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WP3 – Intervention modelling through equitable multilevel needs assessment

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List of Acronyms

COPD	Chronic obstructive pulmonary disease
IPF	Idiopathic pulmonary fibrosis
PC	Palliative care
SPICT	Supportive & Palliative Care Indicators Tool



1. Executive Summary

This study set up aiming to understand patients' needs and diverse perceptions and needs of families/carers and health professionals for accessing and delivering palliative care (PC). It was undertaken across five sites in four European countries including the UK (Leeds and Highland Region (Scotland)), Portugal, Greece and Spain.

A qualitative approach was undertaken that involved one to one interviews and/or focus groups with older patients (aged 65 or over) with severe chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis (IPF), frailty, comorbidities and multimorbidity, their families/carers and health professionals who provided disease-directed services and PC. Framework analysis was used to analyse the data which provides a systematic approach to sifting, charting and sorting data using the key themes and issues.

A total of 157 participants were recruited including 66 patients, 28 families/carers and 63 health professionals who expressed mixed views on their PC needs. The findings of this study suggested that there are unmet needs of patients and families/carers for timely PC including feeling uncertain and a sense of fear, poor awareness and knowledge on PC in non-malignant settings and desire for improved physical, psychosocial and financial status. Unmet needs for health professionals and systems were also identified including the lack of coherent support for patients and families, a consistently used early identification tool, holistic needs assessment and effective referral pathways for PC input.

Understanding and addressing these needs may support the development, implementation, mechanisms, and evaluation of the integration of PC for older people with advanced diseases, for both research and practice. Further studies are needed to enable a systematic and responsive health system that enables efficient integrated PC with standard care. The development of evidence-based tools for early identification and needs assessments with optimised clinical pathways also remains a priority.



2. Introduction

Chronic non-communicable diseases known as a disease of long duration and generally slow progression account for most of the burden of disease globally. Almost a quarter of the total disease burden is attributable to disorders in older people, with the leading contributors being cardiovascular diseases, malignant neoplasms, chronic respiratory diseases and musculoskeletal diseases (1). Chronic diseases are also the major cause of death worldwide, causing more deaths than all other causes combined. The annual deaths are projected to increase from 38 million in 2012 to 52 million by 2030 (2). In Europe, more than 80% of all deaths occurred among people aged 65 or over, and the leading causes of deaths include circulatory diseases (38.7%), cancer (23.8%) and respiratory diseases (8.9%) (3).

Chronic diseases place a significant impact on older people's quality of life, resulting in not only reduced physical functioning but also associated psychological distress and finance concerns(4). The most common symptoms reported include pain, breathlessness and fatigue (5). People living with chronic diseases are also at a high risk of developing multimorbidity, leading to an increase in reliance on family and caregivers due to the progressive decline in health status.

Due to the increased incidence, prevalence and mortality of chronic diseases and multimorbidity, the need for palliative care (PC) resources remains a challenge for health care systems. PC refers to "an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (6). It is currently a high priority for health systems in many countries highlighted in several national guidelines (7). There is also increasing evidence to show that the provision of PC to non-cancer diseases improve patients' symptoms burden and quality of life, resulting in a consistent pattern of reduced health-care use (8-10). Despite the potential benefit of PC, access to PC remains inconsistent and only about 14% of those needing PC receive it (11). The majority of patients who are at the end of life are either under-identified or under assessed. For example, only one in five patients dying from chronic obstructive pulmonary disease (COPD) received PC in the UK. Among those, under half were offered PC during the last six months and one third only in their last month of life (12). Solid evidence on early identification, needs assessment and mapped PC pathways to provide symptoms management and support to patients and their families is still lacking.

The experiences of people living with chronic diseases reveal multiple areas of needs. These needs can become complex and severe for end-stage patients, but the prognosis often remains uncertain for most non-cancer life-limiting conditions such as COPD. Therefore needs-oriented services are at the centre of delivering PC, integrated with standard care. Without evidence synthesising concerns and needs related to PC from patients, families/carers and health



professionals, effective and needs-based integrated PC in the management of chronic diseases seems untargeted. This study, therefore, aims to understand patients' needs and diverse perceptions of families/carers and health professionals for accessing and delivering PC.



3. Methods

3.1 Design

A qualitative approach was undertaken that involved one to one interviews and/or focus groups with older patients (aged 65 or over) with severe COPD, idiopathic pulmonary fibrosis (IPF), frailty, comorbidities and multimorbidity, their families/carers, and health professionals who provided direct care of these patients.

3.2 Setting

This study was conducted across five sites in four European countries including

- Leeds, Highland and Portugal focusing on severe COPD;
- Greece on IPF, frailty and comorbidities;
- Spain on multimorbidity.

3.3 Ethics

Ethics approval was granted by each country's local authority. All of the data were collected with the written informed consent of participants provided before the study.

- UK: Health Research Authority Yorkshire & The Humber - Bradford Leeds Research Ethics Committee 19/YH/0358
- Portugal: The Ethics Committee for Health of Santa Casa da Misericórdia da Amadora 001/CES/2020
- Greece: Committee on Bioethics and Ethics, School of Medicine, AUTH 5.167/18.12.2019
- Spain: Ethics Committee on Research with Medicaments of Hospital La Fe 2019-013-1

3.4 Study participants and sampling

Participants were recruited from disease-specific services such as chest clinics or specialist (community) health professionals and PC services such as hospices.

Patients were eligible if they were aged 65 or over, diagnosed with the conditions listed above for each site and were able to read and speak local languages. Patients were excluded if they lived with or received treatment for cancer. Families/carers were eligible if they were cognitively intact and able to read and speak local languages. Health professionals providing direct care for patients' diseases and PC services were targeted. Participants who were cognitively impaired were excluded.

A purposive sampling strategy was used that allowed the research team to select eligible participants that represented both disease-specific services and PC services. The participants were initially identified by a member of the research team or other key contacts such as research nurses or specialist nurses and consultants. Each potential participant was provided with a copy of the information sheet. With their consent to contact, a member of the research team arranged a time and place for obtaining written consent forms before interviews.

3.5 Data collection

Recruitment and interviews took place between November 2019 and March 2020. Semi-structured interviews using open-ended questions were undertaken.



Separate topic guides were developed for patients, families/carers and health professionals concerning disease symptoms and impact, experiences of services and care provided, management of exacerbations, needs for the future (for patients and families/carers) or PC pathways and integration of PC in the management of severe conditions (for health professionals). These topic guides were further reviewed by a consultant in respiratory medicine.

Each interview/focus group was undertaken by a local researcher with experience in conducting qualitative research in previous studies. All interviews took place either face-to-face in a quiet room or by telephone based on their preferences. Interviews were digitally recorded with permission and transcribed verbatim for analysis.

3.6 Data analysis

Framework analysis was used to analyse the data which provides a systematic approach to sifting, charting and sorting data using the key themes and issues (13). This analysis was performed by initial open line-by-line coding using a constant comparison approach of coding and recoding the interviews. Codes were compared across all interviews to identify similarities and differences to be further grouped into categories, synthesising and explaining large amounts of data. Connections and relationships between codes and categories were further explored enabling the development of themes. A coding framework often developed from the first 5-8 transcripts, was then applied and validated by the rest of the transcripts enabling the whole analysis process to be coherent. Additional codes were added allowing the framework to be developed further. Nvivo software was used to facilitate the management and analysis of the interview transcripts.



4. Results

A total of 157 participants were recruited including 66 patients, 28 families/carers and 63 health professionals across five sites (Table 1).

Table 1: Participants recruited across five sites

	UK (Leeds)	UK (Highland)	Portugal	Greece	Spain	Total
Patients	13	7	26	8	12	66
Families/carers	4	2	8	3	11	28
Health professionals	13	12	14	8	16	63
Total	30	21	48	19	39	157

Table 2 below shows the characteristics of patients. Of these, 46 (70%) had a diagnosis of severe COPD, 12 (18%) had multimorbidity and the rest (12%) had mixed conditions of IPF, frailty and comorbidities. Patients ranged in age from 65 to 96 years, with an average age of 79.2 years old. More than half of them were females (43, 65.2%) and lived alone (45, 68.2%). The majority had a secondary degree or below (60, 91.0%) and were retired (62, 93.9%).

Table 2 Patients' characteristics (n=66)

Socio-demographic characteristics	N	%
Age (mean, range)	79.2	65-96
Gender		
Male	23	34.8
Female	43	65.2
Marital status		
Married/living with partner	21	31.8
Separated/Divorced	8	12.1
Widowed	36	54.5
Single	1	1.5
Education		
University degree	3	4.5
Further (A level or equivalent)	3	4.5
Secondary (GCSE or equivalent)	25	37.9
Primary degree	23	34.8
None	12	18.2
Employment		
Retired	62	93.9
Part-time	0	0.0
Full-time	1	1.5
Unemployed	3	4.5

As shown in Table 3, spouses (14, 50.0%) were the main caregivers of patients followed by their children (6, 21.4%) and professional carers (8, 28.6%) hired for caring responsibilities. Half of the carers interviewed were spouses of the patients. All carers provided daily care for patients although there were people (5, 17.9%) in full-time employment.

Table 3 Carers' characteristics (n=28)

Socio-demographic characteristics		N	%
Relationships with patients			
	Spouse	14	50.0
	Child	6	21.4
	Professional carer	8	28.6
Frequency of caring			
	Daily	28	100.0
	Weekly	0	0.0
Employment status			
	Retired	12	42.9
	Part-time	0	0.0
	Full-time*	13	46.4
	Unemployed	2	7.1
	Unable to work	1	3.6

* 8 out of 13 were professional carers

Health professionals interviewed were recruited from both PC services (22, 34.9%) and disease-specific departments (41, 65.1%) in all sites except Greece in which PC was not adopted in the participating hospitals. About three quarters (38, 60.3%) had received some training in general palliative care, although not all were employed by PC services.

Table 4 Health professionals' characteristics (n=63)

Employment characteristics		N	%
Speciality			
	Palliative care	22	34.9
	Disease-specific care	41	65.1
Training in palliative care			
	Yes	38	60.3
	No	25	39.7
Employment			
	Full-time	52	82.5
	Part-time	11	17.5

Themes emerging from patients and carers interviews include lacking support at diagnosis, life-changing experience, being an “expert” (or providing direct care), receiving insufficient medical support, feelings of uncertainty and concerns and needs for the future. Figures 1- 4 present the themes and categories that emerged at each site for their focused condition.

In general, patients and carers described their experience, often starting from being diagnosed with insufficient information provided by health professionals and experiencing the life-changing impact, to receiving inconsistent medical support and learning to be an expert. Both facilitators and barriers to medical support were reported. Most of the patients and carers expressed their feelings of uncertainty due to the unpredictable prognosis of their conditions, which created a sense of fear and a barrier to identifying specific needs for the future. However, most of them were aware of the decline of their physical and psychological health increasing their desire to improve their quality of life. Being informed, timely accessing health services, having home-based interventions and receiving consistent support by health professionals were suggested as their priorities for the future. They also indicated their financial concerns required to maintain their treatments and daily lives. For carers, improving their wellbeing, being equipped for providing care and getting support for the family were identified as their priorities.

Mixed views were expressed on the access of PC. It was also found that most of the patients and carers had poor, or no, knowledge of PC and interpreted PC as services for cancer or death and dying rather than managing symptoms and improving quality of life, leading to their denial and disengagement with PC. However, this contrasts with those who had had experiences and engaged with PC services. Acceptance of their life-limiting conditions and experiencing severe symptoms were perceived as indicators of considering PC services along with literacy of COPD and the choice and access to services.

Interviews with health professionals mainly focused on the clinical pathways and factors influencing the provision of integrated PC services in the management of conditions. Themes included ways to recognise needs, common symptoms treated, services offered, integrated care, and concerns and needs of health professionals.

Greece was the only site in which PC was not adopted as part of its health system for non-cancer patients, whereas models of integrated PC were in development in some areas of Highland. The establishment of NHS Highlands Palliative Care Network provides a collaborative platform for stakeholders committed to providing excellence in PC across the Highlands. This has helped facilitate innovation. There are standardised identification systems (in the pilot phase), implementation of a poor prognosis letter and palliative care register to identify advanced patients and indicate the delivery of general or specialist PC services. Also, health professionals use various tools such as SPICT (Supportive & Palliative Care Indicators Tool) which supports identification and assessment of unmet PC needs and person-centred relational approaches to assess patients’ needs.



Therefore in addition to specialist PC, generalist PC is also available to advanced patients integrated into a continuous care model in which a PC approach underpins standard care.

Although several clinical factors were used as indicators to the advanced stage of patients' condition, there was no consensus reached among health professionals on their accuracy due to the uncertainty prognosis for non-cancer conditions. Poor public awareness and knowledge of PC were identified as the main barriers to PC provision. Many health professionals lacked confidence in initiating PC conversations with patients and carers. In general, integrated PC was poorly implemented at most of the study sites for different conditions. There was a lack of a systematic approach for early identification of severe patients who may benefit from PC input. A multidisciplinary team meeting involving PC team was identified as the main approach to discuss and decide further referrals. However, no clear pathway existed for decision making in relation to either the setup or delivery of general or specialist PC services. No holistic assessment tool was available for identifying patients and carers' specific priorities and needs for PC input. Up to date training on PC, effective communication, collaborative working across services, reliable tools for early screening and needs assessment, decision aid for effective referrals and sufficient resources (time, staffs and funds) were seen essential for capacity building and achievement of integrated care.



Figure 1 Themes emerged from UK (Leeds and Highland) on PC for severe COPD

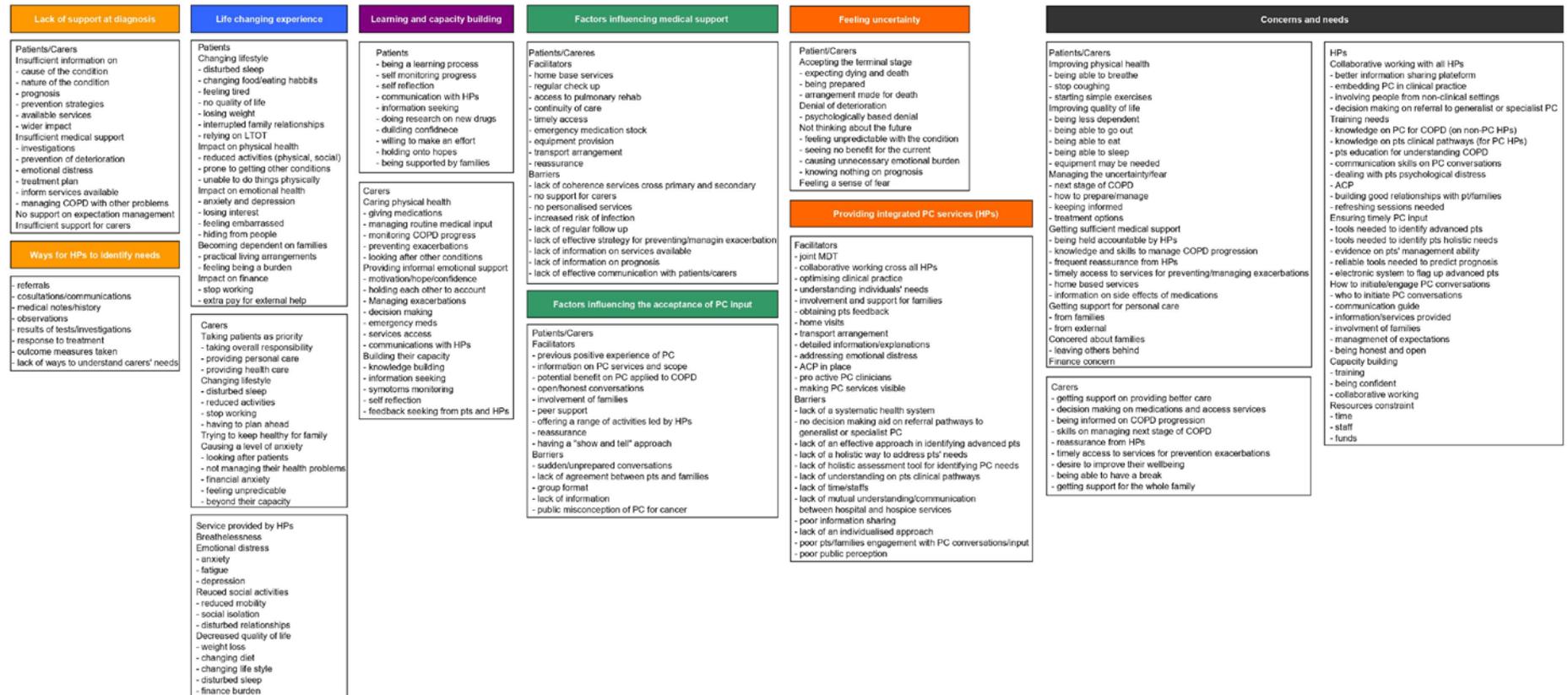


Figure 2 Themes emerged from Portugal on PC for severe COPD

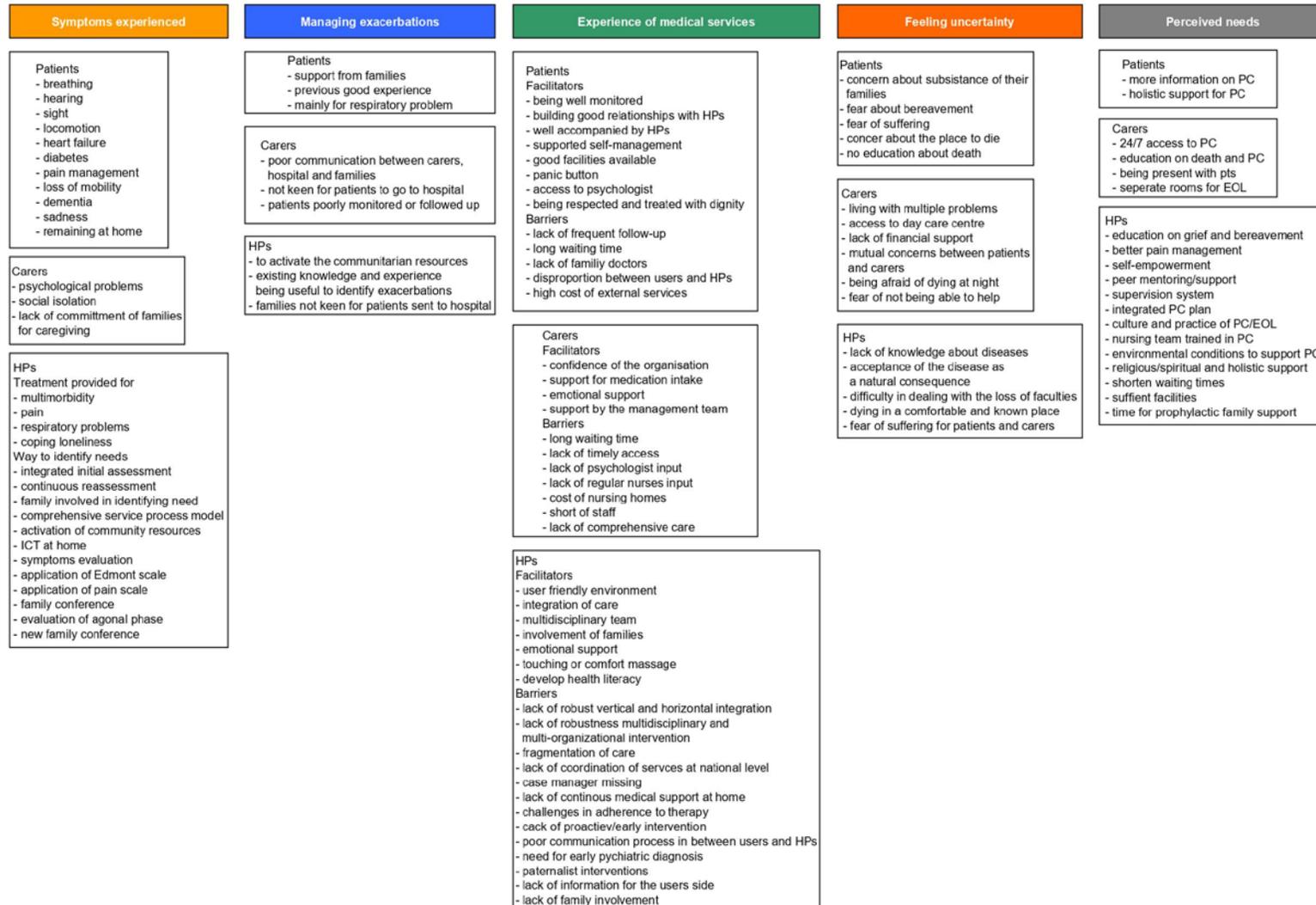


Figure 3 Themes emerged from Greece on PC for frailty and IPF

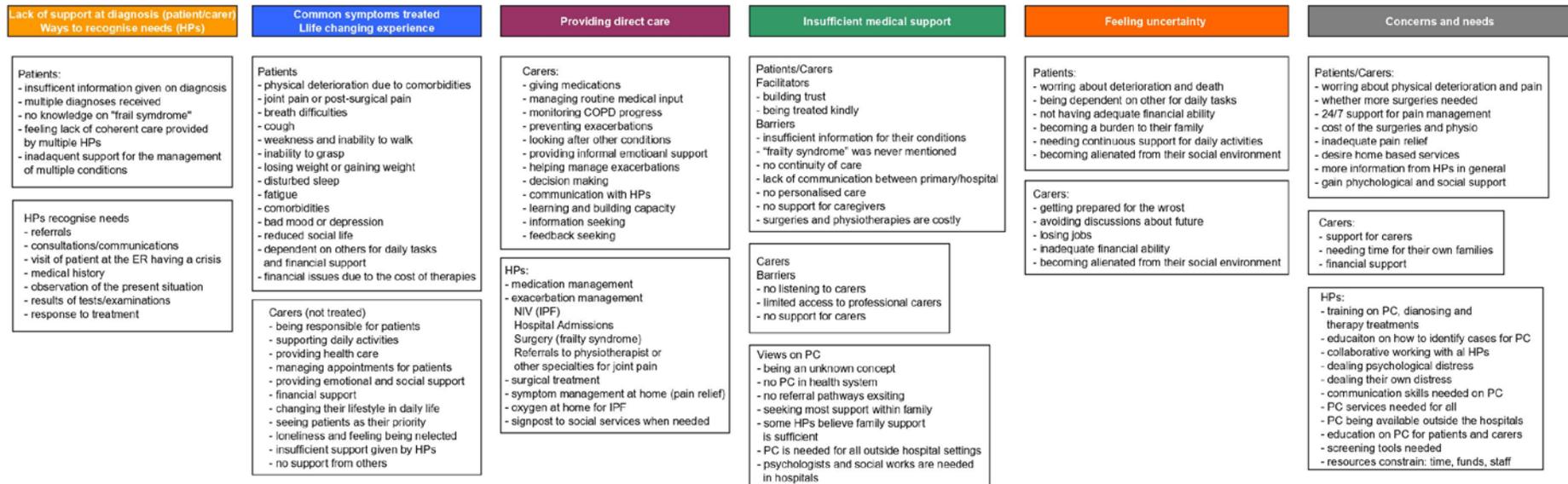


Figure 4 Themes emerged from Spain on PC for multimorbidity

Common symptoms experienced	Accessing health services	Views of PC	Perceived needs
<p>Patients</p> <ul style="list-style-type: none"> - breathlessness - lack of mobility - sadness, anxiety - back pain - respiratory failure - the nervous apparatus, muscles stop working 	<p>Patients/Carers</p> <p>Facilitators</p> <ul style="list-style-type: none"> - professionals' human qualities - being support by HPs - home based services - receiving guidelines and advice <p>Barriers</p> <ul style="list-style-type: none"> - excessive waiting time - lack of information for services - lack of information for carers in waiting rooms - lack of specialists - lack of communication with carers 	<p>Patients/Carers</p> <ul style="list-style-type: none"> - poor knowledge - concern about what end of life will be like - avoiding invasive treatments 	<p>Patients</p> <ul style="list-style-type: none"> - highest level of mobility and independence - physiotherapy - personal support at home - assistive devices - public funding for dependent patients - personalised attention - availability of health provider's time - drugs not funded by the system
<p>Carers</p> <ul style="list-style-type: none"> - overburden - depression - emotional burden - physical and muscle fatigue - supporting all basic needs of patients 	<p>HPs</p> <p>Home hospitalisation unit</p> <ul style="list-style-type: none"> - more time than primary care units - treat patient at home - work with patients and families on prevention and detection of a decompensation - prevent unnecessary visit to ER - NECPAL to identify PC needs - seeing professionals' experience as tools to identify PC patients 	<p>HPs</p> <ul style="list-style-type: none"> - negative vision of PC held culturally - misunderstanding of PC concept - death being a taboo topic - linking with cancer - no existence of early PC - PC applied to last days of life traditionally 	<p>Carers</p> <ul style="list-style-type: none"> - training to support patients (guideline, information and addressing their needs) - support for carers to look after patients - support for housework - emotional support for carers - financial support - havign time and space for their wellbeing - personalised attention and more information - physiotherapy
			<p>HPs</p> <ul style="list-style-type: none"> - no PC training/education at University - specialised training in PC - support on how to deal with sensitive issues - time for personalised care - more and specialised resources for chronicity - early identification of patients for PC - social resources

The concept of the development of a needs assessment tool to identify PC needs was also explored. There seemed an agreement among patients, carers and health professionals about the potential benefit of implementing such a tool in routine practice regularly. Comments received further suggested that an assessment tool should be easy and simple to use, and also have the ability to capture their holistic needs for PC concerns. However, there was a debate on whether it could be used stand-alone or would have to be facilitated by a health professional.



5. Discussion

This study explored the experience and needs of patients living with advanced, non-malignant diseases and their families/carers concerning PC services, as well as the needs of health professionals for delivering PC together with disease-directed care. The findings of this study suggest unmet needs for early integration of PC, which offers coherent support for patients and families, early identification, holistic needs assessment and effective referral pathways for PC input across five sites in Europe.

Both patients and carers identified their needs of being informed and supported for their physical, psychosocial and financial status. Receiving consistent support by health professionals, accessing individualised and continuous care and having the option of home-based services were perceived as facilitators to engaging medical support. No involvement of families, lack of effective communication and regular follow up with insufficient support on exacerbation management were considered as barriers.

Although multiple national guidances (7) recommend early access of PC for older people with non-malignant conditions, this study showed varying degrees of PC input provided for those with advanced conditions. PC viewed as inadequate was related to poor public awareness and knowledge of PC in non-cancer settings, a level of resistance and unwillingness in some patients and families, and a lack of confidence in delivering PC in health professionals. Living with a non-malignant disease with experience of exacerbations generated the feeling of uncertainty and a sense of fear about the future among patients and carers. This was due to insufficient information and support provided on cause of the condition, available treatment and prognosis. However prognosis and life expectancy cannot always be accurately predicted (14), therefore health related decisions cannot be planned to respond to disease trajectory effectively. For many of them, the emotional uncertainty and fear enabled their early preparation and arrangement, leading to acceptance of PC input. However, for some, this led to a denial of specialist PC, such as hospice, until severe deterioration appeared. Future research may be needed on evidence-based interventions for expectation and emotional management for patients and their loved ones. Meanwhile, discussion and education on the disease and prognosis and development of a close relationship with patients and families have been proved valuable (15, 16).

Evidence suggests the integration of PC to tackle the uncertainty for advanced conditions - an approach that advocates needs-based services rather than focusing on prognosis aims to reduce symptoms and improve functioning and quality of life (8). Given the unmet needs of patients and carers, accessible integrated PC services are required that can provide individualised PC with ongoing primary and secondary input and referrals based on the complexity of symptoms and needs. Despite positive evidence showing the benefit of integration of PC with disease-directed services (17), this study suggested that integrated PC was poorly implemented in many areas but there was evidence of a growing desire to



integrate services. Having a multidisciplinary team meeting involving PC specialists seemed the main available approach to decide the potential benefit of specialised PC input and further referrals. There was still a lack of a systematic health system that can enable effective collaborative working cross health professionals and the clinical pathways for generalist and specialist PC input. A lack of a consistently used reliable identification tool for screening and a holistic needs assessment tool in many sites also made integrated PC remain untargeted. Meanwhile, health professionals felt less confident in initiating PC conversations and suggested more training is needed on skills for communication and dealing with sensitive issues. However, an open and honest conversation when patients were in a stable situation was suggested by all for future practice. It was also noted that for severe COPD, there was no agreement reached on clinical features used to effectively identify cases for early PC. Future studies are needed to develop an effective screening tool and a holistic needs assessment with evidence supporting early integration of PC.

5.1 Limitations

This study was undertaken in multiple sites with different health care systems, implying that the findings of this study may not be applicable for all. There was a large number of participants recruited from five sites representing COPD, IPF, frailty and comorbidities and multimorbidity in this study, but there was a lack of balance in the number of patients for each condition. Also, the fact that patients over 65 living with advanced health conditions were vulnerable, which may have limited their capacity and time for in-depth interviews. Therefore it is possible that this study was unable to capture all perspectives on PC needs in the local settings.

Despite these limitations, all data collected were analysed using framework analysis, resulting in common themes and unmet needs of participants. This may suggest that the selection bias in this study was minimal. Further studies could focus on PC needs for one type of condition and compare the findings with other non-cancer diseases.



6. Conclusion

The implementation of early integrated PC is complex. This study synthesised the concerns and needs related to PC of patients, families/carers and health professionals. Understanding and addressing these needs may support the development, implementation, mechanisms, and evaluation of the integration of PC for older people with advanced diseases, for both research and practice. Further studies are needed to enable systematic and responsive health systems that enable efficient integrated PC with standard care. The development of evidence-based tools for early identification and needs assessments with optimised clinical pathways also remains a priority.



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