Patients' perspective of the effectiveness and acceptability of pharmacological and non-pharmacological treatments of fibromyalgia.

TAYLOR, Sophie <http://orcid.org/0000-0001-5838-9993>, STEER, Michael, ASHE, Simon, FURNESS, Penny <http://orcid.org/0000-0003-4916-8800>, HAYWOOD-SMALL, Sarah <http://orcid.org/0000-0002-8374-9783> and LAWSON, Kim <http://orcid.org/0000-0002-5458-1897>

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Title: Patients' perspective of the effectiveness and acceptability of pharmacological and non-pharmacological treatments of fibromyalgia

Sophie J. Taylor,[1] Michael Steer,[1] Simon C. Ashe,[1] Penny J. Furness,[1] Sarah Haywood-Small[2] & Kim Lawson[2]

[1]Centre for Behavioural Science and Applied Psychology, Faculty of Social Sciences and Humanities, Sheffield Hallam University
[2] Biomolecular Sciences Research Centre, Faculty of Health and Wellbeing, Sheffield Hallam University, Sheffield, UK

Author of correspondence:

Dr. Sophie Taylor
Centre for Behavioural Science and Applied Psychology
Heart of the Campus
Collegiate Crescent
Sheffield Hallam University
Sheffield
UK
S10 2BP

s.j.taylor@shu.ac.uk

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Abstract

Background and aims: Fibromyalgia is a complex condition characterised by widespread pain, sleep disturbance, fatigue and cognitive impairment, with a global mean prevalence estimated at 2.7%. There are inconsistencies in guidelines on the treatment of fibromyalgia leading to dissatisfaction from patients and healthcare professionals. This study investigated patient-reported outcomes of pharmacological and non-pharmacological treatment usage and effectiveness with an assessment of acceptability.

Methods: Nine hundred and forty-one participants completed a self-administered anonymous questionnaire giving quantitative data of demographics, treatment usage and treatment outcomes. Participant-reported effectiveness and side effects were compared in the following treatment classes: analgesics, antidepressants, gabapentinoids, gastrointestinal treatments, activity interventions, dietary-based treatments, and psychological, physical and alternative therapies. Participants also reported whether they knew about or had tried different treatments.

Results: The results from the online survey indicated that the range of mean effectiveness ratings were similar for pharmacological and non-pharmacological treatments, whereas non-pharmacological treatments had lower side effects ratings and higher acceptability relative to pharmacological treatments. Participants were not aware of some treatment options.

Conclusions: The results show lower side effects ratings and higher acceptability for non-pharmacological treatments compared to pharmacological treatments despite similar effectiveness ratings.

Implications: This article presents results from a large online survey on fibromyalgia patient perspectives of pharmacological and non-pharmacological treatments. Results will inform healthcare professionals and patients about optimal treatments based on ratings of effectiveness, side effects and acceptability that are tailored to patient symptom profiles. Some participants were unaware of treatment options highlighting the importance of patient education allowing collaboration between patients and healthcare professionals to find optimal treatments.

Key words: Fibromyalgia, patients' perspective, online survey, pharmacological treatments, non-pharmacological treatments

Introduction

Fibromyalgia is a complex condition characterised by widespread pain, sleep disturbance, fatigue and cognitive impairment [1,2] with a global mean prevalence estimated at 2.7% [3]. Fibromyalgia is often comorbid with mood and anxiety disorders impacting on social, family and working identities [4-7].

Treatment interventions include pharmacological, psychological, exercise and alternative therapy approaches [8-11]. Evidence for the effectiveness of these interventions in reducing symptoms is varied and inconsistent, with no treatment approach being universally accepted [12], possibly due to the heterogeneity of the condition and proposal of subgroups [13,14]. Current pharmacological treatment has modest efficacy, high incidence of adverse effects and poor adherence [15,16].

There are inconsistencies in guidelines on the treatment of fibromyalgia [17-19]. Previous EULAR guidelines [20] gave the highest recommendation to pharmacological treatments whereas EULAR revised guidelines [21] suggested that the first treatment should be non-pharmacological and strongly recommended exercise. Treatment should be individualised based on the patient symptom profile and need, which may include psychological therapy (e.g. cognitive behavioural therapy (CBT), mindfulness), physical therapy (e.g. acupuncture or hydrotherapy) and pharmacotherapy (e.g. duloxetine, pregabalin, tramadol or amitriptyline) [21-23]. Multimodal treatments were recommended in people with severe disability. There are inconsistencies between the EULAR guidelines and previous guidelines from Germany [23], Canada [24] and Israel [25]. The Canadian and Israeli guidelines strongly recommended serotonin noradrenaline reuptake inhibitors (SNRIs) and anticonvulsants, although these were weakly recommended in EULAR guidelines. Revised EULAR guidelines did not recommend non-steroidal anti-inflammatory drugs (NSAID), steroidal anti-inflammatory drugs, monoamine oxidase inhibitors or selective serotonin reuptake inhibitors due to lack of efficacy and strongly discouraged the use of corticosteroids, strong opioids, growth hormone and sodium oxybate [21]. Revised German guidelines recommend multimodal therapy combining exercise (endurance, strength or flexibility training) and psychotherapeutic therapy (patient training or cognitive behavioural therapy) [26]. Comparing guidelines shows inconsistencies in terms of the importance given to pharmacological versus non-pharmacological therapies.

Dissatisfaction from patients and health professionals with treatment management [27, 28] highlights the importance of investigating patients' perceptions of treatment efficacy and adverse side effects. Pain reduction is the main criterion for pharmacological regulation, although fibromyalgia is also associated with other symptom domains of pain, sleep disturbance, affective symptoms, fatigue, cognitive impairment and functional deficit [29, 30]. This study involved the investigation of patient-

reported outcomes of pharmacological and non-pharmacological treatment usage and effectiveness, with an assessment of acceptability of therapeutic approaches because pharmacological and non-pharmacological treatments may differ in tolerability [29]. While previous research has reported patient-perceived efficacy of treatments [31], the present study will extend this by assessing self-report effectiveness, including which symptoms are relieved, and side effects for a range of treatments. Randomised control trials in fibromyalgia have been criticised due to limited external validity because participants with comorbidities may be excluded [32] so this study employed a large online survey to ascertain patient reported outcomes.

Method

Questionnaire development

The questionnaire was developed from the outcomes of a pilot study of individual qualitative interviews [28] and a review of existing literature. A self-administered anonymous questionnaire was conducted using Qualtrics [33] that asked participants to provide quantitative and qualitative data about a variety of areas including demographics, condition profile, condition impact, treatment usage and treatment outcomes. Thus, the structure of the survey included items related to the physical and psychological symptoms and management. Members of the fibromyalgia research team at Sheffield Hallam University reviewed the structure, questions and ease of completion to ensure the survey was comprehensive, balanced and user-friendly. This paper focuses on the quantitative data on treatment outcomes from the survey.

This research project received ethical approval from the Sheffield Hallam University Research Ethics Committee.

Recruitment and data collection

Fibromyalgia charities and networks, and affiliated member support groups within the UK posted the survey online with additional notification through emails and on Facebook pages from January 2016 to April 2016. To take part in the survey, participants were required to be over 18 years of age and to have received an official diagnosis of fibromyalgia. Participants were informed about the voluntary and anonymous nature of the survey, the information that would be collected and the expected time for survey completion. Completion and submission of the survey was taken as implied consent and participants were free to withdraw their data up to two weeks after participation. To avoid potential fatigue, participants had the option of taking breaks during survey completion. Average completion time was 1 hour 15 minutes.

Measures

The first section asked participants to provide demographic information including age, gender, employment status, relationship status and qualifications. The next section focused on treatment-specific information with participants asked to state whether they had tried, had not tried, did not know about or would not try identified treatment options. The survey included a range of commonly used pharmacological and non-pharmacological treatments. Participants were asked to rate their personal experience of tried treatments on the basis of the effectiveness and severity of side effects on 11-point Likert scales (effectiveness of treatment 0 = not effective to 10 = very effective and side effects 0 = none to 10 = terrible). Further questions required participants to select one symptom (from a choice of nerve pain, fatigue, brain fog, muscular pain, bone/joint pain, anxiety, depression, irritable bowel syndrome (IBS)/gastric issues) that the treatment was most effective in reducing and select which side effect (from a choice of feeling nauseous, feeling tired, feeling disorientated, made pain worse, worse mood, weight gain, dry mouth, anxiety, incontinence, constipation, pain during treatment or none) gave the worst experience.

Participants completed the 'Sensory Reactivity' and 'Pain and Consequences' subscales from the *Comprehensive Rating Scale for Fibromyalgia Symptomatology* (CRSFS) [34]. Participants rated whether they had experienced a range of symptoms never, once, on several days, more than half of days or almost every day over the previous 2 weeks causing discomfort or affecting daily life. Sensory reactivity items focused on joint discomfort, pain, stiffness, sensation changes, night cramps and tingling sensations. Pain and consequences items assessed sleep quality, neck and back pain, headache and physical and general tiredness and were scored as follows: never/once (0), several days (1), more than half of the days (2) and almost every day (3). Scores of the subscales were totalled giving a possible range of 0-54 for symptoms of sensory reactivity and 0-63 for symptoms of pain and consequences. Higher scores indicate greater sensory reactivity and pain and consequences. The CRSFS Sensory Reactivity (Cronbach's alpha = 0.89) and Pain and Consequences (Cronbach's Alpha = 0.87) subscales had good reliability.

The *Hospital Anxiety and Depression Scale* (HADS) [35] assessed state anxiety and depression with seven items scored between zero and 3 on each subscale. 'I feel tense or wound up' is an example from the anxiety subscale and 'I feel cheerful' is an example from the depression subscale. Scores of 0 to 7 were categorised as normal, 8 to 10 as mild, 11 to 15 as moderate and 16 to 21 as severe [35]. The Anxiety (Cronbach's Alpha = 0.84) and Depression (Cronbach's Alpha = 0.83) subscales had good reliability.

Analyses

Summary statistics were calculated as means and standard deviations (SD) for continuous variables and frequency (%) for categorical variables. Data were ranked by decreasing effectiveness scores. The range of effectiveness and side effects ratings for pharmacological and non-pharmacological treatments were compared by Mann Whitney U test with a significance level of 0.05. A treatment acceptance ratio was calculated for each intervention from the mean effectiveness value and the mean side effects value. The range of acceptance ratios for the pharmacological and non-pharmacological treatments were compared by Mann Whitney U test with a significance level of 0.05. Mann Whitney U tests were used because these analyses were based on ranked data.

The participant-reported outcomes were evaluated within the different classes of treatments to identify the preferred therapies. Between group ANOVAs comparing the effectiveness and severity of side effects were reported for treatment groups with three or more treatments. Hochberg's GT2 post hoc tests were reported because these tests are recommended when sample sizes are different [36] and there is some variation in number of participants who tried different treatments. t-tests are reported when there were two treatment types in a group. The significance level was set at 0.05. Parametric analyses were conducted because box plots and skewness statistics indicated that the data were normally distributed.

Results

Participant demographics

Nine hundred and forty-one participants started the survey with seventy six per cent of participants completing 50% or more of the survey. t-tests were conducted to compare participants who had completed the entire survey with participants who had not completed the entire survey in terms of age, CRSFS sensory reactivity, CRSFS Pain and Consequences and HADS Anxiety and Depression scores. Participants who completed the whole survey were significantly older (M = 48.83, SD = 12.24) than participants who did not complete the whole survey (M = 46.57, SD = 11.84, t (936) = 2.88, p = 0.004). Participants who finished the survey reported significantly lower CRSFS sensory reactivity (M = 34.99, SD = 10.63) relative to participants who did not finish the survey (M = 36.78, SD = 10.27, t (906) = 2.58, p = 0.010). Participants who completed the survey reported significantly lower depression scores (M = 10.29, SD = 4.35) compared to those who did not complete the whole survey (M = 10.97, SD = 4.26, t (931) = 2.42, p = 0.016). There were no differences in terms of CRSFS Pain and Consequences (t (890) = 1.62, p = 0.106) or Anxiety (t (931) = 2.42, p = 0.051).

Participant demographic data are presented in Table 1. The demographic characteristics indicated that the respondents were 94.8% white females with a mean age of 47 years. Fifty-two per cent of

participants were married or in a partnership, 40.1% were in employment and 30.5% had a university education. The time since diagnosis ranged from 0 to 37 years with a mean of 5 years.
[Insert Table 1 approximately here].

Use and knowledge of treatments

Participant engagement with UK-licensed pharmacological and non-pharmacological treatments are presented in Tables 2 and 3. Six of the considered treatments had been tried by 75% or more of the participants: paracetamol (92.5%), heat pad/hot water bottle (81.8%), codeine (79.3%), ibuprofen (77.6%), walking/running (76.1%) and amitriptyline (75.9%). Only five of the treatments were identified by greater than 20% of participants as "would not try": cycling (55%), gym exercise (39.5%), steroid tablets (28.6%), morphine (28.3%) and fluoxetine (24.4%). The participants were aware of the majority of the non-pharmacological treatments considered, other than colpermine which 45.3% of participants did not know (Table 3). In contrast, Table 2 shows that a third of the pharmacological treatments considered were not known by greater than 50% of participants: Audmonal (alverine) (73%), nefopam (72.2%), nortriptyline (58.1%), fentanyl/Butrans (buprenorphine) patches (57.2%), sertraline (55.3%), ranitidine (54.6%) and duloxetine (51.7%).
[Insert Tables 2 and 3 approximately here].

Effectiveness and side effects of treatments

Tables 4 and 5 show the mean effectiveness and side effects ratings of pharmacological and non-pharmacological treatments. The range of mean effectiveness scores, rated on an 11-point Likert scale for pharmacological (2.54–6.85) and non-pharmacological treatments (3.54–6.33) were similar (U = 197.5, $p > 0.05$) (Tables 4 and 5). The predominant symptoms identified as gaining greatest relief, pain, depression and anxiety, again were similar within both types of treatment. In contrast, a significantly lower range of mean side effects scores was reported for non-pharmacological treatments (0.62–6.13) relative to pharmacological treatments (1.17–6.34) (U = 132, p = 0.027). The predominant side effects identified with pharmacological treatments were nausea and disorientation, whilst with non-pharmacological treatments were pain and tiredness (Tables 4 and 5).
[Insert Tables 4 and 5 near here].

Treatment classes

Analgesics

Muscular pain was the most frequently reported symptom alleviated by analgesic treatments (Table 4). There was a significant effect of analgesic type on effectiveness (F (3, 1665) = 38.17, $p < 0.001$) and side effects (F (3, 1661) = 115.34, $p < 0.001$). A comparison of the analgesics paracetamol and

nefopam, which received the lowest mean effectiveness scores (2.54 and 3.35, respectively), indicated there was no difference in effectiveness ($t(732) = 1.76$, $p = 0.383$), however the participant-rated side effects of nefopam were significantly higher than those of paracetamol ($t(732) = 7.12$, $p < 0.001$). Although 33.8% of participants who tried paracetamol reported it relieved muscular pain, 42% of participants reported that it did not alleviate any symptoms. Naproxen was rated as significantly more effective compared to ibuprofen ($t(933) = 3.35$, $p = 0.005$). There were, however, significantly higher scores for side effects for naproxen ($t(931) = 5.17$, $p < 0.001$) relative to ibuprofen.

For opioid analgesics, there was a significant main effect on effectiveness ($F(3, 1342) = 49.11$, $p < 0.001$) with morphine rated by participants as significantly more effective than codeine ($t(798) = 12.05$, $p < 0.001$), tramadol ($t(606) = 7.91$, $p < 0.001$) or fentanyl ($t(288) = 6.72$, $p < 0.001$). Further, tramadol ($t(288) = 5.10$, $p < 0.001$), but not fentanyl, was significantly more effective than codeine. There was a significant main effect for side effects of opioid analgesics ($F(3, 1319) = 15.49$, $p < 0.001$) with the side effects scores significantly greater for tramadol compared to codeine ($t(1041) = 5.33$, $p < 0.001$) and fentanyl ($t(556) = 5.58$, $p < 0.001$). In addition, participants reported greater scores for side effects for morphine relative to fentanyl ($t(278) = 3.89$, $p = 0.001$).

Antidepressants

Participants reported that the symptom most frequently alleviated following treatment with amitriptyline or nortriptyline was pain; however, depression was the most reported symptom to be reduced with the other antidepressants citalopram, sertraline, duloxetine and fluoxetine (Table 4). There was a significant main effect of effectiveness for antidepressant type ($F(5, 1285) = 3.06$, $p = 0.009$). Sertraline was the only antidepressant reported as more effective than amitriptyline ($t(671) = 3.18$, $p = 0.022$). There was a significant main effect of side effects for antidepressant type ($F(5, 1283) = 6.33$, $p < 0.001$). Participants reported significantly greater side effects scores for amitriptyline compared to citalopram ($t(758) = 3.36$, $p = 0.012$) and sertraline ($t(675) = 4.67$, $p < 0.001$), while nortriptyline had significantly greater reported side effects scores relative to sertraline ($t(186) = 2.94$, $p = 0.049$).

Gabapentinoids

Pain reduction was the most frequently reported effectiveness outcome associated with pregabalin and gabapentin (Table 4). The scores for effectiveness ($t(617) = 0.419$, $p = 0.675$) and side effects ($t(631) = 0.886$, $p = 0.376$) for gabapentin and pregabalin were similar.

Gastrointestinal treatments

Eighty-four per cent or greater of participants reported that gastrointestinal treatments suppressed gastrointestinal disturbance and/or IBS (Table 4). There was a significant effect of gastrointestinal

treatment on effectiveness (F (3, 668) = 23.92, $p < 0.001$) with omeprazole rated as significantly more effective than ranitidine (t(480) = 4.72, $p < 0.001$) or audmonal (t(432) = 5.30, $p < 0.001$). The ratings of the side effects associated with the gastrointestinal treatments studied did not achieve significance (F(3, 688) = 0.38, p = 0.765).

Activity interventions

Muscular pain was identified as the symptom most alleviated by all activity type interventions, except walking/running, which was more associated with enhancing mood (Table 5). The most frequently reported side effect, however, with all activity interventions was an enhancement of pain. There was a significant main effect of effectiveness for activity type (F(4, 1550) = 4.41, p = 0.002) with swimming (t(643) = 3.67, p = 0.002) and walking/running (t(795) = 3.67, p = 0.003) rated as significantly more effective than controlled/graded exercise plans (Table 5). There was a significant main effect of side effects for activity type (F(4, 1650) = 10.79, $p < 0.001$). Compared to swimming, participants rated significantly greater side effect scores for gym exercise (t (643) = 6.08, $p < 0.001$), cycling (t(556) = 3.81, p = 0.001), walking/running (t(951) = 4.73, $p < 0.001$) and controlled/graded exercise plan (t(679) = 3.77, p = 0.002).

Dietary-based treatments

The dietary changes that participants reported included healthy eating, gluten free, dairy free, eating more fruit and vegetables, Paleo diet and eating less sugar. Supplements that participants reported taking included multivitamins, vitamin B, vitamin C, vitamin D, magnesium and glucosamine. Participants associated dietary-based treatments with reduced gastrointestinal symptoms and reduced fatigue (Table 5). Dietary changes were rated as significantly more effective compared to vitamin supplements (t(718) = 5.67, $p < 0.001$) (Table 5). The majority of participants (up to 88%) who had used dietary-based approaches to treatment had experienced no undesirable side effects.

Psychological therapies

Participants reported engaging with a range of psychological therapies including talking therapy, integrative psychotherapy, person centred, eye movement desensitisation and reprocessing, hypnotherapy and Mickel therapy, a talking therapy for chronic health conditions. Psychological therapies were most frequently associated with enhancement of mood (Table 5). There was a significant effect of type of psychological therapy on effectiveness (F(4, 1096) = 16.68, $p < 0.001$) with mindfulness (t(432) = 3.75, p = 0.002), counselling (t(458) = 3.75, p = 0.002) and meditation/relaxation (t(507) = 4.63, $p < 0.001$) all rated as significantly more effective than Cognitive Behavioural Therapy (CBT) (Table 5). Participants reported a low frequency of undesirable side effects with psychological therapies (less than 13% of participants for any effect). There was a significant effect for type of psychological therapy for side effects (F(4, 1152) = 29.99, $p < 0.001$)

with the ratings of side effects for counselling and CBT being significantly greater relative to mindfulness ($t(410) = 6.09$, $p < 0.001$ and $t(439) = 3.89$, $p = 0.001$, respectively) and meditation/relaxation ($t(508) = 7.24$, $p < 0.001$ and $t(537) = 4.84$, $p < 0.001$, respectively).

Physical therapies

The symptom that was most frequently reported to be alleviated by physical therapies was muscular pain (Table 5). On the basis of participant ratings, the three non-pharmacological treatments identified as most effective were hydrotherapy, heat pad/hot water bottle and massage (Table 5). Hydrotherapy and heat pad/hot water bottle treatments were rated as significantly more effective than physiotherapy ($t(500) = 9.58$, $p < 0.001$ and $t(920) = 12.84$, $p < 0.001$, respectively), acupuncture ($t(396) = 5.89$, $p < 0.001$ and $t(816) = 7.05$, $p < 0.001$, respectively), or transcutaneous electrical nerve stimulation (TENS) ($t(419) = 7.37$, $p < 0.001$ and $t(839) = 9.15$, $p < 0.001$, respectively) (Table 5). Further, participants reported that massage was significantly more effective than physiotherapy ($t(677) = 11.00$, $p < 0.001$) or TENS ($t(639) = 8.01$, $p < 0.001$).

Enhancement or inducement of pain during physical therapies, however, was the most frequently reported side effect (Table 5). The side effects score associated with heat pad/hot water bottle treatment was significantly lower than that reported for acupuncture ($t(876) = 7.30$, $p < 0.001$), massage ($t(939) = 15.38$, $p < 0.001$), physiotherapy ($t(991) = 23.94$, $p < 0.001$), TENS ($t(913) = 7.28$, $p < 0.001$) and hydrotherapy ($t(764) = 8.95$, $p < 0.001$). Hydrotherapy and massage had significantly lower reported side effects scores than physiotherapy ($t(515) = 7.63$, $p < 0.001$ and $t(690) = 6.71$, $p < 0.001$, respectively).

Alternative therapies

Whilst the effectiveness of aromatherapy, colpermin (peppermint oil) and distraction therapy through hobbies were similar ($F(2, 729) = 2.86$, $p = 0.058$), there was a significant main effect of side effects ($F(2, 785) = 7.07$, $p = 0.001$) with significantly fewer side effects reported for aromatherapy compared to distraction through hobbies ($t(661) = 3.64$, $p = 0.001$).

Participant acceptability of treatments

The relationship between the effectiveness of a treatment and the side effects was determined as an assessment of participant-rated acceptance. An acceptability ratio greater than 1 indicated that the benefits outweighed limitations as assessed from the participants' perspective. The acceptability ratio for pharmacological treatments range was 0.67–3.92 with nine of 21 interventions giving a value greater than 1 (Table 6). For non-pharmacological treatments, the acceptability ratio range was 0.60–9.65 with 15 of 21 interventions giving a value of greater than 1 (Table 7). The acceptability ratio

range for non-pharmacological treatments was significantly higher than that for pharmacological treatments ($U = 141.5$, $p = 0.048$).

Discussion

This study reported results from a large online survey about patients' ratings of effectiveness and side effects of treatments for fibromyalgia. Findings indicated similar effectiveness ratings for pharmacological and non-pharmacological treatments. There were, however, significantly lower mean side effects ratings and a higher acceptability ratio for non-pharmacological treatments compared to pharmacological treatments. There is no universally accepted treatment approach for fibromyalgia [12] with inconsistencies between treatment guidelines [18]. By analysing the effectiveness and side effects ratings from a patient perspective within a range of treatment approaches, this will inform healthcare professionals and patients about optimal treatments based on ratings of acceptability. An individualised treatment approach for fibromyalgia based on patient symptom profile is recommended [21]. The survey data demonstrated the effects of various treatment approaches on different symptoms of fibromyalgia. Such data will allow for tailored, individualised treatment approaches.

Previous research

Survey results supported a previous fibromyalgia survey that found non-pharmacological treatments were more effective at symptom relief than pharmacological treatments with worst side effects reported for strong opioids and gabapentinoids [32]. The current survey results showed limited effectiveness of pharmacological treatments including analgesics, gabapentinoids and antidepressants, supporting the EULAR guidelines that suggested weak evidence for the efficacy of pharmacological treatments [21]. A review of pharmacological therapies in fibromyalgia highlighted the importance of tailoring drug therapy based on key symptoms other than pain, psychological and physical comorbidities and the importance of problematic side effects to the individual e.g. weight gain [15]. Research suggests there are subgroups of fibromyalgia symptoms based on personality with cluster 1 characterised by higher neuroticism and lower extraversion, remaining more anxious and depressed during treatment, compared to cluster 2 [37]. The clusters should be included in the design of future treatments and clinicians should be aware of cluster types during patient interaction. An alternative subgroup categorisation in fibromyalgia patients is based on 1) functional, 2) dysfunctional and 3) highly dysfunctional and distressed profiles [13].

Activity

The EULAR and Canadian guidelines strongly recommended exercise because of pain reduction, wellbeing and low cost [21, 24]. Self-report data from the survey, however, showed acceptability for activity types (gym exercise, cycling, walking/running, swimming and exercise plans) was less than 1

indicating that undesirable effects outweighed effectiveness. It is possible that benefits of activity are only evident when participants take part in regular activity. More research is needed to determine the recommended intensity and frequency of activity for benefits of symptom relief to be achieved [38]. High attrition rates and participants not adhering to activity, however, are problems associated with activity interventions [39]. Comparing the different types of activity included in the survey, swimming was more effective than exercise plans and participants reported lower side effects compared to gym exercise, cycling, walking/running and exercise plans. Swimming may be beneficial to pain because hydrostatic pressure and buoyancy may reduce muscle spasm and increase the pain threshold of nerve endings resulting in decreased pain sensation [40].

Physiotherapy

Enhanced pain was a commonly reported side effect for activity and physiotherapy. A systematic review identified increased pain during activity as a barrier to physiotherapy adherence in musculoskeletal outpatients, together with low levels of physical activity at the start of therapy, low adherence to exercise during therapy, low self-efficacy, depression, anxiety, helplessness, poor social support and greater perceived barriers to exercise [41]. Simple analgesics, heat or ice with passive physiotherapy (e.g. acupuncture or manual therapy) may reduce pain allowing the use of more active treatments [42]. Physiotherapists should aim to change maladaptive pain beliefs when patients believe that pain experienced during physiotherapy is harmful [41]. Patients with fibromyalgia would benefit from more specialist physiotherapists and psychologists in the healthcare system and integrated interdisciplinary care [43].

Dietary changes

Participants reported that diet change helped to alleviate gastric symptoms and had low side effects. Research shows that for subgroups of patients, dietary changes, such as gluten-free diet, were associated with improvements in fibromyalgia symptoms [44]. Noxious macromolecules may trigger release of mast cell mediators and immune system activation, resulting in pain [45] so that reduction in noxious macromolecules through diet change may improve pain symptoms. Dietary changes are not included in current guidelines, although it has been suggested that nutrition has the potential to be recommended as an effective therapy following more research [46]. Fibromyalgia treatment should include specific dietary interventions, weight loss strategies, nutritional education and tailored nutritional supplements [47].

Psychological therapy

The results of this survey showed that mindfulness was more effective than CBT and pain management courses with 33% of participants who had tried mindfulness reporting it alleviated anxiety. This contrasts with the Canadian guidelines that highly recommend CBT [24]. One meta-

analysis reported small short-term effects of mindfulness-based stress reduction on pain and quality of life in people with fibromyalgia, although there was only a weak recommendation due to the small number of studies and low-quality evidence [48]. Developing coping skills is important in treating fibromyalgia [24] and mindfulness encourages an accepting pain coping style, rather than reducing pain [48]. Twenty-six per cent of participants in the current sample reported they did not know about mindfulness as a treatment for fibromyalgia indicating that mindfulness should be more widely recommended with online resources and courses advertised to people with fibromyalgia.

Heat pad treatment

Heat pad treatment had the highest acceptability ratio with high effectiveness and low side effects reported. Heat treatment (i.e. thermotherapy) is a very old method of pain relief [49]. There is evidence that participants who received whole-body hyperthermia showed a significant reduction in pain compared to a control group [50]. In the current survey, 74% of participants who had tried a heat pad reported that it alleviated muscular pain and 94% reported no side effects. This supports the findings of a previous online survey [31] that reported heat pad was the fourth most effective treatment in an internet survey of participants with fibromyalgia (following prescription sleep medication, prescription pain medication and resting). Eleven per cent of participants reported they had not tried this treatment and only 3.8% of participants reported they would not try using a heat pad. Healthcare professionals should discuss using heat pads with people who have fibromyalgia because this treatment was found to be highly acceptable, easy to administer and inexpensive. While the exact mechanism of heat and pain reduction is unclear [51], sedative effects on sensory nerve endings [52] and capillary dilation [53] are possible explanations.

Distraction therapy

Distraction therapy through hobbies was another treatment that participants rated as effective with a low number of side effects. An explanation for this finding is that attention is diverted away from symptoms. A systematic review of distraction-based treatments noted that it is important to examine predictors of treatment outcomes, including personality, so that pain management strategies can be individualised to the patient [54].

Strengths and limitations

Strengths of this study are the relatively large community participant sample exhibiting profiles typically expected of patients with fibromyalgia and the patients' perspective reflecting a real-world setting. In addition, the survey included effectiveness and side effects of treatments, important factors in treatment adherence and acceptance. Furthermore, the survey included a range of treatments: pharmacological, activity, psychological, physical and alternative therapies. Strengths and limitations inherent to online survey research must also be noted and considered in the interpretation of the

results. Strengths include access to specific populations, the collection of a large amount of data quickly and low cost, although self-selection bias is a potential limitation because some individuals may be more likely to respond than others [55].

Limitations of the sample should be acknowledged. For example, the sample contained a lower percentage of participants who had a university education (30.5%) compared to 40% in the general population [56], possibly indicating sampling bias. Furthermore, participants who completed the entire survey were significantly older and reported significantly lower sensory reactivity and depression scores compared to participants who did not complete all the survey. Therefore the current sample may not accurately reflect the wider demographic of fibromyalgia patients. The survey was advertised by fibromyalgia organisations and on social media, thereby participants had Internet access and an active interest in the topic. The use of patient advocacy groups and websites to access respondents could lead to over-representation by individuals seeking support and fellowship because of experienced problems. Although participants were required to have received an official diagnosis of fibromyalgia, the diagnostic method was not determined and could not be confirmed, and fibromyalgia severity was not established. A further limitation was that participants were not asked about current treatments and the past tense emphasis of the questions (e.g. have tried) may have led to recall bias of over- or underestimation of patient reports. It is possible that participants were using more than one treatment, following guidelines that suggest a multimodal treatment approach. The survey did not include dose, intensity or method of administration of treatments and these may have affected effectiveness and side effects ratings. Therefore, survey results show patients' perspectives of effects and side effects of the doses and duration of drug treatments commonly used for fibromyalgia.

In conclusion, the main survey findings were that participants reported lower mean side effects and higher mean acceptability, although mean effectiveness was similar, for non-pharmacological treatments compared to pharmacological treatments. Participants were not aware of some treatment possibilities indicating that patient education is important for highlighting the range of available treatments allowing optimal informed treatment decision making with their healthcare professional.

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Table 1. Demographics of the respondent population (n = 941). Data are expressed and ranked as percentage of responses for each category, except age and time since diagnosis which is presented as mean with standard deviation.

Characteristics	**% (number of participants)**
Gender	
Female, n (%)	94.8 (892)
Male, n	4.8 (45)
Not reported, n (%)	0.3 (3)
Mixed gender, n (%)	0.1 (1)
Age, years (SD)	47.7 (12.1)
Time since diagnosis, years (SD)	5.0 (5.5)
Ethnicity (%)	
White	95.9 (902)
Mixed-race	1.6 (15)
Asian	1.0 (9)
Black	0.6 (6)
Other	0.5 (5)
Not reported	0.4 (4)
Marital status	
Married or civil partnership	52.3 (492)
Single	13.9 (131)
Co-habiting	13.6 (128)
Divorced	13.6 (128)
Separated	3.9 (37)
Widowed	2.1 (20)
Not reported	0.5 (5)
Employment status	
Unemployed due to FM	38.9 (366)
Working full-time	21.8 (205)
Working part-time	18.3 (172)
Retired	10.0 (94)
Homemaker	5.7 (54)
Student	3.0 (28)
Unemployed reason unknown	1.8 (17)
Not reported	0.5 (5)
Areas of employment	
Healthcare	24.1 (227)
Administration	11.8 (111)
Teaching & education	10.4 (98)
Qualification	
GCSE/O-Level	59.4 (559)
Vocational	29.6 (279)
A-Level	26.2 (247)
Graduate	24.3 (229)
Post-graduate	6.2 (58)
None	5.8 (55)
Apprenticeship	2.6 (24)
Non-UK	2.1 (20)

Note. General Certificate of Secondary School (GCSE) qualifications are traditionally completed in the UK at age 16. GCSEs replaced Ordinary Levels (O-Levels) in 1988. Advanced Levels (A-Levels) are traditionally studied between ages 16 and 18.

Table 2. Participant engagement with pharmacological treatments. NSAID = non-steroidal anti-inflammatory drug, SNRI = serotonin noradrenaline reuptake inhibitor, SSRI = selective serotonin reuptake inhibitor, TCA = tricyclic antidepressant.

Drug	**Class of drug**	**Have tried this treatment %**	**Have not tried this treatment %**	**Would not try %**	**Don't know this treatment %**
Paracetamol		92.5	2.3	3.7	1.5
Codeine	Opioid	79.3	7.0	9.8	3.9
Ibuprofen	NSAID	77.6	4.2	16.0	2.2
Amitriptyline	TCA	75.9	8.1	7.6	8.4
Tramadol/Tramacet	Opioid	56	17.1	14.3	12.6
Omeprazole or lansoprazole	Proton pump inhibitor	52.6	10.1	4.4	32.9
Naproxen	NSAID	45.9	45.8	8.3	33.4
Gabapentin	Gabapentinoid	45.6	16.1	11.9	26.5
Pregabalin	Gabapentinoid	36.9	19.9	11.1	32.1
Citalopram	SSRI	27.9	15.4	11.0	45.7
Fluoxetine	SSRI	26.2	17.9	24.4	31.4
Morphine	Opioid	22.1	31.2	28.3	18.4
Duloxetine	SNRI	21.5	17.3	9.5	51.7
Sertraline	SSRI	17.6	15.5	11.6	55.3
Ranitidine	Histamine antagonist	16.6	20.1	8.7	54.6
Steroids	Steroid	16.6	30.5	28.6	24.3
Fentanyl/Butrans patches	Opioid	13.6	24.5	4.7	57.2
Nortriptyline	TCA	9.5	22.9	9.4	58.1
Audmonal or mebeverine	Smooth muscle relaxant	9.4	12.1	5.5	73.0
Lidocaine	Sodium channel blocker	5.3	27.7	9.2	49.0
Nefopam	Non-opioid analgesic	4.7	18.1	5.0	72.2
Zolmitriptan	Serotonin receptor agonist	1.4	14.1	7.7	64.6

Table 3. Participant engagement with non-pharmacological treatments. CBT = cognitive behavioural therapy, NA = details not available, TENS = transcutaneous electrical nerve stimulation. * Diet change included improved content, gluten-free, paleo, or calorie restricted.

Treatment	**Class of treatment**	**Have tried this treatment %**	**Have not tried this treatment %**	**Would not try %**	**Don't know this treatment %**
Heat pad/hot water bottle	*Physical therapies*	81.8	11.2	3.8	3.3
Walking/running	*Activity*	76.1	7.7	12.7	3.5
Distraction therapy (hobbies)	*Alternative therapies*	69.6	20.0	5.0	5.4
Diet change*	*Diet*	54.3	33.8	4.8	7.1
Vitamin/mineral supplement	*Diet*	53.8	32.7	5.5	8.0
Swimming	*Activity*	52.4	25.8	17.5	4.2
Physiotherapy	*Physical therapies*	51.6	38.7	4.9	4.9
Massage	*Physical therapies*	43.4	41.6	10.3	4.7
TENS	*Physical therapies*	39.9	41.3	5.7	13.0
Controlled/graded exercise plan	*Activity*	39.1	37.5	4.2	19.3
Meditation/relaxation	*Psychological therapies*	38.2	47.9	6.6	7.3
Acupuncture	*Physical therapies*	34.9	43.7	13.3	8.1
CBT	*Psychological therapies*	34.2	39.9	10.4	15.5
Gym exercise	*Activity*	33.3	21.1	39.5	6.0
Counselling	*Psychological therapies*	30.6	44.6	11.6	13.2
Pain management course	NA	27.7	54.8	4.6	13.0
Mindfulness	*Psychological therapies*	25.3	41.6	6.7	26.4
Cycling	*Activity*	21.7	17.6	55.0	5.7
Aromatherapy	*Alternative therapies*	21.6	54.4	13.0	11.0
Hydrotherapy	*Physical therapies*	19.4	57.4	6.0	17.3
Colpermine	*Alternative therapies*	17.1	31.2	6.4	45.3
Trigger-point injections	*Physical therapies*	13.1	29.9	10.3	38.0

Table 4. Participants' perspective of the effectiveness and side effects of pharmacological treatments. The effectiveness and side effect scores rated on an 11-point Likert scale are presented as mean with standard deviation (SD) values for n participants. The patients' perception of which symptom was most effectively reduced and the worst side effect for each treatment are presented as percentage of reporting by participants. IBS = irritable bowel syndrome, NSAID = non-steroidal anti-inflammatory drug, SNRI = serotonin noradrenaline reuptake inhibitor, TCA = tricyclic antidepressant.

Drug	**Class of drug**	**n**	**Effectiveness Mean (SD)**	**Symptom most effected (%)**	**Side effects Mean (SD)**	**Worst side effect (%)**
Morphine	*Opioid*	208	6.85 (2.41)	Muscular pain (40.8)	5.84 (2.98)	Feeling disorientated (30.7)
Omeprazole or lansoprazole	*Proton pump inhibitor*	495	6.79 (2.49)	IBS/gastric disorders (91.1)	1.73 (2.39)	Feeling nauseous (7.4)
Steroids	*Steroid*	156	5.46 (3.19)	Bone/joint pain (32.1)	5.78 (3.34)	Weight gain (50.4)
Ranitidine	*Histamine antagonist*	156	5.43 (2.93)	IBS/gastric disorders (89.6)	1.64 (2.61)	Feeling nauseous (8.4)
Sertraline	*SSRI*	167	5.38 (3.04)	Depression (70.5)	4.30 (3.27)	Feeling tired (14.6)
Duloxetine	*SNRI*	202	4.97 (2.98)	Depression (31.6)	5.24 (3.35)	Feeling nauseous (16.1)
Audmonal or mebeverine	*Smooth muscle relaxant*	88	4.90 (2.86)	IBS/gastric disorders (84.4)	1.87 (2.80)	Constipation (8.1); Feeling nauseous (8.1)
Tramadol/Tramacet	*Opioid*	527	4.89 (3.02)	Muscular pain (35.2)	6.20 (3.30)	Feeling disorientated (30.4)
Fluoxetine	*SSRI*	247	4.83 (3.01)	Depression (64.8)	5.03 (3.25)	Feeling tired (13.9)
Fentanyl/Butrans patches	*Opioid*	128	4.61 (2.91)	Muscular pain (39)	4.33 (3.37)	Feeling disorientated (16.7)
Citalopram	*SSRI*	262	4.52 (3.18)	Depression (63)	4.96 (3.40)	Weight gain (12.9)
Amitriptyline	*TCA*	714	4.38 (3.08)	Nerve pain (22.6)	5.89 (3.34)	Feeling tired (23.1)
Naproxen	*NSAID*	432	4.23 (2.79)	Muscular pain (44.5)	4.43 (3.45)	Feeling nauseous (30.1)
Pregabalin	*Gabapentinoid*	347	4.22 (3.05)	Nerve pain (41)	6.34 (3.22)	Feeling disorientated (28.8)
Nortriptyline	*TCA*	89	4.16 (3.26)	Nerve pain (32.1)	5.76 (3.18)	Dry mouth (22.1)
Gabapentin	*Gabapentinoid*	429	4.12 (3.01)	Nerve pain (42.8)	6.10 (3.43)	Feeling disorientated (24.4)
Codeine	*Opioid*	746	4.01 (2.65)	Muscular pain (39.8)	5.14 (3.12)	Feeling nauseous (14.3)
Lidocaine	*Sodium channel blocker*	44	3.75 (3.70)	Muscular pain (28); nerve pain (28)	2.33 (3.16)	Made pain worse (12.2)
Ibuprofen	*NSAID*	730	3.65 (2.61)	Muscular pain (50.1)	3.37 (3.53)	Feeling nauseous (19.7)
Zolmitriptan	*Serotonin receptor agonist*	13	3.54 (3.91)	Nerve pain (23.1)	5.42 (3.78)	Feeling tired (15.4); feeling disorientated (15.4)
Nefopam	*Non-opioid analgesic*	44	3.35 (3.05)	Muscular pain (25); nerve pain (25)	4.97 (3.82)	Feeling nauseous (19.5)
Paracetamol		870	2.54 (2.52)	Muscular pain (33.8)	1.17 (2.10)	Constipation (7.1)

Note. Data on dose and speed of titration of dose are not available.

Table 5. Participants' perspective of the effectiveness and side effects of non-pharmacological treatments. The effectiveness and side effect scores rated on an 11-point Likert scale are presented as mean with standard deviation (SD) values for n participants. The patients' perception of which symptom was most effectively reduced and the worst side effect for each treatment are presented as percentage of reporting by participants. CBT = cognitive behavioural therapy, IBS = irritable bowel syndrome, NA = details not available, TENS = transcutaneous electrical nerve stimulation. * diet change included improved content, gluten-free, paleo or calorie restricted

Treatment	**Class of treatment**	**n**	**Effectiveness Mean (SD)**	**Worked best for (%)**	**Side effects Mean (SD)**	**Worst side effect (%)**
Hydrotherapy	*Physical therapies*	183	6.33 (3.01)	Muscular pain (58.9)	2.90 (3.08)	Feeling tired (39.2)
Heat pad/hot water bottle	*Physical therapies*	770	6.08 (2.30)	Muscular pain (73.7)	0.63 (1.54)	Made pain worse (1.8)
Massage	*Physical therapies*	408	6.03 (2.96)	Muscular pain (77.7)	3.54 (3.44)	Painful during treatment (29.9)
Meditation/relaxation	*Psychological therapies*	359	5.80 (2.56)	Anxiety (43.5)	0.62 (1.57)	Feeling tired (11.5)
Mindfulness	*Psychological therapies*	238	5.67 (3.13)	Anxiety (33.0)	0.73 (1.86)	Feeling tired (7.8)
Aromatherapy	*Alternative therapies*	203	5.66 (3.02)	Muscular pain (34.1)	1.06 (2.19)	Feeling tired (8.7)
Counselling	*Psychological therapies*	288	5.46 (3.17)	Depression (48.4)	2.23 (2.91)	Worse mood/Anxiety (13.3)
Diet change*	*Diet*	511	5.44 (2.96)	IBS/gastric problems (41.8)	1.79 (2.36)	Worse mood (7.5)
Distraction therapy (hobbies)	*Alternative therapies*	655	5.36 (2.85)	Depression (30.9)	1.94 (2.77)	Feeling tired (23.4)
Colpermine	*Alternative therapies*	161	4.82 (2.94)	IBS/gastric disorders (86.1)	1.51 (2.35)	Feeling nauseous 8.9
CBT	*Psychological therapies*	322	4.57 (3.20)	Anxiety (34.6)	1.66 (2.68)	Anxiety (12.9)
Acupuncture	*Physical therapies*	328	4.55 (3.52)	Muscular pain (40.4)	2.11 (2.90)	Painful during treatment (16.3)
Swimming	*Activity*	493	4.39 (2.93)	Muscular pain (42.2)	5.04 (3.28)	Made pain worse (37.2)
Walking/running	*Activity*	716	4.33 (2.91)	Depression (21.6)	6.00 (2.98)	Made pain worse (50.2)
Vitamin/mineral supplement	*Diet*	506	4.19 (2.95)	Fatigue (16.1)	0.99 (2.01)	Constipation (3.6)
TENS	*Physical therapies*	375	4.14 (2.97)	Muscular pain (47.2)	2.04 (2.94)	Made pain worse (13.1)
Pain management course	*NA*	261	4.08 (3.04)	Muscular pain (21.1)	2.67 (3.20)	Feeling tired (15.4)
Cycling	*Activity*	204	4.03 (2.95)	Muscular pain (26.4)	6.13 (3.06)	Made pain worse (58.0).
Gym exercise	*Activity*	313	3.98 (2.86)	Muscular pain (29.6)	6.55 (2.85)	Made pain worse (59.7)
Physiotherapy	*Physical therapies*	486	3.59 (3.00)	Muscular pain (39.8)	4.94 (3.33)	Made pain worse (45.4)
Controlled/graded exercise plan	*Activity*	368	3.54 (2.86)	Muscular pain (32.0)	5.94 (3.21)	Made pain worse (51.8)

Table 6. Participants' perception of acceptability of pharmacological treatments. Acceptability was assessed and ranked as a ratio of the mean effective rating relative to the mean side effects rating of the treatment presented in Table 3. Ratio of unity is indicated by the solid horizontal line. n = number of participants, NSAID = non-steroidal anti-inflammatory, SNRI = serotonin noradrenaline reuptake inhibitor, SSRI = selective serotonin reuptake inhibitor, TCA = tricyclic antidepressant.

Drug	**Class of drug**	**n**	**Acceptability ratio**
Omeprazole or lansoprazole	*Proton pump inhibitor*	495	3.92
Ranitidine	*Histamine antagonist*	156	3.31
Audmonal or mebeverine	*Smooth muscle relaxant*	88	2.62
Paracetamol		870	2.17
Lidocaine	*Sodium channel blocker*	44	1.61
Sertraline	*SSRI*	167	1.25
Morphine	*Opioid*	208	1.17
Ibuprofen	*NSAID*	730	1.08
Fentanyl/Butrans patches	*Opioid*	128	1.06
Fluoxetine	*SSRI*	247	0.96
Naproxen	*NSAID*	432	0.95
Duloxetine	*SNRI*	202	0.94
Steroids	*Steroids*	156	0.94
Citalopram	*SSRI*	262	0.91
Tramadol/Tramacet	*Opioid*	527	0.79
Codeine	*Opioid*	746	0.78
Amitriptyline	*TCA*	714	0.74
Nortriptyline	*TCA*	89	0.72
Gabapentin	*Gabapentinoid*	429	0.68
Pregabalin	*Gabapentinoid*	347	0.67
Nefopam	*Non-opioid analgesic*	44	0.67
Zolmitriptan	*Serotonin receptor agonist*	13	0.65

Note. Omeprazole/lansoprazole, ranitidine and audmonal/mebeverine treat gastrointestinal comorbidities. Dose of drugs and administration process of lidocaine are not known.

Table 7. Participants' perception of acceptability of non-pharmacological treatments. Acceptability was assessed and ranked as a ratio of the mean effective rating relative to the mean side effects rating of the treatment presented in Table 6. Ratio of unity is indicated by the solid horizontal line. CBT = cognitive behavioural therapy, IBS = irritable bowel syndrome, n = number of participants, NA details not available, TENS = transcutaneous electrical nerve stimulation. *Diet change included situations such as improved content, gluten-free, paleo or calorie restricted.

	Class of treatment	**n**	**Acceptability ratio**
Heat pad/hot water bottle	*Physical therapies*	770	9.65
Meditation/relaxation	*Psychological therapies*	359	9.35
Mindfulness	*Psychological therapies*	238	7.77
Aromatherapy	*Alternative therapies*	203	5.33
Vitamin/mineral supplement	*Diet*	506	4.23
Colpermine	*Alternative therapies*	161	3.19
Diet change*	*Diet*	511	3.03
Distraction therapy (hobbies)	*Alternative therapies*	655	2.76
CBT	*Psychological therapies*	322	2.75
Counselling	*Psychological therapies*	288	2.45
Hydrotherapy	*Physical therapies*	183	2.18
Acupuncture	*Physical therapies*	328	2.15
TENS	*Physical therapies*	375	2.03
Massage	*Physical therapies*	408	1.70
Pain management course	*NA*	261	1.52
Swimming	*Activity*	493	0.87
Physiotherapy	*Physical therapies*	486	0.73
Walking/running	*Activity*	716	0.72
Cycling	*Activity*	204	0.65
Gym exercise	*Activity*	313	0.61
Controlled/graded exercise plan	*Activity*	368	0.60

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Informed consent: Participants were informed of the nature of the survey and what information would be collected so they could decide whether to take part. Completion and submission of the survey was taken as implied consent.

Ethical approval: This project received ethical approval from the Sheffield Hallam University Research Ethics Committee.