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Research Article

LONG-TERM OUTCOME OF DROPOUT VERSUS TREATMENT GROUPS OF PATIENTS SUFFERING IDIOPATHIC OROFACIAL PAIN

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ABSTRACT

The long-term outcome of the original group of 565 newly referred patients diagnosed as idiopathic orofacial pain patients at the Department of Maxillofacial Surgery, Eastman Dental Institute, London, United Kingdom, during three years period was carried out after eight years from their initial presentation. Sixty six percent of the patients (n=348) were successfully contacted and accepted answering the long-term questionnaire through telephone interview. The results showed that both the symptoms and dysfunction of these idiopathic orofacial pain disorders seems to go into spontaneous remission regardless their initial diagnosis and/or treatment. Nevertheless, patients who received treatment showed better improvement. The results also confirmed a high rate of patients' satisfaction among the general group of patients, with highly statistically significant differences between the two groups of patients, where 86% of the treatment group as compared to 57% of the dropout patients were fully satisfied with the provided treatment. The results of the current study confirmed that only non-invasive reversible treatment modalities should be used when managing temporomandibular dysfunction and other related idiopathic orofacial pain disorders.

INTRODUCTION

Despite increased attention focused on the need to prevent patient attrition in long-term clinical trials; the high dropout rates have threatened the success of numerous studies. Studies involving long-term follow up periods always face many other methodological problems that in addition to failure to assess the outcome of the dropout group of patients. The long term outcome of idiopathic orofacial pain disorders is not an exception to such studies; and is complicated by the fact that this group of disorders often exhibits periods of remission and exacerbation. Other complicating factors often ignored by many workers; is the strong psychological and emotional component associated with the disorders. Failure to combine psychological therapy with other treatments will further affect the ultimate success or failure of any particular treatment. Most of the long-term outcome studies of the temporomandibular joint and atypical facial pain always reported high percentages of symptoms disappearance or improvement that ranged from 70-90% among the reported series with a variety of conservative therapies (Greene and Laskin, 1972; Greene and Laskin, 1974; Cohen, 1978; Rees and Harris, 1979; Brooke, 1980; Majersjo and Carlsson, 1983; Greene and Laskin, 1983; Greene and Laskin, 1988; Tversky et al., 1991; Schnurr et al., 1991; Feinmann, 1993; Ohrbach and Dworkin, 1998). Furthermore, Green and Laskin (Greene and Laskin, 1988) reported on the long-term outcome of TMJ clicking in patients with TMJ myofacial pain and dysfunction. Their results showed that with a follow up period of up to 15 years 126 patients (63%) of a total group of 203 patients showed either cessation or improvement of TMJ clicking while 36% of the patients had the same, and only 3 patients (1%) had more TMJ clicking than what they had initially. The overall improvement of symptoms was 76% of the patients reporting feeling and functioning better. Green and Laskin[9] concluded that clicking of the TMJ is generally a benign condition, which does not progress to more serious clinical dysfunction or disease. Similarly Mejersjo and Carlsson (Majersjo and and Carlsson, 1983) reported that most of the patients who previously suffered locking of the mandible and TMJ noise had a favorable response with conservative therapy and none required surgery during the seven years follow up period.

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RESULTS

The long-term outcome of 565 patients who were newly referred to the Department of Oral and Maxillofacial Surgery Eastman Dental Hospital London, United Kingdom, during three years period assessed after 8 years after their initial presentation. The patients were contacted by telephone interview and were asked to answer the questions included in

the long-term assessment format. Most of the patients were found to change their contacting address and telephone numbers, therefore the medical records of all the patients were retrieved and screened to get the updated patient's telephone number or patient's general practitioner and/or general practitioner telephone number in order to trace the current address of any particular patient. A total of 372 (66%) of telephone contacts were successful, while 193 patients (34%) were regarded uncontactable as a result of failure to get either their telephone number or their new home address. The results of the 372 successfully contacted cases showed that 348 patients (93.5%) were available and answered the follow-up questionnaire, 11 patients (3%) immigrated or they were outside the country at the time of contacting their families, 7 patients (2%) died, and 6 patients (1.5%) refused to answer the questionnaire and/or to cooperate.

Results of Contacted Available Patients

Patients Attending Treatment

No patient among the contacted patients is still attending treatment for their original orofacial pain disorder, since 1994.

Patients' Pattern of Discharge

Fifty seven percent (n=199) of the 348 contacted patients reported being discharged by the clinicians and this group will be referred to as the treatment group of patients, while 149 patients (43%) reported discharging themselves and this will be referred to as the dropout group of patients.

Reasons for Dropout (Self-Discharged)

Getting better was the most common reason (68 patients; 46%) for self-discharge among the patients included in the current study, followed by 39 patients (26%) who discharged themselves as a result of having no improvement, 19 patients (13%) discharged themselves due to problems with medication or un-acceptance of medication, 8% of the patients related their self-discharge to personal or social reasons, while 11% (7%) patients discharged themselves because they got worse with the provided treatment.

Treatment Seeking after Discharge

Only five patients (2.5%) of the treatment group of patients attended other hospital and/or clinics for further treatment of their orofacial pain after they were discharged from the Department of Oral and Maxillofacial Surgery, Eastman Dental Hospital, as compared to 17 patients (11%) of dropout group. Those differences between the two discharge groups was of high statistical significance (P<0.001). On the other hand only 5 of the dropout patients (3%) attended their general practitioner and/or general practitioner for the further treatment of their orofacial pain disorder. Those differences were found statistically significant (P=0.009) between the two discharge groups. Furthermore, 28% (n=42) of the dropout group of patients had other treatments following discharging themselves following discharging themselves, as compared to only 2.5% (n=5) of the treatment group of patients. Those differences between the discharge groups were high statistical significance. (P<.001)

Types of Post-discharge Treatments

The different types of treatment received by the 42 dropout patients who had other types of treatment after they discharged themselves, included medications that is mainly analgesics (33%), acupuncture (18%), occlusal adjustment and bite guards in 10% of the patients in each group, and 28% of the patients had other types of treatment such as relaxation therapy, etc. While, the five patients in the treatment had other types of treatment group had other types of treatment such as as relaxation therapy, and Yoga lessons.

Current Pain Status

Ninety percent (n=179) of the treatment group of patients were pain free at the time of contacting them, as compared to 59% (n=88) of the dropout patients (Figure 1). Those differences were found to be of high statistical significance (P<0.001).

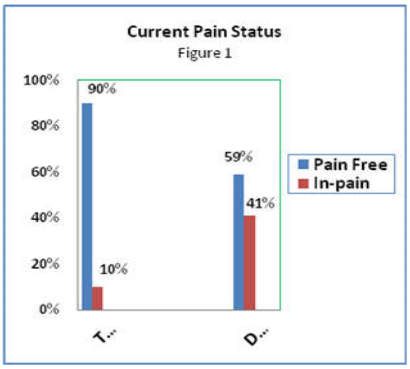

Fig. 1. The Y axis is to be labeled (Patients' percentage)

Seventy two percent of the 61 of the dropout patients who were currently in-pain rated their pain to be mild and occasional, 8%(n=5) were in severe pain, while 20% (n=12) complained of persisting TMJ clicking and locking. While 80% (n=16) of the treatment group of patients who were in-pain rated their pain as occasional and mild pain and 20% (n=4) complained of moderate pain levels (Figure 2). Those differences were found to be of high statistical significance (P<0.001).

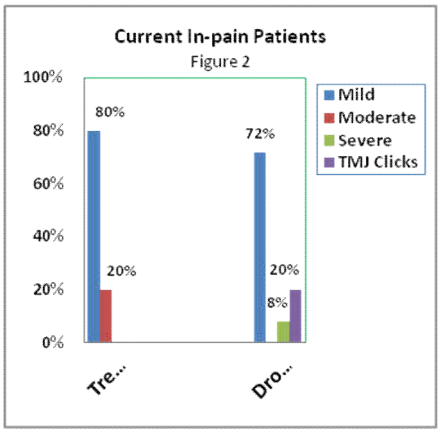

Fig. 2. The X axis is to be labeled (Patients' groups)

Present Pain Sites

Eight percent of the treatment as compared to 23.5% of the dropout patients suffered currently pain in and around the TMJ region. Those differences were found to be of high statistical significance (P<0.001). Three percent of the treatment group of

patients reported persisting facial pain as compared to 15% of the dropout patients (P<0.001). Furthermore, 19% of the treatment group of patients reported having pain in their teeth, as compared to 11% of the dropout patients (P=0.05). It should be noted that this current pain in teeth may not be at the original pain site reported by the patients at the time of their initial presentation. In addition, 4% of the dropout patients reported having pain in their tongue/mouth at the time of contacting them, as compared to no patient among the treatment group of group had the same complaint (P=0.004). The results of the variation in the current pain site are presented in Table 1.

Table 1. Present Pain Sites

	Treatment Group	Dropout Group	Significance
TMJ Pain	17 (8%)	35 (23.5%)	P< 0.001
Facial Pain	6 (3%)	23 (15%)	P< 0.001
Odontalgia	38 (19%)	17 (11%)	P= 0.05
Tongue/ Mouth Pain	-	6 (4%)	P=0.004

Current Other Painful Symptoms

Fifteen percent of the dropout patients reported having headache as compared to 5.5% of the treatment group of patients (P=0.04). Current migraineous attacks were reported by 19.5% of the dropout group, as compared to 7.5% of the treatment group of patients (P=0.001). Non-significant differences existed between the two groups of patients in regards to their current complaint of neck pain, where 29.5% of the dropout group, as compared to 23% of the treatment group of patients. Similarly, non-significant differences existed between the two groups of patients in regards to current complaint of backache, with 26% of the treatment group as compared to 22% of the dropout group reported frequent backaches. Furthermore, 5% of the treatment group of patients reported frequent abdominal pain, while no patient among the dropout patients had the same complaint (P=0.005). Non-significant differences existed between the females of the two groups of patients in regards to dysfunctional uterine bleeding (D.U.B.), where 21% of the dropout group, as compared to 17.5% of the treatment group reported such a complaint. Eight percent of the treatment group of patients reported frequent itchy skin attacks, while no patient among the dropout patients had the same complaint (P<0.001). In addition, 9% of the treatment group complained from arthritic pain, as compared to 5% of the dropout patients, while another 5% of the dropout patients, while another 5% of the dropout patients complained from other joints clicking, and another 5% complained from generalized muscle pain (P=0.005).

Table 2. Current Other Painful Symptoms

	Treatment Group	Dropout Group	Significance
Headache	11 (5.5%)	22 (15%)	P=0.004
Migraine	15 (7.5%)	29(19.5%)	P=0.001
Neck Pain	46 (23%)	44 (29.5%)	NS
Back Pain	52 (26%)	33 (22%)	NS
Abdominal Pain	10 (5%)	-	P=0.005
D.U.B.	28 (17.5%)	27 (21%)	NS
Itchy Skin	16 (8%)	-	P<0.001
Other Pain:			P=0.005
1: arthritic	18 (9%)	8 (5%)	
2: clicking	5 (2.5%)	8 (5%)	
3: myalgia	-	7 (5%)	

NS= Non Significant

The differences between the two groups of patients are presented in Table 2.

Interference with Life

Statistically, non-significant differences in regards to interference with life activities between the two discharged groups existed, with 29 patients (15%) of the treatment group, as compared to 17 patients (11%) of the dropout group reporting interference with daily activities at the time of contacting them.

Final Long –term Outcome

Comparing the current pain and dysfunction (if any) to the symptoms at the time of initial presentation, showed that 81% (n=161) of the treatment group of patients are pain free now, while 17% rated their outcome to be much better, and 2% rated themselves as better now compared to before. On the other hand, only 44% of the dropout patients rated themselves as pain free, 41% reported much better outcome, 4% better outcome, 8% said that their pain disorder still the same, while 3% (n=5) reported that their pain condition is worse now than before (Tab.3). Those differences in regards to the long-term follow up between the two groups of discharged patients were found to be of high statistical significance (P<0.001).

Table 3. Long-term Outcome Variation

	Treatment Group	Dropout Group	Significance
Pain Free	161 (81%)	65 (44%)	P<0.001
Much Better	34 (17%)	61(41%)	
Better	4 (2%)	6 (4%)	
Same	-	12 (8%)	
Worse	-	5 (3%)	

The variation in the long-term outcome between the different pain diagnostic groups was studied. This showed that highly significant differences (P<0.001) existed between the different pain diagnostic groups of the dropout group of patients, where the facial arthromyalgia group showed better outcome since 58.5% of the patients in this group became pain free, while the remaining 41.5% reported much better outcome now. The group with multiple pain diagnoses followed as the group with the second best outcome where 39% of the patients in this group became pain free, 41% reported much better outcome, 10% rated themselves as better now compared to before, while only 10% reported no change in their pain/symptom profile. On the other hand, the atypical facial pain group (which included atypical facial pain, oral dysaethesia, and atypical odontalgia) showed the least favourable outcome with 15% of the patients reporting that their pain became worse, 18% reported no change, 33.5% reported much better outcome, while the remaining 33.5% reported being pain free (Figure 3). In contrast, the treatment group of patients with the diagnosis of atypical facial pain, had significantly (P=0.03) better outcome as compared to the other pain diagnostic groups, where all the atypical facial pain patients reported being pain free now as compared to their initial presentation. While 81.5% and 80% of the facial arthromyalgia and the multiple pain diagnoses groups reported pain-free state with the remaining percentage of patients rated themselves as “much better” now as compared to their initial presentation (Figure 4).

Furthermore, with the patients being encouraged to report frankly about their feeling towards the treatment the patients' satisfaction was analyzed. The result of this analysis showed that 86% of the treatment group of patients was satisfied with the provided therapy, as compared to 57% of dropout group of patients (Figure 5). The difference between the two discharged groups in relation to the patients' satisfaction was highly significant ($P<0.001$).

DISCUSSION

The 8-years follow up of the 565 patients included in the current study was carried out by contacting the patients by telephone interview. This was decided to ensure the maximum collection of data, and to avoid missing data as result of either losing the follow up questionnaires if mailed to old patients' home addresses, or reluctance of those who received mailed questionnaire to either completing or mailing back the follow up formats. The results of the current study in term of contacting the patients was very successful when compared with other studies such as that of Schnurr and Brooke[16] where only 44% of the non-pain patients and 42% of the pain group could be contacted. Similarly, the experience with mailed questionnaires was also not promising (Schnurr et al., 1991). For example in Curran et al. (1995) when only 37.5% of the 120 mailed questionnaires were returned to the investigators. More recently Yatani et al. (1991) in a study of dropout patients had only 62% of the mailed questionnaires returned back to the investigators. No patient among the contacted cases was still under treatment and the latest visit for the included patients was in 1994. This represents that the longest clinical follow up period of any patient was not more than 3 to 4 years, and thereafter most of the patients were treatment-free during the past four years. The results of the current study showed that 57% of the available contacted cases were discharged by their clinicians (treatment group), while 43% discharged themselves (dropout group). Getting better was found to be the main reason of self-discharge as reported by 46% of the dropout patients, followed by 26% of the patients discharging themselves because they had no improvement with the provided treatment. Furthermore, 13% discharged themselves as a result of medication' problems or un-acceptance, 8% of the patients reported that their main reason of self-discharge was personal/social reasons, and lastly 7% of the patients discharged themselves because they became worse with provided treatment. The results of the current assessment agree with the finding of Yatani et al. (1997) where personal reasons, improvement, and dissatisfaction with provided treatment were the main reason for patients' dropout from the treatment program. Furthermore, these results agree with the study of de Oliveira et al. (2008) of Brazilian group of 30 patients suffering TMJ pain and dysfunction where expectations about treatment had significant association with treatment adherence. The findings of this study suggest that a more thorough understanding of individual differences in TMD is warranted. Other reasons for patients' attrition from other medical researches includes; older aged patients, patients with milder symptoms, lower intellectual and social competence, patients with more symptoms of behavioral problems and emotional distress, lower cognitive and social competence skills, and patients with more family conflict and distress than found among participants who remained in the study (Bender et al., 2003).

The highly significant differences between two groups of patients in regards to the post-discharge treatment seeking further documented that the clinicians' discharged patients benefited more from the provided treatment as compared to the other group of patients. In general, a total number of 27 patients (7%) seek treatment at other clinics following their self or clinician's discharge. This represented a low percentage as compared to Yatani et al. (Yatani et al., 1997) results where 10% of the patients had treatments at other hospitals/clinics, and 22% of the patients reported the need for further treatment. The variation in the types of treatment received after discharge further supported the findings of Keefe et al (1986) where self-discharge patients may prefer to seek other treatments, even if they have less demonstrated scientific basis because on the surface they hold a better chance of meeting their primary concern which is symptoms elimination. The treatment group of patients reported significantly higher percentage of pain free (90%) as compared to 59% of the dropout patients. This can be regarded as a valuable support to the effectiveness of the provided treatment to the group of patients who were discharged by the clinicians.

The in-pain group of patients included 61 patients of the dropout group only 20 patients of the treatment group. Furthermore, of the in-pain group of patients, mild occasional pain was the commonest persisting symptom among the two discharged groups of patients, while 20% of the dropout group complained of persisting TMJ clicking. These results showed very favorable prognosis of the idiopathic orofacial pain disorders with the time and with the provided treatment offered to the patients initially. Those results agreed with the finding of most of the long-term studies where favorable outcome is expected with time (Schnurr et al., 1991; Feinmann, 1993; Ohrbach et al., 1998). In addition, this was also documented by the results of the epidemiological study of Lipton et al. (1993) where the frequency of those disorders particularly temporomandibular joint pain decreased with age. Furthermore Allerbring et al. (2004) concluded in their 9-19 years long term follow up that the low success rate of invasive treatments suggests that such therapeutic methods are to be considered contraindicated in patients suffering from idiopathic orofacial pain.

The existing temporomandibular joint clicking in some patients after long-term follow up was also agreeing with the findings of Schnurr et al. (1991) Orhbach & Dworkin (Ohrbach and Dworkin, 1998) and Yatani et al. (1997) where temporomandibular joint clicking persisted while pain either improved or disappear with time. High significant differences existed between the two discharge groups in regards to the current TMJ pain, facial pain and pain in the tongue and/or mouth that was mostly reported by the dropout patients. While the treatment group of patients had higher frequency of reported toothache (19%) as compared to 11% of the dropout patients. Those differences were just significant ($P=0.05$). The high statistical differences between the two discharge groups further supported the benefit of the provided treatment offered to the clinicians' discharged patients as compared to those who discharged themselves. Significantly higher percentages of the dropout patients complained of headache, migraine and other types of pain symptoms that includes arthritis, myalgia and other joints clicking.

While the treatment group of patients had significantly higher percentages of abdominal pain and itchy skin. On the other hand, no significant differences existed between the two discharge groups with regards to frequency of reported neck pain, back pain, and pain during the menstrual period. Those results agreed with the findings of Feinmann (Feinmann, 1993) where other pain symptoms existed in both the pain free and the in-pain group of patients at 4 years after their initial presentation and treatment. Furthermore, non-significant differences existed between the discharge groups in regards to the interference with daily life activities between the two groups of patients. However, 46 patients (13%) of the contacted patients (n=348) reported current interference with daily life activities. Those results showed improvement if the interference with daily life activities with time where 55% of the patients had interference with life activities at their initial presentation. Those findings agree with the findings of Yatani et al. (1997) where they reported improvement with daily life activity limitations with time. The results of current study showed that 81% of the treatment group rated themselves as pain free, while the remaining 19% improved as compared to their initial presentation.

While, 44% of the dropout patients rated themselves as pain free, 45% improved, 8% reported no change and only 3% regarded themselves as worse now compared to their initial presentation. Those differences between the discharge groups were highly significant (P=0.001). The percentage of pain free group among the two groups of patients is very superior to similar studies even with a longer term follow up where the percentage was only about 20% after a follow up period of 9-19 years (Allerbring, 2004). Nevertheless 96% of the general group of patients reported improvement of their pain and/or symptoms currently as compared to their initial presentation. This high improvement rate was also documented by the study of 16 Turkish patients suffering atypical facial pain and followed up for similarly one year (Güler et al., 2005). Similarly, the same high success rate of conservative, reversible, and low-tech treatment success rate for TMD can reach values above 90 percent in a Brazilian study of 124 patients followed up between four to six years after their initial presentation.[21] Therefore, it was concluded by the authors that there is no need for invasive, irreversible, expensive, or high-tech treatments for the majority of patients (Martins-Júnior, 2010). The variation in the long-term outcome with the initial pain diagnosis was also studied. This showed that facial arthromylagia patients had a better outcome among the dropout group of patients, while all of the atypical facial pain patients (including the oral dysaesthesia and atypical odontalgia patients) became pain free with the provided management to the treatment group of patients. Those differences were of high statistical significance (P=0.001) and they disagreed with the findings of Feinmann ()[12] where the atypical facial pain patients over 4-years follow up period reported less better outcome as compared to the facial arthromyalgia patients. Similarly, the correlation between patients' age, clinical, and radiographic findings and their final long term outcome was studied by Kurita et al[24] group of 49 patients suffering temporomandibular joint dysfunction (TMJD) in 2007. Their results suggested that patients who appeared symptomatic at a younger age or who initially had a fixed disc were the most likely to have recurrent or persisting clinical signs/symptoms of TMJD after 8 years.

The long-term results of the current study are also superior to other long-term follow up studies were 96% of the general group of contacted patients reported improvement of their pain and dysfunction with time and with the provided treatment. Yatani et al. (1997) found that about 58% of the patients in a 10 years long-term follow up study improved while 9% became worse with time. Furthermore, Orrbach & Dwarkin (1998) reported that in their 5 years long-term follow up, 49% of the patients, became pain free ad 22% reported either high or low improvement, 13% had the same pain, and 16% of the patients became worse with the provided treatment and with time. Lately, Friction et al. (2002) compared the long-term outcome over ten years among 5 treatment groups of 446 patients suffering painful temporomandibular joint disc displacement. The results, adjusted for gender, baseline tomogram score, and baseline symptom scores, showed that the nonsurgical rehabilitation group and the group having TMJ surgery without implants had statistically better results than the group who underwent surgery with a Proplast implant.

The subjective reports of jaw function score associated with the nonsurgical rehabilitation group was also statistically better than for the Silastic implant groups, including both the temporary and permanent implants (Fricton et al., 2002). These results agreed with our current results of better nonsurgical outcome in all patients' groups. The current study also assessed the patients' satisfaction via asking the patients whether they were satisfied or unsatisfied with the provided therapy at the department of Oral and Maxillofacial Surgery, Eastman Dental Hospital, after being encouraged to report their frank opinion. The results of the patients' satisfaction analysis showed that 86% of the treatment group of patients was satisfied with the provided management, as compared to 57% of the dropout group. Those differences between the two discharge groups were found to be of high statistical significance (P<0.001). The overall patients' satisfaction for the 348 contacted patients was found to be 74% with the dissatisfaction with the provided management was merely a results of un-acceptance to the theory of stress-induced pain disorder and/or the management of these pain disorders with antidepressant drug therapy. Nevertheless, the patients' satisfaction rate in the current study was found to be superior to other similar studies (Majersjo and Carlsson, 1983; Schnurr et al., 1991; Yatani et al., 1997). The results of this study agree with other longitudinal studies tracking the rate of changes that are subject to patient dropout. This dropout process might not only be informative but also heterogeneous in the sense that different causes might contribute to multiple patterns of informative dropout. Furthermore, studying the dropout is often used as an outcome measure in clinical trials of antipsychotic medication (Rabinowitz et al., 2009).

Conclusion

The results of the current long-term follow up study showed that the symptoms and dysfunction of the idiopathic orofacial pain disorders seems to go into spontaneous remission regardless of the initial diagnosis and/or treatment, nevertheless, patients who received treatment showed better improvement. This phenomenon should be taken into consideration prior to treatment. In addition, only non-invasive reversible treatment modalities should be most often used. The results of current study also confirmed a high rate of patients'

satisfaction (74%) among the general group of patients, with highly significant differences between the two groups of patients, where 86% of the treatment group as compared to 57% of the dropout patients were fully satisfied with the provided management.

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