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Patient perspectives on wait times and the impact on their life: A waiting room survey in a chronic pain clinic

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HIGHLIGHTS

- Wait times for chronic pain care exceeded patients' preferences in most cases.
- In 31% of cases, patients reported waiting over a year for care.
- Nearly all patients (94%) felt wait times negatively affected their daily lives.

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ABSTRACT

Background and Aims: Chronic pain is a debilitating condition that requires prompt access to care for effective treatment. Wait times for care often exceed benchmark recommendations, with potential consequences to patient health outcomes. The goal of this paper is to gain the perspectives of patients attending a chronic pain clinic regarding the acceptability of current wait times and the impact of their experiences of waiting for chronic pain care.

Methods: The study took place in a chronic pain clinic at an academic-affiliated teaching hospital in Ottawa, Canada, which housed seven clinicians at the time of the study. New patients attending the chronic pain clinic between July 14, 2014 and August 5, 2015 were eligible to participate based on the availability of the research and clerical staff who administered the survey on a variety of days over the course of the study. Patients completed a self-administered 29-item survey. The survey took approximately five to ten minutes to complete. Questions pertained to patients' socioeconomic factors, chronicity and burden of pain symptoms, and satisfaction with current wait times. Actual wait times were self-reported. Survey results were entered into an Excel spreadsheet, exported to SPSS, and coded numerically to facilitate descriptive analyses using comparative graphs and tables. Open-text responses were reviewed by the authors.

Results: Sixty-six patients completed the survey. While 83% of patients stated that their ideal wait time was less than three months, 32% reported receiving an appointment within this period, and 31% reported waiting a year or more. Only 37% of patients felt the wait time for their appointment was appropriate. During their wait, 41% of patients reported receiving written information about chronic pain and 47% were referred to a local chronic pain management group. 94% reported interference with social/recreational activities and normal activities of daily living, 31% had to miss work or school due to the frequency of ongoing symptoms, and 22% reported being unable to attend work or school altogether. Furthermore, 37% of patients reported visiting the emergency room within the previous year and 65% worried about having a serious undiagnosed disease.

Conclusions: Our study found that wait times for chronic pain care, even those triaged as urgent cases, far exceeded what patients considered ideal. Only a third of patients received care within three months of making their appointment, while nearly another third waited over a year. During the waiting period,

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nearly all patients experienced some impact on their day-to-day activities and work or school attendance, half were unemployed, and nearly a quarter reported a complete inability to attend work or school because of pain.

Implications: Wait times for chronic pain care exceed timelines deemed acceptable by patients, causing anxiety and reducing function. The patient perspective must be considered in initiatives attempting to improve access to care for this population with specific needs and goals. Innovative solutions, such as electronic consultation and shared care models, hold promise.

1. Introduction

Chronic pain is a debilitating condition affecting millions of patients in Canada and the United States [1,2]. In order to effectively manage chronic pain, patients require prompt access to care. If delivered in a timely manner, appropriate pain therapy can substantially improve quality of life [3], whereas increased pain intensity and emotional distress become significant after as little as three months of waiting for chronic pain treatment [4]. In order to mitigate the negative effects of prolonged wait times, the Canadian Anesthesiology Society and the Wait Time Alliance established benchmark wait times for chronic pain treatment at a maximum of six months [5,6]. However, a study of multidisciplinary pain treatment facilities (MPTFs) found that wait times ranged from six months to five years [7,8]. While wait times are less extensive in the United States, research has identified disparities in access to pain treatment based on socioeconomic factors [9,10]. Patients facing poor access to pain treatment may experience health deterioration, lower quality of life, and a reduced ability to fully participate in work, school, and leisure activities [1,7]. Furthermore, chronic pain patients are two to three times more likely to experience suicidal ideation or commit suicide [3].

As part of a larger programme of research examining access to care and the impact of electronic consultation (eConsult) [11], we conducted a series of waiting room surveys to examine the perspectives of patients attending specialist clinics regarding current wait times and the impact of delays on their lives. Patient-reported outcomes are increasingly recognized as a critical aspect of health services improvement activities, and while we have shown that eConsult can improve access to chronic pain services [12], there was a need to better understand the patient experience of living with chronic pain.

The results of this research will help inform the next steps in implementation of eConsult on a broader scale by providing an in-depth look at the perspectives of people living with chronic pain. It will also be relevant for the development of other quality improvement initiatives for chronic pain patients and be of interest to innovators in other jurisdictions seeking to improve care for patients suffering from chronic pain.

2. Methods

2.1. Setting

The study took place in a chronic pain clinic at an academic-affiliated teaching hospital in Ottawa, Canada, which housed seven clinicians at the time of the study. The clinic holds approximately 380 full day chronic pain clinics per year, for a total of about 4350 visits from 1435 patients. At the time of the study, an estimated 500 new patients were seen by the clinic each year, of whom as many as seventy five percent are triaged as urgent and booked as early as possible, whereas those triaged as non-urgent face a wait time of over two years.

2.2. Participants

New patients attending the chronic pain clinic between July 14, 2014 and August 5, 2015 were eligible to participate based on the availability of the research and clerical staff who administered the survey on a variety of days over the course of the study. Patients who were less than 18 years of age, cognitively impaired, or unable to complete the survey in English or French were ineligible to participate.

2.3. Procedure

The clinic receptionist informed patients about the study when they checked in for their appointment and gave them an information sheet. Patients who agreed to participate met with a research assistant in a private location to complete informed consent forms. The patient completed a written self-administered survey prior to their specialist appointment.

2.4. Survey

Patients completed a self-administered 29-item survey. The survey took approximately five to ten minutes to complete, and was adapted from a previous study of patient wait times [13] to include additional questions pertaining to chronic pain. Questions pertained to patients' socioeconomic factors, chronicity and burden of pain symptoms, and satisfaction with current wait times. Patients could also leave additional comments in an open-text field. Actual wait times were self-reported.

2.5. Analysis and interpretation

Survey results were entered into an Excel spreadsheet, exported to SPSS, and coded numerically to facilitate descriptive analyses using comparative graphs and tables. Open-text responses were reviewed by the authors.

3. Results

A total of 71 patients consented to the study, of whom 66 completed the self-administered waiting room survey. The five patients who did not complete the survey were called in to their specialist appointment prior to completion or decided to defer participation during the survey. In some cases, patients declined or were unable to answer questions, and consequently some surveys contain missing data.

Our sample had more women than men (56% versus 44%) and a broad age range (18 to 87 years) with a median of 53 years. The majority (68%) completed some form of post-secondary education. Among patients under 65 years of age, 38% were unemployed. Full demographic details are available in Table 1.

While 46% of referrals to the chronic pain clinic were from the patients' usual family doctor, 48% came from another specialist (Table 2). Sixty-three percent of patients reported having seen

Table 1
Patient characteristics.

Characteristics	%
Gender ($n = 65$)	
Male	44%
Female	56%
Age ($n = 66$)	
Age range	18–87
Median age	53
Education ($n = 65$)	
Elementary school	3%
High school	29%
College or technical school	39%
University	29%
Employment sector ($n = 66$)	
Public sector	12%
Private sector	16%
Self-employed	7%
Not-for-profit organization	1%
Domestic or homecare	1%
Unemployed (under age 65)	53%
Method of transportation to appointment ($n = 66$)	
Regular bus	11%
Para transpo	0%
Relative dropped them off	18%
Walked	2%
Biked	0%
Car	64%
Taxi	3%
Other	3%

Table 2
Appointment characteristics.

Characteristics	%
Referrer ($n = 59$)	
Usual family doctor	46%
Nurse practitioner	2%
Walk-in clinic doctor	0%
Emergency room doctor	2%
Specialist doctor	48%
Other	3%
Wait time for this appointment ($n = 65$)	
Far too short	0%
Somewhat too short	0%
About right	37%
Somewhat too long	32%
Far too long	31%
Frequency of ongoing symptoms causing missed work or school ($n = 64$)	
Never	17%
Less than 5 days per month	16%
Between 5 to 15 days per month	8%
More than 15 days per month	8%
Totally unable to work/go to school all the time	22%
Not applicable (no ongoing symptoms or not working/going to school)	30%
Length of time seeing family doctor/other health care provider for current problem	
0–3 months	3%
3–6 months	6%
6–12 months	8%
More than 12 months	83%

another specialist for their pain problem prior to their pain clinic appointment. The most common specialties accessed by the study population prior to the pain clinic referral were orthopaedic surgery (23%), neurosurgery (19%), physical medicine and rehabilitation (11%), and anesthesiology (11%). In 83% of cases, patients reported seeing their family physician or another health care provider for their condition over the past 12 months or longer.

Ideal and actual wait times are reported in Fig. 1. While 83% of patients stated that their ideal wait time was less than three months, 32% reported receiving an appointment within this period, and 31% reported waiting a year or more. Only 37% of patients felt the wait time for their appointment was appropriate. During their wait, 41% of patients reported receiving written information about chronic pain and 47% were referred to a local chronic pain management group.

Fig. 2 presents the proportion of respondents who reported experiencing various burdens associated with chronic pain. An overwhelming majority reported interference with social/recreational activities (94%) and normal activities of daily living (94%). Thirty-one percent had to miss work or school due to the frequency of ongoing symptoms, and 22% reported being unable to attend work or school altogether. Furthermore, 37% of patients reported visiting the emergency room within the previous year and 65% worried about having a serious undiagnosed disease.

4. Discussion

Our study found that wait times for chronic pain care, even those triaged as urgent cases, far exceeded what patients considered ideal. Only a third of patients received care within three months of making their appointment, while nearly another third waited over a year. During the waiting period, nearly all patients experienced some impact on their day-to-day activities and work or school attendance, half were unemployed, and nearly a quarter reported a complete inability to attend work or school because of pain.

Our findings on the impact of wait times on patients reflect those of previous studies. A systematic review exploring benchmarks for chronic pain treatment found that waiting as little as five weeks for care was associated with deterioration in health-related quality of life [14]. Among eight university-affiliated MPTFs across Canada, 50% of chronic pain patients reported severe levels of depression [4]. Furthermore, research on the economic impact of chronic pain found that patients often miss work or lose employment altogether due to limited functioning associated with their illness, a problem compounded by the fact that many patients fund 95% of the additional costs of their care (a median of $1435 per month) themselves [15]. Many patients expressed interest in treatment strategies beyond pain management, including daily functioning and financial wellbeing [15,16]. Other researchers have found that when wait times are reduced, patients reported higher satisfaction and more active usage of management strategies to treat their pain [17].

Though access to pain management is considered by some as a fundamental human right [18], many patients do not receive care in a timely manner. Reasons for this delay include a lack of knowledge about pain management among family doctors and specialists, inadequate remuneration for the increased time required to care for patients with complex chronic pain, and poor access to publicly funded health practitioners such as physiotherapists, psychologists, and occupational therapists [14]. Many physicians have taken efforts to mitigate the effects of long waits by offering patients advice on self-management or information on community resources they can use while awaiting specialist care. Studies have demonstrated that using digital health and social media to engage patients can result in better psychological and emotional health [19,20]. However, such programmes may not always provide sufficient support to entirely mitigate the effects of long wait times; though nearly half of the patients in our study received written information and a recommendation to attend a chronic pain support group while waiting for a specialist consultation, reports of burden remained significantly high. Fragmentation of care is another serious issue facing chronic pain patients. In our study, nearly half of participating patients had been referred to the pain clinic by another specialist rather than their primary care provider (PCP). Specialist-to-specialist referrals may occur because specialists are more familiar with chronic pain as a specialty group, or as a

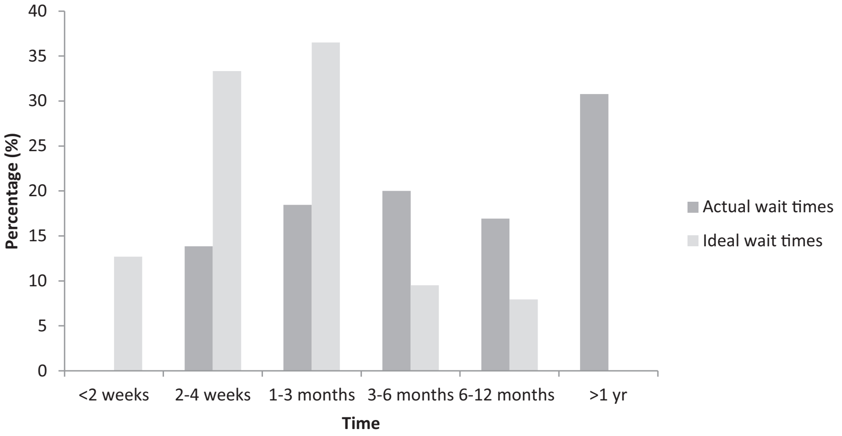

Fig. 1. The proportion of actual and ideal wait times reported by patients.

way to triage patients whom the specialist feels could benefit from expert advice on chronic pain. However, referrals from specialists run the risk of removing PCPs from the centre of the patient's care, which could lead to worse outcomes.

In response to these issues, many jurisdictions have recognized the need for new strategies to reduce wait times for chronic pain care. eConsult services may offer an alternative for chronic pain patients by facilitating communication between PCPs and specialists, allowing many patients to avoid face-to-face specialist appointments by giving PCPs the information they need to care for them directly [18]. eConsult services can also reduce fragmentation of care through adoption of specialist-to-specialist or case conferencing models, which help track the treatment process and ensure patients are receiving sufficient and timely care [11,21]. In a study of an eConsult service used to treat patients with chronic pain, researchers found that PCPs received responses form specialists in a median of 1.9 days, 36% of cases resulted in avoiding an unnecessary referral, and only 44% resulted in a specialist referral [12]. Likewise, in a study examining the perspectives of patients attending an endocrinology clinic, participants cited faster access, reduced travel time, and lower costs as potential benefits of an eConsult service [13].

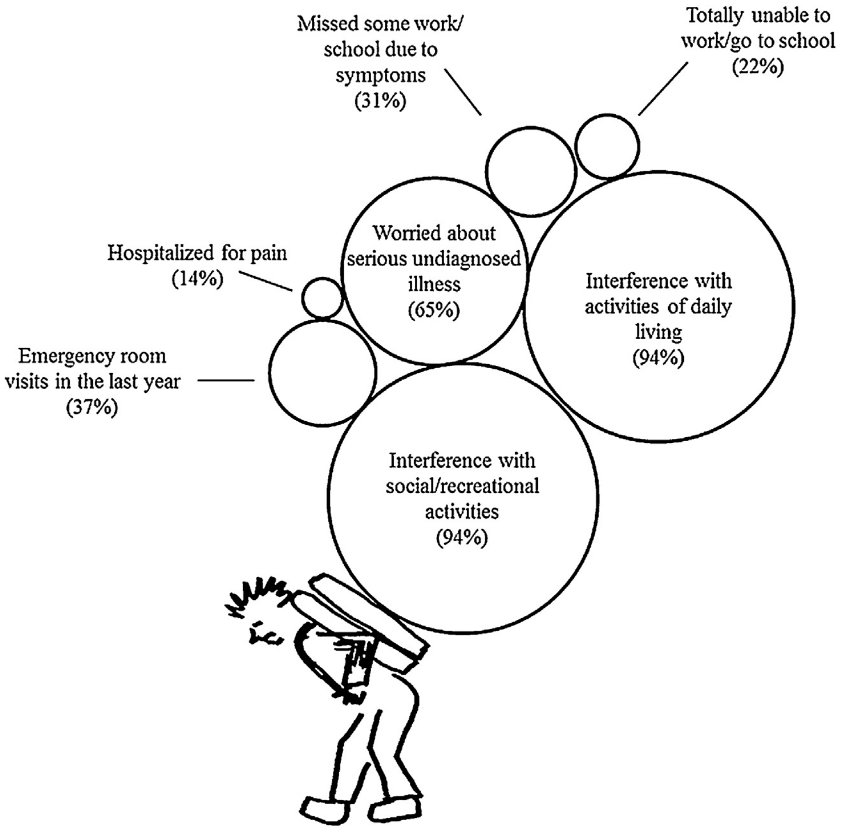

Fig. 2. Percentage of patients reporting common burdens of living with chronic pain.

4.1. Strengths and limitations of the study

This is the first Canadian study to assess patients' perspectives on the impact of wait times for chronic pain specialist appointments. Although opportunities to improve the traditional referral-consultation model exist, the development of any new strategy should include patient feedback. An understanding of the patient experience is imperative in guiding healthcare administrators and policy-makers to create system improvements that are medically appropriate and align with patients' goals.

There are several limitations in the present study. The survey took place in a single academic pain clinic using a convenience sample of patients, limiting its generalizability. The patients included in this study were fast-tracked to their appointments, and thus faced relatively short wait times compared to the general patient population, many of whom waited years for their appointments. Thus, the findings likely underestimate wait times. Although 53% of the sample was unemployed, the reason for unemployment, be it long-term disability, retirement, etc., cannot be distinguished. Future studies should seek to incorporate this into their analyses. Lastly, self-reported data is susceptible to bias.

5. Conclusion

Wait times for chronic pain care exceeded timelines deemed acceptable by patients, causing anxiety and reducing their capacity to participate in daily activities. Patient perspectives must be considered in improving access for this patient population, which has very specific needs. Innovative solutions, such as electronic consultation, should be evaluated as a means of reducing wait-times to pain care and improving patient outcomes.

Ethical issues

This study did not involve any patient intervention and informed consent was not required. Ethics approval for the study was provided by The Ottawa Health Science Network Research Ethics Board.

Conflict of interest

None.

Role of funding source

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