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Exploring People's Experience of Appearance-Altering Orthognathic Surgery

Morna Liddle

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Declaration Page

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Structure and Word Counts

The literature review has been prepared for the Cleft Palate Craniofacial Journal, in accordance with their guidance for authors (Appendix II). The research report has been prepared for Social Science and Medicine, in accordance with their guidance (Appendix III).

Literature Review	7913
References	1499
Appendix	1408
Research Report	11,884
References	1533
Appendix	3810
Total (excluding references and appendices)	19,797
Total (including references and appendices)	28,047

Summary

A review of the literature reporting psychosocial outcomes of orthognathic surgery has generally shown that patients experience positive gains. These are discussed within five main areas – appearance-related outcomes, self-concept, social functioning, satisfaction with treatment and mental health. The influence on outcomes of gender, age and severity are discussed, as well as the stability of outcomes over time. There are considerable conceptual and methodological issues with the study designs such as the differing definition of concepts and wide variety of measurement approaches used, which makes comparison across studies difficult. Areas for future research, including the role of psychological support for patients, are discussed.

Qualitative exploration of the experience of seven people undergoing orthognathic treatment was undertaken. Participants were each interviewed before and after surgery and this data was analysed using interpretative phenomenological analysis. Four major themes were reported which describe the experience of treatment as a long and at times challenging process, the role of appearance issues in their identity, the influence of the views of others and their experiences of uncertainty. The contribution of these results to the understanding of psychological theories of appearance is discussed and avenues for future research, such as exploring clinician-patient communication, are put forward.

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Psychosocial Outcomes in Orthognathic Surgery: A Review of the Literature

Abstract

Objective: To identify and critically appraise the literature on the psychosocial outcomes of orthognathic surgery, reflect on the clinical and theoretical implications and suggest avenues for future research.

Design: A search of the literature was completed using the databases Web of Science, Medline and PsychInfo to identify English language articles published between January 2001 and March 2011 that reported a measure of psychosocial functioning post-treatment.

Results: Of the 699 articles identified, 31 were eligible for inclusion in the review. The studies reported improvements in areas such as satisfaction with facial appearance, self-confidence, self-esteem, anxiety and social functioning. Small percentages of patients were left dissatisfied or had difficulty adjusting to appearance change despite the absence of treatment complications. Gains in psychosocial functioning were maintained over several years and satisfaction increased over time.

Conclusions: There are consistent positive outcomes reported as a result of orthognathic surgery but conclusions are limited by methodological issues in study design such as small sample sizes, limited use of control groups and choice of measures. Further exploration is required of processes such as adjustment to facial change using broader theoretical frameworks and the role of psychological support during treatment.

Introduction

Orthognathic surgery is a specialist branch of oral and maxillofacial surgery, used in combination with orthodontic treatment to correct dentofacial deformities that cause misalignment of the jaw (British Association of Oral and Maxillofacial Surgeons, 2011). Orthognathic surgery is considered a relatively safe and effective medical treatment but there has been increasing attention drawn to the psychological aspects of patient outcomes and well-being. Motivation to undergo orthognathic treatment may result from desire to improve appearance and/or functional difficulties, such as pain and difficulty chewing (Stirling et al., 2007). Malocclusion (misalignment of upper and lower teeth) can also indirectly impact on patients' psychological and social functioning (Zhang et al., 2006). However, success of treatment as determined by clinicians does not always equate to patient satisfaction (Posnick and Wallace, 2008). Orthognathic treatment is carried out over a period of up to three years so is time-consuming and costly. In the current health care climate it is essential to assess the quality of research evidence. Systematic reviews allow evidence to be brought together in an accessible way to determine the effectiveness of interventions and identify areas for future research (NHS Centre for Reviews and Dissemination, 2009).

There have been two major reviews relevant to the psychological outcomes of orthognathic surgery. Hunt et al. (2001) carried out a systematic review to address whether orthognathic surgery results in psychosocial benefits, what these benefits are and whether they are transitory or long-term. Only one study used a control group and the validity of this was questioned due to the controls having untreated

dentofacial deformities. A range of measures were used across the 29 studies, often not validated or designed for this population and providing little consistency across studies. A range of psychosocial benefits were demonstrated by the studies but the authors were critical of the level of scientific evidence used to support these findings. They concluded that well-controlled long-term follow-up studies were needed, as well as increased consistency in the measurement of psychosocial outcomes. This review was rigorous in its approach and provides a thorough summary of the literature but lacks discussion of the theoretical or clinical implications of its findings.

A more recent review took a very broad focus, examining all literature relevant to psychological well-being in patients before, during and after orthognathic treatment (Alanko et al., 2010). This review looked at papers published from 2001 onwards but offers no rationale for this selection criterion and makes no reference to the work of Hunt et al. (2001), despite its direct relevance. It is a more descriptive review with limited critique of the research and does not discuss clinical or theoretical implications of the evidence, nor relate it to previous research in the area. Therefore, there is a need to revisit the review carried out by Hunt et al. (2001) and provide an up-to-date synthesis of the research evidence relating to the psychosocial outcomes of orthognathic surgery.

Aims of Current Review

This review will consider how research over the last decade has addressed the methodological weaknesses in previous research as identified by Hunt et al. (2001) and informed the understanding of the psychosocial impact of orthognathic treatment. For the purposes of this review psychosocial outcomes are defined as those relating to any aspect of emotional and social well-being. Therefore, studies will be identified that have examined patients' psychosocial functioning following treatment. This review will critically appraise the available research, reflect on its clinical and theoretical implications and suggest avenues for future research.

Method

A literature search was carried out using the databases Web of Science and MedLine via Web of Knowledge and PsycInfo and Medline via OvidSP to identify eligible articles published between January 2001 and March 2011. The following search terms were used, with the Boolean operators AND and OR used to combine terms – *orthognathic, surgical, surgical-orthodontic, surgery, jaw, psych*, psychological, psychology, psychosocial, social, emotion*, adjustment, satisfaction, self-esteem, anxiety, depression.*

Articles published in English were included if the study used some measure of psychosocial functioning post-treatment. All methodological designs were considered with the exception of reviews and single case studies. Articles were excluded if they related to orthognathic treatment for dental conditions other than

malocclusion, e.g. cleft palate, if they only studied patients' psychological functioning pre-treatment, or if they were focussed only on orthodontic treatment. Data was extracted from full text articles on a number of variables and entered into a data extraction table. This facilitated comparison between studies on sample size, data collection methods, data collection points, length of follow-up, use of control groups and psychological outcomes reported.

Results

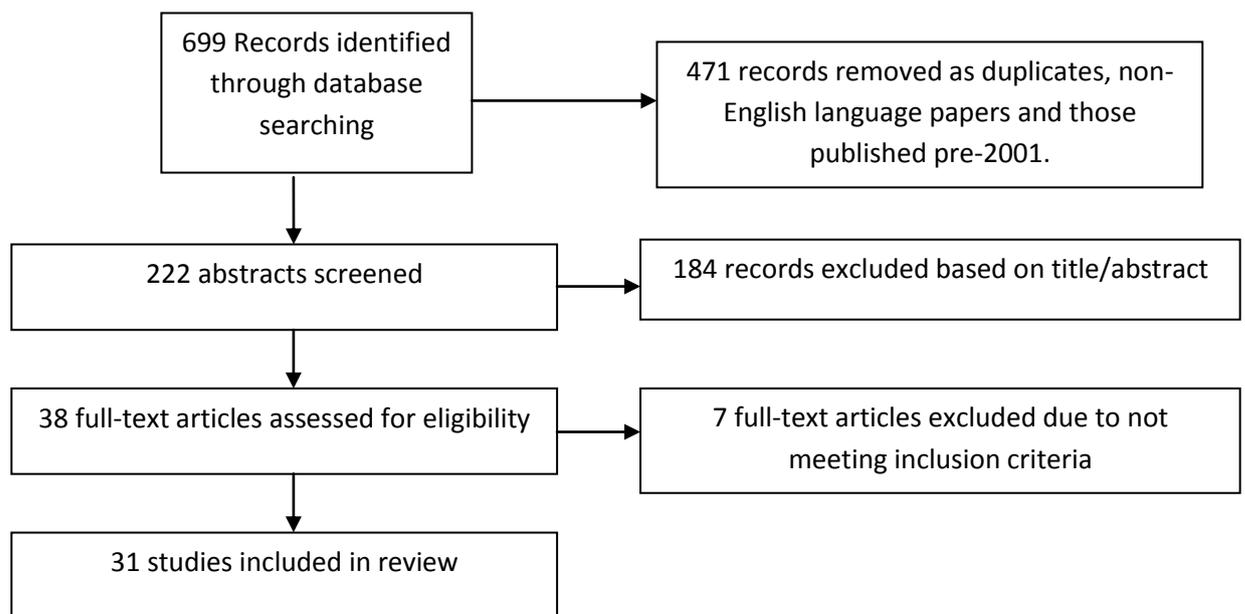


Figure 1 – Flow diagram to show process of study selection

Searching using Web of Knowledge (WoK) and OvidSP yielded a total of 699 results (427 from WoK, 272 from OvidSP), from which duplicates and papers not published in English were removed. The search was then limited to articles published from 2000 onwards, as previously discussed, leaving a total of 222

records. The abstracts of 222 articles were reviewed and 184 were excluded due to not meeting the inclusion criteria. A pilot was carried out for the inclusion/exclusion of articles based on abstracts. Of the 222 abstracts obtained from the initial search, 10 were selected at random and reviewed against the criteria by both the lead researcher and the academic supervisor (AT). This identified a high level of agreement between the two, establishing the utility of the criteria for selection of articles to review in full.

Full-text versions were obtained of the remaining 38 articles and these were reviewed for suitability and the references of these papers were also examined. No additional papers were identified and a further seven were excluded due to not meeting the inclusion criteria, leaving 31 articles eligible for the review, which reported the results of 28 different studies. A summary of the reviewed studies can be found in Table 2 (Appendix A).

The studies utilised a range of methodological designs including prospective (n=17), retrospective (n=9) and cross-sectional (n=5) studies. Common themes can be found throughout the literature in terms of the psychosocial outcomes described. These will be discussed here under the headings appearance-related outcomes, self-concept, social functioning, satisfaction with treatment, mental health and additional factors influencing outcomes. The stability of outcomes over time will also be discussed with reference to studies that have used longer follow-up periods.

Review

Appearance-related Outcomes

Rates of reported improvement in facial appearance vary across studies but are generally high, ranging from 57%-96.6% (Zhou et al., 2001; Phillips et al., 2004; Williams et al., 2004; Modig et al., 2006; Palumbo et al., 2006; Pahkala and Kellokoski, 2007; Espeland et al., 2008; Turker et al., 2008; Kim et al., 2009). The lowest percentage found may be partly attributable to the time patients were surveyed, just four to six weeks after surgery (Phillips et al., 2004); whereas other studies used longer follow-up periods of at least six months post-treatment. In a study where 100% of participants were satisfied with the aesthetic improvement (n=31), the authors speculated this was a result of them all having relatively severe skeletal deformities and therefore greater change in facial appearance following surgery (Siow et al., 2002).

A variety of measurement approaches have been used to assess appearance-related outcomes including validated questionnaires and those designed by authors. Using a questionnaire developed by the authors, Derwent et al. (2001) reported that 25% of their 45 patients rated themselves as unattractive before surgery but none did afterwards. Similarly, their perception of dental appearance improved, with 62.5% considering this unattractive before but only 2.5% reporting the same after surgery. Rustemeyer et al. (2010) also found that patient ratings of facial aesthetics improved significantly from pre to post-op.

The degree of change in appearance has received some attention. Zhou et al. (2001) found that 96% of their sample (n=94) noticed marked changes in appearance, with 39% considering this change 'extreme'. Phillips et al. (2004) found that 24% of patients expected more improvement in their appearance than they got, but for 44% it was as anticipated.

A questionnaire developed by Kiyak et al. (1982) for use with this population examines problems with oral function, general health, appearance and interpersonal relationships. Linear improvement has been shown across time up to 14 years post-treatment in all four areas, with appearance the only domain to improve rather than worsen in the immediate post-operative phase (Lazaridou-Terzoudi et al., 2003; Al-Ahmad et al, 2008; Narayanan et al., 2008). In studies using control groups, patients were shown to achieve higher scores than non-patient and pre-treatment control groups after treatment (Lazaridou-Terzoudi et al., 2003; Narayanan et al., 2008).

The Orthognathic Quality of Life Questionnaire (OQLQ; Cunningham et al., 2000) consists of four domains – oral function, facial aesthetics, social aspects and awareness of dentofacial appearance. This has been used in prospective studies to show significant improvement over time for facial aesthetics (Azuma et al., 2008; Lee et al., 2008; Al-Ahmad et al., 2009; Choi et al., 2010). Whilst Azuma et al. (2008) and Lee et al. (2008) did not find a significant improvement on the awareness of dentofacial appearance domain, Al-Ahmad et al. (2009) did find this

significant. They were able to compare patient scores with those of pre-operative patients, as well as those who declined treatment and dental patient controls. The post-treatment group did not differ significantly from the control groups but all groups had significantly better scores than the pre-treatment group. Lee et al. (2008) showed that although the overall OQLQ score had not changed significantly at six weeks post-op, the scores on the facial aesthetics domain were significantly improved even at this early stage (ES = 0.54), but with a smaller effect size than at six months (ES = 1.01).

The Derriford Appearance Scale (DAS-59; Carr et al., 2000) assesses distress and dysfunction that result from body image disturbance. Sadek and Salem (2007) used three subscales of the DAS-59 in a sample of 120 patients – general self-consciousness of appearance, social self-consciousness of appearance and negative self-concept. Overall the DAS-59 showed improvement in quality of life for 84.2% of participants, with statistically significant improvements on each of the subscales. However, there is lack of clarity in the methodology; it is stated that the DAS-59 was only carried out post-surgery but significant difference between pre and post-surgery scores was reported.

Rates of dissatisfaction with appearance changes are rarely directly reported so it is difficult to know if participants who did not report satisfaction were actively dissatisfied or simply had a neutral response to the changes. Zhou et al. (2001) reported that 4% of patients felt their appearance was worse after treatment

(n=94). Pahkala and Kellokoski (2007) found only two patients (n=82) responded 'yes' when asked if they had difficulty adjusting to their changed appearance and Palumbo et al. (2006) similarly found only one of 30 participants expressed any difficulty. However, Turker et al. (2008) reported 23% of their sample of 30 female patients had problems getting used to their post-operative appearance.

Patients report improvement in their facial appearance after surgery, including feeling more attractive, and this increases over time. Improvements are reported by patients as little as four to six weeks after surgery, despite post-operative swelling and discomfort. However, there are still small numbers of patients reporting dissatisfaction with appearance and/or difficulty adjusting.

Self-concept: Self-esteem, Self-Confidence and Body Image

There are consistent reports among studies of improvements in general self-concept and more specifically self-esteem, self-confidence and body image. Oland et al. (2011) carried out a prospective study of 118 participants with a control group of 47 people recruited via acquaintances of the participants. This is one of few studies to use a 'true' baseline, i.e. before the start of any pre-operative treatment, and a follow-up was carried out up to 36 months after completion of all post-operative treatment. The Problems with Oral Function questionnaire (Ostler and Kiyak, 1991) showed statistically significant improvement over time on all items and each of the subscales - self-concept and social interaction. In comparison to the control group, patients had significantly lower self-concept at

baseline but higher self-concept than controls at follow-up. Overall 88.1% of patients showed improvement in self-concept but 5.9% experienced a negative change. Those with social and appearance-related motives tended to have a greater improvement in self-concept; more so the more their motives had been fulfilled. Increase in self-concept was also correlated with increased satisfaction with treatment.

From this sample 78% completed the Millon Clinical Multiaxial Inventory III (MCMI-III: Millon and Davis, 1997) at least 24 months after the end of treatment (Oland et al., 2010). Participants with a self-defeating or avoidant personality pattern had significantly lower self-concept both before and after treatment. However, patients showed significant improvement in self-concept regardless of MCMI-III scores. This study makes the assumption that personality patterns are stable and would not be affected by treatment, but it would have been valuable to establish this by administering the measure before and after treatment.

The most detailed retrospective study in this area used the Fitts Tennessee Department of Mental Health Self-Concept Scale (Fitts, 1965) with a sample of 117 post-surgery patients, plus two control groups consisting of 39 waiting list controls and 92 age-matched non-patients (Lazaridou-Terzoudi et al., 2003). All groups scored in the intermediate range for self-concept and body image but both patient groups scored significantly lower than the non-patients. The post-surgery group had lower self-concept and facial body image than the non-patients despite

being at least 10 years post-surgery and reporting few problems. Similarly, Rispoli et al. (2004) found that although body image improved significantly post-operatively, negative body image was still apparent, but at a lower level, after surgery. This suggests that some negative impact of dentofacial deformity may still exist after surgical correction.

Gerzanic et al. (2002) applied the Body Image Assessment Questionnaire (Strauss et al., 1983) to 100 patients to show significant improvements in the subscales 'attractiveness/self-confidence' and 'insecurity/concern' at both six weeks and six months post-surgery. Lazaridou-Terzoudi et al. (2003) also used a body image questionnaire (Secord and Jourard, 1953), which showed facial body image was higher for post-surgery patients than those awaiting treatment but not as high as non-patients' ratings.

There is little data specifically on self-esteem and only one study using a validated measure; the Rosenberg Self-Esteem Scale (Rosenberg, 1965). This showed minimally statistically significant improvement six months after surgery and only for female patients (n=29) (Nicodemo et al., 2008a). A second study asked 30 participants whether their self-esteem improved following surgery, to which 66.6% responded positively (Palumbo et al., 2006).

Several studies have shown gains in self-confidence, all using percentage responses so statistical significance is not provided. Derwent et al. (2001) found

that the percentage of patients rating themselves as lacking in confidence decreased from 50% before surgery to 5% 6-24 months after surgery. The percentage of participants rating themselves as 'very confident' rose from zero to 20%. Zhou et al. (2001) reported 67% of their subjects felt more confident, but 9% reported feeling less self-confident following treatment, and Turker et al. (2008) had a similar result of 63% increasing in confidence. Zhou et al. (2001) also found that 49% reported a positive influence on their personality while 12% felt it had a negative impact, but this question is ill-defined so biased by patient interpretation.

Both Rustemeyer et al. (2010) and Williams et al. (2004) report large percentages of participants to have increased self-confidence (67.5% and 81% respectively) but required only a yes/no response in their questionnaires. Therefore, participants did not have the opportunity to give a neutral response or specify the degree of change occurring. In a study of 82 participants Pahkala and Kellokoski (2007) stated that 45% felt treatment had a positive effect on self-confidence when asked 'have you noticed any change in your self-confidence?' Perhaps the slightly lower rate of improvement is a result of dependence on participants who answered 'yes' to specify whether this change was positive. Siow et al. (2002) assumed patients would experience increased self-confidence and only asked participants to rate satisfaction with improvement. Of the 31 participants, 68% reported being satisfied with improvements in self-confidence.

There is some discrepancy in results for change in self-concept; while some patients exceeded scores of control subjects post-op, other studies showed their samples still scored lower than controls several years later. Gains in self-confidence and self-esteem are reported more consistently for large percentages of patients. However, there are issues such as inadequate definition of concepts, assumptions made about the direction of change and simplistic use of yes/no response questions. There is also limited use of validated measures that would determine statistical significance of change.

Social Functioning

Social outcomes have received less attention, in part because social functioning is rarely a principle motivation for treatment. However, measures used in several studies include subscales relating to social functioning. It seems reasonable that changes in areas such as self-confidence and satisfaction with appearance may impact on social life and interpersonal relationships, areas that are often reported as being disrupted by a disfigurement (Thompson and Kent, 2001).

Oland et al. (2011) found a significant improvement in social interaction as measured by the Problems with Oral Function Questionnaire (Ostler and Kiyak, 1991). Social interaction improved for 57.6% of people, but 22% had decreased scores. In addition, when social motives were prominent satisfaction was lower, but social motives correlated with improved self-concept and when appearance motives were fulfilled there was increased improvement in social interaction.

The social interaction, communication, recreation and pastimes elements of the Sickness Impact Profile (Bergner et al., 1981), and social activities domain of the Oral Health Status Questionnaire (OHSQ: Kiyak et al., 1984) have been shown to improve significantly from pre-op to two years post-op, which is maintained at five years (Motegi et al., 2003).

The social disability domain of the Oral Health Impact Profile (OHIP: Slade, 1998) showed that patients did not have any social disability following surgery and reported few problems overall, but lacked a pre-operative score for comparison, so this is not necessarily an improvement (Modig et al., 2006). A questionnaire designed by the authors showed 72% of participants felt more secure in the company of others (n= 32).

Overall the OQLQ (Cunningham et al., 2000), which includes a social aspects domain, has shown significant improvement at six weeks and six months post-treatment (Choi et al., 2010). Studies which reported individual domain scores showed a significant improvement on social aspects post-treatment (Azuma et al., 2008; Lee et al., 2008; Al-Ahmad et al., 2009). Similarly, the communication/social relations scale of the Subjective Oral Health Status Indicators (Locker, 1988) showed significant improvement over time from pre to post-op (Azuma et al., 2008). A questionnaire originally designed by Kiyak et al. (1982), as mentioned previously, includes an interpersonal relationships subscale. Three studies have shown linear improvement from pre to post treatment and up to 14 years post

treatment. When compared, patients scored higher than control subjects after treatment (Lazaridou-Terzoudi et al., 2003; Al-Ahmad et al., 2008; Narayanan et al., 2008). Nicodemo et al. (2008b) found significant improvement in the social domain of the Short Form Health Survey (SF-36; Ware and Sherbourne, 1992) at six months post-op but Al-Ahmad and colleagues (2009) found the improvement in this domain was not significant using an average follow-up period of 21 months.

Using an idiosyncratic questionnaire with 94 participants Zhou et al., (2001) found that after treatment participants felt more comfortable eating with others (53%), reported a positive influence on relationships with the opposite sex (49%), social activities (54%) and upon their 'personal lifestyle' (49%). The term personal lifestyle is not defined so it is unclear how participants may have interpreted this. Similarly, 38% said they had better jobs but it was unclear if they were indicating this was a direct result of treatment. Espeland et al., (2008) asked participants about relationships with family/friends and colleagues and found that 20% felt treatment had a great impact but 44% felt there was no effect. Improvement in social life was reported by 33% of Williams' et al. (2004) 327 participants in response to a yes/no question. Phillips et al. (2004) found that four to six weeks after surgery less than 15% of patients reported anything more than mild problems with social functioning.

Overall studies are able to demonstrate positive outcomes in a variety of areas of social and interpersonal functioning. However, it is difficult to synthesise this

information effectively due to the wide range of questionnaires used and concepts measured.

Satisfaction with Treatment

The majority of studies have included some measure of patient satisfaction with treatment outcome (Table 1).

Table 1 – Summary of Satisfaction Data (missing values indicate data not collected/specified)

Study: First Author and Year	Satisfied with treatment (%)	Dissatisfied with treatment (%)	Would have treatment again (%)	Would recommend treatment to others (%)
Derwent et al., 2001			80	
Zhou et al., 2001	92	8	81	86
Chen et al., 2002	94.5	-	86.3	90.4
Phillips et al., 2004	86		71	5
Modig et al., 2006	91			
Palumbo et al., 2006	100		80	
Pahkala and Kellokoski, 2007	73		84	
Sadek and Salem, 2007	92.5	7.5	-	-
Al-Ahmad et al., 2008	76.6	-	80	
Espeland et al., 2008	92	8.3	88.4	-
Lee et al., 2008				81
Turker et al., 2008	93		63	70
Kim et al., 2009	85.3	5.9	-	-
Oland et al., 2010	90.2	4.3	-	-
Rustemeyer et al., 2010	75			73
Oland et al., 2011	87		65	71

Levels of satisfaction are generally high, with percentage of participants satisfied ranging from 73%-100% (as shown in Table 1). Zhou et al. (2001) measured satisfaction immediately after surgery and 24 months later, showing improvement over time from 75% to 92% of patients satisfied. Rispoli et al. (2004) also showed that satisfaction improved significantly over time, as measured at one week, one month and three month follow-ups.

The percentage of patients who would re-elect to have treatment is consistently high, ranging from 63%-88.4% and between 70% and 90.4% would recommend the treatment to others (Table 1). Rates of dissatisfaction reported have ranged from 4.3%-8% (Table 1). Kim et al. (2009) stated a number of their patients were dissatisfied as a result of financial difficulties in paying for treatment, but it is unclear whether this was specified by participants themselves. Espeland et al. (2008) reported that 8 participants stated their dissatisfaction was related to appearance but no further detail is given.

Studies looking in more depth at satisfaction have reported interactions with other factors, such as linking increased severity and more realistic expectations to higher satisfaction (Chen et al., 2002). Higher levels of satisfaction have also been associated with degree of motive fulfilment and related to type of motive (Oland et al., 2011). Al-Ahmad et al. (2008) divided patients into two groups, 'very satisfied' and 'less satisfied'. Of the less satisfied group 41% reported more problems than they expected after surgery compared to only 21.7% of those very satisfied.

Although satisfaction is consistently shown to be high and to increase over time, there is a great deal of variation in how this is defined and measured, making comparison of studies difficult. Participants are rarely asked to qualify their ratings so there is little information about the reasons for dissatisfaction when it occurs. Zhou et al. (2001) demonstrate that asking about satisfaction in subtly different ways can elicit a range of responses. Similarly, if patients are asked about improvements rather than changes this may create a bias towards responding positively. Many studies are carried out in routine clinical practice, which could also introduce biases dependent on who collects the information. The doctor-patient power imbalance could potentially lead participants to feel positive responses are expected.

Mental Health

There has been slightly more consistency in the area of mental health in terms of outcome measures used, allowing the opportunity to compare studies. Those receiving the most use are the SF-36, OHIP and Symptom Checklist 90 (SCL-90, or SCL-90-R: Derogatis, 1992; Derogatis, 1994).

The SF-36 examines impact of physical and mental status on quality of life within 8 domains – physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health. Component scores are derived for physical and mental health. Shortly after surgery significant decline has been shown in physical and mental health components (Lee et al., 2008).

Six months after surgery mental health showed no significant difference from pre-op scores. Choi et al. (2010) similarly found minimal change in mental health six months post-operatively. Six months after the end of all treatment a significant improvement was found, which was also the case in a study with a 21-month follow-up period (Al-Ahmad et al., 2009). Significant improvement has been shown for the role-emotional subscale at six months post-surgery (Lee et al., 2008; Nicodemo et al., 2008b). However, Al-Ahmad et al. (2009) did not find the improvement in this subscale significant at 21 months post-op. Azuma et al. (2008) found no significant difference on any of the subscales of the SF-36 pre to post-surgery, but the length of follow-up is not clearly specified.

The OHIP measures the impact of an oral health condition on quality of life, including psychological discomfort and disability within its seven domains. Two studies demonstrated no significant change in overall score at six weeks post-op but a significant improvement at six months post-op (Lee et al., 2008; Choi et al., 2008). Follow-up six months after the completion of all treatment showed this improvement continued, as the effect sizes were larger (Choi et al., 2008). In terms of the individual domains, psychological discomfort and disability showed significant improvement at six weeks in over 50% of the sample, which remained at six months post-op with larger effect sizes (Lee et al., 2008). Esperao et al. (2010) used a cross-sectional sample to show that scores were over six times more likely to be above the median value in the initial treatment stage compared to a post-surgery group. Overall scores were relatively low in all groups, suggesting the impact on quality of life is not dramatic at any stage.

The SCL-90-R is a 90-item self-report measure that evaluates a variety of psychological problems and symptoms of psychopathology and has been used alongside other measures by four studies. One study showed the percentage of patients considered psychologically distressed remained largely stable from pre to post op (23% to 20% respectively) and those who were distressed reported a higher level of problems and overall discomfort in recovery (Phillips et al., 2004). Motegi and colleagues (2003), on the other hand, demonstrated an improvement in SCL-90-R scores from pre-op to two years post-op including interpersonal sensitivity, depression and anxiety, which were maintained at a five-year follow-up. They also used the Sickness Impact Profile, which showed significant improvements in the psychosocial domain and all its components at two years that were stable at five years.

Chen et al. (2002) used the SCL-90-R and Minnesota Multiphasic Personality Inventory (MMPI: Hathaway and McKinley, 1967) before treatment and a satisfaction questionnaire at four follow-up points up to 12 months post-op. Personality profiles were within the normal range but the SCL-90 showed increased scores for interpersonal sensitivity, depression and paranoid ideation before treatment. Lower levels of satisfaction were associated with increased interpersonal sensitivity but as the SCL-90 was not repeated post-operatively it is difficult to draw conclusions about this. Kim et al. (2009) used the same measures but repeated the MMPI at six months post-op. Again, personality profiles were within the normal range but showed significant decreases post-op for scores on depression, hypochondriasis and insecurity in gender role.

Another study using a personality measure after treatment (MCMI-III) showed elevation in the areas histrionic, narcissistic, dependent and depressive (Oland et al., 2010). The most elevated clinical syndrome was anxiety (30.4% of patients, n= 92).

As well as general mental health, several studies have looked specifically at anxiety and depression. The Symptom Questionnaire (Kellner, 1976) was used to show that patients did not suffer from depression or anxiety following surgery and their scores did not differ significantly from controls (Nardi et al., 2003). Two further studies showed patients did not have a depressive disorder before or after surgery and scores did not change significantly over time (Rispoli et al., 2004; Azuma et al., 2008). Nicodemo et al., (2008a) did find an improvement in depression scores over time but this was only significant for females. The State Trait Anxiety Inventory (Spielberger et al., 1970) was used by two studies to show that state anxiety improved after treatment, whereas trait anxiety showed no significant change, which is expected due to transitory anxiety experienced before surgery (Rispoli et al., 2004; Azuma et al., 2008).

Three studies used questionnaires designed by the authors rather than standardised measures. Derwent et al. (2001) asked patients and parents about mood swings and depression and found 47.5% of parents felt their child experienced mood swings after surgery, while only 35% of patients felt this was the case.

35% of parents and 37.5% of patients said they experienced depression in the first three months after surgery. Similarly, Williams et al. (2004) reported 39% of patients felt depressed at home after the operation. A further study simply asked patients 'did you suffer from depression pre/post-surgery?' and found the majority (66.7%) were not depressed at any stage (Palumbo et al., 2006). When asked about anxiety most were either not anxious at any stage (33.3%) or only anxious before surgery (36.7%), which would concur with results gained from standardised measures. These studies asked patients to comment retrospectively and the term depression was used in the question but not defined, so it could be suggested that participants interpreted this as low mood rather than what would be considered clinical depression.

Mental health appears to deteriorate in the immediate post-operative period, which is unsurprising considering the side-effects of major surgery. It has been consistently shown that this improves by six months post-op, but there is disagreement about whether this is significant compared to pre-op scores or simply a return to their previous level of functioning. Patients may report feeling 'depressed' immediately after surgery but when evaluated using validated measures patients are not suffering from clinical depression at any stage and there is no significant change from pre to post-op.

Factors Influencing Outcome

A number of factors have been examined in relation to accounting for the variation in outcomes.

Gender

Most studies have a much larger proportion of female than male participants but few gender differences are reported in terms of outcome. No significant differences have been found between genders on satisfaction with treatment (Chen et al., 2002; Rispoli et al., 2004; Pahkala and Kellokoski, 2007; Sadek and Salem, 2007) or changes in quality of life (Choi et al., 2010). However, Espeland et al. (2008) reported that dissatisfaction was expressed significantly more by females in a sample of 516 participants. Using the SF-36 Nicodemo et al. (2008b) found that women showed a significant improvement in role-emotional, whereas men did not but this study used a small sample of 29 participants. Women have also been shown as more likely to have improved self-confidence than men (Pahkala and Kellokoski, 2007) and have greater improvement in depression scores but lower self-esteem than men both before and after treatment (Nicodemo et al., 2008a).

Severity

Several studies have taken into account severity of dentofacial deformity and examined participant outcomes accordingly. Increased severity has been shown to

correlate with increased satisfaction (Chen et al., 2002; Sakek et al., 2007) and more positive impact on relationships with the opposite sex and social activities, but also with increased difficulty adjusting to new appearance (Zhou et al., 2002). There is some suggestion that expectations may be different when participants have a more severe deformity, which may impact on results (Chen et al., 2002).

Age

A number of studies have examined differences between age groups. Several have shown that age has no effect on satisfaction (Chen et al., 2002; Pahkala and Kellokoski, 2007; Espeland et al., 2008) and a further study showed no significant difference for problems reported after surgery (Narayanan et al., 2008). In contrast, Oland et al. (2010) found patients aged 35 and younger were more satisfied than older patients. Lazaridou-Terzoudi et al. (2003) found slightly different results again by analysing patient data in three groups based on current age (patients had undergone surgery 10-14 years previously). Patients aged 32-36 were least concerned about their appearance and most satisfied with treatment outcomes compared to younger (age 26-32) and older (age 36-68) patients, with the youngest group being the least satisfied and most critical of their post-surgery appearance. No significant differences were found for body image or self-concept.

Stability of Outcomes over Time

Few studies follow participants beyond two years post-surgery, which is a relatively short follow-up period considering the length of treatment. Many studies

re-assess patients at specific follow-up points after the date of surgery, whereas the end of treatment can be up to 12 months after the surgery takes place. Therefore, data about the stability of psychosocial outcomes over time is limited.

Espeland et al. (2008) gave patients a questionnaire three years after surgery, which showed high levels of satisfaction with treatment (92%) and a positive impact on relationships for 20% of subjects. It was noted that significantly more patients with a class II malocclusion (overbite) were dissatisfied and would not make the same decision again, as compared to patients with class III malocclusion (underbite). This study surveyed a large sample of 516 participants but was cross-sectional so does not add to understanding of how outcomes change over time.

A prospective study demonstrated that significant gains made at two years post-surgery were maintained at five years, including social interaction, emotional behaviour and satisfaction (Motegi et al., 2003). The longest follow-up used was 10-14 years post-surgery using a retrospective design with waiting list and non-patient control groups (Lazaridou-Terzoudi et al., 2003). Patients were asked to report their feelings before surgery, immediately after and currently. This showed linear improvement over time for oral function, general health, appearance and interpersonal relationships, with scores in all areas being higher than both control groups. However, even 10 years post-surgery the patient group had lower scores for self-concept and body image than non-patients despite being satisfied with the treatment results. These studies suggest that psychosocial benefits achieved from

orthognathic surgery are sustained over the long-term but further studies with longer follow-up periods are required.

Discussion

Gains in psychosocial functioning are consistently reported for the majority of patients following orthognathic surgery, which concurs with previous findings from earlier research reported by Hunt et al. (2001). Whilst patients have been shown not to be suffering from specific mental health problems, such as clinical depression, it is clear that patients' broader well-being is affected by going through the treatment process. Although levels of satisfaction with various aspects of treatment are high and positive gains reported, there are still a number of patients who may experience some degree of dissatisfaction or negative outcome.

There can be an implicit assumption on the part of surgeons that distress can be fully attributed to appearance and therefore solved with surgery. However, the relationship between appearance and satisfaction is complex and patients' own view of themselves may differ from the objective view of others, including clinicians (Van Steenbergen et al., 1996). Patients with a more negative opinion of their appearance regardless of the actual degree of deformity may be more likely to opt for surgery, even if less invasive treatments are available (Mihalik et al., 2003). The biomedical focus in the orthognathic literature has meant the contribution of psychosocial support and intervention has been overlooked, which has also been the case in appearance research more broadly (Rumsey and Harcourt, 2004).

Research has shown that whilst clinicians may feel orthognathic patients could benefit from psychological support, they may be reluctant to offer this in case it is perceived negatively (Juggins et al., 2006). However, a more recent study found that 95.2% of patients surveyed would view this positively (Ryan et al., 2009b).

Investigation into whether less invasive treatments could produce equivalent effects to orthognathic treatment or improve outcomes as an addition to treatment have been lacking. Mihalik and colleagues (2003) compared the utility of orthodontic camouflage as an alternative to orthognathic surgery for patients with less severe class II malocclusion. Camouflage is achieved by altering the dental but not the skeletal discrepancy, so does not change facial appearance. Results showed that stability of treatment over time was good, patients reported high levels of satisfaction and were positive about appearance changes. This study suggests that a less invasive treatment, where applicable, can have at least comparable outcomes with surgery.

Patient experience of adjustment to facial change, which can be dramatic for orthognathic surgery patients, remains under-researched. Whilst the correction of malocclusion with orthognathic surgery clearly offers benefits to patients, physical change does not necessarily result in psychological change (Sarwer et al., 1998). The process of incorporating appearance change into self-image is complex (Lazaridou-Terzoudi et al., 2003), but is often portrayed in the literature as a dichotomous variable, i.e. patients are either adjusted or not. There is a lack of

discussion about this process and appreciation that patients may have adjusted to differing degrees, so more attention should be given to understanding this progression during recovery.

Determining patient satisfaction has similarly been over-simplified in much of the research. Patients report high levels of satisfaction, but as previously discussed there are flaws in how this is measured. Again, researchers fail to take a broader perspective to consider all the possible variables influencing satisfaction. For example, it may be difficult for patients to be objective about treatment outcomes given the lengthy and invasive treatment process they have elected in the pursuit of improvement. There is a risk of patients inflating the difference between pre and post-surgery well-being to validate the experience as worthwhile, or being reluctant to report negative outcomes (Lazaridou-Terzoudi et al., 2003).

Consideration should also be given to the doctor-patient power imbalance and how this may impact on patient response (Rumsey and Harcourt, 2004). Whilst these processes would not explain the overwhelmingly positive outcomes reported in the literature, further consideration of a wider range of theoretical issues is warranted.

Methodological Limitations of the Existing Literature

There are a number of limitations that can be identified in the methodological quality of this body of research, several of which were previously discussed by Hunt et al. (2001) in their earlier review. One of the key issues is the use of

appropriate control groups and lack of randomised controlled trials. Six of the studies reviewed used control groups, with two of these studies also using waiting list controls. One of the studies used age-matched patients with untreated skeletal deformities who were not seeking surgery (Narayanan et al., 2008). The suitability of this population as a control has previously been questioned, as it is more appropriate to make comparison to those without any deformity (Hunt et al., 2001). The remaining five studies used control groups who did not have any dental condition. These were dental students, general dental patients, acquaintances of participants, university staff and unspecified non-patients. Only two of these groups were age-matched, with one also taking gender and socioeconomic status into account but this was implemented by the participants themselves rather than the researchers (Oland et al., 2011).

There are further biases evident in the composition and recruitment of some of the control groups. For example, a convenience sample of university staff who volunteered to participate in a study about body image may have been biased by people being less likely to opt in if they had negative body image (Nardi et al., 2003). Dental students may also be less representative of the general population due to their increased awareness of dentofacial conditions (Kim et al., 2009).

The study with the largest control group does not specify how they were recruited and all studies had small sample sizes, some with uneven group sizes (Lazaridou-Terzoudi et al., 2003). Recruiting an appropriate control group that allows the most meaningful comparison to patient samples is a challenge but more could be done

to ensure that biases are minimised. It is surprising that so few studies have made use of waiting list or pre-surgery control groups considering the length of the treatment process. However, patients should ideally be compared with a group of people who have normal occlusion and can be matched on as many variables as possible to reduce bias.

The measures used to assess psychological outcomes of orthognathic surgery are also an area which requires further attention. The inconsistency created by the wide range of measures used in this area has been discussed previously (Hunt et al., 2001) and this remains the case. This makes synthesising evidence for different outcomes more challenging. However, there has been an increase in the use of measures used that are designed and validated specifically for this population (Kanas and Rogers, 2010). Differences have been demonstrated between validated and un-validated measures, for example large percentages of patients report improvements in self-esteem but a validated measure found the change only minimally statistically significant. Therefore, there is a risk of overstating gains if conclusions are not statistically based.

There are discrepancies in timing of data collection and whether a 'true' baseline was used, i.e. before the start of any treatment as opposed to before surgery. This was raised as an issue in previous literature (Hunt et al., 2001) and it seems there has been limited progress in addressing this. Similarly, participants may be followed up at set points following surgery, or following the end of all post-

operative treatment and this is not always clearly specified. Although there are an increasing number of studies using longer follow-up periods as compared to the earlier literature (Hunt et al., 2001), there can be large variation in when measures are completed between individual participants (e.g. 6-24 months post-op) and studies are not always clear about the spread within this range and how this may have impacted on the results. Even using the same time point for all participants can be problematic, as the treatment course can vary considerably.

Many of the studies reviewed had small sample sizes, limiting the statistical power of the analyses and few report effect sizes. There is also an over-representation of females in most samples. Neither of these issues receives much discussion and in general many studies fail to identify their limitations, justify the methods used or address clinical and theoretical implications. It is difficult for clinical practice to develop without reliable evidence on which to base changes.

The studies reviewed have been carried out in 19 different countries worldwide but there is limited reflection on cultural differences in terms of how this treatment is delivered or attitudes to appearance in general, and how these may influence the results and their interpretation. For example, Siow et al. (2002) provide some discussion of how Malaysian attitudes towards appearance change differ from those of Western cultures.

The research reviewed uses almost exclusively quantitative methodology, which may mean that the subjective experience of patients dealing with the impact of the condition and treatment are not fully comprehended (Thompson and Kent, 2001). Examination of the lived experience of patients going through this treatment process is yet to be undertaken. Studies that have employed qualitative methods have done so as a means to develop questionnaires to gather further quantitative data, rather than analysing the qualitative data itself in more depth (Travess et al., 2004; Ryan et al., 2009a).

Theoretical Implications

In order to gain a greater understanding of patient experience, adjustment to appearance change and satisfaction with appearance, a broader theoretical approach is needed that gives consideration to the complexity of the relationship between variables that impact on these processes. Cunningham and Shute (2009) suggest a model of satisfaction that takes account of the technical result of surgery, psychological factors such as mental health and personality traits, external factors such as social support and communication within the orthognathic team as well as between the patient and the team, particularly around patient expectations. However, this still lacks sufficient consideration of factors such as salience and valence of appearance, appearance beliefs and social and cultural context. A model developed by the Appearance Research Collaboration provides a more comprehensive framework for understanding appearance concern on a broad spectrum by taking into account predisposing factors, maintaining factors, behavioural reactions to appearance distress, such as avoidance, and positive or

negative emotional reactions (Thompson, in press). This could usefully be employed in orthognathic research to better appreciate the complexity of adjustment and satisfaction with a view to identifying variables that could be modified, for example through improved communication with patients.

Clinical Implications

In order to prevent negative outcomes and improve treatment experience and positive outcomes it is essential to pay attention to patients' psychological well-being at all stages of the process. Particular consideration should be given to the immediate post-operative period, when it has been shown that patients may experience decline in well-being (Lee et al.,2008; Choi et al., 2010). The role of psychology in supporting patients during the process should be considered further, as a more multi-disciplinary approach could achieve more holistic patient care (Broder et al., 2000). Support in decision making and availability of interventions such as cognitive behaviour therapy for social anxiety or appearance distress could prove useful in further improving patient outcomes (Thompson and Kent, 2001; Rumsey and Harcourt, 2004).

Avenues for Future Research

As previously discussed there is a need to address some of the current methodological weaknesses apparent in this body of literature. Well-controlled longitudinal studies carried out over longer periods of time, using validated and reliable measures are needed. Standardised measures of psychosocial functioning

give a more in depth assessment of constructs and make it possible to assess change over time in a more scientific way.

The time points used for baseline and follow-up should be given greater consideration and clearly stated, in addition to increased attention to providing the rationale for study design and discussion of limitations and implications. The lack of qualitative research also needs to be addressed. A more in depth exploration of how patients experience the process of going through all stages of orthognathic treatment and how they perceive the benefits and challenges of this would be valuable.

Many studies reviewed discuss the importance of communication in ensuring patients have realistic expectations, which may improve their experience (Phillips et al., 2004; Williams et al., 2004). However, the research has not directly addressed whether better communication at all stages of the treatment process can influence outcomes and patient experience.

Studies examining the utility of alternative or additional interventions to surgical treatment, such as psychological support, are needed to determine what benefit these could add to patient experience and outcome. Increased collaboration between services may be needed to achieve some of these goals. For example, the number of dissatisfied patients is small, so patients from multiple services may be needed to achieve sample sizes adequate to better understand this experience.

Collaboration may also be required to improve understanding of cultural factors and how these may influence outcome and experience of orthognathic treatment.

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Appendix A

Table 2: Summary of studies included in the review

Table 2 - Summary of studies measuring psychological outcomes of orthognathic surgery¹

Study	Sample Size, Age Range, Gender (M, F)	Country	Measures	Main Findings in Relation to Psychosocial Outcomes
<i>Prospective studies with controls</i>				
Oland et al., 2011	118 (47 control) 15+ 51, 67	Denmark	Motives questionnaire pre-op. Questionnaires by authors up to 36 months post-op.	Improved self-concept (88.1%) and social interaction (57.6%) reported. High degrees of motive fulfilment correlated with higher satisfaction and greater improvements in self-concept and social interaction.
Kim et al., 2009	34 (30 control) 19-26 10, 24	Korea	MMPI & SCL-90-R pre-op. Questionnaire by authors 1 week & 6 months post-op.	Patient personality profiles all within normal range. Depression, hypochondriasis and insecurity in gender role decreased significantly post-op.
<i>Prospective studies without controls</i>				
Oland et al., 2010	92 Mean 31 35, 57	Denmark	Questionnaires by authors pre-op and 12-36 months post-op. MCMI-III, 24 months after end of all treatment.	Significant improvements shown in oral function, self-concept and social interaction post-op. High level of satisfaction, patients aged 35 and under significantly more satisfied than older patients. Elevated anxiety on MCMI-III but no pre-op comparison.

¹ Abbreviations used in table – MMPI: Minnesota Multiphasic Personality Inventory, SCL-90: Symptom Checklist 90, MCMI-III: Millon Clinical Multiaxial Inventory III, SF-36: Short Form Health Survey, OHIP: Oral Health Impact Profile, OQLQ: Orthognathic Quality of Life Questionnaire, SRQ-20: Self Report Questionnaire, SRQ-D: Self-Rating Questionnaire for Depression, RSES: Rosenberg Self-esteem Scale, SOHSI: Subjective Oral Health Status Indicators, RSS-M: Recognition and Satisfaction Scale Modified, STAI: State Trait Anxiety Inventory, DAS-59: Derriford Appearance Scale, BDDE: Body Dysmorphic Disorder Examination, SRDS: Self Rating Depression Scale, OHSQ: Oral Health Status Questionnaire, SIP: Sickness Impact Profile, EPI: Eysenck Personality Inventory, BIAQ: Body Image Assessment Questionnaire.

Choi et al., 2010	32 Mean 23 10, 22	USA	SF-36, OHIP and OQLQ. Pre-op (T0), 6 weeks (T1) and 6 months post-op (T2), 6 months after end of all treatment (T3).	Significant improvement in mental health (SF-36) pre-op to T3. OHIP significantly improved at T2 and T3. OQLQ decreased significantly at every follow-up.
Turker et al., 2008	30 18-31 0, 30	Turkey	Questionnaire by authors – part 1, pre-op. Part 2, 12 months post-op.	Improvements reported for post-op appearance (90%), self-confidence (63%) and social adjustment (40%). 23% had difficulty getting used to post-op appearance.
Lee et al., 2008	36 Mean 23 11, 25	China	SF-36, OHIP-14, OQLQ. Pre-op, 6 weeks and 6 months post-op. satisfaction scale post-op only.	Mental health (SF-36) decreased significantly at 6 weeks, no significant change from baseline at 6 months. OHIP and OQLQ showed no significant change at 6 weeks but significant improvement at 6 months.
Nicodemo et al., 2008a	29 17-46 13, 16	Brazil	SRQ-20 and RSES. Both 30 days pre-op and 6 months post-op.	Improvement shown in self-esteem post-op. No depressive disorder shown at any time but depression scores improved post-op (statistically significant for females).
Nicodemo et al., 2008b	29 17-46 13, 16	Brazil	SF-36. Both 30 days pre-op and 6 months post-op.	Significant improvement shown in four of eight domains of SF-36 at post-op – vitality, emotional, physical and social.
Azuma et al., 2008	31 17-42 6, 25	Japan	SF-36, SOHSI, OQLQ, RSS-M, STAI, SRQ-D. All pre and unspecified post-op.	SF-36 and SRQ-D showed no significant changes pre to post-op. State anxiety improved significantly, no change in trait anxiety. SOHSI and OQLQ showed significant improvement over time.
Pahkala and Kellokoski, 2007	82 16-53 29, 53	Finland	Clinical interview pre-op. Questionnaire by authors, average 1.8 years post-op.	Improvements reported in facial appearance (82%) and self-confidence (45%). Change in self-confidence was significantly related to higher satisfaction with treatment.
Sadek and Salem, 2007	120 11-33 48, 72	Egypt	Questionnaire by authors – part 1, pre-op. Part 2 plus DAS-59, 6-12 months post-op.	Statistically significant improvement in quality of life based on DAS-59. High levels of patient satisfaction (92.5%).

Modig et al., 2006	32 20-59 16, 16	Sweden	Questionnaire by authors, pre-op. Questionnaire by authors, OHIP and telephone interview (n=15), 4-6 weeks post-op.	OHIP showed no psychological discomfort, psychological or social disability post-op. Post-op improvements reported for appearance (88%) and bullying (56%).
Rispoli et al., 2004	30 23-35 16, 14	Italy	BDDE, SRDS & OHSQ, 2 months pre-op & 3 months post-op. STAI 1 week pre-op & 3 months post-op. Satisfaction questionnaire 1 week, 1 month & 3 months post-op.	Significant improvements in body image, oral health and function, discomfort with appearance, difficulty with work and social activities. Depression in normal range pre and post-op. State anxiety significantly decreased post-op, trait anxiety showed no change.
Phillips et al., 2004	126 15-53 35, 91	USA	SCL-90-R and Short Term Expectations pre-op. SCL-90-R, Post-surgical Perceptions & Satisfaction 4-6 weeks post-op.	Improvement in appearance reported (57%). Approximately the same percentage of participants was psychologically distressed before surgery (23%) as after surgery (20%). Treatment simulation pre-op did not improve problems or satisfaction post-op.
Motegi et al., 2003	93 14-57 27, 66	USA	SIP, OHSQ, SCL-90-R & EPI. Pre-op, 2 and 5 years post-op.	Significant improvements shown by SIP, OHSQ and SCL-90-R pre to post-op. Improvements remained stable between 2 and 5 years post-op.
Chen et al., 2002	108 16-40 37, 71	China	Interview, MMPI, SCL-90, pre-op. Questionnaire by authors 10 days, 3, 6 & 12 months post-op.	Acceptance of appearance by others improved significantly over time and correlated with patient satisfaction. Satisfaction increased over time and more realistic expectations correlated with greater satisfaction.
Gerzanic et al., 2002	100 14-45 32, 68	Austria	BIAQ, 2 weeks pre-op, 6 weeks & 6 months post-op.	Significant improvement in self-confidence shown at each time point. Insecurity decreased significantly for class III but not class II patients.
<i>Retrospective studies with controls</i>				
Narayanan et al., 2008	21 (21 control) 15+ 7, 14	India	Questionnaire by authors. Post-op unspecified.	Statistically significant improvement in oral function, general health, appearance and interpersonal relationships.

Lazaridou-Terzoudi et al., 2003	117 (39+92 control) 28-69 48, 69	Denmark	Questionnaire designed by authors, Fitts Tennessee Department of Mental Health Self-Concept Scale, Body Cathexis Scale. All 10-14 years post-op.	Statistically significant improvements in oral function, general health, appearance and interpersonal relationships. Facial body image higher after surgery but not as high as non-patient controls.
<i>Retrospective studies without controls</i>				
Rustemeyer et al., 2010	77 17-34 40, 37	Germany	Questionnaire by authors, 12 months post-op.	Ratings of facial aesthetics improved significantly from pre to post-op. 67.5% reported increased self-confidence.
Al-Ahmad et al., 2008	38 17-44 12, 26	Jordan	Questionnaire by authors, 4-56 months post-op.	Statistically significant improvements shown for oral function, general health, appearance and interpersonal relationships.
Williams et al., 2004	327 21-34 85-242	UK	Questionnaire by authors, 1-6 years post-op.	Improvements reported in self-confidence (81%), social life (33%) and facial appearance (86%). 39% reported depression immediately post-op.
Siow et al., 2002	31 17-36 9, 22	China	Questionnaire by authors, 6 months to 15 years post-op.	94% satisfied with results, 100% reported aesthetic improvement, 68% satisfied with improved self-confidence.
Zhou et al., 2002	94 14-41 40, 54	China	Questionnaires by authors, post-op unspecified.	Increased severity correlated with increased positive impact on relationships and social activities, as well as increased difficulty adjusting to new appearance.
Zhou et al., 2001	94 14-41 40, 54	Malaysia	Questionnaires by authors. 6-12 months post-op.	Improvements in appearance (96%), personality (56%), self-confidence (67%), relationships (49%) and social activities (54%). Satisfaction was high and improved over time post-op.
Derwent et al., 2001	45 Mean 23 16, 29	UK	Questionnaires by authors, 6-24 months post-op.	Improvements in facial appearance and confidence. Mood swings (35%) and depression (37.5%) in first three months.

Cross-sectional studies with controls				
Al-Ahmad et al., 2009	36+35+35 (37 control) 17-33 33, 73	Jordan	OQLQ, SF-36, post-op group average 21 months post-surgery.	OQLQ scores significantly lower for post-op than pre-op. No significant difference between post-op group and controls. SF-36 showed mental health was significantly improved from pre to post-op.
Nardi et al., 2003	20 (20 control) 26-46 11, 19	Italy	BDDE, Symptom Questionnaire, Quality of Life Enjoyment and Satisfaction Questionnaire, unspecified time post-op.	No significant difference between patients and controls for anxiety, depression or hostility. Patients had significantly more somatic symptoms. No patients met the criteria for BDD.
Cross-sectional studies without controls				
Esperao et al., 2010	20+70+27 Mean 24.5 52, 65	Brazil	OHIP-14 – pre-treatment, pre-surgery and post-surgery (unspecified).	Patients were significantly more likely to report high impact on quality of life in the pre-surgery groups compared to post-surgery. Women were more likely than men to report high impact on quality of life both before and after surgery.
Espeland et al., 2008	516 12-72 235, 281	Norway	Questionnaire by authors, 3 years post-op.	Reported improvement in facial appearance for over 50% of participants. High levels of satisfaction reported. Dissatisfaction significantly higher for females. 20% reported a great impact on social relationships but 44% reported no effect.
Palumbo et al., 2006	30 19-49 12, 18	Italy	Questionnaire designed by authors (asked about pre and post-op), unspecified time post-op.	Improvements reported in aesthetics (96.6%) and self-esteem (66.6%), 96.6% said they did not have trouble accepting new appearance. 33.3% not anxious at any stage, 36.6% only anxious before. 66.6% not depressed at any stage.

Exploring People's Experience of Appearance-Altering Orthognathic Surgery

Abstract

The aim of the study was to explore participants' experience of undergoing appearance-altering orthognathic surgery including motivation for surgery, decision-making processes, adjustment to appearance change, the role of social support and reactions of others. Semi-structured interviews were carried out with seven participants approximately one week before and six to eight weeks after surgery. Participants also completed the Derriford Appearance Scale, Hospital Anxiety and Depression Scale and Brief Fear of Negative Evaluation Scale at both time points. Interview data was analysed using Interpretative Phenomenological Analysis (IPA) to identify central themes in participant accounts. Themes were identified around the course of treatment, the relationship between appearance and identity, the influence of the views of others and the uncertainty experienced in the treatment process. Participants' scores on the psychometric measures did not change significantly from pre to post surgery and were within general population norms. Participants described a much more complex process of adjustment to change in facial appearance than is represented elsewhere in the literature. The role of communication in influencing patient expectations and experience of treatment is highlighted. Clinical implications and avenues for future research are discussed.

Introduction

Orthognathic surgery is a specialist branch of oral and maxillofacial surgery, literally meaning 'surgery to create straight jaws' (British Association of Oral and Maxillofacial Surgeons, 2011). Surgery is used to correct malocclusion; misalignment of the jaws which creates a discrepancy, either an under-bite or over-bite. Malocclusion is associated with facial and dental appearance concerns and functional problems such as difficulty chewing and jaw pain. The treatment can last up to three years as orthodontic treatment is required both before and after surgery. Orthognathic surgery is considered a relatively safe and effective treatment and has seen increasing demand, especially from younger patients (Bennett & Phillips, 1999).

Recently greater consideration has been given to the psychological outcomes of treatment, in order to demonstrate the impact of surgery on patient well-being. High rates of satisfaction have consistently been found for orthognathic surgery but there are still a small percentage of patients who report dissatisfaction (Oland et al., 2010). Severity of dentofacial deformity does not predict patient satisfaction with appearance; a finding reported elsewhere in the literature on appearance concern for those affected by an objective medical condition (Van Steenberg et al, 1996; Grossbart & Sarwer, 2003). Similarly, the cosmetic surgery literature indicates that people who have undergone surgery may remain dissatisfied with their appearance, even after the perceived problem has been 'corrected' (Sarwer et al., 2002).

Motivation for orthognathic treatment has been debated. While some studies have shown primary motives are functional, others have shown that desired improvements in appearance, self-confidence and social interaction also play an important role, with patients stating multiple reasons for seeking treatment (Williams et al., 2005; Stirling et al., 2007). Whilst patients may not seek surgery for primarily aesthetic reasons, orthognathic treatment often has a dramatic impact on appearance, so aesthetics remain a central issue.

There is societal emphasis on the value of physical appearance and whilst the strength of attractiveness stereotypes have been shown to be less robust than previously thought, there is consistent evidence that people are judged more favourably if they are physically attractive (Langlois et al., 2000). However, appearance research has developed in recent decades from over-simplistic consideration of the processes involved to appreciation of the complexity of the interpersonal perception of appearance (Rumsey & Harcourt, 2005).

Appearance concern has increased in the general population, particularly for women (Cash et al., 2004). Visible differences in appearance can result in psychological distress, discrimination and negative reactions from others (Thompson and Kent, 2001). The mouth and teeth are central to facial attractiveness and problems are difficult to conceal, so therefore visible in most social interactions (Broder et al., 2000) Studies have shown that images of patients with malocclusion are consistently rated as being less attractive

than 'average' faces by both dental clinicians and lay people (Fabre et al., 2009).

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 still within the normal range on these factors, as well as for general psychological functioning (Stirling et al., 2007; Burden et al., 2010). Treatment can convey psychosocial benefits such as improved self-esteem, self-confidence, body image and social functioning (Hunt et al., 2001). However, there is a lack of methodological rigour due to a high level of inconsistency across studies and lack of long-term controlled designs. Studies in the last decade have continued to use a diverse range of measurement approaches, making comparison difficult, but there has been a slight increase in the use of control groups and benefits continue to be demonstrated (Oland et al., 2011). A small number of longer term studies have shown improvements are stable over time, but patients may remain more critical of their appearance than controls (Lazaridou-Terzoudi et al., 2003).

Understanding of complex issues such as satisfaction with treatment and adjustment to appearance change remains inadequate. There is some evidence for the role of unrealistic expectations in dissatisfaction (Chen et al., 2002). However, Kiyak et al. (1988) found that patients who anticipated fewer problems prior to surgery had better psychological outcomes, while those who expected more problems went on to experience more problems. Social

support and the reactions of significant others have also been shown to play an important role in adjustment and satisfaction (Holman et al., 1995).

The age at which surgery takes place is a further issue to consider. Although treatment can be given at any time during adulthood, many patients opt for surgery as soon as it is available, in late adolescence and early adulthood. Focus on appearance increases during adolescence and living with a visible difference is an on-going stressor, which may add to the pressures experienced during such transitional periods (Rumsey and Harcourt, 2004). Younger people may be more influenced by external feedback and negative comments at a young age can have a longer term effect on body image (Broder et al., 2000).

As previously discussed the extant research that has sought to explore the impact of orthognathic surgery has been difficult to draw firm conclusions from due to the scientific rigour of the studies. In addition, there is a lack of research about people's experience of treatment. Qualitative methods have been used sparsely, most commonly in questionnaire development, and have not undertaken detailed analysis. For example, Travess et al. (2004) conducted focus groups with patients who had undergone orthognathic surgery to develop an understanding of the process and outcomes of treatment. A 'grounded theory approach' was used which generated a wide range of descriptive themes. There was a low response rate (25%, n=26) and as patients had already completed treatment the decision to take part may have

been influenced by the outcomes they experienced. Participants may also have responded differently due to the social influence of the group than they would have on an individual basis.

Two studies carried out descriptive analysis of data from large samples using telephone interviews and focus groups to examine decision-making processes (Broder et al., 2000; Stirling et al., 2007; n=118 and n=61 respectively). These revealed a large number of themes including quality of information, consequences of treatment, barriers and facilitators in decision-making. Ryan et al. (2009a) used thematic content analysis after interviewing 10 patients and 10 clinicians about their attitudes towards referral to a mental health professional and reported main themes around service provision and how mental health professionals are perceived. Clearly there is a need for more rigorous qualitative methods to explore the complexity of personal experience and the emotional and psychological processes involved (Rumsey and Harcourt, 2005).

As yet no studies have followed the same group of people through the course of treatment or analysed the data in enough depth to comment on processes such as adjustment to facial change and experience of treatment.

Consequently, patient satisfaction and adjustment to appearance change in orthognathic surgery remain poorly understood. Correcting a disfigurement may have a positive impact for many patients, but the relationship between appearance and psychological wellbeing is not straightforward. Much of the

research on appearance has focussed on negative adjustment and, as is the case with orthognathic research, taken a biomedical approach with lack of attention given to psychological or sociocultural perspectives (Thompson, in press). The minimisation of the role of these additional variables and focus on enhancing appearance has reinforced the stereotype that physical attractiveness is preferential (Rumsey & Harcourt, 2005). Furthering understanding of patient experience could enable services to provide more comprehensively for patients' needs and to inform them more accurately about treatment.

The present study used a longitudinal design to capture participants' experiences throughout the process of orthognathic treatment utilising mixed methods of data collection, focussing on patients in the 16-25 age range undergoing bimaxillary surgery (surgery to both upper and lower jaws). The majority of patients fall within this age range and bimaxillary surgery has the greatest impact on appearance, as compared to single jaw surgery. The focus of the study was on exploring the nature of participants' experience and the sense they make of going through an appearance altering surgery.

Interpretative phenomenological analysis (IPA; Smith et al., 2009) was one of the most suitable approaches due the relevance of its goals; to understand how participants make sense of a particular experience and the quality and nature of phenomena (Willig, 2008). This study uniquely sought to gather data before and after the experience of interest, giving a richer account of the treatment process.

To further enhance the depth of information gained from participants photo elicitation methodology was also employed. This involves the use of photos, taken either by participant or researcher, as part of the research interview (Harper, 2002). This methodology has been used previously to explore experience of appearance change and recovery in health and illness research (Radley and Taylor, 2003). It allows the researcher to elicit richer descriptions of experiences and phenomena than with words alone.

Aims of the Study

The aims of the study were to explore participants' experience of going through the process of orthognathic surgery, including:

- a) Motivation for undertaking surgery, the decision-making process and expectations about what surgical treatment would entail both physically and emotionally.
- b) The meaning of appearance in the individual's perception of themselves and feelings about change over the course of treatment.
- c) How people perceive the role of others in the treatment process, specifically their experience of the reactions of others towards their appearance.

Method

Design

The principles of IPA were used to guide collection and analysis of data. IPA involves attempting to access the meaning of the person's experience through an interpretative process of the researcher's engagement with the participant and with the data during analysis (Biggerstaff & Thompson, 2008). Reflexivity was considered throughout in order to maintain awareness of the researcher's position and assumptions, and how these influence interaction with the data (Spencer & Ritchie, 2011). IPA has a well-defined analytic process and the flexibility of the semi-structured interview permits exploration of areas of interest that arise (Smith et al., 2009). The addition of photo elicitation to the data collection process allows images to be used as prompts through which participants can both relive the experience it represents and reflect on it from their current perspective (Harper, 2002).

Participants took part in semi-structured interviews approximately one week before and six to eight weeks after surgery, lasting between 15 and 50 minutes. At the first interview they were invited to take photos to illustrate their experience prior to the second interview. Participants completed three questionnaires on both occasions, along with a satisfaction rating scale at the post-surgery meeting. These measures were employed to contextualise the sample and provide additional idiographic information on change.

Recruitment

Participants were recruited through the Charles Clifford Dental Hospital in Sheffield. In keeping with IPA methodology purposive sampling was used to obtain a homogenous sample of participants. Patients aged 16-25 due to undergo orthognathic surgery on both the upper and lower jaws (bimaxillary), were identified by the lead surgeon, who informed them about the study and offered the opportunity to meet with the researcher.

Participants

Nine participants were recruited but only seven completed both stages of the study. One participant chose not to complete the second interview due to personal circumstances and the second did not attend two follow-up appointments so data could not be collected before the end of the study. Both participants provided limited data in the first interview so have not been included in the analysis. Participants were aged 18-25 years (five females, two males) and all were in paid employment. The demographic characteristics of the participants are shown in Table 3.

Table 3 – Characteristics of Participants (n=7)

Pseudonym	Sex	Age	Family Status	Ethnicity
Fiona	F	18	Living with relatives	White British
John	M	25	Living alone	White British
Charlotte	F	21	Living with relatives	White British
Chloe	F	20	Living with relatives	White British
Joe	M	19	Living with relatives	White British
Anita	F	22	Living with relatives	Pakistani British
Emily	F	21	Living with relatives	White British

Piloting and Service User Involvement

The information sheets and interview schedules were piloted informally with two former patients at the dental clinic, who commented on the suitability of the information provided and relevance of the interview topics.

No amendments were made to the interview schedules but advice was utilised on providing a clear explanation of confidentiality and the researcher's independence from the clinical team.

Data Collection

The data collection process consisted of two stages as follows:

Time 1

Participants were invited to meet with the researcher whilst attending a regular appointment approximately one week before surgery and were given detailed information about the study (Appendix VII). Written consent was obtained

(Appendix VI) and participants had the opportunity to ask questions. A semi-structured interview was conducted focussing on their motivations for and expectations of treatment, feelings towards appearance and the role of social support (Appendix VIII). Participants completed three questionnaires and were given an information sheet about the photo elicitation aspect of the study (Appendix VII).

Participants were given a disposable camera to record images representing significant aspects of their experience. They were encouraged to be creative in the images they chose, with a focus on feelings towards change in appearance. A later amendment resulting from participant feedback allowed participants to use their own cameras, rather than those provided. Participants were informed this aspect of the study was optional and encouraged to attend the second interview even if they chose not to take photos.

Time 2

Follow-up interviews were arranged via the dental clinic six to eight weeks after surgery to coincide with a regular appointment. A reminder letter was sent along with a stamped addressed envelope to return the camera if applicable (Appendix IX). A second semi-structured interview was carried out focussing on experiences of change, the treatment process as a whole and the reactions of others following surgery (Appendix VIII). Participants were also prompted with information from the first interview and asked to reflect on

what they had said to gain a more in depth account of their experience.

Participants who had taken photos were invited to discuss these in order to gain further understanding of significant experiences.

Measures

Measures were selected to contextualise the sample in terms of participants' mood, feelings about appearance and concern about being evaluated negatively by others (Appendix V).

Derriford Appearance Scale (DAS-24)

The DAS-24 (Carr et al., 2005) is a standardised and psychometrically robust measure that assesses distress and dysfunction resulting from body image disturbance. It has been used to examine processes that contribute to problems with appearance, with the underlying construct being adjustment to problems of appearance. The scale has good internal consistency (Cronbach's alpha of 0.92) and test-retest reliability, with a correlation of 0.82 in a clinical population and 0.88 in the general population. The questionnaire collects demographic information then asks participants to comment on concerns about their appearance and to specify which, if any, features they are unhappy with. They are then asked to complete 24 self-report items relating to general appearance concerns. Two additional items determine whether the person experiences physical pain or limitation due to any features they specified being unhappy with.

Brief Fear of Negative Evaluation Scale (BFNE)

The BFNE Scale (Leary, 1983) is a 12-item self-report measure which assesses level of concern about being evaluated negatively by others. This shortened version of the original 30-item scale is quicker to administer and psychometrically robust. It has good internal reliability with Cronbach's alpha of 0.90 and good test-retest reliability with a coefficient of 0.75. Participants are asked to rate how characteristic each of 12 statements is of them, using a given scale. High scores indicate the person is likely to try to avoid situations where they may potentially be evaluated negatively.

Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond & Snaith, 1983) is a widely used reliable self-report measure assessing anxiety and depression. It has 14 items asking participants to consider how they have felt over the past week and rate their responses accordingly, with seven items assessing symptoms of depression and seven of anxiety. It has good internal consistency with Cronbach's alpha of 0.82 for the depression items and 0.83 for the anxiety items (Bjelland et al., 2002). The scale also achieves a suitable balance between sensitivity and specificity, so is an appropriate screening measure for depression and/or anxiety.

Satisfaction Rating

Each participant was asked to complete a five-point Likert scale to rate the success of the surgery in terms of their facial appearance.

Analysis of Measures

The reliable change index (RCI) calculation was used to determine whether individual patient scores changed significantly over time on the DAS-24 and BFNE (Jacobson & Truax, 1991). Mean scores were calculated for each measure and compared with population norms. The HADS provides clinical cut-off scores for normal, mild, moderate and severe anxiety and depression so the number of participants falling into each category was calculated before and after surgery.

Analysis of Interview Data

All interviews were tape recorded and transcribed verbatim, by the researcher or a professional transcriber. The researcher kept field notes after each interview and a reflexive diary throughout the study. Data was analysed using IPA methods as outlined by Smith et al. (2009). Both transcripts were formally analysed for each participant at the same time to allow themes about the entire treatment process to emerge. However, data from the first interviews was examined to identify topics to follow up during the second interviews. The transcripts were analysed using the following stages:

1. The researcher listened to recordings of each interview, reading and re-reading the transcripts to fully engage with the text.
2. The researcher read through each transcript line by line, making notes in the right hand margin based on three types of analysis – descriptive, conceptual and linguistic (Appendix X).

3. Initial themes capturing the essence of what was being said were then noted in the left hand margin for each transcript, taking the analysis to a more abstract level but still tied to the data (Appendix X).
4. A list of themes was typed along with corresponding quotations, which were then printed, individual themes cut up and clustered together into broader themes.
5. These themes were further clustered together and reduced to form a table of themes and sub themes for each participant, illustrated by quotations to show how the themes were present in the data (Appendix X).
6. The tables of themes for each transcript were then viewed together to identify patterns across cases and generate higher order themes representative of the sample.
7. A final table of themes was produced, prioritised by the aims and interests of the study and richness of the available data (Table 8).

Quality control

Methodological validity was achieved by adhering to the protocol for the analysis of data and keeping a record of decisions made at key points, producing a clear audit trail from the initial data to the final themes. The researcher also kept a reflexive diary to consider the impact of their views on the analytic process and engaged in regular supervision, during which reflexivity was a key focus. Emerging themes were discussed with and verified by the research supervisor as part of this process. The researcher also

engaged in regular peer supervision with other trainee clinical psychologists. The analysis was audited by a member of this peer researcher group and by the research supervisor (AT), who each reviewed one transcript and the analysis trail in detail.

Ethical Considerations

Ethical approval was obtained from Nottingham Research Ethics Proportionate Review Sub-committee and research governance approval from Sheffield Teaching Hospitals NHS Foundation Trust (Appendix IV). Written consent was obtained from participants following thorough explanation of the requirements of the study and emphasis on the right to withdraw at any time. Patients were informed about how to complain about the study and confidentiality was maintained by making all interview material anonymous and using pseudonyms for each participant. Patient information was stored securely at the study site and the transcriber signed a confidentiality agreement. Inconvenience for participants was minimised by meeting them at scheduled clinic appointments and none of the meetings lasted longer than one hour. It was anticipated that emotional distress displayed by participants would be managed by the researcher in the first instance and further clinical support required would be provided by the primary supervisor (AT), but this did not prove to be necessary.

Results

Seven participants were interviewed before and after surgery (Table 3) and two of these participants engaged in the photo elicitation aspect of the study. Within those interviews the photographs were used to stimulate further discussion about participants' experiences. The remaining participants chose not to take photos, giving reasons such as being unsure what was required, feeling too unwell after surgery and not wanting to record the process for fear of being dissatisfied with the result of treatment.

Psychometric measures

Measures from the seven participants were scored and pre and post comparisons conducted.

Derriford Appearance Scale

Pre-operatively all participants reported concern about an aspect of their appearance; six specified this was related to their teeth/jaw/smile, while the remaining participant was concerned about body shape. After surgery, two participants were no longer concerned about any aspect of their appearance, one restated their dissatisfaction with body shape and the remaining four expressed dissatisfaction with facial appearance due to side-effects of treatment, i.e. swelling and braces.

The reliable change index (RCI) was used to examine whether participants' scores changed significantly from pre to post treatment. In order to achieve a significant RCI a change in score of 11.9 points for female patients and 9.6 for male patients was required. No scores met this threshold, therefore none of the participants showed significant change from pre to post treatment (scores in Table 4).

Table 4 – Raw scores for Derriford Appearance Scale

Participant	Time 1	Time 2
1	27	23
2	35	35
3	34	24
4	30	21
5	33	34
6	39	39
7	30	33
Mean	32.57	29.86
Standard Deviation	3.95	7.03

Both before and after treatment all participant scores were within one standard deviation of the mean score for the general population (females mean=38.25, sd=15.29; males mean=29.6, sd=12.3), suggesting participants did not suffer from body image disturbance.

Brief Fear of Negative Evaluation Scale

The difference in score needed to achieve a statistically significant reliable change was calculated as 7.10. One of the participants change score was

above this threshold by a small margin (score= -8.0). Overall very little change was seen between the two time points (Table 5).

Table 5 - Scores for Brief Fear of Negative Evaluation Scale

Participant	Time 1	Time 2
1	31	35
2	24	23
3	37	29
4	28	25
5	38	37
6	33	33
7	21	20
Mean	30.29	28.86
Standard Deviation	6.37	6.44

A higher score on the BFNE scale indicates increased fear of negative evaluation. Before surgery five participants scored within one standard deviation of the general population norm (mean= 35.7, sd= 8.10) and the remaining two scored below this level, indicating slightly lower than average fear of negative evaluation. After surgery, three participants had below average scores and the remainder stayed within the average range.

Hospital Anxiety and Depression Scale

The HADS allows participant scores to be classed as normal (0-7), mild (8-10), moderate (11-14) or severe (15-21) for anxiety and depression. The participants all scored within the normal range for depression before and after surgery (Table 6).

Table 6 - Scores for Hospital Anxiety and Depression Scale

	Anxiety		Depression	
Participant	Time 1	Time 2	Time 1	Time 2
1	4	3	2	0
2	7	4	2	2
3	11	5	2	4
4	6	4	4	0
5	9	9	5	4
6	12	9	3	0
7	6	4	3	1
Mean	7.86	5.43	3.00	1.57
Standard Deviation	2.91	2.51	1.15	1.81

Before surgery one participant was in the mild range for anxiety and two in the moderate range. After surgery two participants scored in the mild range and the remainder in the normal range.

Satisfaction Scale

Five participants said they were 'mostly satisfied' (score= 4) with the result of surgery in terms of their facial appearance. The remaining two participants were 'completely satisfied' (score= 5; Table 7).

Table 7 - Satisfaction Scores

Participant	Rating
1	4
2	4
3	4
4	4
5	5
6	4
7	5

Interview data

Four main themes emerged from the data, along with 15 subthemes (Table 8).

There were contrasting experiences reported by participants but these idiographic differences remain visible within the common themes. Due to meeting with participants before and after treatment it was possible to gain an understanding of their experience as a whole, which is captured in the first theme 'the course of treatment'. This highlights feelings towards treatment and the prominence of the process in patients' lives, their engagement with decision-making in the initial stages, through to the end of treatment and moving on. 'Appearance and its impact on identity' was a central issue for participants, as they discussed feelings of self-consciousness as a result of their appearance and the treatment itself. This theme also describes how patients dealt with the change in their appearance resulting from surgery. The 'influence of the views of others' was apparent in participants' descriptions of the impact of others' opinions before and after treatment and the value of support. The final theme explores 'uncertainty and never being prepared', which arose when discussing making the decision for treatment, knowing what

to expect from the process and making sense of experiences in the context of these expectations after treatment.

Table 8 – Master themes and subthemes

<p>The course of treatment: ‘it is a journey, isn’t it?’</p>	<p>Treatment as a hurdle to overcome Engaging with the decision End of treatment and moving on</p>
<p>Appearance and its impact on identity: ‘It’s not me looking back at myself’</p>	<p>Impact of being self-conscious about appearance Increased awareness of appearance as a result of treatment Distress and shock due to appearance change Appearance change and identity Adjusting to appearance change</p>
<p>Influence of the views of others: ‘...it doesn’t bother me what people think, but it’s nice to be normal’</p>	<p>Sense of difference – bullying and the desire for ‘normality’ Influence on decision making Support during treatment Impact of the reactions of others</p>
<p>Uncertainty and never being prepared: ‘Until you’ve seen the change, you don’t really believe it’s going to happen’</p>	<p>Knowing what to expect from treatment The decision for treatment Experience as compared to expectations</p>

The Course of Treatment: ‘it is a journey, isn’t it?’

Treatment as a hurdle to overcome

Participants described treatment as a long, staged process that had been a feature in their lives for a long time and the majority of participants had been aware of the surgery from a young age, usually their early teens.

It is a journey isn't it? Because I've been coming for so long. Emily²

I think I were about 14, 15 when they asked me if I wanted it, Chloe

Charlotte said she had ‘always known’ there was a discrepancy with her jaw and Anita first remembered a ‘problem with [her] jaw’ being mentioned when she was just seven years old. Frequent dental appointments had been a feature of participant’s lives, as well as having to wear braces for long periods.

I actually can't remember myself not having braces. I've got no pictures of me without braces ... it's part of me, I can't imagine not having them.

Joe.

The idea of treatment being a journey was represented through descriptions of the ups and downs of the process, for example Anita describes a ‘roller-coaster of emotions’, exacerbated by the long wait for surgery followed by its sudden impact. Surgery was seen as the focal point of the long treatment

² All names used for participants are pseudonyms

process, despite awareness it was not the end. 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'.

Engaging with the decision

Perhaps influenced by the young age at which participants first encountered the idea of treatment, they were not always engaged in the decision and portrayed themselves as having a passive role in this process. Some participants were strongly influenced by their parents' view, which is discussed within the 'influence of the views of others' theme.

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. Emily.

I went along with it. Anita.

This sense of passivity was also seen through descriptions of warding off thoughts of surgery until nearer the time.

I were at such a young age I didn't think much about it at all. And I've not like, read that much into it, only recently. And I think because it's been as long as it has, I've sort of pushed it to the back of my mind and not thought about it at all. Emily.

End of treatment and moving on

The treatment is a slow and lengthy process, which participants had not completed at the time they were last interviewed (i.e. post-surgical orthodontics). The treatment had become part of their lives and some participants viewed this as something to move on from and put behind them.

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.

People were also keen to get to the end of treatment in order to see and experience the 'end result'.

I can't wait to just have it done, get it over with, have me braces off and go out and smile! Chloe

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. Anita and John in particular described feeling a new sense of ambition having had the surgery, giving the opportunity to 'start over' and get on with their lives, for example looking for new jobs.

No regrets at all, none whatsoever. In fact I think probably when I'm, I don't know, twenty odd years older I might look back on this and think it was the best decision that I ever made. John.

I thought I can't do this and I can't do that so it should be that from now on I can do this and I can do that. Anita.

Appearance and its impact on identity: 'It's not me looking back at myself'

Impact of being self-conscious about appearance

Discussion of appearance was central in the accounts of all the participants.

Appearance change formed part of the motivation for treatment for all, 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 led to feeling self-conscious, which was most noticeable in social situations and could make people feel others were focussing on this.

When there's a bigger environment and there's lots of people there and I'm talking to somebody that I might not know then I feel like they'll stare at me. Anita.

Participants spoke about coping with self-consciousness in their daily lives through strategies to disguise the problem or avoid situations when it was more apparent (i.e. eating in front of people).

I don't think I try to hide it. I think I just hid it naturally. ... I don't bite my teeth together. Like, normally I leave my teeth open but close my mouth. Joe.

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.

However, participants also spoke about remaining resilient in spite of their difficulties and keeping their problems in perspective.

There are people that are genuinely handicapped, who have limits in what they are able to do and this is trivial compared to what they have to deal with. John.

Increased awareness of appearance as a result of treatment

Some participants felt they had more appearance concerns as a result of the treatment process. In particular, having to wear braces meant there was iatrogenic visible difference that might on occasion be more visible than the condition itself.

I'm a lot more self-conscious than I used to be, obviously since I got my brace on as well my bottom teeth have straightened up so my front teeth don't join at all. Charlotte.

Some participants commented on their sense of difference emerging through the process of treatment consultations, when aspects of their bite or their appearance itself had been observed as 'incorrect'.

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

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.

Initial distress and shock due to appearance change

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.

It was quite stressful but, it were a bit upsetting but I think it's just the initial shock of looking so different. Charlotte.

Some participants 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

Appearance change and identity

Accompanied by the initial shock of the change in appearance was the sense that participants were questioning their own identity due to these changes, as some no longer felt they resembled 'themselves'.

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

I didn't look like myself, so, yeah, it was quite difficult. Anita

However, John felt his adjustment was helped by noticing his new appearance was similar to when he was younger, which he felt 'reinforced [his] identity'.

Anita also commented on finding reassurance in similarities with her former appearance and reminding herself 'I am still me inside', having initially felt she did not look like 'herself'.

Adjusting to appearance change

Despite the initial emotive descriptions of participants' reactions to appearance change, they went on to describe a process of adjustment that followed. Most still felt a degree of uncertainty but talked about 'getting used to it' over time, even if this process was still on-going.

It's been hard to, you know, get used to, the new, erm, the new me. But I'm finding, like, I've come to terms with it I think. Anita.

Adjustment was influenced by the reduction in swelling, which was often part of the cause of the initial distress. People benefitted from seeing progress occur and gaining a better approximation of their final appearance. However, swelling also added to participants' stress by drawing further attention to their appearance, in a way that was perceived as negative.

When the swelling started to go down I, my confidence come back and I started to feel more normal. Fiona.

You always feel like, quite conscious because there's a lot of swelling ... you still feel conscious that people are still looking at you. Anita.

There was a sense of further change being anticipated and one of the participants felt he would not be able to decide how he felt about it all until he had reached the end of the process.

I think it's going to take a lot longer as well, it's... really weird, I can't explain it because, I don't know, I'm not going to get used to it, I'm not going to try and get used to it until the swelling's gone down. Joe

The degree of change was an important factor for some participants in their acceptance of and adjustment to their altered appearance. Before surgery some did not want to look 'too' different, so were relieved when this was achieved, whereas for others the change was greater than anticipated.

Nothing's changed really. I were glad because I didn't want to look different, that wasn't why I was having the operation done anyway. Fiona

...good and bad days. Erm, but that was just mainly due to the swelling going down and me, myself getting used to how I look, because it is a big change. Emily

Participants also commented on the process of adjustment to change in terms of getting used to not having to cover up the problem any longer and learning to be less self-conscious.

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.

Influence of the views of others:

'...it doesn't bother me what people think, but it's nice to be normal'

Sense of difference – bullying and the desire for 'normality'

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 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 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.

A further overlap with the appearance theme was participants' experience of wearing braces. This made people feel self-conscious, in part due to the stigma associated with having braces at the 'wrong' age and making negative comparisons with peers.

Being 20 years old with braces on, it's not, it's not something you see. I think that's why I don't like them as much as I do. If I'd have been 14 with braces I don't think it would have bothered me because all my friends had braces. Chloe

Influence on decision making

While some participants felt they had made an independent decision about surgery, others were influenced by the opinions of others or sought their agreement with their own decision. The views of parents were 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

Support during treatment

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.

Impact of the reactions of others

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 this 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.

Uncertainty and Never Being Prepared:

‘Until you’ve seen the change, you don’t really believe it’s going to happen’

Knowing what to expect from treatment

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.

I do think I'll be more confident about my appearance. John.

They tell you that it does change you quite a bit but I'll have to wait and see til after, see what I look like. Fiona.

The Decision for Treatment

In making the decision for surgery some participants gave it little thought, as discussed previously in terms of being passive in the process, but some participants also expressed their own certainty about the decision to have treatment.

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.

As soon as I found out about it I wanted it done. Fiona.

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.

It's only a few weeks of pain after it for something that I feel really self-conscious about. Charlotte.

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. The uncertainty about what the condition would be like in future, i.e. if it would get worse, was often mentioned as a motivator for getting the treatment done straight away.

Then there's the risks of not having it done, it can get worse over time, things like that. Joe.

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

Experience as compared to expectations

After surgery participants compared their experiences to what their expectations had been. Everyone commented on their experience being different to what they had expected, but for some this was positive while for others it was negative. Those who felt the process was worse than expected commented on not having appreciated the severity of the operation, the physical impact in the initial stages and the degree of change in appearance, as previously discussed.

I didn't expect it, you know like that first two weeks like, the food dribbling down my face, not being able to talk, do you know like, just not having the energy to do anything for the first, I didn't expect any of that ... didn't think it were going to be that bad. Chloe.

I just thought, oh, you know, quick in and out of surgery, they'll fix my jaw, I'll be home in a couple of days. Fiona.

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.

I kind of half expected, come out of my operation and be like 'wayhey, now look!' and that was it, but it's just dragged on a little bit more than that. Chloe.

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.

When the experience was better than expected, participants felt relief and increased satisfaction with the process, which assisted their adjustment.

I expected it to be of a benefit because everything I learned of up until that point in the course of the treatment suggested that it would be of a benefit. A complete benefit, as in something that I wouldn't feel even remotely negative about? No, I wasn't expecting that. John

I just expected it to be a lot worse than it actually was. I was really worried about it, I think before like the morning of the operation, everything was a lot simpler and a lot easier and a lot quicker than I expected it to be really, a lot better. Charlotte.

Discussion

This is the first qualitative study to follow patients through orthognathic treatment from pre to post-surgery and the themes derived from the qualitative data capture the most salient features for the participants. Treatment had been a major focus in participants' lives; they had been anticipating the surgery often 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. The immediate aftermath of surgery was difficult due to the physical side-effects in addition to emotional reactions related to significant appearance change. Participants described a process of adjustment to changes in their appearance and the need to incorporate these changes into their identity.

The role of significant others was apparent in several areas of participants' accounts. Friends and family played a part in the decision-making and preparation for surgery, as well as providing support during the process. Participants' perceptions of how they were viewed by others were prominent; they referred back to being bullied at school and the lasting impact this had in terms of a desire to be 'normal'. Others' reactions were also highly valued after surgery as a source of feedback. There was a high level of uncertainty involved in participants' experience of treatment. They had been through the decision-making process and some continued to weigh this up due the uncertainty about the outcomes of surgery. After the operation participants reflected on how their experience had compared to their expectations and how they had coped when expectations were not met.

The psychometric data contextualised the sample, showing that participants were not suffering from depression before or after surgery; a result replicated previously (Rispoli et al., 2004). Before surgery there was some mild to moderate anxiety but no more than mild anxiety afterwards, which has been shown in other studies (Azuma et al., 2008). Participants did not show elevated fear of negative evaluation or serious appearance concern before or after treatment despite qualitatively reporting self-consciousness and dissatisfaction with appearance.

The DAS-24 did not show any statistically significant change from pre to post surgery, but the BFNE showed a significant improvement for one participant.

This could potentially be accounted for by participants' concern about their appearance after surgery due to swelling, so improvements may not be shown at this stage. Previous research has shown deterioration in well-being in the immediate post-operative phase and improvement, or return to previous functioning, only at the later six-month follow-up (Lee et al., 2008). This demonstrates the value of qualitative material to enhance understanding of an experience, as the complex and emotional process described by participants is not captured by standardised measures. This could also relate to the choice of measures so there is a need to pilot further measures of appearance concern in this context.

Theoretical Implications

Decision-making and adolescence

Participants talked about the young age at which the idea of surgery had been introduced. Although the final decision was usually made later, participants were going through this process during adolescence; an important transitional stage. Physical and social development can mean appearance concerns become more prevalent, due to increased focus and value placed on appearance (Rumsey & Harcourt, 2004).

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 & 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 which 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 (Rumsey & Harcourt, 2004). 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 & 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 appreciate patients' coping responses prior to surgery, as this may impact on their expectations and their adjustment after surgery.

Communication and expectations

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 & 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 spoke about the value of the support from 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.

The provision of information links closely to patients' expectations about the treatment process and outcomes. This study provides some insight into the impact of patient expectations and how these compare to experience. Most participants reported their experience to be worse than they had expected, but two of the participants felt it had been better than expected. 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).

This seems to be mirrored in the current participants' accounts, although conclusions cannot be drawn from such a small sample. The two participants whose experience of surgery was better than expected expressed the strongest satisfaction with the results, whereas those who were shocked by the outcomes reported more distress. 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.

Managing appearance difficulties

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. Models of stigma may be useful in understanding how people cope with concerns about their appearance, for example through avoidance or concealment, due

to either 'felt' or 'enacted' negative responses from others (Thompson, in press).

There is a lack of information about how people might positively adapt to living with a dentofacial condition and therefore not wish to have surgery. There is some suggestion from current participants that coping with the problem was influenced by the knowledge that it would at some point be 'fixed'. More research is needed to determine the characteristics of people of who decline surgery and factors that may influence this decision. As previously discussed, if attention is drawn to a difficulty at a young age and treatment offered this may influence the patient's perception of its necessity.

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., 2009b).

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 (Rumsey & Harcourt, 2005).

Adaptation to appearance change

Appearance research has been hampered by an association with vanity, despite appearance concern being increasingly prevalent in society (Rumsey & Harcourt, 2005). Orthognathic patients may be reluctant to state that their primary motive for treatment is appearance for this reason. Clinicians may be less likely to discuss appearance issues due to a desire to dissociate this procedure from cosmetic surgery, which may be particularly important in countries where aesthetic motives are less acceptable, or would not warrant treatment (Siow et al., 2002). However, regardless of patient motivation for treatment, surgery is designed to alter appearance to more closely approximate a societal norm and patients may have difficulty adapting to these changes.

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).

A more comprehensive model for understanding the complexities of appearance concern developed by the Appearance Research Collaboration could be usefully employed to gain a better understanding of adjustment and identify strategies that may be used to enhance adjustment (Thompson, in press). This framework highlights a wide range of factors influencing beliefs

about appearance, many of which were raised by participants, such as parental and peer influences, salience and valence of appearance and safety behaviours such as concealment. It identifies the need to consider early experiences in relation to the development of appearance concern and the impact of social and cultural factors, for example the internalisation of societal ideals of appearance and body image. 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.

Satisfaction

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.

All participants were satisfied with treatment and although they were still adjusting they were able to say it had been of benefit to them, despite many having distressing experiences immediately after surgery. Comments suggest they were able to appreciate the technical result but this did not necessarily match their emotional acceptance of changes. There is also the issue of cognitive dissonance in participant accounts of satisfaction, as after such a lengthy emotional and physical commitment to treatment it may be difficult for patients to admit, even to themselves, that it was not necessary or they were dissatisfied in some way. John articulated this by saying:

If I was to think that the fact that I've undergone the treatment now was for a trivial reason ... it would make it seem ridiculous and it would have amounted to a lot of wasted time. John

The role of social support

As previously discussed there is an important role for significant others, as well as professionals, in influencing patients' decision for surgery and feelings towards their appearance. The views of others are influential after surgery, as patients seek feedback on their appearance from external sources, perhaps as a way of reducing the uncertainty they feel about their sense of self following treatment (Vartanian, 2009). Social support has a positive influence on satisfaction and acceptance of appearance is associated with greater satisfaction (Chen et al., 2002). Therefore it is important to gauge support available to patients during treatment and for significant others to be aware of patients' sensitivity to comments about their appearance following surgery.

Clinical Implications

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).

Professionals have a pivotal role in patient decisions so maintaining awareness of the doctor-patient power imbalance is essential, especially for younger patients who may be sensitive about their appearance and more influenced by the views of others. Patients should be encouraged to evaluate the pros and cons of treatment, consider how they may feel about the consequences of surgery and their expectations evaluated to ensure they are realistic and well-informed. Involving significant others in treatment planning provides patients with valuable social support and allows clinicians to be aware of potential influences on decision-making.

Patients may experience distressing low mood in the immediate aftermath of surgery. They should be informed about possible negative effects of treatment, with a focus on reducing their anxiety about the process. Advances in the

integration of psychology into orthognathic teams may make it be possible to enhance patient experience by providing support at critical times as well as potentially offering alternative treatments for issues such as social anxiety and low self-esteem. Psychological interventions provide the potential to mediate appearance concern and adjustment to appearance change by targeting beliefs about appearance and identifying issues such as negative social comparisons, fear of negative evaluation and discrepancy between expectations and outcomes.

Limitations

Attention was paid to ensuring the validity of the data by keeping clear records of the analytic process and considering reflexivity to examine the researcher's own position in relation to the data. Interviews were carried out within the clinic for the convenience of the participants and it was made explicit that the researcher was not part of the clinical team. However, it is possible responses were affected by the researcher being viewed in a similar position of power to clinicians and not distinct enough from the staff team. The nature of qualitative research does not allow broad generalisations, so the experience of these participants may not be representative. In particular, as the focus was on patients in the younger age group it is unclear whether older patients experience similar issues.

The photo elicitation aspect of the study had limited success. This did not impact on the validity of the study because the photos were not intended to be additional data, but a means to a more in-depth discussion of experience.

Photo elicitation is designed to inspire collaboration but this was difficult to achieve due to limited contact with the participants. Given the opportunity to form a relationship with the researcher, participants may have felt more able to engage in this aspect of the study.

Areas for Future Research

The importance of improving communication between patients and clinicians has been highlighted by this study, as well as 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. Analysis of consultations with patients could clarify the apparent mismatch between information patients are given and how they interpret this.

No other in depth qualitative studies have been carried out in this area so it would be beneficial to expand this to different age groups and additional time points in the treatment process. Following patients for a longer period during treatment may provide a better insight into the emotional processes involved, as could methods of data collection such as daily diaries which have been used to good effect in health psychology research (Furness & Garrud, 2010).

The role of more inclusive biopsychosocial models in orthognathic research also demands attention. In particular, there has been a lack of consideration of cultural diversity and its impact. The potential role for psychology within orthognathic treatment is receiving some recognition but requires further investigation to determine what contribution could be made to enhancing patient experience.

Conclusions

The aims of the study were to explore patients' motivations, decision-making and expectations about treatment, their feelings towards appearance and adaptation to appearance change. 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 appreciated before. This study provides a more in depth understanding of patients' experience of undergoing orthognathic surgery, which in combination with existing literature provides avenues for development of clinical practice and directions for future research. Orthognathic surgery can provide significant benefits to patients, but this is rarely a straightforward process and more could be done to improve patient experience.

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Appendix

Appendix I: Letter of journal approval

Appendix II: Guidelines for authors: The Cleft Palate-Craniofacial Journal

Appendix III: Guidelines for authors: Social Science and Medicine

Appendix IV: Ethical approval letter

Appendix V: Copies of measures

- i. Derriford Appearance Scale
- ii. Brief Fear of Negative Evaluation Scale
- iii. Hospital Anxiety and Depression Scale
- iv. Likert satisfaction scales

Appendix VI: Consent form

Appendix VII: Information sheets

Appendix VIII: Interview schedules

Appendix IX: Letter inviting participants for follow-up

Appendix X: Examples of analysis work

- iii. Initial noting and themes
- iv. Individual participant table of themes

Appendix I

Letter of Journal Approval



Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

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Telephone: 0114 2226550
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29th March 2011

Morna Liddle
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Morna

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Cleft-Palate and Craniofacial Journal

Research Report: Social Science and Medicine

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely

Dr Rebecca Knowles
Research Tutor

Appendix II

Guidelines for Authors:

The Cleft Palate-Craniofacial Journal

Author Guidance for the Cleft Palate-Craniofacial Journal

(Extracts taken from full document)

Scope

The Cleft Palate–Craniofacial Journal (CPCJ) is directed to a multidisciplinary readership of clinicians and scientists interested in craniofacial anomalies, including cleft lip and cleft palate. The CPCJ publishes original research articles, clinical reports, brief communications, articles related to new ideas or innovations, letters to the editor, editorials, invited book reviews, and meeting announcements.

Format

The CPCJ follows guidelines published in the American Medical Association Manual of Style. Manuscripts should be typed double-spaced with 1" margins, left justified, and use a standard 12-point font. Pages should be numbered consecutively in the upper right hand corner, beginning with the second page. Do not print a running title. Turn off the word processing program's hyphenation feature and "smart quotes" feature before typing. Headings must be used to designate the major divisions of the manuscript. Up to three levels of headings may be used.

Appendix III

Guidelines for authors:

Social Science and Medicine

Author Guidance for Social Science and Medicine

(Extracts taken from full document)

Scope

Social Science & Medicine provides an international and interdisciplinary forum for the dissemination of social science research on health. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and organization. We encourage material which is of general interest to an international readership.

Reference style

All publications cited in the text should be presented in a list of references following the text of the manuscript. In the text refer to the author's name (without initials) and year of publication e.g. "Since Peterson (1993) has shown that..." or "...as claimed elsewhere (Kramer, 1994)". For more than 2 authors the first author's name and "et al." should be used e.g. (Annandale et al., 1994). The manuscript should be carefully checked to ensure that the spelling of authors' names and dates are exactly the same in the text as in the reference list. Responsibility for the accuracy of bibliographic citation lies entirely with the author(s). Authors are also responsible for the accuracy of the content of the references.

References should be given in the following form:

Adkins, L. (2002). *Revisions: Gender and Sexuality in late modernity*. Buckingham: Open University Press.

Macintyre, S., & Ellaway, A. (2000). Ecological approaches: Rediscovering the role of the physical and social environment. In L.F. Berkman, & I. Kawachi (Eds.), *Social epidemiology* (pp. 332-348). New York: Oxford University Press.

Glenton, C. (2003). Chronic back pain sufferers - striving for the sick role. *Social Science & Medicine*, 57, 2243-2252.

Appendix IV

Ethical Approval Letter

10/H0408/79 Favourable opinion with conditions letter reissued to correct document name
22/09/2010



National Research Ethics Service

Nottingham Research Ethics Committee 2

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 0115 8839368
Facsimile: 0115 9123300

24 August 2010

Miss Morna Liddle
Trainee Clinical Psychologist
Sheffield Health and Social Care NHS Foundation Trust
Clinical Psychology Unit
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Dear Miss Liddle

Study Title: How do people experience the process of having
appearance-altering Orthognathic surgery?
REC reference: 10/H0408/79
Protocol number: 3

The Proportionate Review Sub-committee of the Nottingham Research Ethics Committee 2 Research Ethics Committee reviewed the above application at the meeting held on 23 August 2010.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Add a point on the consent form asking consent to be audio recorded in the interview.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the
National Patient Safety Agency and Research Ethics Committees in England

10/H0408/79 Favourable opinion with conditions letter reissued to correct document name
22/09/2010

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		02 August 2010
Investigator CV	Andrew Thompson	09 July 2010
Protocol	3	01 March 2010
Appendix E - Instruction sheet for keeping a photo journal	3	01 March 2010
Appendix G - Doctorate in clinical psychology, University of Sheffield - Confidentiality form	3	01 March 2010
Appendix H - Research proposal costing form	3	01 March 2010
REC application	51420/13974 3/1/723	29 July 2010
Covering Letter		02 August 2010
Interview Schedules/Topic Guides	3	01 March 2010
Participants follow-up letter	3	01 March 2010
Participant Information Sheet: Appendix A	3	01 March 2010
Participant Consent Form		
Questionnaire: Brief fear of negative evaluation scale	3	01 March 2010
Questionnaire: Appendix C - Copies of measures	3	01 March 2010
Questionnaire: Hospital anxiety and depression scale (HADS)	3	01 March 2010
Questionnaire: The derriford appearance scale (DAS 24)	3	01 March 2010
Referees or other scientific critique report		13 April 2010

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

10/H0408/79 Favourable opinion with conditions letter reissued to correct document name
22/09/2010

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

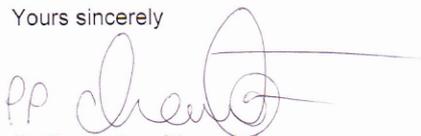
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0408/79

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Martin Hewitt
Chair

Email: heather.harrison@nottspct.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: R&D office for NHS care organisation at lead site - Ms Ramila Patel

Appendix V: Copies of Measures

Derriford Appearance Scale: removed from e-thesis due to copyright legislation

Brief Fear of Negative Evaluation Scale

Hospital Anxiety and Depression Scale: removed from e-thesis due to copyright legislation

Likert satisfaction scale

Brief Fear of Negative Evaluation Scale

Read each of the following statements carefully and indicate how characteristic it is of you according to the following scale:

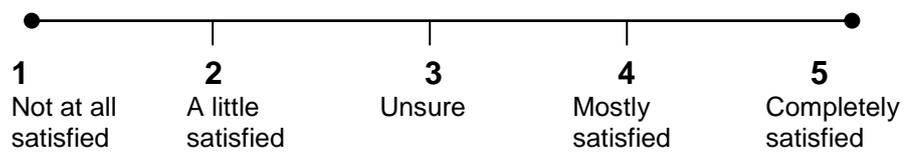
- 1 = Not at all characteristic of me
- 2 = Slightly characteristic of me
- 3 = Moderately characteristic of me
- 4 = Very characteristic of me
- 5 = Extremely characteristic of me

- _____ 1. I worry about what other people will think of me even when I know it doesn't make any difference.
- _____ 2. I am unconcerned even if I know people are forming an unfavourable impression of me.
- _____ 3. I am frequently afraid of other people noticing my shortcomings.
- _____ 4. I rarely worry about what kind of impression I am making on someone.
- _____ 5. I am afraid others will not approve of me.
- _____ 6. I am afraid that people will find fault with me.
- _____ 7. Other people's opinions of me do not bother me.
- _____ 8. When I am talking to someone, I worry about what they may be thinking about me.
- _____ 9. I am usually worried about what kind of impression I make.
- _____ 10. If I know someone is judging me, it has little effect on me.
- _____ 11. Sometimes I think I am too concerned with what other people think of me.
- _____ 12. I often worry that I will say or do the wrong things.

Likert satisfaction scale

How would you rate the success of your operation in terms of your satisfaction with your facial appearance following treatment?

Please circle the number which best applies to you.



Appendix VI
Consent Form

Sheffield Teaching Hospitals

NHS Foundation Trust

CHARLES CLIFFORD DENTAL HOSPITAL

Department of Oral & Maxillofacial Surgery

Wellesley Road, Sheffield, S10 2SZ

Telephone 0114 2717878

Consent Form

Title of Project: A study of how people experience the process of having Orthognathic surgery.

Name of Researchers: Miss Morna Liddle, Dr Andrew Thompson, Dr Sarah Baker and Dr Keith Smith.

Participant Identification Number for this project:

- | | Please initial box | |
|---|---------------------------|--------------------------|
| | Yes | No |
| 1. I confirm that I have read and understand the information sheet dated 01.03.2010 (version 3) for the above project and have had the opportunity to ask questions. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and this will not affect my medical care in any way. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I agree to take part in the above research project. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I agree to my interviews being audio recorded. | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I understand that my responses will be made anonymous before analysis. I give permission for members of the research team to have access to my anonymous responses. (I understand that relevant sections of data collected during the study may be looked at by individuals from Sheffield Teaching Hospitals NHS Foundation Trust or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records). | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I give permission for anonymous quotes to be used in presentation, publications and teaching | <input type="checkbox"/> | <input type="checkbox"/> |

Name of Participant

Date

Signature

Morna Liddle
Trainee Clinical Psychologist

Date

Signature

N.b. You will be given a copy of this form and the researcher will also keep a copy.

Appendix VII

Information Sheets

A Study about the Impact of Having Orthognathic Surgery

You are being invited to take part in a research study and the information below is designed to help you decide whether you want to take part. It is important for you to understand what the research is for and what it will involve if you decide to take part. Please read the following information carefully and take time to decide whether or not you want to take part. Please let us know if you have any questions or if anything is not clear.

➤ **What is the purpose of the study?**

The purpose of this study is to find out more about what the process of having Orthognathic surgery is like for patients. We want to talk to patients who are having this surgery to find out how they feel about it and how it affects the way they feel about themselves and the reactions they get from others. We hope that the study will help us to make sure that patients get the support they need when having this treatment.

➤ **What will happen if I agree to take part?**

The study has three parts, an interview and some questionnaires before your surgery, keeping a photo log/journal following your surgery and then another interview and some questionnaires around 8 weeks after your surgery.

First Interview

This would be around one week before your surgery. You will be interviewed by Morna Liddle (lead researcher), who will ask you questions about your expectations of treatment, feelings about your appearance and support you have from those around you. This will last about an hour and you will also be asked to fill in some short questionnaires.

Photo Journal

Having surgery means that you will be going through a physical change and we are interested in how this feels and the impact it has on your life. To help capture this as it happens we will ask you to take photographs of anything that is important to you about your experience of having this surgery, either with your own camera or the one provided. This will focus on changes you notice in the way you feel and look, and the role of important people in your life. You do not have to take photos of yourself; they can be of anything that is meaningful to you

about this process. We will also give you a diary in case you want to jot down any details about your experiences that may jog your memory when we meet again. We would really like you to be creative in what you take pictures of and write about but if you do not do this, for any reason, we would still like you to come to the second interview to talk about your experiences.

Second Interview

Around 8 weeks after your surgery we would like to interview you again and if you have taken any photos we will look at these together during this interview and talk about what they mean to you. The second interview will focus on what your experience of surgery has been like and any changes you have noticed since the operation. This will also last about an hour and you will be asked to fill in the same questionnaires again.

➤ **Do I have to take part?**

No. You can decide whether you wish to take part and this will not affect your treatment in any way. If you do decide to take part you can change your mind and withdraw from the study at any time. You do not have to give a reason for this and it will not affect your treatment.

➤ **When and where will the interviews take place?**

The interviews can take place at the Charles Clifford Dental Hospital clinic, either when you are attending an appointment or at another time. We would like to interview you before you have your surgery and then eight weeks afterwards to find out whether you feel things have changed.

➤ **Will taking part affect my treatment?**

No. Taking part in this study will not affect your treatment in any way.

➤ **Will the information I give be confidential?**

All the information you give will be treated in confidence and your name will not be used in any reports that are written about the study. However, if you tell us anything in the interviews that makes us concerned about your safety or the safety of others we may need to discuss these concerns with other people. This would be discussed with you before any information was shared with anyone not involved in the research.

➤ **What will happen if I feel upset during the interviews?**

If you seem upset in any way during the interviews the interviewer will check with you about whether you want to carry on and remind you that you can leave or take a break at any time. If they have serious concerns about your safety and well-being this might need to be discussed with the medical team treating you in the first instance and this would be discussed with you.

➤ **Is there anything to worry about if I take part?**

There are no risks involved in taking part in this study but if there is anything you are unhappy about we will be happy to discuss your concerns at any time. You can stop taking part in the study at any point and you do not have to answer any questions that you do not feel comfortable with. What you tell us will be kept private and will not affect your medical care in any way.

➤ **What do I do if I want to complain about the way the study is being carried out?**

If you have *any* cause to complain about *any* aspect of the way in which you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you and are not compromised in any way because you have taken part in a research study. You can make a complaint by contacting the Patient Advice and Liaison Service (PALS) (details below). In the first instance you may also contact the supervisor of the research, Dr Andrew Thompson using the details below.

Dr Andrew Thompson
Senior clinical lecturer
Foundation Trust

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield
S10 2TN
Tel: 0114 222 6637

PALS Manager
Sheffield Teaching Hospitals NHS

Patient Partnership Department
B Floor, Royal Hallamshire Hospital
Glossop Road
Sheffield
S10 2JF
Telephone: 0114 271 2450
Email: pals@sth.nhs.uk

➤ **Who has reviewed the study?**

This study has been reviewed by the Nottingham Research Ethics Proportionate Review Sub-committee.

➤ **What if I need to get in contact with the researcher?**

You are free to contact the researcher about any aspect of the project at any time using the details below. The project co-ordinator is Morna Liddle, who can be contacted via the Research Support Officer at the Clinical Psychology Unit. Messages will be taken and passed on to the researcher, who will then get in contact with you as soon as possible. The Research Support Officer is not able to answer any queries directly.

Morna Liddle

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield, S10 2TN

Telephone: 0114 2226650
Email: pcp08ml@sheffield.ac.uk

➤ **What will happen after the interviews are finished?**

A report will be written about the findings of the study once all the interviews are finished. The results from the study will be prepared for presentation and publication after the completion of the project. You will be able to tell us whether you would like a summary of the results to be sent to you. You will also be able to contact us if you have any further questions or concerns.

Thank you very much for reading this!

Instruction Sheet for keeping a photo journal

During our first meeting we talked about taking some photos or jotting down some of your thoughts and experiences to document the changes you are going through after you have your surgery. These instructions are a reminder of what we discussed so that you understand what you have been asked to do.



- ❖ We would like you to take photos or write down a few words about anything relating to changes you notice after your surgery. We want to capture what is important to you as it happens. This might be about how you are feeling, things you are thinking about, how other people react to you or any other experiences you think are important.
- ❖ Try to take photos that focus on the most important parts of your experience of going through the process of having Orthognathic surgery. The photos can be of anything you like, as long as they are related to some aspect of how things have changed for you since the surgery, i.e. you do not necessarily have to take photos of your facial appearance. For example, you might see a friend for the first time since your surgery and what they said was important to you. You could photograph the person, the place you met, an object that reminds you of them. Anything at all that is a reminder for you about what was important about that experience.
- ❖ You will be sent a letter to remind you of when we are next going to meet, which will have a stamped addressed envelope for you to return the disposable camera if you have used it. If you have used your own camera you will have the option to email pictures to the researcher or bring them along to the next interview.
- ❖ We can look at the photos together in the interview and talk about what the pictures mean to you and what you were thinking about when you took them. If you have decided to write things down you can bring this with you on the day for us to look at together.
- ❖ If you don't manage to take any photos or write anything down we would still like you to come along to the second interview and tell us about your experiences.

If you have any questions or concerns about any part of this process please contact Morna Liddle at the Clinical Psychology Unit, Department of Psychology, University of Sheffield, Western Bank, S10 2TN. Email: pcp08ml@shef.ac.uk. You can telephone the Research Support Officer at the Clinical Psychology Unit on 0114 2226650. They cannot answer your questions but messages will be passed on to Morna, who will get back to you as soon as possible.

Thank you very much for taking part!

Appendix VIII

Interview Schedules – Time 1 and Time 2

Interview 1

- 1) Tell me about how you have come to be having Orthognathic surgery.

When did you first have/notice a problem?

How did you find out about this surgery?

- 2) How did you go about making the decision to have surgery?

Did you talk to anyone about it?

Did anyone help you make the decision?

What was important for you when making a decision?

- 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?

How do you think it will affect the way you feel about yourself?

How do you think it will affect the way you look?

How do you think anything else will be different?

- 5) What do you most want to get out of having this surgery?

General prompts will be used throughout, such as 'can you give me an example of that?', 'can you tell me a little bit more about that?' etc.

Interview 2:

How have things been since we last met?

Key experiences:

Can you tell me about any experiences you had whilst going through this treatment that stand out for you? What was important about that?

Change:

What's different for you since you had the surgery?

Do you feel differently about yourself/the way you look?

How do you feel about changes you've noticed?

Photos (if applicable):

How did you find taking photos to capture your experience of having this surgery?

How did you decide what to take photos of?

Can you tell me about some of the photos you took and what they represent?

Can you tell me about any times when you wanted to photograph something and didn't, for whatever reason?

Reflecting on Interview1:

Thinking back to what you wanted to get out of surgery (prompt with information from interview 1), what do you think about that now?

Reactions of others:

How have other people reacted to you since having this surgery?

Has having the surgery affected your relationships in any way?

Feelings towards the process:

How has your experience compared to what you thought it would be like?

How do you feel about having had the surgery looking back on it now and what you've been through?

Appendix IX

Letter inviting participants to follow-up

Sheffield Teaching Hospitals 

NHS Foundation Trust

CHARLES CLIFFORD DENTAL HOSPITAL

Department of Oral & Maxillofacial Surgery

Wellesley Road , Sheffield, S10 2SZ

Telephone 0114 2717878

DATE

Dear

RE: Study about the Impact of Having Orthognathic Surgery

Thank you again for taking part in the first part of this study by being interviewed before your surgery. Now that you have had your surgery I would very much like to meet with you and interview you again, as we discussed at our first meeting. I would like to meet with you after you attend your appointment at the clinic on DATE. I hope this is convenient for you but if it is not please contact me as soon as possible using the details below.

At our last meeting we also talked about the idea of taking some photos to capture some of the important elements of your experience of surgery and any changes you went through, as they were happening. If you were able to take any photos please return the camera in the stamped addressed envelope enclosed and these will be developed before our next meeting. Alternatively, if you have used your own camera you can email photos to the address below or bring them along with you. If you did not manage to take any photos for any reason I would still very much like to meet with you again to talk to you about your experiences. If you wrote down anything about your experiences in the diary then please bring this along with you as well.

I look forward to meeting with you again. If you need to contact me about any aspect of the study please do so on 0114 222 6650, via staff at Charles Clifford or email pcp08ml@shef.ac.uk. If you call the above number you will speak to the Research Support Officer at the Clinical Psychology Unit, who cannot answer any queries but will pass on a message to me and I will get in touch with you as soon as possible.

Many thanks again for taking part in the study.
Best wishes

Morna Liddle
Trainee Clinical Psychologist

Appendix X

Examples of analysis work:

Initial noting and themes

Individual participant table of themes

Initial Themes:

133 R: So, do you think, so you said that you, you will be, that your appearance will be something that will
134 be different, do you think it's going to change the way you look?

135 P: Yeah, I feel quite, I think so, quite significantly, erm...yeah, because like obviously since I was
136 younger it's been mentioned and then it was always the dentist and then it's like, you know, the
137 dentist has been a big part of my life (laughs)

138 R: (laughs) yeah

139 P: so it's like, you know, maybe it will mean I don't have to come to the dentist as much (laughs), erm,
140 but, yeah, I think it will make a big difference to my appearance, erm, because like, there's lots of,
141 erm, like with Asians as well there's lots of functions and there's always loads of people there and,

142 you know, you just feel like sometimes, like even like people that I know, they might just like be
143 staring, I feel like they're staring at me but they, I don't know, so in that way it might, you know, be a
144 bit, when people are coming up to you, when they're talking to me they won't look at my mouth
145 (small laugh).

12

Initial noting
Black - conceptual
Red - linguistic
Blue - (dis)course

Hesitant
Expect significant
change
Focus on treatment,
part of life
Sense of her caught
up in this process

Practical changes
Big - degree of change
change in appearance
cultural values of
appearance
social functions
feels they are
staring, as opposed to
they are staring
Negative attention
Self-consciousness
because of appearance
hope for less
attention on
mouth...

Linking social
confidence to
appearance/attractiveness.

List of themes and subthemes for participant 9

Themes and subthemes	Quotes	Line
<i>Being 'normal' and fitting in</i> The problem makes me different Desire to feel 'normal' Bullying and staring	People looked at me Didn't feel like everybody else You can tell a difference just wanted to fit in nice to be normal wanted to be normal People used to laugh at me They won't always be staring Used to get bullied call me a horse	190 151 76 145 146 141 16 194 162 163
<i>Avoidance and Uncertainty</i> Don't think about it Don't know what it will be like Didn't believe advice given Not what I expected	If I think about it I'll get scared Put it to the back of your mind Pushed it to the back of my mind Don't know until I've had it done Have to wait and see Don't know how it'll affect me Oh no, it'll be alright They'll be exaggerating Didn't prepare myself Knew it was going to be swelled up but not that bad Bigger than I thought	95 26 41 82 60 207 35 218 39 18 214
<i>Security and Certainty</i> Sure of the decision Would do it again Secure in myself	I found out about it I wanted it done My choice and I said yeah I said I wanted it just said yeah go through it again to be where I am now worth it in the end Not bothered what other people think Still me It's me, isn't it?	52 36 7 40 242 218 64 181 79
<i>Adjustment and Change</i> Coping with change Regret and anger Impact of on-going change	looked horrible thought I was ugly Nothing's changed subtle so it doesn't matter Wished I'd not had it done Thought it had made me uglier Couldn't see it getting better Hated myself Changing every week Swelling going down, felt better.	13 236 90 99 9 236 24 25 174 65