

Quality of rheumatology care for patients with fibromyalgia and chronic pain syndromes

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To cite: Pang HYM, Farrer C, Wu W, *et al.* Quality of rheumatology care for patients with fibromyalgia and chronic pain syndromes. *BMJ Open Quality* 2021;**10**:e001061. doi:10.1136/bmjopen-2020-001061

► Additional material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2020-001061>).

Received 12 June 2020
Revised 19 February 2021
Accepted 4 March 2021



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ABSTRACT

Background One-third of primary care providers (PCPs) refer patients with fibromyalgia or chronic pain (FM/CP) to specialist care, typically rheumatology. Yet, comprehensive data on the quality of rheumatology care for patients with FM/CP are currently lacking.

Methods Records of patients referred for rheumatology consultation for FM/CP and seen at a single academic centre between 2017 and 2018 were extracted by retrospective chart review. Variables were diagnostic accuracy (at referral vs consultation), resource utilisation (investigations, medications, medical and allied health referral), direct costs (physician billing, staff salary, investigation fees) and access (consult wait time). Patient experience and referring PCP experience surveys were administered.

Results 79 charts were identified. Following consultation, 81% of patients (n=64) maintained the same diagnosis of FM/CP, 19% (n=15) were diagnosed with regional pain and 0% of patients (n=0) were diagnosed with an inflammatory arthritis or connective tissue disease. Investigations were ordered for 37% of patients (n=29), medication prescribed for 10% (n=8) and an allied health referral provided for 54% (n=43). Direct costs totalled \$19 745 (average \$250/consult; range \$157–\$968/consult). Consultation wait time averaged 184 days (range 62–228 days). Out of the seven (64%) responses to the patient experience survey, 86% of patients (n=6) were satisfied with provider communication but the consultation 'definitely' met the expectations of only 57% (n=4). The PCP survey returned an insufficient response rate.

Conclusions This study found that no patient referred to rheumatology care for FM/CP was diagnosed with an inflammatory arthritis or connective tissue disease. Furthermore, patients with FM/CP experience lengthy wait times for rheumatology care which delay their management of chronic pain. Interdisciplinary and collaborative healthcare models can potentially provide higher quality care for patients with FM/CP.

INTRODUCTION

Chronic pain is estimated to affect one in five adults worldwide.^{1–4} It is associated with considerable disability and a significant impact on daily activities and quality of life.⁵ Fibromyalgia, a primary chronic pain disorder, is diagnosed on the basis of a history of widespread pain and severity of somatic symptoms, including but not limited

to fatigue, cognitive symptoms, headaches, depression and pain or cramps in the lower abdomen.^{6,7} The prevalence of fibromyalgia has been estimated to range from 0.5% to 5.0%, with females being nine times more likely to develop the syndrome than males.^{8–10}

Chronic pain is one of the most common reasons for seeking medical care, and has been estimated to be associated with \$7.2 billion in annual direct costs in Canada.^{11–14} Fibromyalgia also has a substantial economic impact, accounting for \$C2298–\$C3804 per patient in annual direct costs and weeks worth of annual employment and household productivity losses.^{8,15,16} The annual health-care costs of patients with fibromyalgia have been estimated to be \$C493 higher than age, sex and geographically matched controls.¹⁷

The most recent 2012 Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome recommend that the diagnosis and management of fibromyalgia be concentrated in the primary care setting.⁶ Although a majority of primary care providers (PCPs) (63%) manage patients with fibromyalgia after diagnosis, 37% of PCPs refer patients with fibromyalgia to a specialist, typically a rheumatologist, for diagnosis.^{18,19}

Rheumatologists are central to the treatment and management of inflammatory arthritis and other autoimmune conditions.²⁰ However, the number of patients with inflammatory arthritis has doubled between 1996 and 2010, and is expected to double again over the next 30 years, with no proportional increase in the number of practising rheumatologists.^{20–23} In addition, delayed access to rheumatologists has been extensively recognised as a barrier to providing adequate care for rheumatological diseases, particularly with inflammatory arthritis in which early intervention improves clinical outcomes.^{20,24–27} With the rising population-based disease burden, identified shortage of rheumatologists in Canada and wait times exceeding target benchmarks, there is an

urgent need for a strategic approach to the planning and delivery of rheumatology care.²⁰

Chronic pain and its syndromes have historically been the second most common disorders observed by rheumatologists, after osteoarthritis.^{28–30} Yet, comprehensive data on the quality of rheumatology care for patients with fibromyalgia and chronic pain are currently lacking. The need to balance health resource constraints while providing equitable and sustainable care is an opportunity for quality improvement. It requires the simultaneous pursuit of the triple aim: bettering health outcomes, optimising the value of healthcare dollars and improving the care experience.³¹ Thus, the aim of this study was to characterise the quality of rheumatology care for fibromyalgia and chronic pain, specifically across six domains: diagnostic accuracy on referral, healthcare resource utilisation, cost, access, patient experience and provider experience.

MATERIALS AND METHODS

Context

This study took place in the rheumatology department in a large, urban and academic ambulatory care hospital. This department operates under a centralised triage model where all incoming referrals are triaged by an advanced practice physiotherapist using a standardised priority algorithm.^{32–33} This algorithm contains four priority levels with increasing wait time benchmarks: urgent (24–48 hours), priority 1 (P1; 31 calendar days), priority 2 (P2; 90 calendar days) and priority 3 (P3; 240 calendar days). P1 includes conditions such as inflammatory arthritis (including rheumatoid arthritis, psoriatic arthritis, spondyloarthritis, polymyalgia rheumatica) and connective tissue disease (including systemic lupus erythematosus). P2 is designated for non-inflammatory arthritis, such as osteoarthritis, crystal arthropathies and non-articular rheumatism. P3 is categorised for referrals for fibromyalgia or chronic pain syndromes.

Priority-level pathway

The priority level of an incoming P3 patient may change throughout their rheumatology consult pathway. Patients may have an undifferentiated diagnosis (P4) while awaiting the results of their investigations. For example, a patient's priority-level pathway may be P3→P4→P3: the patient was referred for fibromyalgia (P3) and after the return of their investigations which show no evidence to suggest a P1 or P2 diagnosis, they may be discharged back to their PCP with a discharge diagnosis of fibromyalgia (P3).

Inclusion and exclusion criteria

Records of patients triaged as P3 and seen by a rheumatologist for their initial consultation between June 2017 and July 2018 were extracted by retrospective chart review. Exclusion criteria included non-rheumatological outgoing diagnosis (n=1/102, 1%), no show to consult (n=11/102, 11%) and pending results of investigations

on study conclusion (n=9/10, 9%) (online supplemental figure 1).

Measures

Variables included diagnostic accuracy, which was described as the incoming priority level triaged at referral compared with the outgoing priority level designated at end of the initial consultation. Healthcare resources used as a result of the initial consultation were described in terms of the investigations ordered (imaging, labs and others), medications prescribed (non-steroidal anti-inflammatory drugs [NSAIDs], neuropathic [pregabalin, gabapentin and duloxetine], cortisone injections, muscle relaxant), referrals to allied health and referrals to other medical specialty. Direct costs (in \$C) of the initial consultation were estimated based on the hospital-based time-adjusted salary of an advanced practice physiotherapist (based on average salary of publicly available online job recruitment postings) as well as the Ontario Health Insurance Program (OHIP) physician billing code for an initial rheumatology consult (A485), and investigation fees that are publicly funded by OHIP. Access, described as wait time, was defined as the number of calendar days between the date of referral and the date of the first scheduled consultation.

To explore patient perspectives, an adapted version of the Picker Patient Experience Questionnaire was prospectively disseminated to P3 patients who attended an initial rheumatology consultation between June 2018 and July 2018 (online supplemental appendix 1). Variables included provider communication and patient expectations.

In order to explore provider perspectives, a nine-item survey on the practice patterns of PCPs involved in the care of patients with fibromyalgia, barriers to diagnosis and management, and areas for quality improvement was created (online supplemental appendix 2). The survey was prospectively disseminated with a financial incentive, through phone and electronic means, to the referring providers of the patient cohort.

Statistical analysis

Descriptive statistics were used to analyse the data; continuous data were described using the median and range, while categorical data were described using frequencies. Analyses were performed using SAS statistical software V.9.4 (SAS Institute).

RESULTS

There were 79 new P3 consultations seen in clinic between June 2017 and June 2018 (table 1). The average age of patients with a P3 triage level was 48.3 years. Most of these patients were female (n=70, 89%). A majority of P3 referrals were from a PCP (n=71, 90%). Most patients triaged as P3 had at least one previous medical consult for the same concern as their rheumatology consult (n=52, 66%).

Table 1 Patient and consult characteristics

| Characteristics | Incoming P3 patients (n=79) |
|--|-----------------------------|
| Age, years (±SD) | 48.3 (±15) |
| Sex | |
| Male | 9 (11%) |
| Female | 70 (89%) |
| Specialty of referring provider | |
| Family medicine | 71 (90%) |
| Sports medicine | 2 (3%) |
| General internal medicine | 1 (1%) |
| Rheumatology | 1 (1%) |
| Endocrinology | 1 (1%) |
| Environmental health | 1 (1%) |
| Infectious diseases and medical microbiology | 1 (1%) |
| Psychiatry | 1 (1%) |
| Previous consults | 52 (66%) |
| Rheumatology | 19 |
| Psychiatry | 10 |
| Neurology | 13 |
| Pain clinic | 7 |
| General internal medicine | 5 |
| Other | 36 |

Diagnostic accuracy

On referral and after their initial consult, patients were designated with an incoming and outgoing priority level, respectively. For patients triaged as P3, 81% (n=64) maintained their incoming P3 designation. Of these patients, 27% (n=21) had further investigations which did not impact their outgoing priority ranking and 5% (n=4) had a P2 designation after investigations. Notably, 0% (n=0) of patients with an incoming P3 priority designation were subsequently diagnosed with a P1 priority ranking (table 2).

Table 2 Diagnostic accuracy

| Characteristics | Incoming P3 patients (n=79) |
|--------------------------------|-----------------------------|
| Outgoing priority level (n, %) | |
| P1 | 0 (0) |
| P2 | 15 (19) |
| P3 | 64 (81) |
| Priority-level pathway (n, %) | |
| P3→P4→P3 | 21 (27) |
| P3→P3→P3 | 43 (54) |
| P3→P4→P2 | 4 (5) |
| P3→P2→P2 | 11 (14) |

Resource utilisation

Among all incoming P3 patients, 29 (37%) had investigations ordered for them. X-ray (n=26, 33%) was the most likely imaging modality to be ordered, followed by MRI (n=5, 6%) and ultrasound (n=3, 4%). For patients who had labs ordered for them (n=14, 18%), all were asked to complete a rheumatological workup (n=14, 18%) and some were asked to complete routine (n=8, 10%) and non-rheumatological workup (n=5, 6%) (table 3).

Eight patients (10%) had medications prescribed for them. NSAIDs (n=4, 5%), neuropathic medications (n=2, 3%), steroids (n=1, 1%) and muscle relaxants (n=1, 1%) were prescribed.

Only one patient (1.3%) was referred to another medical specialty, which was dermatology. Compared with referrals to medical specialties, patients were more likely to be referred to allied health (n=43, 54%). Referrals to allied health services (athletic therapy, physiotherapy, occupational therapy, chiropractor clinic, foot care clinic) (n=37, 47%) were most common, followed by referral to an internal interdisciplinary pain clinic (n=5, 6%) and an internal mental health service (n=3, 4%). It was more likely that patients were discharged back to their referring provider following the initial consult, but 14 patients (18%) had at least one follow-up appointment after their initial consultation.

Cost

Direct costs of the initial consultation were described as provider remuneration and investigations fees. Among incoming P3 patients, they were more likely to be seen by an advanced practice physiotherapist and rheumatologist (n=65, 82%) than a rheumatologist only (n=14, 18%). The median cost of provider, as identified through physician billing code and time-adjusted and averaged salary of an advanced practice physiotherapist, was \$197.59 per patient (range \$157.00–\$197.59 per patient). The median and average direct costs per patient were \$197.59 (range \$157.00–\$967.63) and \$249.94, respectively. The sum of these direct costs for this study period among this study cohort was \$19744.95 (table 4).

Access and patient experience

The average wait time between the date of the P3 referral and date of the first scheduled P3 consultation was 183.5 days (median 184 days). The shortest wait time was 62 days and the longest wait time was 228 days (table 5).

A patient experience survey was prospectively disseminated to all P3 patients (n=11) who presented to the rheumatology clinic between June and July 2018. Out of the 11 P3 patients who were recruited to complete the patient experience survey, seven responded (64%). Most patients (n=6 out of 7 survey respondents, 86%) were 'definitely' satisfied with their consultation with the rheumatologist and thought that it was easily understood who was involved in their care plan. Although all patients were discharged back to the care of their referring and/or PCP and 86% (n=6) of patients stated that it was easily understood how

Table 3 Healthcare resource utilisation

| Characteristics | Incoming P3 patients (n=79) | Priority-level pathway | | | |
|--|-----------------------------|------------------------|-----------------|----------------|-----------------|
| | | P3→P4→P3 (n=21) | P3→P3→P3 (n=43) | P3→P4→P2 (n=4) | P3→P2→P2 (n=11) |
| Investigations ordered (n, %) | 29 (37%) | 21 (100%) | 2 (5%) | 4 (100%) | 2 (18%) |
| Imaging (n, %) | 28 (35%) | 20 (95%) | 2 (5%) | 4 (100%) | 2 (18%) |
| MRI | 5 (6%) | 5 (24%) | 0 | 0 | 0 |
| X-ray | 26 (33%) | 19 (90%) | 1 (2%) | 4 (100%) | 2 (18%) |
| Ultrasound | 3 (4%) | 1 (5%) | 1 (2%) | 1 (25%) | 0 |
| Labs (n, %)* | 14 (18%) | 12 (57%) | 0 | 2 (50%) | 0 |
| Rheumatological workup | 14 (18%) | 12 (57%) | 0 | 2 (50%) | 0 |
| Non-rheumatological workup | 5 (6%) | 3 (14%) | 0 | 2 (50%) | 0 |
| Routine workup | 8 (10%) | 6 (29%) | 0 | 2 (50%) | 0 |
| Other investigations (EMG/NCS, ECG) | 1 (1%) | 1 (5%) | 0 | 0 | 0 |
| Medications prescribed (n, %) | 8 (10%) | 4 (19%) | 2 (5%) | 2 (50%) | 0 |
| NSAID | 4 (5%) | 3 (14%) | 1 (2%) | 0 | 0 |
| Neuropathic | 2 (3%) | 1 (5%) | 1 (2%) | 0 | 0 |
| Steroid | 1 (1%) | 0 | 0 | 1 (25%) | 0 |
| Muscle relaxant | 1 (1%) | 0 | 0 | 1 (25%) | 0 |
| Referral to medical specialty (n, %) | 1 (1) | 0 | 0 | 0 | 1 (9) |
| Neurology | 0 | 0 | 0 | 0 | 0 |
| Dermatology | 1 (1%) | 0 | 0 | 0 | 1 (9%) |
| Referral to allied health profession (n, %) | 43 (54%) | 8 (38%) | 26 (60%) | 4 (100%) | 5 (45%) |
| Athletic therapy, physiotherapy, occupational therapy, chiropractor clinic, foot care clinic | 37 (47%) | 6 (29%) | 22 (51%) | 4 (100%) | 5 (45%) |
| TAPMI pain clinic | 5 (6%) | 2 (10%) | 3 (7%) | 0 | 0 |
| Mental health in medicine | 3 (4%) | 1 (5%) | 2 (5%) | 0 | 0 |
| Follow-up | | | | | |
| Follow-up scheduled after initial consult | 14 (18%) | 8 (38%) | 2 (5%) | 2 (50%) | 2 (18%) |
| Median number of follow-ups per patient | 0 | 0 | 0 | 0 | 0 |
| 0 | 60 (76%) | 9 (43%) | 40 (93%) | 2 (50%) | 9 (82%) |
| 1 | 14 (18%) | 9 (43%) | 3 (7%) | 1 (25%) | 1 (9%) |
| 2 | 3 (4%) | 2 (10%) | 0 | 1 (25%) | 0 |
| 3 | 1 (1%) | 0 | 0 | 0 | 1 (9%) |

*Labs:

- Rheumatological workup: HLA-B27, CRP, ESR, RF, anti-CCP (funded through hospital laboratory services), anti-dsDNA, C3, C4, ENA, CK, microalbumin/creatinine urine ratio, urinalysis, blood fluid cell count, cytology, fluid differential and uric acid.
- Non-rheumatological workup: PTH, serum protein electrophoresis, lactate dehydrogenase, folate, calcium profile, magnesium, IgG/IgA/IgM, coeliac profile and blood film.
- Routine workup: albumin, ALT, CBC, AST, liver profile (bilirubin, ALT, ALP), serum creatinine, vitamin D 25-OH, vitamin B₁₂, TSH, free T4, HbA1c and ferritin.
- Other investigations: EMG/nerve conduction studies and echocardiogram.

ALP, alkaline phosphatase; ALT, alanine aminotransferase; AST, aspartate aminotransferase; CBC, complete blood count; CCP, cyclic citrullinated peptide; CK, creatine kinase; CRP, C-reactive protein; EMG, electromyography; ENA, extractable nuclear antigen; ESR, erythrocyte sedimentation rate; NCS, nerve conduction studies; NSAID, non-steroidal anti-inflammatory drug; PTH, parathyroid hormone; RF, rheumatoid factor; TAPMI, Toronto Academic Pain Medicine Institute; TSH, thyroid-stimulating hormone.

Table 4 Direct healthcare costs (in \$C)

| Characteristics | Path of priority-level classification | | | | |
|---|---------------------------------------|------------------------------|---------------------------|------------------------------|---------------------------|
| | Incoming P3 patients (n=79) | P3→P4→P3 (n=21) | P3→P3→P3 (n=43) | P3→P4→P2 (n=4) | P3→P2→P2 (n=11) |
| Consultation | | | | | |
| Rheumatologist only | 14 (18%) | 3 (14%) | 7 (16%) | 0 | 4 (36%) |
| Rheumatologist and advanced practice physiotherapist | 65 (82%) | 18 (86%) | 36 (84%) | 4 (100%) | 7 (64%) |
| Median cost of rheumatologist+advanced practice physiotherapist (per patient) | \$197.59 (\$157-\$197.59) | \$197.59 (\$157-\$197.59) | \$197.59 (\$157-\$197.59) | \$197.59 (\$197.59-\$197.59) | \$197.59 (\$157-\$197.59) |
| Median cost of investigations (per patient) | \$0 (\$0-\$770.14) | \$165.66 (\$32.05-\$770.14) | \$0 (\$0-\$59.75) | \$68.28 (\$32.05-\$307.7) | \$0 (\$0-\$101.15) |
| Among patients who had investigations ordered for them (n=29) | \$99.35 (\$32.05-\$770.14) | \$165.66 (\$32.05-\$770.14) | \$49.48 (\$39.2-\$59.75) | \$68.28 (\$32.05-\$307.7) | \$95.33 (\$89.5-\$101.15) |
| Median cost (per patient) | \$197.59 (\$157-\$967.73) | \$354.05 (\$229.64-\$967.73) | \$197.59 (\$157-\$236.79) | \$265.88 (\$229.64-\$505.29) | \$197.59 (\$157-\$258.15) |
| Average cost (per patient) | \$249.94 | \$379.29 | \$193.29 | \$316.67 | \$200.16 |
| Total cost | \$19744.95 | \$7965.10 | \$8311.34 | \$1266.70 | \$2201.81 |

Table 5 Patient experience

| Characteristic | Incoming P3 patients (n=79) |
|---|-----------------------------|
| Average wait time (days) (range) | 184 (62–228) |
| Survey question | Incoming P3 patients (n=7) |
| <i>Were you satisfied after your appointment with the rheumatologist?</i> | |
| Definitely | 6 (86%) |
| For the most part | 1 (14%) |
| Somewhat | 0 |
| Not at all | 0 |
| <i>Was it easily understood who is involved in your care plan?</i> | |
| Definitely | 6 (86%) |
| For the most part | 1 (14%) |
| Somewhat | 0 |
| Not at all | 0 |
| <i>Did a member of the staff explain your care plan in a way you could understand?</i> | |
| Definitely | 6 (86%) |
| For the most part | 1 (14%) |
| Somewhat | 0 |
| Not at all | 0 |
| <i>I did not need an explanation</i> | |
| 0 | |
| <i>Before your appointment, what were your expectations for your appointment? Check all that apply.</i> | |
| To receive a diagnosis | 6 |
| To receive a care plan to be carried out by my rheumatologist | 1 |
| To receive a care plan to be carried out by my primary care/family doctor | 1 |
| To receive education about my condition | 2 |
| Other | 0 |
| <i>During your appointment, you received (check all that apply):</i> | |
| A diagnosis | 4 |
| A care plan to be carried out by my rheumatologist | 3 |
| A care plan to be carried out by my primary care/family doctor | 1 |
| Education about my condition | 2 |
| A plan for further investigations | 1 |
| <i>After your appointment, did your appointment meet your expectations?</i> | |
| Definitely | 4 (57%) |
| For the most part | 2 (29%) |
| Somewhat | 1 (14%) |
| Not at all | 0 |
| <i>Following today's appointment, how likely do you think your care plan can be put into action?</i> | |
| Very likely | 6 (86%) |
| Somewhat likely | 1 (14%) |
| Neutral | 0 |
| Somewhat unlikely | 0 |

Continued

Table 5 Continued

| Characteristic | Incoming P3 patients (n=79) |
|--|-----------------------------|
| Very unlikely | 0 |
| <i>Did you receive written information by the end of your appointment?</i> | |
| Yes | 3 (43%) |
| No | 4 (57%) |
| <i>Do you have a family doctor?</i> | |
| Yes | 6 (86%) |
| No | 1 (14%) |

their care plan was explained, three out of seven patients believed that their care plan would be carried out by the rheumatologist. Six out of seven patients (86%) expected to receive a diagnosis, while only four patients (57%) received a diagnosis during their consultation. Only 57% of patients stated that the consultation 'definitely' met their expectations. Comments on what patients liked about their consult included 'astonishing high quality of attentiveness & care', 'doctors were very professional' and that the providers were 'really patient in listening unlike other doctors, and educated me, explained everything in detail'. Comments on what could be improved about their consultation centred around consultation wait time, such as 'wait for appointment was very long'.

Provider experience

Multiple attempts to collect responses to the PCP survey were made. It was disseminated by phone and electronic means, and a financial incentive of \$C20 was provided. Despite these efforts in contacting the 71 referring PCPs, only three responses (4.2%) were received.

DISCUSSION

Chronic pain and fibromyalgia are associated with significant patient disability. This study found that no patients referred to rheumatology care for fibromyalgia or chronic pain syndrome had evidence of an inflammatory arthritis or connective tissue disease. Rheumatology consultations for patients referred for fibromyalgia or chronic pain syndrome incurred health system costs and resource utilisation. Wait times were lengthy, an average of approximately 6 months, and patient experiences were not universally positive.

Diagnostic accuracy

Fibromyalgia and other chronic pain syndromes carry a wide differential diagnosis.³⁴ It is not an inflammatory disorder but a chronic pain syndrome. It may present like a rheumatological disease, but the pattern of pain is often distinct. For example, patients with fibromyalgia may present with musculoskeletal pain and possibly morning stiffness, but the pain is often described as diffuse and not typically isolated from joints or muscles. In addition, fibromyalgia is a diagnosis of exclusion, and referral to rheumatology is often done in

order to rule out an inflammatory arthritis or connective tissue disease. A previous study found that almost 60% of patients referred for fibromyalgia were found to be misdiagnosed, and instead had a primary rheumatological condition to account for their symptoms, with inflammatory arthritis making up 40% of these misdiagnoses.³⁵ This delay has been shown to alter disease progression, where timely referral to a rheumatologist for the diagnosis of inflammatory arthritis significantly increases early initiation of treatment, improves patient outcomes, reduces disability, reduces the need for costly surgical interventions and decreases global disease burden.^{23 25 26} As such, diagnostic accuracy is of increased importance.^{26 36}

This present study found that no patients referred for fibromyalgia or chronic pain had evidence of an inflammatory arthritis or connective tissue disease after their rheumatologist consultation at that time. This is different from previous studies noted above. The findings in our study can be associated with the use of a well-developed centralised triage algorithm for potential inflammatory arthritis, connective tissue disease and chronic diffuse pain referrals.³³ In this powered study, the sensitivity and specificity of a P3 diagnosis at triage were calculated to be 82% and 94%, respectively; sensitivity and specificity of a P1 diagnosis at triage were calculated to be 92% and 81%, respectively.³³ Patients in this study were discharged back to their referring provider as current guidelines recommend that the diagnosis and management be followed in the primary care setting and that specialist consultation be reserved for patients with atypical symptoms that suggest an alternate diagnosis.⁶ This study offers new evidence in the diagnostic accuracy by the referring provider. Although this was a quality study and not powered, it also reaffirms the accuracy of the centralised triage model in identifying P3 versus P1 patients.^{32 33}

Healthcare utilisation: resource and cost

PCPs have self-reported an uncertainty when diagnosing and managing chronic pain syndromes, including fibromyalgia and its diverse set of manifestations.¹⁹ Fibromyalgia can also be comorbid with various clinical conditions, including rheumatoid arthritis, depressive disorder, irritable bowel syndrome and tension-type headache, which span the scope of numerous medical specialties.^{37 38} As such, chronic pain syndromes have often been underdiagnosed, leading to excessive testing and inappropriate treatment as well as resulting in increased and prolonged healthcare utilisation.^{34 39}

This study found that 37% and 54% of P3 patients had investigations ordered for them and were referred to an allied health programme, respectively. Direct costs incurred to the health system of one rheumatology consultation averaged almost \$250 per patient. Although these costs may seem lower than that of previous studies, the direct costs calculated in this study can only be attributed to publicly funded OHIP fees (physician remuneration and investigation fees) and hospital-based costs (advanced practice physiotherapist remuneration) at this single centre within this study period for one consultation. These direct costs did not include costs of prescription medications and allied health appointments

due to the wide variation of public insurance, private insurance and out-of-pocket coverage among patients.⁴⁰

A Canadian study found that the annual average incremental per-patient cost to manage chronic pain was \$1742, a 51% increase in cost compared with patients with no chronic pain.¹⁴ A US study by Berger *et al* showed that patients with fibromyalgia had fourfold more physician visits, twofold more outpatient visits and fourfold more visits to the emergency department.¹⁵ Mean total costs over 12 months, composed of inpatient care, outpatient care and medication costs, were three times higher among patients with fibromyalgia (US\$9573) than patients without fibromyalgia (US\$3291).¹⁵ Another US study estimated that patients with fibromyalgia incurred comparably equal direct costs as patients with rheumatoid arthritis, but with more emergency department, physician and physical therapy visits.⁴¹ Characterisation of the economic impact of chronic pain and fibromyalgia may aid healthcare providers and health service decision makers to prioritise these syndromes and build innovative care models that facilitate cost-effective and positive health outcomes.

Access

P3 patients in this study waited an average of 183.5 days for their rheumatology consultation. Out of all patients referred to the clinic and triaged as P3 (initial study cohort n=102), 11% (n=11) did not attend their scheduled consultation, which exceeded the institution target no-show rate of 10% (online supplemental figure 1). Long wait times have been shown to be a predictor for non-attendance to healthcare appointments.⁴² Timely diagnosis of fibromyalgia can diminish patient uncertainty and frustration, and allows attention to be focused towards symptom management and improvement of quality of life.^{39 43–45} In addition, patients diagnosed with fibromyalgia report significant improvements in health satisfaction and fewer symptoms.⁴⁶

Patient experience

Patients' care experience is at the core of a successful health system. Prioritising care to be patient centred through increasing access and building patient partnerships encourages continuous quality improvement. In this study, patients were satisfied with their rheumatology consultation, as indicated by their positive comments and high scoring on the communication aspects. However, only 57% were 'definitely' satisfied with the outcome of their appointment.

For decades, fibromyalgia has provoked debate among healthcare providers regarding the clinical usefulness of its diagnostic label and its diagnostic criteria.^{47 48} This has been associated with barriers to accessing care; it has been found that 50% of Canadian rheumatologists have endorsed refusing referrals for consultation from patients with a reported diagnosis of fibromyalgia.⁴⁷ The patient voice has not been sufficiently heard during this debate. For patients with fibromyalgia followed at a rheumatology subspecialty clinic, 40% of patients found that contact with a rheumatologist was unhelpful.⁴⁹ In an international survey study of patients with fibromyalgia across six European countries, Mexico and South Korea, 59% of patients agreed that they

found it difficult to communicate their symptoms to physicians.⁴⁵ Patients in Europe most commonly presented to PCPs (95%–98%), rheumatologists (62%–72%), neurologists (51%–61%) and psychiatrists (21%–32%) about their diagnosis of fibromyalgia.⁴⁵ A majority of these patients had at least one experience where their physician did not take their symptoms seriously and felt that a lengthier consultation was needed for the physician to make a diagnosis of fibromyalgia.⁴⁵ The lack of a clear pathway for patients to navigate within the healthcare system has often led to siloed care, multiple medications to treat different symptoms and worsened disability.^{50–53}

Improving quality of chronic pain and fibromyalgia care

There is increasing evidence that fibromyalgia is no longer a rheumatological disease process. Rather, it is associated with a disturbance in the processing of sensory information within the central nervous system resulting from central sensitisation and leading to an amplified pain perception (allodynia and hyperalgesia).^{49 54–57} In addition, fibromyalgia is frequently comorbid with clinical conditions of other medical specialties including irritable bowel syndrome, migraine and mood disorders.^{37 38} Lastly, management of chronic pain and fibromyalgia is multidisciplinary and is composed of various non-pharmacological options, including patient education, sleep hygiene, exercise and cognitive therapies, as well as neurological and psychiatric pharmacotherapy if non-pharmacological management is inadequate, including tricyclic antidepressants (eg, amitriptyline), serotonin-norepinephrine reuptake inhibitors (eg, duloxetine) and anticonvulsants (eg, pregabalin), as first-line medication options.^{6 29 58 59} As such, it is timely to reconsider the siloed role of the rheumatologist in the care of patients with chronic pain syndromes. Considering the multimodal nature of these management options and syndrome pathophysiology, interdisciplinary collaboration between PCPs, rheumatologists, psychiatrists, neurologists, other medical specialties and allied health providers can provide a unique and innovative care model to support the care of patients with chronic pain syndromes and fibromyalgia.^{20 22 30 33}

For example, the patient-centred medical home (PCMH) is a model of primary care transformation that is based on the principles of interdisciplinary team-based care with coordination by PCPs across healthcare and community providers.⁶⁰ Although there are various barriers to the PCMH, including provider capacity, financial resources and infrastructure needs, it has been successfully implemented for chronic diseases, such as diabetes and post-traumatic stress disorder.^{50 61} It has resulted in reduced rates of hospitalisation, decreased specialty care visits and lowered long-term costs.^{62–64} Designing and implementing a PCMH for patients with chronic pain and fibromyalgia may be a potential strategy to improve quality of care.

Alternatively, the implementation of an advanced access model in a rheumatology practice has been shown to improve access, patient satisfaction and costs.⁶⁵ For example, a referral effectiveness programme that provides PCPs an education package on diagnosis, investigation and management

protocols on referral has been shown to increase interdisciplinary engagement and quality of care for osteoarthritis.⁶⁵ This model can potentially be applied in the setting of fibromyalgia and chronic pain syndromes.

Limitations

There were various limitations in this current study. This was a retrospective chart review, which presents limitations in the generalisability of results. The patient experience survey was limited in the number of respondents due to the restricted study period, limitations in research resources, as well as the limited number of patients triaged as P3. PCPs, who made up 90% of referring providers, were identified as key perspectives to obtain and a survey was disseminated. However, a lack of responses (response rate 4.2%) was received despite multiple attempts through phone and electronic means as well as offers of a financial incentive. This could have been attributed to various factors, including survey fatigue. It could also suggest a lack of a topical salience.^{66 67} The lack of responses highlighted the general need to bring the care needs of patients with fibromyalgia and chronic pain syndromes into the forefront of primary care. Designing and implementing strategies to align with the interests of PCPs, including a PCMH or referral effectiveness programme, to improve quality of care for patients with fibromyalgia and chronic pain syndromes is an important area of further exploration.

CONCLUSION

This study found that no patient referred to rheumatology for fibromyalgia or chronic pain syndrome was diagnosed with an inflammatory arthritis or connective tissue disease. Therefore, these referrals divert rheumatological care from those patients who have an inflammatory arthritis or connective tissue diagnosis for whom data support improved outcomes with timely access. Furthermore, patients with fibromyalgia and chronic pain syndromes experience lengthy wait times for rheumatology consultation, which delay their management. Rheumatology care does not currently provide the interprofessional model of care that is required for managing chronic pain. Designing and implementing collaborative solutions to support PCPs, other medical specialties and allied health providers can potentially offer timelier and higher quality care for patients with fibromyalgia and chronic pain syndromes.

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Contributors HYMP conducted the design of the research, data collection, data analysis, data interpretation, drafting of the manuscript and critical revisions of the article. CF contributed to the design of the research, data interpretation and critical revisions of the article. WW contributed to data analysis. NKG contributed and supervised the design of the research, data interpretation and critical revisions of the article. All authors approved the final version of the submitted manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval This study was approved by the institution's Ethics Assessment Process for Quality Improvement Projects (APQIP). The review board determined this

study as minimal risk using the ARECCI Screening Tool and was granted a waiver of Research Ethics Board review.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Please contact HYMP (corresponding author) at hilary.pang@mail.utoronto.ca.

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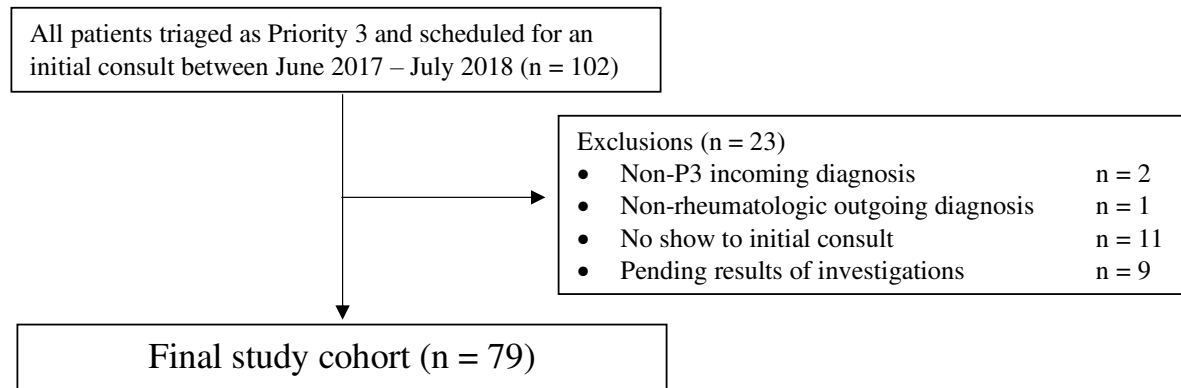
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Supplemental Figure 1

APPENDIX 1: Patient Experience

Patient Perspectives on Rheumatology Care for Chronic Pain and Fibromyalgia**CONSENT LETTER**

You are invited to participate in a survey about patient satisfaction of rheumatology consultations at Women's College Hospital. Your participation is voluntary, anonymous, and has no impact on your care plan. You can complete some or all of this form as you feel comfortable. You can skip any question on this survey as you wish and still submit this survey.

Please do not include any identifying information, such as names, dates, etc.

Where to submit this survey?

Once you are finished with this survey, please drop it off in the designated box at the nurses station, labelled "Patient Experience Survey".

What is this study about?

The purpose of this survey is to find out what patients think about their experience of their rheumatology consultation across various domains including satisfaction, communication, and use of health resources. This survey is part of an overarching project that aims to determine how effective certain rheumatology referrals are by looking at patient experience, wait times, use of health resources, and costs.

Who is conducting this study?

This study is being conducted by the Department of Rheumatology at Women's College Hospital. The investigators of this study are Hilary Pang (MD/MSc student), Chandra Farrer (Advanced Practice Physiotherapist), and Dr. Natasha Gakhal (Rheumatologist).

The results from this survey will help inform how services are provided at Women's College Hospital. Thank you for your participation.

Patient Perspectives on Rheumatology Care for Chronic Pain and Fibromyalgia**SURVEY**

Were you satisfied after your appointment with the rheumatologist?

- Definitely
- For the most part
- Somewhat
- Not at all
- Don't know / Can't remember

Was it easily understood who is involved in your care plan?

- Definitely
- For the most part
- Somewhat
- Not at all
- Don't know / Can't remember

Did a member of the staff explain your care plan in a way you could understand?

- Definitely
- For the most part
- Somewhat
- Not at all
- Don't know / Can't remember
- I did not need an explanation

Before your appointment, what were your expectations for your appointment?

- To receive a diagnosis
- To receive a care plan to be carried out by my rheumatologist
- To receive a care plan to be carried out by my primary care/family doctor
- To receive education about my condition
- Other: _____

During your appointment, you received:

- A diagnosis
- A plan to return for ongoing care by rheumatology
- A plan to return for ongoing care by my primary care/family doctor
- To receive education about my condition
- Other: _____

After your appointment, did your appointment meet your expectations?

- Definitely
- For the most part
- Somewhat
- Not at all
- Don't know / Can't remember

Following today's appointment, how likely do you think your care plan can be put into action?

- Very likely
- Somewhat likely
- Neutral

- Somewhat unlikely
- Very unlikely
- Don't know / Can't remember

Did you receive written information by the end of your appointment?

- Yes
- No

After today's appointment with the rheumatologist, were you provided with any of the following services? Check all that apply.

- Exercise prescription
- Sleep study
- Medications for pain
- Medications for mood
- Management for mood
 - Examples: Cognitive Behavioral Therapy/CBT, mindfulness-based stress reduction, journaling, self-management programs, etc
- Referral to a medical specialist
 - Examples: Neurology, physiatry, psychiatry, etc
- Referral to an allied health professional
 - Examples: Physiotherapist, occupational therapist, dietician, etc

Do you have a family physician?

- Yes
- No

If yes, did your family physician provide any of the following services? Check all that apply.

- Exercise prescription
- Sleep study
- Medications for pain
- Medications for mood
- Management for mood
 - Examples: Cognitive Behavioral Therapy/CBT, mindfulness-based stress reduction, journaling, self-management programs, etc
- Referral to a medical specialist
 - Examples: Neurology, physiatry, psychiatry, etc
- Referral to an allied health professional
 - Examples: Physiotherapist, occupational therapist, dietician, etc

What did you like about your appointment? Please do not include any identifying information (such as names, dates, etc).

How could your appointment have been better? Please do not include any identifying information (such as names, dates, etc).

Any other feedback you would like to add? Please do not include any identifying information (such as names, dates, etc).

Thank you for your participation in this survey. Your participation is valuable to the research and services provided at Women's College Hospital. Once you are finished with this survey, please submit it in the designated box at the nurses station, labelled "Patient Experience Survey".

APPENDIX 2: Provider Experience

Perspectives of Primary Care Physicians Involved in the Care of Patients with Fibromyalgia**CONSENT LETTER**

Title of Study: Effectiveness of Fibromyalgia Referrals to Rheumatology Care: An Evaluation of Access, Resource Utilization, and Interdisciplinary Perspectives

To help you make an informed decision regarding your participation, this letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you have any questions about this letter or the study, please email the investigators prior to consenting to the study.

What is this study about?

You are invited to participate in a research study about the referral effectiveness of fibromyalgia patients to rheumatology care. One of the goals of this study is to engage with primary care physicians involved in the care of fibromyalgia patients. To gain a better understanding of the nature of the patient-provider relationship, we want to identify the practice patterns, barriers, and needs of practicing Canadian physicians who care for patients with fibromyalgia. This study also aims to determine the access, health resource utilization, and patient perspectives of referrals to Rheumatology.

This study has received ethics approval through the Women's College Hospital Ethics Assessment Process for Quality Improvement Projects.

What does participation involve?

Your participation in this study is voluntary. You may decline to answer any question(s) at any time.

This survey is anonymized; please do not provide any information that identifies you.

Participation in the study consists of an 9-item survey. This survey is expected to take a maximum of 3-5 minutes to complete. If you choose to participate, your responses will be compiled with other participants' and used in presentations and/or publications.

What are the possible benefits and risks of the study?

Participation in the study may not provide any personal benefit to you. However, the results of this study will be used to inform Rheumatology practices at Women's College Hospital on how to engage primary care physicians in the care of patients with fibromyalgia.

Will my identity be known to others?

No, this survey is anonymized. You will NOT be asked to provide any personal identifying information.

Will my information be kept confidential?

The information you share will be kept confidential. Only the research team will have access to study data. No identifying information will be used in any presentations and/or publications based on this research.

Who is funding this study?

There are no external funding sources.

Financial Incentive

At the completion of this survey, you will be directed to a separate link where you can choose to enter your email so that you can be sent a \$10 gift card. Survey responses will not be linked to identifying data collected for the gift card.

Consent to study

By participating in this survey, you have read the above information regarding this research study on the care of patients with fibromyalgia, and consent to participate in this study.

If you have any questions regarding this study, or would like additional information about your participation, please contact Hilary Pang at hilary.pang@mail.utoronto.ca.

Thank you for your participation in this study.

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**Perspectives of Primary Care Physicians Involved in the Care of Patients with Fibromyalgia
SURVEY**

1) What is your approach to managing patients with fibromyalgia? Please choose all that apply.

- Pharmacological (prescription)
- Pharmacological (over the counter)
- Counselling and/or psychological interventions
- Exercise and/or physical therapy
- Lifestyle modification
- Sleep optimization
- Self-management
- Referral to specialist
- Other (please specify):

2) Have you referred patients with fibromyalgia to Rheumatology?

- YES
- NO

If you answered YES to question 2, please proceed to questions 3 and 4.

3) What is the estimated number of patients with fibromyalgia you have referred to Rheumatology in a year?

4) What are your reason(s) for referring patients with fibromyalgia to rheumatology? Please choose all that apply.

- For diagnosis
- For management
- For monitoring outcomes to management therapies
- For patient reassurance / patient request for referral
- For transfer of care so patient can access interdisciplinary services

Other (please specify):

- 5) The following represents a barrier to the diagnosis of fibromyalgia: Unclear diagnostic criteria / guidelines
- Strongly agree
 Moderately agree
 Neutral
 Moderately disagree
 Strongly disagree
- 6) The following represents a barrier to the diagnosis of fibromyalgia: Competency/ability to diagnose fibromyalgia
- Strongly agree
 Moderately agree
 Neutral
 Moderately disagree
 Strongly disagree
- 7) The following represents a barrier to the management of fibromyalgia: Knowledge of management strategies
- Strongly agree
 Moderately agree
 Neutral
 Moderately disagree
 Strongly disagree
- 8) Do Rheumatology consults sufficiently address your reason(s) for referral?
- Always
 Usually
 Sometimes
 Rarely
 Never
- 9) What would aid your care of patients with fibromyalgia? Please choose all that apply.
- Medical education tools
- E.g. written explanation of guidelines, diagnostic criteria and multi-modal management strategies of fibromyalgia
 - E.g. online reference links and tools
- Patient education tools
- Access to mental health services
- Access to movement therapy services (e.g. athletic therapy, PT, OT)
- Referral to rheumatology

- Referral to interdisciplinary pain clinic
- Referral to other medical specialty or other interdisciplinary care provider (please specify in Comment box below)
- Other medical specialty, interdisciplinary care provider, aids, or tools (please specify):