

An assessment of the relative influence of pain coping, negative thoughts about pain, and pain acceptance on health-related quality of life among people with hemophilia

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ABSTRACT

Many people with hemophilia are affected by chronic arthritic joint pain as well as acute bleeding pain. In this cross-sectional study, 209 men with hemophilia A or B completed the Hemophilia Pain Coping Questionnaire (HPCQ), the Chronic Pain Acceptance Questionnaire (CPAQ), and the RAND 36-item Health Survey (SF-36), a measure of health-related quality of life. Multiple regression was used to test the influence of active pain coping, passive adherence coping, and negative thoughts about pain (HPCQ scales), and activity engagement and pain willingness (CPAQ scales), on physical and mental components of quality of life (SF-36 PCS and MCS scales), taking account of age, hemophilia severity, use of clotting factor, and pain intensity. Pain intensity had the main influence on physical quality of life and negative thoughts had the main influence on mental quality of life. Activity engagement and pain willingness had small but significant influences on physical and mental quality of life. Pain willingness also moderated and partly mediated the influence of pain intensity on physical quality of life, and activity engagement and pain willingness mediated the influence of negative thoughts on mental quality of life. Negative thoughts moderated and partly mediated the influence of pain intensity on mental quality of life. There was no evidence that active pain coping influenced quality of life. The findings suggest that quality of life in hemophilia could potentially be improved by interventions to increase pain acceptance and reduce negative thoughts about pain.

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1. Introduction

Hemophilia can cause arthritic pain when joints are damaged by repeated joint bleeds, as well as causing acute pain during joint bleeds [6]. Clotting factor concentrates can minimise the impact of spontaneous bleeds, but many patients, especially those aged over 40, are affected by arthritic joint damage caused before factor concentrates were available.

In hemophilia, age and indicators of illness severity typically explain only small proportions of the variance in the physical component of health-related quality of life, as measured by the SF-36, and are not usually associated with the mental component [11,28,29,38,39,42], so further variance could be explained by factors such as pain coping and acceptance, which have been extensively studied in chronic pain conditions but not those where pain is an important but secondary feature. In hemophilia, there

is limited evidence about pain coping [7,36] and none to our knowledge about acceptance.

Pain coping usually refers to purposeful efforts, including both active and passive strategies, to manage pain or to reduce its impact, irrespective of whether those efforts are successful [16,17,44]. Pain coping inventories sometimes also include negative thoughts about pain, such as fear, anger and catastrophizing [12,33], which probably reflect emotional distress associated with pain rather than efforts at coping [13,43,44].

Pain coping is sometimes characterised as efforts to overcome pain by controlling, reducing, or avoiding it [21], whereas pain acceptance involves 'willingness to experience continued pain without needing to reduce, avoid or otherwise change it' [20, p. 93] and 'disengagement from struggling with pain' [21, p. 198]. The rationale for acceptance is that when pain is chronic, attempts to control or avoid it can be counter productive, and better adjustment can be achieved by directing efforts towards more achievable goals [19].

Among studies that compared the relative influence of those factors in chronic pain conditions, two showed that acceptance-related

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factors were more closely associated with improved functioning [22,25], one found that changes in acceptance and catastrophizing both influenced treatment outcome [47], and another showed that acceptance influenced functional status whereas coping influenced emotional distress [9]. We therefore wished to assess the relative influence of coping, negative thoughts and acceptance as predictors of quality of life in hemophilia.

Coping, negative thoughts and acceptance could also mediate and/or moderate the effects of pain. A mediator 'accounts for the relationship' and a moderator 'affects the direction and/or strength of the relationship' between predictor and outcome [4, pp. 1174, 1176]. Negative thoughts mediated the effects of pain intensity on depression and interference with daily life in sickle cell disease [3], and low acceptance partly mediated the effects of catastrophizing on physical and psychological functioning in chronic pain [46]. Acceptance moderated the effect of pain severity in chronic pain, such that 'expected increases in negative affect during pain exacerbations were buffered by higher levels of pain acceptance' [18, p. 291]. We therefore wished to assess the mediation of pain intensity by negative thoughts, the mediation of negative thoughts by acceptance, and the moderation of pain intensity by pain coping, negative thoughts and acceptance.

2. Methods

2.1. Participants

Recruitment to the study was through the membership and registration list of the Haemophilia Society UK. The procedure for recruitment and data collection preserved the anonymity of participants. The Haemophilia Society retained all information about the identity and contact details of participants, and mailings using the Society membership and registration list were undertaken by the Society. For data management, participants were identified only by a number assigned specifically for the study.

The inclusion criteria were having hemophilia A or B, being aged over 18 years, and Society membership or registration with good mailing status. The exclusion criteria were medical conditions that complicate pain coping (such as Alzheimer's disease) or having previously indicated unwillingness to participate in research.

Individuals meeting the study criteria were sent an invitation to participate, along with a questionnaire booklet and return envelope. A reminder invitation with a 6-item questionnaire about reasons for non-participation was sent to those who did not return a completed questionnaire within four weeks. Of 568 individuals who met the inclusion criteria, 209 (37%) returned completed questionnaires. All the individuals in the sample were male. Mean age was 49.5 years (SD 12.8 years). There were 165 (78.9%) with hemophilia A, 39 (18.7%) with hemophilia B, and 5 (2.4%) where hemophilia type was not known. There were 46 (22%) with mild hemophilia, 24 (11.5%) with moderate hemophilia, 132 (63.2%) with severe hemophilia, and 7 (3.3%) where severity was not known.

Information about reasons for non-participation was provided by 85 individuals (24% of non-participants). The most common reason given was having a mild form of hemophilia or experiencing little or no bleeding and/or pain (71 individuals, or 84% of those giving reasons). There were 21 individuals (25% of those giving reasons) who indicated that they did not wish to take part in research, 14 (17%) who indicated that they did not have time to complete the questionnaire, and 5 (6%) who indicated that they were 'too old' (some individuals indicated more than one reason).

Group-level comparisons between participants and non-participants were possible for age and type and severity of hemophilia. Participants were more likely than non-participants to have severe

rather than mild or moderate hemophilia ($\chi^2_{(1)} = 18.5, p < 0.001$), but there were no significant differences in age ($F_{(1,526)} = 0.75, p = 0.39$) or hemophilia type A vs. B ($\chi^2_{(1)} = 0.10, p = 0.75$).

Comparisons between the sample and the national UK population of adults with hemophilia, using summary data from returns made by the UK Haemophilia Centres (John Morris, personal communication), showed that the proportions of hemophilia types A and B were similar in both sets of data, but the sample had higher proportions with severe hemophilia and people aged over 40.

2.2. Measures

2.2.1. Joint pain

Participants rated the frequency and intensity of arthritic joint pain. Pain frequency was rated on a five-point scale where 1 = never, 2 = rarely, 3 = once a week, 4 = more than once a week, and 5 = daily. Pain intensity in the last month was rated on a 10 cm visual analogue scale labelled 'no pain' to 'worst pain possible'.

2.2.2. Use of clotting factor

This was measured using two items ('I treat myself with factor VIII or IX when I feel a bleed' and 'No matter where I am I treat myself with the correct amount of factor'), both scored from 0 ('never do that') to 6 ('always do that'). Both items were taken from the long version of the hemophilia-adapted Pain Coping Strategies Questionnaire [5] but are not included in the pain coping measure used in the present study. A single score was computed as the mean of the two items.

2.2.3. Pain coping and negative thoughts about pain

The Hemophilia Pain Coping Questionnaire (HPCQ) is a 27-item measure of pain coping and negative thoughts about pain in hemophilia [8]. Respondents rate each item on a seven-point scale, with each item scored from 0 ('never do that') to 6 ('always do that'). Scores are computed for three scales: 'active coping', 'negative thoughts' and 'passive adherence'. The active coping scale is made up of 10 items about diverting attention from pain, ignoring pain sensations, reinterpreting pain sensations, increasing behavioral activity when in pain, and coping self-statements. Higher scores indicate greater use of active pain coping strategies. The negative thoughts scale is made up of nine items about catastrophizing, anger, fear and seeking isolation when in pain. Higher scores indicate greater negative and emotional thinking about pain. The passive adherence scale is made up of six items about resting, using painkillers and using ice when in pain. Higher scores indicate greater use of passive pain coping strategies. Scale scores are obtained by summing across items and dividing by the number of items. Internal reliabilities were 0.86 for negative thoughts, 0.80 for active coping and 0.76 for passive adherence. Six-month test-retest reliabilities were 0.73 for negative thoughts, 0.70 for active coping and 0.64 for passive adherence. Validity was demonstrated by differential relationships with other measures of responses to pain [8].

2.2.4. Pain acceptance

The Chronic Pain Acceptance Questionnaire (CPAQ) 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. Each item is scored on a six-point scale, from 'never true' (0) to 'almost always true' (5). Subscale scores are obtained by summing scores across items. The revised scoring method was used, in which 20 items give scores for two subscales [23]. The activity 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. Higher scores indicate higher

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