

ORIGINAL RESEARCH

The common sense model in Raynaud's phenomenon: do illness perceptions account for variance in symptom severity and quality of life?

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Abstract

People with Raynaud's phenomenon (RP) experience poorer mental health and quality of life than the general population, and there is limited evidence for treatment options in RP. The Common Sense Model of illness representations (CSM) is a well-established theoretical model, which has not yet been robustly investigated in RP, but may provide potential avenues for psychological interventions with the ability to explore perceptions and beliefs, such as cognitive behavioural therapy (CBT). The study aims were to investigate illness perceptions and examine the relationship between illness perceptions and symptom severity and quality of life in RP to explore a theoretical basis for potential treatment avenues. A cross-sectional online questionnaire design was employed and 169 adults with RP (primary or secondary) were analysed. Illness perceptions significantly differed between primary and secondary RP types on all but one domain ($p < .05$). Hierarchical multiple regressions indicated that illness perception subscales made a significant unique contribution to the models explaining 65% variance in symptom severity ($R^2 = .65$, $p < .001$) and 30% variance in quality of life ($R^2 = .30$, $p < .001$). This novel study provides preliminary evidence regarding the applicability of the CSM to RP in a clinically meaningful way. CBT, which can specifically target illness perceptions within a wider psychological formulation, may be helpful for individuals with RP who are experiencing psychological distress in relation to symptom severity. Further work is needed to develop outcome measures specific to RP and tailor interventions to manage distress and impaired quality of life.

Key learning aims

- (1) The Common Sense Model is applicable and relevant to Raynaud's phenomenon (RP) and there are important differences between illness perceptions in those with primary and secondary RP subtypes.
- (2) Findings show that illness-specific cognitions make a significant contribution to the variance in symptom severity and quality of life in those with both subtypes of RP, which has notable implications for the assessment, formulation and treatment of psychological difficulties in RP.
- (3) This offers a basis for further replication and development and adaptation of an intervention for this group, drawing on the evidence base for long-term conditions.

Keywords: Common Sense Model; Illness Perceptions; Raynaud's phenomenon; RP

Introduction

Raynaud's phenomenon (RP) is characterised by episodic 'attacks' of vasoconstriction (restricted blood flow) which ranges from intrusive but 'benign', to severe ischaemia which threatens tissue viability (Pauling *et al.*, 2019a). During RP 'attacks' blood flow to extremities is reduced, causing skin discolouration, pain, numbness and paraesthesia (ICD-11, World Health Organization, 2018; Pauling *et al.*, 2019b), which interferes with performance of everyday activities (Shapiro and Wigley, 2017) due to the hands being the most common extremities to be affected. Cold temperature reliably triggers RP episodes; however, a third of attacks are triggered by 'emotional stress', hypothesised as a result of an overactive autonomic nervous system which exaggerates vasoconstriction in RP (Freedman and Ianni, 1983; Hughes *et al.*, 2015).

There are two subtypes of RP, described as 'primary RP' (pRP) and 'secondary RP' (sRP). pRP is independent of any other health condition, being present in 5% of the general population (Garner *et al.*, 2015) and representing approximately 80–90% of RP cases (National Institute for Health and Care Excellence, 2019; National Institute for Health and Care Excellence, 2020b). In sRP, Raynaud's occurs alongside another condition, commonly autoimmune or connective tissue disorders such as systemic sclerosis (SSc), where 95% of patients have sRP (Merkel *et al.*, 2002). When compared with pRP, sRP is recognised as having more severe symptoms (Pauling *et al.*, 2018) with significant medical consequences (Pauling *et al.*, 2019a).

Individuals with RP report higher levels of anxiety and depression and poorer quality of life compared with the general population; those with sRP are more severely affected (Fabian *et al.*, 2019), with around 50% meeting criteria for an anxiety disorder (Sierakowska *et al.*, 2019). Anxiety exacerbates RP symptoms, causing greater frequency and severity of attacks and higher levels of pain (Brown *et al.*, 2001). In conditions similar to RP, where anxiety contributes to distress and symptom exacerbation, (and indeed anxiety as a standalone condition) evidence favours cognitive behavioural therapy (CBT). For example, in irritable bowel syndrome (IBS), which also has unpredictable episodic attacks, CBT successfully reduces symptoms and distress, and enhances quality of life (Windgassen *et al.*, 2019). A systematic review of the mechanisms of change within CBT for IBS found targeting illness-specific cognitions was key to a reduction in anxiety and subsequent improvement in symptom severity and adjustment (Windgassen *et al.*, 2017). Cognition and behavioural response to health and illness are a core component of the CBT model for any health condition, offering promising results for other related conditions such as chronic pain (National Institute for Health and Care Excellence, 2021) and psychological difficulties often seen in physical health problems (National Institute for Health and Care Excellence, 2020a; National Institute for Health and Care Excellence, 2022). There is an emerging evidence base for a biopsychosocial understanding of these conditions, and with it a more holistic and multi-disciplinary approach to treatment is required.

Treatment options for RP are limited, given that pharmacological interventions are often ineffective, and/or with unpleasant side-effects (Hughes *et al.*, 2015; Daniels *et al.*, 2018) and there is currently insufficient evidence to support or refute behaviour change interventions (Daniels *et al.*, 2018), although prior research indicates cognitive affective factors are closely related to symptom severity and quality of life in RP (Irving and Daniels, 2024), indicating that psychological interventions such as CBT may be efficacious. Self-management strategies such as 'keeping warm' and 'minimising emotional stress' are currently recommended for those with RP, to try to manage the impact of symptoms (National Institute for Health and Care Excellence, 2020b). In practice, this guidance is challenging to implement, making it difficult to reduce or minimise RP attacks and leading to the development of coping strategies, such as avoiding activities (Pauling *et al.*, 2018), which are detrimental to quality of life. It is clear more research is needed to identify further treatment avenues, with a focus on both improving quality of life and symptom management (Shapiro and Wigley, 2017), for those who would benefit from support.

Table 1. Illness perception domains within the CSM

Domain	Description
Identity	The label used to describe the illness and symptoms viewed as part of the illness
Consequences	Expected effects and outcomes of the illness
Cause	Personal ideas about the cause of the illness
Timeline	How long the patient believes the illness will last
Cure or control	The extent to which the patient believes they can recover from or control the illness

Adapted from Broadbent *et al.* (2006).

The Common Sense Model of illness representation (CSM; Leventhal *et al.*, 1980) proposes that coping responses to illness are guided by inter-related beliefs called ‘illness perceptions’, which in turn impact upon medical, behavioural and psychological outcomes (Petrie *et al.*, 2007). Illness perceptions are influenced by life experiences, socio-cultural beliefs and knowledge, as well as implicit cognitive and emotional perceptions of illness (Hagger and Orbell, 2003; Petrie and Weinman, 2006). The CSM identifies five cognitive illness perception domains (Leventhal *et al.*, 1980), as outlined in Table 1.

‘Negative’ illness perceptions (for example that illness will have severe consequences) are associated with increased disability, slower recovery and reduced quality of life – independently of medical severity (Petrie and Weinman, 2006). This is replicated in chronic pain (Costa *et al.*, 2016); chronic obstructive pulmonary disease (Zoeckler *et al.*, 2014); ME/chronic fatigue syndrome (Haines *et al.*, 2019); asthma (Kaptein *et al.*, 2010) diabetes (Broadbent *et al.*, 2011) and SSc (Arat *et al.*, 2012).

A recent meta-analysis across medical conditions found that illness perceptions account for between 25 and 30% of the variance in anxiety, depression and quality of life (Dempster *et al.*, 2015). Encouragingly, illness perceptions are amenable to change, for example in response to new information, and are therefore useful targets for psychological intervention (Petrie and Weinman, 2006). The relationships between these variables are undoubtedly complex; however, there is an emerging evidence base for a biopsychosocial understanding of these conditions, and with it a more holistic and multi-disciplinary approach to treatment is required.

To date, no studies have applied the CSM to RP or assessed differences between the two subtypes. This is surprising given its prevalence and strong association with symptom severity, mental health and quality of life. This is a significant gap which, if addressed, offers a foundation for future interventions to successfully target illness cognitions to improve quality of life, as we have seen in many long-term health conditions that are amenable to a cognitive behavioural approach (White, 2001). In the absence of evidence-based treatment options in RP (Daniels *et al.*, 2018), it is important to ascertain whether the CSM may provide a theoretical basis and useful intervention target for those struggling with the psychological impact of living with RP.

Based on previous literature, it was anticipated that illness perceptions would differ between adults with pRP and sRP and that they would be significantly predict quality of life and symptom severity in RP. More specifically:

- (1) Adults with sRP will have higher scores on ‘consequences’, ‘timeline’, ‘identity’, ‘concern’ and ‘emotional response’, and lower ‘personal control’ than those with pRP.
- (2) Adults with sRP will report greater ‘understanding’ of their condition, than those with pRP.
- (3) There will be no statistically significant difference in perceptions of ‘treatment control’ between groups.
- (4) ‘Consequences’, ‘identity’, ‘timeline’, ‘personal control’ and ‘concern’ will significantly predict quality of life and symptom severity in RP, and this relationship will remain when controlling for anxiety and depression.

Method

This study analysed primary data collected as part of a larger project exploring cognitive affective factors in RP (Irving and Daniels, 2024).

Design and procedure

A cross-sectional questionnaire design was used to collect data via an online survey. A Qualtrics link leading to an information sheet, consent and questionnaire measures was shared via social media. Following completion of the study, participants were offered debriefing information. Inclusion criteria were that respondents needed to be adults (aged 18+) with Raynaud's (pRP or sRP).

Participants

Two hundred and sixty-nine participants completed the main survey between June and July 2020 which was advertised via the social media pages of the research team and two Raynaud's charities (Scleroderma & Raynaud's UK and Raynaud's Association). Data from 57 participants were removed due to attrition, two were excluded due to age inclusion criteria (18+) and 14 did not complete measures relevant to this project. The final respondent sample was 196 (87 pRP; 95 sRP; 14 RP type missing).

Measures

Demographic questions included participants' age, gender, ethnicity, education level, marital status, smoking status, RP diagnosis (pRP vs sRP) and illness duration. See Table 2 for details of included measures.

Analysis

Analysis was conducted using SPSS version 26. Alpha levels were set at .05.

Analytic strategy

Screening

During comprehensive data screening (as outlined by Tabachnick and Fidell, 2013), outcome measure data (BIPQ, DASS, BAS-G and ONS4) were found to largely violate assumptions of normality and homogeneity of variance. Bootstrapping methods were therefore employed (MacKinnon *et al.*, 2002) to enable use of powerful parametric tests (Field, 2013) whilst retaining valuable information relating to non-normality of data (Pek *et al.*, 2018; Wright *et al.*, 2011) and avoiding deletion of 'true' values (Bakker and Wicherts, 2014; Wilcox, 2012).

As an exception, non-parametric tests (Spearman's rho) were used to ensure robustness to non-normality during correlation analyses (as recommended by Bishara and Hittner, 2017).

Outliers

Potential outliers were visually identified through inspection of box plots and statistically assessed using pre-determined Z-score cut-offs of $Z > 3.29$, $p < .001$ (Tabachnick and Fidell, 2013). One univariate statistically significant outlier was identified on the DASS Anxiety Scale ($Z = 3.36$) which was a plausible, albeit high, value. However, review of Cook's distance values (Pallant, 2016) indicated it was not influential during analyses.

Table 2. Measures included within Qualtrics survey

Measure	Domain	Details
The Brief Illness Perceptions Questionnaire (BIPQ; Broadbent <i>et al.</i> , 2006)	Illness perceptions	A 9-item self-report questionnaire, adapted from the 84-item Illness Perceptions Questionnaire-Revised (Moss-Morris <i>et al.</i> , 2002). The BIPQ assesses illness perceptions using a single item scale approach whereby five items measure cognitive illness representations ('consequences', 'timeline', 'personal control', 'treatment control' and 'identity') and two items assess emotional representations ('concern' and 'emotional response'). Item 9 has three parts, qualitatively assessing respondents' beliefs about causal attributes of illness. The BIPQ has good test-retest reliability and is appropriate for use across medical conditions (Broadbent <i>et al.</i> , 2006)
The Depression, Anxiety and Stress Scales (DASS-21; Lovibond and Lovibond, 1995)	Depression and anxiety	A 21-item self-report measure containing three 7-item subscales separately measuring depression, anxiety and stress, which have been validated for use with clinical and non-clinical populations (Gloster <i>et al.</i> , 2008; Sinclair <i>et al.</i> , 2012). The DASS-21 was designed to provide distinct measures of depression, anxiety and stress, despite them commonly co-occurring clinically (Clara <i>et al.</i> , 2001). Internal consistency for grouped data was 'acceptable' for Anxiety ($\alpha = .69$) and 'excellent' for Depression ($\alpha = .91$) subscales of the DASS-21. Despite variation between groups, all alpha values were above the cut-off of 0.5, as is appropriate for scales with fewer than 10 items (Pallant, 2016)
The Bath Ankylosing Spondylitis Patient Global Score (BAS-G; Jones <i>et al.</i> , 1996)	Symptom severity	A 2-item self-report measure, requiring participants to use a visual analogue scale to indicate the effect of their condition over (1) the last week and (2) the last 6 months. A global score is calculated by averaging the two scores. Test-retest reliability for the global measure was 'good' at both 24-hour intervals and up to 6 months in the original sample (Jones <i>et al.</i> , 1996; Zochling, 2011) and for use with an alternative clinical population (Madsen <i>et al.</i> , 2010)
The ONS4-Life Satisfaction measure (Tinkler and Hicks, 2011)	Quality of life	In the absence of quality of life measures specific to RP, a broad measure validated for use with a UK population was used. The ONS4-Life Satisfaction is a single item self-report measure, included within the Office for National Statistics Annual Population Survey (Office for National Statistics, 2018) to measure subjective well-being, which is comparable to quality of life (Camfield and Skevington, 2008). Single item scales have been found to have comparable efficacy in measuring quality of life, compared with multiple item questionnaires (de Boer <i>et al.</i> , 2004)

Missing data

2.45% of values across the dataset were found to be missing completely at random (MCAR), as identified by Little's test ($c^2 = 1521.763$, d.f. = 1604, $p = .929$; Parent, 2012). The majority, dispersed throughout the dataset, were replaced by series means, as is appropriate for a large sample with minimal missing data (Tabachnick and Fidell, 2013).

The BIPQ, which had been the final measure within the online questionnaire battery, contained notably higher levels of missing data than other variables, which at 6.9% (> 5%) was 'non-ignorable' (Graham, 2009). The amount of missing data varied across individual BIPQ subscales, ranging from 0.5% (Q2: 'timeline') to 11.2% (Q4: 'treatment control') but a series of two-tailed *t*-tests demonstrated this was not statistically significant ($p > .05$ in all instances). SPSS frequencies indicated that there were more instances of missing BIPQ data from primary RP respondents; however, this was also not statistically significant ($p = .142$, Fisher's exact test, two-tailed). Visual inspection of missing values graphs and Little's MCAR test ($c^2 = 174.788$, d.f. = 161, $p = .216$) indicated BIPQ data were MCAR.

Non-normally distributed, missing BIPQ subscale values were managed using series mean replacement, as is widely used within psychology research (Cook, 2021), thus, avoiding risk of introducing bias or error from *ad hoc* data transformation (Leys *et al.*, 2019). As we are aware that caution is advised when using series mean substitution (Cook, 2021; Scheffer, 2002), for example due to potential loss of variance and subsequent inflated risk of Type 1 errors (McKnight *et al.*, 2007) a sensitivity analysis was completed, comparing results with original data only, as suggested by Thabane *et al.* (2013).

Power analysis

A priori power analysis using G*Power (version 3.1; Faul *et al.*, 2009) indicated that the sample was sufficiently powered for analysis, as a total sample of 118 participants was required to detect a 'medium' effect size (Cohen, 1988) observed in prior related work (Broadbent *et al.*, 2015) using $\alpha = 0.05$, $1-\beta 0.8$.

Statistical analysis

Tables 4 and 5 outline descriptive statistics and between-group differences that were evaluated on demographic and predictor variables. Categorical variables (gender, ethnicity, education, marital status, smoking) were analysed using chi-squared tests for independence, whilst independent samples *t*-tests were used for continuous variables (anxiety, depression, quality of life, symptom severity, BIPQ subscales 1–8). Fisher's exact probability test statistics and likelihood ratios were reported in cases of violation of chi-squared assumptions (Field, 2013).

To enable quantitative analysis, qualitative responses to item 9 of the BIPQ were thematically coded into categorical data. As within prior research (Broadbent *et al.*, 2015) only causal item 1 (top cause) were used for further analyses. Differences in causal attributions between groups were explored using chi-squared tests for independence. Bivariate correlations (Spearman's rho) were calculated to assess the relationships between anxiety, depression, quality of life, symptom severity and the eight continuous BIPQ subscales.

Finally, two bootstrapped hierarchical multiple regressions (1000 resamples) were conducted to assess how much of the variance in (1) symptom severity and (2) quality of life across the whole sample, can be explained by BIPQ subscales. Assumptions for hierarchical multiple regression were met (Pallant, 2016; Tabachnick and Fidell, 2013) and no instances of multi-collinearity were observed (Field, 2013).

As outlined in Table 3, IVs were added in three blocks, using the entry method with RP Type added at step 1 to control for differences between groups. Predictor variables anticipated to be

Table 3. Details of hierarchical multiple regression

Regression 1	Regression 2
DV: Symptom severity	DV: Quality of life
IVs:	IVs:
Step 1:	Step 1:
RP type (group)	RP type (group)
Step 2:	Step 2:
Anxiety	Anxiety
Depression	Depression
Quality of life	Symptom severity
Step 3:	Step 3:
Consequences	Consequences
Timeline	Personal control
Personal control	Identity
Identity	Concern
Concern	Emotional response
Emotional response	

Table 4. Demographic information by group

	Primary RP group (n = 87)	Secondary RP group (n = 95)
	<u>n (%)</u>	<u>n (%)</u>
Gender		
Male	5 (5.7%)	2 (2.1%)
Female	82 (94.3%)	93 (97.9%)
Ethnicity		
White	82 (94.3%)	92 (96.8%)
Black/African/Caribbean/Black British	0 (0%)	1 (1.1%)
Asian/Asian British	0 (0%)	1 (1.1%)
Mixed/multiple ethnic groups	3 (3.4%)	0 (0%)
Other ethnic group	2 (2.3%)	1 (1.1%)
Education level		
Up to GCSEs	1 (1.1%)	15 (15.8%)
GCSEs or equivalent (16+)	4 (4.6%)	7 (7.4%)
A-levels or equivalent (18+)	20 (23%)	33 (34.7%)
Batchelor's degree	35 (40.2%)	24 (25.3%)
Master's degree	16 (18.4%)	12 (12.6%)
Doctorate	9 (10.3%)	2 (2.1%)
Missing	2 (2.3%)	2 (2.1%)
Marital status		
Single	21 (24.1%)	10 (10.5%)
Partnered	15 (17.2%)	9 (9.5%)
Married	43 (49.4%)	66 (69.5%)
Separated	1 (1.1%)	3 (3.2%)
Divorced	5 (5.7%)	6 (6.3%)
Widowed	2 (2.3%)	1 (1.1%)
Smoking history		
Current smoker	0 (0%)	9 (9.5%)
Non-smoker	63 (72.4%)	59 (62.1%)
Ex-smoker	24 (27.6%)	27 (28.4%)
	Mean (SD)	Mean (SD)
Age (years)	42 (12)	51.4 (13)
Illness duration (years)	19.8 (14.7)	18.5 (15)

Table 5. Qualitative responses to BIPQ Q9.1

Cause	Primary RP (<i>n</i> = 87) <i>n</i> (%)	Secondary RP (<i>n</i> = 95) <i>n</i> (%)
Unknown	11 (15.3%)	14 (17.3%)
Hereditary factors	23 (31.9%)	25 (30.9%)
Temperature changes	19 (26.4%)	5 (6.2%)
Trauma/stress	3 (4.2%)	12 (14.8%)
Health factors	10 (13.9%)	19 (23.5%)
Lifestyle	5 (6.9%)	3 (3.7%)
Medical intervention	—	2 (2.5%)
Age	1 (1.4%)	—
Other	—	1 (1.2%)

Table 6. Between-groups comparison scores on BIPQ and predictor variables

	Primary RP	Secondary RP	<i>P</i> -value
	Mean (<i>SD</i>)	Mean (<i>SD</i>)	
Consequences	5.06 (2.16)	6.76 (1.91)	<.001*
Timeline	9.54 (1.20)	9.91 (.44)	.023*
Personal control	3.35 (2.31)	3.89 (2.49)	.127
Treatment control	3.01 (2.64)	5.41 (2.73)	<.001**
Identity	5.83 (2.01)	7.00 (1.70)	<.001**
Concern	4.59 (2.51)	7.01 (2.07)	<.001**
Understanding	5.94 (2.52)	7.59 (2.22)	<.001**
Emotional response	4.53 (2.74)	6.15 (2.51)	<.001**
Anxiety	7.25 (5.17)	9.86 (7.61)	<.001**
Depression	8.30 (8.15)	10.74 (9.53)	.05*
Symptom severity	4.35 (2.31)	5.94 (2.18)	<.001**
Quality of life	6.6 (1.74)	5.55 (2.26)	<.001**

p* < .05, *p* < .001.

potentially confounding (anxiety, depression, quality of life, symptom severity) were added as controls (second step), whilst BIPQ IVs were added in the final (third) step.

Results

Descriptive statistics

As outlined within Table 4, groups significantly differed on education level [$\chi^2(5) = 23.02$, $p = .000$], marital status (likelihood ratio of $\chi^2(5) = 11.52$, $p = .042$) and smoking history [likelihood ratio of $\chi^2(2) = 12.43$, $p = .002$]. Groups did not significantly differ on gender or ethnicity. Between-group differences were statistically significant for the factors that participants stated they believe caused their condition (BIPQ, Q9), [$\chi^2(8) = 20.85$, $p = .008$], as outlined in Table 5.

Between-group differences on illness perceptions and predictor variables

There were statistically significant differences between those with pRP and sRP on all but one illness perception domains, and so it was not felt meaningful to summarise patterns of illness perceptions across RP. Instead, between group patterns of illness perceptions are reported below.

As outlined in Table 6, participants with pRP reported significantly less severe ‘consequences’, $t(172.58) = -5.59$, $p = .000$, a significantly shorter ‘timeline’, $t(107.01) = -2.70$, $p = 0.2$, significantly less ‘treatment control’, $t(180) = -6.01$, $p = .000$, and significantly lower levels of ‘understanding’, $t(180) = -4.70$, $p = .000$, than those with sRP. Participants with sRP reported

significantly higher scores on 'illness identity', $t(169.17) = -4.20, p = .000$, significantly greater 'emotional response' $t(174.61) = -4.15, p = .000$, and significantly higher levels of 'concern', $t(166.91) = -7.06, p = .000$. Groups did not significantly differ on 'personal control', $t(180) = -1.51, p = .13$.

As anticipated, participants with pRP ($M = 7.25, SD = 5.17$) reported significantly lower levels of anxiety ($M = 9.86, SD = 7.61$), $t(166.41) = -2.73, p = .006$, and depression ($M = 8.30, SD = 8.15$) than those with sRP ($M = 10.74, SD = 8.53$), $t(180) = -1.97, p = 0.05$. Those with pRP ($M = 6.6, SD = 1.74$) also reported significantly higher quality of life ($M = 5.55, SD = 2.26$), $t(174.88) = 3.53, p = .000$, and lower symptom severity ($M = 4.35, SD = 2.31$) compared with those with sRP ($M = 5.94, SD = 2.18$), $t(180) = -4.78, p = .000$.

Relationships between variables

Bivariate correlations (Table 7) demonstrated that across the whole sample, BIPQ 'consequences', 'timeline', 'personal control', 'identity', 'concern', 'emotional response', anxiety, depression and quality of life were significantly correlated with symptom severity in expected directions. BIPQ 'consequences', 'personal control', 'identity', 'concern', 'emotional response', anxiety, depression and symptom severity were significantly correlated with quality of life in expected directions. Minor between-group differences were noted when correlations were conducted for pRP and sRP separately. In pRP only, BIPQ 'consequences' and anxiety were both negatively correlated with quality of life, whilst 'timeline' was significantly positively correlated with symptom severity. In sRP only, depression was significantly positively correlated with symptom severity and 'personal control' was significantly positively correlated with quality of life. No instances of multicollinearity were identified according to cut-offs of 0.8 as outlined by Field (2013).

Variance explained by illness perceptions

Both bootstrapped hierarchical multiple regressions (1000 resamples) met assumptions of linearity and homoscedasticity of residuals.

Symptom severity

At Step 1, RP type significantly explained 11% of the variance in symptom severity, $R^2 = .11, F_{1,180} = 22.89, p < .001$. After entry at Step 2 anxiety, depression and quality of life explained an additional 14% of the variance in symptom severity, R^2 change = .14, F change (3,177) = 10.80, $p < .001$. At Step 3 the BIPQ subscales explained an additional 40% of the variance in symptom severity, R^2 change = .40, F change (6,171) = 32.25, $p < .001$. At Step 3, anxiety, $\beta = .041, p < .05$, 95% bootstrapped CI [.003, .079], BIPQ 'consequences', $\beta = .439, p = .001$, 95% bootstrapped CI [.260, .614] and BIPQ 'concern', $\beta = .160, p < .05$, 95% bootstrapped CI [.016, .316], made statistically significant unique contributions to the model. Total variance explained by the model as a whole was 65%, $R^2 = .65, F_{10,171} = 31.51, p < .001$. See Table 8 for summary of results.

Quality of life

At Step 1, RP type explained 6% of the variance in quality of life, $R^2 = .063, F_{1,180} = 12.18, p = .001$. At Step 2 anxiety, depression and symptom severity explained an additional 20% of the variance in quality of life, R^2 change = .20, F change (3,177) = 16.1, $p < .001$. At Step 3, R^2 change was not statistically significant, $p = .09$.

However, at Step 3, RP type ($\beta = -.861, p = .017$, 95% bootstrapped CI [-1.56, -.14]), depression ($\beta = -.089, p = .001$, 95% bootstrapped CI [-.132, -.046]) and BIPQ 'emotional response' ($\beta = -.162, p = .01$, 95% bootstrapped CI [-.273, -.043]) made statistically significant unique contributions to the model. Total variance explained by the model as a whole was 30%, $R^2 = .30, F_{9,172} = 8.32, p < .001$. See Table 9 for summary of results.

Table 7. Bivariate correlations (Spearman's rho) for BIPQ and control variables

	Consequences	Timeline	Personal control	Treatment control	Identity	Concern	Understanding	Emotional response	Anxiety	Depression	Symptom severity	Quality of life
Consequences	—	.248***	-.156*	.132	.696***	.589***	.137	.573***	.373***	.365***	.714***	-.270***
Timeline		—	.047	.124	.197**	.112	.082	.106	.004	.085	.197**	-.090
Personal control			—	.327***	-.130	-.211**	.189**	-.210**	-.129	-.187**	-.177*	.149*
Treatment control				—	.174*	.174*	.237**	.105	.023	-.058	.055	-.032
Identity					—	.593***	.138	.503***	.301***	.217**	.637***	-.154*
Concern						—	.065	.612***	.405***	.209**	.655***	-.218**
Understanding							—	-.021	-.036	.002	.058	.009
Emotional response								—	.399***	.413***	.588***	-.394***
Anxiety									—	.480***	.416***	-.314***
Depression										—	.288***	-.463***
Symptom severity											—	-.238**
Quality of life												—

Significant at * $p < 0.05$, ** $p < 0.01$, *** $p < .001$ (2-tailed).

Table 8. Summary of hierarchical multiple regression analysis – symptom severity

	Step 1			Step 2			Step 3		
	Unstandardised coefficients		β	Unstandardised coefficients		β	Unstandardised coefficients		β
	<i>B</i> [95% CI]	<i>SE B</i>		<i>B</i> [95% CI]	<i>SE B</i>		<i>B</i> [95% CI]	<i>SE B</i>	
RP type	1.591 [.932, 2.209]	.321	.336	1.165 [.485, 1.823]	.332	.246	-.055 [-.539, .432]	.244	-.012
Anxiety				.125 [.078, .174]	.025	.350	.041 [.003, .079]	.018	.115
Depression				-.001 [-.043, .047]	.023	-.005	-.017 [-.045, .013]	.015	-.061
Quality of life				-.098 [-.279, .097]	.095	-.087	-.036 [-.152, .090]	.061	-.032
Consequences							.439 [.260, .614]	.088	.407
Timeline							.150 [-.038, .379]	.102	.057
Personal control							-.059 [-.154, .045]	.049	-.060
Identity							.177 [-.016, .360]	.092	.145
Concern							.160 [.016, .316]	.075	.174
Emotional response							.112 [-.002, .222]	.059	.130
<i>R</i> ² change	.113			.137			.398		
<i>F</i> for change in <i>R</i> ²	22.89**			14.76**			31.51**		

p* < .05, *p* < .001, 95% bootstrapped confidence interval (CI) based on 1000 resamples.

Table 9. Summary of hierarchical multiple regression analysis – quality of life

	Step 1			Step 2			Step 3		
	Unstandardised coefficients		β	Unstandardised coefficients		β	Unstandardised coefficients		β
	<i>B</i> [95% CI]	<i>SE B</i>		<i>B</i> [95% CI]	<i>SE B</i>		<i>B</i> [95% CI]	<i>SE B</i>	
RP type	-1.05 [-1.614, -.434]	.295	-.252	-.673 [-1.242, -.158]	.272	-.161	-.861 [-1.555, -.140]	.353	-.206
Anxiety				.001 [-.058, .057]	.029	.003	-.004 [-.066, .053]	.029	-.013
Depression				-.107 [-.145, -.066]	.020	-.430	-.089 [-.132, -.046]	.022	-.360
Quality of life				-.075 [-.214, .052]	.068	-.085	-.061 [-.254, .125]	.100	-.069
Consequences							-.032 [-.227, .172]	.104	-.034
Personal control							.088 [-.044, .231]	.073	.102
Identity							.123 [-.076, .327]	.100	.115
Concern							.109 [-.063, .279]	.088	.135
Emotional response							-.162 [-.273, -.043]	.059	-.212
<i>R</i> ² change	.063			.201			.039		
<i>F</i> for change in <i>R</i> ²	12.176*			16.1**			1.932		

Sensitivity analyses

Sensitivity analyses were conducted using only complete data (pairwise exclusion of missing BIPQ values) and yielded similar results to those outlined above. Final models explained 72% of variance in symptom severity, $R^2 = .72$, $F_{10,123} = 31.65$, $p < .001$, and 33% of the variance in quality of life, $R^2 = .33$, $F_{9,124} = 6.68$, $p < .001$. This demonstrates that series mean replacement of missing BIPQ values did not unduly influence results.

Discussion

This study addressed an important gap within the literature, being the first to apply the CSM to RP. Aiming to identify and compare illness perceptions across pRP and sRP, this study investigated the relationship between illness perceptions and symptom severity and quality of life in RP, to explore a theoretical basis for potential treatment avenues.

Characteristics of included participants were as expected, given prior research and known between group differences. Both pRP and sRP participants had higher levels of anxiety and depression than the general population (Henry and Crawford, 2005), with sRP respondents scoring within the ‘moderate’ range for depression and anxiety on average (Lovibond and Lovibond, 1995). Quality of life scores were consistent with prior research (Hughes *et al.*, 2015) and as anticipated were lower than the general population for both groups (Office for National Statistics, 2020). Statistically significant between-group differences on anxiety, depression, quality of life and symptom severity echo findings from previous research (Fabian *et al.*, 2019, Hughes *et al.*, 2015; Sierakowska *et al.*, 2019).

A key finding was that illness perceptions significantly differ between pRP and sRP, and so it was not felt meaningful to summarise illness perceptions ‘across RP’ as had been a study aim. Instead, the between-groups pattern of illness perceptions is discussed, which partially supported hypotheses. Participants with sRP reported more severe ‘consequences’, longer ‘timeline’, higher illness ‘identity’, greater ‘emotional impact’ and greater ‘concern’ than those with pRP. SRP participants also reported greater ‘understanding’ and more ‘treatment control’ than those with pRP, reflecting differences between clinical features and patient experience of pRP and sRP (Pauling *et al.*, 2018; Pauling *et al.*, 2019a). Contrary to hypotheses, there was no statistically significant difference between groups on ‘personal control’ which may reflect both the lack of evidence-based treatment interventions for RP (Daniels *et al.*, 2018) as well as the intrusive nature of RP attacks (Pauling *et al.*, 2018) and indicates that the ‘little personal control’ previously reported by SSc participants (van Leeuwen *et al.*, 2020) may apply similarly to those with pRP.

As was anticipated, BIPQ subscales made a statistically significant contribution to overall models predicting both symptom severity and quality of life, when controlling for anxiety and depression. However, in contrast to prior research across medical conditions (Dempster *et al.*, 2015) and within SSc (van Leeuwen *et al.*, 2020), ‘personal control’, ‘timeline’ and ‘identity’ did not make statistically significant contributions to final models. This may reflect variability in the participant sample for this project, as both pRP and sRP groups were pooled to ensure adequate statistical power for analysis. Future research would benefit from an appropriately powered between-groups evaluation of the relationship between illness perceptions and quality of life and symptom severity. The amount of variance in quality of life explained by the final model as a whole was consistent with a prior meta-analysis (Dempster *et al.*, 2015); however, the variance in symptom severity accounted for in the final model in this study was significantly greater than in prior research in carpal tunnel syndrome where BIPQ subscales added 13% variance in symptom severity (Sun *et al.*, 2019). It would be helpful for future research to further explore the reasons for this difference, for example to identify possible mediating/moderating variables which were beyond the scope of this research.

It is possible that the relationship between illness perceptions and symptom severity may vary between medical conditions, according to moderating or mediating factors. Given those with RP are known to experience significant levels of anxiety, which importantly triggers and exacerbates symptoms (Brown *et al.*, 2001), it is notable that the illness perceptions most predictive of symptom severity were ‘consequences’ and ‘concern’, both of which relate to threat appraisal, an important aspect of the well-established cognitive behavioural model of anxiety (Beck and Clark, 1997). Future research is needed to explore the role of variables such as anxiety which potentially mediate the relationship between illness perceptions and symptom severity in RP; however, taken together with the CSM findings, this provides a strong basis from which to develop and adapt existing models of CBT for RP as an adjuvant therapy for this group.

Prior research in IBS has identified differences in the relationships between illness perceptions and quality of life depending on whether measures captured global or individual domains (de Gucht *et al.*, 2015). Although there is a lack of an agreed definition of health-related quality of life, several prominent conceptualisations are multi-dimensional, for example including ‘physical, psychological, social, spiritual, role functioning, and general well-being dimensions of health’ (Finlayson *et al.*, 2004; p. 337). Illness-specific cognitions are likely to have differing relationships with different dimensions of quality of life, but may be more strongly related to symptom severity, which is a less varied construct. As single item measures such as the ONS4 used within this project capture a ‘global’ measure of quality of life, future research would benefit from exploration of these relationships using a multi-dimensional measure specific to health-related quality of life in RP.

Clinical implications

Overall, the findings of this study support the relevance of the CSM in RP, demonstrating that illness specific cognitions make a significant contribution to the variance in symptom severity and quality of life in those with pRP and sRP. In the absence of a robust evidence base for intervention in RP (Daniels *et al.*, 2018) and as illness perceptions have been demonstrated to be amenable (Petrie and Weinman, 2006), this has notable implications for the assessment, formulation and treatment of psychological difficulties in RP. It is important that any psychological intervention takes into account the neurobiological components which underpin exaggerated physiological responses to anxiety in RP alongside treating illness specific perceptions which may serve to maintain the problem (Irving and Daniels, 2024; Moseley and Butler, 2015).

Results highlight the importance of particular illness perceptions to both symptom severity (‘consequences’, ‘concern’) and quality of life (‘emotional response’) in RP, which importantly differ from those found to be significant across medical conditions (Dempster *et al.*, 2015) and within SSc (van Leeuwen *et al.*, 2020). This indicates the importance of considering illness perceptions holistically as part of a neuro-biopsychosocial assessment and formulation to enable appropriately tailored psychological interventions for those with RP.

Psychological interventions such as CBT which specifically target illness perceptions, within a comprehensive wider psychological formulation, may be helpful for individuals with RP who are experiencing psychological distress in relation to symptom severity, particularly the 50% of those with sRP who are known to also experience moderate-severe anxiety disorders (Sierakowska *et al.*, 2019). CBT interventions targeting illness perceptions have been successfully used in IBS (Windgassen *et al.*, 2017), which shares some clinical features with RP such as episodic ‘attacks’ triggered by anxiety. Interventions for RP may sit well within the Improving Access to Psychological Therapies Long Term Conditions pathway as part of a multi-disciplinary approach (IAPT LTC; Panchal *et al.*, 2020) which was developed further as part of the NHS *Five Year Forward View for Mental Health* (Mental Health Taskforce, 2016) to encompass long-term conditions, with the recent NHS Long Term Plan (2019) acknowledging further the reciprocal nature of physical and mental health. However, further work is needed.

Limitations and future research

This study was limited by online recruitment via Qualtrics. While a pragmatic approach to data collection, it obscured the possibility of being able to clinically verify or reliably confirm participants' diagnoses. Future research would benefit from the recruitment of a clinically verified sample; however, the distinct and unique features of RP (white and purple fingers) indicate a good degree of confidence in the self-selected sample.

It is also important to note that the cross-sectional design of this study means that it is not possible to infer how relationships between the variables studied may differ over time. This is notable given that illness perceptions have been found to be amenable to change, evolving for example with lived experience of a health condition or access to new information (Petrie and Weinman, 2006). Similarly, we know that symptom severity may also be changeable for those living with RP, for example sRP symptoms are known to increase in severity and new symptoms may also develop with increasing illness duration (Pauling *et al.*, 2019a). Given that the average illness duration of respondents in this study was notable (19.5 years pRP, 18.5 years sRP), future researchers may wish to further explore these relationships within a heterogeneous group of individuals living with RP. The absence of RP specific outcome measures is a significant barrier in the field, also highlighted in prior research (Daniels *et al.*, 2018; Irving and Daniels, 2024). In the absence of measures specific to RP, symptom severity and quality of life were measured using generic single item questionnaires. Whilst single item measures are a pragmatic option and useful for preliminary and novel research (Waltz *et al.*, 1991; Wanous *et al.*, 1997), they cannot facilitate exploration of multiple dimensions of these constructs. Future research would benefit from building upon these initial findings with development and use of a validated measure of health-related quality of life specific to RP, and perhaps more importantly, building on this research to develop interventions to manage the physical and psychological distress and impaired quality of life for this neglected group.

Conclusion

This study provides preliminary evidence of the applicability of the CSM to RP, identifying different patterns of illness perceptions in individuals with pRP and sRP, as well as demonstrating that illness perceptions significantly contribute to variance in symptom severity and quality of life in RP. Findings have notable implications for the provision of psychological interventions such as CBT which, as part of a wider psychological formulation, target cognitions to improve mental health, symptom severity and quality of life. Future research would benefit from the development of a validated measure of health-related quality of life in RP, and further development which would underpin future interventions.

Key practice points

- (1) It is important to consider illness perceptions as part of a biopsychosocial assessment and formulation to enable appropriately tailored psychological interventions for those with RP.
- (2) Illness perceptions most predictive of symptom severity were 'consequences' and 'concern', both of which relate to threat appraisal, an important aspect of the well-established cognitive behavioural model of anxiety, which is known to trigger episodes.
- (3) Taken together with the support for the relevance of the CSM in RP, this is a strong basis from which to develop and adapt existing models of CBT for this group, which have been successfully used in other long-term conditions.

Further reading

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Data availability statement. The data that support the findings of this study are available from the corresponding author, J.D., upon reasonable request.

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