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Young Adults Experience of Appearance-Altering Orthognathic Surgery: A longitudinal interpretative phenomenological analysis

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Abstract

Objective: To gain an experiential account of the processes of change associated specifically with orthognathic surgery.

Design: A qualitative design was used. Semi-structured interviews were carried out with seven participants approximately one week before and six to eight weeks after surgery. The data was analysed using Interpretative Phenomenological Analysis (IPA).

Setting: Participants were recruited from an NHS Dental Hospital.

Participants: Patients aged 16-25 scheduled to undergo orthognathic surgery on both the upper and lower jaws, were purposively sought to participate. Seven participants aged between 18-25 years and who had undergone a bimaxillary osteotomy completed interviews (five females and two males).

Results: Themes were identified in connection with the overall journey of treatment being a right of passage; the treatments role in raising awareness about anomalies in appearance; the initial shock at the changes that followed surgery; the uncertainty about treatment; the impact of actual negative reactions of others; and the role of significant others in the decision making process.

Conclusions: Participants described undergoing a much more complex process of adjustment to change in appearance than has been identified elsewhere within the literature, and the study highlights the nuanced fashion in which both medical and parental communication influence patient expectation and experience of surgery. There is a need to improve communication between clinicians, families, and young adults seeking orthognathic surgery. Further studies are needed to investigate the

processes associated with seeking to change facial appearance resulting from other forms of dentofacial condition.

Key Words: Orthognathic Surgery, Qualitative, Interpretative Phenomenological Analysis, Facial Appearance, Appearance concern, Disfigurement

Introduction

Orthognathic treatment is a combined orthodontic and surgical approach, used to treat malocclusions that are largely the result of a skeletal discrepancy between the upper and lower jaws (Royal College of Surgeons of England, 2013). Orthognathic treatment can be used to treat sleep apnoea, temporomandibular joint disorders, and be used with congenital conditions such as cleft palate. The focus of this study is on orthognathic treatment in connection with congenital skeletal jaw discrepancy not associated specifically with craniofacial conditions.

Combined orthodontic and surgical treatment aims to correct the facial and skeletal discrepancy and improve occlusal function. Orthodontic treatment will often take a minimum of two to three years, as orthodontic intervention is normally required both before and after surgery, with the surgery not normally being carried out until after the patient has stopped growing, usually 16 years' for females and 18 or 19 years' for males. Treatment is provided to adults of all ages, with several studies suggesting that those undergoing the procedure are typically aged in their twenties (Venugoplan et al., 2012).

Pre-operatively orthognathic patients have been shown to have lower facial satisfaction, body image and self-esteem compared to controls (Cunningham et al., 2000; Johnston et al., 2010), but are within the normal range on these factors and on general measures of psychological functioning (Stirling et al., 2007; Burden et al., 2010). Further, the severity of the dentofacial condition associated with considering

orthognathic treatment has not been found to predict psychosocial distress, and this finding is consistent with other studies across a range of other disfiguring conditions (Van Steenberg et al., 1996; Grossbart and Sarwer, 2003; Thompson and Kent, 2001).

The motivations associated with seeking and providing orthognathic treatment has been debated (Royal College of Surgeons of England, 2013). While some studies have shown that primary motives are functional, others have reported that desired improvements in appearance, and associated self-confidence also play a role, and patients (and clinicians) describe multiple reasons for seeking treatment (Burden and Pine, 1995; Williams et al., 2005; Stirling et al., 2007; Royal College of Surgeons of England, 2013). Even where patients do not primarily seek surgery for aesthetic reasons, orthognathic treatment has such a dramatic impact on appearance that the effect on identity requires consideration.

Recently greater consideration has been given to the psychological outcomes associated with orthognathic treatment, and a number of reviews indicate that the majority of patients derive a range of benefits that include, improved self-esteem, reduced appearance concern, and improved quality of life (Hunt et al., 2001; Liddle et al., 2015). There are however reports of a small number of patients that are dissatisfied following treatment (Liddle et al., 2015). In addition there are a number of limitations with the existing outcome studies (such as small sample sizes, and measures that fail to tap into relevant areas of psychosocial functioning), and consequently some caution should be expressed before drawing firm conclusions

about the benefits of orthognathic treatment (Liddle et al., 2015). In addition, it is difficult to draw firm conclusions about the long-term psychological benefits of the treatment due to the lack of longitudinal studies that have provided data for longer than 6 months (Hunt et al., 2001; Liddle et al., 2015).

Alongside the methodological limitations of previous research in this area, there has also been limited use of qualitative methods that could elucidate the experience of treatment in more depth (Liddle et al., 2015). Two studies have used focus groups with patients post-operatively (Santos et al., 2012; Travess et al., 2004), and two further studies have used telephone interviews and focus groups to examine decision-making processes (Broder et al., 2000; Stirling et al., 2007). These studies have reported a large number of descriptive themes associated with decision-making, but they have not investigated the experience of undergoing treatment. Cadogan and Bennun (2011) have carried out an in-depth qualitative study that suggested their sample benefitted from surgery, although they initially experienced challenges in adjusting to the changes in appearance. However, Cadogan and Bennun's sample was heterogeneous and included four patients with cleft lip and palate and one with micrognathia. Most studies have excluded cleft patients or those with craniofacial syndromes due to the differences in treatment course and so it is difficult to interpret the transferability of Cadogan and Brennun's findings to people seeking orthognathic surgery. More recently Sadat-Marashi et al. (2015) examined the perspective of young adults who had undergone orthodontic and orthognathic treatment and found they were generally satisfied despite the difficulties experienced during treatment. They commented on the shock of family and friends in relation to their appearance

immediately post-surgery, the importance of talking to others who had been through the process, and the physical side effects of treatment. Patients were interviewed one to three years after treatment, and so whilst this provides a retrospective account of the process, it does not provide an account of the experience of undergoing the treatment.

Currently, there are no studies that have followed patients through the course of orthognathic treatment. We sought to get close to the individual embodied experience of undergoing this transformative treatment, and this aim is best addressed by a qualitative phenomenological methodology. Consequently in the present qualitative study we chose to use the methodological approach of interpretative phenomenological analysis (IPA: Smith, Flowers, and Larkin, 2009; Larkin and Thompson, 2012). IPA is a method that was designed specifically for the purpose of enabling collection and interpretation of individual experiential accounts. IPA is essentially a case series approach, and the present study sought to gather detailed data from young adults undergoing orthognathic surgery, prior to the commencement of the surgery, and shortly following the surgery. The objective was to gain an experiential account of the processes of change associated specifically with orthognathic surgery in a way that might illuminate the psychological issues involved.

Method

Design

The principles of Interpretative Phenomenological Analysis (IPA: Smith et al., 2009; Larkin and Thompson, 2012) were used to guide both collection and analysis of data. IPA has been widely used within clinical health psychology and has been used specifically in relation to examining adjustment to visible difference (e.g. Hamlet and Harcourt, 2015; Saradjian et al., 2008). It is an approach that enables researchers to get a detailed and theoretically meaningful account of first hand experience (Biggerstaff and Thompson, 2008). As IPA makes use of the researcher perspective, reflexivity was considered throughout the study in order to both enhance the analytic process and guard against researcher bias (Spencer and Ritchie, 2012).

Ethical approval was obtained from Nottingham Research Ethics Proportionate Review Sub-committee and research governance approval from Sheffield Teaching Hospitals NHS Foundation Trust.

Data collection

Participants took part in two semi-structured interviews with the first author. The interview schedules were piloted with two former patients prior to use. Both interviews ranged in duration of one hour to ninety minutes. The interviews were conducted approximately one week before, and six to eight weeks after surgery. The rationale for the timing of the second interview was based on the likelihood that patients would still have a good recollection of their surgical treatment, and would also have recovered sufficiently from the post-operative swelling and discomfort in order to be able to have experience of the permanent changes achieved by the surgery.

The first interview focussed on the participants' motivations for, and expectations of treatment, and consisted of the following five questions (with additional prompts used if necessary): 1) 'Tell me about how you have come to be having orthognathic surgery?' 2) 'How did you go about making the decision to have surgery?' 3) 'What do the people closest to you think about you having this surgery?' 4) 'What do you think things will be like for you after surgery?' 5) 'What do you most want to get out of having this surgery?'

The content of the first interview was examined prior to the second interview being conducted in order to inform the use of specific follow-up questions. The second interview focussed on experience of change, the treatment process, and the perceived reactions of others, and consisted of the following six question areas (with additional prompts used if necessary): 1) 'How have things been since we last met?' 2) 'Can you tell me about any experiences you had whilst going through this treatment that stand out for you?' 3) 'What's different for you since you had the surgery?' and 'Do you feel differently about yourself/the way you look?' and 'How do you feel about changes you've noticed?' 4) 'Thinking back to what you wanted to get out of surgery (prompts from first interview used)... what do you think about that now?' 5) 'How have other people reacted to you since having surgery?' and 'Has having the surgery affected your relationships in any way?' 6) 'How has your experience compared to what you thought it would be like?' and 'How do you feel about having had the surgery looking back on it now and what you've been through?'

Participants and Recruitment

In keeping with IPA methodology purposive sampling was used to obtain a small homogenous sample of participants. Small sample sizes are a requirement for IPA in order to enable an in-depth individual analysis that combines data from individuals with similar characteristics whilst maintaining the idiographic focus that is usually the aim of such studies (Smith et al., 2009).

Patients aged 16-25 who were scheduled to undergo orthognathic surgery on both their upper and lower jaws (bimaxillary osteotomy), in a large NHS teaching Hospital, were purposively selected by a NHS Consultant in Oral and Maxillofacial Surgery (the third author) and invited to discuss the study with the interviewer (the first author).

Patients who had already undergone pre-surgical orthodontic treatment lasting 18-24 months and were ready for surgery were eligible to participate. Patients were not invited to participate if they had any significant health condition. Approximately eight participants were sought for this study and nine participants were recruited. Seven completed both stages of the study and were included in the analysis. One participant chose not to complete the second interview due to personal circumstances and the second failed to attend the follow-up interviews without providing explanation. The participants included in the analysis were five females and two males, aged 18-25 years (mean age 20.9 years). All of the participants were of White British ethnicity with the exception of one female participant who was of British Pakistani ethnicity. All of the participants were living with their parents, with the exception of one male who was living alone. None of the participants revealed experiencing any significant pre-surgery levels of anxiety or depression.

Analysis

Data was analysed using IPA methods as outlined by Smith et al. (2009) and Larkin and Thompson (2012). All interviews were recorded and transcribed. Field notes were recorded after each interview, and the first author maintained a reflexive diary detailing decisions made during the research and analytical process. Both transcripts from each participant interview were analysed together. Each interview was read several times, noting areas of descriptive, conceptual and linguistic importance. Initial themes were noted for each transcript, which were then clustered together into broader themes. Themes from each transcript were viewed together to identify patterns across cases and generate higher order themes and subthemes.

To ensure that the themes were warranted, and that the analysis process had been rigorous, the results of the analysis were audited by the fourth author, who checked the first author's coding process (and records) and reviewed the interview transcripts alongside the reflexive diary (Spencer and Ritchie, 2012).

Results

Despite a range of experiences during the process participants talked about how positive the treatment had been for them, their satisfaction with the care delivered and how it had already made a difference. Six superordinate themes emerged from the data, along with 14 subthemes (Table 1).

Insert table 1 here

The journey of treatment – a right of passage

Participants described treatment as a long process with the majority of participants having been aware of the prospect of surgery from their early teens.

It is a journey isn't it? Because I've been coming for so long. Emily (all names used are pseudonyms)

Anita first remembered a 'problem with [her] jaw' being mentioned at the dentist when she was just seven years old. The idea of treatment being a journey was represented, for example with Anita describing it as a 'roller-coaster of emotions', exacerbated by the long wait for surgery followed by a dramatic and relatively quick change. Prior to surgery John felt it was 'unfinished business' and Emily, Joe and Chloe spoke about wanting to get it 'sorted' and 'out of the way', almost speaking of it as a right of passage.

Perhaps as a result of the young age at which participants first encountered the concept of requiring treatment, they appeared to describe the process as one in which they were not always fully engaged in decision making, and they often portrayed themselves as having a passive role. Consequently there was a degree of expectation that it was going to happen as an almost *fait accompli*

I think because I'd been coming for so long and I wanted my teeth to improve as well I just thought, yeah, I'll go along with it.

I've sort of pushed it to the back of my mind and not thought about it at all.

Emily.

For some the treatment had also become a significant part of their lives and they expressed concern as to what it would be like without contact with the treating team.

It was quite a big part of my life and then, you know, now it just seems like, oh, it's all done now and all that fuss and faff now it's, you know, it's all done now, what do I do with myself? Anita.

The course of treatment and appearance sensitivity

Research has shown that most patients who request surgical-orthodontic treatment do so because of a desire to improve their facial and dental appearance and not as a result of concerns about occlusal function (Burden and Pine, 1995). Appearance change formed part of the motivation for treatment for all of the participants, but even those who felt it was not their primary motive spoke about dissatisfaction with appearance or the idea that surgery would make them look 'better'. Discomfort with appearance was reported as being associated with self-consciousness:

I won't let people take pictures of me or if I do I won't smile or open my mouth and I don't really eat out in public as much as I used to. Charlotte.

Some participants reported the experience of visible difference was associated with, or at least heightened by the treatment process itself. For example, some participants described having been fitted with braces that were more visible than the condition itself. In addition, participants also commented on a sense of difference emerging via the language used in treatment consultations, when aspects of their bite or their

appearance being described as requiring correction or being likely to be improved following surgery.

I think I've noticed it a lot more, since it's been pointed out and that. I think I'm more self-conscious of it as well. Joe

It's the little defects what they point out to you, you know you're sat in that chair and they're like 'this and this' and you're like 'oh'. They said my top lip is a bit flat which I'd never ever noticed it before, and then it was pointed out and then I started noticing it. Chloe.

The initial shock at the changes that followed surgery

Participants described their initial reactions towards their changed appearance following surgery. Joe talked about seeing himself for the first time in the mirror and finding it 'shocking', which was also evident in other participants' accounts. Some experienced distress as a result of this initial shock and the feeling of dissatisfaction with what they saw caused some to question their decision for treatment in the first instance.

I were ugly, I couldn't see it ever getting better, I just thought I were going to be like that all the time, didn't want to go out, I just... hated myself for doing, for putting myself through it. Fiona

Accompanied by the initial shock of the change in appearance participants described experiencing a sense of needing to revise their sense of identity so as to incorporate these changes:

When I look in the mirror and I think 'it's a different person'. Joe.

It's weird you know, looking at yourself thinking, like it's not me looking back at myself. Chloe

Despite the initial emotive descriptions of participants' reactions to appearance change, they all went on to describe 'getting used to it' over time.

Participants also commented on the process of adjustment and noted that self-consciousness did not always spontaneously disappear.

I need to sort of recognise the fact that I don't have to feel self-conscious anymore. John.

Sometimes I'll be sat there and I can feel, it's like before when I bite together I could actually feel that my bottom jaw was sticking out a bit and I still get that feeling and then I look in the mirror just to make sure, yes, it's not there. Joe.

Uncertainty and never being prepared

Participants expressed uncertainty about many aspects of the treatment process.

Before surgery they were uncertain how they would look and feel afterwards and what the experience of surgery would be like.

One of my main worries is, just if I'm unhappy with how I look afterwards. I'm, if I don't like it because it's like I've got to live with it for the rest of my life. Emily.

Some had clear expectations for change they hoped to see, while others were unsure what the outcomes of surgery would be. Participants were aware of the 'trade-off' involved in having surgery, in that there would be some pain and discomfort but this was bearable with the long-term aim in mind.

I just thought I've got to have it done. I just had to convince myself that I didn't really have a choice in it. Because I'd regret it if I would've said no, I know I would have. Chloe.

There was also uncertainty expressed about the need for treatment and participants often contradicted themselves in this respect, for example saying they were 'not too bothered' by their condition but did feel they needed to have the treatment.

It's not debilitating in any way but I do think I can't underplay it because the point that I'm at now is, because I feel as though it's something that does need treatment. John

I'd noticed it but it wasn't a problem for me, but I've come for this treatment and I'm looking forward to the end results now. Joe.

Some participants also felt some disappointment because they had expected an instant result from surgery, whereas their appearance was severely affected by swelling and they still needed to continue treatment, including braces, for several months. Some acknowledged their lack of preparation or avoidance of information before the surgery contributing to their expectations not being accurate, while one participant was explicit about feeling they had not been well enough informed.

I didn't prepare myself I don't think for it. ... I don't think I could have prepared myself more, I just, I pushed it to the back of my mind that I were having it done until the day I were having it done, because I get scared of stuff like that so I should have thought about it. Fiona.

I feel like I've had to find things out for myself. So.... like, up until about five month ago, I only just found out it were gonna change me nose as well. ... I didn't know nowt about that coming through all the years and the process with it. Emily.

Impact of actual negative reactions of others

Several participants spoke about their experiences of bullying, which they felt had occurred as a result of their condition and had a lasting impact.

It were me lad friends who used to say things but then still, they still stick in your mind now. Even though it were when I were at school I still think about it at times. Emily.

Fiona explained that she 'just wanted to fit it' and the difference in her appearance made her stand out from her friends. She went on to explain the perceived benefit of a change in appearance.

I just wanted to fit in. I mean it doesn't bother me what people think but it's just, it's nice to be normal isn't it? Fiona.

As previously discussed, participants were self-conscious as a result of perceived differences in their appearance, and John described the impact he felt this had on how he was viewed by others.

Signs of nervousness or being unsure about anything in particular, regardless of what the reason for that is, erm, can be, er, it can cause people to have a lack of confidence in your ability. John.

Influences of significant others on decision-making

Views of parents were described as being especially prominent in the decision-making process. Chloe and Emily both had a parent with the same dental condition, so felt their views were particularly important, while Joe, John and Anita described their parents encouraging them to have the procedure.

Dad says if I had the chance to have it done on the NHS, he say, I'd have it done. Chloe.

It was mainly my mum that pushed me into it to be honest. Joe.

Several participants talked about their experiences of getting information about the surgery from previous patients, either in person, via a DVD provided by the clinic or on the internet. Finding out about the experiences of others provided valuable reassurance about going through the treatment process themselves.

From seeing a lot of before and after pictures that they've shown me already it does massively improve your appearance. ... there's not any sort of, that don't look as good as they did before. Charlotte

Participants were aware that their condition may not be as noticeable to others as it is to them and some participants experienced others questioning their need for surgery. This difference of opinion could be reconciled if it was felt others understood the decision regardless of their own view.

Most of my friends said 'oh, you don't need it'. Most of my relatives said you don't need it. Apart from my mum again, who said I do need it. ... In the end though, if there is a chance that it's going to get worse it's better to get it sorted now. So in the end they all agreed, sort of, that I'd need it. Joe

Participants talked consistently about the value of support from family and friends. As previously mentioned, this was important in the decision making process, as participants generally felt well supported. Participants valued the practical and emotional support offered by friends and family, particularly in the immediate period post-surgery and spoke of others being unconditionally supportive.

Everyone's supported me and they'd all just think that it's my decision, whatever I decide I want to do. Emily.

It was having my family around me that, you know, helped me through the day. Joe.

The support of the clinical team was also mentioned as a benefit during treatment.

Everybody involved with the treatment has been absolutely fantastic. John.

I think people who work at [dental hospital] who I've been seeing on a regular basis who are very helpful and supportive. Emily.

Reactions and comments from others both before and after surgery were highly valued and participants could be particularly sensitive to these. Some reflected on how visible they felt the problem was to others and how they felt when times it was commented on, or their need for treatment questioned.

Sometimes when they say 'oh, I don't think, you know, I never even noticed that' I think, well, what was the point of me having it done in the first place if nobody really noticed there was a problem there, so I think I went through all that for no reason. Joe.

After surgery the reactions of others were an important indicator of the success of treatment and the degree of change. However, there was also a sense of uncertainty about whether to fully trust the opinions of others.

I felt in myself that I'd be able to tell by their reaction what they really thought and also if I saw someone and they said like 'oh, it looks, oh it looks nice' and they were like a bit hesitant, it made me feel a bit like, 'do they think I've made the right decision?' and 'do I look worse?' Emily

This also impacted on participants' own feelings about change, in some cases validating the decision for treatment. Receiving positive feedback resulted in a confidence boost and made people feel more positive themselves about the result.

I mean they've all said like "even though you were beautiful before it's like, you know, just enhanced your beauty" so have to really, just makes me feel like I'm, you know, a superstar or whatever (laughs), like a model or something. Anita

However, some found the increased attention uncomfortable and were unsure how to react to the focus of others on their appearance.

I felt everybody was looking at me but they weren't, I was a bit self-conscious at first. Joe.

I wasn't frightened so much as , you know, anybody saying 'oh, I liked the way you looked better before' ... just the idea that I'd maybe be scrutinised more than perhaps I was comfortable with. John.

Some participants had the experience of not being recognised and were unsure how to feel about this, particularly when their own perception was that their appearance had not changed as much as the comments suggested.

When one of them said to me "I'm so sorry, I didn't even know it was you until somebody told me at the club later" and I was like I see them all the time and they didn't even realise it was me, which is really strange. So it's definitely changed how I look but I wouldn't say that much. Charlotte.

Participants had to make sense of receiving different opinions from different people, as well as trying to establish their own feelings about the changes in their appearance.

Some people have said I look different and they wouldn't recognise me at all if they saw me, some people think it hasn't changed me much. Emily.

Discussion

This is the first qualitative study to follow patients through orthognathic treatment from pre to post-surgery and the themes derived from the data capture the most salient features of this process for the participants. Some of the themes identified in the existing qualitative research were also found in this study, such as the physical impact of treatment, the initial distress caused by this, the importance of social support, and the need to adjust to changes to appearance occurring during treatment (Cadogan and Bennun, 2011; Sadat-Marashi et al., 2015). However, this study uniquely highlights the extent to which young adults receiving orthognathic treatment may require greater support in taking ownership of the decision to pursue surgery and also in adapting to the changes to appearance that occur post surgery. In addition, they may also require assistance in building social confidence regardless of whether or not surgical treatment is pursued.

In this study 'treatment' was described as having been a major focus in participants' lives; they had been anticipating the surgery for several years and their investment in the process gave meaning to the end of treatment as an important milestone. Some participants felt self-conscious as a result of their appearance and the process of

treatment served to draw further attention to this. For some, the awakening of feeling different had emerged within the context of being observed by healthcare professionals, and this process warrants further close scrutiny and is discussed in more detail below. The period immediately following surgery was reported as difficult due to both the physical and emotional effects of the structural changes achieved.

Parents have an influence on the development of children's understanding of the relationship between self-esteem and appearance and their behaviour can impact on the child's attitude towards their own appearance, intentionally or unintentionally (Rumsey and Harcourt, 2005). Most participants mentioned the significant role their parents played in the decision-making process, which may have contributed to expressions of passivity in the decision for surgery, a factor that has been linked to dissatisfaction with treatment (Chen et al., 2002). Adolescents making decisions about treatment for dentofacial conditions may be faced with conflict between their own views and those of their parents and clinicians (Kapp-Simon, 1995).

Professionals have an influential role in the patient's decision, with the potential to indirectly pressure people to have a treatment that will improve their looks. Patient and clinician understanding may differ in terms of what the improvement will mean and their expectations for treatment. Juggins et al. (2005) showed that orthognathic surgeons rated patients' need for treatment in terms of their facial appearance more highly than patients themselves, which may influence how the offer of surgical treatment is presented. The power imbalance between doctor and patient may also mean patients are more likely to agree, which may be further exacerbated if dealing

with younger patients in more of an adult-child mode than adult-adult, not giving sufficient recognition to the patient's autonomy (Goodyear-Smith and Buetow, 2001).

None of the participants in this study felt coerced in any way by the professionals involved but did describe increased appearance concern as a result of consultations that highlighted abnormalities in appearance. Studies that have attempted to show the impact of viewing 'ideal' facial images on satisfaction with appearance have produced conflicting results. Newton and Minhas (2005) showed that this decreased facial satisfaction but Williams et al. (2008) found no significant impact. However, both studies showed that orthognathic patients had less satisfaction with facial appearance than controls. Patients' may be more sensitive to information about their appearance, especially in adolescence, so the way information is presented should be carefully considered. If the treatment process itself increases patients' dissatisfaction with appearance, this may impact on their motivation for more radical treatment.

Research has shown patients may not make well-informed decisions, as they fail to fully take account of the pros and cons of treatment and the option of no treatment (Stirling et al., 2007). Patients may also be given the appropriate information but choose not to attend to it, which was also highlighted in the present study. This may bear some relation to patients' coping strategies during treatment, as it has been suggested that coping may be on a continuum between avoidant and confrontational styles (Newell, 2000). Whilst confrontational coping would result in seeking out information, avoidance may be prompted by fear of surgery or uncertainty about the

outcomes. It would be useful to assess patients' coping responses prior to surgery, as this may impact on their expectations and their adjustment after surgery.

One of the current participants spoke specifically about the lack of information provided and this was a source of dissatisfaction. There has been emphasis on communication in the literature but lack of research into the relationship between information provision, experience and outcomes of treatment. There is agreement that better, more accurate information is required and this needs to be communicated effectively (Cunningham and Shute, 2009). It has also been suggested that caregivers be more involved in the consultation and preparation for surgery (Derwent et al., 2001). Participants in the current study certainly spoke about the role that had been played by significant others, and as some patients did not fully take on board information given about treatment, the presence of a supportive other could be beneficial.

Previous studies have shown many patients find surgery is worse than expected including severity of swelling, eating difficulties and pain which were all identified by current participants (Williams et al., 2004). Cunningham et al. (1996) found that patients felt technical aspects of surgery were well-explained but almost 25% did not think this was the case for post-surgery side-effects. Evidence suggests patient satisfaction may be increased if the experience was better than expected, but the opposite may be true if it was worse than expected (Phillips et al., 2004). Cunningham and Shute (2009) suggest that optimal results can be achieved if patients are realistic

about what surgery entails and stress that expectations can change during the course of treatment so should be regularly revisited.

Orthognathic surgery has a significant impact on appearance and coping with this was a strong narrative in all of the participants' accounts. Although it is not a purely cosmetic treatment, issues of appearance concern and adaptation to facial change are central to understanding patient experience. Appearance issues in orthognathic surgery tend to be viewed from a biomedical perspective. The complex nature of the relationship between appearance and self-concept, including adaptation to dentofacial deformity and adjustment to appearance change following treatment, requires further investigation. Indeed, there may be some parallels to be drawn from our findings and other similar groups such as those from craniofacial population, and in-depth studies examining this with such populations are needed. Models of stigmatisation and self-objectification may be particularly useful in framing our understanding of how people come to have concerns about their appearance, for example via internalisation of dominant stereotypes of attractiveness and over focus on the aesthetic meaning of conditions of the jaw and face (Clarke et al., 2013; Thompson, 2012).

The role of psychology is raised in a number of studies in relation to supporting patients during the treatment process but less attention has been paid to the potential to enhance or provide an alternative to medical treatment for issues such as appearance concern, social anxiety and self-esteem problems. It has been suggested that clinicians may fear negative reactions from patients if they suggest referral to a

mental health professional (Juggins et al., 2006), but contrary to this a study of patient views showed that 95.2% would welcome this input (Ryan et al., 2009).

There is a lack of attention to adjustment to appearance change in the orthognathic literature and it is often assumed that if patients report satisfaction with treatment, this equates to successful adjustment. However, as was captured in the current data patients may express recognition of improvement and satisfaction with the process whilst still coming to terms with the change. Participants reported distress in relation to their appearance immediately after surgery and although their emotional and physical well-being had improved quite rapidly, they placed emphasis on the continued process of adjustment. Adjustment to appearance change in the aftermath of surgery can be a long process and changes need to be incorporated into self-image (Lazaridou-Terzoudi et al., 2003). Participants talked about needing to adapt and build confidence following surgery, in the immediate aftermath and the longer term. This suggests correction of facial discrepancy may not confer an immediate amelioration of all difficulties associated with appearance concern. Previous research has reported that negative body image persists for orthognathic patients, although at a lower level, after surgery (Rispoli et al., 2004). Greater insight into the development and maintenance of appearance concern may help to predict vulnerability to distress after surgery and therefore provide the opportunity to intervene in order to improve patient outcomes.

Participants commented that despite some negative experiences they would go through treatment again, which has been used as an indicator of satisfaction in quantitative studies (Al-Ahmad et al., 2008). However, Oland et al. (2011) highlight

patients may be more likely to say this whilst still receiving positive attention after surgery. Patients may also be more likely to report being satisfied due to not wanting to criticise professionals, which links again to the issue of power in this relationship (Williams et al., 2004). This resonates with the current participants, as one person commented they did not want to appear 'ungrateful' and another said they felt "an obligation thanks to all the work that everybody had put in here, to be positive about it", in the context of advising a prospective patient.

The importance of improving communication between patients and clinicians has been highlighted by this study, as well as in much of the previous literature. There has been insufficient exploration of how this can be achieved and what impact it can have on patient outcomes. Conversational analysis of consultations with patients could provide huge insights into patients experience of having an 'orthognathic condition', and the choices they make with regards to treatment. Certainly, the results of this study suggest more could be done to improve patient experience, as treatment has the potential to be a stressful process. Effective communication of information has implications for decision-making, expectations of treatment, emotional and physical preparation for surgery and its outcomes. Participants valued additional information sources such as an informative DVD and contact with former patients. Discussions with other patients could be offered routinely, rather than on request, in addition to high quality written and verbal information (Derwent et al., 2001). Further the use of online tools and resources to describe the patient journey (and choices) should be routinely used, so as to enable patient's time to consider the intricacies that are involved in treatment. Some such resources already exist such as the British

Orthodontic Society: 'Your jaw surgery' webpages (see <http://www.bos.org.uk/Public-Patients/Your-Jaw-Surgery1>).

Whilst attention was paid to ensuring the validity of the data by keeping clear records of the analytic process and considering reflexivity to examine our own positions in relation to the data are study has a number of limitations. It was made explicit that the interviewer was not part of the clinical team, nevertheless, participant responses may have been influenced by the interviewer being known to be a clinician (a NHS clinical psychologist) and therefore being perceived to be part of the treating healthcare system. Whilst our study uniquely used a longitudinal qualitative design and deliberately focused on experiences following physical recovery it was limited to a short follow-up period. Further studies are needed with longer follow-up periods or/and multiple follow-up periods in order to ascertain patients longer term reactions and experience. The nature of this type of qualitative research does not allow generalisation, however, our clear description of the sample should facilitate some transferability of our findings. However, we might have collected further demographic information on our participants such as their social economic status and relationship history. Finally, as the sample deliberately consisted entirely of younger adults our findings clearly have less transferability to older patients.

Psychologists have the potential to make a significant contribution to orthognathic care by assessing suitability for surgery, supporting patients during decision-making and providing psychological interventions (Morris, 2006). The severity of physical discrepancy does not predict the level of distress caused so there are other internal

factors contributing to adjustment (Van Steenbergen et al., 1996). Conceptualising the person's difficulties as purely physical can mean that psychological factors related to adjustment and well-being are overlooked. There is potential to intervene with these factors as well as intervening medically, by exploring beliefs about appearance and addressing issues such as social anxiety and low self-esteem. There is evidence for the value of interventions such as social skills training and cognitive behavioural therapy, which can be cost-effectively delivered through self-directed and web-based programmes (Clarke et al., 2013).

Conclusions

Participants described uncertainty and mixed feelings throughout the process of treatment. In particular, their responses indicated a complex process of adjustment to appearance change, both emotionally and physically. The over-reliance on quantitative methods in this area has meant this complexity has not been fully appreciated. Further studies are clearly required to examine the influence of others (parents, family, clinicians) on the psychological functioning of young people living with conditions that might be subject to orthognathic surgery.

Orthognathic surgery can undoubtedly provide significant benefits to patients, but this is rarely a straightforward process and more could be done to improve patient experience via clearer communication and use of other strategies to improve social confidence.

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Table 1 – List of themes and subthemes derived from the data.

Themes	Subthemes
<p>The journey of treatment – a right of passage:</p> <p><i>'it is a journey, isn't it?'</i></p>	<p>Treatment as a hurdle to overcome</p> <p>Engaging with the decision</p> <p>End of treatment and moving on</p>
<p>The course of treatment and appearance sensitivity</p> <p><i>'it was pointed out and then I started noticing it'</i></p>	<p>Increased awareness of appearance as a result of treatment</p> <p>Impact of being self-conscious about appearance</p>
<p>The initial shock at the changes that followed surgery</p> <p><i>'It's not me looking back at myself'</i></p>	<p>Distress and shock due to appearance change</p> <p>Appearance change and identity</p> <p>Adjusting to appearance change</p>
<p>Uncertainty and never being prepared:</p> <p><i>'Until you've seen the change, you don't really believe it's going to happen'</i></p>	<p>Knowing what to expect from treatment</p> <p>Experience as compared to expectations</p>
<p>Impact of actual negative reactions of others:</p> <p><i>'Even though it were when I were at school I still think about it at times'</i></p>	<p>Sense of difference – bullying and the desire for 'normality'</p> <p>Impact of the reactions of others</p>
<p>Influences of significant others on decision-making</p> <p><i>'So in the end they all agreed, sort of, that I'd need it'</i></p>	<p>Influence on decision making</p> <p>Support during treatment</p>

