

A Qualitative Study to Assess the Impact of Iatrogenic Trigeminal Nerve Injury

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Aims: To deepen knowledge of the impact of iatrogenic trigeminal nerve injury on dental patients. **Methods:** One-to-one semi-structured interviews and workshops were conducted with 12 patients who had incurred a nerve injury from dental treatment. Nerve injury was diagnosed by oral surgeons via a series of neurosensory tests. Interpretive phenomenologic analysis was used to analyze the narratives from the interviews. **Results:** Key themes are presented and discussed. These include the personal impact for the patient (which includes a change in self-perception), the impact on relationships, the impact on oral health care, and adjustment to the injury over time. Patients also discussed a change in how they perceived their dentist and other health care professionals and highlighted factors they would like to change within the dental care system. **Conclusion:** Recommendations are made for clinical practice and future research. *J Oral Facial Pain Headache* 2019;33:153–159. doi: 10.11607/ofph.2054

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Iatrogenic trigeminal nerve injury is the most problematic consequence of dental surgical procedures. Injury of the trigeminal nerve is a recognized complication of several dental procedures, including removal of the mandibular third molars, implants, endodontics, and local anesthetic injury.¹ It is estimated that between 1% and 20% of mandibular third molar removal result in some form of trigeminal injury, most of which are temporary. However, about 0.5% to 2% of nerve injuries lead to ongoing symptoms, which include neuropathic pain, altered sensation, and numbness in the majority of patients.²

The incidence of lingual nerve injury is increasing, particularly in the USA, possibly due to the increased rate of implant surgery and endodontic therapy.³ The majority of lingual nerve injuries resolve when related to lingual access third molar surgery, which is now rarely undertaken; however, inferior alveolar nerve injuries are predominantly temporary when related to local anesthesia but permanent when related to implant, endodontic, or third molar surgery. The consequences of injury are complex and present patients with a variety of functional and psychologic issues. Approximately 34% to 70% of nerve injuries lead to neuropathic pain, while other troublesome symptoms include intra- and extraoral numbness, loss of taste function, dribbling, and difficulties with articulation and mastication, kissing, shaving or applying makeup, and sleeping.⁴ Nerve injury patients report impairment in work roles, socializing, and family roles and have a more negative view of themselves and dental professionals.⁴ The emotional and psychologic impact of such injuries is often great, and some patients referred for specialist assessment require additional support to improve their mental health and return to a good quality of life (QoL).⁵

Current management of iatrogenic trigeminal injuries is generally conservative, although occasionally surgical repair may be indicated. At present, conservative management mainly consists of explanation, reassurance, analgesics, and prevention of secondary dental problems (eg, by encouraging dental hygiene despite pain).⁶

Surgery is not effective for trigeminal neuropathic pain⁷; thus, the emphasis of care is predicated on medical and psychological intervention.⁶ Specialist assessment of these patients reveals marked levels of anxiety, posttraumatic symptoms, and phobic avoidance of dentists.⁶ Oral health-related quality of life (OHRQoL) becomes an important issue in the assessment and treatment of patients who suffer from chronic facial pain.⁸ The general literature on chronic pain also shows that chronic pain has a significant personal impact on patients and a detrimental impact on their social life, family relationships, and health care services.^{9,10} Further information is needed on how trigeminal nerve injury patients perceive their injury and the impact on their life.

Qualitative research exploring narrative representations of health and illness offers a counterbalance to the dominant biomedical focus. Philosophers have suggested that we create frames for understanding and judgment and link them to everyday circumstances in our lives by drawing on diverse moral and political discourse. The narrative is a central way in which we perceive experience and judge our actions and the course and value of our lives.¹¹ There are three different kinds of illness narratives: illness as narrative; narrative about illness; and narrative as illness.¹¹ Increasingly the way in which people talk about and present events is seen as critical and reflects something of the self-image that the narrator hopes to convey to others. It has been suggested that chronic illness or injury can be thought of as a disruption of a person's identity and surrounding world.¹² Attention is paid to bodily processes not normally paid attention to, as well as to decisions about seeking help. Pain becomes a form of bodily alienation or betrayal.¹³

It has been suggested that a chronic illness or injury changes the focus of attention, and people can become focused on seeking help. A chronic condition impacts at a core level on identity.⁹ When pain is a factor of illness or injury, people can feel betrayed by their body. This in turn raises its salience and threat and is a key factor in hypervigilance.¹⁰

This study aimed to explore the impact of iatrogenic trigeminal nerve injury on dental patients, with the additional aim of developing targeted psychological support. Qualitative methods were used in order to gain a more complete understanding of patients' experience of sustaining these injuries and to ensure that important areas were not overlooked. The results of this study will be compared to the results of similar work that has been undertaken with facial pain patients and the similarities and differences used to inform ongoing efforts to develop effective management strategies for patients with iatrogenic nerve injury.

Materials and Methods

Ethical approval for the study was obtained from the NRES Committee South West - Central Bristol (Study Number: 12/SW/0349). The authors drew on approaches within qualitative research of interpretive work that aims to see through the eyes of chronic pain patients and, to a lesser extent, of grounded theory to identify and refine key themes from interviews through a process of iteration and saturation.^{14,15} These themes were then shared in a patient workshop to provide a point of triangulation with a different set of iatrogenic injury patients. This was a workshop run for the clinical benefit of patients who had incurred a nerve injury and was run by an oral surgeon, a psychologist, and a psychiatrist. This was developed further by comparison with clinical records and interview narratives of patients who had sustained noniatrogenic trigeminal injuries. The one noniatrogenic interview and the five cases reviewed did not share the same traumatized illness narrative found in the iatrogenic cases. Although a relatively small sample, no negative cases (ie, iatrogenic injury with a narrative more similar to noniatrogenic cases) were discovered. Sharing the iatrogenic injury narratives in the workshop also suggested future opportunity for comparative action research¹⁶ to inform subsequent clinical work in individual sessions and group workshops.

A pragmatic approach was adopted for selection of research subjects, with opportunistic sampling via the clinics within which one of the research team was working as clinical psychologist. One-to-one interviews were held with 12 patients who had sustained an iatrogenic trigeminal nerve injury within the past 3 years. Patients were recruited from the assessment service for this patient group, which operates from King's Dental Institute in London and receives referrals nationally from general dental practitioners, oral surgeons, and maxillofacial surgeons. Patients included were those diagnosed with nerve injury of the sensory divisions of the maxillary or mandibular branches of the trigeminal nerve. Prior to recruitment, all patients underwent a trigeminal nerve examination carried out by a qualified oral surgeon that included neurosensory tests and patient interviews⁴ to confirm trigeminal nerve injury.

Interviews were conducted entirely separately from clinic contact, and it was strongly emphasized at initial invitation, when seeking consent, and during the interview that care was in no way dependent on participation. As consent is an ongoing process, participants were free to withdraw from involvement at any time during and after contact with the researchers. Interviews were conducted by telephone and tape recorded.

Interviews were conducted by a trained researcher who followed a semi-structured interview schedule adapted from use with facial pain patients. The interviews lasted for approximately 30 minutes and covered a small number of questions (5 to 10) designed to elicit the participants' narratives of the circumstances of their iatrogenic injury and subsequent impact on everyday life, plus more general background about their approach and attitude to dental and other medical care before and after the injury. This schedule was based on narratives from clinics and a previous clinical workshop run for nerve injury patients. Interviews were digitally recorded and transcribed by an independent transcription service before being qualitatively analyzed. Anonymity was assured, and where quotes were subsequently used for illustrative purposes in documentation, any individual-identifying details were removed.

Statistical Analyses

An interpretive phenomenologic approach was used to analyze the narratives from the interviews, with the emphasis on seeing through the eyes of the participants. Grounded theory was also used to a lesser extent to identify and refine key themes from interviews through a process of iteration and saturation.^{11,12} Analysis was ongoing, and as is usual with such qualitative approaches, data collection ceased once saturation of emerging themes was judged to have been achieved within the confines of the small-scale nature of the study. Coding involved the development of themes and categories that were relevant to the impact of these injuries on patient experience.¹³ Memo documents that summarized the interviews and identified emergent themes were created by the social science member of the research team (S.O.) and circulated for discussion within the team as each couple of interviews were conducted. This allowed for checking that the original interview schedule was suitable and to assess, refine, and agree on themes as the study progressed.

Multiple strong themes emerged from this analysis. To ensure that the account was rich, robust, comprehensive, and well-developed, the themes were then presented to another workshop for nerve injury patients, and patients were asked for responses. O'Donoghue and Punch¹⁷ note that triangulation is a "method of cross-checking data from multiple sources to search for regularities in the research data" and also suggested the opportunity for a form of action research. Action research is an interactive collaborative inquiry process that aims to bring parties together to enable future personal and organizational change.¹⁸

A change in how I see myself
Relationship issues
A change in how I care for my teeth
Adjustment to the injury over time
A change in how I see my dentist and other health care professionals
Changes I think should be made to dental practice

Fig 1 Key themes.

Results

Broad themes emerged from the research, which are illustrated in the text below with patients' statements and shown in Fig 1.

The theme "a change in how I see myself" was striking among patients. Respondents varied in how much they said the nerve injury had affected how they saw themselves, but this theme emerged for most people.

One patient said, "I didn't realize at first how much, but I think it made me shy and nervous, less confident, a bit snappy and angry." People often felt they were more sensitive. Another commented, "I'm now very paranoid because I can only eat on the left and then I'm paranoid that I've got fillings in every teeth and my teeth hurt." This patient said they now felt enclosed and paranoid about their speech.

People talked about the sensation that following the nerve injury they felt their face was now distorted. People described feeling like a "freak" and said they felt less attractive. Some said that they felt like a victim, while others commented that they felt tougher as they had to learn to cope with an injury.

The second theme was relationship issues. Post-nerve injury relationships were universally described as more negative. The nerve injury embodied a sense of betrayal that permeated other relationships and sometimes led to them ending. Respondents talked about how having a nerve injury had affected how they related to other people. They said they were frequently stressed and irritable and that they were harsher with other people. One said:

My sister commented that since I have had the injury I have changed, I am very harsh, you know, and I'm more harsh and isolated, a lot less sociable. I don't want to socialize, one because at the beginning although it is not happening now, at the beginning I was feeling uneasy to eat.

Another said, "It's so difficult, where do you go from here? Trying to have your everyday life is so hard. I'm not taking on board what people are saying."

People coped in different ways. Many tried to hide how they were feeling, but this then affected relationships:

I hide things quite a lot and when I came here I didn't realize how much I brushed over or hid . . . because I was on such a mission to fix it and then when I found out I couldn't . . . coming here and obviously the more you learn about it and the more you hear and the more you talk to people and stuff, the more you realize how much you've buried of how it bothered you..

Patients said they knew other people were often aware of the injury but avoided discussing it, as they did not want to upset the patient.

The third theme was “a change in how I care for my teeth.” This theme varied widely between patients and could be seen as a continuum. Some patients just avoided brushing/touching the area of injury: “Sometimes it overwhelms you with the pain and you have to do something else.” Others reported becoming more “paranoid” about oral health care and spent a lot of time focused on cleaning: “It's like a paranoia; I'm constantly worrying about teeth.” All patients worried about future extractions.

The fourth theme was how respondents had adjustment to the injury over time. Most patients were angry when the injury first occurred. Patients often initially coped by thinking sensation would return and pain would subside. When they were told the injury was permanent, it shattered this way of coping and led to depression. This depression gradually moves onto acceptance of the situation: “I've got to get my head around the fact this is permanent, but I keep saying ‘what if . . .?’ My counsellor is doing bereavement work with me”; and “Some days it's unbearable, and other days I think I'm doing OK.”

The fifth theme was “a change in how I see my dentist and other health professionals.” The lengthy wait between the initial identification of the problem and an eventual referral to specialist dental services was mentioned by many.

Our dentist was very dismissive in telling me that there was nothing wrong with me and that I was overreacting and that it will be fine even though he wouldn't put an injection in that side, nor would he touch it and then the, the other doctors and stuff telling me . . . just get on with it.

The initial lack of diagnosis makes it harder for the patient to be legitimately “sick” and access associated benefits, which some said could sometimes lead

to them being seen as a “difficult” patient. Legal services were often involved, and the patient was forced to advocate and campaign for help across health care services. This led to a loss of trust and confidence in dental care, and patients were universally a lot more cautious with dentists and more aware of the business side of dentistry. The lack of trust in dentists was typically extended across health care to doctors and nurses and changed people's decision-making on how to obtain help in the future from health care services. However, patients praised the benefits of specialist dental services:

Coming here I don't feel like a freak. I think that was a big turning point to see other people with the injuries, to find out that other people are . . . like they were getting more success than me but seeking legal action so I didn't then feel like I was being like bad for doing that . . .

The sixth theme was changes that nerve injury patients want in dental practice. Consent issues were frequently mentioned. They stressed that general dental practitioners should explain the procedure and what they are doing more and should be prepared to stop and reassess if a procedure is going wrong rather than to just try and continue. They thought that there should be leaflets on trigeminal nerve injury so people would be more aware of the issue and specialist treatment:

I think all dentists should really sit down with patients and explain, sit down and explain that consent form properly. Because it doesn't say you will get a nerve injury, it doesn't so we need to have it documented so that you know that they read it for you and you understood it. I remember I sat on that long chair and then he said oh before you put your head up just sign here, so he gave me that paper and I signed.

Discussion

While limited to a small-scale study, the authors' experience was that the identification and subsequent use of the narrative themes in workshops and individual sessions enabled patients to reflect and identify with others. Chronic pain is known to have a significant impact on QoL. The narratives provided by respondents provided rich insight into the impact of trigeminal nerve injury. Presentation of the themes provided a framework to help patients more readily articulate their own feelings and difficulties. This

in turn helped them to feel more supported and be more accepting of themselves with an injury, which facilitated processing of the associated grief. A discussion of the identified themes is presented below. These are discussed in relation to current literature.

Change in Self-Perception

The theme “a change in how I see myself” fits with other literature on chronic pain. Nicole Tang discussed the concept of mental defeat; essentially, negative self-evaluation resulting from pain experiences.¹⁹ Pain-specific mental defeat may be linked to disability and the seeking of specialist treatment. Elevated levels of mental defeat in chronic pain patients distinguish treatment-seeking from non-treatment-seeking individuals.²⁰ One patient in the triangulation group discussed how she had a conversation with a friend who was dying from cancer, and both confided that each would like to be in the others’ place. To this patient, death seemed preferable to a lifetime of living with chronic facial pain from a nerve injury.

Patients who had incurred an injury to the trigeminal nerve talked about feeling like a freak and a victim. Many felt that their injury was highly apparent to other people, as their face looked distorted and their speech was affected. Many talked about feeling less attractive, and when combined with being unable to kiss without being in pain, the impact on relationships was significant. Some patients felt the experience made them see themselves as stronger, as they had had to fight to get recognition of the injury and its impact. Williamson and Wallace²¹ discussed the impact of iatrogenic adverse changes in appearance and discussed how medical procedures can impact on body attachments. The present findings added to this body of research on the impact of iatrogenic injuries.

Addressing this change in self-perception through psychologic therapies would seem fruitful. Studies with chronic pain patients have demonstrated that working with feelings of mental defeat could prevent severe depression, anxiety, and interference with daily life.^{19,20} Nagata et al have demonstrated that mental defeat can be effectively targeted in panic disorder using cognitive-behavioral therapy.²² Future studies could apply this to the mental defeat associated with trigeminal nerve injury.

Relationship Issues

Patients discussed how the nerve injury had impacted on their relationships. This is again not surprising, given that persistent pain is known to have a profound impact on relationships.²³ A common theme for patients with trigeminal nerve injury was feeling they treated others more harshly; they were more irritable and felt constantly stressed. For some patients their

relationship was so affected it ended. Trust was also affected. The breakdown of trust with their dentist permeated other relationships, and patients said they were hypervigilant to being betrayed again.

Avoidance of talking about the nerve injury was discussed as a strategy used by the patient and also by close relatives and friends. Patients often hid their injury, and friends and relatives avoided talking about the injury, as they did not want to upset the patient. Herta Flor discussed the impact of chronic pain on spousal relationships²⁴ and noted that not only did chronic pain impact on marital relationships, it also led to heightened distress and physical symptoms in spouses as well. This is something that could be investigated in further research on trigeminal nerve injury.

The third theme, “a change in how I care for my teeth,” reflected issues of avoidance or more commonly, increased focus, again consistent with the chronic pain literature. Models of pain-related fear predict hypervigilance and catastrophizing.²⁵ The process of hypervigilance involves a rapid scan of the situation, which then narrows to a highly focused level of attention if a potential threat is spotted. Hypervigilance is characterized by increased physical and psychologic arousal and is often associated with posttraumatic stress disorder (PTSD). Further research as to whether nerve injury patients fulfill criteria for PTSD is warranted. Patients discussed paying increased attention to their oral health care as a way of preventing the need for further dentistry. Psychologic support could usefully address this hypervigilance to enable patients to achieve a positive balance between good oral health care and overfocusing. Support to return to mainstream dentistry is also useful for patients following a nerve injury, as many had avoided returning to their general dental practitioner.

The fourth theme, “adjustment to the injury over time,” encompassed issues of loss and the myriad of emotions of shock, denial, anger, depression, and trying to make sense of the change. In trigeminal nerve injuries, the level of disability is often a shock to patients, and they typically move through a cycle of loss as the reality of the permanent change in how their face feels and functions becomes apparent.

Chronic pain is often accompanied by loss and can lead to feelings that mirror those involved in a grief reaction involving anger and depression. The grief cycle by Elizabeth Kübler-Ross outlines the emotional stages that many people go through, although it is rare that a person follows the stages in a straightforward way.²⁶ More common is for feelings from the different stages to emerge at different salient times. Addressing these feelings in psychologic therapy would seem an essential role of the specialist

dental service working with trigeminal nerve injury patients. Acceptance and commitment therapy, a third-wave cognitive behavioral therapy, can provide a framework for addressing these issues in an evidence-based way.²⁷

The fifth theme was “a change in how I see my dentist and other health care professionals.” There was often a significant loss of trust in health care professionals that impacted on how patients coped. When in “survival” mode, individuals made themselves “safe” by looking after their own interests, avoiding or denying threats or difficult issues, or attacking others who they perceived as threats. This can have a significant impact on patients’ overall health, as they may avoid visiting dentists and doctors or end up in conflict-laden encounters if they do not get the results they expect from a consultation. It has been suggested that there is also a generic declining trust in health care,²⁸ and this may compound issues associated with iatrogenic injury. Recognizing the impact that iatrogenic injury has on a patient can facilitate understanding and treatment. Staff themselves are often affected by iatrogenic injury, and support for the shame, guilt, and depression that can result would further help to smooth potential barriers in the care pathway. Despite an entrenched belief that doctors should be infallible, errors are inevitable, and practitioners often take personal responsibility for errors, which can impact on their self-confidence and subsequently on performance.²⁹ Penson et al³⁰ discussed how iatrogenic injury can impact on staff practice, sometimes positively, sometimes negatively, as staff practice in a more defensive way. In five Harvard emergency departments, it was found that introducing benchmarking as well as quality improvement methods helped to reduce patient-related medical errors,³¹ and this should be considered to help reduce trigeminal nerve injury.

The sixth theme was “changes I think should be made to dental practice.” Patients stressed the importance of ensuring informed consent at the earliest stages. Patients who had incurred an iatrogenic nerve injury said they wished the risks of treatment had been more fully explained to them and that they could have weighed the options of alternative treatments or no treatment against intervention. Most risk management professionals recommend using written consent documents for all treatment procedures that are invasive or present a high risk. As the law on informed consent has changed following a Supreme Court judgment (2015),³² a radical reassessment of current consent practice in dentistry is underway. It is possible that the dental practitioners involved did consent patients, but this was not the recollection of the patients.

Patients said that they wanted it known that the dentist should be prepared to stop and reassess if a

procedure is going wrong and not to just try and continue. They wanted greater explanation about what was happening during a procedure and said there should be leaflets on trigeminal nerve injury so people are more aware of the issue. Renton and Yilmaz⁶ reviewed management of iatrogenic nerve injury and conducted a literature review. They advised a holistic approach to management and provided a summary of key changes in practice that will reduce iatrogenic nerve injuries related to dentistry.

This was a small qualitative study, and several limitations must be noted. Quantitative research designs the study to address threats to validity through features such as randomization and controls. Norris³³ noted that although the traditional notion of validity is not applicable to qualitative research, a practical way to think about the issue of validity is to focus on error and bias. The method of participant selection may have introduced some bias, since all potential participants were attending an NHS clinic. It is possible that there are people with iatrogenic nerve damage who are living full and rewarding lives who do not seek support from specialist services or those who access private health care instead. It might have been interesting to purposely select for the degree of expressed impact in order to explore factors that aid resilience. This is a potential project for future exploration. There was also the issue that some patients were also being seen by the clinical psychologist who conducted the interviews. Despite the methodology, this might have impacted on their ability to be truly candid about the impact of iatrogenic nerve injury, and again may have introduced some bias.

Contrary to the common approach in both natural and social sciences to avoid researcher effect and bias, action research has developed with the express intention of engaging with participants through research feedback in order to influence practice and change outcomes. While the present authors did not design an action research study per se and cannot claim to have undertaken such a project, the data were a useful addition to existing workshop sessions and enabled patients to reflect and identify with others and more readily articulate their own feelings and difficulties. This in turn helped them to feel more supported and feel that their voice was heard and acted upon for future practice.

Conclusions

Through qualitative methods, this study has provided insight into the significant psychologic impact of trigeminal nerve injury. Further quantitative research in a larger population would shed further light on the impact of this condition on the population of affected

patients. Further qualitative research could investigate staff perspectives and experiences to provide another angle on trigeminal nerve injury with a view of improving support.

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