100 000 individuals per year.[5] IPF is more frequently diagnosed in the sixth or seventh decade of life.[6] The median survival for patients with IPF is approximately 3–5 years if left untreated.[7]

Several qualitative research studies have been published on patients' experiences with IPF.[8–12] These studies have identified issues with patients obtaining a correct and timely diagnosis; accessing suitable information about their condition; and substantial physical and psychosocial impacts on themselves and carers, affecting their overall Ouality of Life (QOL).[10 13] We have also published preliminary work which noted that around a third of patients with IPF reported difficulties with eating and drinking using a patient-reported measure.[14] Further qualitative work is warranted to understand this problem in more depth.

Qualitative studies on eating and drinking issues have rarely been published in patients with chronic respiratory disease, with limited work in Chronic Obstructive Pulmonary Disease (COPD).[15 16] Coughing and shortness of breath were the most common symptoms experienced by patients with COPD during eating and drinking resulting in anxiety, fear and embarrassment.[16] As a result, they developed coping strategies including modifying the way they ate, for example, eating soft food, chewing well and taking small, regulated sips.[16] These findings supported survey findings (n=133) which identified 75% of patients had breathing discomfort when eating or drinking and similar strategies were employed.[17]

Furthermore, there has been limited research on nutritional issues of patients with IPF. Known problems include sustained weight and muscle loss, loss of appetite and vitamin D deficiency, negatively affecting IPF prognosis.[18] A December 2023 action on pulmonary fibrosis report commissioned to form the fundamentals of a new national integrated care pathway identified the need for research and 'support with diet'. The extent of the unmet need identified by the pulmonary fibrosis community was reflected in the title of the report 'I wish it was cancer: Experience of Pulmonary Fibrosis in the UK'.[19]

This study aims to explore eating and drinking experiences of patients with IPF, the impact of any changes associated with their diagnosis and any coping mechanisms they deploy. Eating and drinking is multidimensional, including physical, emotional and social aspects. In light of this complexity, a qualitative approach was chosen to facilitate a deep and diverse understanding of their lived experiences.

METHODS

Interviews were recorded using a password-encrypted audio recording device (Sony ICD-TX650, slim digital PCM/MP3 stereo voice recorder) or videoconferencing call platform (Zoom).

The interview transcripts were coded for confidentiality and anonymity before analysis and kept in secure, locked storage which was only accessible to the research team. In the transcripts, any details specific to the patients' demographics were removed, for example, country of origin, name of the doctor treating them and other names mentioned during the conversation. Pseudonyms were used instead of the real names of the patients for the purpose of presenting these quotations. In accordance with the guidelines of the National Institute for Health and Care Research, participants were compensated for their time with vouchers, delivered either via e-gift cards or mailed gift cards.

Research design

This is a descriptive qualitative study to gain a deeper understanding of IPF eating and drinking experiences from the patients' perspective, using semistructured interviews. The research objectives were to (1) understand the perceived eating and drinking changes experienced by patients with IPF, (2) understand the impact of eating and drinking changes on patients with IPF and (3) explore any coping strategies for and adjustments for these changes.

Patient and public involvement

This qualitative study focused on the opinions of patients and their families. There was no direct involvement of patients in the design of the study.

Participants and recruitments

Patients were recruited from six pulmonary fibrosis support groups around the UK and the regional Interstitial Lung Diseases (ILD) Clinic, Royal Victoria Infirmary hospital, Newcastle upon Tyne, from February 2021 to November 2021.

Inclusion criteria included competent adults (over the age of 18 years) with a secure diagnosis of IPF as defined by international consensus guidelines.[20] Patients were required to have sufficient English language competence to consent and participate in an interview. Exclusion criteria included a history of other lung diseases; a history of pre-existing swallowing problem of other causes such as head and neck pathology excepting tonsillectomy/adenoidectomy, previous thoracic surgery, stroke and neurological diagnosis that may be associated with dysphagia; and individuals with significant communication difficulties, cognitive impairment or memory difficulties that render them unable to participate in an interview.

The recruitment process was designed to encompass all eligible patients from both clinic and support groups. Specifically, during clinic recruitment, the researcher approached all eligible patients for study participation. For support group recruitment, leaders within the support groups facilitated the distribution of study details and encouraged patients to directly reach out to the researcher. Subsequently, all individuals meeting the eligibility criteria were approached.

Patients were recruited based on purposive sampling method using maximum variation sampling approach, to ensure heterogeneity in the sample as well as to elicit diverse views and experiences. In the first few interviews, the sample was based on age (≤65 years vs >65 years) and gender (male or female), because eating and drinking

can vary by age and gender. After a few interviews, the selection criteria were discussed by the research team. Living status (alone or with someone) appeared to have an influence on eating and drinking experiences; therefore, it was included as a selection criterion for maximum variation.

The number of conducted was informed interviews by the concept of 'information power'. Information power is an alternative approach to 'data saturation', which indicates that the more information the sample holds, relevant for the actual study, the lower number of participants is needed.[21–24] Indeed, researchers have shown that indices of saturation in qualitative interview-based studies are often inadequately described, and authors focus on the number of participants in order to convince readers (or themselves) that a sufficiently large sample was recruited to achieve their study aim. Instead, many qualitative researchers have shifted to describing quality findings as sufficient, which covers both analytical sufficiency and data sufficiency.[21 25] Given the limitations of the data saturation concept, information power is considered a more appropriate measure of evaluation sufficiency.[25] The use of information power to determine whether qualitative findings are sufficient involves assessing five items: (1) their study aim, (2) sample specificity, (3) use of established theory, (4) quality of dialogue and (5) analysis strategy, together with an iterative analysis of the results and discussion with research team, which were sufficient to inform the decision on information power and when to stop recruitment.[21 23]

Data collection

The semistructured interviews were conducted by a PhD respiratory researcher (AAA), who had no role in the patients' care. The interviews took place either via telephone or virtually through video conferencing call platforms (Zoom or FaceTime), depending on the participants' preference due to COVID-19 restrictive measures. The mean duration of the interviews was 40 min.

An interview topic guide (online supplemental material) was devised and piloted in two online interviews to elicit detailed responses from each patient. The interview topic guide followed existing guidelines for the design of qualitative interviews.[26 27] It was developed following a comprehensive review of relevant medical literature.[10 12 28 29] Input from healthcare practitioners with expertise in IPF and discussion with the research team were also included. The interviewer asked open-ended questions about each area of interest in the guide, and in addition, a range of sub-questions and prompts were developed to explore the issues in more depth. When necessary, questions were rephrased to aid a participant's understanding. Interviewing is an iterative process in nature; data collection and analysis are conducted simultaneously, as in all qualitative research. An ongoing and iterative analysis of the transcripts was conducted. After each interview, the research team reviewed the recording and reflected on the interviewer's responses and the patient's responses. This was done to inform the direction of the next interviews to ensure sufficient depth is reached.

Analysis

The data analysis was conducted using inductive thematic analysis 'analyst-driven' approach described by Clarke and Braun,[30 31] who suggested the six phases analysis methods which were followed in this study.[30 31] Briefly, these included initial reading and familiarisation of the transcripts, coding and identification of candidate themes, followed by checking that themes reflected the entire dataset. Finally, themes were named and the story behind them was considered before writing up the analysis. Using thematic analysis, the researchers were able to draw themes across the interview transcripts for patients with IPF, on a semantic and explicit level. The six phases process of analysis of the transcripts was iterative and reflective with a substantial overlap between the six phases with an attitude of inquiry and interpretation. Common codes and themes were discussed and approved by the research team to ensure an accurate reflection of the data and to help guide the process and validity of the analysis. The analysis was performed using the qualitative data analysis software package NVivo V.R1.6 (QSR International). The 15-point checklist criteria for good thematic analysis was followed to ensure the quality of the thematic analysis.[31]

RESULTS

42 patients were invited to participate. 22 patients did not respond to the invitation, and 15 patients with IPF (9 men and 6 women) were interviewed. Of those who consented to be interviewed, 10 were recruited from the IPF support groups and 5 from the ILD Clinic. Patients were interviewed via telephone calls (n: 5), Zoom video calls (n: 7) and FaceTime video calls (n: 3). One interview transcript was excluded from the analysis as during the interview, the patient reported a history of tongue cancer, making him ineligible for the study (figure 1).

Demographics and clinical characteristics

The patients' demographics and clinical characteristics are presented in table 1. In total, 14 interview transcripts were analysed. The median age of patients was 71.0 years (range 54–92 years). Eight (57%) patients were men. Most patients were non-smokers (10/14, 71%). Eight patients were using antifibrotic medications (8/14, 57%), and six (42.8%) patients were using long-term oxygen therapy. Most patients lived with partners (n: 10), and 4 patients lived alone.

Themes

Three main themes were developed from the data: (1) Eating, as such, is no longer a pleasure; (2) It is something that happens naturally and just try and get on with it; and (3) What is normal? (table 2).

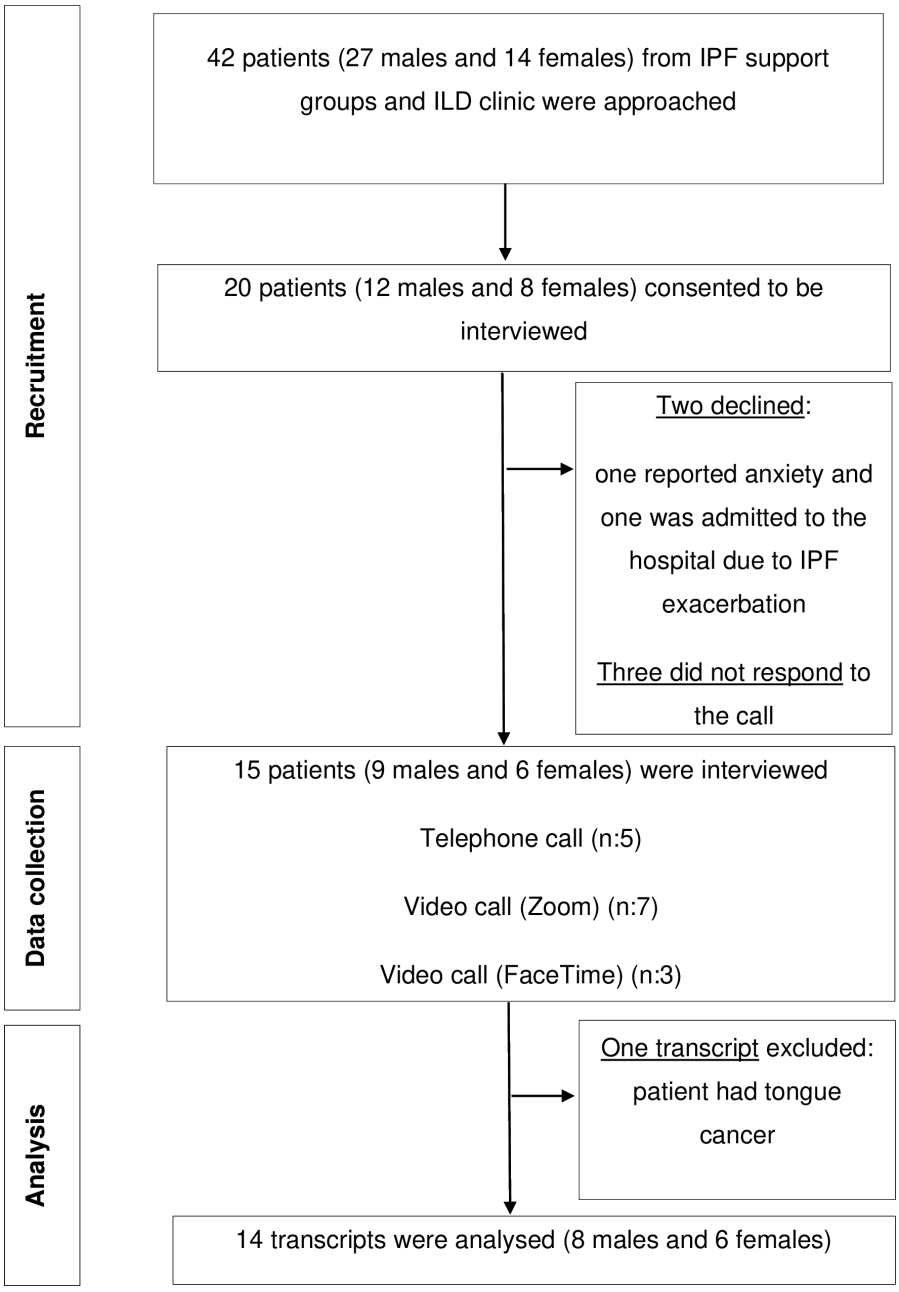

Figure 1 Consolidated Standards of Reporting Trials flow diagram for the patient recruitment for the study. ILD, Interstitial Lung Diseases; IPF, idiopathic pulmonary fibrosis.

Theme 1: Eating, as such, is no longer a pleasure

This theme reports the experiences of patients with IPF who relate directly to the changes in their eating and drinking. The changes that were reported encompassed both physical and sensory aspects of the eating and drinking process and their effects and the patients' emotional and social reactions to these changes.

Subtheme 1: physical and sensory eating and drinking changes and their effects

Patients experienced a range of problems related to their eating and drinking lived experience. Breathlessness when eating and drinking was frequently reported by the patients, forcing adjustments in the pace and frequency of swallowing. One IPF patient said she cannot drink a cup of water, without having to stop many times to catch her breath and continue drinking again, whereas before the IPF that was never an issue:

> Before, I could have drunk, like, a bottle of water, taken quite a lot of it without having to stop. Now, it would be smaller mouthfuls that I would have to stop too. I couldn't, basically: half a bottle or 500ml of water before I continued drinking. Now, I would have just maybe a few mouthfuls and then you have to stop to get a breath and then continue drinking.

Table 1 The patients' demographics and clinical characteristics

Factor	Level	Value
N		14
Age in years, median (minimum–maximum)		71 (52–92)
Gender	Female	6 (42.8%)
	Male	8 (57.2%)
Recruitment method	IPF support group	10 (71.4%)
	ILD Clinic	4 (28.6%)
Interview method	Video call (Zoom)	7 (50%)
	Video call (FaceTime)	3 (21.4%)
	Phone call	4 (28.6%)
Smoking	Non-smoker	10 (71.4%)
	Ex-smoker	4 (28.6%)
Using oxygen	Yes	6 (42.8%)
	No	8 (57.2%)
Using antifibrotic medication	Yes	8 (57.2%),
	No	6 (42.8%)
Living status	With someone	10 (71.4%)
	Alone	4 (28.6%)

ILD, Interstitial Lung Diseases; IPF, idiopathic pulmonary fibrosis.

Another IPF patient attributed this to physiological changes, linking stomach expansion to restricted diaphragmatic movement, impeding oxygen intake during meals:

> I do have shortness of breath when I eat. If I feel like that, I put my oxygen on because I view eating in the same manner as exercising: my body needs the extra oxygen. If I eat too much, then the problem I face is that the diaphragm can't. As the stomach expands, the diaphragm cannot expand in the normal manner so therefore it cannot get enough oxygen into my body. It makes it really difficult.

The prolonged duration of meals due to shortness of breath became a common experience, impacting daily routines:

> It takes me longer to eat a meal because you always have to get a breath between every mouthful. Well, taking longer, like, you have all your plans worked out in your head, what you are doing next or whatever .

Patients conveyed challenges with food inhalation, especially with dry items like toast, leading to coughing and discomfort:

> The other thing is when eating, the biggest thing is if I eat toast. Say I bite into some toast and the dry part of the toast is sort of inhaled into a certain part of your throat. God, I end up coughing really badly .
>
> There has been a sticky texture of food, and that might be, I don't know, a minute amount, and it seems as if it's lodged in my throat.
>
> Sometimes, something will, as we call, go down the wrong tube, like a crumb or something and then it starts coughing, cough, cough, cough, although the biscuits we have, we like to nibble and break up and crunch, and a bit sometimes can whizz into the wrong tube.

This has also happened with saliva, particularly when lying in bed:

Table 2 Themes, subthemes and codes

Eating, as such, is no longer a pleasure		It is something that happens naturally and just try and get on with it		What is normal?	
Physical and sensory eating and drinking changes and their effects	Emotional and social impact of eating and drinking changes.	Direct strategies	Indirect strategies	Information needs	Patients' beliefs
Breathlessness	Fear	Portion size	Oxygen	Desire to learn	Being old
Fatigue	worry	Regulated sips	Rest	Comparing experience with other patients with IPF	Other underlying health issues
Taking longer to eat and drink	Frustration	Being slower	Medications	Swallowing services	
Weight loss	Embarrassment	Chew more	Sleep		
Poor appetite	Loss of enjoyment	Softer food	Clam		
Mouth dryness	Social life	Avoid some foods	Distraction		
Food or drink goes to the wrong pipe			Fear reduction		
Nauseous					
Smaller portion size					
Changes in taste and smell					

> Drinking, I can drink and then maybe a little drop will go down the wrong way. But it does that even with saliva, quite honestly, especially when I'm in bed. And that can start me coughing. There are times when I'm eating when the food actually gets stuck, and I can't.

Fatigue was reported by all patients, living alone, even missed meals due to exhaustion: "I cannot cook so much, because standing can be quite exhausting, just standing. Some days I go without a meal because I'm so tired, I just stay in bed". Similarly,another patient, who lives alone, added that she lived on pre-prepared meals, 'the frozen foods', because she felt tired all day.

Further, patients reported they felt tired and exhausted during and after eating, especially after their evening meal. After the evening meal, one patient said that she always felt tired and wanted to sit on the sofa to rest. Another patient also reported feeling very tired after the evening meal and normally went to bed. For another patient, eating often left him exhausted, and he saw it as similar to exercise.

Patients noted persistent mouth dryness, night-time thirst and changes in taste and smell.

> I would say I drink a bit more. I drink water, perhaps once or twice in the evening, because my throat gets fairly dry, at nighttime, when I'm asleep. I always carry water with me when I am going to bed.

The metallic taste reported by patients seemingly linked to antifibrotic medication use, with associated altered food experiences:

> Well, I couldn't taste my food properly because it has this irony taste in my mouth, and I couldn't taste my food. And before the fibrotic medication, I didn't have this horrible taste in my mouth .

The patients conveyed a profound shift in their relationship with food, marked by a significant loss of appetite and diminished interest in eating. One patient questioned the purpose of consuming food when both hunger and the ability to taste were compromised. Others echoed this sentiment, expressing a general lack of appetite: "With the IPF I didn't want to eat. I don't know. I just didn't have really an appetite at all" and "I've got a very poor appetite". Another patient mentioned that both the sight of a plate full of food piled up and the smell of cooking food affected him. It also made him want to be sick and vomit. Another attributed this change to antifibrotic medication side effects: "I suddenly become very nauseous and want to go to the toilet and whatever. I'd just come off nintedanib for one day, just one day. Once I've come off for one day and then it's okay, I come back to normal". In reflecting on the broader experience of IPF, one patient expressed a diminished desire to eat: "Well, with the IPF I didn't want to eat. I don't know".

This change in appetite and taste preferences manifested in altered eating behaviours, with patients describing evening meals reduced to what one patient termed a 'snack' rather than a full dinner, reflected in significantly smaller portion sizes.

> The evening meal, it's more of what a normal person would call a snack rather than a proper meal. Right, the portion of the food, that's gone down dramatically – probably down to a tea-plate size rather than, what I call, a dinner-plate size.

Weight loss was a common concern for most of the patients: "I've probably lost more muscle than fat, especially on my legs. I used to have quite broad thighs through my running: now they're like chicken's legs, according to my wife. That's where the majority of my muscle has gone" . Patients attributed weight loss to poor appetite and infrequent feelings of hunger. One patient linked his weight loss to antifibrotic medication, as indicated by a 6 lb reduction since starting the treatment. Another patient compared her weight before IPF and now. She said in her prime she had nine stones, which later decreased to eight stones and now she had only seven stones.

Subtheme 2: the emotional and social impact of eating and drinking changes

In this subtheme, wide ranges of negative emotions linked to eating and drinking were described by many patients. Fear of choking was the most common emotion expressed: "Whenever this happens, you panic because you think you're going to choke. So, my reaction to that, my family laugh at me, when I get that the food seems to be stuck and I get the urges of, 'I'm going to choke', I jump to my feet".

Additionally, patients reported feeling worried about how their choking events might affect others:

> I'm quite selective with food as well. I eat things that I know are not a major problem. Actually, I probably shouldn't have done, but my granddaughter comes after school, because we live next to her school, and I had had a little bit of not breathing very well when I was eating. So, I just said to her, 'If grandma is waving her hands, go and get her a drink'. And if I collapse, call 999. She's only 10, but I thought… I've worried her but I said, 'It's probably not going to happen, I just wanted you to know'.

Frustration, embarrassment and a sense of diminished enjoyment turned meals into challenging experiences. The following quotes show how patients felt about the increase in eating time. One patient felt frustrated about the time it took her to eat a meal: "Whereas, before, I would have just maybe grabbed something and ran, you can't do that now because it takes you ages to eat". Furthermore, another patient said that sometimes taking longer to eat left him not able to finish his meals: "I don't have the time to finish them, because it takes ages and ages". Additionally, some patients articulated feelings of embarrassment and shame as they took longer to eat compared to those around them. One patient acknowledged, "I

am definitely slower, though, because when I'm with my family, I'm always the last one, recently, to finish".

The loss of pleasure in eating, expressed by several patients, mirrored the emotional toll: "It used to be. When I was fit and well, I really used to enjoy my food. Now it's something I do".

Eating was simply seen as a task that had to be done as a means of nourishment. Another patient expressed "I don't think I enjoy my food as much as I used to, because of the coughing, choking, that's not easy. I don't enjoy my food. I have to eat to live" .

A few patients outlined a general loss of interest in eating outside home, eating out, "I would get a bit nervous about what happens if this happens when I'm out, having a meal outside, in a restaurant or something. Because you feel like all eyes would be on you. So, yes, I suppose, because we haven't been out for a long time, I'd forgotten about that. Yes, it is a worry" .

Theme 2: It is something that happens naturally and just try and get on with it

This theme covers strategies that patients developed in response to and to help cope with the changes in their eating and drinking. Adaptation strategies were divided into two categories, direct and indirect. The direct strategies were the methods of managing changes in eating and drinking that directly related to diet and eating and drinking habits. Indirect strategies involved the alternative supportive methods used by patients that were not directly related to food and drink, such as using oxygen, medication and going to sleep.

Subtheme 1: the direct strategies

Patients described strategies used to manage the changes in their eating and drinking. Most reported being mindful about taking small, well-chewed bites, pacing rate of eating and having regulated sips during the eating or drinking process. One patient mentioned that she chewed food much longer so as not to choke on it and took frequent sips of a drink.

Co-ordinating breathing and swallowingbecame a conscious effort for some patients:

> I've got to concentrate on my eating, to make sure that, again, I don't breathe in, for it to go– It's as if it's gone to my lung and not– It seems as if I'm coughing for a little particle to get out of my throat. It's really bad.

A majority of patients had adapted their food preparation, for example, having softer food (steamed or mashed) and with additional sauces to reduce the likelihood of choking events and/or to reduce the effort of eating.

Patients reported that they frequently chose soft food: "They are all mushed up", and knew what food they should avoid to protect their airways: "much softer and moist food, because I know I'm not going to choke on it, really" . One patient explained: "If I do eat meat it has to be very lean and very thin" and Steve joked that there would be "no fish and chips" (with laughter) as he did not like hard food which was difficult to consume. Another patient shared: "I have started steaming quite a lot of my food now. As I say, that helps the food stay moist, so it's easier to swallow that way".

Some patients reported being careful about their food choices. Fibre-rich and spicy foods were often avoided. This was due to the diarrhoea which many experienced as a side effect of the antifibrotic medication. For example, "I restrict my intake of fibre. If I eat too much, if I have too much fibre, which is what it is, then I can spend days on the toilet" ; "No vegetables as such, I just can't tolerate them any more, Amal"; and "At one time I'd be quite happy with spicy food, now I have very bland food. I no longer enjoy spicy food".

Besides the effects of spicy food on bowel function, one patient stated that she avoided spicy food because it caused coughing or choking.

In addition, several patients indicated that they avoided steak, because "If I eat steak, it always seems to – even small pieces – it seems to stick in the back of my throat" ; "Steak. any meat that's hard to chew or to do anything. any meat that is a big lump, you know what I mean?"; and "It's more difficulty in swallowing".

Subtheme 2: the indirect strategies

Patients devised strategies not directly related to their diet and eating and drinking habits, to cope with their eating and drinking changes. This was a smaller subtheme.

A few patients reported that they needed to use oxygen to combat post-meal fatigue and the need for rest or sleep after eating:

> I do have shortness of breath when I eat. If I feel like that, I put my oxygen on because I view eating in the same manner as exercising, my body needs the extra oxygen. If I eat too much, then the problem I face is that the diaphragm can't. As the stomach expands, the diaphragm cannot expand in the normal manner so therefore it cannot get enough oxygen into my body. It makes it really difficult .
>
> After my dinner I sit down on the sofa and just recover. But I usually go to bed quite soon, I don't stay up late.
>
> After the evening meal I normally go, I'm very tired and I normally go to bed.

Patients developed self-soothing techniques like calming, reassurance and distraction to manage anxiety during meals: "I'm trying not to draw my attention to it, because I think the more I realise it's happening, the more I'll think about it and make it happen" . In another approach, a patient mentioned using anxiety medication before meals to reduce fear and induce calmness.

Theme 3: what is normal?

The final theme focused on patients' beliefs and information needs regarding changes in eating and drinking.

Subtheme 1: information needs

Patients expressed a desire for information to understand and contextualise their experiences. One patient statement, "It wasn't the money side of it, so much, I wanted to learn more from you than probably you learnt from me", illustrates a deeper desire for knowledge beyond tangible considerations.

Seeking insights from others with IPF, served as a way to gauge the normalcy of their challenges. Reflection on group sessions, one patient said "We used to go to a group, and there were people there who had IPF, and it affected their appetite quite badly". Another patient emphasised this by stating, "I know from other people with the disease that they go through exactly the same thing. I'm not an exception to the rule".

Additionally one patient added, "I'm not alone in feeling like that. I know, from my friends who have this disease, they're in exactly the same position". Apart from the practical side of things, one patient expressed how comforting it is to know that others are going through similar challenges: "It was comforting to know that my struggles were shared by a community going through the same journey".

One patient noted that their interview made him consider swallowing services: "After meeting you I have been thinking about swallowing service[s]. I didn't know about swallowing service[s] and nobody suggested that".

Subtheme 2: patients' beliefs

Beliefs about the ageing process as a contributor to eating changes were expressed by some patients, deflecting attribution solely to IPF. One patient acknowledged the multifaceted nature of ageing, stating, "When you reach my age, you've got lots of other problems as well". Her perspective suggests a recognition that various aspects of health can influence eating habits. Similarly, another patient cautiously considered the role of age in his changes, noting, "That could be an age thing, but it's never, ever really thinking because it's because of IPF".

Another patient shared a reflective insight into her experience, highlighting the complex balance between adapting her eating habits and the natural ageing process: "Age brings its own set of challenges. I find myself adjusting my eating habits, not just because of IPF but also as part of the natural ageing process. It's a delicate balance between the two".

One patient's decision to avoid spicy foods was explained through the lens of ageing, offering a unique angle to dietary modifications. Another patient contributed to this narrative by suggesting that as individuals get older, they may find they need less food, influencing their overall eating patterns.

Furthermore, some patients revealed that considerations about changes in eating and drinking were not at the forefront of their minds before the interview. One patient noted, "Certainly, the eating and drinking and swallowing side probably is slightly worse than what it was, but I tend, maybe, not to notice that because of these other symptoms". This observation suggests that it is hard for patients to decide which health issues are most important, and it is challenging for them to notice changes in their eating habits because they have many health concerns.

Another patient expanded on this idea, expressing, "Because of the other parts of the condition, like the cough and the chest discomfort, I don't tend to think much about the swallowing side of it to be honest". Another patient further emphasised the intricate nature of symptoms, describing swallowing as "a smaller piece of a much larger puzzle". This metaphor highlights the challenge patients' face in isolating and understanding the impact of specific symptoms within the broader context of their health.

In summary, the themes are interconnected in a way that reflects the progression from the raw experiences of patients (theme 1) to their coping mechanisms (theme 2) and the context and beliefs that influence these experiences (theme 3). For example, the physical challenges outlined in theme 1, such as breathlessness and fatigue, prompt patients to develop coping mechanisms like pacing their eating or using oxygen, which are discussed in theme 2. Fears of choking, frustration, embarrassment and loss of pleasure in eating discussed in theme 1 contributes to the development of both direct and indirect coping strategies. Examples include, patients may choose softer foods, co-ordinating breathing when swallowing or seeking calmness during meals. Patients' beliefs, as discussed in theme 3, serve as a context for their experiences. Beliefs about the ageing process or the multifaceted nature of health challenges shape how patients perceive and interpret their eating and drinking changes, as highlighted in theme 1.

DISCUSSION

To our knowledge, there is no published research exploring the eating and drinking experiences of patients with IPF using qualitative research methods. The aim of this study was to explore the eating and drinking lived experience for patients with IPF. This provides rare data that directly addresses an unmet need for research and 'support with diet' identified by the UK-based charity Action for Pulmonary Fibrosis in a December 2023 report 'I wish it was cancer: Experience of Pulmonary Fibrosis in the UK'.[19] Our novel findings indicate that some patients have substantial struggles and challenges with eating and drinking, affecting them physically, emotionally and socially. Our findings can be summarised under three inter-related themes: (1) Eating, as such, is no longer a pleasure; (2) It is something that happens naturally and just try and get on with it; and (3) What is normal?

Patients reported breathlessness during meals. This is perhaps not surprising as dyspnoea is a commonly reported symptom of IPF across many activities of daily life.[32] Elsewhere, qualitative work has also identified breathlessness as affecting daily life activities of people

with IPF, such as carrying shopping, bending at the waist and taking a shower.[13 33] This is the first study where patients have reported this symptom also affecting their eating and drinking.

This study focused on the patients' experience of eating and drinking, which revealed that patients frequently had to pause to catch their breath while drinking. They have also described the effects of breathlessness as not being able to get enough air in to their lungs while eating, which resulted in them taking more time to finish their meals. This could be attributed to the expansion of the stomach during digestion, which can push against the diaphragm and lungs, making it harder to breathe.[34] Additionally, eating can also increase the demand for oxygen in the body, further exacerbating breathlessness in those patients with already compromised lung function.[35] The patients shared some techniques they applied in order to alleviate breathing discomfort, including being slower, eating smaller meals and eating more frequent meals throughout the day rather than large, heavy meals. These findings are in line with previous qualitative literature in patients with COPD.[16] On the other hand, taking longer to eat can result in various consequences, including food going cold, challenges in maintaining nutritional intake and an increased risk of overeating due to extended exposure to food. Further, these consequences can affect not only the physical health but also social lives, as the pacing of eating is difficult, this may affect the ability to maintain conversation over mealtimes. Feelings of being ashamed and frustrated when taking longer and not managing to finish meal on time when being with other people were also reported by the patients.

The interviews also shed light on other issues that contribute to the challenge the IPF patients' experience with eating and drinking. Fatigue, a state of tiredness, was reported to have an impact on activities of daily living by the patients. This is consistent with the findings of the European IPF registry (eurIPFreg, 2018), which reported that dyspnoea, fatigue and loss of appetite were the most common clinical symptoms experienced by patients with IPF with a percentage of 90%, 69% and 67%, respectively.[32] In this study, the patients reported experiencing fatigue and the need to rest after eating. The extra effort required for eating and drinking was likely to curtail mealtimes, which could potentially affect nutritional intake. The relationship between fatigue and the difficulty of swallowing has also been reported in other groups of individuals with swallowing disorders.[36]

Prior studies have examined the eating situations of patients with COPD, and the results indicate that patients often experience a decrease in oxygen saturation levels while eating or shortly afterward, leading to the need for supplemental oxygen.[34 37–40] Similar findings were reported by patients with IPF in this study, with patients describing feeling fatigued after meals and requiring the use of oxygen and rest. In addition, patients with IPF who live alone mentioned experiencing fatigue while cooking and preparing meals, resulting in their reliance on premade meals. The previous study on patients with COPD reported that 23% of the patients experienced fatigue while preparing meals.[15]

Fear of choking was the most common emotion expressed. Patients used words such as 'panic' and 'scary' when describing their experience of choking. This fear was typically associated with worries about being able to breathe. Chocking-related fear was associated with avoidance of eating, adopted by the patients as a safety behaviour.[41]

Avoidance behaviour refers to any action or behaviour taken by an individual to avoid a particular situation, task or stimulus that causes discomfort, anxiety or fear.[42] Avoidance behaviour can not only be a natural response to perceived threats or stressors but it can also become a maladaptive coping mechanism that interferes with daily functioning and overall well-being.[42] Avoidance behaviour in eating and drinking can manifest in various ways, including restricting food intake, avoiding certain types of food or food groups and avoiding situations that involve eating or drinking in public or with others.[43]

In addition to the fear, patients in this study reported a range of emotional responses related to their experiences with eating and drinking, including embarrassment, anxiety, panic, anger, sadness and frustration. This is consistent with broader previous research on dysphagia.[44 45] Studies on anxiety in patients with IPF have shown a high prevalence of anxiety (31%) and its association with reduced quality of life.[46] While this study did not examine emotional responses related to other daily activities, it is likely that the emotional distress reported by the patients with IPF in this study contributes to the broader emotional distress observed in previous literature.[47]

In this study, a few patients experienced a general loss of interest in eating outside their home. However, they did not feel socially isolated due to their eating and drinking issues, which was different from other studies conducted with different populations.[36 48 49] It is worth noting that the study was conducted during the COVID-19 lockdown, which meant that people were limited to socialising at home. Consequently, the study may not have fully captured the effects of eating and drinking problems on the social lives of patients with IPF since social life was restricted during the pandemic.

Patients discussed various methods that they had tested by trial and error, to enhance their overall eating and drinking experiences. Thorne *et al* refer to this process as the 'evolution of expertise,' which occurs as individuals with chronic illnesses learn to manage their symptoms over time.[50] These methods comprised adjusting the texture and size of their food, eating at a slower pace, chewing their food thoroughly, taking small sips of water, practising mindfulness while eating, using supplemental oxygen after the meal, resting and going to sleep afterwards.

Previous studies in patients with COPD have reported similar results which suggest that individuals with COPD modify their eating habits to ease breathing difficulties.[16 17]

Similar approaches were employed by patients with head and neck cancer, which involved consuming smaller meal portions, reducing overall food consumption and opting for softer foods.[36] It was clear that the level of eating ability varied from day to day depending on the severity of IPF symptoms, making it challenging for the patients with IPF to plan meals or social activities beforehand.

The patients often did not attribute their eating and drinking status to IPF. In their view, the eating and drinking changes observed were influenced by other underlying medical conditions such as dental issues, diabetes and the chronic nature of the IPF disease itself. In their view, the eating and drinking changes observed were influenced by other underlying medical conditions such as dental issues, diabetes and the chronic nature of the IPF disease itself. Furthermore, several patients linked their changes in eating and drinking to old age. IPF is considered an age-related disease, as highlighted by the BTS national registry, where the average age of presentation was reported as 74 years.[51] This age range aligns with the median age of 71 years observed in this study. In regard to swallowing performance, previous researches have shown age-related changes in various aspects, such as the time it takes for a swallow response, prolonged transition time between the oral and pharyngeal stages of swallowing, extended hyolaryngeal excursion, reduced pharyngeal pressure generation and loss of muscle mass, which affect swallowing.[52–57] Previous studies in different populations have shown that individuals with swallowing difficulties tend to not seek treatment due to the perception that such problems are a natural aspect of getting older. For example, in a study conducted by Turley and Cohen, only 23% of elderly individuals with swallowing problems sought medical help. They also showed that the most common reasons for not seeking treatment were a lack of knowledge about the treatment options available and a belief that the symptoms experienced were a natural part of the ageing process.[58]

Future directions and conclusion

We have previously provided quantitative data showing that dysregulated swallowing physiology can occur in patients with IPF, which included fluoroscopic evidence of aspiration.[14] Non-sterile aspiration represents a candidate source of complex lung injury and microbiome dysregulation and the present study provides novel complimentary information that provides qualitative data regarding eating and drinking in patients with IPF.

The study indicates that patients with IPF face physical, social and emotional consequences due to the changes in their eating and drinking abilities, which can significantly impact their overall quality of life. The findings in this study emphasise the importance of educating both patients and healthcare providers about the eating and drinking changes that may occur in IPF disease. Such education could increase awareness of potential challenges in eating and drinking and might ultimately help to reduce the risk of additional health problems resulting from exacerbation of the disease. It is noteworthy that patients have been innovative in finding their own solutions to cope. This presents an opportunity to develop resources and materials based on their experiences. By capitalising on this patient-driven approach, valuable resources can be created to support individuals living with IPF and their specific needs related to eating and drinking and further research is required.

Contributors AAA: protocol development; designed and recruited for the study; analysed the study; and wrote all drafts of the manuscript. CW and MD: designed, analysed and cowrote the study. IF: provided clinical interpretation and input into integrated studies of dysphagia in IPF. JP: study design; protocol development; and analysed and cowrote the study. AAA and CW acted as the guarantor for the overall content, accepting full responsibility for the work and decision to publish.

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