

Online supplement

**eTable 1. Participant characteristics for all patients included in the construct validation (n=68) and those who report having a carer (n=45).**

<b>Characteristic</b>	<b>Patients (n=68)</b>	<b>Patients with a carer (n=45)</b>
<b>Age, years</b>		
<i>Mean (SD)</i>	66.5 (10.3)	68.4 (8.9)
<b>Gender, n (%)</b>		
<i>Male</i>	42 (61.8)	27 (60.0)
<i>Female</i>	26 (38.2)	18 (40.0)
<b>Location, n (%)</b>		
<i>North West England site 1</i>	39 (57.4)	23 (51.1)
<i>South England</i>	17 (25.0)	12 (26.7)
<i>East England</i>	9 (13.2)	7 (15.6)
<i>North West England site 2</i>	3 (4.4)	3 (6.7)
<b>Type of ILD, n (%)</b>		
<i>IPF</i>	38 (55.9)	25 (55.6)
<b>Time since diagnosis, months</b>		
<i>Mean (SD)</i>	40.4 (53.7)	37.1 (48.2)
<b>Oxygen therapy, n (%)</b>		
<i>Yes</i>	24 (35.3)	20 (44.4)
<i>No</i>	41 (60.3)	23 (51.1)
<i>Missing</i>	3 (4.4)	2 (4.4)
<b>MRC breathlessness scale, n (%)</b>		
<i>1 Not troubled by breathlessness</i>	3 (4.4)	1 (2.2)
<i>2</i>	9 (13.2)	6 (13.3)
<i>3</i>	21 (30.9)	12 (26.7)
<i>4</i>	25 (36.8)	16 (35.6)
<i>5 Too breathless to leave the house/breathlessness on getting dressed</i>	8 (11.8)	8 (17.8)
<i>Missing</i>	2 (2.9)	2 (4.4)
<b>Carer, n (%)</b>		

<i>Spouse</i>	37 (54.4)	37 (82.2)
<i>Son or Daughter</i>	5 (7.4)	5 (11.1)
<i>Other relative</i>	2 (2.9)	2 (4.4)
<i>Friend/Neighbour</i>	1 (1.5)	1 (2.2)
<i>No carer</i>	20 (29.4)	0 (0.0)
<i>Missing</i>	3 (4.4)	0 (0.0)

**eTable 2. Summary of responses to the Caregiver Strain Index (n= 27) and Carers' Support Needs Assessment Tool (n=29).**

<b>Carer Strain Inventory</b> "I am going to read a list of things that other people have found to be difficult. Would you tell me whether any of these apply to you?"			<b>Carers' Support Needs Assessment Tool</b> "Do you need more support with..." Responses: A = No; B = A little more; C= Quite a bit more; D = Very much more; E = Missing					
	<b>Yes (%)</b>	<b>No (%)</b>		<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<b>E</b>
Sleep is disturbed	14 (51.9)	13 (48.2)	...understanding your relative's illness?	14 (48.3)	9 (31.0)	5 (17.2)	1 (3.5)	0 (0.0)
It is inconvenient	3 (11.1)	24 (88.9)	...having time for yourself in the day?	18 (62.1)	5 (17.2)	5 (17.2)	1 (3.5)	0 (0.0)
It is a physical strain	5 (18.5)	22 (81.5)	...managing your relative's symptoms, including giving medicines?	22 (75.9)	4 (13.8)	2 (6.9)	1 (3.5)	0 (0.0)
It is confining	12 (46.2)	14 (53.9)	...your financial, legal or work issues?	20 (69.0)	5 (17.2)	2 (6.9)	1 (3.5)	1 (3.5)
There have been family adjustments	7 (25.9)	20 (74.1)	...providing personal care for your relative?	23 (79.3)	2 ( 6.9)	3 (10.3)	0 (0.0)	1 (3.5)
There have been changes in personal plans	16 (64.0)	9 (36.0)	...dealing with your feelings and worries?	14 (48.3)	12 (41.4)	3 (10.3)	0 (0.0)	0 (0.0)
There have been emotional adjustments	8 (29.6)	19 (70.4)	...knowing who to contact if you are concerned about your relative?	15 (51.7)	6 (20.7)	5 (17.2)	2 (6.9)	1 (3.5)
Some behaviour is upsetting	8 (29.6)	19 (70.4)	...looking after your own health?	20 (69.0)	5 (17.2)	4 (13.8)	0 (0.0)	0 (0.0)

It is upsetting to find [patient] has changed ...	16 (59.3)	11 (40.7)	...equipment to help care for your relative?	21 (72.4)	6 (20.7)	2 (6.9)	0 (0.0)	0 (0.0)
There have been work adjustments	8 (29.6)	19 (70.4)	...your beliefs or spiritual concerns?	26 (89.7)	0 (0.0)	2 (6.9)	0 (0.0)	1 (3.5)
It is a financial strain	8 (29.6)	19 (70.4)	...talking with your relative about his or her illness?	19 (65.5)	4 (13.8)	5 (17.2)	1 (3.5)	0 (0.0)
Feeling completely overwhelmed	13 (48.2)	14 (51.9)	...practical help in the home?	18 (62.1)	5 (17.2)	5 (17.2)	1 (3.5)	0 (0.0)
			...knowing what to expect in the future when caring for your relative?	6 (20.7)	13 (44.8)	4 (13.8)	6 (20.7)	0 (0.0)
			...getting a break from caring overnight?	25 (86.2)	2 (6.9)	1 (3.5)	1 (3.5)	0 (0.0)