A brief haemophilia pain coping questionnaire (HPCQ)

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Abstract

Pain coping strategies are important influences on outcomes among people with painful chronic conditions. The pain coping strategies questionnaire (CSQ) was previously adapted for sickle cell disease and haemophilia, but those versions have 80 items, and a briefer version with similar psychometric properties would facilitate research on pain coping. The full-length haemophilia-adapted CSQ, plus measures of pain frequency and intensity, pain acceptance (CPAQ), pain readiness to change (PSOCQ), and health-related quality of life (RAND-36) were completed by 190 men with haemophilia. Items were selected for a 27-item short form, which was completed six months later by 129 (68%) of the participants. Factor structure, reliability and concurrent validity were the same in the long and short forms. For the short form, internal reliabilities of the three composite scales were 0.86 for negative thoughts, 0.80 for active coping and 0.76 for passive adherence. Test-retest reliabilities were 0.73 for negative thoughts, 0.70 for active coping, and 0.64 for passive adherence. Negative thoughts were associated with less readiness to change, less acceptance of pain, and more impaired health-related quality of life, whereas active coping was associated with greater readiness to change and more acceptance of pain. The short form is a convenient brief measure of pain coping with good psychometric properties, and could be used to extend research on pain coping in haemophilia.

Keywords: CPAQ, hemophilia, HPCQ, PSOCQ, RAND-36, SF-36.

Introduction

Pain coping strategies are cognitive, behavioural and emotional responses to pain that play an important role in adjustment, disability and quality of life among those affected by chronic painful conditions. The pain coping strategies questionnaire (CSQ) was first developed for chronic low back pain (Rosenstiel & Keefe, 1983) , and was adapted for sickle cell disease (Gil *et al*., 1989) and haemophilia (Barry & Elander, 2002), two chronic conditions that involve

persistent recurrent pain. In chronic pain conditions such as low back pain, pain is the primary symptom of the disorder, and the causes of pain are often not well understood, whereas pain in sickle cell disease and haemophilia is secondary to a diagnosed disorder and has well understood physiological causes, so measures of pain coping should take account of behaviours that are known to be effective responses to pain. In haemophilia, for example, resting, using ice and treatment with clotting factors are recommended responses to bleeding episodes and would be expected to reduce pain. In the adaptations of the CSQ, therefore, certain items were reworded to make them appropriate to each condition, and subscales were added to cover the range of behaviours that could affect pain coping in each condition.

The original CSQ comprised eight subscales of six items each, called diverting attention, reinterpreting pain sensations, coping self-statements, ignoring pain sensations, praying and hoping, catastrophising, increasing behavioural activities, and increasing pain behaviours, plus two single items about the effectiveness of pain coping: how much control people believed they had over their pain, and how much they were able to decrease it (Rosenstiel & Keefe, 1983). The increasing pain behaviours subscale was dropped from subsequent versions because of low internal reliability. The sickle cell disease version added two subscales about emotional aspects of pain (fear self-statements and anger self-statements), one about avoiding social contact when in pain (isolation), and three about specific pain behaviours relevant to sickling pain (taking fluids, resting, and heat/cold/massage). The haemophilia version comprised the seven subscales with good internal reliability from the original version, four subscales from the sickle cell disease version (fear self-statements, anger self-statements, isolation and resting), plus three new subscales (using treatment factor, using ice, and using painkillers or alcohol). Both the SCD and haemophilia versions also retained the two single-item measures of coping effectiveness.

The haemophilia version had good internal reliability and a three-factor structure, with composite scales called negative thoughts, coping attempts, and passive adherence. Negative thoughts were associated with beliefs about pain being controlled by chance happenings, whereas passive adherence was associated with more frequent visits to health professionals, greater use of analgesics, and beliefs about pain being controlled by doctors (Barry & Elander, 2002). Negative thoughts were associated with concerns about drug use independently of other factors, including frequency of pain and analgesic use (Elander & Barry, 2003).

With 80 items, both the sickle cell disease and haemophilia versions are long, time consuming measures, especially when used alongside other measures. The fact that there were six items for each subscale also meant that many participants found the questionnaire repetitive. A briefer measure of the same constructs, with similar psychometric properties, would enable measures of pain coping to be included in more studies of pain in haemophilia.

A further limitation of both the CSQ and the adaptations for SCD and haemophilia is that contradictory findings have been produced because the questionnaire can be scored in two ways. Individual items can be grouped to give subscale scores, and subscales can be grouped to give composite scale scores (Dozois *et al*., 1996). Factor analytic studies of the original CSQ found different numbers of factors depending on whether individual items or subscales were analysed. Those using subscales found two factors (Riley *et al*., 1999) or three factors (Hill, 1993; Lawson *et al*., 1990; Rosenstiel & Keefe, 1983), whereas those using individual items found four factors (Santavirta *et al*., 1996), five factors (Tuttle *et al*., 1991; Swartzman *et al*., 1994), or six factors (Hastie *et al*., 2004; Riley & Robinson, 1997), and in some cases there were as many as

nine potential factors (Robinson *et al*. 1997; Swartzman *et al*., 1994; Santavirta *et al*. 1996). Factor analyses of the sickle cell disease and haemophilia versions have all to our knowledge been based on subscale scores, and produced either two factors (Gil *et al*., 1989) or three factors (Anie *et al*., 2002; Barry & Elander, 2002) that have clearer and more distinctive meanings than factors derived from the original CSQ.

A two-stage scoring process, with scores summed across subscales that are then combined in composite scales, reduces the transparency of scoring and obscures the contribution of individual items to composite scales, so we wished to produce a version with a standard method for computing composite scale scores from individual items. At the same time, however, we wished to be able to produce subscale equivalent scores, based on two items per subscale rather than six, for comparison with research where subscales were used. Two-item measures have been shown to be valid abbreviated measures of pain beliefs and coping strategies (Jensen *et al*., 2003; Tan *et al*., 2006).

The aim was therefore to produce a briefer measure with a clearer focus on the three composite scales that have been shown to be meaningful in studies of pain coping. This paper describes the process used to select items for the short form, and compares the factor structure, internal reliability, and concurrent validity of the long and short forms.

Methods

The study was a postal questionnaire survey in which participants completed the full-length haemophilia-adapted CSQ, plus measures of pain frequency and intensity, pain readiness to change (Pain Stages of Change Questionnaire), pain acceptance (Chronic Pain Acceptance Questionnaire) at time one, and measures including the short form haemophilia pain coping questionnaire (HPCQ) six months later.

Participants

The sample included men with haemophilia A or B who were aged over 18 and registered with the Haemophilia Society UK. Invitations to participate were sent to 568 individuals, of whom 209 (37%) returned completed questionnaires. Six months later, questionnaires were completed by 140 individuals (67% of participants in the first survey). The sample for this analysis is restricted to individuals with complete pain coping data at baseline (n = 190) and follow-up (n = 129). Sample characteristics are given in table 1.

Measures

Participants completed the full length haemophilia-adapted CSQ as described above (Barry & Elander, 2002). Each item is rated on a seven-point Likert-type scale, with responses scored from 0 (‘never do that’) to 6 (‘always do that’). Scores for each subscale are obtained by summing the scores for each item and dividing by the number of items.

Separate measures of frequency and intensity were obtained for acute and chronic pain. Pain frequency was rated on a 5-point scale where 1 = never, 2 = rarely, 3 = once a week, 4 = more than once a week, and 5 = daily. Pain intensity was rated on a 10cm visual analogue scale, with one end labelled ‘no pain’ and the other ‘worst pain possible’.

The Pain Stages of Change Questionnaire is a 30-item self-report questionnaire measuring readiness to adopt a self-management approach to chronic pain. There are four scales: precontemplation (7 items), contemplation (10 items), action (6 items) and maintenance (7 items). High precontemplation scores indicate little perceived personal responsibility for pain control and little interest in making behavioural changes. High contemplation scores indicate consideration of behavioural changes and increasing awareness of personal responsibility for controlling pain. High action scores indicate involvement in learning self-management strategies to control pain. High maintenance scores indicate incorporation of self-management techniques in daily life and a strong sense of personal responsibility for pain control (Kerns *et al*., 1997).

Table 1. Participant details

	Baseline	6-month follow-up
N	190	129
Mean age (SD, range)	49.2 (12.7, 20-84)	51.6 (12.5, 25-84)
Type of bleeding disorder		
Haemophilia A	151 (79.5%)	101 (78.3%)
Haemophilia B	34 (17.9%)	24 (18.6%)
Not known	5 (2.6%)	4 (3.1%)
Severity		
Severe	102 (53.7%)	71 (55%)
Moderate	16 (8.4%)	12 (9.3%)
Mild	30 (15.8%)	20 (15.5%)
Not known	42 (22.1%)	26 (20.2%)
Marital status		
Single	37 (19.5%)	21 (16.3%)
Married/cohabiting	128 (67.4%)	91 (70.5%)
Divorced/separated	21 (11.1%)	12 (9.3%)
Other	4 (2.1%)	5 (3.9%)

Note: The sample is restricted at both stages to those with complete pain coping questionnaire data.

The Chronic Pain Acceptance Questionnaire is a 34-item self-report measure of the extent to which individuals are able to desist from attempts to avoid or reduce their chronic pain. The revised scoring method was used, in which 20 of the items are scored to give scores for two subscales (activities engagement and pain willingness) and a total pain acceptance score. The activities engagement subscale comprises 11 items about engaging in activities when in pain, and the pain willingness subscale comprises nine items about recognising that avoidance and control are often unworkable methods of adapting to chronic pain. The total score is the sum of the two subscale scores. Higher scores indicate higher levels of acceptance (McCracken *et al*., 2004).

The RAND 36-item Health Survey 1.0 is a 36-item questionnaire giving scores on eight domains of health-related quality of life: physical functioning (10 items), role limitations due to physical health problems (4 items), role limitations due to emotional problems (3 items), energy/fatigue (4 items), emotional well-being (5 items), social functioning (2 items), pain (2 items), and general health (5 items). For each scale, higher scores indicate greater quality of life (Hays et al., 1993; Hays & Morales, 2001; www.rand.org).

Data analysis

The data analysis followed a series of steps to select items for the short form and compare factor structure, reliability and concurrent validity between long and short forms. First, we factor analysed the long form, using both individual items and subscales, to identify the most robust factor structure. Second, we selected items for the short form that met certain criteria in the long form, factor analysed those items to confirm the factor structure was the same, and tested the internal and test-retest reliability of the short form. Third, we tested the concurrent validity of composite scales in the long and short forms, by examining correlations between composite scales and other pain-related measures. Degrees of freedom vary in some of the analyses because of missing data for certain items.

Results

Factor analysis of the long form

Table 2 shows the means and standard deviations for subscales in the long form, together with alpha coefficients of internal reliability, which were above 0.7 for 13 out of 16 subscales. In the factor analysis of subscale scores there were five factors with Eigen values above 1.0, but the scree plot (fig 1) indicated two major factors and a smaller third factor that together accounted for 52% of the total variance. In the factor analysis of individual items there were 20 factors with Eigen values above 1.0, but the scree plot again indicated two major factors and a smaller third factor.

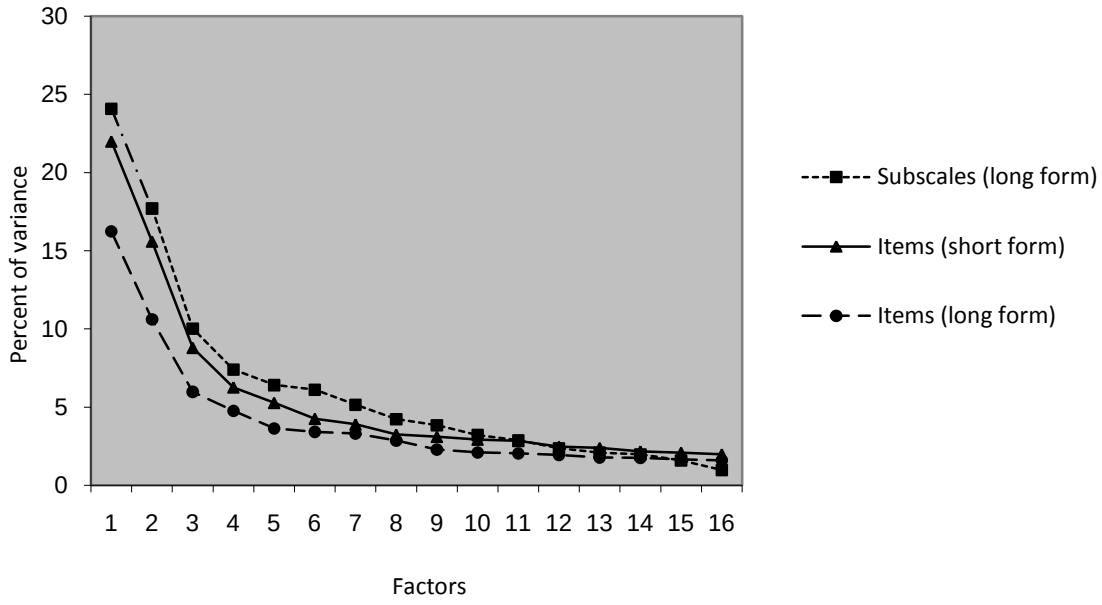
Table 2. Subscales and factors in the long form: Descriptive statistics and loadings of subscales on factors from factor analysis of subscale scores

Subscale	Mean (SD)	Alpha	Factor loadings[1]		
			Negative thoughts	Active coping	Passive adherence
Catastrophising	1.8 (1.4)	0.86	0.89		.34
Anger self-statements	2.0 (1.3)	0.78	0.85		
Fear self-statements	2.6 (1.4)	0.81	0.78		.42
Isolation	2.9 (1.7)	0.91	0.65		
Using alcohol[2]	1.2 (1.6)	0.76	0.53		
Ignoring pain sensations	2.1 (1.2)	0.74		0.81	
Reinterpreting pain sensations	1.4 (1.2)	0.79	0.35	0.79	
Increasing behavioral activities	2.7 (1.0)	0.55		0.67	
Coping self-statements	3.6 (1.2)	0.79		0.66	
Diverting attention	2.3 (1.4)	0.83		0.63	0.41
Resting	3.8 (1.0)	0.62			0.73
Hoping[3]	2.1 (1.4)	0.43			0.61
Using painkillers[4]	3.5 (1.9)	0.86		-0.39	0.58
Using ice[3]	3.0 (2.0)	0.91			0.52
Praying[3]	1.4 (1.8)	0.86			0.42
Using clotting factor[3]	3.3 (2.0)	0.82			0.32

1. Only loadings above 0.3 are shown
2. Two items
3. Three items
4. Four items

Note: Subscales comprise six items unless otherwise indicated. In the long form, hoping and praying were combined, and using alcohol and using painkillers were combined, but in this analysis each was treated as a separate subscale to give the most accurate picture. When hoping and praying were combined, alpha was .70 and the loadings were .46 on negative thoughts and .37 on passive adherence. When using alcohol and using painkillers were combined, alpha was .76 and the loadings were .50 on negative thoughts and .45 on passive adherence.

Fig 1. Scree plots from three factor analyses



Note: For the factor analyses of items, only the first 16 factors are shown.

Three factors were extracted and rotated using the oblique (Oblimin) method, and the loadings of subscales on those rotated factors are shown in table 2. The three factors, interpreted as negative thoughts, active coping and passive adherence, are the same as in previous research with the haemophilia-adapted CSQ (Barry & Elander, 2002) and the sickle cell disease-adapted CSQ (Anie *et al*., 2002).

The short form

Items were selected for the short form if they came from subscales with alpha coefficients of at least 0.5 and factor loadings of at least 0.4, and had item-factor correlations of at least 0.4. That meant no items were included from the hoping, praying, and using clotting factor subscales, and only one was included from the using alcohol subscale. From the items that met those criteria, the two items from each subscale with the highest item-factor correlations were selected. One item from the using painkillers subscale was preferred over another to avoid repetition of very similar items. This resulted in the selection of 25 items, plus the two items about control over pain and ability to decrease it, which were retained as additional single items but were not included in the subscale or factor analyses.

A factor analysis of the 25 items produced six factors with Eigen values above 1.0 but the scree plot again showed two major factors and a smaller third factor that together accounted for 46% of the variance (fig 1). Three factors were extracted and the loadings of items on those rotated factors (table 3) indicated a factor structure the same as in the long form.

Table 3. Rotated factor loadings of items in the short form

	Negative thoughts	Active coping	Passive adherence
It is terrible and never going to get better*	0.80		
I feel I can't stand it any more	0.74		
I worry that the bleeding is never going to stop	0.72		
I think no one wants to hear my problems	0.70		
I have been unlucky and it is not fair*	0.69		
I worry that I really am going to get sick	0.68		
I know I need to get away from everyone	0.67		
I go off by myself	0.60		
I think about getting drunk	0.54		
I try to feel distant from the pain		0.72	
I tell myself that it doesn't hurt		0.68	
I pretend that it is not there		0.67	
I play mental games with myself*		0.61	
I write a letter or plan a project*		0.60	
I think of it as a dull or warm feeling*		0.58	
I tell myself I can overcome the pain		0.55	
I try to think of something pleasant		0.54	
I see it as a challenge*	-0.41	0.52	
I do anything to get my mind off the pain		0.46	
I go and find some ice			0.75
I put an ice pack around the painful area*			0.75
I take painkillers throughout the day			0.64
I take some painkillers			0.62
I lay down on the couch or the bed*			0.61
I go to lie down for a while			0.55

Note: Only factor loadings above 0.4 are shown

* Truncated item wording.

The short form questionnaire is shown in appendix 1. Scores for the three composite scales were computed by adding together the scores for individual items and dividing by the number of items, as shown in the scoring instructions in appendix 2. (The correlations with scores derived from factor analysis, where item scores are multiplied by item-factor loadings, were 0.99, 0.98 and 0.97, indicating that the two methods produced almost identical scores.) For negative thoughts the mean was 2.03 (SD 1.38) and Cronbach's alpha was 0.86. For active coping the mean was 2.42 (SD 1.12) and Cronbach's alpha 0.80. For passive adherence the mean was 3.40 (SD 1.40) and Cronbach's alpha 0.76. The correlations among composite scales were 0.07 (p = .40) between negative thoughts and active coping, 0.36 (p < .001) between negative thoughts and passive adherence, and -0.04 (p = .55) between active coping and passive adherence.

At 6-month follow-up the short form was re-administered and scored as described above. For negative thoughts the mean was 2.13 (SD 1.27) and Cronbach's alpha 0.86. For active coping the mean was 2.73 (SD 1.13) and Cronbach's alpha 0.85. For passive adherence the mean was 3.20 (SD 1.30) and Cronbach's alpha 0.75. The correlations between baseline and follow-up were .73 ($p < .001$) for negative thoughts, .70 ($p < .001$) for active coping, and .64 ($p < .001$) for passive adherence, indicating good test-retest reliability.

Table 4. Pain-related measures: descriptive statistics and correlations with long and short form pain coping composite scales

			Negative thoughts		Active coping		Passive adherence		Coping effectiveness	
	Mean (SD)	Range	Long	Short	Long	Short	Long	Short	Control	Decrease
Coping effectiveness										
Control	3.45 (1.54)	0-6	-.27**	-.24**	.32**	.27**	-.17*	-.22*	1.0	.52**
Decrease	3.47 (1.55)	0-6	-.16*	-.16*	.22*	.22*	-.04	-.10	.52**	1.0
Pain measures										
Acute pain frequency	2.79 (1.09)	1-5	.11	.16*	-.04	.01	.20*	.13	-.18*	-.17*
Acute pain intensity	3.93 (3.07)	0-10	.16*	.20*	-.11	-.04	.23*	.19*	-.23*	-.27**
Chronic pain frequency	4.15 (1.28)	1-5	.05	.07	-.07	-.06	.08	.07	-.24**	-.29**
Chronic pain intensity	5.12 (2.99)	0-10	.21*	.19*	-.16*	-.13	.13	.15	-.37**	-.35**
Pain readiness to change										
Precontemplation	2.88 (0.76)	1.0-4.7	.49**	.45**	-.16*	-.11	.21*	.25*	-.32**	-.32**
Contemplation	3.16 (0.66)	1.0-4.8	.34**	.32**	.17*	.29**	.27**	.12	-.15	-.12
Action	2.81 (0.66)	1.0-5.0	.10	.13	.45**	.50**	.21*	.06	.16*	.07
Maintenance	3.32 (0.70)	1.43-5.0	-.16*	-.14	.44**	.43**	.10	-.07	.25**	.16*
Chronic pain acceptance										
Activities engagement	39.5 (11.0)	10-65	-.36**	-.37**	.40**	.32**	-.24**	-.27**	.42**	.20*
Pain willingness	24.5 (8.5)	3-47	-.45**	-.42**	.14	.08	-.31**	-.25**	.29**	.19*
Total pain acceptance	63.7 (16.3)	25-105	-.48**	-.47**	.34**	.26**	-.33**	-.32**	.44**	.25**
Health-related quality of life										
Physical functioning	41.5 (30.5)	0-100	-.13	-.13	.24**	.17*	-.19*	-.14	.26**	.13
Role physical	28.9 (39.0)	0-100	-.28**	-.29**	.10	.10	-.21*	-.15*	.22*	.17*
Role emotional	56.6 (44.2)	0-100	-.46**	-.47**	.10	.03	-.25**	-.17*	.25**	.00
Energy/fatigue	43.3 (19.8)	0-100	-.40**	-.39**	.08	.07	-.06	-.08	.24**	.18*
Emotional well-being	65.1 (18.3)	16-100	-.57**	-.56**	.08	.04	-.08	-.12	.24**	.10
Social functioning	55.6 (26.6)	0-100	-.40**	-.41**	.08	.02	-.23*	-.18*	.33**	.19*
Pain	45.0 (24.9)	0-100	-.27**	-.26**	.12	.05	-.19*	-.16*	.37**	.35**
General health	40.3 (23.4)	5-95	-.42**	-.41**	.15	.06	-.25*	-.28**	.31**	.11

* $p \leq .05$; ** $p \leq .001$

Concurrent validity of long and short forms

Baseline short form composite scales and scores from factor analysis of subscales in the long form were then correlated with pain frequency and intensity, pain readiness to change, pain

acceptance, and health-related quality of life, to assess the concurrent validity of the short form relative to the long form. Summary descriptive statistics and correlations are given in table 4.

The patterns of correlations were very similar for the long and short forms. Ability to control pain and decrease pain (the two single item measures of coping effectiveness, which are scored separately) were associated negatively with negative thoughts and positively with active coping, and were also associated negatively with pain frequency and intensity and precontemplation. Ability to control pain was associated positively with action and maintenance, both chronic pain acceptance scales, and all the scales of health-related quality of life.

Acute pain intensity was associated most closely with passive adherence, whereas chronic pain intensity was associated most closely with negative thoughts. Precontemplation and contemplation were associated most closely with negative thoughts, whereas action and maintenance were associated most closely with active coping. Activities engagement and pain willingness were associated negatively with negative thoughts and passive adherence. Activities engagement was associated positively with active coping. Physical functioning was associated positively with active coping and negatively with passive adherence, and all other domains of health-related quality of life were most closely, and negatively, associated with negative thoughts. Few pain-related measures were correlated in the same direction and to the same extent with more than one pain coping scale, indicating good discriminant validity.

Discussion

The short form provides a briefer questionnaire with the same psychometric properties as the long form. Factor analyses revealed the same three factors. Internal and test-retest reliability was high. Concurrent validity, as indicated by distinct patterns of correlation with other pain-related measures, was good, especially for negative thoughts and active coping. Negative thoughts about pain were associated with less readiness to change, less acceptance of pain, and more impaired health-related quality of life, whereas active coping was associated with greater readiness to change and more acceptance of pain.

The questionnaire could easily be adapted for other painful conditions, for none of the items refer specifically to haemophilia and only one (item 6) refers to bleeding. Adaptations could be achieved either by rewording unsuitable items or deleting those items and adjusting the scoring so that sums of item scores are divided by the number of items. This method should also be used to delete item 21 for studies of populations where questions about drinking alcohol are not culturally appropriate.

Availability of a short form means that measures of pain coping can be included more easily in future research in haemophilia and other painful chronic illnesses, and the measure could be used to address a number of issues. By treating pain coping as an outcome, the measure could be used to test whether demographic, illness and treatment variables predict pain coping, or could be used to evaluate specific interventions, such as self-management programmes for pain. By treating pain coping as a predictor, the measure could be used to test the effect of pain coping on outcomes such as functional impairment and health-related quality of life. By treating pain coping as a potential mediator or moderator, the measure could be used to test whether improvements in outcomes associated with interventions or other changes were brought about

as a result of changes in pain coping, or whether the effects of interventions differed between groups with different patterns of pain coping.

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Appendix 1. The Haemophilia Pain Coping Questionnaire (HPCQ)

Individuals with pain related to haemophilia have developed a number of ways to cope with their pain, including saying things to themselves or engaging in different activities when they are in pain. For each of the activities listed below, please indicate how much you do it when you are in pain, or did it when you were in pain in the past, by ticking or circling one of the numbers.

1. I try to think of something pleasant

Never do that 0 1 2 3 4 5 6 Always do that

2. I take some painkillers

Never do that 0 1 2 3 4 5 6 Always do that

3. I think that I have been unlucky in this situation and that it is not fair

Never do that 0 1 2 3 4 5 6 Always do that

4. I tell myself that it doesn't hurt

Never do that 0 1 2 3 4 5 6 Always do that

5. I put an ice pack or a cryo cuff around the painful area

Never do that 0 1 2 3 4 5 6 Always do that

6. I worry that the bleeding is never going to stop

Never do that 0 1 2 3 4 5 6 Always do that

7. I play mental games with myself to keep my mind off the pain

Never do that 0 1 2 3 4 5 6 Always do that

8. It is terrible and I feel that it is never going to get better

Never do that 0 1 2 3 4 5 6 Always do that

9. I tell myself that I can overcome the pain

Never do that 0 1 2 3 4 5 6 Always do that

10. I go to lie down for a while

Never do that 0 1 2 3 4 5 6 Always do that

11. I think no-one wants to hear my problems

Never do that 0 1 2 3 4 5 6 Always do that

12. I do anything to get my mind off the pain

Never do that 0 1 2 3 4 5 6 Always do that

13. I go off by myself

Never do that 0 1 2 3 4 5 6 Always do that

14. I pretend it is not there

Never do that 0 1 2 3 4 5 6 Always do that