

Supplement 5.1.1. Between-groups mean differences and mean change from baseline within intervention group in RCTs measuring exercise capacity using the 6-minute walk test (6MWT) (n=15)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	6-minute walk distance		Number of participants in intervention group
						Between-groups mean difference	Mean change from baseline in intervention group	
Cerdán-de-las-Heras <i>et al.</i> (1)	RCT	IPF	PR, telerehab	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing treatments • Self-monitoring • Managing physical symptoms • Psychosocial support 	12 weeks	39.5 * p = 0.03	8.5	15
Dowman <i>et al.</i> (2)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Sexuality/self-esteem 	8 weeks	ILD: 25 p = 0.03 IPF: 31 * p = 0.006	ILD: 23 IPF subgroup: 27	ILD: 74 IPF subgroup: 32
Holland <i>et al.</i> (2008) (3)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Self-monitoring 	8 weeks	ILD: 35 * p = 0.01	ILD: 31.2 * IPF subgroup: 25.1	ILD: 30 IPF subgroup: 20
Jackson <i>et al.</i> (4)	RCT	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Managing treatments • Managing physical symptoms • Understanding disease • Psychosocial support 	3 months	9.1 (NS)	-6.2	11

Jarosch <i>et al.</i> (5)	RCT	IPF	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Goal setting • Psychosocial support 	3 weeks	61 * p = 0.006	54.7 *	34
Ku <i>et al.</i> (6)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Managing treatments • Self-monitoring • Understanding disease • Psychosocial support 	8 weeks	23.8 p = 0.037	27	20
Naz <i>et al.</i> (7)	RCT	Sarcoidosis	PR, outpatient	<ul style="list-style-type: none"> • Home exercise program • Self-monitoring • Managing physical symptoms 	12 weeks	67.3 * p = 0.009	44.3 *	9
Nishiyama <i>et al.</i> (8)	RCT	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education 	10 weeks	46.3 * p = <0.01	42 *	13
Perez-Bogerd <i>et al.</i> (9)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Psychosocial support 	6 months	72 * p = <0.001	49 *	30
Prajapat <i>et al.</i> (10)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Understanding disease • Psychosocial support 	8 weeks	38.2 * p = <0.05	54.7 *	18
Shen <i>et al.</i> (11)	RCT	IPF	Breathing exercise training, outpatient/home-based	<ul style="list-style-type: none"> • Home exercise program • Managing physical symptoms 	12 months	55 * p = 0.041	-27.3	30
Vainshelboim <i>et al.</i> (2014) (12) Vainshelboim <i>et al.</i> (2016) (13)	RCT	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing physical symptoms 	12 weeks	81 * p = <0.001	70.4 *	13w= 15

Zaki <i>et al.</i> (14)	RCT	ILD	PR with IMT, outpatient	<ul style="list-style-type: none"> • Behavioural modification • Managing physical symptoms • Psychosocial support 	8 weeks	47.9 * P = 0.01	74.6 *	26
Zhou <i>et al.</i> (15)	RCT	IPF	PR (Daoyin), outpatient/ home-based	<ul style="list-style-type: none"> • Home exercise program • Managing physical symptoms • Psychosocial support 	2 months	48 * p = 0.001	60.4 *	32

6MWD: 6-minute walk distance; RCT: randomised controlled trial; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; IMT: inspiratory muscle training; ADL: activity of daily living.

* Mean change reached the minimal important difference of 30-33 meters for people with ILD. Positive value indicates improvement (17).

Note: Data reported by a total of 15 out of 16 RCTs that measured exercise capacity with 6-minute walk test are included in this table (one RCT did not report data immediately post-intervention (16). Two RCTs reported the same data (12, 13).

Supplement 5.1.2. Mean change from baseline within intervention group in non- RCTs measuring exercise capacity using the 6MWT (n=32)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	Mean change in 6MWD from baseline in intervention group	Number of participants
Arizono <i>et al.</i> (18)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education 	10 weeks	26.9	22
Brunetti <i>et al.</i> (19)	Pre-post study (retrospective)	ILD	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Psychosocial support 	3-4 weeks	52.5 *	240
Chéhère <i>et al.</i> (20)	Pre-post study (prospective)	Fibrotic idiopathic interstitial pneumonia	PR, home-based	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Goal setting • Psychosocial support • Sexuality/self-esteem 	8 weeks	23	19
da Fontoura <i>et al.</i> (21)	Pre-post study (retrospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing disease/comorbidities/ADLs • Psychosocial support 	12 weeks	58 *	31
Deniz <i>et al.</i> (22)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms 	8 weeks	49.7 *	57
Devani <i>et al.</i> (23)	Pre-post study (retrospective)	ILD/restrictive disease	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Psychosocial support 	8 weeks	61.8 *	100
Elganady <i>et al.</i> (24)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing disease/comorbidities/ADLs • Preventing infections/exacerbation 	6 weeks	132.8 *	20
Ferreira <i>et al.</i> (2006) (25)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Psychosocial support 	8 weeks	39.6 *	28

Ferreira <i>et al.</i> (2009) (26)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support • Palliation and EOL planning 	6-8 weeks	56 *	99
Fuschillo <i>et al.</i> (27)	Pre-post study (retrospective)	ILD	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Managing physical symptoms 	4-6 weeks	68.5 *	38
Grongstad <i>et al.</i> (28)	Pre-post study (prospective)	Sarcoidosis	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Understanding disease • Psychosocial support 	4 weeks	27	41
Guler <i>et al.</i> (29)	Cohort	ILD	PR, outpatient/ inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Understanding disease • Psychosocial support 	Outpatient: 6-12 weeks Inpatient: 2-4 weeks	Inpatient: 55 * Outpatient: 34 *	Inpatient: 196 Outpatient: 505
Holland <i>et al.</i> (2012) (30)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Self-monitoring 	8 weeks	ILD: 43 * IPF: 21	Whole cohort: 42
Huppmann <i>et al.</i> (31)	Pre-post study (prospective)	ILD	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Psychosocial support 	30 (1) days	46 *	369

Igarashi <i>et al.</i> (32)	Non-randomised controlled study	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Self-monitoring • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support 	3 months	15	13
Kerti <i>et al.</i> (33)	Pre-post study (prospective)	ILD	PR, inpatient	<ul style="list-style-type: none"> • Managing physical symptoms 	4 weeks	ILD: 33 * IPF: 47 *	ILD: 30 IPF: 23
Keyser <i>et al.</i> (34)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Palliation and EOL planning 	10 weeks	52 *	13
Kozu <i>et al.</i> (35)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation 	8 weeks	16.2	36
Lingner <i>et al.</i> (36)	Pre-post study (prospective)	Sarcoidosis	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support 	3 weeks	39.8 *	262
Matsuo <i>et al.</i> (37)	Pre-post study (retrospective)	ILD	PR, outpatient/inpatient	<ul style="list-style-type: none"> • Managing physical symptoms 	6-10 weeks	5.5	28
Nasrat <i>et al.</i> (38)	Non-randomised controlled study	ILD	PR with IMT, outpatient	<ul style="list-style-type: none"> • Managing physical symptoms 	8 weeks	68 *	30
Ochmann <i>et al.</i> (39)	Longitudinal	Silicosis, asbestosis	PR, inpatient	<ul style="list-style-type: none"> • Behavioural modification • Managing physical symptoms 	4 weeks	Silicosis: 19.6 Asbestosis: 2.9	Silicosis: 42 Asbestosis: 66

Ozalevli <i>et al.</i> (40)	Pre-post study (prospective)	IPF	PR, home-based	<ul style="list-style-type: none"> • Home exercise program • Managing physical symptoms 	12 weeks	40.2 *	15
Rammaert <i>et al.</i> (41)	Pre-post study (prospective)	IPF	PR, home-based	<ul style="list-style-type: none"> • Patient education • Home exercise program • Self-monitoring 	8 weeks	-8	13
Rifaat <i>et al.</i> (42)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms • Psychosocial support 	8 weeks	60.6 *	30
Ryerson <i>et al.</i> (43)	Cohort	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing treatments 	6-9 weeks	57.6 *	54
Salhi <i>et al.</i> (44)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Managing disease/comorbidities/ADLs • Understanding disease • Psychosocial support 	12 or 24 weeks	12 weeks PR: 79 * 24 weeks PR: 102 *	12weeks PR : 11 24weeks PR: 10
Sanchez-Ramirez (45)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Palliation and EOL planning 	8 weeks	45.1 *	127
Sciriha <i>et al.</i> (46)	Non-randomised controlled study	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing treatments • Self-monitoring 	12 weeks	52.04 *	60
Swigris <i>et al.</i> (47)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support • Palliation and EOL planning 	6-8 weeks	61.6 *	8

Tonelli <i>et al.</i> (48)	Pre-post study (prospective)	ILD	PR, outpatient/inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support • Palliation and EOL planning 	>24 sessions (6 days/week for 1 st week; twice daily thereafter)	54.1 *	39
Tsang <i>et al.</i> (49)	Pre-post study (retrospective)	Pneumoconiosis	PR, community-based (CBRP)/ home-based (HBRP)	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support 	CBRP: 4-6 weeks HBRP: 8 home visits	CBRP: 59.5 * HBRP: 47.6 *	CBRP: 155 HBRP: 26

RCT: randomised controlled trial; 6MWT: 6-minute walk test; 6MWD: 6-minute walk distance; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; IMT: inspiratory muscle training; ADL: activity of daily living; EOL: end-of-life.

* Mean change reached the minimal important difference of 30-33 meters for people with ILD. Positive value indicates improvement (17).

Note: Data reported by a total of 32 out of 34 studies that measured exercise capacity with 6-minute walk test are included in this table (one pre-post study did not report data (50); one pre-post study did not report data immediately post-intervention (51)).

Supplement 5.2.1. Between-groups mean differences and mean change from baseline within intervention group in RCTs measuring health-related quality of life with St. George's Respiratory Questionnaire (SGRQ) total score (n=14)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	SGRQ total scores		Number of participants in intervention group
						Between-groups mean difference	Mean change from baseline in intervention group	
Bajwah <i>et al.</i> (52)	Mixed methods: RCT & qualitative	IPF	Hospital2Home program with case conference, home-based	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms • Preventing infections/exacerbation • Goal setting • Psychosocial support • Palliation and EOL planning 	2 months	Data not reported for 2m	At 8w: -4.3	22
Cerdán-de-las-Heras <i>et al.</i> (1)	RCT	IPF	PR, telerehab	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing treatments • Self-monitoring • Managing physical symptoms • Psychosocial support 	12 weeks	Data not reported (NS)	1.4	15
Dowman <i>et al.</i> (2)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Sexuality/self-esteem 	8 weeks	ILD: -5.8 p = 0.04 IPF subgroup: -5.7 p = 0.01	ILD: -4.8 IPF subgroup: -3	ILD: 74 IPF subgroup: 32

Gaunaurd <i>et al.</i> (53)	RCT	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Managing treatments • Managing physical symptoms • Understanding disease • Psychosocial support 	3 months	-6.8 (NS)	-4.1	11
Janssen <i>et al.</i> (54)	RCT	IPF	Palliative care program, outpatient	<ul style="list-style-type: none"> • Managing physical symptoms • Understanding disease • Goal setting • Psychosocial support • Palliation and EOL planning 	6 months	3.7 (NS)	3.8	9
Ku <i>et al.</i> (6)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Managing treatments • Self-monitoring • Understanding disease • Psychosocial support 	8 weeks	-8.8 * p = 0.03	-8.9 *	20
Naz <i>et al.</i> (7)	RCT	Sarcoidosis	PR, outpatient	<ul style="list-style-type: none"> • Home exercise program • Self-monitoring • Managing physical symptoms 	12 weeks	-7.3 * p = 0.048	-14.3 *	9
Nishiyama <i>et al.</i> (8)	RCT	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education 	10 weeks	-6.1 p = <0.05	-2.9	13
Perez-Bogerd <i>et al.</i> (9)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Psychosocial support 	6 months	-12 * p <0.001	-7 *	30
Shen <i>et al.</i> (11)	RCT	IPF	Breathing exercise training, outpatient/ home-based	<ul style="list-style-type: none"> • Home exercise program • Managing physical symptoms 	12 months	-8.5 * p = 0.003	-3.7	30
Vainshelboim <i>et al.</i> (2014) (12) Vainshelboim <i>et al.</i> (2016) (13)	RCT	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing physical symptoms 	12 weeks	-9.7 * p = <0.001	-6.9	13w= 15

Zaki <i>et al.</i> (14)	RCT	ILD	PR with IMT, outpatient	<ul style="list-style-type: none"> • Behavioural modification • Managing physical symptoms • Psychosocial support 	8 weeks	-4 p = 0.038	-13.2 *	26
Zhou <i>et al.</i> (15)	RCT	IPF	PR (Daoyin), outpatient/ home-based	<ul style="list-style-type: none"> • Home exercise program • Managing physical symptoms • Psychosocial support 	2 months	-13.6 * p = 0.005	-18.4 *	32

RCT: randomised controlled trial; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; IMT: inspiratory muscle training; ADL: activity of daily living; EOL: end-of-life.

* Mean change reached the minimal important difference of 7 units for people with ILD and IPF. Negative value indicates improvement (55).

Note: Data reported by a total of 14 out of 15 RCTs that measured health-related quality of life with St. George's Respiratory Questionnaire are included in this table (one RCT did not report data immediately post-intervention (16). Two RCTs reported the same data (12, 13).

Supplement 5.2.2. Mean change from baseline within intervention group in non-RCTs measuring health-related quality of life with SGRQ total score (n=15)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	Mean change in SGRQ total score from baseline in intervention group	Number of participants
Arizono <i>et al.</i> (18)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education 	10 weeks	-3.8	22
Deniz <i>et al.</i> (22)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms 	8 weeks	-7.6 *	57
Elganady <i>et al.</i> (24)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing disease/comorbidities/ADLs • Preventing infections/exacerbation 	6 weeks	-24.3 *	20
Igai <i>et al.</i> (56)	Mixed methods: pre-post study (prospective) + qualitative	IPF	Dignity-centred palliative care program, outpatient/home-based	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Sexuality/self-esteem • Palliation and EOL planning 	45 days	-5.5	12
Igarashi <i>et al.</i> (32)	Non-randomised controlled study	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Self-monitoring • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support 	3 months	6.8	13
Kaymaz <i>et al.</i> (57)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing disease/comorbidities/ADLs • Managing physical symptoms • Understanding disease • Psychosocial support 	8 weeks	-10.1 *	10

Lingner <i>et al.</i> (36)	Pre-post study (prospective)	Sarcoidosis	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support 	3 weeks	-6.7	296
Matsuo <i>et al.</i> (37)	Pre-post study (retrospective)	ILD	PR, outpatient/inpatient	<ul style="list-style-type: none"> • Managing physical symptoms 	6-10 weeks	-1.6	28
Naji <i>et al.</i> (58)	Pre-post study (retrospective)	ILD	PR, outpatient/inpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing treatments • Self-monitoring • Managing physical symptoms 	8 weeks	-13.7 *	26
Ochmann <i>et al.</i> (39)	Longitudinal	Silicosis, asbestosis	PR, inpatient	<ul style="list-style-type: none"> • Behavioural modification • Managing physical symptoms 	4 weeks	Silicosis: 0.2 Asbestosis: -1.1	Silicosis: 42 Asbestosis: 66
Rifaat <i>et al.</i> (42)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms • Psychosocial support 	8 weeks	-34.8 *	30
Ryerson <i>et al.</i> (43)	Cohort	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing treatments 	6-9 weeks	-6.1	54
Sanchez-Ramirez (45)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Palliation and EOL planning 	8 weeks	-5.8	127
Sciriha <i>et al.</i> (46)	Non-randomised controlled study	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing treatments • Self-monitoring 	12 weeks	-5.5	60

Tonelli <i>et al.</i> (48)	Pre-post study (prospective)	ILD	PR, outpatient/ inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support • Palliation and EOL planning 	>24 sessions (6days/week for 1 st week; twice daily thereafter)	-12.1 *	39
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RCT: randomised controlled trial; SGRQ: St. George's Respiratory Questionnaire; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; ADL: activity of daily living; EOL: end-of-life.

* Mean change reached the minimal important difference of 7 units for people with ILD and IPF. Negative value indicates improvement (55).

Note: Data reported by a total of 15 out of 16 studies that measured health-related quality of life with St. George's Respiratory Questionnaire are included in this table (one pre-post study did not report data) (41).

Supplement 5.3.1. Between-groups mean differences and mean change from baseline within intervention group in RCTs measuring symptom burden with the Medical Research Council (MRC) Dyspnoea scale (n=9)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	MRC Dyspnoea scores		Number of participants in intervention group
						Between-groups mean difference	Mean change from baseline in intervention group	
Bajwah <i>et al.</i> (52)	Mixed methods: RCT & qualitative	IPF	Hospital2Home program with case conference, home-based	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms • Preventing infections/exacerbation • Goal setting • Psychosocial support • Palliation and EOL planning 	8 weeks	-0.3 (NS)	At 4w: 0	23
Dowman <i>et al.</i> (2)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Sexuality/self-esteem 	8 weeks	ILD: -0.3 p = 0.06 IPF subgroup: 0.009 p = 0.03	ILD: -0.3 IPF subgroup: 0.009	ILD: 74 IPF subgroup: 32
Holland <i>et al.</i> (2008) (3)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Self-monitoring 	8 weeks	ILD: -0.7 * p = 0.04	ILD: -0.6 * IPF subgroup: -0.6 *	ILD: 30 IPF subgroup: 20
Naz <i>et al.</i> (7)	RCT	Sarcoidosis	PR, outpatient	<ul style="list-style-type: none"> • Home exercise program • Self-monitoring • Managing physical symptoms 	12 weeks	-0.8 * p = 0.001	-0.8 *	9
Perez-Bogerd <i>et al.</i> (9)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Psychosocial support 	6 months	0.3 (NS)	0.1	30

Vainshelboim <i>et al.</i> (2014) (12) Vainshelboim <i>et al.</i> (2016) (13)	RCT	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing physical symptoms 	12 weeks	-1.1 * p = <0.001	-0.7 *	15
Wallaert <i>et al.</i> (2020) (59)	RCT	Sarcoidosis	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Goal setting • Psychosocial support • Sexuality/self-esteem 	2 months	Data not reported for 2m	-0.7 *	18
Zaki <i>et al.</i> (14)	RCT	ILD	PR with IMT, outpatient	<ul style="list-style-type: none"> • Behavioural modification • Managing physical symptoms • Psychosocial support 	8 weeks	-1 * p = <0.001	-2 *	26
Zhou <i>et al.</i> (15)	RCT	IPF	PR (Daoyin), outpatient/ home-based	<ul style="list-style-type: none"> • Home exercise program • Managing physical symptoms • Psychosocial support 	2 months	-0.4 * p = 0.005	-0.5 *	32

RCT: randomised controlled trial; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; IMT: inspiratory muscle training; ADL: activity of daily living; EOL: end-of-life.

* Mean change reached the minimal important difference of 0.4 unit for people with ILD and IPF. Negative value indicates improvement (55).

Note: Data reported by a total of 9 out of 10 RCTs that measured symptom burden with the Medical Research Council Dyspnoea scale are included in this table (one RCT did not report data (6)).

Supplement 5.3.2. Mean change from baseline within intervention group in non-RCTs measuring symptom burden with the MRC Dyspnoea scale (n=18)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	Mean change in MRC scores from baseline in intervention group	Number of participants
Brunetti <i>et al.</i> (19)	Pre-post study (retrospective)	ILD	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Psychosocial support 	3-4 weeks	-1 *	240
da Fontoura <i>et al.</i> (21)	Pre-post study (retrospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing disease/comorbidities/ADLs • Psychosocial support 	12 weeks	-1 *	31
Deniz <i>et al.</i> (22)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms 	8 weeks	-0.5 *	57
Elganady <i>et al.</i> (24)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing disease/comorbidities/ADLs • Preventing infections/exacerbation 	6 weeks	-1.2 *	20
Igai <i>et al.</i> (56)	Mixed methods: pre-post study (prospective) & qualitative	IPF	Dignity-centred palliative care program, outpatient/ home-based	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Sexuality/self-esteem • Palliation and EOL planning 	45 days	0	12
Igarashi <i>et al.</i> (32)	Non-randomised controlled study	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Self-monitoring • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support 	3 months	-0.4 *	13

Kaymaz <i>et al.</i> (57)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing disease/comorbidities/ADLs • Managing physical symptoms • Understanding disease • Psychosocial support 	8 weeks	-0.8 *	10
Kerti <i>et al.</i> (33)	Pre-post study (prospective)	ILD	PR, inpatient	<ul style="list-style-type: none"> • Managing physical symptoms 	4 weeks	ILD: -0.8 * IPF subgroup: -0.6 *	ILD: 30 IPF subgroup: 23
Kozu <i>et al.</i> (35)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation 	8 weeks	-0.4 *	36
Lingner <i>et al.</i> (36)	Pre-post study (prospective)	Sarcoidosis	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support 	3 weeks	-0.4 *	262
Nolan <i>et al.</i> (60)	Pre-post study (prospective)	IPF	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Preventing infections/exacerbation • Understanding disease • Psychosocial support 	8 weeks	-0.7 *	113
Ochmann <i>et al.</i> (39)	Longitudinal	Silicosis, asbestosis	PR, inpatient	<ul style="list-style-type: none"> • Behavioural modification • Managing physical symptoms 	4 weeks	Silicosis: -0.3 Asbestosis: 0	Silicosis: 42 Asbestosis: 66
Ozalevli <i>et al.</i> (40)	Pre-post study (prospective)	IPF	PR, home-based	<ul style="list-style-type: none"> • Home exercise program • Managing physical symptoms 	12 weeks	-0.9 *	15
Rammaert <i>et al.</i> (41)	Pre-post study (prospective)	IPF	PR, home-base	<ul style="list-style-type: none"> • Patient education • Home exercise program • Self-monitoring 	8 weeks	0.2	13

Sanchez-Ramirez (45)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Palliation and EOL planning 	8 weeks	-0.2	127
Shimoda <i>et al.</i> (61)	Pre-post study (prospective)	Interstitial pneumonia	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification 	median 9 days (ranged 6-12)	-1	8
Tonelli <i>et al.</i> (48)	Pre-post study (prospective)	ILD	PR, outpatient/inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support • Palliation and EOL planning 	>24 sessions (6days/week for 1 st week; twice daily thereafter)	-1.1 *	40
Trivedi (62)	Non-randomised controlled study	Silicosis	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms • Understanding disease 	4 weeks	PR with education: -1.4 * Education only: -0.4 *	PR with education: 24 Education only: 24

RCT: randomised controlled trial; MRC: Medical Research Council; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; activity of daily living; EOL: end-of-life.

* Mean change reached the minimal important difference of 0.4 unit for people with ILD and IPF. Negative value indicates improvement (55).

Note: Within-group mean change for a total of 18 studies that measured symptom burden with the Medical Research Council Dyspnoea scale are included in this table.

Supplement 5.4.1. Between-groups mean differences and mean change from baseline within intervention group in RCTs measuring psychological wellbeing with the Hospital Anxiety and Depression Scale (HADS) (n=6)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	HADS scores		Number of participants in intervention group
						Between-groups mean difference	Mean change from baseline in intervention group	
Bajwah <i>et al.</i> (52)	Mixed methods: RCT & qualitative	IPF	Hospital2Home program with case conference, home-based	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms • Preventing infections/exacerbation • Goal setting • Psychosocial support • Palliation and EOL planning 	2 months	Data not reported for 2m	A: -1.5 D: 0.4	23
Dowman <i>et al.</i> (2)	RCT	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Sexuality/self-esteem 	8 weeks	Data not reported	ILD A: -0.9 D: -0.6 IPF subgroup A: -0.3 D: -0.1	ILD: 74 IPF subgroup: 32
Janssen <i>et al.</i> (54)	RCT	IPF	Palliative care program, outpatient	<ul style="list-style-type: none"> • Managing physical symptoms • Understanding disease • Goal setting • Psychosocial support • Palliation and EOL planning 	6 months	A: -1.2 (NS) D: 0 (NS)	A: -0.8 D: 0.7	9
Moor <i>et al.</i> (2020) (63)	RCT	IPF	Home spirometry and monitoring program, home-based	<ul style="list-style-type: none"> • Patient education • Managing treatments • Self-monitoring 	24 weeks	A: -0.05 (NS) D: -0.4 (NS)	A: 0.1 D: 0.3	38
Naz <i>et al.</i> (7)	RCT	Sarcoidosis	PR, outpatient	<ul style="list-style-type: none"> • Home exercise program • Self-monitoring • Managing physical symptoms 	12 weeks	A: -2.5 * p = 0.04 D: -3.1 * (NS)	A: -2.3 D: -1.8	9

Wallaert <i>et al.</i> (2020) (59)	RCT	Sarcoidosis	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Goal setting • Psychosocial support • Sexuality/self-esteem 	2 months	Data not reported for 2m	A: -0.5 D: -0.4	18
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RCT: randomised controlled trial; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; ADL: activity of daily living; EOL: end-of-life; A: anxiety; D: depression.

* Mean change reached the minimal important difference of 2.4 units for people with ILD and IPF. Negative value indicates improvement (55).

Note: Data reported by a total of 6 out of 7 RCTs that measured psychological wellbeing with the Hospital Anxiety and Depression Scale are included in this table (one RCT did not report data immediately post-intervention (5)).

Supplement 5.4.2. Mean change from baseline within intervention group in non- RCTs measuring psychological wellbeing with the HADS (n=11)

Study	Study design	Type of participants	Setting delivering self-management components	Self-management components delivered	Study period	Mean change in HADS scores from baseline in intervention group	Number of participants
Chéhère <i>et al.</i> (20)	Pre-post study (prospective)	Fibrotic idiopathic interstitial pneumonia	PR, home-based	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Goal setting • Psychosocial support • Sexuality/self-esteem 	8 weeks	A: -0.9 D: -0.1	19
Deniz <i>et al.</i> (22)	Pre-post study (prospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Managing physical symptoms 	8 weeks	A: -1.7 D: -1.3	57
Igai <i>et al.</i> (56)	Mixed methods: pre-post study (prospective) & qualitative	IPF	Dignity-centred palliative care program, outpatient/home-based	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing treatments • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support • Sexuality/self-esteem • Palliation and EOL planning 	45 days	A: -0.3 D: -1.6	12
Kaymaz <i>et al.</i> (57)	Pre-post study (retrospective)	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing disease/comorbidities/ADLs • Managing physical symptoms • Understanding disease • Psychosocial support 	8 weeks	A: -1.5 D: -3.1 *	10

Lingner <i>et al.</i> (36)	Pre-post study (prospective)	Sarcoidosis	PR, inpatient	<ul style="list-style-type: none"> • Patient education • Behavioural modification • Understanding treatment options • Managing disease/comorbidities/ADLs • Managing physical symptoms • Psychosocial support 	3 weeks	A: -1.6 D: -0.9	296
Moor <i>et al.</i> (2021) (64)	Pre-post study (prospective)	Sclerosis-associated ILD	Home spirometry and monitoring program, home-based	<ul style="list-style-type: none"> • Patient education • Managing treatments • Self-monitoring 	3 months	A: 0.6 D: 0.1	10
Naji <i>et al.</i> (59)	Pre-post study (retrospective)	ILD	PR, outpatient/inpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing treatments • Self-monitoring • Managing physical symptoms 	8 weeks	A: -2.7 * D: -2.4 *	26
Ochmann <i>et al.</i> (39)	Longitudinal	Silicosis, asbestosis	PR, inpatient	<ul style="list-style-type: none"> • Behavioural modification • Managing physical symptoms 	4 weeks	Silicosis A: -2.9 * D: 0.1 Asbestosis A: -2.1 D: 0.1	Silicosis: 42 Asbestosis: 66
Sciriha <i>et al.</i> (46)	Non-randomised controlled study	ILD	PR, outpatient	<ul style="list-style-type: none"> • Patient education • Home exercise program • Managing treatments • Self-monitoring 	12 weeks	A: -0.4 D: 0.5	60
Tsang <i>et al.</i> (49)	Pre-post study (retrospective)	Pneumoconiosis	PR, community-based (CBRP)/ home-based (HBRP)	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Managing treatments • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Psychosocial support 	CBRP: 4-6 weeks HBRP: 8 home visits	CBRP A: 0.1 D: -1.5 HBRP A: -1.6 D: 0.1	CBRP: 155 HBRP: 26

Wallaert <i>et al.</i> (2019) (62)	Pre-post study (retrospective)	Fibrotic idiopathic interstitial pneumonia	PR, home-based	<ul style="list-style-type: none"> • Patient education • Home exercise program • Behavioural modification • Understanding treatment options • Self-monitoring • Managing disease/comorbidities/ADLs • Managing physical symptoms • Preventing infections/exacerbation • Understanding disease • Goal setting • Psychosocial support • Sexuality/self-esteem 	2 months	A: -1.1 D: -0.7	101
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RCT: randomised controlled trial; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; PR: pulmonary rehabilitation; ADL: activity of daily living; EOL: end-of-life; A: anxiety; D: depression.

* Mean change reached the minimal important difference of 2.4 units for people with ILD and IPF. Negative value indicates improvement (55).

Note: Data reported for a total of 11 out of 13 studies that measured psychological wellbeing with the Hospital Anxiety and Depression Scale are included in this table (two pre-post studies did not report data (41, 66)).

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