



Diagnostic delay and suboptimal management in persistent idiopathic facial pain and persistent dentoalveolar pain; a cross-sectional study

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Objectives. The aim of this study was to explore the diagnostic and therapeutic challenges encountered by patients with persistent idiopathic facial pain (PIFP) and to investigate factors influencing its delayed diagnosis.

Study Design. In this cross-sectional study, 34 patients with newly diagnosed PIFP were interviewed. Data about diagnostic delay, number and nature of previous consultations, and previous medical and surgical interventions were recorded. Pearson's correlation and Student *t* test were used to examine the differences among the variables in relation to diagnostic delay.

Results. The average time between the onset of symptoms to correct diagnosis was 19.3 ± 11.1 months. Diagnostic delay was significantly longer in patient with pain localized to intraoral sites (22.6 ± 7.4) compared with patients with extraoral pain (16.1 ± 9.3). The average number of health care professionals consulted before correct diagnosis was 3.7 ± 2.3 . General dental practitioners were the most commonly consulted health care professionals ($n = 27$; 79.4%). On average, patients were given 2.3 ± 0.24 misdiagnoses before the correct diagnosis was determined and were prescribed 3.5 ± 2.4 classes of drugs. Twenty-five patients (73.5%) underwent unnecessary surgical/dental interventions.

Conclusions. Patients with PIFP are frequently misdiagnosed, leading to prescription of ineffective medications and unnecessary investigations and surgical interventions. Educational efforts should emphasize on improving knowledge and awareness of this condition. (Oral Surg Oral Med Oral Pathol Oral Radiol 2019;127:498–503)

Persistent idiopathic facial pain (PIFP), previously known as *atypical facial pain*, is an ill-defined type of chronic orofacial pain. The International Classification of Headache Disorders describes PIFP as a poorly localized, dull, aching, or nagging facial pain recurring daily for more than 2 hours per day in the absence of clinical neurologic deficit or a dental cause.¹ Atypical odontalgia, also known as *persistent dentoalveolar pain* (PDAP), is a subtype of PIFP, where the pain is localized to intraoral sites, including teeth.¹ The underlying mechanism for PIFP is poorly understood, but a growing body of evidence suggests that PIFP is a neuropathic pain syndrome associated with increased neuronal excitability at the brainstem level, disturbed inhibitory function of the prefrontal cortex, and alterations in the dopamine systems associated with pain transmission and/or modulation.²⁻⁶ PIFP, however, is a rare condition, with an estimated life time prevalence of 0.03% and an incidence rate of 4.4 per 100,000 persons.^{7,8}

The pain in PIFP has varying presentations. It is usually deep, but can be superficial, and mostly unilateral, but can be bilateral as well.⁹ PIFP is usually poorly localized, often radiating in a nondermatomal pattern, and commonly described as aching, burning, nagging, throbbing, and stabbing.⁹ The onset of PIFP is often ambiguous, and patients usually report a dental, surgical, or otolaryngologic procedure as the

initiating event.¹⁰ Typically, pain characteristics, severity, location, and associated features change over time.¹¹ PIFP often coexists with other chronic pain conditions, and patients usually present with symptoms of anxiety and depression.¹²

The diagnosis of PIFP is often challenging because of the loose diagnostic criteria and the nonspecific clinical presentations that may resemble other chronic facial pain disorders. PIFP is often diagnosed by exclusion after the clinician has exhausted all possible alternatives that are within his knowledge base.¹³ Patients with PIFP, therefore, may end up with multiple repeated consultations with different specialists, multiple diagnostic procedures, and multiple therapeutic interventions potentially leading to pain aggravation and worsening pain experience.^{14,15}

Previous studies demonstrated that facial pains, including the more common and better-defined types, such as migraine and cluster headache, are widely misdiagnosed, leading to prescription of inappropriate diagnostic examinations and ineffective treatments.¹⁶⁻¹⁸ It is not surprising, therefore, to know that patients with less common and less defined types of facial pain are more likely to experience difficulty in accessing the care

Statement of Clinical Relevance

Persistent idiopathic facial pain is frequently misdiagnosed, leading to prescription of ineffective medications and unnecessary investigations and surgical interventions. Efforts to improve knowledge and awareness about chronic orofacial pain are needed.

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they need. Rossi et al., for example, reported that the mean time to reach the correct diagnosis in patients with hemicrania continua, an uncommon primary headache disorder, was 5 years and that the average number of specialists seen before a proper diagnosis was 4.8.¹⁹ Similarly, Mignogna et al. demonstrated that the average delay from the onset of symptoms to definitive diagnosis in patients with burning mouth syndrome was 34 months, and patients consulted, on average, 3.1 health care professionals before obtaining a definitive diagnosis.²⁰

Although delayed diagnosis of PIFP is frequently encountered in clinical practice, the literature has few reports of the diagnostic experience of patients with PIFP and factors influencing delayed diagnosis. The purpose of the present study, therefore, was to explore the diagnostic and therapeutic challenges encountered by patients with PIFP and to investigate potential factors that cause diagnostic delay in this type of facial pain.

MATERIALS AND METHODS

The protocol of this cross-sectional study was reviewed and approved by the Institutional Review Board at the University of Jordan Hospital (No. 10/2018/17813). The study was conducted in the Oral Medicine unit in accordance with the Declaration of Helsinki and the Strengthening the Reporting of Observational Studies in Epidemiology statement for observational studies.

All patients who presented with pain in their teeth, mouth, or face during the study period were eligible to participate. All patients were examined by an Oral Medicine consultant with adequate training and experience in the diagnosis and management of orofacial pain conditions. Patients were examined to exclude disorders relating to soft or hard oral tissues (i.e., teeth, mucosa, jaw, and temporomandibular joint [TMJ]). Furthermore, all patients were examined with clinically indicated radiography to exclude any underlying cause. Patients were included only if their pain met the diagnostic criteria for PIFP and PDAP, and their pain could not be better accounted for by another ICHD diagnosis

(Table I).¹ Patients were excluded if they had any neurologic deficit, an underlying dental/oral disease, or a diagnosis of burning mouth syndrome, trigeminal neuralgia, maxillary sinusitis, sialadenitis, TMJ dysfunction, or myofascial pain.

Patients who met the inclusion criteria and granted their consent were interviewed by one of the authors, who explained the purpose and the nature of the study. Participants were asked specific questions about the onset of symptoms, character and location of pain, date of first medical or dental consultation, number of previous consultations and nature of specialties consulted, and any temporal association between their symptoms and previous dental or surgical treatment in the maxillofacial region. Participants were also asked about previous diagnostic tests, therapeutic interventions, and explanations offered by health care professionals. Average pain intensity was graded on a 0–10 numeric rating scale. The duration between the first medical or dental consultation and the definitive diagnosis was considered professional delay. Patients’ medical records were also reviewed to control for any potential bias resulting from patients being unable to recall the history of their consultations. When necessary, health care professionals previously consulted by the patient were contacted by phone to obtain any missing information on consultation dates, diagnostic tests, and therapeutic interventions.

Statistical analysis was performed by using SPSS for Windows version 16.0 (SPSS Inc., Chicago, IL), and descriptive statistics were generated. The effect of various variables, including patient age and gender, site and localization of pain, number of previous consultations, and pain intensity, on diagnostic delay was examined. Student *t* test was used to compare the differences in diagnostic delay in males vs females, intraoral vs extraoral pain, and unilateral versus bilateral pain. Pearson’s correlation test was used to examine any correlation between diagnostic delay and age of patients, number of previous consultations, and pain intensity score. The significance level was stated as *P* < .05.

Table I. Inclusion and exclusion criteria adopted from the ICHD-3¹

Inclusion criteria	Exclusion criteria
Pain in face or mouth or teeth or jaw recurring daily for greater than 2 hours for greater than 3 months	Acute or recent onset pain (<3 months) in face, mouth, teeth, or jaw
Pain does not follow the distribution of peripheral nerves	Pain follows the distribution of peripheral nerves
Normal clinical neurologic examination	Clinically detectable neurologic deficit
No underlying cause related to the teeth, oral mucosa, salivary glands, TMJ, maxillary sinus can be identified	The pain is caused by an underlying dental, oral, salivary gland, sinus, or TMJ disease
Pain cannot be better accounted for by another ICHD diagnosis	Pain can be better accounted for by another ICHD diagnosis
Continuous pain in one or more teeth or in a tooth socket after extraction in the absence of dental cause	A dental cause of pain can be identified using relevant investigations

ICHD, International Classification of Headache Disorders; TMJ, temporomandibular jaw.

RESULTS

Patients demographic characteristics

A total of 34 patients met the inclusion criteria and were included in the study. The sample was composed of 21 females (61.8%) and 13 (38.2%) males, with a mean age at presentation of 49.8 years (range 28–79 years). A previous diagnosis of anxiety and depression was reported by 5 (14.7%) and 3 (8.8%) patients, respectively.

Pain distribution and characteristics

The pain was localized to intraoral sites in 58.8% of the patients (n = 20 [7 males and 13 females]), whereas it affected extraoral sites, with variable distribution, in 41.2% (n = 14; [6 males and 8 females]) (Table II). Among patients with intraoral pain, nearly all patients (n = 17; 85%) related the onset of pain to a recent dental procedure, mainly tooth extraction or root canal treatment. In contrast, less than half the patients with extraoral pain (n = 5; 35.7%) recalled a history of dental or surgical treatment in relation to their pain. The average pain intensity score in patients with intraoral pain was 6.4 (range 3–9), whereas it was 7.1 (range 2–10) in patients with extraoral pain (P > .05). No significant difference was observed in pain intensity scores in males (6.81; range 3–10) compared with females (6.53; range 2–9) (P > .05). Considering the whole study group, the average pain intensity score was 6.7 (range 2–10).

Diagnostic experience and delay

All patients reported that they consulted a health care professional regarding their pain within 1 month of the onset of pain, and none of the patients had received a correct diagnosis of their PIFP or PDAP before attending our clinic. Overall, the average amount of time elapsed between the onset of pain to the correct diagnosis (i.e., diagnostic delay) was 19.3 ± 11.1 months (range 6–34 months). In patients with extraoral pain, the average diagnostic delay was 16.1 months ± 9.3

Table III. Factors associated with diagnostic delay

Diagnostic delay in relation to gender, location, and site of pain		P value
Gender		
Male	18.6 ± 14.5 months	> .05
Female	20.1 ± 11.4 months	
Location		
Extraoral	16.1 ± 9.3 months	< .05
Intraoral	22.6 ± 7.4 months	
Site		
Unilateral	18.1 ± 15.1 months	> .05
Bilateral	20.6 ± 13.3 months	
Correlation between diagnostic delay with pain intensity, age, and number of consultations		
Pain intensity	r = 0.21	> .05
Age	r = 0.32	> .05
Number of consultations	r = 0.76	< .05

(range 6–25 months), whereas it was significantly longer in patients with intraoral pain (22.6 ± 7.4; range 7–34 months) (P < .05). Overall, delayed diagnosis did not differ significantly between males and females (P > .05), and no significant correlation was observed between the pain intensity score or the age of patients and the amount of time elapsed between the onset of pain and the correct diagnosis (Table III).

Overall, the average number of health care professionals consulted before the pain was correctly diagnosed was 3.7 ± 2.3 (range 1–9) (Table IV). There were no significant differences in the number of health care professionals consulted between patients with intraoral pain (3.5 ± 1.9) and those with extraoral pain (3.9 ± 2.1) or between males (3.41 ± 3.1) and females (3.98 ± 2.7) (P < .05).

General dental practitioners were the most commonly consulted health care professionals (n = 27; 79.4%), followed by maxillofacial surgeons (n = 21; 61.7%); general medical practitioners (n = 16; 47.1%); ear, nose, and throat (ENT) surgeons (n = 15; 44.1%); endodontists (n = 13; 38.2%); neurologists (n = 11; 23.3%);

Table II. Pain distribution and characteristics in study sample

	Intraoral pain (n = 20 patients)	N (%)	Extraoral pain (n = 14 patients)	N (%)
Side affected				
	Left side	6 (30)	Left side	6 (42.8)
	Right side	7 (35)	Right side	3 (21.4)
	Bilateral	7 (35)	Bilateral	5 (36)
Site affected				
	Posterior maxilla	7 (35)	Middle face (including maxilla, upper lip, zygoma, and nose)	6 (42.8)
	Posterior mandible	6 (30)	Lower face (including mandible, lower lip, chin)	5 (35.7)
	Anterior Maxilla	4 (20)	Upper face (including temporal and frontal area)	3 (21.4)
	Anterior mandible	3 (15)		
Localization				
	Well localized	3 (15)	Well localized	2 (14.3)
	Poorly localized	17 (85)	Poorly localized	12 (85.7)

Table IV. Number of health care professionals consulted before the correct diagnosis of PIFP or PDAP was reached

Number of health care professionals consulted before the correct diagnosis	Patients: n (%)
0	0 (0)
1	5 (14.7)
2	6 (17.6)
3	4 (11.8)
4	4 (11.8)
5	7 (20.6)
6	3 (8.8)
7	3 (8.8)
8	1 (2.9)
9	1 (2.9)

PDAP, persistent dentoalveolar pain; PIFP, persistent idiopathic facial pain.

periodontists (n = 9; 26.5%); ophthalmologists (n = 4; 11.8%); rheumatologists (n = 2; 5.8%); and orthopedic surgeons (n = 1; 2.9%). Interestingly, none of the patients consulted or was referred to a pain specialist or an orofacial pain specialist before the correct diagnosis was achieved. A significant correlation was observed between the number of consultations and the time elapsed between the onset of pain and the correct diagnosis (see Table III). General dental practitioners were the first health care providers to be consulted by all patients with intraoral pain (n = 20; 100%); and ENT specialists (n = 7; 50%); general dental practitioners (n = 4; 28.6%); general medical practitioners (n = 2; 14.35); and maxillofacial surgeons (n = 1; 7.1%) were the first health care providers to be consulted by patients with extraoral pain.

Most patients (n = 28; 82.4%) had received >1 diagnosis before being correctly diagnosed. On average, patients were offered 2.3 ± 0.24 (range 1–4) diagnoses before the correct diagnosis. Dental pain (n = 24; 70.6%), including pulpitis, apical periodontitis, tooth sensitivity, cracked tooth, failed root canal treatment, postoperative pain, and occlusal trauma were the most frequent diagnoses. Others included sinusitis (n = 6; 17.6%); TMJ dysfunction (n = 5; 14.7%); migraine (n = 4; 11.8%); myofascial pain (n = 4; 11.8%); burning mouth syndrome (n = 1; 2.9%); osteomyelitis (n = 1; 2.9%); neuralgia (n = 1; 2.9%); and iatrogenic nerve trauma (n = 1; 2.9%). Patients underwent, on average, 2.7 paraclinical examinations before the correct diagnosis. Multiple and repeated intraoral and extraoral radiographic examinations were the most common type of investigations (n = 27; 79.4%). Other investigations included computed tomography, brain magnetic resonance imaging, sinus radiography, spinal radiography, and chest radiography.

Therapeutic attempts

Patients tried, on average, 3.5 ± 2.4 classes of drugs, including prescribed and over-the-counter medications. Nonsteroidal antiinflammatory drugs and paracetamol were tried by all patients (n = 34; 100%), and various types of antibiotics were prescribed to most patients (n = 25; 73.5%). Other types of drugs that were prescribed by health care providers included muscle relaxants (n = 13; 38.2%); various types of mouth washes (n = 13; 38.2%); decongestants (n = 11; 32.4%); anti-anxiety medications and antidepressants (n = 8; 23.5%); antiepileptics (n = 6; 17.6%); antihistamines (n = 4; 11.8%); systemic and topical steroids (n = 5; 14.7%); and opioids (n = 4; 11.8%). Of note, polypharmacy was encountered in nearly one-third of patients (n = 9; 26.5%). Twenty-five patients (73.5%) underwent surgical or dental interventions. Patients with intraoral pain, underwent, on average, 2.9 ± 1.8 dental treatments, including root canal treatments, extractions of teeth, repeat root canal treatments, occlusal splints, and dental fillings. Surgical interventions were less frequent among patients with extraoral pain but included dental treatment in 3 patients, TMJ arthrocentesis in 2 patients, and sinus lavage in 1 patient.

DISCUSSION

Delayed diagnosis of PIFP is a common clinical scenario; nevertheless, there are few reports in the literature about the diagnostic experience and factors associated with delayed diagnosis in patients with PIFP. This is the first study to investigate the diagnostic and therapeutic challenges encountered by patients with PIFP and to examine factors causing delayed diagnosis.

The findings of the present study suggest that PIFP is frequently misdiagnosed; on average, patients with PIFP obtain 3.7 consultations before the correct diagnosis is reached. Possible reasons include nonspecific symptoms, poorly understood etiology, loose diagnostic criteria, infrequent incidence of the condition, and similarity of the symptoms to other more common causes of facial pain.^{2,8,10,11} Furthermore, inadequate knowledge and awareness among health care professionals about the various types and symptoms of facial pain, and referrals to the wrong type of specialists may be contributing to the diagnostic delay.²¹

There are 2 phases in diagnostic delay: (1) patient delay from the onset of symptoms to consultation with a health care professional, and (2) professional delay from the first consultation to definitive diagnosis.²² Our data suggest that diagnostic delay in PIFP is primarily caused by factors related to health care professionals in contrast to other oral diseases, such as oral cancer and immune-mediated blistering diseases, where patients-related delays contribute significantly to total diagnostic delay.^{23,24} Patients with PIFP do not

delay seeking medical help; in fact, they actively seek treatment and do consult multiple health care providers during their diagnostic journey. Some patients, however, might take a break from seeking answers to their problem, leading to some overestimation of the recorded professional delay.

The findings of our study demonstrated that the period between the onset of symptoms to the correct diagnosis was significantly longer in patients with intraoral pain compared with those with extraoral pain. The reason for this is not known, but it suggests that a particular lack of knowledge exists among dentists with regard to the diagnosis of chronic facial pain. It may also be related to the fact that most of these patients underwent dental or surgical procedures in an attempt to obtain relief from their pain; this implies that patients would need to wait for a while to feel the effect of an intervention, further contributing to the diagnostic delay. Our study also demonstrated that patients with PIFP often consult multiple health care professionals from different specialties, indicating the complex and the interacting nature of orofacial pain. General dental and medical practitioners, maxillofacial surgeons, ENT specialists, and neurologists were the health care professionals most commonly consulted by patients with PIFP. Similar to the findings of our study, multiple consultations have been shown to be associated with delayed diagnosis and a negative patient experience in several other diseases, including oral mucosal diseases and various types of cancer.^{24,25}

The clinical phenotype of PIFP is variable and often overlaps with other causes of facial pain, which can lead to misdiagnosis.^{9,10} Our study demonstrated that odontogenic pain, TMJ dysfunction, migraine, and myofascial pain are the most common misdiagnoses in patients with PIFP despite the fact that these types of pain have different pathophysiologic mechanisms.² Although this can be justified, to an extent, by the overlapping symptomatology and the loose diagnostic criteria, the frequent occurrence of multiple consultations with various health care specialists underscores the need to improve the knowledge and awareness of health care professionals about PIFP. In fact, several studies have emphasized the need to improve teaching about orofacial pain in undergraduate and postgraduate education.²⁶⁻²⁸

Delayed diagnosis of PIFP can worsen the pain experience, reduce the quality of life in affected individuals, and may cause the pain to interfere chronically with patient's daily activities, social interaction, and sleep pattern.¹² In addition, delayed diagnosis can cause significant emotional stress on patients who are, sometimes, suspected of imagining or exaggerating their pain.^{12,20}

It is not unreasonable to assume that misdiagnosis of PIFP will lead to inappropriate management. In fact, our study demonstrated that most patients with PIFP

were subjected to unnecessary investigations, underwent unnecessary and ineffective dental or surgical interventions, and were prescribed multiple empirical therapies. Similar results were reported by studies investigating other types of chronic pain, including cluster headache, burning mouth syndrome, and hemi-crania continua.¹⁸⁻²⁰ Inappropriate management not only worsens the pain experience and imposes frustration and emotional stress but also exposes patients to unjustified side effects and complications of medical and surgical therapies. Proper information, counseling, and patient education, together with reassurance, are essential components in the management of patients with chronic pain, including PIFP; nevertheless, none of the patients in our study was given an adequate explanation for their pain.^{11,15,28}

The limitations of our study include the relatively small sample size, which probably reflects the low prevalence of this type of pain. In addition, the present study did not assess the effect of diagnostic delay on treatment response and pain severity, which is an interesting topic to be investigated in future studies. Furthermore, the present study examined the diagnostic experience of a referred population in Oral Medicine clinic and does not necessarily match the diagnostic experience of patients examined in other clinical settings. Recall bias is another important limitation of our study; however, we attempted to minimize the potential bias resulting from patients being unable to recall the history of their consultations by reviewing patients' medical records and, when necessary, contacting health care professionals previously consulted by patients.

CONCLUSIONS

Despite the limitations of our study, the findings indicate that patients with PIFP are frequently misdiagnosed and wrongly treated. Delayed diagnosis is more likely to be encountered in patients with intraoral pain and in those who undergo multiple consultations for interventions.

The findings of the present study emphasize the importance of improving the knowledge and awareness of health care professionals about chronic orofacial pain conditions. This should improve the early recognition of patients with PIFP, resulting in appropriate referral and management.

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