

Can self-compassion help us better understand the impact of pulmonary hypertension on those with the condition and their carers? A cross-sectional analysis

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Abstract

Pulmonary hypertension (PH) can have a multifaceted impact both on the affected individual and close family members. However there are relatively few studies that have sought to identify potential protective factors. Individual differences in ability to be self-compassionate are known to be implicated in adjustment in other long-term conditions and are now featuring in the provision of care for a number of conditions. This is a cross-sectional study that investigated the relationship between self-compassion, demographic, PH-related information, and measures of psychosocial functioning in adults with PH ($n = 65$) and caregivers ($n = 29$). Individuals with PH and caregivers of someone with PH completed self-report measures on demographic and clinical factors, anxiety, depression, self-compassion, and in those with PH, health-related quality of life, and in carers, caregiver burden. Data were analyzed using hierarchical regression analyses. Surprisingly, participants with PH and caregivers did not significantly differ on rates of depression ($p = 0.19$) or anxiety ($p = 0.57$) with both scoring relatively high. Components of self-compassion were associated with psychological functioning in both individuals and caregivers. Greater self-compassion was associated with fewer symptoms of anxiety and depression, and greater health-related quality of life in individuals with PH and lower burden in caregivers. More specifically, multiple regression analyses revealed after controlling for age, gender, and duration of PH, self-compassion was a significant predictor of anxiety and depression in people with PH, and of anxiety and caregiver burden in carers. These findings add to the evidence base indicating that there can be a range of burdens experienced by both people living with PH and their wider families. Further, this study uniquely suggests that psychological and supportive interventions that seek to build self-compassion may be useful to develop and test in this clinical group.

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KEYWORDS

anxiety, caregiver burden, depression, health-related quality of life, self-compassion

INTRODUCTION

Pulmonary hypertension (PH) is a set of progressive and life-altering diseases characterized by high blood pressure in the pulmonary circulation.¹ Self-reported symptoms of PH often include breathlessness, as well as fatigue, pain, and syncope or near-syncope.^{2,3} Advancements in our understanding of the condition, diagnostic procedures, medical treatments, and how care is delivered have helped to greatly improve mortality rates associated with PH.^{4,5} High rates of psychological conditions such as anxiety and depression associated with PH are now well established within the literature.^{6,7} As more people are living with the condition and for longer, research is now needed to understand the impact of the disease and importantly identify variables that might be targeted to reduce distress.⁸

Understanding the role played by disease-specific factors alone is highly unlikely to explain individual differences in psychosocial impacts commonly reported in this clinical group.^{9,10} Indeed, in a recent study, prospective and retrospective analyses of data collected as part of a self-help intervention using cognitive-behavioral therapy (CBT) for anxiety in PH, found that changes in unhelpful cognitions and behaviors (as measured by the cognitive behavioral processes questionnaire: CBP-Q) mediated the relationship between intervention group (CBT vs. wait-list) and a reduction in anxiety and depression.¹¹ Participants' cognitions and behaviors from the CBP-Q also predicted anxiety and depression, even after controlling for PH-specific factors such as functional class or self-reported dyspnea.¹² Taken together, the results suggest that individual difference variables in people with PH can help to identify those at risk of developing mood disturbance, as well as serve as a target for intervention.

Given the debilitating nature of PH, the need for regular visits to healthcare services, and intensive treatment such as detailed and complex medication regimens,¹³ it is not that surprising to find support from social networks has a vital effect on patient well-being. In a study of 121 individuals with all forms of PH, receiving support from others was found to moderate the relationship between depression, health-anxiety, and health-related quality of life (HRQoL).⁹ While there are only a limited number of studies investigating carers of people with PH, findings have demonstrated high rates of burden,

including symptoms of depression and reduced HRQoL.¹⁴ Carers have reported physical, relational, financial, and social difficulties, with some evidence suggesting psychosocial factors play an important role. For example, caregivers who experience lower levels of perceived support are more likely to experience symptoms of depression.¹⁵ It is clear that the impact of caring is multifaceted and understanding what factors may help to protect this group is an important research agenda.

Self-compassion has been conceptualized as being made up of a number of facets. It has described as being kind to oneself by taking a patient, gentle, tolerant, accepting, and nonjudgmental approach, especially in times of pain, failure, and life difficulties (sometimes referred to as, *self-kindness vs. self-judgment*). Mindfulness has been viewed as an important technique associated with self-compassion, promoting the practice of actively acknowledging and regulating thoughts and emotions by being curious, open and taking a balanced perspective rather than suppressing challenging emotions, fixating on or over-identifying with them (*mindfulness vs. over-identified*). Moreover, a self-compassionate approach recognizes difficulties are an inevitable part of the human condition and should not be a reason to isolate oneself from others (*common humanity vs. isolation*).^{16,17}

In carers and people with other medical conditions, evidence has demonstrated an association between self-compassion and symptoms associated with functioning and well-being, including depression, anxiety, stress, shame, and HRQoL,^{17–20} regardless of age and gender in some groups.²¹ Such findings have helped to inform and develop a range of stand-alone and supplementary interventions aimed at reducing psychological distress by cultivating compassion towards self and others.^{22,23} Indeed, compassion-based interventions have been associated with significant changes in depression, anxiety, psychological distress, and well-being,²⁴ as well as positive outcomes in terms of quality of life, shame, acceptance of the condition, improved emotion regulation skills, and reduced feelings of isolation.^{22,25} Further, self-compassion-based interventions are now being utilized in many mainstream mental health services to treat common mental health problems.^{26,27}

Self-compassion has been examined in an ever-growing number of clinical populations, although it has not been investigated specifically in people with PH or their carers. As such, the current study explored the

relationship between self-compassion and measures of psychosocial functioning in people with PH and caregivers. First, we compared the two groups (individuals with PH and caregivers) on demographic characteristics, PH-related factors, and measures of psychosocial functioning, namely anxiety and depression. Next, we examined the association between anxiety, depression, HRQoL (in those with PH), caregiver burden (in caregivers), demographic and clinical factors related to PH, and self-compassion. We hypothesized that there would be an association between self-compassion and measures of psychosocial functioning, even after controlling for demographic and PH-specific variables as per other studies in this area.

METHODS

Design

This was a cross-sectional descriptive study. Convenience sampling was used as we recruited participants using services from Pulmonary Hypertension Association United Kingdom (PHA UK). PHA UK is the largest charity in the United Kingdom specific to PH. Favorable opinion was granted by the Schools of Business, Law and Social Sciences Research Ethics Committee at Nottingham Trent University (2021/417).

Participants

To be eligible, participants had to be aged 18 years or older, able to complete self-report questionnaires in English and without help and give informed consent. Individuals with PH had to confirm that they had been given a diagnosis of PH by a healthcare professional. All forms and severity of the condition were accepted. Carers were asked to confirm they provide care, in a non-professional capacity, for someone with PH, such as to a family member or friend. Participants had to live in the United Kingdom—this was to help control for any differences in the provision of care and external support between countries.

Procedure

Participants responded to an advert via PHA UK. Participants were first asked to read a participant information sheet before completing a consent form. Participants were then asked to complete a series of questionnaires using Qualtrics.

Measures

Demographic and clinical factors

Participants reported their age, gender, ethnicity, employment status, and education. Those with PH were asked to report their PH diagnosis, functional class, and years since their diagnosis. To avoid reporting errors or prevent people from self-diagnosing, we gave people the option of selecting “not sure.” Caregivers were also asked what their relationship was to the individual with PH, how many years they had cared for them, and whether they live with another person.

Anxiety

This was measured using the generalized anxiety disorder-7 (GAD-7). This is a seven-item measure asking individuals how often they have been bothered by anxiety related difficulties over the previous 2 weeks.²⁸ A score of 0–4 suggests nonclinical levels of anxiety, 5–9 mild, 10–14 moderate, and 15–21 severe. A score of 8 or greater indicates a clinical level of anxiety. Cronbach's α was 0.91 for individuals with PH and 0.87 for caregivers. The GAD-7 has been previously used in people with PH⁶ and in nonclinical samples.²⁹

Depression

The patient health questionnaire-9 (PHQ-9) was used to measure depression.³⁰ Respondents were presented with nine-items asking how often they have been bothered by a range of depression related difficulties over the previous 2 weeks. Scores of 0–4 suggest minimal symptoms, 5–9 mild, 10–14 moderate, 15–19 moderately severe, 20 or more severe. A score of 10 or more suggests they are experiencing clinical levels of depression. Cronbach's α was 0.93 for individuals with PH and for caregivers. This measure is commonly used in people with PH⁶ and nonclinical samples.³¹

Self-compassion

The self-compassion scale was used, which is a 26-item measure investigating six constructs: self-kindness (5-items), self-judgment (5-items), common humanity (4-items), isolation (4-items), mindfulness (4-items), and over-identified (4-items). Participants were asked to respond to each question using a 5-item Likert scale ranging from “Almost never” to “Almost always.” An

overall self-compassion score was calculated by reverse scoring non-self-compassion behaviors (self-judgment, isolation, and over-identified) and summing participant's responses. A higher score suggested greater self-compassion.^{16,32} The measure has been used in clinical¹⁷ and nonclinical samples.^{19,33} Internal consistency for overall self-compassion for individuals was 0.88 and caregivers 0.72. α values for each subscale for individuals and caregivers were: self-kindness (0.87; 0.62 respectively), self-judgment (0.86; 0.75), common humanity (0.87; 0.77), isolation (0.79; 0.83), mindfulness (0.82; 0.67), and over-identified (0.85; 0.78).

HRQoL

Participants with PH were asked to complete the emPHasis-10, which is a measure of HRQoL specifically developed for people with PH.³⁴ Participants were asked to score 10 items asking about common challenges that people with PH experience. A higher score suggests lower HRQoL. Cronbach's α was 0.92.

Caregiver burden

The Zarit burden interview was used to measure caregiver burden.³⁵ Caregivers were asked 22-items about the impact of caregiving replying either "Never," "Rarely," "Sometimes," "Quite frequently," or "Nearly always." An overall score of 0–21 suggests little or no burden, 21–40 mild to moderate, 41–60 moderate to severe, and 61–88 severe. It has previously been used in caregivers of people with PH.³⁶ Cronbach's α was 0.92.

Data analysis

Descriptive statistics were used to describe both samples. To compare individuals with PH and caregivers, independent sample *t*-tests were used for continuous variables, and χ^2 analyses for categorical variables. Preliminary correlational analyses using Pearson's correlation coefficient were first performed to examine the relationships between self-compassion, demographics, PH-related factors, anxiety, depression, HRQoL (in people with PH), and caregiver burden (carers). Next, hierarchical multiple regression analyses were conducted. In individuals with PH, anxiety, depression, and HRQoL were used as outcome variables, and predictor variables were entered in the order of demographics (age, gender), years of PH diagnosis, and finally, self-compassion. This allowed us to assess the

contribution of self-compassion after demographic and disease-related factors had been controlled for. Controlling for age, gender and years impacted by PH (illness duration) is consistent with other studies examining self-compassion in long-term health conditions.¹⁷ In carers, anxiety, depression, and caregiver burden were used as outcome variables, with demographics, years of providing care and self-compassion entered as predictors. An α value of 0.05 was used for all statistical analysis. Data was analyzed using SPSS 26.

RESULTS

Individuals with PH versus caregivers

In total, 65 individuals with PH and 29 caregivers took part in the study (Table 1). The groups were well matched on age, ethnicity, and education. Most individuals with PH were female, whereas a more even split was seen in caregivers.

Findings from self-report measures of psychosocial functioning for individuals with PH and caregivers are reported in Table 2. Surprisingly, there were no significant differences between the two groups on scores of depression and anxiety. Overall, 35.4% and 30.8% of individuals with PH scored above the clinical cut off for depression and anxiety, respectively. In caregivers, these values were 27.6% and 20.7%. Most carers (51.7%) experienced mild to moderate levels of caregiver burden, the second largest group reported moderate–severe levels (27.6%), followed by the smallest group experiencing little or no burden (20.7%). No significant differences were observed between individuals with PH and carers on measures of self-compassion. Scores from both groups suggest self-judgment was more commonly observed when compared to other self-compassion related behaviors.

Correlational analyses

Bivariate correlations were performed to examine the relationship between anxiety, depression, HRQoL and demographic, condition-related factors, and self-compassion behaviors in people with PH (Table 3). Age and gender were the only demographics significantly correlated with any of the psychosocial measures. Participants who were female and younger were more likely to report greater levels of anxiety. Of the PH-specific factors, functional class was significantly related with HRQoL, with higher class associated with worse HRQoL. There was a negative association between

TABLE 1 Demographic and clinical factors of individuals with PH ($n = 65$) and caregivers ($n = 29$).

	Individuals with PH <i>n</i> (%)	Caregivers <i>n</i> (%)	<i>p</i>
Age (mean [SD])	56.91 (14.45)	56.03 (14.5)	0.78
Gender			0.001
Male	12 (18.5%)	15 (51.7%)	
Female	53 (81.5%)	14 (48.3%)	
Ethnicity			0.73
White	61 (93.8%)	27 (93.1%)	
Asian	1 (1.5%)	0 (0%)	
Mixed	3 (4.7%)	2 (6.9%)	
Employment			0.07
Employed	16 (24.6%)	10 (34.5%)	
Not employed	6 (9.2%)	3 (10.3%)	
Benefit recipient	12 (18.6%)	1 (3.4%)	
Retired	29 (44.6%)	11 (38%)	
Student	1 (1.5%)	1 (3.4%)	
Full time carer	0 (0%)	3 (10.3%)	
Prefer not to say	1 (1.5%)	0 (0%)	
Education			0.94
High school/college	35 (53.8%)	15 (51.7%)	
Undergraduate or higher	27 (41.5%)	13 (44.8%)	
Prefer not to say	3 (4.7%)	1 (3.5%)	
Living with another person (mode [range])	-	1 (3)	-
Person with PH			-
Parent	-	8 (27.6%)	
Partner	-	18 (62%)	
Child	-	2 (6.9%)	
Friend	-	1 (3.5%)	
PH diagnosis			
Chronic thromboembolic PH	10	-	
Congenital heart disease related PAH	8	-	
Connective tissue disease	5	-	
Familial PH	1	-	
Idiopathic PAH	27	-	

TABLE 1 (Continued)

	Individuals with PH <i>n</i> (%)	Caregivers <i>n</i> (%)	<i>p</i>
Other	4	-	
Not sure	10		
Functional class			
I	4	-	
II	9	-	
III	14	-	
IV	1	-	
Not sure	37		
Years since PH diagnosis	8.23 (9.27)	-	-
Years giving care	-	11.59 (10.74)	-

Abbreviation: PH, pulmonary hypertension.

anxiety, depression, HRQoL, and overall self-compassion suggesting the more self-compassionate an individual was, the fewer symptoms of anxiety and depression they reported in addition to better HRQoL. More specifically, negative subscales of self-compassion were all associated with measures of psychosocial functioning, whereas none of the positive scales were significantly related. Depression was correlated with anxiety ($r = 0.79$, $p < 0.001$) and HRQoL ($r = 0.68$, $p < 0.001$), as were anxiety and HRQoL (0.47 , $p < 0.001$).

Correlation analyses in caregivers demonstrated gender and years providing care were significantly correlated with caregiver burden. Carers who were female and had been providing care for a longer period reported greater levels of burden. Overall, self-compassion was negatively associated with depression, anxiety, and burden. In terms of specific subscales, isolation and over-identifying were significantly related with all measures. In contrast to individuals with PH, positive self-compassion traits, namely self-kindness and common humanity, were negatively correlated with anxiety (Table 4). Depression was correlated with anxiety ($r = 0.75$, $p < 0.001$) and caregiver burden ($r = 0.56$, $p = 0.002$), as were anxiety and caregiver burden ($r = 0.43$, $p = 0.02$).

Regression analyses

A hierarchical multiple regression analysis of individuals with PH, with depression as the outcome variable, showed that age and gender explained 6.6% ($p = 0.12$),

TABLE 2 Measures of psychosocial functioning for individuals with PH ($n = 65$) and caregivers ($n = 29$).

	Individuals with PH		Caregivers		<i>p</i>
	M (SD)	<i>n</i> (%)	M (SD)	<i>n</i> (%)	
Depression	8.62 (6.69)		6.72 (5.61)		0.19
Minimal		21 (32.3%)		11 (37.9%)	
Mild		21 (32.3%)		10 (34.5%)	
Moderate		12 (18.4%)		5 (17.3%)	
Moderately severe		4 (6.2%)		2 (6.9%)	
Severe		7 (10.8%)		1 (3.4%)	
Clinical range		23 (35.4%)		8 (27.6%)	
Anxiety	6.22 (5.78)		5.52 (4.88)		0.57
Minimal		32 (49.2%)		12 (41.4%)	
Mild		17 (26.2%)		13 (44.8%)	
Moderate		9 (13.8%)		2 (6.9%)	
Severe		7 (10.8%)		2 (6.9%)	
Clinical range		20 (30.8%)		6 (20.7%)	
Self-compassion	76.22 (17.84)		75.45 (17.7)		0.85
Self-kindness	12.69 (4.93)		12.38 (3.31)		0.76
Self-judgment	14.97 (5.38)		15.69 (4.28)		0.53
Common humanity	11.88 (3.88)		12.07 (3.67)		0.82
Isolation	11.12 (4.28)		11.93 (4.11)		0.39
Mindfulness	11.57 (3.88)		12.48 (3.03)		0.26
Over-identified	11.83 (4.75)		11.86 (3.73)		0.98
HRQoL	25.99 (11.54)		-		-
Caregiver burden	-		32.34 (15.35)		-
Little or no burden	-			6 (20.7%)	
Mild–moderate	-			15 (51.7%)	
Moderate–severe	-			8 (27.6%)	
Severe	-			0 (0%)	

Abbreviations: HRQoL, health-related quality of life; PH, pulmonary hypertension.

years since diagnosis, 0% ($p = 0.64$), whereas self-compassion explained a significant proportion, 11.7% ($p = 0.005$). For anxiety, age and gender explained 14.8% of the variance ($p = 0.008$). Years since diagnosis did not explain any of the variance, 0% ($p = 0.9$), whereas self-compassion explained an additional 7.4% ($p = 0.02$). Finally, for HRQoL, none of the factors explained a significant amount of the variation, neither did the overall model ($p > 0.05$). In summary, the evidence suggests when controlling for age, gender, and years of living with PH, self-compassion was a significant and unique predictor of anxiety and depression in people with PH. Moreover, when self-compassion was added to the model for anxiety and depression, none of the other

variables (age, gender, and years of diagnosis) remained significant (Table 5).

With anxiety as the outcome variable in a hierarchical multiple regression analysis for caregivers, age and gender explained 7.2% ($p = 0.38$) of the variance. Years caring explained a further 1.6% ($p = 0.52$); however, self-compassion explained 33.4% ($p = 0.001$) of the variance. This mean that after controlling for age, gender and years caring, which were all nonsignificant predictors of anxiety, 33.4% of the variance in the scores of anxiety observed in the current sample could be explained by the measure of self-compassion also indicating it was a significant predictor. For caregiver burden, age and gender explained 24.7% ($p = 0.03$), although gender was

TABLE 3 Bivariate correlation analyses between anxiety, depression, health-related quality of life and demographic, PH-specific measures, and self-compassion in individuals with PH ($n = 65$).

	Anxiety	Depression	HRQoL
Demographic			
Age	-0.33**	-0.19	0
Gender	-0.29*	-0.22	-0.23
Ethnicity	0.05	0.1	0
Employment	-0.21	-0.24	-0.03
Education	0.14	0.13	-0.07
PH specific			
PH diagnosis	-0.25	-0.24	-0.21
Functional class	0.07	0.32	0.67***
Years with PH	0.05	-0.1	0.03
Self-compassion			
Self-kindness	0.02	-0.13	-0.04
Self-judgment	0.51***	0.42**	0.26*
Common humanity	0.12	0.05	0.05
Isolation	0.5***	0.49***	0.36**
Mindfulness	0	-0.05	-0.04
Over-identified	0.56***	0.45***	0.38**

Abbreviations: HRQoL, health-related quality of life; PH, pulmonary hypertension.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

the only significant individual predictor ($p = 0.009$). Years caregiving was also a significant predictor ($p = 0.01$) explaining 17.2% ($p = 0.01$) of the variance, and finally, self-compassion explained a further 9.1% ($p = 0.045$). None of the factors or overall model explained a significant amount of the variation when depression was the outcome variable ($p > 0.05$). To conclude, self-compassion was a significant predictor of anxiety and caregiver burden but not depression. Self-compassion still predicted caregiver burden after controlling for gender and years providing care, which remained significant predictors (Table 6).

DISCUSSION

Our findings add to the small but growing evidence highlighting the role of psychological factors in the burden of PH on individuals and carers. While self-compassion has been suggested as a helpful concept to examine when understanding the impact of illness and how people adjust, as well as a target for intervention in

TABLE 4 Bivariate correlation analyses between anxiety, depression, caregiver burden and demographic, years caring, and self-compassion in caregivers of people with PH ($n = 29$).

	Anxiety	Depression	Caregiver burden
Demographic			
Age	-0.21	-0.22	-0.14
Gender	-0.18	-0.29	-0.49**
Ethnicity	-0.17	0.11	-0.06
Living with others	0.25	0.24	0.22
Employment	0.16	-0.14	0.2
Education	-0.12	-0.09	-0.04
Person with PH	0.06	0.39*	-0.07
Years caring	-0.18	0.1	0.38**
Self-compassion			
Self-kindness	-0.61***	-0.47*	-0.44*
Self-judgment	-0.54**	-0.32	-0.16
Common humanity	0.47*	0.34	0.43*
Isolation	-0.45*	-0.33	-0.22
Mindfulness	0.53**	0.45*	0.57**
Over-identified	-0.36	-0.33	-0.17
	0.59**	0.46*	0.46*

Abbreviation: PH, pulmonary hypertension

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

clinical populations, this study is the first to examine it specifically in the context of PH.

It is important to first note that rates of anxiety (30.8%) and depression (35.4%) in people with PH identified in the present study are comparable to a meta-analysis of mood disorders involving over 2000 patients with PH.⁶ Their analyses revealed the pooled prevalence of depression was 28% (95% CI: 20.5–36.8) and anxiety, 37.1% (95% CI: 28.7–46.4). To help put these rates into context, a study conducted in Germany compared scores on the PHQ-9 between patients with cancer ($n = 2059$) and the general population ($n = 2693$). Results suggested 15% of patients and 6.6% of the general population scored above the cut off.³⁷ Another study in Germany examined the GAD-7 in individuals with a diagnosis of GAD ($n = 73$), people accessing primary care services ($n = 956$) and the general population ($n = 5030$). Rates of 89.6% in the clinical group, 23.3% in the primary care group, and 5.1% in the public were observed.²⁹ Overall, this adds to growing concerns that people with PH are more likely to report symptoms of psychopathology above the clinical threshold, compared to the

TABLE 5 Summary of hierarchical multiple regression analysis for individuals with PH.

Model		<i>B</i>	β	ΔR^2
Depression				
1				0.07
	Age	-0.07	-0.14	
	Gender	-3.03	-0.18	
2				0
	Age	-0.07	-0.14	
	Gender	-3.25	-0.19	
	Years of diagnosis	-0.04	-0.06	
3				0.12**
	Age	-0.03	-0.07	
	Gender	-1.84	-0.11	
	Years of diagnosis	-0.08	-0.11	
	Self-compassion	-0.14	-0.34**	
Anxiety				
1				0.15**
	Age	-0.11	-0.27*	
	Gender	-3.15	-0.21	
2				0
	Age	-0.11	-0.27*	
	Gender	-3.2	-0.22	
	Years of diagnosis	-0.01	-0.02	
3				0.7*
	Age	-0.08	-0.21	
	Gender	-2.22	-0.15	
	Years of diagnosis	-0.03	-0.06	
	Self-compassion	-0.1	-0.3*	
HRQoL				
1				0.06
	Age	0.06	0.08	
	Gender	-7.45	-0.26	
2				0
	Age	0.06	0.08	
	Gender	-7.6	-0.26	
	Years of diagnosis	-0.03	-0.03	
3				0.06
	Age	0.1	0.13	
	Gender	-5.9	-0.2	

TABLE 5 (Continued)

Model	<i>B</i>	β	ΔR^2
Years of diagnosis	-0.07	-0.06	
Self-compassion	-0.17	-0.26	

Note: *B*, unstandardized beta, β , standardized beta, ΔR^2 , increase in the model R^2 .

Abbreviation: HRQoL, health-related quality of life.

* $p < 0.05$; ** $p < 0.01$.

general population and other clinical groups. Notably, the rates of anxiety (20.7%) and depression (27.6%) were also alarmingly high in carers and not significantly different from individuals with PH.

While this is the first study that has administered clinical measures of anxiety to carers of people with PH, depression has been previously explored. A study in the United States asked 35 carers to complete a measure of depression (PHQ-8) reporting 14% ($n = 5$) scored above the cut off.¹⁵ While this value is greater than expected in the general population, our rate may be higher because we used the PHQ-9—this asks the same questions as the PHQ-8 but includes an item assessing whether respondents have had thoughts of self-harm or suicide.³⁸ One reason for choosing the PHQ-8 over the PHQ-9 in the Hwang et al.¹⁵ study was because the perceived risk of suicide was low. However, 20% ($n = 6/29$) of our sample scored on this item. In other words, 20% of the sample of carers had some risk of self-harm or suicide—and 15.4% ($n = 10/65$) of individuals with PH. Carers' symptoms of anxiety and depression should also be viewed in the context of the fact that the minority of our sample were experiencing moderate to severe (27.6%) caregiver burden, with none reporting severe levels (0%). Given burden was associated with anxiety and depression, if carers were more impacted by their caregiving role, their mood difficulties may be even greater.

The psychological impact of living with a long-term, life-limiting health condition on both patients and informal caregivers has been well documented.^{39,40} Our results indicate that routine screening for psychopathologies may be beneficial not only for those with PH but also for their carers. Indeed, care plans should be holistic and reflect the multifaceted impact of PH. Based on the current findings, those who are female and had been providing care for longer may be most at risk. This is consistent with the wider caregiver literature.³⁹ Longer duration of caregiving could be associated with carers' internal resources becoming depleted over time,

TABLE 6 Summary of hierarchical multiple regression analysis for caregivers.

Model		B	β	ΔR ²
Depression				
1				0.12
	Age	-0.08	-0.2	
	Gender	-3.02	-0.27	
2				0.03
	Age	-0.1	-0.26	
	Gender	-2.83	-0.26	
	Years caregiving	0.1	0.18	
3				0.13
	Age	-0.02	-0.5	
	Gender	-1.99	-0.18	
	Years caregiving	0.08	0.15	
	Self-compassion	-0.13	-0.42	
Anxiety				
1				0.07
	Age	-0.07	-0.2	
	Gender	-1.64	-0.17	
2				0.02
	Age	-0.05	-0.15	
	Gender	-1.76	-0.18	
	Years caregiving	-0.06	-0.14	
3				0.33**
	Age	0.07	0.21	
	Gender	-0.57	-0.06	
	Years caregiving	-0.08	-0.18	
	Self-compassion	-0.19	-0.69**	
Caregiver burden				
1				0.25*
	Age	-0.11	-0.11	
	Gender	-14.46	-0.48**	
2				0.17*
	Age	-0.29	-0.27	
	Gender	-13.18	-0.44**	
	Years caregiving	0.64	0.45*	
3				0.09*
	Age	-0.09	-0.08	
	Gender	-11.22	-0.37*	

TABLE 6 (Continued)

Model	B	β	ΔR ²
Years caregiving	0.6	0.42*	
Self-compassion	-0.31	-0.36*	

Note: B, unstandardized beta, β, standardized beta, ΔR², increase in the model R².

*p < 0.05; **p < 0.01.

as well as an increase in financial difficulties and their loved one's symptoms becoming worse resulting in a greater level of dependency—this certainly is supported by the evidence as research has shown an association between caregiver burden and patient quality of life³⁶ as well as patient functional status.³⁹

We accept our hypothesis as we found significant relationships between self-compassion and measures of psychosocial functioning in both individuals with PH and caregivers. Focusing on individuals with PH first, overall self-compassion was related with anxiety, depression and HRQoL (p < 0.05). The multiple regression analyses demonstrated that even after controlling for age, gender, and years living with PH, self-compassion was a significant and unique predictor of depression and anxiety, but not HRQoL.

On closer examination, only non-self-compassion behaviors (self-judgment, isolation, and over-identified) were significantly associated with psychosocial functioning in individuals with PH. While positive aspects of self-compassion may not be a direct protective factor for individuals with PH, non-compassionate behaviors may exacerbate some of the challenges associated with PH. For example, someone with PH who scores low on self-compassion, may be more prone to judging themselves because of their symptoms or decline in functioning. They may unfairly compare themselves to others, or to their own premorbid functioning or abilities. This could precipitate low mood, anxiety, isolation, and loneliness, which individuals may begin to over-identify. The impact of this cycle on other PH-related symptoms such as fatigue and pain remain to be examined. For instance, it is a fair assumption that isolation and low mood could contribute to deconditioning through reduced activity, which could contribute to tiredness. Moreover, in those with other long-term conditions, such difficulties including depression have been shown to negatively impact on treatment adherence and disease management,^{41,42} which may lead to further deterioration of disease-related symptoms. Self-compassion was found to be positively associated with treatment adherence in

conditions such as chronic fatigue syndrome, fibromyalgia, and cancer.⁴³ While there are few studies examining health-promoting behaviors such as medication adherence in people with PH; self-compassion may be an important variable.

The lack of a significant relationship between mindfulness and depression and anxiety should be viewed alongside the findings from a pilot randomized controlled trial, which investigated a group mindfulness-based intervention in people with PAH. While effectiveness was not examined, poor attendance was observed suggesting this approach is less acceptable to this clinical group.⁴⁴ Mindfulness has been an effective tool in reducing self-reported measures of functioning in other clinical population^{45,46}; therefore, future research is required before eliminating it as a useful approach for people with PH.

While HRQoL was correlated with self-compassion, it was not a significant predictor. Intervention studies examining self-compassion in other long-term health conditions have largely found improvements in HRQoL, with results being more mixed for functional status, activity engagement and general health.²² Interestingly, in our study, HRQoL was most strongly related with functional class ($r=0.67$), which in turn was not correlated with either anxiety or depression. The nature of this relationship is consistent with Mai et al's., review discussed earlier, where functional class was not a significant risk factor for depression or anxiety.⁶ This is further evidence to suggest disease-specific variables cannot fully account for psychopathology in PH.

In carers, non-self-compassionate behaviors were associated with anxiety, depression, and caregiver burden (except for self-judgment and depression). While this suggests that uncompassionate behaviors may exacerbate challenges linked with the caregiving role, the fact we also found self-kindness and common humanity to be negatively associated with anxiety hints that it is also a protective factor. This is consistent with the hierarchical multiple regression analyses which found self-compassion to be a unique predictor of anxiety after controlling for demographics and years caring. Psychological interventions, possibly with a self-compassion focus, could be helpful for caregivers of people with PH. Indeed, self-compassion and self-compassion interventions have shown promising findings in carers of people with dementia^{19,47} and terminal illness.⁴⁸ However, any interventional studies in PH have been aimed at patients, with no published studies focusing on caregivers, when it appears there may be an equal need. Our findings support the notion of developing interventions based on principles of

self-compassion for this group, particularly those targeting isolation and over-identification.

Limitations

It is a limitation that we did not examine patient–carer dyads. In other clinical populations, factors such as the level of patient's dependence on their carer, as well as the nature of their relationship (e.g., adult–child dyads) were found to be predictive of caregiver burden.³⁹ Indeed, our analysis suggested an association between the relationship to the person with PH and levels of depression in carers. Exploring patient–carer dyads in PH could provide further insight into the relational impact of the condition, as well as highlight protective practices. While we did attempt to recruit dyads by asking participants to share the invitation with their carer or the person they cared for, we were unable to obtain a sufficient sample. A more helpful recruitment strategy may be to ask people who are accessing healthcare settings, as they are often accompanied by their carer. Of course, this may pose difficulties when generalizing findings to a community sample who may be less impacted by the condition or may not have as severe symptoms.

The current study had a cross-sectional design, which means cause and effect cannot be established; for example, do uncompassionate behaviors precipitate depression, or are they in fact a characteristic of depression. Finally, the number of carers who contributed to this study was modest. That said, a systematic review of published studies ($k=8$) examining this group reported a median sample size of 50. Clearly more research is needed with this group and there is a need for longitudinal studies.

CONCLUSIONS

Self-compassion can help us to better understand symptoms of psychopathology in people with PH and their caregivers. Uncompassionate behaviors were associated with anxiety, depression and HRQoL in those with PH, and caregiver burden in carers. Self-compassion may also be a protective factor for anxiety in carers. It is safe to claim that mood disorders are a common symptom in PH, and rates also appear to be high in caregivers. However, there is a dearth of evidence examining treatments. There is also a worryingly limited number of studies focusing specifically on caregivers. Our findings support the benefits of further examining the use of compassion-based interventions in this clinical

group, particularly as such approaches have been found to be helpful in those with other long-term conditions.

AUTHOR CONTRIBUTIONS

Gregg H. Rawlings developed the concept of the study and was involved in data collection, analysis, and write up. He approved the final manuscript for submission. Barbora Novakova developed the concept of the study and was involved in data collection, analysis, and write up. She approved the final manuscript for submission. Iain Armstrong was involved in the concept of the study. He provided feedback on an earlier version of the manuscript. He approved the final manuscript for submission. Andrew R. Thompson was involved in the concept of the study. He provided feedback on an earlier version of the manuscript. He approved the final manuscript for submission.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data is available upon reasonable request.

ETHICS STATEMENT

Favorable opinion was granted by the Schools of Business, Law and Social Sciences Research Ethics Committee at Nottingham Trent University (2021/417).

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