

Supplement 2.2. Comprehensive information of included studies that reported qualitative results

Study (year) Country	Study aim Study period	Design Comparison (where relevant)	Target population Sample size Age (years)	Intervention description	Setting Delivery format	Themes reported
Albright <i>et al</i> (2016) (1) USA	Analyse content of three websites to better understand the needs and interests of people with PF and their loved ones. Aug 2013 - May 2014	Qualitative content analysis	PF * <i>Intervention was open to public</i> Users engaged with blog entries = 149 Users started forum strings = 23 Users responded to forum strings = 26 Age: <i>unclear</i>	Three public websites (2 blogs; 1 forum) aimed at raising disease awareness, educate, and providing platforms for exchanging information and experiences. Components: <ul style="list-style-type: none"> • Patient education • Peer support Materials used: <ul style="list-style-type: none"> • Websites 	Community <ul style="list-style-type: none"> • Remote • Individual 	Reader-participants primarily used the websites for one or more of the following three purposes: <ul style="list-style-type: none"> • To share their personal narratives about PF • To seek information from the PF community • To offer contributions to the PF community Content generated by reader-participants included: <ul style="list-style-type: none"> • Personal narratives about their own PF experiences or their loved one’s experiences (n=264) • Questions seeking information about PF-related topics (n=181) • Expressions of gratitude for the blog(s), a specific post, or a reply (n=179) • Descriptions of activities or behaviours personally found to be helpful with PF symptoms (n=64) • Sharing of resources or information about PF (n=62) • Supportive comments from one PF sufferer to another (n=41) • Requests for new or additional PF-related posts or research (n=28) • Clarification questions about post content (n=11) • Other casual comments not relevant to PF such as polite remarks concluding a thread (n=78)

<p>Bajwah <i>et al</i> (2015) (2) UK</p>	<p>Examine the effects of Hospital2Home program on palliative care concerns and evaluate the feasibility and acceptability of the intervention.</p> <p>Oct 2011 - Dec 2013</p>	<p>Mixed methods:</p> <ul style="list-style-type: none"> Phase II fast-track RCT Semi-structured interviews <p>Case conference within 1 week (IG) vs Case conference at 4 weeks (CG)</p>	<p>IPF (82% in CG; 85% in IG), fibrotic non-specific interstitial pneumonia</p> <p>10 completed interviews Patients=5 Carers=5</p> <p>Mean age (SD): CG – patients=70.6 (10.3); carers=60.3 (13.1) IG – patients=67.1 (10.9); carers=61.3 (14)</p>	<p>One case conference with 3 follow ups (Hospital2Home)</p> <ul style="list-style-type: none"> Duration of intervention: 2 months Frequency of follow ups: at 2 weeks, 1 month and 2 months Duration of case conference: approximately 90min <p>Components:</p> <ul style="list-style-type: none"> Palliative care Discussions of physical, psychological, social, spiritual concerns Individualised care plan EOL planning Goal setting Patient education 	<p>Home</p> <ul style="list-style-type: none"> Remote Individual 	<p>Eight themes:</p> <ul style="list-style-type: none"> Support in the community – increased awareness of community support; all participants received support from community HCPs through the study. Individual care plans and practical problems addressed – issues were addressed quickly after having the case conference. Coordination of care and efficiency – improved communication across the primary and specialist care setting; care plan gives clear information about the HCPs involved in the patient’s care. Crisis management – participants felt relieved to have crisis management plans with direct contact numbers for HCP 24/7. Palliative care and psychological support – improved understanding of what palliative care and who it is suitable for; improved psychological symptoms; participants recognised that support for loved ones and carers was needed. Symptom control – clear evidence based strategies on managing symptoms within the care plan were seen as invaluable. Empowering HCPs – the study guided HCPs in conducting conversation around ACP. Advance care planning – the study facilitated introduction of palliative care at a specialist centre and open discussion between the patient and their family members; participants were grateful to discuss options.
<p>Bischoff <i>et al</i> (2021) (3) USA</p>	<p>Examine the effects of a multidisciplinary palliative care model on access to palliative care</p>	<p>Mixed methods:</p> <ul style="list-style-type: none"> Longitudinal Open-ended interviews 	<p>Various ILD (15% IPF)</p> <p>17 completed interviews Patients = 13</p>	<p>Multidisciplinary specialty palliative care model including meeting with a multidisciplinary healthcare team and follow up telephone calls</p> <ul style="list-style-type: none"> Duration: median 9.9 months 	<p>Outpatient / home</p> <ul style="list-style-type: none"> In person/ remote 	<p>Ways that the intervention was helpful:</p> <ul style="list-style-type: none"> Supportive, compassionate, patient-centred Available, responsive, reliable Comprehensive, coordinated, interdisciplinary care

	including treatments and ACP. May 2018 – Feb 2020		Carers = 4 Mean age (95% CI): Whole cohort=75.8 (72.4 – 79.2)	(ranged 2.7-19.7) • Number of visits: median 3 (ranged 1-9) Components: • Palliative care • Managing physical and psychological symptoms • Assessing and promoting function including referral to PR • Discussion of the disease, treatment options and prognosis • Psychosocial support • Managing medications • ACP and advance directives	• Individual	<ul style="list-style-type: none"> • Symptom management, reduction of medication side effects • Help with illness understanding and advance care planning • Helpful to family • Video visits improved convenience, access <p>Ways that the intervention complicated or detracted from care:</p> <ul style="list-style-type: none"> • Provided differing opinions <p>Expectations of the intervention:</p> <ul style="list-style-type: none"> • Assumed it was for advanced stages of illness or end-of-life • Preparing for the future • Did not know what to expect <p>The meaning of palliative care:</p> <ul style="list-style-type: none"> • Emotional comfort • Physical comfort • Maximise quality of life • Coping with a serious and terminal illness • Team-based care • A step before hospice
Duck <i>et al</i> (2015) (4) UK Austria	Describe the structure and benefits of IPF Care program in two countries. 2013 - 2014	Post intervention evaluation	IPF UK=465 Austria=27 Mean age: <i>unclear</i>	Patient support program for people prescribed pirfenidone including meeting with a HCP and follow up telephone calls • Frequency: UK – 1 initial telephone call; then weekly or fortnightly for month 1; tailored to the participant thereafter. Austria – 1 initial telephone call and 1 in person meeting; then	Outpatient / home • In person/ remote • Individual	Reasons for the score that participants gave to a question ‘Do you think the IPF Care program would be useful to other patients taking Esbriet?’: • “Knowing support is a phone call away makes me feel less panicky” • “It provides a human element” • “It is helpful to know someone is keeping an eye on you” • “Being able to speak to someone over the

				<p>weekly or fortnightly for month 1; monthly for month 2-4; once every 4-6 weeks thereafter with additional in person meeting once every 6-8 weeks as required</p> <p>Components:</p> <ul style="list-style-type: none"> • Patient education and support • IPF care meeting with other patients, family and friends, and IPF experts (Austria only) <p>Materials used:</p> <ul style="list-style-type: none"> • Information booklets • 'My health journal' booklet • Visit log (completed by nurse to document issues with the disease or treatment; participants encouraged to bring the log to their clinic appointments) 		<p>phone about my problems has been very reassuring, rather than having to wait until my next clinic visit"</p> <ul style="list-style-type: none"> • "The extra support is reassuring" • "There is always help on the end of the phone when you are struggling with breathing" • "Gives you more confidence and peace of mind" • "It enables me to discuss all aspects of IPF and ask questions that may seem insignificant" • "They have changed my life, they have given me freedom" • "They put my mind at rest regarding the side effects".
Hoffman <i>et al</i> (2021) (5) Australia	Determine the proportion of people with ILD referred to PR program; and explore participants' experiences and reasons of non-participation or non-completion of the program. 2015 – 2019	Semi-structured interviews	Various ILD (43% IPF) 21 completed interviews Mean age (SD): 71 (6)	* <i>Same intervention as Dowman et al (2017)</i> PR program <ul style="list-style-type: none"> • Duration: 8 weeks • Frequency: twice/week • Number of sessions: 16 <p>Components:</p> <ul style="list-style-type: none"> • Supervised exercise training • Unsupervised home exercise program • Optional educational lectures 	Outpatient <ul style="list-style-type: none"> • In person/ remote • Group/ individual 	Three major themes: <ul style="list-style-type: none"> • Valued components of PR program Subthemes: <ul style="list-style-type: none"> - Supervision/individualised program - Build confidence in exercising - Education sessions - Peer support • Limited knowledge about PR • Barriers to attending PR Subthemes: <ul style="list-style-type: none"> - Lack of perceived benefits - Fear of exercise - Accessibility

				<p>Materials used:</p> <ul style="list-style-type: none"> • Home exercise diary • Education manual 		- Too sick to attend
Igai <i>et al</i> (2022) (6) Japan	<p>Evaluate the effects of a dignity-centred palliative care program on self-esteem, QoL, anxiety, depression, dyspnoea, cough, program satisfaction and the acceptability of the program.</p> <p>18 Apr 2018 – 18 Mar 2019</p>	<p>Mixed methods:</p> <ul style="list-style-type: none"> • Pre-post study (prospective) • Semi-structured interviews 	<p>IPF</p> <p>12</p> <p>Mean age (SD): 77.3 (4.6)</p>	<p>Dignity-centred palliative care program including clinic and home visits</p> <ul style="list-style-type: none"> • Duration: 45 days • Frequency: 2 clinic visits; 1 home visit <p>Components:</p> <ul style="list-style-type: none"> • Palliative care • Discussion of various topics including self-management, symptom management and observation, daily activities and life review <p>Materials used:</p> <ul style="list-style-type: none"> • Booklet 	<p>Outpatient / home</p> <ul style="list-style-type: none"> • In person • Individual 	<p>Nine participants who maintained or had an improvement in self-esteem identified the following themes:</p> <ul style="list-style-type: none"> • Getting information about illness • Changing thinking and behaviours to cope with physical and psychological distress • Supported by interactive interchange • Holding a positive attitude for living with IPF <p>Three participants who had a decline in self-esteem identified the following themes:</p> <ul style="list-style-type: none"> • Uncertainty about the progress of IPF • Uncertainty about their prognosis • Continued self-management • Do not need the life review
Kalluri <i>et al</i> (2021) (7) Canada	<p>Explore the effects of self-management education and action planning on self-efficacy, perceptions of symptoms and symptom management strategies.</p> <p>Aug 2018 - Jan 2019</p>	<p>Mixed methods:</p> <ul style="list-style-type: none"> • Post intervention evaluation • Semi-structured interviews 	<p>IPF</p> <p>Questionnaires=12</p> <p>Semi-structured interviews=13</p> <p>Mean age (range): 71 (59-83)</p>	<p><i>* Same intervention as Kalluri et al (2018) with additional focus on patient education and action planning</i></p> <p>Multidisciplinary care model that adopts an early integrated palliative approach focusing on early symptom management and ACP with emphasis on community-based care</p> <ul style="list-style-type: none"> • Duration: mean month between first visit and death (SD) – IG=14.4 (13.3); CG=17.4 (17) 	<p>Outpatient / home</p> <ul style="list-style-type: none"> • In person • Individual 	<p>Self-management strategies and education appeared to facilitate participants to manage their illness with confidence and dignity.</p> <p>Four non-discrete themes:</p> <ul style="list-style-type: none"> • Participants integrated and personalised coping strategies • Participants became intentional and confident • Participants shifted focus to living well • Participants engaged in anticipatory planning

				<ul style="list-style-type: none"> Frequency: once every 3 months (clinic visits); in between clinic visits (community care team visits) <p>Components:</p> <ul style="list-style-type: none"> Patient education ACP Action plans (written/verbal) Goal setting 		
Khor <i>et al</i> (2021) (8) Australia	<p>Test the feasibility and acceptability of conducting a RCT to evaluate the use of a hand-held fan for dyspnoea management.</p> <ul style="list-style-type: none"> Study period: <i>unclear</i> 	<p>Mixed methods:</p> <ul style="list-style-type: none"> RCT Semi-structured interviews <p>Hand-held fan (IG) vs No hand-held fan (CG)</p>	<p>Fibrotic ILD (33% IPF)</p> <p>30 completed interviews</p> <p>Mean age (SD): CG=71.7 (7.3) IG=73.7 (10.5)</p>	<p>Use of hand-held fan</p> <ul style="list-style-type: none"> Duration: 2 weeks <p><i>Frequency and number of times use depends on the participant</i></p> <p>Components:</p> <ul style="list-style-type: none"> Participants received instructions to use the fan at home and during outing for symptom management <p>Materials used:</p> <ul style="list-style-type: none"> Hand-held fan 	<p>Community / Home</p> <ul style="list-style-type: none"> Remote Individual 	<p>Three major themes:</p> <ul style="list-style-type: none"> Varying initial attitudes towards using a handheld fan as an intervention (scepticism, uncertainties and expectation of beneficial effects) Benefits of using a handheld fan (relieve of dyspnoea sensation, a sense of security, relaxation and the ease of use in daily life) Relative effects of handheld fans, oxygen, and inhaler therapies for symptom management <p>One minor theme:</p> <ul style="list-style-type: none"> Challenges of using a handheld fan (embarrassment when using the fan in public and difficulties with sourcing a fan)
Lindell <i>et al</i> (2010) (9) USA	<p>Test whether participation in a disease management program improves symptom burden and perceptions of QoL in people with IPF and their carers.</p>	<p>Mixed methods:</p> <ul style="list-style-type: none"> RCT Open-ended interviews <p>PRISM program (IG) vs No PRISM program (CG)</p>	<p>IPF</p> <p>21 patient/carer dyads CG=11 IG=10</p> <p>Mean age (SD): CG – patients=67.1 (11.9); carers=67 (8.6)</p>	<p>Disease management program (PRISM: Program to Reduce Symptoms and Improve Lifestyle Management)</p> <ul style="list-style-type: none"> Duration: 6 weeks Frequency: weekly Number of sessions: 6 <p>Components:</p>	<p>Community</p> <ul style="list-style-type: none"> In person Group 	<p>Three themes:</p> <ul style="list-style-type: none"> Did not feel isolated when participating in a disease management program Able to put my disease into perspective Felt it was important to participate in research to help others with the disease

	<ul style="list-style-type: none"> Study period: <i>unclear</i> 		<p>IG – patients=65.2 (10.3); carers=63.3 (12.7)</p>	<ul style="list-style-type: none"> Patient education <p>Materials used:</p> <ul style="list-style-type: none"> A book – ‘Feeling good: the new mood therapy’ for both groups; IG used the book in group education sessions 		
Lo <i>et al</i> (2007) (10) China	<p>Examine results of a community rehabilitation program held in a rural village.</p> <p>Mar 2005 - Dec 2005</p>	<p>Post intervention evaluation – qualitative feedback</p>	<p>Pneumoconiosis</p> <p>1st phase=40 2nd phase=14</p> <p>Mean age (range): 2nd phase=41.1 (28-48)</p>	<p>2-phase rehabilitation program including one initial group education and two home visits</p> <ul style="list-style-type: none"> Frequency: home visits delivered 2 months apart Number of session/visits: 1 group sessions (phase 1); 2 home visits (phase 2) <p>Components:</p> <ul style="list-style-type: none"> Patient education Home management and modification (phase 2) Goal setting (phase 2) 	<p>Community / home</p> <ul style="list-style-type: none"> In person Group/ individual 	<p>General participant feedback on the program:</p> <ul style="list-style-type: none"> A better knowledge and understanding of pneumoconiosis Understanding that there were strategies in coping with and managing the disease and dyspnoea in daily living Demonstration of a strong motivation to learn the coping strategies for preventing further deterioration of their health Reduced anxiety Increased confidence in performing light duties in farming and household tasks
Moor <i>et al</i> (2021) (11) Netherlands	<p>Investigate the feasibility of an online home monitoring application and optimal frequency of home spirometry.</p> <p>Study period: <i>unclear</i></p>	<p>Pre-post study (prospective)</p>	<p>Sclerosis-associated ILD</p> <p>10</p> <p>Mean age (SD): 60.3 (9.9)</p>	<p>Home spirometry and monitoring application (ILD-online)</p> <ul style="list-style-type: none"> Duration: 3 months Frequency: daily home spirometry for the first 6 weeks; 3 times/week for the second 6 weeks <p>Components:</p> <ul style="list-style-type: none"> Home spirometry Self-monitoring and online reporting of symptoms Access to an overview of spirometry results 	<p>Home</p> <ul style="list-style-type: none"> Remote Individual 	<p>Patient experiences with home monitoring were positive:</p> <ul style="list-style-type: none"> All participants considered the monitoring application and spirometer easy to use. None considered home spirometry burdensome 90% of participants found it pleasant to see an overview of their lung function over time and would be willing to perform weekly FVC measurements for a prolonged period of time for study purposes 70% of participants stated that home monitoring could provide them with more insights into their disease course Only two participants reported that they had encountered minor technical issues

				<ul style="list-style-type: none"> • Patient education • eConsultation <p>Materials used:</p> <ul style="list-style-type: none"> • Mobile application • Hand-held spirometer • Tablet • Video and weblink providing information about IPF and medication use 		<ul style="list-style-type: none"> • All participants would recommend home monitoring to other patients with sclerosis-associated ILD • 90% would like to continue using the monitoring application in routine daily care
Sharp <i>et al</i> (2017) (12) UK	<p>Determine the sustained benefits of a PR program; identify baseline characteristics associated with the responses; and evaluate PR experiences using qualitative assessment.</p> <p>Study period: <i>unclear</i></p>	<p>Mixed methods:</p> <ul style="list-style-type: none"> • Pre-post study (retrospective audit) • Semi-structured focus group 	<p>Various ILD (35% IPF)</p> <p>79</p> <p>Mean age (SD): 68.8 (11.9)</p>	<p>PR program</p> <ul style="list-style-type: none"> • Duration: 6 weeks • Frequency: twice/week • Number of sessions: 12 <p>Components:</p> <ul style="list-style-type: none"> • Supervised exercise training • Unsupervised home exercise program • Educational sessions <p>Materials used:</p> <ul style="list-style-type: none"> • PowerPoint presentation • Handouts 	<p>Outpatient</p> <ul style="list-style-type: none"> • In person/remote • Group/individual 	<p>Suggestions for development of PR program in ILD:</p> <ul style="list-style-type: none"> • Longer sessions to give more time for exercise • Longer course duration • To enable carers to be present for at least some of the course, to benefit from the educational component • On-going supervised exercise sessions after course completion • Specific ILD focused lectures and content more tailored to ILD concerns (e.g. oxygen use, diet, control of breathing and entitlements to social support and benefits advice) <p>Experience of the PR program:</p> <ul style="list-style-type: none"> • All felt the program was valuable, especially the social elements and its role in reducing feelings of isolation • Many felt there was insufficient time for exercise • The program was too short • Concern over the predominance of COPD, with participants reporting feeling distinct and isolated from the group, as well as

						<p>feelings of stigma due to oxygen use</p> <ul style="list-style-type: none"> • Many patients expressed anxiety about unsupervised exercise after PR
<p>Tikellis <i>et al</i> (2020) (13) Australia</p>	<p>Report the experiences of people participated in the Peer Connect Service.</p> <p>2018</p>	<p>Semi-structured telephone interviews</p>	<p>PF</p> <p>32</p> <p>Primary peer=16</p> <p>Secondary peer=15</p> <p>Both primary and secondary peer=1</p> <p><i>* Primary peers – those agreed to initiate contact</i></p> <p><i>* Secondary peers – those seeking a peer match</i></p> <p>Mean age (SD): 71 (7)</p>	<p>Peer Connect Service that matches people with PF with similar disease experience and demographic background for mutual support</p> <p>Number of staff contacts: 7</p> <p><i>Duration and frequency of contacts between peers depends on the participants</i></p> <p>Components:</p> <ul style="list-style-type: none"> • Peer support 	<p>Community / home</p> <ul style="list-style-type: none"> • Remote • Individual 	<p>Major themes identified by both primary and secondary peers:</p> <p>Major themes:</p> <ul style="list-style-type: none"> • Positive value of shared experience • Mutual support • Importance of shared personal characteristics • Face-to-face meetings desirable • Ongoing contact not needed <p>Minor theme:</p> <ul style="list-style-type: none"> • Death of a peer <p>Themes identified by primary peers only:</p> <p>Major themes:</p> <ul style="list-style-type: none"> • Role is not to give medical advice • Setting limits <p>Minor theme</p> <ul style="list-style-type: none"> • Unmet support needs of primary peers

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