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Title page

Title: Long-term impact of living with an obturator following a maxillectomy: A qualitative study

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TITLE: Long-term impact of living with an obturator following a maxillectomy: A qualitative study

ABSTRACT

Objectives: To explore the long-term impact for patients living with an obturator prosthesis, following a maxillectomy for a head and neck neoplasm.

Methods: A qualitative approach was employed, using semi-structured interviews. A purposive sample of eight men and four women, living with an obturator prosthesis for at least five years, were recruited. Interviews were digitally recorded and transcribed. Using thematic analysis, two researchers analysed the data.

Results: The data were categorised into four themes: 1. Preparedness for living with an obturator, 2. Impact of living with an obturator – what changes to expect, 3. Stability and retention of the obturator, and 4. Coping strategies to aid adjustment.

Long-term effects of living with an obturator spanned many aspects of life to include: chewing and eating, speaking, dealing with nasal leakage and altered body image, employment and intimacy issues, along with embarrassment during social encounters. Optimal retention and stability of the obturator, as perceived by the patient, lead to improved social confidence and engagement. The emotional impact varied greatly on peoples' lives.

Conclusions: Patients experiencing the greatest long-term challenges had larger defects, were of employment age and had not returned to work. Gaining an improved understanding of the psychology of coping overtime is clearly important, as this can inform interventions to facilitate adjustment for those who are emotionally struggling. Furthermore, the findings of this study could inform the design of a communication tool to facilitate shared-decision making and aid preparedness for living with an obturator following a maxillectomy.

Clinical significance: The multidisciplinary head and neck team should provide patients with detailed pre-operative information, including potential effects on social, work and personal relationships. The restorative dentistry team has a pivotal role in the long-term management of these patients, as obturators have a finite lifespan with ongoing maintenance necessary to promote optimal retention and stability.

Keywords: Obturator, maxillectomy, long-term impact, shared-decision making, qualitative research, survivorship, head and neck cancer, restorative dentistry

1. Introduction

Oral cancer is one of the most commonly encountered head and neck cancers (HNCs). Worldwide, approximately 355,000 new cases of oral cancer were diagnosed in 2018 (1). Cancer affecting the hard and soft palate is uncommon, accounting for less than 13% of all oral cancers, however, its incidence appears to be increasing (2). In England, 68.5% of all oral cavity tumours were treated surgically between 2013 and 2014 (3). A maxillectomy is defined as an ablative surgical procedure that involves the removal of part or all of the maxilla, which creates a pronounced discontinuity defect, resulting in a communication between the nasal and oral cavities.

The most common approach to reconstruct the maxillary defect remains the use of a removable prosthetic obturator (4, 5, 6). Consistently, the literature reports that good obturator retention correlates with improved oral function and enhanced health-related quality of life (QOL) (7, 8, 9, 10, 11). Today, more complex surgical management may be offered for surgical closure of the maxillectomy defect, providing a permanent division between the oronasal communication. These increasingly established techniques include soft tissue microvascular free tissue transfer, or reconstruction using pre-fabricated or digitally planned composite flaps (12). However, these techniques are not suitable for all cases and are not available in all treatment centres.

Optimal technique for reconstruction of the maxillary defect remains controversial today (13, 14). A recent systematic review by Brandão et al (15) was unable to draw any definitive conclusions about how an obturator prosthesis compared with free tissue transfer in terms of affecting patients' QOL. It raised more questions than answers due to the small number of studies available for inclusion (n=10); characterised as low in quality, with short-term follow-up and having small sample sizes. The only firm conclusion drawn after scoping the literature is that studies examining QOL following a maxillectomy remains rare, with a lack of research focusing on patients' perceptions of living with an obturator prosthesis and how this impacts on their everyday life.

This evident gap in the literature is disconcerting given the grave potential of permanent physical, functional and social changes to include avoiding family and social events following a maxillectomy, reconstructed with an obturator prosthesis (16, 17). Informing patients preoperatively of the expected impacts and long-term lifestyle changes is paramount, in order to establish meaningful informed consent. This knowledge will provide clinicians with patient-centred information for preoperative patient counselling, to enable appropriate person-centred care and aid shared decision-making.

Furthermore, there are no studies known to the authors exploring the long-term impact, of living five years and beyond, with an obturator following a maxillectomy. This is a key gap in much of the cancer literature, but is gaining increasing relevance, with the steady increase in cancer survival rates (1). It's important to note, that being disease-free doesn't equate to being symptom-free. Healthcare providers need to have an adequate understanding of the long-term consequences of treatment, to include late-effects for this patient group. This is necessary to ensure that current models of care are responsive to rehabilitation and supportive care needs of long-term survivors. The study is timely and clearly aligned to the current national cancer survivorship research agenda (18), as it distinctly addresses a number of the top 10 research priority areas, to include '*gaining understanding, appropriately informing patient and carers and managing long-term consequences*

and late effects of treatment for cancer patients'. The aim of this study is to explore from a patient's perspective the long-term impact of living with an obturator to rehabilitate a maxillary defect.

2. Methods

2.1 Recruitment of participants

Twelve patients who had received an obturator prosthesis following a maxillectomy as part of their treatment plan for a head and neck neoplasm were interviewed. All patients had been wearing an obturator for at least 5 years. Purposive sampling was employed to ensure recruitment of a representative sample of participants according to age, gender, socioeconomic backgrounds and range maxillary defects. Recruitment continued until data saturation was reached. All participants were recruited from Feb – Aug 2018 in the Belfast Health and Social Care Trust where regional specialist restorative dentistry services are based in Northern Ireland.

Participant inclusion criteria included: patients aged 18 or over, an understanding of written or verbal English and the presence of an obturator prosthesis for a least five-years following a maxillectomy as part of their definitive treatment plan for a head and neck neoplasm. The only exclusion criteria applied was a medical diagnosis of dementia or severe cognitive impairment. Patients who met the study criteria were made aware of the study via telephone and potentially interested participants were forwarded a patient information sheet. They were then contacted by the researcher at a subsequent clinic visit and a time was arranged to conduct the interview, which often coincided with a clinic appointment at the dental hospital. Before the interview commenced, informed written consent was obtained. Full ethical approval was obtained from the NHS Research Ethics Committee (IRAS project ID 201767).

2.2 Topic guide

A topic guide for the interviews was developed based on a review of the literature and moderated by the research group. The research group included two clinical academics: one with a background in restorative dentistry and health service research and the other in head and neck oncology nursing and qualitative research; and one NHS Consultant in Restorative Dentistry. The topic guide covered the following areas:

- information received before surgery – how prepared patients felt before undergoing surgery to remove the tumour from their upper jaw
- effects of living with an obturator (physical, social and emotional)
- challenges to wearing an obturator – both immediately and long-term
- rehabilitation needs over time
- coping strategies
- what facilitated and / or impeded adjusting to living with an obturator over time

The semi-structured interview format enabled the researcher to probe and follow-up on cues from participants, allowing new themes to be uncovered as participants shared their experience of living with an obturator following a maxillectomy.

2.3 Data Collection

Interviews were conducted by a trained qualitative researcher, in a private room within a dental hospital. The participants were very familiar with the surroundings of the dental hospital setting, having attended there for outpatient appointments. Before the interview commenced participants were given the opportunity to ask questions and informed, written consent was obtained. Interviews lasted approximately 45 to 80 minutes. Interviews were recorded with their permission and transcribed verbatim.

2.4 Data Analysis

The transcripts were analysed using thematic analysis as described by Miles and Huberman (19), including the techniques of labelling, coding, categorising and theme development. Firstly, the raw data was read, labelled and re-read, then codes identified and processed into categories with the use of diagrams, which allowed for a visual representation of how individuals see their worlds and connections to be identified (20). Through a process of comparing and contrasting data and exploring connections, themes were developed and tested. Further refinement of the themes was achieved through critical dialogue with members of the research team.

3. FINDINGS

3.1. Overview of the results

The research team discussed the interviews and the emerging themes throughout the data collection phase. Data saturation was reached following 12 in-depth interviews with participants. Eight participants were males and four were females. Four of the participants were never smokers. The profile of participants seems to reflect the profile of patients with head and neck neoplasms (males and smokers being more at risk of the disease). The age range for patient who were interviewed, spanned from 38 – 84, with a mean age of 64. Within this study, ten were married or with a long-term partner, one widower and one single person (see Table 1).

The vast majority of participants had been treated for squamous cell carcinoma. The maxillectomy defects were classified according to Brown et al (21) modified classification.

According to Brown's classification three of the participants were Class 1, three Class 2a, one Class 2b, two Class 3a and a further three Class 3b, with no Class 4 patients. The uniqueness of this study is exemplified by the recruitment of participants who were many years living with an obturator prosthesis. The shortest timeframe was five years, and up to 27 years with a mean of 13 years. Further characteristics of this patient population can be found in Table 1.

The data were categorized into four main themes, namely: 1. Preparedness for living with an obturator, 2. Impact of living with an obturator – what changes to expect, 3. Stability and retention of the obturator, and 4. Coping strategies to aid adjustment. The number at the end of quotes refer to individual patients followed by the classification of the maxillary defect according to Brown et al (21).

3.2 Main theme 1: Preparedness for living with an obturator

The degree to which patients considered they were prepared for their maxillectomy and insertion of obturator varied considerably and was influenced by a number of factors which will be addressed through the following subthemes: 'Preference for pre-treatment information' and 'pursuing a curative option'. As the participants were now a considerable period of time from their surgery they provided 'reflections on how to aid preparedness' for other patients and this will be the final sub-theme reported in this section.

3.2.1 Sub-theme: Preference for pre-treatment information

There was a variation in participants' desire for amount and type of information; which often centred on individual's attitude and perceived threat from cancer on their life and strategies for coping with their illness. Preference for information did not appear to be influenced by age or gender or how invasion the procedure was according to Brown's classification. While all patients wanted basic information on diagnosis and treatment plan, not all wanted detailed information surrounding the surgical procedure or the anticipated effects. A number of patients who could be described as 'active information seekers', gleaning information from their healthcare team and often from other sources, such as the internet. These participants often wanted clear, factual information about the surgery, to include: what was being removed; anticipated changes to daily-life following surgery, in particular, the impact on social interactions and family relationships; and their prognosis. Such information was deemed important for informed, shared-decision making; aiding preparedness for this life-changing operation. When patients reported confidence in their specialist team this often reduced the need for patients to seek other sources of information.

> *They were able to tell me that the upper jaw bone would have to go along with some of the roof of the mouth area and the sinus would have to be taken out and they fully explained how they were going to do it. Where they were going to have to do an incision from across the eye, down on my nose, up in the edge of the nose, under the nasal and then initially they would cut the lip (P1, Class 1)*

> *Basically, um I think they prepared me quite well because they told me I would have difficulty eating, I'd have difficulty drinking. Um, the liquid would come down my nose, which it did in those early stages quite a bit (P3, Class 2a).*

Having a good insight, understanding and opportunity to seek information and support appeared to help patients' cope after surgery.

> *But I accepted what I'd be told pretty. I well remember saying to myself, this isn't so bad after all. I thought this could be worse (P10, Class 3b).*

Conversely, individuals' who felt overwhelmed, reporting a high degree of anxiety surrounding having oral cancer, necessitating a maxillectomy (irrespective of planned procedure based on Brown's classification), had a greater tendency to avoid gaining information, especially if they considered it 'too detailed', with the fear of mental discomfort or dissonance. Many of these highly anxious patients had a tendency to attend pre-treatment consultations alone. Those

patients' who avoided pre-treatment information, more often appeared shocked and unprepared for the gravity of the surgery, especially at the point of their first obturator change.

> *I nearly passed out looking what had to go in my mouth (referring to the obturator) (P12, Class 3b).*

> *I didn't want to hear it. And that's the truth, and I'm not like that but I just didn't want to talk to anybody in there. I didn't even know there was such a thing (referring to the obturator). 'Til he told me he'd take it out, I didn't even know it was in my mouth…I didn't think it was going to be anything like that. Anything I'd dreamt of losing the roof of my mouth (P7, Class 2a).*

3.2.2 Sub-theme: Keen to pursue a curative treatment option

Patients reported they were pursuing surgery in an effort to remove the cancer, highlighting that getting rid of the cancer was foremost in their mind at this early stage in their cancer journey.

> *He explained to me everything, I agreed to everything because I wanted to be alive. He explained to me they would remove, drew a diagram and said he would remove the tumour and there would be a big hole in the hard palate and they would need to put in an obturator. At that time, I had no idea what an obturator would like it. They then explained that it was a denture plate with an extra bit on the top to fill the hole (P4, Class 3a).*

> *I just thought 'it is what it is' just… my son was making his first communion, daughter was doing, they were the first ones to do the transfer exam (P6, Class 2a).*

For some, they wanted as much information as possible and time to process the consequences of treatment to ensure the 'cost' of pursing a cure was 'worth it' in terms of how they could eat, speak and how life would be after surgery.

3.2.3 Sub-theme: How to aid preparedness?

Participants' reported on how the following factors could aid preparedness for surgery, namely, having social support present (close relative) during pre-treatment consultations not only for emotional support but to help update other family members to include dependent children, seeing a 'model' obturator, and for some meeting a patient who had underwent similar surgery.

> *Good to have the wife for moral support and it was only my wife I was talking to at the start as cancer is scary (P4, Class 3a).*

This patient went on to highlight:

> *It would be good to have meet someone before the operation as at that time I'm very worried to myself about what will happen. I know that they are going to remove my hard palate but it would have been better to have met someone who has recovered, it would have been nice to have met someone before (P4, Class 3a).*

The benefits of meeting another patient was offering positive reinforcement and hope at a time of much uncertainty, presenting from a patient's perspective what could be considered a 'new normality' and an opportunity to learn practical ways of managing lifestyle changes to include eating and drinking. On numerous occasions Participant 7 has undertaken the role of an 'expert patient' and her reflections on *how this is very beneficial can be seen in the following quote.*

> *I don't think it's too bad because they've seen me with it in beforehand and I look normal so, you know, their first point of contact with me is, I'm normal. And I speak and I am normal and you wear a pair of jeans and a pair of DM's and you're fit and you're healthy. That's what they see. Em, when that comes out and then the speech (P6, Class 2a)*

Patients also highlighted what they considered were 'essentials, need to know' aspects of the operation in layperson terms to include clear understanding of the anatomical site being removed with teeth plus resulting in a hole in the palate; fitted with an obturator which is best visualized in terms of a model obturator, diagrams or photographs; necessity of learning to take the obturator in and out to clean; greatest impact in the early days often referred to as a 'bumpy start' but things would improve over the following months, to include eating and drinking, speaking, nasal leakage and possibility of altered appearance. Patients reflected on how these details would aid preparedness for this invasive surgery, promote shared-decision making and patient-centred care.

3.3 Main theme: Impact of living with an obturator

The two subthemes are 'functional changes' and 'psychosocial challenges'. The greatest challenges of living with an obturator following a maxillectomy were encountered in the 'early days' and by individuals who had larger resections (according to Brown's classification), adjuvant radiotherapy and those participants experiencing poorer retention and stability of their obturator. Nonetheless, it must be reinforced that for all patients, functional and psychosocial challenges were closely intertwined and cannot be compartmentalised. However, for the purpose of reporting the findings the functional changes will be described first.

3.3.1 Sub-theme: Functional changes

Findings revealed that the main long-term functional changes were issues with eating and drinking, nasal leakage and speech. Other matters reported were paresthesia, notable physical changes to their facial appearance and having the daily routine of obturator maintenance.

> *I have no feeling there, and ##wife## would be shouting at me, "wipe your nose". Just if I was in a crowd, like, because I wouldn't know and it would be coming down there and I'd be too late when I'd know I'd be dripping (P7, Class 2a).*

'Oh! I need a tissue'. And then I'll blow my nose. Even, you know, if you're eating like, Indian sometimes as well, you know, red will come down my nose as well. And then stuff will drip down and then you have to blow your nose and, you know, like the other day, the bits of porridge (P11, Class 1).

Many participants reported how these functional changes were longstanding and became part of their daily life, like the quote above, from a patient who has been living with an obturator for 12 years.

From a long-term survivors' viewpoint, it was important that patients had an awareness that there would be a process of rehabilitation, encumbered with more functional limitations in the first six months following surgery.

It will get better…it was maybe 6 months, like. It took me a long time. It was all liquid for maybe 6 months (P5, Class 2b).

Um, you gradually moved off liquids and onto things like porridge, custard, jelly, ice cream and I stayed on that for about 3, 6 months and I gradually worked through toast. It was probably a year before I tackled a steak but I can do that now (P3, Class 2a).

3.3.2 Sub-theme: Psychosocial challenges

For some, these daily struggles inhibited them eating outside the home, reporting social embarrassment especially as a result of nasal leakage and oral incontinence.

I prefer maybe having most meals in my own home or with friends rather than dining out. Well, just the simple point of the messiness. I'm a messy eater. And I wear a bib and you know it's just better, your own people and their people. Drinking out of an ordinary tumbler or out of a cup, is very messy. Usually ends running down your chin. Makes you self-conscious (P10, Class 3b).

This experience is more typical for patients with larger defects as seen in the following two quotations who both had class 2 and 3 defects.

That was the hard bit. You didn't, maybe at a wedding or something, you know, where you're put around a table. Ach well just embarrassment. You didn't want it, you know yourself, it would turn people's stomach. Especially with the food, I maybe would've choked. You'd choke you see, and when you choked and coughed. The whole lot would want to come out. You maybe would've run to a toilet or somewhere and clean it out (P7, Class 2a).

If we go to the restaurant, it only on a special occasion and I look for a corner to go to as I don't want people seeing me. Every time I eat I need to clean the obturator, as the food goes into my sinuses. Even a little bit is irritating I need to take it out and clean the obturator. When I go out I need to go to the bathroom but there is no privacy as the sinks are shared and you can't remove it in the public. Every time I clean it I need a

lubricant and that's my problem when we are outside the home and I have to wait until there is no one and around in the bathroom and do it very quickly (P4, Class 3a).

Moreover, several patients expressed how eating and drinking difficulties did not only alter and limit their family and recreational opportunities, but also their employment.

It's a very big change to my life, my condition. For example, when I'm eating I isolate myself, even in my work and that is why I've just left my work. Even if there was a party in the office or at Christmas I would not go. At lunch time I didn't go with my co-worker, because every time I would chew the food and the juicy parts of the food would go out my two nostrils. If the fluid goes down the left I do not feel it and it goes down the chin. The right I can, then use a tissue as I can feel it. Even at home I ask my family to eat first and then when they are finished I will eat as I don't want them to see what is happening (P4, Class 3a).

Irrespective of these life-altering changes, he shares that '*I'm still happy that I'm still alive even when I'm isolating myself for eating, after that I can join them again*'.

Others had challenges with employment not directly related to their functional changes but needing time off to recover from surgery and or ongoing appointment over a long timeframe for refashioning of obturators to optimize oral rehabilitation.

The small firm I worked for unfortunately couldn't really take the pressure of me not being there so they ended up letting me go as an employee. It was unexpected and IT firms around XX (town where he lives) aren't very plentiful, so I ended up not getting back into IT. It was disappointing and didn't feel like I had many rights to do anything about either so I just let it go (P1, Class 1).

Patients reported how having this surgery often impacted their self-esteem and confidence and for several people it affected their intimacy with partners. On occasions this was related to how the patient considered the obturator, with P3 (Class 2a) describing it as kissing someone with an *artificial mouth.* For others it was reluctance from their partner as they were afraid of causing hurt or harm.

No, I think he was afraid of hurting me. Em, if we were kissing I would've gone "oh for Christ's sake, catch yourself on". Em, and he'd go "are you sure it's ok? Did they said it was ok?" and I go, "no, will I ask ##Surg##, phone him 'excuse me, is it ok if my husband snogs?'" I think he was afraid in case he hurt my face (P6, Class 2a).

However, others spent time second guessing as to the reason for the change in their intimate relationships and sexual functioning, wondering was it them or their partner.

You know, the love life side of things. That goes out the window as well. I don't know whether it cause of the appearance or they were scared of hurting you. XX (wife) didn't kiss you anymore because your lip's away up, they don't match anymore…. You feel very small. You're inadequate. It goes out the window and then you say to your wife or your partner "is it because of the way I look? Is it because I changed so much? What is it?". It doesn't work

anymore. Your penis doesn't work anymore, you can't get an erection anymore. So it doesn't. XX (wife) feels it's her fault it's not working but it's not her fault. You don't feel attractive to her anymore. This is what my eyes see. She does, she says it doesn't really matter to her but it matters to me. That's my opinion (P2, Class 3a).

Having attended the erectile dysfunction clinic, with trial of medications and injections, followed by psychological interventions aiming to maximise sexual wellbeing, the couple reported ongoing dissatisfaction with their sexual relationship.

Some patients spoke about the unanticipated long-term changes to their hobbies, especially if they played wind-instruments. One participants shared how he used to play the saxophone in a band, but now he plays the drums. Whereas the meaning and emotion associated with the permanent loss of playing the clarinet was much more significant for the following gentleman.

I've never blown a clarinet since. Because of the obturator…wasn't sealed, eh, get the air coming down my nose. That was sickener for me. Well I miss it, and I still miss it. I mean, there were occasions when there would be somebody playing a clarinet or a piece of music that the clarinet is in and I mean it makes you emotional because you know, I could do that and now I feel like I lost that (P8, Class 1).

This male participant went onto share the significance of his loss.

Yes, like a bereavement. Because, although I went to a college, I joined the forces and I was a musician in the forces. And that's how I met my wife. So yes, it's an important part of my life and I miss it (P8, Class 1).

Small lifestyle changes such as even blowing balloons or whistling were also noted.

3.4 Main theme: Stability and retention of the obturator

The stability and retention of the obturator were key determinants of an individuals' long-term quality of life and will be addressed under the following two sub-themes: 'Greater stability – now I can get on with life' and 'Obturators have a 'shelf-life', then 'start to fail'.

3.4.1 Sub-theme: 'Greater stability – now I can get on with life'

An overriding factor in patient's long-term QOL was centred on the stability and retention of their obturator. In reality, as the fit and retention of the obturator improved this often translated into less functional issues such as reduced nasal leakage, with patients reporting improved social confidence.

Brilliant. Brilliant, it's far more secure. That's what I'm saying, I haven't had a leak down my nose. But it's far more secure. I could smile now. A big smile now instead of, you know, half a smile. I'm not worried about this dropping down. Yeah…It's easy, steadier, it's easier to eat (P6, Class 2a).

Most participants reported how they had noticed a change in service delivery, with developments over the years. One of the key improvements was the insertion of implants. Those long-term

survivors who had implants inserted in more recent years, reported how this intervention aided the retention and stability of their obturator, often describing a marked improvement in food choices.

> *Well, you see when they put them new wee screws in there and clipped that one down, I had no bother. Yeah. Once that one was clipped down, I have no bother. They made an awful difference, aye, you have no idea. Oh, I had a steak last night! (P7, Class 2a)*

3.4.2 Sub-theme: Obturators have a 'shelf-life', then start to fail

The reality was that the obturator started to become looser over a period of time, generally reported as five years, with patients describing it as '*past it's sell by date'*. For some of these patients they had six obturators in their life-time and each time they knew exactly what was ahead with multiple trips to the restorative dentistry team to get the '*new one made'*.

Participants were highly complementary of the person-centred service received at the dental hospital by the restorative team. Key factors that were pivotal for participants having ongoing long-term input, was confidence in their team, collaborative approach between the patients and dental team and rapid access to the specialist team when their obturator started to fail.

3.5 Main theme: Coping strategies to aid adjustment

Over time patients and their families developed and utilised various coping strategies to aid adjustment. Encouragingly, most patients reported how they had overcome many of the overt challenging experienced during the immediate recovery phase and they were finding their 'new normalcy' as an acceptable way of living disease-free. Helpful coping strategies are sub-themed as 'social support', 'acceptance', 'positive reframing', 'problem-solving', 'return to work – business as usual' and 'faith'.

3.5.1 Sub-theme: Social support

The positive aspects of social support included coaching, especially with eating and encouraging and providing a degree of confidence for earlier social reintegration. Furthermore, it was apparent that those who had involvement of a partner, with open communication and sharing of the experience from the onset benefited from this relationship.

> *Whoever you're with, be it a he, be it a she, whatever, get your family support network. See that wrap round support? They all need to be involved with you from day one. If you exclude them from day one, then it's as if they're not a part of your life. Do you know XX (husband) sees me the same as he did before I got the surgery done? And the kids do too (P6, Class 2a).*

3.5.2 Sub-theme: Acceptance

Many participants freely acknowledged that the operation was life-changing, but even with this they were 'glad to be alive' and able to participate in important family milestones such as seeing their children graduate or get married.

I mightn't have been here to watch my daughter graduate through two universities. I mightn't have been here to see my son go to university… you know. A lisp is a lisp (P4, Class 2a).

Others adopted a philosophical approach to their adverse situation, which aided their acceptance.

Em, and knowing that it's ok, it's ok if things don't end well. You know, if it can't be cured, that's all ok. And I guess there's something quite liberating about that too, I know it takes that worry and that stress. You know, look, it's not in my hands, it's fine (P11, Class 1).

3.5.3 Sub-theme: Positive reframing & reappraisal

As result of being diagnosed with a life-threatening illness and being a long-term survivor participants shared not only about their increased and richer appreciation of life but also having a new personnel insight and empathy for others in adverse situations. This also include placing less value on what was perceived as material and temporal and more value on important relationships.

See the most important thing? It's positivity and think well, alright ok, I've had it. Now it's gone I have to learn to adjust to this, work around it. It's no big deal. You know, you start wallowing in self-pity, you're finished ….it's a wake-up call. It's a wake-up call for you to embrace life (P6, Class 2a).

Well, life's beautiful. You have no idea how good life is. It's just special, it is special. Aye. I don't worry so much. I still like money, but I don't, it's not God (P7, Class 2a).

3.5.4 Sub-theme: Problem-solving

Many participants demonstrated much resilience, pushing forward to confront their difficulties especially when it came to eating and drinking with 'trial and error' to minimize nasal leakage and increase the range of food choices.

Eh, in the initial six to twelve months, yes but once you've trial and error you can – look, there's now nothing I wouldn't tackle on this side of the mouth rather than that side of the mouth (P3, Class 2a).

Other techniques included goal setting and planning ahead.

3.5.5 Sub-theme: Return to work – business as normal

For those that managed to return to work this was often embraced with positivity, viewed as regaining a sense of control and normalcy.

I need signed off here, I want to go back to work" and she went, "Oh, I don't know" and I said, "you're not listening to me, mentally, I have to feel like me" (P6, Class 2a).

3.5.6 Subtheme: Religion / spirituality

To help cope and accept the long-term impact and post-treatment challenges, a number of patients reflected on the importance of their personal faith.

> *My faith to God and my family helped me accept what was happening (P4, Class 3a).*
>
> *And I'm a Christian so I, you know, left myself to the providential care of the Almighty.. I know that there's a time to go on and a time to die. I'm always very humbled when I think I'm still alive (P10, Class 3b).*

DISCUSSION

This qualitative study has gained insights into the long-term rehabilitation needs from a patient perspective and raised issues regarding information needs to aid preparedness for this life-altering procedure. It is essential that patients undergoing a maxillectomy, reconstructed with an obturator are adequately assessed and well prepared for this life-changing event, to include the long-term consequences.

A key area that unfolded was living with an obturator has a sustained impact on social activities, employment, sexual wellbeing and interpersonal relationships, which was under-discussed prior to surgery. This is of vital concern given the large body of empirical evidence, highlighting that preoperative information and support is predictive of improved post-treatment outcomes (22). Of interest, relatively limited attention has been paid specifically to the informational and support needs of HNC patients, despite the complexity of treatment regimens and challenging recovery process. Of those available (23), findings are similar to this study, demonstrating that most consider they received adequate information about the details of the surgical procedure but unprepared for a number of the unexpected long-term lifestyle changes that occur. This is of vital concern given the large number of people (25-35%), who are known to avoid family and social events after a maxillectomy, reconstructed with a prosthetic obturator (17, 18). The findings from this study could inform the design of a communication tool to aid shared decision-making and preparedness for this ablative surgical procedure.

Another issue this study highlighted was patients and carers often find it difficult imagining life after treatment, valuing opportunities to see how others cope. Patient experiences are central to UK policy and have an important role in supporting shared and informed decision-making and improving health (24). Receiving support from peers in similar situations, and being appraised of patient experiences, both have a central role in facilitating longer-term coping and adaptation.

Optimal retention and stability of the obturator was instrumental to long-term functional ability and social interaction. Previous studies report that greater obturator stability was evidenced when patients are dentate (15, 25). However, it is not uncommon for patients with HNC to have poor oral health, often as a consequence of lifestyle factors and lack of engagement with their dentist, coupled with a heavy burden of dental loss related to their multi-modality treatment for HNC (26, 27). It is therefore imperative that patients are educated about maximising the dental health of their remaining teeth with the proper use of fluoride toothpaste, brushes and dental floss to remove food particles and dental plaque, to optimise preservation of existing dentition, for anchorage and

stability of their obturator.

Furthermore, patients who had dental implants (participants 2,4,6 and 8) viewed this intervention very positively, highlighting a greater degree of satisfaction with the obturator as a result of improved retention and oral functioning. Additional retention also prevents noticeable obturator movement during speech, which improves psychosocial interactions. Given the knowledge, that social activity is highly dependent on good fit and function of the obturator prosthesis, it is important as restorative options and techniques evolve, that the surgical and restorative dentistry team collaborate at the pre-treatment stage to explore how best to aid retention, which may include insertion of implants at the time of resection. Implant-retained obturators should also be considered by the restorative dentistry team for those individuals who are living with poorly retained obturators; however, it is known that adjuvant radiotherapy can negatively impact implant survival (28).

This study, focusing specifically on long-term survivors also revealed two discreet time points when 'fit and function' of obturators are poorest, namely in the immediate period following surgery and when obturators 'started to fail', which was approximately after a 5-year period. This is a significant finding, in that prosthetic obturators have a finite life-span. As more patients survive their cancer, head and neck oncology rehabilitation services will need to resource the requirement for ongoing long-term obturator maintenance.

This study has also provided a window into a group of participants who had more pervasive, long-term issues. This was patients with larger defects, who were previously employed, but unable to return to their work (P2, 4 and 9), who also reported challenges surrounding sexual dysfunction, social isolation, altered appearance and poor self-esteem. This is in keeping with Rogers et al. (9), who noted that patients with larger defects had lower scores for activity, recreation, physical function, and overall QOL. Similarly, Okay et al. (29) reported that stability of the prosthesis was compromised as defect size increased, resulting in poor obturator function and QOL. These patients could possibly be good candidates for surgical microvascular reconstruction. Some of the participants in this study, who mirror the above description, were on a waiting list for a secondary microvascular reconstruction procedure.

As noted earlier, evidence suggests that good obturator retention accounts for improved function and improved social engagement and QOL (7, 8, 9, 10, 11); nonetheless, it is important to emphasise, that this is not a simple unidirectional cause and effect relationship. This in-depth qualitative study unearthed a number of coping strategies, that aided long-term adaption and adjustment, which contributed to improved satisfaction of living with an obturator. These findings have important implications for the design and implementation of post-treatment psychosocial intervention to facilitate long-term adjustment, thus transiting from a life with cancer to a new 'normality', incorporating the impact of cancer and treatment. Based on this study, psychosocial intervention should support patients to redefine self with a focus on confronting change and loss and accepting the 'new normal' and reframing expectations of self and life. Such adjustment focused interventions should also effectively foster self-efficacy, encouraging patients to take ownership of health needs to include daily maintenance of their obturator. Where possible, mechanisms to support return to work and cherished social activities should be fostered, which can

improve coping by signifying minimal disruption by the cancer (30, 31). Furthermore, routine screening for unmet needs with a disease-specific tool such as the Patient Concern Inventory (32, 33) is likely to identify those who benefit for early, targeted support or intervention.

Ensuring rigour

Qualitative researchers use different criteria from those conducting quantitative studies to ensure rigour, commonly referred to as the concept of trustworthiness and has four dimensions: truth-value, applicability, consistency and neutrality (34). Truth-value was achieved by the researcher seeking clarity throughout the interviews when there was a degree of uncertainty as to the meaning of the participant's response, and summarised at the end of each interview to ensure the interviewer's understanding and interpretation weren't different for the patient being interviewed.

Provision of a clear audit trail (35) throughout the conduct of the study, as outlined in this methods section, is also key to ensuring rigour and is the marker by which others are able to judge the relevance of the findings to their own clinical settings. This was enhanced through a reflexive approach to data collection and analysis, complemented by peer debriefing following a number of the interviews between the researcher collecting the data and other team members (two Consultants in Restorative Dentistry) (34). The team also met at key junctures to discuss the findings to ensure consistency and neutrality. Furthermore, in the findings section we have provided a 'thick' interpretation of data, which includes the complexities within this data set (38). We have endeavoured to display the diversity of viewpoints among the participants and have presented findings in sufficient depth to support the development of the themes.

Limitations

There are a number of limitations as well as strengths to this study. As this study was cross-sectional in nature, recruiting participants at least 5 years following their maxillectomy (unlike a longitudinal qualitative study), we have been unable to establish a precise timeline of when challenges emerged or conversely, improved over time. It must also be acknowledged that recruiting participants at least five years from diagnosis, may have led to selective recall of events at diagnosis. However, there is no way of knowing if this happened but from the researcher perspectives, the response of those recruited was especially vivid for this time point in their cancer trajectory. Although there were only 12 participants recruited to this study, the credibility and trustworthiness of the research is evidenced by the depth and richness of the data obtained.

Conclusions

This qualitative study has provided an in-depth understanding of how patients live and cope long-term with a maxillary obturator. Those experiencing the greatest long-term challenges were patients with larger defects of working age, who were unable to return to work. This group of patients should be considered as possible candidates for surgical microvascular reconstruction of their maxillary defect. There is also a need for long-term resourced, rehabilitation pathway for patients with maxillary obturators, as obturators have a finite lifespan, with most needing replaced after five-years. Finally, some patients appear to cope better than others with the emotional impact of living with an obturator. Gaining an improved understanding of the psychology of coping with the aftermath of having an obturator is clearly important, as this can inform psychosocial interventions

to facilitate adjustment for those who are emotionally struggling.

CLINICAL IMPLICATIONS

- Patients should receive adequate pre-operative information about the challenges of wearing and maintaining prosthetic obturators, to include how this can potentially impact their social and personal relationships.
- Optimising function of the obturator prosthesis following maxillectomy is of utmost importance to maximise social engagement and confidence.
- Patients can emotionally struggle long-term following a maxillectomy and should be screened for psychosocial distress and if required, offered tailored psychological intervention.
- Implant retained obturators should be considered to improve retention and stability.
- Prosthetic obturators have a finite lifespan with ongoing maintenance required. Services provided for head and neck oncology rehabilitation should factor in ongoing patient needs in resource allocation.

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Table

Table 1: Participant characteristics

ID	Gender	Age	Marital status	Occupation/ working status	Timeframe since maxillectiomy (yrs)	Brown's Classification	Adjuvant Treatment	Registered with General Dental Practitioner	Smoker at time of diagnosis
1	Male	48	Married	Manuel (builder) / full-time	10	1	No	Yes	No
2	Male	59	Married	Chef / unemployed	5	3a	Radiotherapy & chemotherapy	Yes	Yes
3	Male	69	Married	Retired from textile industry, with part-time job	7	2a	No	Yes	Yes
4	Male	49	Married	Registered Nurse / unemployed	7	3a	Radiotherapy	No	No
5	Male	80	Married	Teacher / retired	16	2b	Radiotherapy	Yes	No
6	Female	58	Married	Registered Nurse / retired	26	2a	No	Yes	Yes
7	Male	77	Married	Lorry driver / retired	25	2a	Radiotherapy	No	Yes
8	Male	69	Married	Sales representative / retired	27	1	No	Yes	No
9	Female	53	Married	Child minder / unemployed	5	3b	No	Yes	No
10	Male	84	Widower	Teacher / retired	14	3b	Radiotherapy	No	No
11	Female	38	Married	Teacher / full-time	12	1	No	Yes	No
12	Female	81	Single	Cook / retired	30	3b	No	No	No