RESEARCH

Professor Zakrzewska told delegates that this year is the International Association for the Study of Pain (IASP) global year of increased awareness about orofacial pain, which has resulted in the production of a variety of materials for downloading from their website or the European Section called EFIC. There have been more pain conferences having a keynote address or workshop on the topic of facial pain this year.

The first thing that is important is achieving the correct diagnosis, as over 50% of sufferers have had their diagnosis made by either GPs or dentists, with the remainder made by specialists. Dentists tend to under diagnose, GPs over diagnose TN. Once the correct diagnosis has been made, correct treatment needs to be started. The information is out there, but many are not aware of how to treat TN. The NICE Guidelines now state that carbamazepine should be tried in the first instance, but if this is unsuccessful referrals should be made to secondary care professionals.

Very few medical or dental schools run an identifiable programme on pain and its management, despite this being the reason for a consultation in up to 60% of consultations.

Patients benefit from having a good understanding of TN once a diagnosis is made, and the information is available on the internet. The Cochrane Collaboration have produced several systematic reviews, there are e-learning modules, NHS evidence-based clinical knowledge summaries, a TN review in the 2014 British Medical Journal and various books about dealing with TN and other orofacial pain.

Currently there is some research taking place into the genetics of TN. It is believed that there is something in the genes that predisposes sufferers to TN, when combined with other factors. It has been noticed that there are several families where at some point different members, possibly from different generations, suffer with TN. This suggests there is a link with genetics. Once the genes have been identified, it will be easier to look at ways of curing the condition and this could include stem cell research which is currently being done in California.

Cohort studies are also continuing, where a group of people with common characteristics are followed up after a period of time. This group is selected prior to any results being known, and both medics and patients do not know what treatment is being used. Any currently taken medications need to be known at the start of the study and questionnaires are used to monitor the results.

Clinical trials are continuing, but several criteria need to be fulfilled prior to commencing the trial. There are two main types of trial that can be used: open trials where everyone uses their old medication, before commencing the new medication, after which time the outcome is measured and also the side effects. This, however, is open to bias. Randomised Controlled Trials (RCTs) are designed to reduce bias and are of a variety of types. All are carefully reviewed by an ethics committee to ensure no harm will come to the patients. In the parallel RCT, participants are split into groups where there is a run-in period, before some being randomly assigned to either the new medication or to the placebo or control medication, but neither the clinicians nor patients know which they have been given. After a set time the final outcome and side effects are measured.

Randomised cross-over trials are also used, where there is a run-in period before patients are assigned into one of two groups, unknown to them and the clinicians. They will either take the new medication or the placebo or control medication for a set time before the outcome and side effects are measured. After this, the two groups switch over for a set period of time and the outcome and side effects measured once again.

The final type of randomised controlled trials are the enhanced enriched trials, where there is a run-in period, then everyone tries the new drug, with the outcome and side effects being measured.

Then those who responded positively to the drug are randomly designated blindly to either the new medication or placebo, then the outcome and side effects are measured. With this type of trial people may drop out at any time, it being anticipated that those on the placebo will drop out quickly.

Trials are difficult to conduct for several reasons: TN is relatively rare; other medications being taken can interact with the trial medications; many of the medications take time to work; spontaneous remission is common; side effects may take time to appear; and the pain is so severe that using a placebo medication cannot be justified. Trials are very expensive and take a considerable time to set up and then run.

A new compound has been developed by a small biotech company, Convergence, and they have just used the enhanced enriched trial method. The Phase II trial of this sodium channel blocker CNV1014802 has shown to have a 22% lower failure rate, a 37% higher decrease in pain severity, and a 48% reduction in the number of paroxysms compared to the placebo medication. These initial results have proved the medication to be worth continuing into a larger international study, for which further funding of around £55 million needs to be achieved.

Whilst the scientists are deciding on the areas of research to be pursued, it is important to engage patients in what they think needs to be done and then for them to be a part of the research team deciding on the design of the study, rather than just being recruited into the study as participants.

Professor Zakzrewska then split the room into four groups, enabling the participants to explain where they would like research to be carried out. The groups came up with several questions they think need addressing, which included: reasons for the causes of TN; epidemiology generally; pre-disposition to TN; stem cell research; neuro-transmitters ("chemical soup"); frequency of misdiagnoses; differences in the quality of MRI scans; the reason for remissions; the lack of medications with immediate effect; the value and effectiveness of complimentary medication and topical treatments; the effect of vitamin B12 on consolidating treatment; possible healing of the myelin sheath; preventing recurrences; the psychological impact of TN; why there are so many difficulties in treating pain; why GPs seem afraid of pain and why dealing with pain is not well taught in medical schools; raising awareness of dentists/hygienists; and respect for patient input.