Oral cancer: A ticking time bomb?

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Key points

- 14m missed appointments means potentially thousands of undiagnosed cases
- Impact of lockdown could be felt for years
- Support for existing oral cancer patients critical

Introduction

I'm not ashamed to say a decade ago I had no idea what oral cancer was, what the risk factors were and what I needed to look out for if I had any concerns in my mouth. Fast forward 10 years – four of them seeing me involved with a charity campaign *specifically* about mouth cancer – and I now confidently know the triumvirate; heard of the disease, can list the risk factors and know the signs and symptoms. According to a new survey, that puts me in the 1% of people who have increased their knowledge of the disease in the last decade,[1] which isn't the most reassuring figure you would wish to read.

And so to the present day, where a pandemic continues to sweep the UK like a heavyweight boxer landing punches on an opponent that doesn't know where or when the next punch is coming. At some point COVID-19 is going to land a knockout punch – specifically to health services – and in the meantime all it can do is struggle along.

That feels very much like where dentistry is. Recent BDA research suggests the number of missed appointments has exceeded the 14 million mark throughout lockdown in England alone.[2] That's an awful lot of patients not having an oral cancer examination as part of their check-up, not to mention those who would be referred. New data show 8,722 new cases of oral cancer were recorded along with an estimated 2,702 fatalities.[1] With dentistry suffering from chronic access issues pre-pandemic – and the impact of lockdown still to fully reveal itself – COVID-19 could leave the profession with an oral cancer ticking time bomb waiting to go off.

True impact

Gerry McKenna, Chair of BDA Northern Ireland Hospitals Group, thinks the true impact will be felt next year.

'I don't think it will be until 2021', he said. 'The picture here is that presentation of cases shows patients are not entering and making their way through the system. Cases are going to be at a more advanced stage with poorer prognosis and more invasive surgery.

'But that's not a problem solely due to the pandemic. Late presentation of oral cancer has been a problem in Northern Ireland for some time. Those T1/T2 lesions just aren't being seen. It's a scary thought thinking people are walking around now probably sensing there's a problem but not doing anything about it. By the time they do the disease is at an advanced stage requiring complex care plans, and that's what we're more accustomed to seeing and I fear will continue to see in larger numbers.

'Could that put pressure on the health service in Northern Ireland? It's hard to say. Any presentation that has a large surgical impact makes recovery and care more difficult, which is more costly than prevention. In the context of a challenging climate where every element of the health service is focused on COVID-19, there will be questions about where that funding is going to come from.'

Dervilia Kernaghan, Head of Care Services, Cancer Focus Northern Ireland, believes we're starting to see an impact now.

'To a certain extent it's already starting to happen in Northern Ireland', she said. 'We didn't have a first peak of COVID-19 similar to that seen in England, for example, but we're seeing it now. Cancer patients in some areas are being turned away from clinics because of staffing issues and to free up beds.

'We are extremely concerned about the number of cancer related procedures that have already been postponed during the second wave of coronavirus. We acknowledge the extreme pressures that the health service is under and welcome the Health Minister's £12.1m funding to prioritise diagnostic services. However, we are worried about what lies ahead with the likelihood of further postponements if too many patients are admitted to hospital with COVID-19 and medical resources are diverted to deal with them.

'Gerry is right – on top of this there will be an inevitable backlog and wave of later stage diagnoses creating further pressure on our health system, as those diagnosed at a later stage often need more intensive and expensive treatment compared to those diagnosed at an early stage. More resources need to be made available on a long-term basis and built into the new Cancer Strategy for Northern Ireland. Delays in treatment place enormous stress on patients and on their families, who are waiting and worrying. For many cancer patients, time is not a luxury they can afford.

'It means 2021 could be a very difficult year for an already overstretched health system here. We have the longest cancer waiting times, and a backlog caused by restrictions and lockdown will only make that problem worse. While many have rightly taken the stay at home message to heart and followed it, I fear there will be many more late stage diagnoses than in previous years.

'What it has shown is how much COVID-19 has masked some deep, long-standing problems within our healthcare system. It was in crisis pre-pandemic – in December and January it was very much on the brink. Workforce planning in Northern Ireland is exceptionally poor, and we're now starting to feel the pinch.

'On the flip side, every challenge presents an opportunity. Things cannot continue as they are now nor how they were pre-pandemic. A full reconfiguration is needed to galvanise the system, which, in order to be successful, might see some difficult decisions being made.'

Alex Crighton, Consultant in Oral Medicine NHS Greater Glasgow and Clyde, took a different view.

'In all likelihood, not until routine dentistry can restart in Scotland without being restricted again. The very basic principle here is that you can't see what you didn't see – if patients can't, don't or won't seek to get an issue checked out, we're relatively powerless. At the moment, that is the situation we find ourselves in. Hospitals have tried to keep in touch with patients under review post-oral surgery due to their high-risk status, but getting them in for a consultation is challenging.

'What is of some concern is the number of people walking around with that 'something suspicious' they haven't done anything about. It will inevitably lead to later presentations and worse outcomes.'

Chet Trivedy, qualified dentist and Consultant in Emergency Medicine, Brighton and Sussex University Hospital and founder of Boundaries for Life, agreed with Alex's assessment.

'Like Alex, I think – in England – that point will come when there is greater public confidence in people's attitude to risk and visiting the dentist. There are reports of a huge backlog of cases, and that will only continue to grow until dentistry resumes routine face-to-face consultations. While patients still have avenues to pursue if they have concerns about their health – pharmacists, GPs hospitals, for example – dentists rely on getting patients in the chair. It's impossible to see small, suspicious lesions via digital means, as useful as they have been this year in bridging access to patients.

'It is worth noting the financial impact the pandemic has potentially had on oral cancer. It remains that this form of the disease is the only one you have to pay for to get a diagnosis. That is fundamentally wrong. Vast swathes of people in England have been furloughed. Many continue to be, and on less than the 80% they were over the summer. Jobs are at stake, and even pre-pandemic we know money was a barrier for some people. In these extraordinary times, would someone on 60% of their wage choose to pay for a dental appointment or Google their symptoms? There's a fair chance it would be the latter.'

Tom Bysouth, Chair of the Welsh General Dental Practice Committee, also agrees.

'Unfortunately it may not be for some time to come, whilst we all hope the good work of dental teams can mitigate problems in access to care and wider public health messages, the risk is patients may not be able to seek the care that they need. I hope I will be proved wrong.'

An exacerbated problem

There are plenty of rumblings across healthcare that COVID-19 hasn't caused many of the problems we're reading about, it's merely exacerbated them. NHS cancer waiting times are understandably the worst in 10 years with 20,000 suspected patients not seen within 14 days of an urgent GP referral.

Some 88% of 170,000 patients in England suspected to have the disease had a consultation within two weeks of their doctor referring them — the lowest since records began in October 2009. It means 12% had to wait longer.[3]

Macmillan Cancer Support reported In Scotland 2,250 people who should have started cancer treatment between April and September did not. It was a similar story in Wales, where data for August show a 23% year-on-year drop in the number of people entering the system for cancer diagnosis. In Northern Ireland, the number of people starting first treatment was at 20% behind 2019 levels in June, with a backlog of 200 fewer people starting their first cancer treatment.[3]

As statistics from Public Health Wales suggest that since the turn of the century the incidence of mouth cancer has continued to rise in Wales, with over 300 new cases per year, Tom pointed to early diagnosis as a key issue.

'Unfortunately, many mouth cancers are still being diagnosed at a late stage resulting in poorer long-term outcomes for patients, with a typical 55% five year survival following diagnosis. an important aspect remains being the ability to see patients for routine examinations and reinforce prevention. The pandemic resulted in colleagues having to prioritise emergency treatments resulting in delays to routine examinations and generating large treatment backlogs as practices seek to catch up on patients not seen during the spring lockdowns. Additional changes to practice via social distancing and the introduction of fallow times has further reduced the numbers of patients colleagues are able to see each day, so reducing availability of an important resource. The advice has been to risk assess patients as to those most in need of care, so aim to see those who we think have higher risk for mouth cancer. Unfortunately, though, in spite of this the risk is that some patients will fall through the cracks.'

According to Chet, dentistry is all too well aware of these issues now posed.

'Many of the problems that are now beyond critical were issues that were there to solve pre-pandemic. I've been working with the FGDP(UK) in putting together guidance and support for practitioners throughout the pandemic, and access problems, waiting lists, referral times – all things suspected oral cancer patients cannot afford a delay in – have been mentioned.

'This 'process' is something I have expressed major concerns about. Patients are struggling to get appointments and access – for a plethora of reasons – to a dental practice. Oral cancer adversely affects BAME populations due to risk factors such as chewing tobacco and areca nut consumption, both prevalent in South Asian communities. It is also a segment of the population that studies show are at greater risk of COVID-19, so that affects the choices patients could make. There are language barrier issues that a digital consultation struggles to overcome, so it's a very difficult time for practitioners.

'Once you overcome these obstacles, you have to get the patient referred to a specialist, and both of these have been impacted. We have seen some hospitals reporting a delay in operations for cancer patients. We have to get people through the system and provide the workforce with the right infection control protocols and the right PPE. In the circumstances, the profession is doing its very best. They feel for their patients, particularly the ones who were diagnosed with oral cancer and had surgery pre-pandemic. It's a difficult time where every issue has been magnified and multiplied.'

It is a similar story in Scotland.

'Oral cancer prevention messages and access have always been a problem in Scotland', Alex added. 'In reality, for many people unable to make an appointment, that's been no different to what the situation was pre-pandemic.

'What we have tried to do here is use our time wisely and solidify the reasonably well-established pathway for getting patients in to be seen. In some areas, if that provision doesn't exist, that's when the problems start. In the West of Scotland there has been a good set-up, broadly replicated across the country. GPs had access to a hotline for referrals of anything suspicious, and we've all had clear advice from local public health teams on how to get patients safely into the system. The Louisa Jordan Hospital has acted as our 'Nightingale Centre' with increased levels of infection control, ventilation, adequate PPE. It's a safe space. This gives us the option to perform a digital consultation first before bringing them in, which is a system perhaps worth pursuing in the future.'

In Gerry's opinion, Northern Ireland may have been impacted the most.

'This theory is exactly what we're dealing with in reality. There are so many long-standing issues with oral cancer here. We have a population of oral cancer patients who present late – later than any other part of the UK – and that's been made worse by the pandemic.

There are access issues too, and it's worth considering the profile of those who don't access dental services. Roughly 44% of patients in Northern Ireland present symptoms to their GMP rather than dentist, and at the moment, all access routes to healthcare services are significantly more difficult.'

A difficult situation

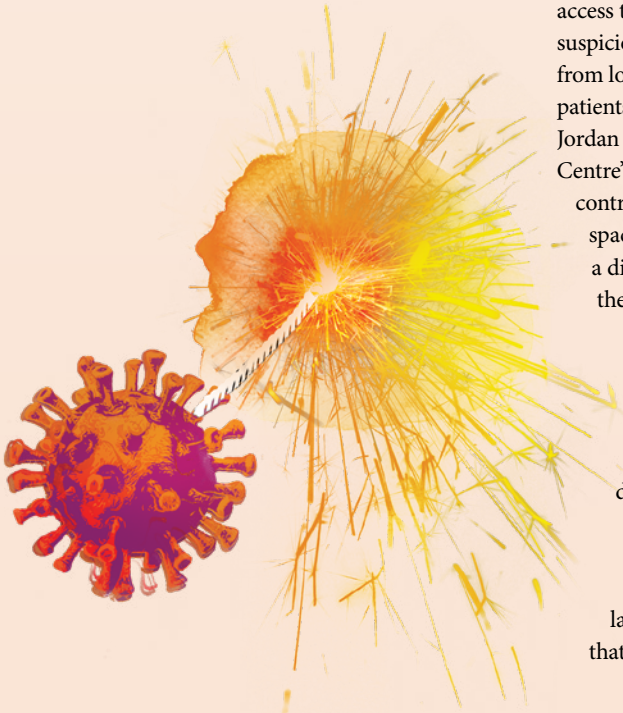
Chet's observation about the difficulties faced by practitioners may seem like an obvious one, but like an onion, the more you peel away the layers, the more you find underneath. How can you possibly balance current patients with a backlog of cases, not to mention supporting those patients who may have undergone life-changing oral cancer surgery prior to COVID-19?

'The issue comes with identifying patients and then understanding their needs', Alex suggested. 'During lockdown, we manually went through our patient list checking to see where they were in their journey and what they were in for. Like other areas we had to assess those who were considered a priority, so there are ways of picking them up. For those under care the pathways and systems we had supported them well.

'What we have learned is that it is amazing what you can do with a mobile phone. Oral cancer patients – and this is a generalisation – tend to present later than other cancers, so it's easy to spot some of the bigger lumps and lesions in a patient's mouth with a phone. There is nothing that can replicate the dentist getting an eyeball on a problem. It is the subtle, early developing lesions that are problematic and cannot be spotted through remote consultations. Any catch-up programme is going to have to be focused on those people who thought they may have had a problem but have done nothing about it only to find 12 to 18 months later their condition has deteriorated. Remote consultations have been great for bridging access, but they cannot be used on their own.'

'To be able to keep working to provide a full range of care to their patients many have made extensive modifications to the practices', Tom explained. 'It has not been easy and has caused a considerable amount of stress for many. As Welsh GDPC we will continue to make the case for all dental practices and teams.'

Gerry added: 'Like others we've done everything we possibly can to see all patients, but the issue is capacity, and as a result many aren't being seen, whether they're presenting with a new problem or have made it into the system. As every hospital has had to do, we've



also prioritised patients, but the logistics mean we're not going to see anything like the same number of patients we previously have done. That's a problem when it comes to oral cancer in Northern Ireland.'

In Chet's opinion, it all comes down to the basic principles of being in healthcare.

'Not being able to get an appointment and that security of having their complaint addressed – or at the very least identified – can lead to anxiety in patients. While there are business considerations to be mindful of, for me it's about the basics – we always put patients first and we have a duty of care to do so.

'Dentists have done an incredible job under the circumstances. Being told to close your doors and not see patients because it was unsafe must have been shocking for so many. With policies changing on a seemingly weekly basis, and varying depending on whether you offer NHS treatment or private, it wouldn't surprise me to find practitioners have had trouble policing what they can and cannot do.'

It's not just dentists that have been impacted with their patients. According to Dervilia, charity work and supporting oral cancer patients has also been severely impacted.

'Naturally it's been difficult, but like many we've had no choice but to rise to the challenge. From March we've been working remotely, trying to offer a blended approach. It's obviously difficult to see high-risk patients, many of whom have said they'd rather wait until they can see us in person, but we don't know when that will be. As a charity we rely on funding, and thankfully stop smoking services are funded by local agencies. Our annual Head and Neck Cancer Conference was postponed, which always provided a valuable touchpoint for a number of service users and providers. The integration of care pathways has simply collapsed, and there's no telling when they will fully recover.'

Problematic solutions

When lockdown was announced in March, the associated restriction of movement meant socialising was kept within your own four walls. There was no going to the pub for a quick drink with friends after work, no Sunday lunches at your favourite restaurant. For many it was solitary confinement – bar the odd walk to remind yourself what other humans were – and pubs and restaurants would have to come to you. This had consequences.

In July, Alcohol Change UK commissioned a report that discovered 28% of respondents stated they drunk more alcohol than usual during lockdown. There was a shift towards drinking more frequently; before lockdown 33% of people drank twice a week or more, and this rose to 38% during lockdown. Heavier drinkers had increased the amount they drank; 38% of those who typically drank heavily on pre-lockdown drinking days (seven plus units) said they drank more during lockdown,[4] an issue also highlighted for those with alcohol use disorders.[5]

In October, ITV News reported that UK households ordered nearly 50 million meals in the three months prior from one delivery service *alone*.[6] On top of that, the government's Eat Out to Help Out scheme reported that restaurants had claimed for more than 64 million discounted meals in the first four weeks of going live.[7]

On top of that, The British Association for Sexual Health and HIV reported in April service capacity had been significantly reduced with 54% of sexual health services closing, and the majority of respondents (53%) stating they had less than 20% capacity for face-to-face services.[8]

> 'Recent BDA research suggests the number of missed appointments has exceeded the 14 million mark throughout lockdown in England alone.'

While these three reports sound like every promiscuous student's dream scenario, they're also risk factors for oral cancer. So how – at a time where even the most basic public health messages relating to COVID-19 are falling on concrete deaf ears – can the profession successfully get across risk factors relating to oral cancer?

'It's extremely challenging', Gerry said. 'COVID-19 has some of the most basic hygiene messages – washing your hands isn't difficult. For me it points to a wider issue about oral health in general. It's been somewhat forgotten about. Most of the population probably know that smoking and drinking alcohol are linked to a number of systemic diseases and cancers, but clearly oral cancer doesn't form part of that.

'It's an opportunity to engage more with medical colleagues. Let's raise awareness that smoking, drinking alcohol to excess, poor diet and HPV are linked to and can cause oral cancer. Let's work with colleagues in other disciplines of public health to push the message about signs and symptoms of the disease. Rightly so the focus is on COVID-19, and that will certainly dilute other health messages at the moment, but there is an opportunity to re-think and re-design health services in general. If dentistry was integrated better, these would be closer to being attainable. We can take a look at the remuneration policy for primary care colleagues. We can look to give patients the COVID-19 vaccine as and when it becomes available. We can be seen as a wider part of the healthcare system, which means when we talk about dental health the focus isn't just on the aesthetic.'

'Quite right. They're simple and straight forward, but that doesn't make them easy to follow', Chet added. 'Stop tobacco use, reduce alcohol intake, poor diet, HPV; these tie into socio-economic factors. As you have already stated, reports suggest an increase in alcohol consumption and takeaways throughout lockdown, not to mention the government's Eat Out To Help Out Scheme, which some restaurants are still doing. We have to look at integrated approaches with wider public health colleagues.'

Tom also pointed to the need for additional voices to push the message.

'Dental colleagues from within the BDA and across Wales have always stressed the importance of a mouth cancer assessment being a key part of a routine dental examination, and a vital reason for the opening up of dental services, indeed this was a key point raised when I spoke to the Senedd Cymru Health Select Committee in July 2020. The point has also been made within national media that dental practices have always been leaders in cross infection control to reassure patients that a visit to the dentist is safe, and that as always patient safety is the dental teams' priority. We have asked Welsh Government to help put these messages across.'

According to Dervilia, it's a tricky balancing act.

'Getting messages across to a young, male audience without pointing the finger isn't always easy. There is a degree of complacency setting in with COVID-19 messages, and that in itself is an issue. In our view, the onus always has to be on prevention and reducing the risk. You cannot treat your way out of oral cancer. It involves some invasive, life-changing surgery which will affect you for the rest of your life, so the messages relating to tobacco use, alcohol, poor diet and HPV need to be targeted and heeded.

'We need targeted health promotion campaigns taking into account the specific health literacy needs of different groups, so we

have to strip back blanket approaches to public health.'

Alex forecast a more definitive outlook.

'Any messages of prevention are simply going to get lost, and it would be foolish to think otherwise,' he said. 'There are signs that every country in the UK is suffering from health message fatigue, no matter how simple or straightforward we believe it to be. Oral cancer's messages are just as simple as those relating to COVID-19, but we know much of the population still goes ahead and ignores them.

'Because patients can't get an appointment – or for their own reason don't feel safe or comfortable attending one – this puts the onus on health education messages relating to oral cancer. I have said to my students many times that dentists are possibly the only healthcare touchpoint that have the opportunity to stop a patient becoming unwell. If they get an appointment with their dentist, that dentist knows their history well, can track and monitor changes and there's a relationship and element of trust there. If a patient can't get an appointment and searches the internet for their symptoms, it's going to cause more anxiety than relief and a breakdown in trust in public health messages. Until things return to normal, this is what the new normal is.'

Plugging the gap

Ultimately, services across the four nations are going to resume to pre-COVID-19 levels. But like a hurricane leaving a trail of destruction, who knows how much damage will have been done or how much it will cost to put it right. Gerry believes dentistry's relevance in the health system will dictate how much of a priority that restoration is.

'How much it will take to reverse the damage is a difficult question because what the pandemic has revealed is the long history of under-investment in dentistry and the wider health service. Have we been taken for granted? Perhaps. Colleagues in primary care need to have their funding model re-structured, which will impact on secondary and tertiary services like ours.

'You have to question whether even pre-pandemic dental services were fit for purpose. Now we're faced with the prospect of them not being the same way for a very long time, if at all. I shudder to think how much it will take financially to recover. Take dental hospitals as an example. We're going to have to run at lower capacity due to COVID-19, so do they need to be refurbished or re-designed to cope with social distancing requirements? I would suggest they do because the current set-up is not conducive to gold-standard patient care, never mind peace of mind. That's even before we have carried out an AGP and ensured the safety of the workforce. There are going to have to be some difficult but long overdue conversations about how we safeguard the future of dental services in Northern Ireland.'

Dervilia echoed Gerry's thoughts about an opportunity for change.

'We're at a critical juncture. Maybe I'm naïve hoping for this, but with the right leadership and financing, perhaps we can achieve the gold standard of service patients need.

'Professor Mark Lawler of Queen's University Belfast co-authored research that suggests we need to see 130% investment to improve services on where they were. COVID-19 has exposed the flimsy funding model in Northern Ireland, and we need a rigorous model to protect services. The alternative is scaling back, and for us that's an untenable prospect. We're the only region without a cancer strategy – why? We need reassurances that the strategy will be adequately resourced and implemented to ensure better outcomes for cancer patients in Northern Ireland.'

Tom believes it could hinge on any decisions about fallow time.

'Reduction of fallow time is key to allowing practices to provide care to their normal patient base, as we learn more about COVID-19, and note the high standards of cross infection control used by dental teams that we can reduce fallow time further. Supporting all practices to make these changes will help to preserve our dental services.

'Wider availability of NHS care has always been key, but availability of dentistry as a whole will also be vital. NHS elements of care have been supported by Welsh Government including removal of UDA targets until April 2021 and the provision of PPE which have been welcomed by the profession. Unfortunately private care, which makes up a significant amount of all dentistry provided in Wales, in most cases supporting the dental practice's NHS care, has not been supported in the same way. At the very least it must be ensured that we don't lose further access to what is an already stretched service.'

In Scotland, Alex cites those on the frontline of the profession that will need help.

'It will be colleagues in primary care services that will need the most financial assistance, but what is evident is how far down the priority list dentistry is. Until the resumption of face-to-face dentistry, their financial black hole is only getting bigger. Waiting lists could well increase – both in length and time – which will put a strain on an already stretched service. On top of that you will have new referrals on top of the backlog, so any oral medicine service is also going to find their resources stretched. While we are reasonably well-funded, we're part of a system. If that crumbles, we'll go with it.'

According to Chet, it's too early to even assess the damage, let alone plot a course out.

'Turning around a ship is based on assessing the waters you are in,' he explained. 'You can't do it in choppy waters, which we're still in. Once there is some stability, only then can we really look at the damage caused and how to resolve these issues. Unfortunately, there is really no telling when that will be, and I am concerned for patients and the system in the interim and beyond.' ◆

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