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# Women with fibromyalgia syndrome in New Zealand: the symptom experience

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**Abstract**

**Aims** Diagnosis and treatment of fibromyalgia syndrome (FMS) currently focuses on the experience of widespread pain. However, the symptom experience described by patients with FMS in clinical practice is far more diverse. This study aims identify the most common and severe symptoms in female patients diagnosed with FMS.

**Methods** This study interviewed 56 patients diagnosed with fibromyalgia syndrome about their symptoms using the Clinical Interview Schedule – Revised.

**Results** The most frequent and disabling symptoms reported by participants were fatigue, sleep disturbance and cognitive difficulties.

**Conclusions** These findings highlight the need for a range of symptoms to be considered in the assessment and treatment of FMS to help improve patient outcomes.

Fibromyalgia syndrome (FMS) is recognised as one of the most common conditions in patients with musculoskeletal pain.[1,2] It is a complex disorder that affects women more than men.[3,4] The pathophysiology of FMS requires further research. Emerging evidence suggests that there are abnormalities of both peripheral and central nervous system resulting in augmented sensory processing in the brain and decreased central nervous system inhibition of peripheral nociceptive signalling.[5] Genetic and environmental factors have also been linked to an increased risk of developing FMS.[6,7]

FMS is associated with significantly high societal and health care costs[8-12] with patients making more than double the number of visits to health care services than non-FMS controls and revealing higher levels of medication use.[10] This increased level of health care use has been found to remain stable over the course of the illness (despite an initial decrease in service utilisation during the year following diagnosis).[13]

FMS is also associated with high indirect costs to society, as many people with FMS are forced to leave employment, reduce their working hours or have increased absence from work as a result of their FMS symptoms.[12,14-16] In a general population study conducted in New Zealand (NZ), the prevalence of FMS has been estimated to be 1.1% in Maori and 1.5% in NZ European,[17] although internationally prevalence rates vary considerably, between 0.7% to 11%.[13,15,18–20]

FMS is diagnosed based on the experience of widespread chronic pain and tender points, however, according to the American College of Rheumatology Criteria,[3] many people with FMS and clinicians report a number of associated psychological and physical symptoms including; mood disturbance,[21–23] fatigue, sleep disturbance,

morning stiffness, paresthesias, headache, Raynaud's phenomenon and irritable bowel symptoms.[18,24,25]

The occurrence of symptoms, in addition to pain may contribute to the significantly lower quality of life and reduced physical functioning found in this population in comparison to other chronic pain conditions, such as rheumatoid arthritis.[26] Pharmacotherapy has demonstrated effective symptom reduction in FMS, although the side effects can limit tolerability[27–32]. It is widely acknowledged that medication should be integrated into an individualised treatment regime including exercise and psychological therapy (such as cognitive behavioural therapy).[33–35]

As the symptom profile of FMS is so diverse it is difficult for practitioners to identify the symptoms most likely to impact on patients with FMS to help to guide their treatment. Research exploring the nature and extent of diagnosed psychological disorders from a review of studies completed into FMS has revealed higher levels of anxiety and depressive disorders in people within FMS in comparison to controls[36] However further research is needed to explore the nature and severity of the common symptoms that people with FMS may experience, particularly in NZ.

To develop appropriate health care provision that meets the needs of patients, a clear understanding of the symptom experience is essential. This study aims identify the most common and severe symptoms in female patients diagnosed with FMS and to compare the findings in relation to community norms.

## Methods

An interview was conducted to explore the frequency and severity of common symptoms using a Structured Clinical Interview Schedule.

**Participants—**Participants were included in the study if; 1) they had been diagnosed with FMS by a GP or consultant; 2) FMS was reported to be their primary diagnosis; 3) they were over 18 years of age; 4) they were female (as the population of FMS predominantly affects females this enabled comparison of the findings with a general population female sample). Participants were excluded if; 1) they are unable to speak or understand English or; 2) they have a serious medical condition that is likely to affect the findings of the study, such as cancer or a specific diagnosed psychiatric disorder (such as schizophrenia, anxiety or depressive disorders).

Advertisements for the study were placed in patient newsletters distributed through Arthritis New Zealand and patient support groups for people with FMS across New Zealand. Patients who contacted the research team in response to the advertisements were sent an information sheet explaining the study and a consent form.

Participants were given the opportunity to talk to a member of the research team before they were asked to sign and return the consent in the prepaid envelope provided. Participants were only able to participate on receipt of the signed consent form.

**Assessments—**Information on age, gender, ethnicity, co morbid medical diagnoses, FMS symptom duration and medication use were recorded. The Structured Clinical Interview Schedule (CIS-R)[37] was then administered to all participants via the telephone or in person.

Two modes of administration were provided to enable those who were unable to travel to attend an in person interview to take part and also to provide the option of an in person interview for those who preferred this approach. The CIS-R has been validated for use by telephone and face to face presentation with no evidence of difference in outcomes found by the different modes of administration.[38]

The CIS-R is a standardised assessment that explores the occurrence of a wide range of symptoms in patients with physical health conditions.[39] The interview comprises of 14 sections (somatic symptoms, fatigue, concentration difficulties, sleep problems, irritability, worry about physical health, depression, depressive ideas, worry, anxiety, phobias, panic attacks, compulsions and obsessions) and asks patients about the existence of each symptom over the past month.

If the symptom is reported to have occurred in the past month, a more detailed assessment is completed to establish the frequency, duration, severity and time since onset and is intended for use by non-professional interviewers. Symptom sub-scales are scored between 0 to 4 (the depressive ideas subscale is scored between 0 to 5) with scores ≥2 indicating the symptom is frequent and severe. A total scale score is also calculated (0–57) with scores of ≥12 reflecting more severe symptoms. Norms are available for a female sample of (N=4728) collected from a household survey of people aged 16 to 74 years.[40]

The total telephone assessment took approximately 40 minutes to complete, with high scores indicative of greater symptom severity.

**Data analysis**—Frequencies, means and standard deviations (or medians and interquartile ranges if data did not meet parametric assumptions) were used to describe the characteristics of the participant sample. Descriptive analysis was completed to state the nature, frequency, duration, severity and symptoms duration of the 14 symptom domains explored in the CIS-R for the FMS participants. Adjusted odds ratios (95% confidence intervals) were calculated comparing the frequency of domain scores of ≥2 (indicating severe symptom experience) on each of the 14 symptom domains in comparison to the CIS-R community norms.

A priori power calculation for $\chi^2$ goodness of fit test using G*power 3.1 based on a medium effect size of 0.4, power 0.8 and alpha level of 0.05 (df 1) revealed that a minimum sample of N=50 would be required to detect significant differences between the FMS population and community norms.

## Results

Sixty-one participants contacted the research team in response to the advertisement and were sent an information pack in the post. Fifty eight participants (95%) returned the signed consent form, and were screened for eligibility. One participant was excluded as they had not been diagnosed by a clinician or consultant and one participant was no longer contactable, consequently fifty six female participants completed the interview either by telephone (n=52) or face to face (N=4). Characteristics of the FMS participants are described in Table 1.

**Table1. Participant characteristics (N=56)**

| Characteristic | Value |
|---|---|
| **Age (mean, SD)**<br>**Age range** | 56.89 years (13.99)<br>20–85 years |
| **Symptom duration (mean, SD)** | 15.84 years (13.32) |
| **Medication use**<br>Yes<br>No | <br>51 (91.1%)<br>5 (8.9%) |
| **Comorbidity**<br>Yes<br>No | <br>49 (87.5%)<br>7 (12.5%) |
| **Ethnicity**<br>New Zealand European | <br>56 (100%) |

The most common comorbidities in the sample included arthritis (N=8), irritable bowel syndrome (N=8) chronic fatigue syndrome (N=7), heart disease (N=4) and migraines (N=4). The most common medications taken included paracetamol, codeine, ibuprofen, prednisone and gabapentin.

The most frequent symptoms reported by FMS participants to be severe were; fatigue, somatic pain, sleep problems, and concentration difficulties. There were significantly higher rates of symptoms in the FMS sample on each of the 14 domains, in comparison to the community norms, with the exception of depression, compulsions and obsessions (see Table 2).

**Table 2. Percentage of participants scoring ≥2 on domains of the CIS-R**

| Symptom domain | NZ FMS female population N=56 | General female population N=4728[40] | Odds ratio (95% CI) | Chi-squared |
|---|---|---|---|---|
| Somatic pain | 48% | 8% | 10.62 (4.67–24.15) | 39.68** |
| Fatigue | 88% | 32% | 15.58 (7.47–32.50) | 65.33** |
| Concentration/forgetfulness | 57% | 11% | 10.73 (5.11–22.50) | 47.15** |
| Sleep problems | 77% | 34% | 6.50 (3.49–12.12) | 37.43** |
| Irritability | 50% | 22% | 3.55 (1.92–6.55) | 17.01** |
| Worry about physical health | 29% | 7% | 5.43 (2.25–13.10) | 16.40 ** |
| Depression | 16% | 12% | 1.40 (0.62–3.13) | 66.40 n.s. |
| Depressive ideas | 30% | 11% | 3.47 (1.62–7.40) | 11.08** |
| Worry | 43% | 21% | 2.84 (1.52–5.29) | 11.12 ** |
| Anxiety | 25% | 9% | 3.37 (1.48–7.67) | 9.07** |
| Phobias | 18% | 6% | 3.44 (1.30–9.07) | 6.82** |
| Panic | 7% | 2% | 3.69 (0.75–18.21) | 2.91** |
| Compulsions | 9% | 4% | 2.37 (0.71–7.98) | 2.06 n.s. |
| Obsessions | 13% | 7% | 1.99 (0.76–5.21) | 2.00 n.s. |

** $p<0.01$; n.s. = non-significant.

The mean total score on the CIS-R for the FMS population was 16.52 (SD 8.19) with N=40 (71.43%) receiving a total score of >12.

Participants who were taking medication revealed a higher total mean score than those who were not medication (16.73, SD 8.50 and 14.40, SD 3.65 respectively), although this difference did not reach statistical significance, U = 109.50, p = 0.62. Exploring the effect of comorbidity on the symptom profile, there were also no significant differences between those with and without comorbid conditions on the total symptom score, U = 94.00, p = 0.06.

The only significant difference observed on the subscale scores of the CIS-R was that those with a comorbid condition scored significantly higher on the fatigue subscale in comparison to those with no comorbid condition U = 84.50, p = 0.01.

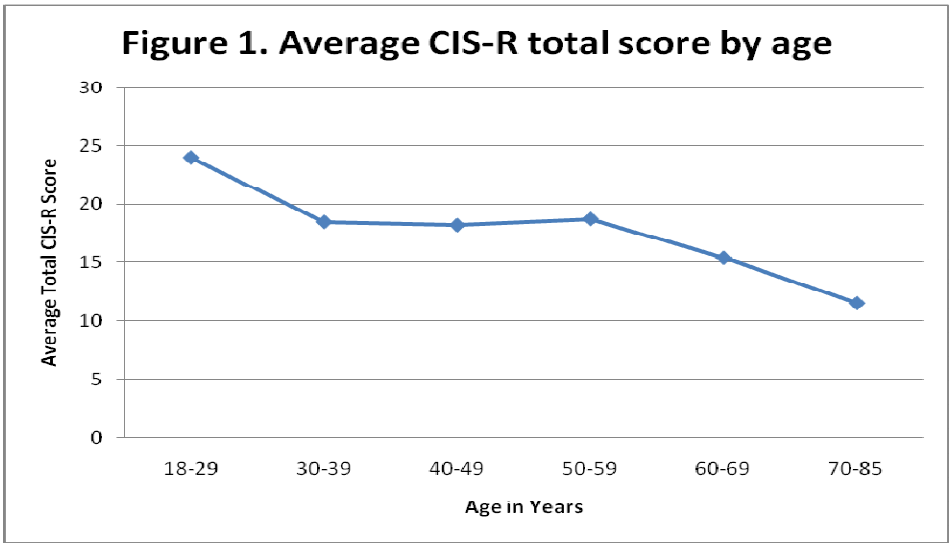
**Table 3. Correlations between age, length of illness and subscales of the CIS-R**

| | Age | Len | Som | Fat | Con | Irr | Wph | Dep | Di | Wor | Anx | Pho | Pan | Com | Obs |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Len | .18 | | | | | | | | | | | | | | |
| Som | -.37 | .56 | | | | | | | | | | | | | |
| Fat | -.08 | .14 | -.05 | | | | | | | | | | | | |
| Con | -.47 | .10 | .31 | .17 | | | | | | | | | | | |
| Sle | .03 | .02 | .17 | .27 | -.05 | | | | | | | | | | |
| Irr | -.36 | -.07 | .26 | .14 | .35 | | | | | | | | | | |
| Wph | -.17 | -.12 | .08 | .13 | .49 | .21 | | | | | | | | | |
| Dep | -.18 | -.03 | .08 | .21 | .44 | .14 | .40 | | | | | | | | |
| Di | -.26* | -.04 | .06 | .30 | .37 | .02 | .40 | .89 | | | | | | | |
| Wor | -.24 | .08 | .25 | .04 | .40 | .25 | .48 | .47 | .54 | | | | | | |
| Anx | .02 | -.24 | -.06 | .07 | .11 | .15 | .47 | .11 | .09 | .30 | | | | | |
| Pho | -.22 | -.05 | .23 | .07 | .38 | .17 | .43 | .23 | .34 | .53 | .27 | | | | |
| Pan | .04 | .22 | .21 | .20 | .26 | -.01 | .26 | .18 | .24 | .34 | .38 | .45 | | | |
| Com | -.20 | -.14 | .19 | .02 | .25 | .08 | .11 | .17 | .17 | .12 | .07 | .04 | .13 | | |
| Obs | -.17 | -.28 | .23 | .09 | .12 | .11 | .02 | .11 | .07 | -.01 | -.13 | .26 | -.12 | .21 | |
| Tot | -.45 | -.06 | .46 | .31 | .65 | .40 | .64 | .62 | .65 | .70 | .37 | .65 | .39 | .25 | .27 |

Shading indicates that correlation is significant at the 0.01 level (2-tailed).

Age = Age in years
Len = Length of illness duration in months
Som = Somatic symptoms
Fat = Fatigue
Con = Concentration and forgetfulness
Sle = Sleep problems
Irr = Irritability
WPh = Worry about physical health
Dep = Depression
Di = Depressive ideas
Wor = Worry
Anx = Anxiety
Pho = Phobias
Pan = Panic Com = Compulsions
Obs = Obsessions
Tot = Total score

All significant correlations are shown in Table 3. Length of illness did not correlate with any of the variables and sleep only correlated with fatigue. As can be seen in Table 3. younger age was associated with more frequent and severe total symptoms and higher scores on the somatic symptoms, concentration difficulties, depressive ideas and irritability subscales. All subscales were associated with the total symptom score with the exception of the sleep and compulsions subscales. The relationship between age and the total CIS-R score is shown in Figure 1.




## Discussion

This study aimed to explore the symptom profile of females with FMS in NZ using a structured clinical interview schedule. This study revealed that the most frequent and severe symptoms were fatigue, somatic pain, sleep and concentration difficulties. Significantly higher rates of symptoms were revealed in women with FMS on each of the subscales (with the exception of depression, compulsions and obsessions) and the total score, in comparison to community norms. The high frequency and severity of a wide range of symptoms in this sample of females with FMS highlights the need for clinical interventions to focus on addressing a range of symptoms in addition to pain.

Although medication use revealed no significant effect on the findings of this study, this may be due to the low numbers of participants who were not taking medication. Participants with a comorbid condition revealed higher levels of fatigue and total symptom scores than those without. This was to be expected with participants reporting comorbid conditions, such as arthritis, chronic fatigue syndrome and heart disease however, this highlights the need to consider the occurrence of comorbid conditions when assessing symptoms in FMS.

It was revealed that younger age was significantly associated with higher scores on somatic pain symptoms, concentration difficulties, irritability and depressive ideas sub-scales and also for the total score. Unexpectedly total symptom scores continued to decline into older age, when women were more likely to have comorbid conditions that may affect their scores. The negative correlation between age and FMS symptom

severity is similar to the results revealed in a previous study in FMS[41] and may reflect either the acute phase of symptom onset, that people learn to manage their symptoms more effectively or that symptoms may improve over time.

It was interesting to note that the sleep problems and compulsions subscales were not significantly associated with the total symptom score. This may suggest that the scales are measuring separate domains. Evidence has revealed that sleep is associated with physical outcomes such as pain and fatigue in FMS,[41] However, previous studies have focused on the components of sleep quality rather than exploring sleep as one symptom domain as in the CIS-R.

This study did not aim to explore the complexities of sleep quality in this population, but to explore generic perceived sleep disturbance in comparison to other symptoms of FMS and these results may therefore reflect a measurement issue. Few women with FMS reported experiencing compulsive symptoms in the previous month and these findings for the compulsions subscale may reflect the low variance for this variable.

In contrast to previous findings, where levels of clinically significant depressive symptoms have been found to be high (approximately 83%),[23] low levels of anxiety and depression were revealed in this study. Comparisons of the findings to community norms (which revealed no significant differences between females with FMS and the general population on levels of depression), suggests that depression is a more general public health issue than one specific to FMS.

Studies looking specifically at levels of depression and anxiety in FMS have revealed inconsistent findings and may reflect differences between the populations studied, (e.g. hospital or community based), the measurements used (such as focusing on depression levels or depressive disorders as well as lifetime experience or current experience of depression) and the type of comparison groups used (e.g. general population norms and chronic pain controls). This may also support the proposal that depression is a consequence of chronic pain[42] rather than a direct symptom of the FMS.

The aim of the study was to recruit a sample that would be broadly representative of the NZ FMS population, however the ethnicity of the participants in this study was 100% NZ European which limits the generalisability of the findings and the observed prevalence of symptoms should be considered with some caution. Studies exploring the impact and symptom experience of FMS for Māori are needed.

The findings in this study are limited as they do not reflect the variability in the symptom experience over time. Participants often commented when completing the interview that their responses to the question would change according to the time of day or the activities that they had recently been engaged in.

People with FMS frequently describe that their symptoms vary over the course of a day, with greater levels of pain and fatigue in the late afternoon/evening.[43] Although the study was powered to detect significant differences between the FMS participants and normative data, the sample size is relatively small, did not include males with FMS and the possibility of random error in the findings cannot be excluded.

It should also be noted that the community norms used as a comparison for this study were taken from a study conducted in the UK, rather than in NZ and therefore may

not truly represent the existence of common symptoms in the NZ community. These limitations may be reflected in the wide confidence intervals found in this study. The wide intervals could also highlight the wide variation in the symptom experience and it is likely that sub-groups of FMS may exist,[7],[44] emphasising the need to assess and treat the individual symptom experience in FMS.

Despite the limitations of the study, the results reveal that consideration needs to be given to addressing a wider range of FMS symptoms in clinical practice, with a particular focus given to levels of fatigue, sleep problems and concentration difficulties. in order to meet patients needs,

Since the completion of this study, the ACR diagnostic criteria have been revised to include a wider range of symptoms[45]. The findings of this study support the inclusion of a symptom impact scale into the criteria, particularly as the scale focuses on the three symptoms (fatigue, cognitive symptoms and feeling un-refreshed on awakening which is linked to sleep disturbance) found to be most problematic for women with FMS in this study.[44,45]

**Competing interests:** None declared.

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