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Exploration of the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis: a scoping review protocol

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ABSTRACT

Introduction Interstitial lung diseases consist of a range of lung disorders, the most prevalent being idiopathic pulmonary fibrosis (IPF). IPF is a chronic, progressive disease, resulting in loss of lung function and potentially significant impacts on quality of life. There is an increasing need to address unmet needs in this population as there is evidence that unmet needs may impact quality of life and health outcomes. The key objective of this scoping review is to define the unmet needs of patients living with a diagnosis of IPF and to identify gaps in the literature relating to unmet needs. Findings will inform the development of services and the introduction of patient-centred clinical care guidelines for IPF.

Methods and analysis This scoping review is guided by the methodological framework for conducting scoping reviews developed by the Joanna Briggs Institute. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist is used for guidance. The following databases will be searched: CINAHL, MEDLINE, PsycINFO, Web of Science, Embase and ASSIA and include a comprehensive grey literature search. The review will report on adult patients >18 with a diagnosis of IPF or pulmonary fibrosis and be limited to publications from 2011 onwards, with no language restrictions applied. Two independent reviewers will screen articles in consecutive stages for relevance against the inclusion and exclusion criteria. Data will be extracted using a predefined data extraction form and analysed using descriptive and thematic analysis. Findings will be presented in tabular form, coupled with a narrative summary of the evidence.

Ethics and dissemination Ethics approval is not required for this scoping review protocol. We will disseminate our findings using traditional approaches that include open access peer-reviewed publications and scientific presentations.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A comprehensive peer-reviewed search strategy will guide this review, incorporating expertise from multiple disciplines to maximise the effectiveness of the search strategy.
⇒ This review will provide a comprehensive mapping of the literature related to idiopathic pulmonary fibrosis (IPF) and unmet needs, including a comprehensive grey literature search with no language limits applied.
⇒ This scoping review will apply the Joanna Briggs Institute scoping review methodological framework, with reporting guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist; a team-based analysis will enhance analytical rigour and integrity of the findings.
⇒ The full-text review will be limited to articles from 2011 onwards, as anti-fibrotic medication for IPF was not widely available prior to 2011.
⇒ Although we have developed a comprehensive search strategy, it may not have the scope to capture all non-English articles, and our proposed use of Google translate to assist with the translation of non-English articles may not be entirely accurate.

INTRODUCTION

Background

Interstitial lung disease (ILD) describes a large group of diseases that are identified by inflammation and fibrosis of the lung interstitium.[1–3] A large subset of patients who are diagnosed with ILD have pulmonary fibrosis (PF). Most types of PF are identified by a progressive phenotype, characterised by breathlessness, cough and fatigue.[3 4] The most common type of PF is idiopathic pulmonary fibrosis (IPF), accounting for around 17%–37% of all ILDs.[5] IPF is a chronic progressive disease, carrying with it potentially significant impacts on both physical and emotional well-being.[6–8]

IPF is identified by irreversible loss of lung function with limited proven treatment options, resulting in a life-limiting condition, coupled with impaired quality of life.[9 10] IPF typically occurs in older adults and is characterised by several disabling symptoms, including progressively worsening breathlessness, cough, impaired lung function and for some patients anxiety and depression,

carrying with it a poor prognosis.[4 11 12] The disease course can be varied from one patient to another. Some patients experience a slow disease progression and may encounter periods of stability while other patients experience a rapid decline or a disease trajectory with acute exacerbations, which can occur at any time and are associated with high mortality.[13 14] An IPF diagnosis can have functional, psychological and social impacts on individuals who benefit from an integrated care approach across the continuum from diagnosis and along the disease course.[15] Many patients with IPF die from respiratory failure within 3–5 years of diagnosis.[4 10]

Patients diagnosed with IPF have an uncertain prognosis, high symptom burden and may experience significant physical and emotional impacts related to potential comorbidities, including other pulmonary conditions, culminating in significant deterioration in quality of life.[16 17] Many patients also require complex respiratory care toward the latter part of the disease course, leading to an increased burden on patients, their families and the healthcare system.[17]

The mean age range of patients with IPF is 65–70 years, with incidence increasing with age and with higher rates seen in men than women.[18–20] The number of patients with IPF is rising globally due to several factors, including an ageing population, increased awareness of the disease and more advanced diagnostic tools.[21] Maher and colleagues estimate the adjusted incidence and prevalence of IPF, based on the countries they included in their analysis, to be in the range of 0.09–1.30 and 0.33–4.51 per 10 000 persons, respectively.[21]

Clinical management of patients with IPF includes outpatient care coupled with appropriate referral of patients to areas such as lung transplantation assessment,[22 23] pulmonary rehabilitation,[24 25] oxygen requirement assessment[26] and palliative care.[27 28] A cure for IPF does not currently exist, although there are two approved drugs, pirfenidone and nintedanib, that can slow disease progression.[24 29–32] In recognition of the availability of pharmacological treatments, international IPF guidelines, including the European IPF Patient Charter, further emphasise the importance of early diagnosis and access to essential care and services.[33] The arrival of anti-fibrotic drugs signified a major improvement in patient care, with several studies qualifying the impacts of both. However, despite the advances in current treatments, there is minimal evidence regarding impacts on quality of life.[34]

In line with emerging evidence on the pathogenesis of the disease, knowledge is evolving regarding the impact of IPF on patients' lives, including not only the physical needs of patients, but also the psychosocial needs of patients and carers.[4] The experiences of patients with IPF and consequent needs are broad and can vary along the clinical course of the disease. Many of the anticipated needs of patients diagnosed with IPF remain challenging, with many unmet needs persistently not being addressed.[6 35 36] A diagnosis of IPF can carry with it a marked socioeconomic burden and financial strain on patients and their families, reflected by the negative effects on quality of life, healthcare utilisation and the ability to work.[8]

An initiative by 11 European patient advocacy groups for PF identified five key needs of patients with IPF, which formed the basis for the European IPF Patient Charter and further qualified in numerous other studies: (1) early and accurate diagnosis, (2) early access to care, including medication and transplantation irrespective of age, (3) a holistic approach to standardise IPF management, (4) comprehensive and high quality information about IPF and (5) better access to palliative and end-of-life care.[33] It is understood that many of these needs remain unmet for this patient group. There is an urgent necessity to quantify patients' unmet needs. Better understanding of lived experience of patients with IPF and comprehensively recording their unmet needs will enhance the patient care pathway.[24 25 37]

The literature widely reports continuing delays in early diagnosis and referrals to specialist centres.[3 8 38] According to van der Sar, some of the delays relating to diagnosis relate to the heterogeneity of the disease and rarity of PF as well as the requirements for multiple investigations, resulting in a prolonged delay in diagnosis.[3]

Non-pharmacological treatment options, such as pulmonary rehabilitation, oxygen therapy, psychological support, lung transplantation and access to a specialist ILD nurse, are a vital part of holistic care for patients with IPF.[33 39–42] Previous studies have demonstrated that non-pharmacological treatment options are not equally available for patients in different European countries.[24 33] There exists a need for relevant up-to-date information about IPF, more education and continuous counselling, in order to adequately support patients along the disease course.[38 40]

Palliative care referral and a symptom-based approach to care, complimenting disease-focused care, is one of the key recommendations in the European IPF Patient Charter, yet most patients with IPF receive limited palliative care throughout the course of their disease or at the end-of-life.[33 43 44]

Rationale

A scoping review is considered the most appropriate method in this case to map the available evidence, identify gaps in knowledge and guide potential research in a comprehensive and systematic way.[45] This evidence synthesis will outline the characteristics of the unmet needs of patients diagnosed with IPF. It will aim to outline some of the barriers and facilitators outlined in the literature in meeting patients' needs.

This review is guided by a central question, which is to map the available evidence related to the unmet needs of patients living with a diagnosis of IPF. For the purpose of this review, patient needs will be mapped to the care needs identified by the European IPF Patient Charter, in addition to emerging needs that may be identified in

the literature, and to date have not been included in the European IPF Patient Charter.[33]

A preliminary review of the literature (MEDLINE and CINAHL, conducted on 14 September 2022) did not reveal any existing scoping reviews of patients' unmet needs. Much of the available research in relation to IPF and patients' needs took place pre-COVID-19 and did not consider for example, a hybrid care model, using a mix of telephone clinics coupled with face-to-face appointments. There also seems to be a sparsity of research reflecting the needs of patients with IPF in the community. This is particularly significant as we move toward a model of community-based care across several international healthcare systems.

The mapping of the evidence will benefit planning for future care resources, including an IPF clinical care pathway. This proposed scoping review will use Joanna Briggs Institute (JBI) methodology and will highlight the available evidence and identify any deficiencies in the sources.[45 46] A preliminary search of JBI evidence synthesis, the Cochrane database of systematic reviews and Prospero, was conducted prior to this protocol development, and no current or in-progress systematic or scoping reviews on the topic were identified.

A scoping review approach can offer several important features, including providing a broad overview of the landscape in relation to available literature, and is therefore the most appropriate design for this evidence synthesis.[47]

Review aim and objectives

The aim of this scoping review is to identify what evidence exists about the unmet needs of patients living with a diagnosis of IPF.

The objectives of the review are:

1. To synthesise the unmet needs of patients living with a diagnosis of IPF.
2. Define barriers and facilitators to meeting patients' needs.
3. Provide an overview of relevant concepts and terminology.

METHODS AND ANALYSIS

This scoping review will be conducted in accordance with the JBI framework for scoping reviews,[45] and includes the following steps: (1) identifying the research question, (2) developing a search strategy, (3) study selection and (4) data analysis and presentation. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist will be used to guide the reporting of this study.[48] This protocol will use the PCC framework (population, concepts and contexts) for the scoping review search strategy inclusion criteria (see online supplemental file 1, appendix 1).[45]

Inclusion criteria

Types of participants

This scoping review will focus primarily on literature reporting on adult patients >18 with a diagnosis of IPF. Studies that refer to patients with a diagnosis of PF will be included, owing to the similarities in the disease course between IPF and some forms of PF.

Concept

The main concept in this review is the unmet needs of patients living with a diagnosis of IPF throughout the disease course. Selected studies will be required to include information on unmet needs, such as information needs, digital literacy needs related to home monitoring, diagnostic needs, psychological needs, access to healthcare services and personnel or needs related to access to pharmacological treatments and/or oxygen, or physical health needs.

Context

This review will consider studies on unmet needs in all settings, such as clinics, hospitals, long-term care centres, community centres, respiratory community hubs, ambulatory care, home and remote access services such as telemedicine, face-to-face outpatient appointments and virtual clinics, either phone consultations or using technology such as Zoom video calls, or a mix of both. There will be no geographic limits in this review. The review will be limited to publications in or after 2011 as anti-fibrotic treatment for IPF became available in Europe at that time.

Types of information sources

This review will consider studies that describe the unmet needs of patients living with a diagnosis of IPF and will also include studies that reference PF. We will include all review types, including systematic, scoping and narrative reviews, which describe unmet needs of our patient group. This review will not include case reports, protocols, letters, posters, commentaries or opinion pieces. It will include sources that relate to patients with a diagnosis of PF, but these sources must also refer to patients with IPF.

Search strategy

The search strategy for this review was developed with the assistance of a JBI-trained medical research librarian and peer-reviewed by experts in the field of chronic disease, specifically IPF. The search strategy was externally peer-reviewed by a second librarian using the Peer Review of Electronic Search Strategies guidelines.[49] First, a limited preliminary search of MEDLINE (EBSCO) and CINAHL (EBSCO) was conducted on 14 September 2022 (see online supplemental file 1, appendix 2). The preliminary search was followed by an analysis of the text words contained in the titles and abstracts of relevant articles, including all identified keywords and index terms. The next step will be to adapt and tailor the preliminary search for each subsequent information source. Through this iterative process, new search terms may be identified and used. There will be no date or language restrictions applied at this initial stage.

The search will be extended beyond MEDLINE and CINAHL (EBSCO) to the other databases identified for

inclusion in this review namely APA PsycINFO (EBSCO platform), Embase (Elsevier) and Web of Science (Core Collection) and ASSIA (Applied Social Science Index) (Proquest), to search for studies that meet the review's inclusion criteria. These databases are selected for their combined ability to generate a wide range of evidence, specific to the research topic, across a range of interdisciplinary fields. There will be no date limits used in the initial screening criteria; instead, databases will be searched from inception to present and date limit criteria applied at full-text review (2011–present). The search will be limited to human participants over 18 years of age. Google translate will be used to translate non-English sources.

Grey literature and unpublished studies will be included: sources include ProQuest Dissertations and Thesis Global, Google Scholar and ClinicalTrials.gov, WHO International, Clinical Trials Registry Platform and OpenGrey. There will also be a comprehensive online search of key websites to include relevant policies, guidelines and research related to this inquiry including the American Thoracic Society, British Thoracic Society, Irish Thoracic Society, Irish Lung Fibrosis Association and European Respiratory Society, the Health Service Executive, Ireland and the Irish Hospice Association. Online searches will use search engines on the internet (eg, Google) to obtain information sources. There will also be a manual search of the reference lists of included studies, to identify studies that may have been missed within the initial search. Annual conference abstracts from relevant international conferences will also be reviewed.

Source of evidence selection

All identified records will be collated and uploaded onto EndNote X9.3.3 (Clarivate Analytics, Pennsylvania, USA) and duplicates removed. All identified citations will be transferred into Covidence software (Veritas Health Innovation, Melbourne, Australia) where any remaining duplicates will be removed.

Once the records have been transferred to Covidence software, the titles and abstracts will be screened by two independent reviewers for assessment against the inclusion criteria. The criteria will be pilot-tested on a sample of search results to ensure 'substantial' inter-rater reliability (ie, Kappa statistic >0.61) among screeners.[50] Potentially relevant studies which meet the inclusion criteria will be retrieved in full text and uploaded to Covidence. Additional exclusion criteria may be applied to the full-text review, due to the iterative nature of scoping reviews.[45]

The full text of these selected citations will be assessed in detail against the inclusion criteria by two independent reviewers (PCC inclusion criteria). Resources that do not meet the inclusion criteria will be recorded and reported in the scoping review and the reason for their exclusion provided. If disagreements arise about the inclusion or exclusion of a paper, then the reviewers will discuss in detail so that the issue can be resolved. A third reviewer will arbitrate in such instances.

Data extraction

Data will be extracted from articles and other evidence sources included in the scoping review by two independent reviewers, using a data extraction tool developed by the study's research team in adherence with the review objectives (see online supplemental file 1, appendix 3). The design of the instrument for data extraction follows the guidelines from the JBI. A number of specific domains will be included in the data capture tool, including but not limited to study characteristics such as author, year of publication, geographic location, context (where the study was conducted), status of the publication (eg, published or grey literature), journal, aims/purpose, sample characteristics (study population, sample size (if applicable)) and key findings that relate to the scoping review question (specific needs categories) study aims, methodology/methods (study design and measures and analysis approach), the study findings (eg, quotes, themes, concepts and study results) and limitations.

The draft data extraction tool will be modified and revised as necessary during a pilot-testing phase prior to reviewing all articles independently. Data extraction will be done electronically. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where necessary.

Analysis of the evidence and data presentation

Data analysis will involve descriptive quantitative (ie, frequency analysis) and qualitative (ie, thematic) analysis. An overview of the literature will be undertaken through a descriptive numerical summary (eg, characteristics of included studies, types of study design, characteristics of the study population and geographical location, study aims, methodology and limitations) and through emerging themes (deductive thematic analysis). The extracted data will be presented in tabular and graphic form in a manner that aligns with the study's objectives. A narrative summary will accompany the tabulated results, describing how the study's findings relate to the review's objectives and research question (see online supplemental file 1, appendix 4).

Patient and public involvement

Patient and public representatives (n=5) from the Irish Lung Fibrosis Association patient and public involvement (PPI) group were involved in reviewing the research protocol. PPI involvement enables translation of knowledge into practice by disseminating results among potential knowledge users. The stakeholders comprise of patient representatives, family members of patients diagnosed with IPF and experts in the field of IPF. This iterative process will continue to seek stakeholders' perspective on data screening, data extraction and analysis phases. The PPI meetings will continue to take place through video-conferencing to allow wider participation.

All members of the PPI group have read and acknowledged the group's terms of reference. The authors anticipate continued work with the stakeholder group to provide ongoing consultation and feedback relating to dissemination of the evidence synthesis.

Ethics and dissemination

Ethical approval for the conduct of this scoping review, essentially a secondary analysis of existing literature, is not required. We aim to engage our PPI partners in rigorous peer review throughout the development of the protocol and various aspects of the scoping review. We will disseminate the findings to a wide range of stakeholders, including researchers, clinicians, policymakers, health service administrators, patient groups and lay and public audiences in order to widen participation. We will disseminate the findings in academic peer-reviewed journal publications and local, national and international conference presentations and social media platforms.

DISCUSSION

The primary purpose of this evidence synthesis is to identify the breadth and scope of the literature relating to unmet needs for patients diagnosed with IPF. This research will aim to identify gaps in the literature and to provide a backdrop for future research focus regarding the unmet needs of patients diagnosed with IPF, as no scoping review of evidence relating to patients with IPF in a COVID-19 era currently exists. The findings from this review could enhance service provision for patients living with IPF, based on the unmet needs identified in this review. The findings may also help guide policymakers when developing clinical care programmes in respiratory disease to consider the specific needs of patients diagnosed with IPF.

In relation to the search strategy, although it is comprehensive, there is a risk that we may still miss potentially relevant literature. To overcome this limitation, we have recruited an experienced health science librarian to help us develop the search strategy and to engage in discussions to refine and amend the search strategy to maximise its reach. In addition, as scoping review studies include a diverse range of literature, including grey literature, there are potential practical concerns regarding time, funding, staffing and access to resources which should be considered when planning a scoping review. We have not extended the search to sources pre-2011, owing to the introduction of anti-fibrotic treatment in Europe at that time. A publication date limit can be viewed as a limitation; however, the authors believe that the use of this filter will maximise the inclusion of suitable articles that reflect the current landscape in IPF. Studies that refer to patients with a diagnosis of PF will be included, owing to the similarities in the disease course between IPF and some forms of PF. Finally, we intend to include non-English sources in our review, and although we have developed a comprehensive search strategy, it may not have the scope to capture all non-English articles. There is also a further limitation in our proposed use of Google translate to assist with the translation of non-English articles, as it may not be entirely accurate.[51]

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Contributors CB and A-MB led the conceptualisation, design and development of this study. DL and HM assisted with the scoping review approach. CB, A-MB and A-MR were involved in developing the review questions. CB drafted the protocol. CB and JE-C developed the search strategy with input from A-MB. A-MR provided feedback from a clinical perspective. All authors reviewed and approved the final version of the manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

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