
Psychological Aspects of Dentofacial Discrepancy and Orthognathic Treatment

Fiona Siobhán Ryan

BDS(Hons), MFDS RCS, MSc, MOrth RCS, FDSOrth RCS

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Abstract

This mixed methods study, conducted in four sections, examined a number of key areas in relation to dentofacial discrepancy and orthognathic treatment:

Chapter 1: Pre-treatment psychological characteristics of orthognathic patients

This was a cross-sectional study using validated questionnaires to assess the pre-treatment psychological profile, personality, quality of life, and perceptions of appearance of 68 orthognathic patients. These factors were compared with normative values and significant differences were found between the patients and normative population for several psychological traits.

Chapter 2: Impact, motivations, and expectations in relation to orthognathic treatment: A qualitative study

This was a qualitative study exploring the impact of dentofacial deformity, orthognathic patients' motivations for, and expectations of, treatment. Data were collected from 18 pre-treatment patients using in-depth interviews and these were analysed using the Critical Qualitative Theory method. The full range of impacts, motivations, and expectations was analysed and reported, together with a clinically useful typology of patients based on expectations.

Chapter 3: Social anxiety in orthognathic patients

This study involved assessing social anxiety in orthognathic patients. The Brief Fear of Negative Evaluation Scale was used. As no UK normative data existed, initially a national survey was conducted of a random sample of 1196 individuals from the general UK population to establish norms for social anxiety with which to compare the cohort of 61 pre-treatment orthognathic patients. The results revealed that orthognathic patients had significantly higher levels of social anxiety than the general population.

Chapter 4: Shared decision-making in orthognathic treatment

There is increasing evidence that the extent to which patients are involved in their treatment decisions may affect outcomes. In this study, the extent to which clinicians

involved 61 orthognathic patients in treatment decision-making was assessed using the OPTION scale. The results revealed overall low levels of shared decision-making and reasons for this are discussed.

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I. **Ryan FS, Moles DR, Shute JT, Clarke A, Cunningham SJ**

Normative values of fear of negative evaluation in the general population.
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Social anxiety in orthognathic patients.

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Introduction: Psychological aspects of
dentofacial discrepancy and
orthognathic treatment – an overview of
this research



Overview of this research

Introduction

Dentofacial discrepancy, also known as dentofacial deformity or disharmony, has been defined as a '*malformation of the dentofacial complex with resultant disabling disharmony in size and form, as well as function*' (Mosby, 2007). The presence of such a defect can adversely affect an individual's oral health, appearance, function, speech, and general well-being (Proffit and White, 1991). The condition is relatively common, with estimates of a quarter of a million potential orthognathic patients in the United Kingdom (Sandy *et al.*, 2001). Indeed, the number of orthognathic procedures is increasing every year, according to hospital episodes statistics (Moles and Cunningham, 2009). Individuals present for treatment for a number of reasons, including problems with speaking or eating, dissatisfaction with their appearance, psychosocial issues, or a combination of these factors (Ryan *et al.*, 2012).

Dentofacial deformity has been quoted as being the most difficult oral condition to treat, due to the fact that perception of outcome is largely subjective (Cohen and Jago, 1976; Esperão *et al.*, 2010). The goal of orthognathic treatment is not to create physical perfection but to correct the defect as the patient sees it (Cunningham *et al.*, 1995). Despite this, satisfaction rates are generally high, with most studies reporting over 90% of patients being happy with the outcome of treatment (Garvill *et al.*, 1992; Finlay *et al.*, 1995; Cunningham *et al.*, 1996; Motegi *et al.*, 2003; Modig *et al.*, 2006; Rustemeyer *et al.*, 2010). However, an important minority remain dissatisfied. The reasons for this have proven difficult to verify, but it has been suggested that poor patient preparation, psychological profile, source of motivation, and unrealistic expectations may play a significant role in dissatisfaction with long-term outcomes. Although there has been a relatively large body of research examining many of these factors, frequently the pooled results are equivocal or inconclusive. Some postulate that it is impossible to identify either the factors which lead to dissatisfaction or the 'bad risk' orthognathic patient who is likely to be dissatisfied (Pogrel and Scott, 1994).

Limitations of the methodology adopted in previous studies have contributed to the lack of conclusive evidence, however, high level quantitative or qualitative studies are difficult to conduct in this field due to the fact that the alternative to orthognathic treatment is often no intervention and thus it would not be ethical to undertake randomised controlled trials in most situations (British Association of Oral and Maxillofacial Surgeons, 2013). With regards to past research, there remains no consensus on which psychological factors to assess, with a large range of conditions and traits being examined on a relatively small number of patients. Further targeted research using both quantitative and qualitative methods is needed in order to provide more in-depth understanding of these issues. However, as research methods progress, increasingly robust evidence is emerging. The aim of research in this area is to identify a set of easily-measurable characteristics which predict those individuals who may not be satisfied with physical treatment alone. Other treatment modalities which may be more suitable could be offered either in conjunction with, or instead of, orthognathic treatment, with the ultimate goal of improving outcomes for all involved in this care pathway.

Principal research questions

This study aimed to look at a number of key areas in orthognathic treatment, in particular, the baseline pre-treatment psychological profile of orthognathic patients, the impact of dentofacial deformity, expectations of treatment and motivating factors, social anxiety in orthognathic patients, and patient involvement in orthognathic treatment decision-making. This research project was divided into four main parts and each section is described in a separate chapter with its own abstract. The four parts are:

Chapter 1. Pre-treatment psychological characteristics of orthognathic patients

The psychological profile of orthognathic patients has been subject to much scrutiny in the past, with no general consensus on whether these individuals encompass a distinct psychological group with differences from the general population (Kiyak *et al.*, 1981, 1982a,b; Flanary *et al.*, 1990; Finlay *et al.*, 1995; Kindelan *et al.*, 1998; Phillips *et al.*, 1998; Bertolini *et al.*, 2000; Cunningham *et al.*, 2000a; Stirling *et al.*, 2007; Williams *et al.*, 2009; Alanko *et al.*, 2010; Burden *et al.*, 2010; Kovalenko *et al.*, 2012). Limitations

of some of these studies include mixed study groups (for example including patients who have finished treatment or those with craniofacial or acquired defects), not using validated instruments, administering questionnaires before surgery rather than before all treatment has commenced, retrospective data collection, and inappropriate comparison groups.

This study aimed to address some of these issues by recruiting a cohort of orthognathic patients with congenital dentofacial discrepancies, prior to commencement of any treatment and utilising easy-to-use, validated questionnaires for data collection. The results were then compared with established normative data. The choice of which psychological factors to assess was established following a review of the literature of which conditions are most likely to affect orthognathic patients, together with clinical experience and advice from mental health experts. These factors included:

- Anxiety
- Depression
- Appearance related concern
- Body image disturbance
- Quality of life
- Personality

Chapter 2. Impact, motivations, and expectations in relation to orthognathic treatment – a qualitative study

Impact, motivations, and expectations in relation to dentofacial deformity and orthognathic treatment have been researched for a number of years. The vast majority of research has focused on quantifying the relative hierarchical importance of these factors and most studies have used self-report questionnaires to gather this data. While much is now known regarding what percentage of individuals seek treatment for certain reasons or in what proportion expectations are met, the in-depth meaning of these issues has not fully been explored. Robust qualitative research methods are needed to understand these factors from the patient's perspective and to elucidate the real meaning of living with dentofacial deformity and undergoing orthognathic treatment. There is a paucity of

purely qualitative research in this field but, in order to treat patients holistically, qualitative research is the vital missing part of the puzzle which needs to be addressed.

This study aimed to investigate the following factors using purely qualitative methodology:

- The impact of dentofacial deformity on individuals' lives
- The motivation for undergoing orthognathic treatment
- The expectations of how orthognathic treatment will affect individuals' lives

The data were collected prior to commencement of any treatment using in-depth interviews and the data were analysed using a form of thematic analysis.

Chapter 3. Social anxiety in orthognathic patients

Dentofacial deformities can present as a considerable social handicap for affected individuals and there is evidence that individuals with a visible defect experience increased anxiety in social situations (Rumsey *et al.*, 2004). This can lead to a cycle of negative behaviour where affected people fear negative judgements by others and thereby avoid social interaction and become more reclusive, thus impacting on the problem (Newell and Marks, 2000). Indeed, social anxiety disorder is one of the most common psychological conditions; with over one in 10 adults affected (Kessler *et al.*, 2005a). Clinical experience of the orthognathic team has raised the question of whether some orthognathic patients may be motivated to undergo treatment to alleviate this fear of negative evaluation in the hope of relieving the resultant social anxiety. If this is the case, physical treatment alone may not improve the symptoms and may lead to dissatisfied patients.

This study aimed to ascertain the extent and severity of social anxiety in orthognathic patients prior to commencement of treatment, using an easy-to-administer, self-report questionnaire called the Brief Fear of Negative Evaluation Scale (Leary, 1983). These results were then compared to normative data from a randomly recruited sample of the UK population. As no pre-existing UK norms existed, it was necessary to conduct a nationwide survey to obtain these data.

Chapter 4. Shared decision-making in orthognathic treatment

There has been an increasing emphasis on engaging patients as partners in their healthcare and providing more patient-centred care in recent years (Department of Health, 1991; NHS Executive, 1996; General Medical Council, 2013). The ideal patient-clinician relationship is thought to be one of egalitarianism, where healthcare decisions are made with equal input from both parties (Roter and Hall, 1989). The concept of ‘shared decision-making’ has evolved in recent times and is now enshrined in UK legislation (Department of Health, 2012), where healthcare decisions are made *with* rather than *for* patients (Légaré *et al.*, 2010). Shared decision-making is now an ethical and legal obligation of all clinicians. There is evidence that shared decision-making can lead to improved patient knowledge, care which is better aligned with patients’ values, less anxiety, improved health outcomes, reduced costs, and less variation in care (Crawford *et al.*, 2002; Légaré *et al.*, 2010; Lee and Emanuel, 2013). Increasingly, outcomes are being measured to include such patient-centred concepts and it is incumbent upon clinicians to demonstrate that shared decision-making is being adopted.

This study aimed to assess the extent of shared decision-making in orthognathic pre-treatment consultations. This was achieved by independently rating audio-recorded consultations using the OPTION scale (Elwyn *et al.*, 2003) for measuring to what degree clinicians involve patients in decisions. This has not been assessed to date.

The value of this research

As discussed previously, there has been a relatively large volume of research investigating some of the psychological aspects of dentofacial deformity and orthognathic treatment. However, there still remain areas of ambiguity and even more unanswered questions. While it is acknowledged that research in this area is difficult, this research project aims to utilise robust methodology to answer some of these enigmas, with the ultimate objective of improving the quality of patient care and satisfaction with treatment outcomes.

Chapter 1: Pre-treatment psychological characteristics of orthognathic patients



Abstract

Background

There has been much debate regarding the psychological characteristics of individuals with dentofacial deformity, with research yielding equivocal results. Some studies have found that orthognathic patients represent a distinct psychological group with deviations from the norm, whereas others have concluded that these individuals are well-adjusted psychologically.

Aims

This study aimed to ascertain a number of pre-treatment psychological characteristics of a group of individuals with dentofacial deformity prior to embarking on orthognathic treatment and to compare these with established normative data.

Subjects and methods

This was a cross-sectional questionnaire study conducted at two sites. Five self-report validated questionnaires were administered to orthognathic patients prior to commencing treatment: the Hospital Anxiety and Depression Scale (HADS), the Derriford Appearance Scale 24 (DAS24), the Body Image Disturbance Questionnaire (BIDQ), the Orthognathic Quality of Life Questionnaire (OQLQ), and the Neo Five-Factor Inventory (Neo-FFI). The questionnaires measured anxiety, depression, appearance related concern, body image disturbance, quality of life, and personality. Inclusion criteria were patients undergoing combined orthodontic/orthognathic treatment but who had not yet started treatment, those aged 16 years or over, and who were able to give informed consent. Exclusion criteria were patients with congenital craniofacial anomalies, for example, syndromes or clefts of the lip or palate, patients with acquired facial defects, and patients who had previously received orthognathic treatment.

Results

In total, 128 patients were recruited and 68 returned completed questionnaires, yielding a response of 53%; 60.3% were female and 39.7% were male. The mean age was 28 years. When compared with normative data for each instrument, patients had several statistically significant differences, which included;

- higher appearance related concerns ($P<0.001$),
- different personality traits - more neurotic and less conscientious ($P<0.001$),
- higher body image disturbance ($P<0.001$), and
- poorer quality of life ($P<0.001$).

Orthognathic patients mean scores showed no significant differences compared with the general population means for the other personality traits (extroversion, openness, and agreeableness), or for anxiety and depression. When the results were compared with established cut-off points for diagnosis and severity of the HADS, the majority of patients scored within the normal range for both anxiety (65.67%) and depression (91.04%). However, importantly, almost a quarter of patients exhibited mild anxiety (22.38%) and almost 9% had mild depression. Just over 10% of patients had moderate anxiety but only 1.49% had severe anxiety and no patients were in the moderate or severe categories for depression. The majority of participants scored within the low or very low range for each of the five personality traits measured by the Neo-FFI. Twenty per cent of individuals had a total BIDQ score of 21 or above, indicating that one fifth of the sample could be screened as being potentially positive for body dysmorphic disorder (BDD).

Conclusions

From the results of this study, it can be concluded that orthognathic patients appear to be different psychologically from the normative population. Accordingly, consideration should be given to routinely assessing key psychological variables for all patients presenting for orthognathic treatment using simple, validated, self-report instruments.

1.0 Review of the literature

1.0.1 Introduction

Dentofacial deformity has been said to interfere with the general well-being of an individual by “*adversely affecting dentofacial aesthetics, mandibular function, or speech*” (Proffit and White, 1991). It is tempting to assume that patients seeking orthognathic treatment to correct their discrepancy may be psychologically different from those without such a condition. Previous research has demonstrated a link between somatic symptoms and psychological disturbances in general (Katon and Russo, 1989) and it has been said that one of the primary motivations for undergoing orthognathic treatment is for psychological benefit (Laufer *et al.*, 1976; Ouellette, 1978; Williams *et al.*, 2005). Indeed, much of the research involving orthognathic patients in the past 30 years has focused on assessing their psychological status and the effect of treatment on this. There is, however, equivocal and sometimes conflicting evidence as to whether orthognathic patients are psychologically different as a result of the fact that their physical appearance deviates from the norm.

Evidence has shown that attractive people are generally viewed more favourably. Attribution bias has been proven in numerous studies, where attractive individuals are judged to be happier, more sociable, more trustworthy, and more successful than those who are less attractive (Dion *et al.*, 1972; Eagly *et al.*, 1991). This, so-called, ‘halo effect’, where physical beauty is generalised to other characteristics, has been shown to be prevalent in school teachers’ perceptions of intelligence, voters’ preferences for political nominees, employment decisions, and jury judgements (Clifford and Walster, 1973; Efran, 1974; Efrain and Patterson, 1974; Foster and Ysseldyke, 1976; Watkins and Johnston, 2000). The stereotype of ‘what is beautiful is good’ has been upheld for decades and continues in present day research (Dion *et al.* 1972; Langlois *et al.*, 2000; Lorenzo *et al.*, 2010).

It has also been suggested that dentofacial deformities may have a negative effect on a person’s personality, attitude, or behaviour either directly or indirectly as a result of

stigma (Baldwin, 1980; van Steenberg *et al.*, 1996). Previous studies have demonstrated that over 60% of orthognathic patients felt that their facial appearance had a negative effect on their personal lives and over 40% said their social life had been negatively affected (Garvill *et al.*, 1992; Barbosa *et al.*, 1993). There is evidence that society can negatively judge people who are visibly different, to the extent that the defect becomes a component of that person's social identity (van Steenberg *et al.*, 1996).

Bull and Rumsey (1988, cited in Bull, 1990) noted that those with facial deformity experienced feelings of powerlessness with respect to social interaction and suffered loneliness and isolation. Importantly, these individuals also experienced a lack of privacy. Most people can '*blend into the crowd*' in social situations if so desired, however, those with facial discrepancies do not have this luxury and often feel their privacy is violated (Macgregor, 1979, 1989, 1990). Koo and Young's research (2002, cited in Rumsey *et al.*, 2004) echoed Rumsey's findings that facially disfigured people experience negative effects on well-being, including lower self-esteem, depression, and anxiety. Macgregor (1979) concluded that people with facial discrepancies, no matter how minor, pay a high price for attempting to engage in society and that some become reclusive and introverted as a result.

Newell and Marks (2000) carried out a study examining social difficulty in those with facial disfigurement and explored the part that fear and avoidance play. They compared fearful avoidance in these individuals with a group of patients with agoraphobia and social phobia and found that facially disfigured people had similar agoraphobic/social phobic avoidance and experienced anxiety and depression in the same way as patients with social phobia. Their findings supported the model of exaggerated pain perception proposed by Lethem *et al.* (1983), which suggests that the social difficulties these patients experience are maintained primarily by the fear of a negative response from society. Of course, these individuals may genuinely encounter negative attitudes from the public, but there is still no explanation why some individuals develop psychological problems and others do not (Newell and Marks, 2000).

Shaw and co-workers conducted research in the 1980s on the reaction of society to dentofacial disfigurement. They noted that society's negative reaction to individuals with visible deformity was a double-edged sword, as it can often become a '*self-fulfilling prophecy*' (Rosenthal and Jacobsen, 1968, cited in Shaw and Humphreys, 1982; Shaw, 1981). Shaw and colleagues (1985) carried out a study in which children and lay adults were shown pictures of individuals with varying degrees of dental or facial disfigurement and noted that those who were less attractive were consistently rated as having lower intelligence, social class, and popularity. Richman (1978) found that teachers consistently underestimated the intelligence of children with facial disfigurements and there is potential for this to impact on future achievements. However, Shaw and Humphreys (1982) did not find this negative bias in their study. In a large interview-based study of 531 school children, Shaw and colleagues (1980) found that dental deviations attracted teasing, and came fourth in the hierarchy of 'target' features for teasing. These children were particularly upset by their dental appearance and twice as likely to suffer from general harassment compared with those teased about other features such as hair or weight (Shaw *et al.*, 1980). There is also an argument in educational psychology that a teacher's attitudes towards, and expectations of, a child may actually influence their performance (Rosenthal and Jacobson, 1968, cited in Shaw and Humphreys, 1982).

Bull and Rumsey (1988, cited in Bull, 1990) carried out a series of experiments into reactions to facial deformity. In one study, a researcher knocked on people's doors collecting money for charity with either her normal facial appearance or with a large artificial port-wine stain applied to her face and found that less money was donated when she had the birthmark. When the same researcher ventured out on the underground railway system in Glasgow, members of the public avoided her when she was 'facially deformed', but not with her normal appearance. Another study in that series revealed that, when the researcher stood on the pavement of a busy shopping street, people tended to stand further away from her when she had the port-wine stain and observers also tended to stand towards the unaffected side of her face (Rumsey *et al.*, 1982, cited in Bull, 1990).

Interestingly, there seems to be little correlation between the severity of a problem and the degree of psychological distress associated with it (Macgregor, 1981; Baker, 1992; Pruzinsky, 1992; Robinson, 1997, cited in Rumsey *et al.*, 2004). Thus, individuals with facial disfigurement, no matter how mild, can be at a disadvantage psychosocially. How an individual reacts to these negative psychological stressors is unpredictable and depends on many complex interrelated variables.

1.0.2 Psychological profile of orthognathic patients

As described previously, conflicting evidence exists as to whether orthognathic patients are psychologically different from the general population. Many studies and reviews have concluded that orthognathic patients do not experience psychological difficulties as a result of their deformity and are generally well-adjusted (Kiyak *et al.*, 1981, 1982a; Heldt *et al.*, 1982; Auerbach *et al.*, 1984; Flanary *et al.*, 1990; Finlay *et al.*, 1995; Kindelan *et al.*, 1998; Stirling *et al.*, 2007; Kim *et al.*, 2009; Williams *et al.*, 2009; Alanko *et al.*, 2010; Burden *et al.*, 2010). However, other studies have demonstrated psychological differences in orthognathic patients compared with either control groups or normative population data (Phillips *et al.*, 1998; Bertolini *et al.*, 2000; Cunningham *et al.*, 2000a; Zhou *et al.*, 2001; Kovalenko *et al.*, 2012). These apparent conflicting findings could be due to a number of factors, including;

- I. *Study power*: Many studies found differences between orthognathic patients and either control groups or population normative data but often this did not reach statistical significance. It is possible that larger sample sizes may have shown statistically significant differences between the groups (Cunningham *et al.*, 2000a; Burden *et al.*, 2010). None of the studies reviewed reported an *a priori* sample size calculation or retrospective power calculation and thus may have been underpowered to detect statistically significant differences.
- II. *Comparison groups*: These may not have been similarly matched for important factors and thus confounding variables may not have been equally distributed (Williams *et al.*, 2009). Some studies used a control group consisting of patients with dentofacial deformities who refused treatment and this may be

inappropriate as it is possible that they are similar in many ways to the orthognathic patients under investigation (Al-Ahmad *et al.*, 2009).

- III.** *Retrospective protocol:* Some studies collected data retrospectively which may have led to recall bias (Stirling *et al.*, 2007).
- IV.** *Data collection time-point:* Many studies administered questionnaires immediately prior to surgery (following the pre-surgical orthodontic phase) instead of prior to all treatment and this may not reflect baseline psychological characteristics as there may be changes following the initial pre-surgical orthodontic treatment (Cunningham *et al.*, 2001; Hunt *et al.*, 2001; Rispoli *et al.*, 2004).
- V.** *Validated questionnaires:* Some studies did not use validated questionnaires and thus the validity of their findings should be questioned (Vulink *et al.*, 2008).
- VI.** *Reporting the mean values:* Many studies reported mean scores and therefore individual variation was not demonstrated. It has been suggested that, in addition to reporting the mean, the percentage of patients lying outside the normal range or above a cut-off for a positive diagnosis should be reported where possible (Alanko *et al.*, 2010; Burden *et al.*, 2010).
- VII.** *Condition-specific measures:* It may be that the lack of condition-specific measures also leads to an incorrect estimation of the degree of psychological disturbance in this cohort of patients (Hunt *et al.*, 2001).

A review of the literature revealed that the main psychological features that have been studied to date are anxiety, depression, personality, self-esteem, body image, and quality of life.

Anxiety

Anxiety is a general term to describe an emotional state comprising feelings of nervousness, tension, or worry. It encompasses several different subtypes; social anxiety disorder, generalised anxiety disorder, obsessive compulsive disorder, panic disorder, and post-traumatic stress disorder (Shelton, 2004). Anxiety can be further subdivided into state anxiety, which denotes transient feelings of anxiety, and trait anxiety, which is

a more generalised and stable long-standing quality (Spielberger *et al.*, 1983). Anxiety in orthognathic patients has been measured using a number of different scales, most commonly the State-Trait Anxiety Inventory (STAI) (Spielberger *et al.*, 1983) and the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).

Kovalenko and colleagues (2012) recently administered the STAI to 96 orthognathic patients at bond-up and 30 controls with normal occlusion and harmonious facial appearance. They found that 42% of orthognathic patients with severe facial deformity (as measured by the Facial Aesthetic Index) had high levels of trait anxiety compared with 23% of controls, and the authors reported that this was statistically significant. However, they did not define the cut-off score for 'high trait anxiety' and did not report the statistical results or significance level. They stated that they found no significant difference in trait anxiety between controls and patients with mild or moderate facial deformity. The results for state anxiety were not reported.

The STAI was used in another recent study to measure anxiety in a sample of 162 orthognathic patients and 157 controls who did not require treatment (Burden *et al.*, 2010). The results were adjusted for age as this was shown to have an effect on scores and the patient group was further subdivided into skeletal Class II and Class III. Individuals in the control group had lower anxiety scores than the patients, and skeletal Class III patients had lower scores than skeletal Class II but none of the results reached statistical significance.

Williams and co-workers (2009) used the HADS to assess anxiety in a group of 30 female orthognathic patients compared with a control group of 30 volunteers but found no significant difference between the groups. However, caution should be exercised when interpreting the findings of this study as the volunteers were not screened for facial abnormalities and thus may not be a valid control group and this could potentially mask any differences in anxiety. In addition, the patient group included individuals who had actually completed orthognathic treatment, and thus did not present with a dentofacial discrepancy at the time of data collection.

Similarly, Stirling and colleagues (2007) found no difference in overall mean STAI scores in orthognathic patients compared with population norms, although this was not

analysed statistically. Their sample consisted of 61 orthognathic patients, 30 of whom had completed treatment. Thus, the results do not reflect the true baseline psychological status of patients with dentofacial deformities as almost half of the participants had completed treatment.

Another study using the STAI measured anxiety in 30 patients one week before orthognathic surgery and noted that state and trait anxiety were elevated but they did not report what the patient data were compared with or how results were considered (Rispoli *et al.*, 2004). In addition, measuring anxiety levels one week prior to surgery may not reflect baseline, pre-treatment levels, as patients may be affected by the pre-surgical orthodontic phase or the imminent surgery.

Cunningham *et al.* (2000a) used the STAI to compare anxiety in 81 orthognathic patients prior to commencing treatment and a control group of 95 adults recruited from local colleges and offices. State anxiety was statistically significantly higher in the patient group than in the control group ($P < 0.001$) but there was no difference in stable trait anxiety between the groups. However, as the authors conceded, the sample may have been underpowered to detect such a difference. Nevertheless, the anxiety levels were assessed at the appropriate time before commencement of any treatment, and thus this study does contribute to the knowledge of baseline characteristics of orthognathic patients.

Therefore, from the evidence reviewed, it is not clear whether orthognathic patients have significantly higher anxiety levels, but it appears that there may be a tendency towards increased anxiety.

Depression

The most commonly used psychometric instruments to measure depression in orthognathic patients are the HADS, the Beck Depression Inventory (BDI) (Beck *et al.*, 1961), and the Symptom Checklist 90-Revision (SCL-90-R) (Derogatis *et al.*, 1976).

A recent cross-sectional study discussed in the previous section investigated a variety of psychological traits but found no difference in depression between orthognathic patients aged between 10 and 58 years and a control group (Burden *et al.*, 2010). The study used

the BDI-II for adults and the Children's Depression Inventory. The control group was recruited from university and hospital premises and was appropriately screened for the presence of any dentofacial discrepancies. There was a trend for increased depression in the orthognathic patients, but this did not reach statistical significance. Similar to the authors' findings regarding anxiety in these individuals, it may be possible that a larger sample size may detect a significant difference should one exist.

Kim and colleagues (2009) measured depression using the SCL-90-R and the Minnesota Multiphasic Personality Inventory (MMPI) (Butcher *et al.*, 1989) in 34 orthognathic patients prior to surgery and compared results with a control group of 30 dental students with Class I occlusions. They found statistically significantly higher levels of depression in the patient group ($P < 0.01$) as measured by the SCL-90-R but no difference when using the MMPI. The authors did not comment on this difference but concluded that there were no psychological differences between the groups. This may be because they felt that the mean difference (0.34 on the five point MMPI scale) was not clinically relevant. They did, however, suggest that the MMPI may have limitations when applied as a single tool and other tests should be used to confirm a diagnosis (Kim *et al.*, 2009).

The HADS was used in a recent study previously discussed to compare depression in female orthognathic patients and a control group and the authors found that there was no significant difference between the groups (Williams *et al.*, 2009). However, no sample size calculation was reported and the P -value was quite close to significance ($P = 0.08$) so this may be worthy of further investigation with a larger sample size. As stated before, the patient group in this study included those who had completed treatment and this may clearly affect the results. In addition, as discussed, the control group was not screened for the presence of dentofacial discrepancies or matched for key demographic features such as age. Women in the control group were significantly older than the patient group and this may have an effect on the results as depression in females has been shown to decrease with advancing age in some groups (Gutiérrez-Lobos *et al.*, 2002). The results are limited to female orthognathic patients, however, the study does provide some data on psychological characteristics using validated questionnaires from a UK sample of orthognathic patients which is useful for comparison with other studies.

Cunningham and colleagues (2000a) used the BDI to assess depression in 81 orthognathic patients compared with a control group of 95 adults and found no statistically significant difference between the groups. However, scores were generally low in both groups so it would appear that the prevalence of depression is generally low. No sample size calculation was reported so it is possible that a larger sample may have yielded different results. In addition, the control group was recruited from local offices and was not screened for the presence of dentofacial deformity. However, the questionnaires used were validated and were administered prior to commencement of treatment. Also, the method of analysis allowed age, gender, and ethnicity to be controlled for. Additionally, the response rate in this study was excellent (96% in the intervention group and 90% in the control group) and it was conducted over three sites to increase participant numbers and enhance generalisability of the findings. Thus, this study provides useful information to compare with other studies investigating baseline characteristics of orthognathic patients.

Notwithstanding the limitations of the studies, it would seem from the evidence available that orthognathic patients do not suffer from depression more commonly than non-patients.

Personality

Personality can be defined as '*the unique psychological qualities of an individual that influence a variety of characteristic behaviour patterns*' (Gerrig and Zimbardo, 2002). The most commonly used measure of personality in orthognathic research is the Eysenck Personality Inventory (EPI) (Eysenck and Eysenck, 1975). The EPI measures extroversion/introversion, neuroticism/stability, and psychoticism/socialisation.

Flanary and co-workers in the US (1990) applied the extroversion and neuroticism items of the EPI to 61 pre-treatment patients who were offered a reduction in treatment fee as an incentive to participate. Questionnaires were administered one to four weeks prior to surgery. Mean patient values were slightly lower than normative means but this was not tested statistically, and the authors concluded that orthognathic patients were generally well-adjusted. The authors did not reveal the source of the normative data or the statistical tests used and no sample size calculation was reported.

In a very similar study, the EPI was used by Finlay and colleagues (1995) in a longitudinal study of 61 orthognathic patients in the UK. They found that mean patient EPI values one month pre-operatively were higher than normative data but, again, this was not statistically significant. The authors did not give details of the source of the norms and no sample size calculation was described.

In the aforementioned cross-sectional study performed by Kovalenko *et al.* (2012), the EPI was used to assess personality in a group of 96 pre-treatment orthognathic patients and 30 non-patient controls without dentofacial defects. It is not clear from the paper from where the control group was recruited. The questionnaire was administered at the bond-up appointment. Patients with severe dentofacial deformity exhibited higher introversion (31.6% compared with 21.5% in controls) and neuroticism (20% compared with 16.7% in controls). The authors stated that these differences were statistically significant but did not provide the data to support this in the article and no sample size calculation was discussed. Therefore, the results should be interpreted with some caution.

Other studies have assessed personality longitudinally but did not necessarily report baseline personality data compared with a control group or normative values (Kiyak *et al.*, 1982a; Øland *et al.*, 2011). Thus, from the limited research on the personality of orthognathic patients, it is not clear whether they express different personality types to individuals without dentofacial discrepancies.

Self-esteem

Self-esteem is a term used to describe an individual's perception of their own worth and encompasses how they *feel* about themselves. It has been defined as a favourable or unfavourable attitude toward oneself (Rosenberg, 1965). It is the evaluative component of self-concept, which involves what an individual *thinks* about themselves (Smith and Mackie, 2007). The most commonly used measure of self-esteem is the Rosenberg Self-Esteem Scale (RSES), in which higher scores denote poorer self-esteem (Rosenberg, 1965).

In a previously described study, Burden and colleagues (2010) used the RSES with adults and the Self-Esteem Index (Brown and Alexander, 1991) with participants under

the age of 18 but found no statistically significant differences between orthognathic patients and a control group. Williams and co-workers (2009) also used the RSES and found no statistically significant difference in self-esteem between female patients and controls. However, as stated before, the patient group included those who had completed treatment and the control group was not screened to exclude individuals with dentofacial deformity. Stirling *et al.* (2007) also reported no significant difference in self-esteem between orthognathic patients (mean score=31, SD 5) and published norms (mean score=35, SD 5). However, as discussed, the patient group included some individuals who had completed treatment and their self-esteem may have been altered by treatment which may have affected the score. In addition, no statistical testing of the difference between self-esteem values was reported. Cunningham and colleagues (2000a) found no significant difference in self-esteem using the RSES between their patient and control groups, but did comment that the findings were close to significance and a larger sample may have detected a difference if one existed.

Therefore, it does not seem that orthognathic patients may have lower self-esteem compared with non-patients.

Body image

Body image is a complex construct which most commonly pertains to how an individual feels about their body, based both on subjective opinion and considering the reactions of others (Cash and Smolak, 2011). It has most commonly been measured in orthognathic studies using the Body Satisfaction Scale (BSS) (Slade *et al.*, 1990) or the revised version of the Body Cathexis Scale (BCS), which includes specific items on facial body image (Kiyak *et al.*, 1986).

In a previously described study, Cunningham and co-workers (2000a) found a statistically significant difference ($P<0.001$) for mean body image and facial body image scores between patients and controls, with patients experiencing greater dissatisfaction with their image. The authors used the BCS to assess body and facial body image and also found that satisfaction with facial body image decreased with age and was lower in females. Williams and colleagues (2009) found that orthognathic patients had higher dissatisfaction with facial body image than controls ($P=0.002$) when

using the BSS head subscale. Additionally, they found that patients gave a wider variation in responses than controls, possibly reflecting the fact that the patient group included both pre- and post-operative patients. Stirling *et al.* (2007) noted lower facial body image in orthognathic patients compared with controls but higher overall satisfaction with body image. However, these results were not statistically significant.

Thus, from these studies, it seems that orthognathic patients may have lower body image and facial body image as a result of their dentofacial problems. However, as the results are not conclusive, further research is necessary to establish a clearer picture.

Body dysmorphic disorder (BDD)

Body dysmorphic disorder is defined as a '*preoccupation with an imagined defect in one's appearance*' or, if a physical defect is present, the concern is markedly disproportionate and the individual's social functioning is affected (American Psychiatric Association, 1994). BDD is classified as a psychiatric disorder according to the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV).

The DSM-IV diagnostic criteria for BDD are:

- '*Preoccupation with an imagined defect in appearance. If a slight physical anomaly is present, the person's concern is markedly excessive.*
- '*The preoccupation causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.*
- '*The preoccupation is not better accounted for by another mental disorder (e.g. dissatisfaction with body shape and size in anorexia nervosa, however these disorders can co-occur).*'

BDD is a condition that is associated with a high level of depression and suicide and poor quality of life (Philips, 2000; Veale, 2004). The prevalence of BDD in the general community is said to be less than 2% (Faravelli *et al.*, 1997; Otto *et al.*, 2001; Rief *et al.*, 2006). In studies of cosmetic surgery patients, the incidence of BDD varied between 3% and 53% (Phillips *et al.*, 2000; Dufresne *et al.*, 2001; Vindigni, 2002; Aouizerate *et al.*, 2003; Veale, 2004; Vulink *et al.*, 2008). Patients with BDD tend to be less satisfied

with the outcome of aesthetic surgery and the presence of the condition is often considered as a contraindication for such intervention (Veale, 2000; Sarwer, 2002).

The most commonly used measure for the preliminary diagnosis of BDD is the Body Dysmorphic Disorder Examination (BDDE) which was developed by Rosen and Reiter (1996). This is a clinician administered semi-structured interview which comprises 34 items with good psychometric properties (Rosen and Reiter, 1996). Another commonly used measure for the screening of BDD is the Body Dysmorphic Disorder Questionnaire (BDDQ) (Dufresne *et al.*, 2001). The potential importance of BDD in orthognathic patients has recently been recognised because, even though the problem may not be imagined or slight, an individual's concern can still be excessive and disproportionate (Cunningham and Shute, 2009).

Vulink and colleagues (2008) carried out a cross-sectional study of 160 patients who were referred for orthognathic consultation. They administered a questionnaire based on nine of the 20 questions in the Body Dysmorphic Disorder Questionnaire: Dermatology version (Dufresne *et al.*, 2001) and 11 items from the BDDE (Rosen and Reiter, 1996). They found that 10% of the patients screened positive for BDD, which is considerably higher than estimates of BDD in the general population. A limitation of this study is that the questionnaire selected by the authors was not validated or psychometrically tested as they used items from two different instruments and thus it may not be diagnostic for BDD in its administered state. In addition, selection bias may have existed due to the fact that the sample was self-selecting based on their desire to change their appearance. However, this study is the first to examine BDD in orthognathic patients and, thus, contributes to the knowledge base.

Therefore, it can be seen that there is limited research regarding the presence of BDD in orthognathic patients. However, the evidence that does exist suggests a higher prevalence than normal among these patients. As a result, it is important that the prevalence of this condition in patients with dentofacial deformity is ascertained using validated instruments.

Quality of life

'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (World Health Organisation, 1946). Health-related quality of life encompasses those features of quality of life that impact on physical or mental health (McHorney, 1999). The importance of health-related quality of life is being increasingly recognised as a key subjective measure of treatment outcomes (Cohen and Jago, 1976; Muldoon *et al.*, 1998; Allen, 2003; Slade, 2012). It has been said that patients seeking orthognathic treatment are motivated by a desire to improve their quality of life from a physical, social, and psychological perspective (Nardi *et al.*, 2003; Kiyak, 2008) and there is evidence from longitudinal studies that oral health-related quality of life improves after orthognathic treatment (Esperão *et al.*, 2010; Murphy *et al.*, 2011).

Generic measures used in previous research include the Short Form Health Survey (SF-36) (Ware and Sherbourne, 1992) and the Oral Health Impact Profile (OHIP-14) (Slade, 1997). It is worth noting that, although the OHIP-14 is described as a generic measure, it is specific to oral, and not general, health. The most commonly used condition-specific measure of oral health-related quality of life in orthognathic research is the Orthognathic Quality of Life Questionnaire (OQLQ) (Cunningham *et al.*, 2000b, 2002). Baseline data are available for the orthognathic patient population which the scale was developed on (Cunningham *et al.*, 2000b) and mean values for individuals without dentofacial discrepancies have also been published (Lee *et al.*, 2007a). The condition-specific OQLQ has been shown to be a better discriminator of the impact of dentofacial deformity than the generic SF-36 (Lee *et al.*, 2007a; Al-Ahmad *et al.*, 2009).

Rusanen and co-workers (2010) used the OHIP-14 to measure oral health impacts in 151 patients with severe malocclusion compared with Finnish general population data. They found that patients with severe malocclusions had a significantly greater number of oral health impacts than the general population and that females suffered more than males. However, they did not find any differences between the various malocclusion subtypes.

Another study using the OHIP-14 was conducted by Esperão *et al.* (2010) who carried out a cross-sectional study involving three groups of patients with dentofacial deformity:

a group of 20 patients who presented for orthognathic treatment but had not commenced treatment, a group of 70 patients undergoing pre-surgical orthodontics, and a group of 27 post-surgery patients still in fixed appliances. They administered the Brazilian version of the OHIP-14 and found a median score of 11 (range 0-56). They then used this as a cut-off point to divide the patients into a high impact group (>11) and a low impact group (≤ 11). There was a tendency for scores to decline from the pre-treatment to the pre-surgical group, and the pre-surgical to the post-surgical group, indicating fewer oral health-related impacts on quality of life following orthognathic treatment. Odds ratios indicated that patients who needed orthognathic treatment but had not yet started were 6.5 times more likely to have OHIP-14 scores above the median cut-off of 11. Those in the pre-surgery group were 3.14 times more likely to report high impacts compared with those who had received surgery. However, caution should be exercised when interpreting these results due to the small sample size in two of the groups. In addition, due to the cross-sectional nature of the study, confounding factors could contribute to the differences between the groups.

Al-Ahmad and co-workers (2009) conducted a case control study in Jordan with 143 participants divided into four groups: pre-surgery ($n=36$), post-treatment ($n=35$), individuals with dentofacial discrepancies who declined treatment ($n=35$), and control subjects with normal occlusion and good facial balance ($n=37$). Using the OQLQ and the SF-36, the pre-surgery group were found to have significantly higher scores (poorer quality of life) than any of the other groups ($P<0.001$), with the condition-specific OQLQ exhibiting better discriminatory properties between the groups than the generic SF-36. The control group had the lowest scores followed by those who had declined treatment.

Another case control study was conducted by Lee and colleagues (2007a) involving 152 Chinese patients: 76 patients presenting for orthognathic treatment and 76 patients presenting for wisdom teeth removal but there was no mention of whether the control group was screened for the presence of dentofacial deformity. The authors administered the SF-36, the OHIP-14, and the OQLQ to both groups and found significantly poorer quality of life in orthognathic patients for both the OHIP-14 and the OQLQ. With the

OQLQ, the magnitude of this significant difference was judged to be large (effect size>0.80).

Thus, from the available evidence, it appears that patients with dentofacial deformity have poorer quality of life than those without. This may have implications for how they cope with treatment and also for satisfaction with post-treatment outcomes.

1.0.3 Conclusions

The available evidence is somewhat equivocal as to whether orthognathic patients are psychologically different from individuals without facial discrepancies. However, there is some evidence that psychological status may influence satisfaction with outcome. Thus, it is important to investigate the baseline psychological status of orthognathic patients using validated measures administered at appropriate time-points with a view to trying to identify factors which may influence satisfaction in the long-term (Peterson and Topazian, 1976; Kiyak *et al.*, 1986; Finlay *et al.*, 1995; Sarwer and Crerand, 2002; Rispoli *et al.*, 2004; Cunningham and Shute, 2009).

1.1 Aims and objectives of this study

1.1.1 Aims

The aim of this study was to investigate pre-treatment psychological characteristics of a group of individuals with dentofacial deformity prior to embarking on orthognathic treatment and to compare these with established norms.

1.1.2 Objectives

The specific objectives were;

- I. To utilise validated self-report questionnaires in a cohort of individuals with dentofacial deformity seeking orthognathic treatment to ascertain pre-treatment levels of:
 - Anxiety
 - Depression
 - Appearance related concern
 - Body image disturbance
 - Quality of life
 - Personality

- II. To compare these values with established normative data.

1.2 Subjects and methods

1.2.1 Subjects

Multi-site ethical approval was granted by the Joint Research and Ethics Committee of University College London Hospitals (UCLH) Foundation Trust prior to commencement of the research (MREC reference number: 09/H0719/10; Appendix 6). Information leaflets were distributed and written informed consent was obtained from all participants (Appendices 7 and 8). All participants had been accepted for orthognathic treatment and intended to continue with the process but had not yet commenced pre-surgical orthodontics. Inclusion criteria were:

- patients undergoing combined orthodontics/orthognathic surgery,
- patients aged 16 years and over, and
- patients able to give informed consent.

Exclusion criteria were:

- patients with congenital craniofacial anomalies, for example, syndromes or clefts of the lip and/or palate,
- patients with acquired facial defects, and
- patients who had previously received orthognathic treatment.

Patients who had previously received orthodontic treatment alone were included as it was felt that this would not significantly alter their baseline psychological characteristics. In addition, many orthognathic patients have undergone a course of simple orthodontic alignment previously so including these individuals was felt to be representative of the orthognathic population.

Potential participants were recruited as they attended a pre-treatment Orthognathic Clinic appointment at one of two sites: the Eastman Dental Hospital, UCLH, which is a large central London teaching hospital, and Croydon University Hospital, which is a large district general hospital outside London.

1.2.2 Methods

This was a cross-sectional questionnaire study. To assess the variables under examination, a questionnaire booklet was developed incorporating five previously validated instruments (Appendix 9). Following completion of consent forms, questionnaires were distributed to patients as they attended routine pre-treatment appointments. Participants were encouraged to complete the questionnaire on site, but were also given a stamped addressed envelope for return if they preferred. If the completed questionnaire was not returned within three weeks, a further copy was posted with a cover letter. A final questionnaire was posted if it had not been returned within an additional two weeks.

1.2.3 Psychometric scales used in this study

Following a thorough review of the literature and after obtaining expert opinion from colleagues in the fields of Psychiatry, Psychology, and Social Sciences, it was decided to assess a number of psychological variables. The instruments used were chosen either because they were the most robust psychometrically or they were the most appropriate condition-specific measures. The psychological variables examined and the instruments used are shown in Table 1.1. Social anxiety was also measured in this group of patients, but the results of this are discussed separately in Chapter 3.

Variable assessed	Instrument used
Anxiety	Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)
Depression	Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)
Appearance related concern and adjustment	Derriford Appearance Scale 24 (Carr <i>et al.</i> , 2005)
Body image disturbance	Body Image Disturbance Questionnaire (Cash <i>et al.</i> , 2004)
Quality of life	Orthognathic Quality of Life Questionnaire (Cunningham <i>et al.</i> , 2000b)
Personality	Neo-Five Factor Inventory (Costa and McCrae, 1989)

Table 1.1. Psychological variables assessed and instruments used in this study.

Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale was developed by Zigmond and Snaith in 1983 as a ‘case finder’ for anxiety and depression in general medical patients. It is a self-completion screening instrument for identifying and quantifying anxiety and depression. The initial cohort of patients was general medical outpatients but, since its introduction, it has also been tested and validated on many medical and surgical subgroups and the general public. The scale consists of 14 statements, seven relating to anxiety (HADS-A) and seven to depression (HADS-D), and it takes only a few minutes to complete. The type of anxiety measured is trait anxiety, which is a generalised anxiety state not relating to a specific situation. The type of depression measured is that resulting in a loss of interest and decreased pleasure response (Snaith and Zigmond, 1994). Responses are given with respect to feelings over the ‘last few days’ and all items are scored on a four point scale (0 to 3). Interpretation of the results involves comparing the scores with the cut-off points described by the authors of the scale where, for both the anxiety and depression scales, scores of 0 to 7 indicate no anxiety or depression, 8 to 10 indicate mild cases, 11 to 14 moderate cases, and 15 or above severe cases (Table

1.2) (Snaith and Zigmond, 1994). Another approach is to compare an individual's score with normative values and normative data are available based on a large UK non-clinical sample of 1792 adults (Crawford *et al.*, 2001). The anxiety and depression subscales should always remain distinct and be analysed separately.

Score	Interpretation
0-7	Normal (no anxiety/depression)
8-10	Mild
11-14	Moderate
15-21	Severe

Table 1.2. Cut-off scores for HADS (Snaith and Zigmond, 1994).

The HADS has been shown to be acceptable, reliable, and valid for screening individuals for the presence of anxiety and depression in both clinical and non-clinical settings (Bjelland *et al.*, 2002). The psychometric properties are reasonable, with good test-retest reliability ($r > 0.80$), acceptable internal consistency with Cronbach's alpha values between 0.80-0.90, and good discriminant, construct, and concurrent validity (Herrmann, 1997; Bjelland *et al.*, 2002; Michopoulos *et al.*, 2008).

The HADS has been used in only a small number of studies of orthognathic patients, however, it has been used recently in a very large study of cosmetic surgery patients (A. Clarke, personal communication, 2012) and on consultation with experts in the field of facial deformity it was advised that its use was appropriate as a clinically useful assessment in these patients.

Derriford Appearance Scale (DAS)

The Derriford Appearance Scale 24 (DAS24) is a 24 item scale that was developed to assess distress and dysfunction related specifically to problems of appearance (Carr *et al.*, 2000; Moss *et al.*, 2004; Carr *et al.*, 2005). The scale was developed on both clinical and non-clinical groups of UK adults (Moss *et al.*, 2004). It measures emotions evoked

including fear, shame, and social anxiety, as well as the behavioural responses of avoidance and withdrawal. The instrument is self-completed and takes between five and 10 minutes to complete. There is a combination of negatively and positively worded statements and either four or five response options are given for different items (for example: almost always, often, sometimes, never, not applicable) with scores between 0 and 4 or 1 and 4 depending on the item. The total score is summed, with a possible range of 11 to 96.

The psychometric properties are good to excellent with good internal consistency (Cronbach's $\alpha=0.92$) and high test re-test reliability over six months ($r=0.82$). Validity is also good when compared with the criterion measure, the DAS59 (Pearson correlation coefficient= 0.88). Normative data for the general population have been established for both clinical and non-clinical groups (Moss *et al.*, 2004; Carr *et al.*, 2005).

The Derriford Appearance Scale has been used in studies involving cosmetic facial surgery (Kosowski *et al.*, 2009) but has only been used in a limited number of studies on orthognathic patients to date (Sadek and Salem, 2007).

Body Image Disturbance Questionnaire (BIDQ)

Studies have investigated the presence of Body Dysmorphic Disorder (BDD) in adult orthodontic and orthognathic patients (Hepburn and Cunningham, 2006; Vulink *et al.*, 2008). The prevalence of BDD in patients seeking orthognathic treatment has been reported to be around 10% (Vulink *et al.*, 2008). However, as dentofacial defects requiring orthognathic treatment are usually quite visible, and therefore rarely imagined, experts in the field of BDD have suggested that it is more appropriate to measure body image disturbance rather than BDD (D. Veale, personal communication, 2009). Body image disturbance includes body image dissatisfaction, dysfunction (or impairment), and distress (or dysphoria) (Cash *et al.*, 2004).

The Body Image Disturbance Questionnaire (BIDQ) was developed specifically to measure negative body image (Cash *et al.*, 2004) and is derived from Phillips' Body Dysmorphic Disorder Questionnaire (Phillips, 1996). It can be used to screen for BDD;

a preliminary study showed that a mean BIDQ score greater than or equal to 21 would detect 98% of individuals with BDD (T.F. Cash, personal communication, 2010).

The BIDQ is a self-administered questionnaire which contains seven items pertaining to ‘*appearance-related concerns, mental preoccupation with these concerns, associated experiences of emotional distress, resultant impairment in social, occupational, or other important areas of functioning, interference with social life or with school, job, or role functioning, and consequential behavioural avoidance*’ (<http://www.body-images.com/assessments/bidq.html>). Each of the seven items has response options on a five-point Likert scale and all items are summed, giving a possible score range of 7 to 35. It has good internal consistency and test-retest reliability and normative data have been established, subdivided on the basis of gender (Cash *et al.*, 2004; Cash and Grasso, 2005). It was used in this study to assess the prevalence of body image disturbance in orthognathic patients as an indicator of BDD as this may ultimately relate to satisfaction with treatment outcomes.

Orthognathic Quality of Life Questionnaire (OQLQ)

There is increasing emphasis on patient reported outcome measures and health-related quality of life (Deshpande *et al.*, 2011). Outcomes of orthognathic treatment are difficult to measure as this treatment does not ‘cure’ the patient or make them ‘better’, neither does it increase life expectancy. Cunningham and colleagues (2000b) developed the Orthognathic Quality of Life Questionnaire (OQLQ) which includes 22 statements marked on a four-point Likert scale, where 1 means it bothers the patient a little and 4 means it bothers the patients a lot (N/A means the statement does not apply to that individual). The scale takes five to 10 minutes to complete, with total possible scores ranging between 0 and 88. Lower scores indicate a better quality of life and higher scores reflect a poorer quality of life (Cunningham *et al.*, 2000b). The psychometric properties of the questionnaire were tested in a multi-centre trial and reliability and validity were good (Cunningham *et al.*, 2000b; 2002). Principal component analysis also identified four separate components or domains: social aspects of deformity, facial aesthetics, oral function, and awareness of facial deformities. Each domain has high internal consistency (Cronbach’s alpha between 0.83 and 0.93).

Studies have shown that this condition-specific quality of life measure performs favourably when compared with other generic instruments, for example, the Short Form Health Survey (SF-36) and the Oral Health Impact Profile (OHIP-14) (Allen, 2003; Lee *et al.*, 2007a). No cut-off score has been suggested but normative values have been published by Lee and colleagues (2007a) based on a sample of 76 adults without dentofacial discrepancy.

The purpose of using the OQLQ in this study was to assess the impact of dentofacial deformity on quality of life.

Neo Five-Factor Inventory (Neo-FFI)

Personality has been described as the dynamic organisation of the physical and psychological systems within a person, which motivate that person's patterns of actions, thoughts, and feelings (Allport, 1961, cited in Carver and Connor-Smith, 2010). The five-factor model of personality is now widely accepted and includes the five broad dimensions of: extroversion, neuroticism, agreeableness, conscientiousness, and openness to experience (Goldberg, 1990; McCrae and John, 1992; McCrae and Costa, 1999, 2004). Each of the five traits represents a cluster of more specific sub-traits and collectively are known as 'The Big Five' (Goldberg, 1990).

The most commonly used measures of personality have been developed by Costa and McCrae (1989, 1992) and the Neo-FFI was used in this study (Costa and McCrae, 1989). It is a shortened version of the original Neo-Personality Inventory (Neo-PI) (Costa and McCrae, 1985) and is a 60 item self-report measure, with 12 items in each of the five domains. The responses are given on a five-point Likert scale and it has been shown to have good validity and reliability (Costa and McCrae, 1992).

The following cut-off points have been suggested for each of the domains (Table 1.3), and the different domains are considered separately.

TOTAL DOMAIN SCORE	INTERPRETATION
≥66	Very high
56-65	High
55-45	Average
35-44	Low
≤34	Very low

Table 1.3. Cut-off points for Neo-FFI (Costa and McCrae, 1992).

The set of scores for any one individual can be plotted on a profile form to visualise the overall configuration of their personality relative to the appropriate normative group (Costa and McCrae, 1992). Alternatively, results can be compared with established US norms based on a sample of 500 men and 500 women aged 21 to 89 years (Costa and McCrae, 1992). Norms also exist for college age individuals (17 to 20 years).

1.2.4 Statistical analysis

Statistical analysis was undertaken using the Statistical Package for Social Sciences (version 19.0; SPSS Inc., Chicago, IL, USA). Demographic data were analysed using descriptive statistics and all data were assessed for normality. All analyses were conducted at the 0.05 level of significance. Comparisons between the clinical groups from the two different sites and also between the clinical groups and established norms were made using Student *t*-tests for numerical data and chi squared tests for categorical data.

1.3 Results

1.3.1 Participants

Of the 128 people recruited, 68 participants returned the questionnaire booklet, 51 from the Eastman Dental Hospital (EDH) and 17 from Croydon University Hospital (CUH) (Table 1.4). The response was the same for both sites: 53% following three mailings of the questionnaire. Data were considered sufficiently normally distributed and therefore parametric statistical tests were employed throughout.

Centre	Number of participants recruited	Number of participants who returned questionnaires	% Response	Percentage of total returned
EDH	96	51	53	75
CUH	32	17	53	25
Total	128	68	53	100

Table 1.4. Distribution of participants recruited from both sites.

There were more females than males recruited at both sites (Table 1.5). A chi squared test for gender distribution revealed no statistically significant differences between the two sites ($P=0.886$).

Centre	Male	Female
EDH	21 (41.2%)	30 (58.8%)
CUH	6 (35.3%)	11 (64.7%)
Total	27 (39.7%)	41 (60.3%)

Table 1.5. Gender distribution of participants.

The average age of the participants was 28 years, however, the CUH cohort was significantly older than the EDH group ($P=0.018$) (Table 1.6).

	Mean age (years)	Standard deviation (years)	Mean difference (years)	95% CI of the mean difference	Significance (P-value)
EDH	26.29	9.74	-7.06	-12.89 to	0.018
CUH	33.35	12.32		-1.23	

Table 1.6. Age distribution of participants at EDH and CUH.

Due to the relatively low response rate, the demographic characteristics of the non-responders were examined to assess if any participation bias may have been introduced. The average age of the non-responders was 26 years and 56% were female and 44% were male. Thus, they were not considered to be considerably different to the responders with respect to these characteristics.

1.3.2 Questionnaire results

There were some missing data where participants did not respond to all instruments within the composite questionnaire (for example, HADS) in their entirety (Table 1.7). Where there were one or two missing item scores within an instrument, the average of all the responses was taken and used to complete the questionnaire. Where there were three or more missing items, that specific component of the composite questionnaire was not included in the analysis.

There were no statistically significant differences between the sites for any of the questionnaires, with the exception of the openness domain of the Neo-FFI. It was, therefore, decided that it was appropriate to combine the results from both sites in subsequent analyses (Tables 1.8 and 1.9).

Questionnaire	Number of participants who did not complete this component of the composite questionnaire
HADS-A	1
HADS-D	1
DAS24	0
NEON	4
NEOE	4
NEOO	4
NEOA	4
NEOC	4
BIDQ	2
OQLQ	0

Table 1.7. Number of participants, from a possible total of 68, who did not complete sub-sections of the questionnaire.

Questionnaire	Total sample		EDH		CUH	
	Mean	SD	Mean	SD	Mean	SD
HADS-A (range 0-21)	6.39	3.66	6.75	3.59	5.25	3.77
HADS-D (range 0-21)	3.19	2.58	3.14	2.51	3.38	2.87
DAS24 (range 11-96)	41.15	12.13	41.31	12.19	40.65	12.31
NEON (range 0-48)	23.81	9.52	23.67	9.75	24.25	9.07
NEOE (range 0-48)	28.81	7.04	29.67	6.53	26.25	8.09
NEOO (range 0-48)	28.33	6.47	29.46	6.36	24.94	5.74
NEOA (range 0-48)	32.20	5.42	32.90	5.08	30.13	6.03
NEOC (range 0-48)	30.92	7.68	30.96	8.57	30.81	4.22
BIDQ (range 7-35)	15.79	5.96	16.61	5.94	13.41	5.50
OQLQ (range 0-88)	54.56	19.25	53.22	20.13	58.59	16.19

Table 1.8. Mean questionnaire results for the total sample (EDH and CUH). [SD=standard deviation. HADS-A=anxiety, HADS-D=depression, NEON=neuroticism, NEOE=extroversion, NEOO=openness, NEOA=agreeableness, NEOC=conscientiousness].

Questionnaire	Mean difference (EDH – CUH)	95% CI of the mean difference	Significance (<i>P</i> -value)
HADS-A (range 0-21)	1.500	-0.590 to 3.580	0.156
HADS-D (range 0-21)	-0.238	-1.726 to 1.251	0.751
DAS24 (range 11-96)	0.667	-6.164 to 7.498	0.846
NEON (range 0-48)	-0.583	-6.116 to 4.949	0.834
NEOE (range 0-48)	3.417	-0.586 to 7.420	0.093
NEOO (range 0-48)	4.521	0.936 to 8.106	0.014
NEOA (range 0-48)	2.771	-0.304 to 5.846	0.077
NEOC (range 0-48)	0.146	-3.112 to 3.404	0.929
BIDQ (range 7-35)	3.200	-0.029 to 6.430	0.052
OQLQ (range 0-88)	-5.373	-15.199 to 4.454	0.274

Table 1.9. Statistical comparison of mean questionnaire results between EDH and CUH participants using independent samples *t*-tests.
[N.B. Statistically significant differences are in bold font].

The data from all patients (EDH and CUH combined) were then compared with established normative values for each scale (Table 1.10). Comparisons were made using two sample *t*-tests (1.11).

Questionnaire	Patients	Normative cohort	Source
HADS-A (range 0-21)	Mean = 6.39 SD = 3.66 N = 67	Mean = 6.14 SD = 3.76 N = 1792	Crawford <i>et al.</i> , (2001). General adult population, UK.
HADS-D (range 0-21)	Mean = 3.19 SD = 2.58 N = 67	Mean = 3.68 SD = 3.07 N = 1792	Crawford <i>et al.</i> , (2001). General adult population, UK.
DAS24 (range 11-96)	Mean = 41.15 SD = 12.13 N = 68	Mean = 30.99 SD = 13.88 N = 1107	Harris & Carr (2001). General adult population, UK.
NEON (range 0-48)	Mean = 23.81 SD = 9.52 N = 64	Mean = 19.07 SD = 7.68 N = 1000	Costa & McCrae (1992). General adult population, US.
NEOE (range 0-48)	Mean = 28.81 SD = 7.04 N = 64	Mean = 27.69 SD = 5.85 N = 1000	Costa & McCrae (1992). General adult population, US.
NEOO (range 0-48)	Mean = 28.33 SD = 6.47 N = 64	Mean = 27.03 SD = 5.84 N = 1000	Costa & McCrae (1992). General adult population, US.
NEOA (range 0-48)	Mean = 32.20 SD = 5.42 N = 64	Mean = 32.84 SD = 4.97 N = 1000	Costa & McCrae (1992). General adult population, US.
NEOC (range 0-48)	Mean = 30.92 SD = 7.68 N = 64	Mean = 34.57 SD = 5.88 N = 1000	Costa & McCrae (1992). General adult population, US.
BIDQ (males)* (range 7-35)	Mean = 15.19 SD = 5.26 N = 26	Mean = 1.57 SD = 0.60 N = 104	Cash and Grasso (2005). College adults, US.
BIDQ (females)* (range 7-35)	Mean = 16.18 SD = 6.41 N = 40	Mean = 1.81 SD = 0.67 N = 433	Cash and Grasso (2005). College adults, US.
OQLQ (range 0-88)	Mean = 54.56 SD = 19.25 N = 68	Mean = 21.37 SD = 13.67 N = 76	Lee <i>et al.</i> (2007a). Adults without dentofacial deformity, China.

Table 1.10. Mean, standard deviation, sample size number, and source of data for clinical sample.

[* Normative data only exist subdivided on gender, thus BIDQ results are presented as separate male and female cohorts].

Questionnaire	Observed difference (clinical cohort mean - normative cohort mean)	95% CI of the mean difference	Significance (<i>P</i> -value)
HADS-A (range 0-21)	0.25	-0.644 to 1.144	0.593
HADS-D (range 0-21)	-0.49	-1.124 to 0.144	0.197
DAS24 (range 11-96)	10.16	7.160 to 13.160	<0.001
NEON (range 0-48)	4.74	2.357 to 7.123	<0.001
NEOE (range 0-48)	1.12	-1.243 to 3.483	0.157
NEOO (range 0-48)	1.30	-0.328 to 2.928	0.087
NEOA (range 0-48)	-0.64	-2.005 to 0.725	0.320
NEOC (range 0-48)	-3.65	-5.569 to -1.731	<0.001
BIDQ (males) (range 7-35)	13.62	11.576 to 15.664	<0.001
BIDQ (females) (range 7-35)	14.37	12.378 to 16.362	<0.001
OQLQ (range 0-88)	33.19	27.631 to 38.749	<0.001

Table 1.11. Observed differences between mean values for the clinical and normative cohorts.

[N.B. Statistically significant findings are marked in bold font].

1.3.3 Comparison with normative data

When compared with previously published normative results for each instrument, individuals with dentofacial deformity exhibited some statistically significant differences, namely appearance related concerns (DAS24), some aspects of personality (neuroticism and conscientiousness) (NEON and NEOC), body image disturbance (BIDQ), and quality of life (OQLQ). These individuals had higher appearance related concerns as measured by the DAS24 ($P < 0.001$). With regards to stable personality traits,

orthognathic patients were significantly more neurotic than the normative cohort and were also less conscientious. With respect to body image disturbance, individuals with dentofacial defects scored on average 13 (males) to 14 (females) points higher than the norms ($P<0.001$). Orthognathic patients also had significantly poorer quality of life than the general population ($P<0.001$), with total scores on average 33 points higher than the normative mean. Orthognathic patients showed no significant differences compared with the general population for anxiety or depression as measured by the HADS or for the remaining personality traits.

Cut-off scores

There are suggested cut-off scores for some of the scales for diagnosis and screening purposes, namely the HADS, Neo-FFI, and BIDQ, therefore the patient data were compared with these also.

Hospital Anxiety and Depression Scale

The HADS has the following cut-off scores (Snaith and Zigmond, 1994) (Table 1.12):

Cut-off score	Interpretation	Anxiety		Depression	
		(participants in each category)		(participants in each category)	
		%	n	%	n
0-7	Normal	65.67	44	91.04	61
8-10	Mild	22.38	15	8.96	6
11-14	Moderate	10.45	7	0	0
15-21	Severe	1.49	1	0	0
Total		100%	67	100%	67

Table 1.12. Cut-off scores for HADS, together with percentage of participants in this study in each category.

In this study, the majority of patients scored within the normal range for both anxiety (65.67%) and depression (91.04%). However, almost a quarter of patients exhibited

mild anxiety (22.38%) and almost 9% had mild depression. Around 10% of patients had moderate anxiety, but only 1.49% of patients scored within the severe range for anxiety and no patients were in the moderate or severe categories for depression.

Neo-Five Factor Inventory

The Neo-FFI has cut-off scores as shown in Table 1.13 (Costa and McCrae, 1992).

Total domain Score	Interpretation	NEON % (n)	NEOE % (n)	NEOO % (n)	NEOA % (n)	NEOC % (n)
≥66	Very high	0	0	0	0	0
56-65	High	0	0	0	0	0
45-55	Average	1.56 (1)	0	0	0	0
35-44	Low	15.63 (10)	21.87 (14)	20.31 (13)	35.94 (23)	31.25 (20)
≤34	Very low	82.81 (53)	78.13 (50)	79.69 (51)	64.06 (41)	68.75 (44)
Total		100% (64)	100% (64)	100% (64)	100% (64)	100% (64)

Table 1.13. Cut-off scores for Neo-FFI, together with percentage of patients in each category.

From Table 1.13 it can be seen that the majority of participants scored within the low or very low range for each of the five personality traits.

Body Image Disturbance Questionnaire

It has been suggested that a score of 21 or higher on the BIDQ will detect 98% of individuals with BDD (T.F. Cash, personal communication, 2010) and thus the BIDQ is considered an appropriate screening tool for the presence of BDD. In this study, 20% of

individuals had a total BIDQ score of 21 or above, indicating that one fifth of the sample could be screened as being potentially positive for BDD.

1.4 Discussion

The majority of orthognathic patients are satisfied with the outcome of treatment; however, an important minority are not (Flanary and Alexander, 1983; Flanary *et al.*, 1985; Cunningham *et al.*, 1995; Chen *et al.*, 2002). It is vitally important to understand why this may be the case and to take steps to reduce it. It is possible that the source of this dissatisfaction may lie in the pre-treatment psychological make-up of some individuals with dentofacial deformity. In addition, it is important to appreciate the impact and effects of dentofacial problems on an individual's psychological characteristics. As stated in the introduction, despite research in this area there remains no general consensus on the psychological make-up of these patients. This is partly due to variances in methodology of the studies, including the use of many different psychometric scales at differing time-points. This study aimed to address some of these issues by assessing relevant psychological traits before commencement of any treatment and by using instruments that have been carefully selected as appropriate to measure the constructs under investigation.

1.4.1 Study design

This was a cross-sectional, two-centre questionnaire study of individuals with dentofacial deformity seeking orthognathic treatment. All participants were screened as having a severe malocclusion and being eligible for orthognathic treatment prior to being invited to participate in the study. Initially, it was intended to undertake a longitudinal study and administer the questionnaires at several different time-points during and following completion of treatment. However, due to the relatively low response rate at time-point one and further attrition at the follow up time-points, it was not possible to collect enough data for meaningful interpretation within the timescale of this study.

The study commenced in only one centre, however, when it became apparent that recruitment was proving difficult, participants were recruited from a second site in an attempt to recruit as large a sample as possible and to increase the generalisability of the

results by including different geographical locations and potentially different patient demographics. Relatively fewer participants were recruited at CUH due to a lower throughput of patients in that unit compared with EDH.

Psychometrically robust questionnaires were used to collect the data. All were accessible, relatively straightforward to complete and analyse, standardised, had good psychometric properties, and required no training to administer. An alternative to questionnaires for some of the psychological variables would have been interviews. However, structured interviews only exist for very few of the constructs under investigation in this study (for example, the BDDE) (Rosen and Reiter, 1996).

It was important to administer the questionnaires prior to commencement of active treatment as there is evidence that pre-surgical orthodontics may alter a patient's psychological state (Cunningham *et al.*, 2001; Hunt *et al.*, 2001). The sample was a self-selecting group who had chosen to embark on corrective orthognathic treatment and thus may be different to individuals with dentofacial deformity who do not seek treatment (Al Ahmad *et al.*, 2009). However, this was the patient group of interest for the study so would not generally be considered a source of bias.

1.4.2 Participants

An *a priori* sample size calculation was not undertaken due to the fact that no hypothesis was being tested initially as the study was intended to be a longitudinal one comparing psychological characteristics at different time-points, with no control group for comparison. The comparison with normative data was added at a later date when it became evident that the longitudinal study was not feasible. In addition, it was acknowledged from the outset that the number of participants recruited would be dependent on the through-put of patients within the time-scale of the study. It was decided to exclude patients under the age of 16 years as individuals are rarely offered orthognathic treatment at this young age and there is evidence that some psychological variables are not stable until adulthood is reached (Caspi and Roberts, 2001). Patients with craniofacial anomalies, including clefts, and those with acquired facial defects (for example, traumatic) were also excluded due to the fact that these patients may be psychologically different from other orthognathic patients (Versnel *et al.*, 2010). Finally,

patients who had previously received orthognathic treatment were excluded as it was thought that this experience could influence an individual's psychological status. Patients who had received orthodontic treatment alone were not excluded as many patients presenting for orthognathic treatment have had some previous orthodontic treatment, and thus are representative of the general orthognathic patient population.

Participants were not subdivided on the basis of type of malocclusion, even though there is some evidence that certain malocclusions may have more psychological impact (Burden *et al.*, 2010). The relatively small numbers of patients recruited precluded such sub-group analysis.

1.4.3 Psychological variables under investigation and scales used

A number of different psychological variables have been investigated in orthognathic patients to date. For the purposes of this study, it was decided to assess anxiety, depression, appearance related concern, personality, body image disturbance, and quality of life. This decision was based on a thorough review of the literature, together with advice from a group of experts in the field, including orthodontists, psychologists, psychiatrists, and social science researchers.

Anxiety and depression have long been associated with somatic illness and have also been extensively investigated in individuals with all types of conditions (Snaith and Zigmond, 1994). The HADS was chosen in this study due to the fact that it has been widely tested and used on other populations and has good psychometric properties.

Clinical experience of the research team, together with advice from experts in psychology and psychiatry relating to physical appearance, suggested that appearance related concern was another important variable to investigate. The DAS24 was chosen because it is psychometrically sound and it was developed on large UK clinical and non-clinical cohorts (Moss *et al.*, 2004). Other measures of appearance related concern were considered but were felt to be less appropriate due to the over-emphasis on eating disorders (Moss *et al.*, 2004).

Personality may be a key factor in adaptation to the results of orthognathic treatment and this has not been extensively researched, but has recently been investigated in cosmetic

surgery patients (Nikbakht, 2012). A search of the literature revealed no study of orthognathic patients using the NEO-FFI or acknowledging the Five-Factor Model of personality. Discussions with mental health professionals involved in this research, advised using the NEO-FFI, despite the lack of comparative data, as it is widely used and accepted in other fields (K. Woolf, personal communication, 2009). Personality was investigated in this study as a relatively stable trait that may influence satisfaction with treatment and outcomes (Zojaji *et al.*, 2007). Theories of personality have changed considerably over the past few decades with advancing research (Allport, 1961; Cattell *et al.*, 1970; Eysenck and Eysenck, 1975; Goldberg, 1990; Costa and McCrae, 1992). There is now a general consensus that the ‘Big Five’ model of five domains of personality (neuroticism, extroversion, openness, agreeableness, conscientiousness) is most appropriate (Saucier and Goldberg, 1998). The Neo scales are amongst the most commonly used measures of personality and, thus, the Neo-FFI was used in this study (Costa and McCrae, 2004).

Body Dysmorphic Disorder has been investigated in patients with dentofacial deformity and those seeking cosmetic surgery (Crerand *et al.*, 2006; Vulink *et al.*, 2008; Cunningham and Shute, 2009). However, BDD is defined as a preoccupation with an ‘imagined’ defect in one’s appearance or a marked concern with a ‘slight’ defect (American Psychiatric Association, 1994). Most orthognathic patients have an appreciable defect and it has therefore been suggested that it is more appropriate to measure body image disturbance rather than BDD (D. Veale, personal communication, 2009). Thus, the BIDQ was used in this study as it is a psychometrically sound measure of body image disturbance. In addition, research has shown it to be a predictable screening tool for BDD (T.F. Cash, personal communication, 2010).

As stated previously, health-related quality of life is increasingly being assessed as a subjective measure of treatment outcomes (Cohen and Jago, 1976; Muldoon *et al.*, 1998; Allen, 2003). There is growing evidence that quality of life may be adversely affected in patients with dentofacial deformity (Lee *et al.*, 2007a; Al-Ahmad *et al.*, 2009). It was decided to use the OQLQ as a condition-specific measure of quality of life in this study

as there is evidence that it performs better than other commonly used generic instruments (Lee *et al.*, 2007a; Al-Ahmad *et al.*, 2009).

1.4.4 Results

Participants

The total number of patients recruited initially was 128 but the final number who returned questionnaires was 68 (51 from EDH and 17 from CUH) (Table 1.4). A smaller number of individuals were recruited at CUH as the through-put of patients was less and the researcher did not have dedicated research time to recruit participants there. The overall response was disappointing at 53% from both sites, a figure which has been described as ‘barely acceptable’ for postal questionnaires (Mangione, 1995). Bryman (2008) suggested a number of steps to increase response rates;

- Writing a good cover letter which is personalised and signed in pen,
- Including a stamped addressed envelope and the address on the questionnaire in case this is lost,
- Follow up reminders two or three times, together with a further questionnaire,
- Clear instructions and an attractive layout for the questionnaire, and
- Professional booklet format.

All of these suggestions were employed during this study, but the percentage of returned questionnaires remained relatively low. Possible reasons for the low number of returned questionnaires were that the composite questionnaire was quite long, participants did not see the relevance of some of the questions, or questions may have been deemed too personal by some. Ten non-responders were asked why they did not return the questionnaire when they returned for routine appointments and all said that they had forgotten it or lost it. When asked if the questionnaire was too long or felt to be irrelevant, none of them felt this was the case. Although this response is low, it is similar to that of other studies using some of these questionnaires (Carr *et al.*, 2005). It is the impression of senior researchers at EDH that participation in research among orthognathic patients is declining gradually, with patients less keen to be involved (S.J.

Cunningham, personal communication, 2012). The reasons for this are unclear and no trend has been reported in the literature. This could have negative implications for services, as patient reported outcomes are increasingly utilised for quality assessment and resource planning. If a reducing percentage of patients are choosing to participate in such research, the results may not be accurate and representative of the total patient population or reflective of the service.

The age and gender of the non-responders was examined to ascertain if an element of response bias could have been introduced by the number of individuals not returning the questionnaire. However, the groups were similar in both age and gender and therefore, the non-responders were not considered to be different in these respects.

More females were recruited than males (approximately 60% compared with 40%) at both sites (Table 1.5). This was expected due to the general demographic of orthognathic patients, where females comprise about two thirds of patients (Stirling *et al.*, 2007; Ryan *et al.*, 2009).

The mean age of participants was 28 years, which is slightly older than the average age reported in some other large orthognathic studies but comparable with other research (Cunningham *et al.*, 2002; Stirling *et al.*, 2007; Al-Ahmad *et al.*, 2009). EDH is a tertiary referral centre for orthognathic treatment, which may explain the slightly older age range seen at this site. However, participants at CUH were significantly older (mean age 33 years) than those at EDH (Table 1.6), which may be because some patients are referred internally via the Restorative Department due to functional problems, especially advanced tooth surface loss secondary in part to their malocclusion, and thus tend to be older. As a result of the higher numbers of patients receiving orthognathic treatment for functional rather than aesthetic reasons at CUH, it is theoretically possible that these individuals may be different psychologically but the small numbers of patients recruited there precluded further investigation of this.

Questionnaire results

With regards to the results of the questionnaires, there were no statistically significant differences for any of the questionnaires between the two sites, with the exception of the

openness domain of the Neo-FFI (Table 1.9). Thus, the results were combined for the purposes of further statistical analyses.

The pooled questionnaire results were also compared with normative data previously established in other studies. A review of the literature for each scale was conducted and the choice of which norms to use was based on the group that was considered to be most comparable with the group in the current study with regards to demographics (Table 1.10). Ideally, a prospectively recruited control group without dentofacial deformity would have been used for comparison with the clinical cohort, however, resource, logistical, and ethical constraints prevented this.

There were statistically significant differences between the orthognathic patient group and normative data for several of the scales, indicating that the psychological profile of orthognathic patients is different from population norms (Table 1.11). However, it must be borne in mind that some of the normative data are derived from selected subgroups, such as college students, and thus may not be representative of the general UK population.

Anxiety and depression

Encouragingly, patients with dentofacial deformity exhibited no significant difference to normative data with regards to the presence of anxiety or depression (Table 1.11). This is similar to the findings of other studies (Stirling *et al.*, 2007; Williams *et al.*, 2009; Burden *et al.*, 2010). In addition, levels of anxiety and depression as measured by the HADS were comparable with the results of a large cross-sectional study of 1265 individuals in the UK with self-perceived disfigurement (Rumsey *et al.*, 2012). Participants in that study included those presenting at dermatology, plastic surgery, and cleft lip and palate outpatient clinics and levels of anxiety and depression were generally low.

Appearance related concerns

Unsurprisingly, appearance related concerns were elevated in the patient group in comparison with norms (Table 1.11). A review of the literature did not reveal any other orthognathic studies using the DAS24, despite the fact that this measure appears to be

the only one currently in existence which specifically measures distress associated with visible disfigurement. The national study conducted by the Healing Foundation (Rumsey *et al.*, 2008) mentioned in the previous section found that DAS24 scores were elevated in individuals with disfigurement (mean score 41.26, SD 16.38) and these values are very similar to the findings in this study, where orthognathic patients had a mean DAS24 score of 41.15 (SD 12.13). A recent study of patients with scleroderma with associated visible facial disfigurement, also found that DAS24 scores were elevated relative to the severity of the defect (Amin *et al.*, 2011). Elevated appearance related concerns are perhaps to be expected in a cohort of patients prepared to go through orthognathic treatment to improve their dentofacial appearance and function. However, it is important to assess the extent of these concerns in relation to the actual discrepancy, as a high level of appearance related concern associated with a mild defect may indicate body image disturbance. The severity of the defect was not assessed in this study but it may be worth investigating in future research.

Not all of the patients recruited were having treatment for appearance related concerns, some had functional motivation. It would have been interesting to examine these patients as a separate subgroup and compare them with patients for whom appearance was the primary motivating factor. However, the numbers recruited were too small to enable such a comparison.

Personality

The participants in this study had higher neuroticism scores and lower conscientiousness scores than the normative values (Table 1.11). No other studies of orthognathic patients have used the Neo-FFI scale to date; despite this being the most widely used measure of personality and the general acceptance of the five-factor model of personality (Goldberg, 1990; McCrae and Costa, 2004). Some studies of orthognathic patients using the Eysenck Personality Inventory found that neuroticism scores were elevated (Kovalenko *et al.*, 2012), although others failed to find this relationship (Kiyak *et al.*, 1982a; Kiyak and Bell, 1991). Interestingly, Kiyak and colleagues (1982b), in their longitudinal study of 74 orthognathic patients, found that those patients with higher pre-treatment neuroticism scores experienced lower satisfaction with outcome immediately

post-surgery, but this relationship disappeared one month after surgery. Finlay and colleagues (1995) also found that neuroticism was higher in orthognathic patients who exhibited higher levels of dissatisfaction. The higher level of neuroticism noted in the current study is important as it may impact negatively on post-treatment satisfaction. Kiyak and colleagues (1982b) suggested that patients should be screened for elevated neuroticism prior to commencing orthognathic treatment and that counselling should be offered to patients exhibiting these personality traits if treatment is to be undertaken.

Conscientiousness, with respect to personality, describes an individual who is efficient, dependable, organised, responsible, and reliable (McCrae and John, 1992). Decreased conscientiousness may be associated with reduced compliance with treatment as has been proven in other areas of medicine, where lower levels of conscientiousness were significantly associated with poorer adherence to medical regimens (Christensen and Smith, 1995). With regards to orthognathic treatment, a patient who cannot be relied upon to be responsible for maintaining their appliances or keeping regular appointments, for example, may not obtain a good outcome. In individuals with lower conscientiousness it may therefore be prudent to consider other, less lengthy, forms of treatment where appropriate. Where it is decided to proceed with orthognathic treatment, additional support and close monitoring may be necessary. These may include shorter appointment intervals, regular discussion of the patient's responsibilities, and written logs of tasks such as elastic wear. It should also be considered that it is possible that the reduced conscientiousness exhibited by individuals with dentofacial defects is, in part, a result of their appearance, self-image, and any negative experiences they may have had. It is generally believed that personality traits are stable over time and not affected by life experiences, which is called the 'hard plaster theory' (Costa and McCrae, 1980; McCrae and Costa, 1990), however, recent research has suggested that some traits may be susceptible to change (Specht *et al.*, 2011). It is possible that conscientiousness may improve when patients know that treatment is being offered and following correction of their problem, but this would require further longitudinal research to ascertain.

Body image

The BIDQ is distinct from the DAS24 in that it not only measures body image dissatisfaction, but also the degree of distress and dysfunction (or impairment) that an individual suffers as a result of this negative body image. As mentioned previously, it is probably more important to measure this than to assess BDD. Body image disturbance in this clinical cohort was found to be markedly elevated in comparison with published normative data (Table 1.11). Body image disturbance in orthognathic patients has not been studied using the BIDQ to date, however, studies using other measures of body image have found it to be lower in orthognathic patients compared with controls (Cunningham *et al.*, 2000a; Williams *et al.*, 2009). This poorer body image potentially has a two-fold effect on orthognathic patients; firstly, elevated scores indicate that individuals suffer from distress and dysfunction in their personal and social lives as a result of this body image disturbance. Higher scores reveal the extent of mental preoccupation with these image concerns and an individual's associated experiences of emotional distress and impairment in social functioning. Affected individuals may also adopt avoidance behaviours, which could in turn have further negative impacts on their lives. Secondly, elevated body image disturbance may be associated with higher levels of dissatisfaction following orthognathic treatment. This has not been researched with respect to orthognathic treatment, however, it has been demonstrated that patients with elevated levels of psychological distress before orthognathic surgery showed higher levels of discomfort and dissatisfaction in the short-term following surgery (Phillips *et al.*, 2004). There is some evidence that low appearance evaluation results in dissatisfaction with facial cosmetic and dental procedures (Honigman *et al.*, 2011). These authors administered a selection of validated self-report questionnaires to 84 patients about to undergo cosmetic facial surgery (for example, facelift, blepharoplasty, rhinoplasty) or cosmetic dental procedures. They also administered a questionnaire assessing satisfaction with treatment outcome six months later and found that low appearance evaluation was predictive of reduced satisfaction with treatment outcome. Thus, it is important for clinicians to assess the extent of body image disturbance in any individual being considered for orthognathic treatment if optimum satisfaction is to be achieved.

Quality of life

In the current study, orthognathic patients had significantly poorer quality of life than normative values, which is consistent with other published studies in this area (Table 1.11) (Lee *et al.*, 2007a; Al-Ahmad *et al.*, 2009; Rusanen *et al.*, 2010). However, it must be borne in mind that the OQLQ was not developed for use on individuals without dentofacial defects and the results for normative populations must be regarded with some caution. There is evidence that orthognathic treatment significantly improves quality of life (Lee *et al.*, 2008; Choi *et al.*, 2010) and thus the relevance of this finding may be useful in resource allocation and commissioning in publically funded health systems (Cunningham *et al.*, 2000b). As resources become increasingly restricted with efficiency savings, there is increasing emphasis on patient recorded outcome measures when evaluating services (Devlin and Appleby, 2010). As NHS commissioning increasingly considers patient recorded outcome and quality of life measures, it is imperative that condition-specific measures are utilised (National Health Service, 2012).

Comparison with cut-off values

Comparison of data with established norms has the disadvantage that certain trends may be missed. Therefore, some authors highlight the importance of not just looking at mean values but also looking at proportions above and below clinical cut-offs, where they exist, for diagnosis and severity (Alanko *et al.*, 2010; Burden *et al.*, 2010).

The suggested cut-off scores for the HADS concur with the mean findings that orthognathic patients do not suffer with high levels of anxiety or depression and the majority of respondents were within the normal range (Table 1.12). However, when examining the percentage of patients in each of the categories, 22% exhibited mild anxiety, 10% moderate anxiety, and 1% severe anxiety. In addition, 9% had mild depression. These numbers may be considered high enough to indicate pre-treatment screening for all potential orthognathic patients. These findings may also be relevant as there is some evidence that depressed individuals show decreased compliance with medical interventions (DiMatteo *et al.*, 2000) and closer monitoring and additional support may be warranted if treatment is embarked upon.

With regards to personality, even though orthognathic patients had significantly higher neuroticism and lower conscientiousness scores than the general population, when compared with cut-off points, scores were generally low or very low for all traits (Table 1.13). This view of the results suggests that orthognathic patients do not have personality traits that are of concern and thus the routine personality screening of all patients may not be warranted. However, as mentioned before, the numbers studied were relatively small and the response was low, and therefore these findings must be treated with caution.

The final cut-off that exists is for the BIDQ, where it has been suggested that a total score of 21 is diagnostic of BDD (T.F. Cash, personal communication, 2010). In this study, 20% of participants had a score of 21 or above and thus would screen positive for BDD. This is higher than the only other published study of BDD in orthognathic patients, which found a prevalence of 10% (Vulink *et al.*, 2008). It is also higher than the prevalence of BDD in adult orthodontic patients of 7.5% found in a study by Hepburn and Cunningham (2006). This highlights the importance of reporting the percentage of individuals above a cut-off score. This high prevalence of is of concern, as there is a general consensus that patients with BDD are more likely to be dissatisfied with treatment outcomes (Sarwer *et al.*, 2002; Vulink *et al.*, 2008). However, it is likely that a higher proportion of patients with psychological disturbances is seen at EDH due to the fact that there is a dedicated liaison psychiatrist on the orthognathic team and many patients are referred specifically due to the presence of mental health support. Therefore, these findings may be specific to the cohort studied and may not be generalisable to other orthognathic patient populations. Nonetheless, consideration should be given to screening all potential orthognathic patients for body image disturbance using the BIDQ as this may indicate the presence of BDD. Where BIDQ scores are elevated above the cut-off of 21, orthognathic treatment should be postponed until the individual can be assessed by a mental health professional and treated accordingly.

Throughout this study, psychometric instruments have been used which are applicable to orthognathic populations and can be administered by any clinician. Therefore, it should

be possible for orthognathic teams in any unit to screen patients using these questionnaires. Where results highlight concern and the need for more in-depth psychological assessment and possible intervention, referral can be made to a mental health professional in the same hospital or via the patient's general medical practitioner, if support does not exist locally.

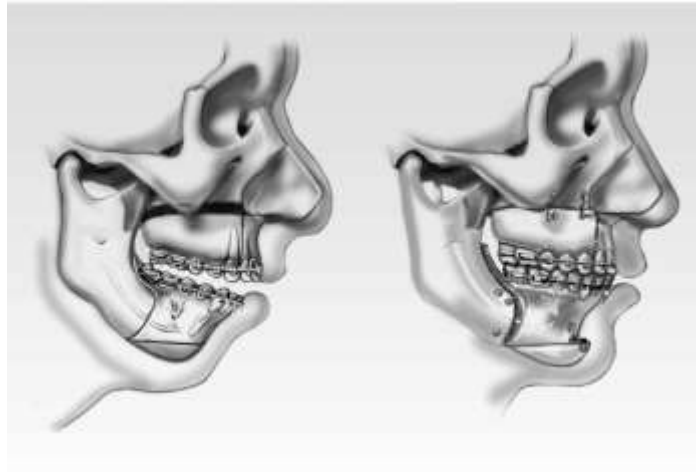
1.4.5 Recommendations for future research

Ideally these baseline psychological characteristics should be related to satisfaction with treatment outcome in a longitudinal study. The questionnaires could be administered at different time-points during and after treatment in the same cohort of patients to ascertain how these factors change as a result of treatment. Following treatment, an assessment of satisfaction should be made and related to the baseline characteristics. Then these data could provide clinicians with an indication regarding which characteristics to screen patients for prior to treatment with the ultimate aim of improving outcomes.

1.4.6 Conclusions

From the results of this study, it can be concluded that orthognathic patients are different psychologically from the normative population and represent a distinct group. In view of these findings, consideration should be given to routinely assessing key psychological variables for all patients presenting for orthognathic treatment using simple, validated, self-report instruments. Where the findings reveal deviations from normative values, clinicians should consider the possible impact on outcomes of treatment and seek additional support or psychological evaluation where warranted. In some cases it may be prudent to postpone, or even withhold, treatment in order to avoid adverse outcomes for all involved.

Chapter 2: Impact, motivations, and expectations in relation to orthognathic treatment: A qualitative study



Abstract

Background

There has been a considerable body of research investigating the impact of living with dentofacial deformity, the motivations for seeking treatment, and patients' expectations of outcome. However, the vast majority of these studies have used quantitative methodology, usually in the form of questionnaires. These studies yield valuable data concerning the prevalence and relative importance of different impacts, motivations, and expectations; however, they cannot elucidate the in-depth meaning of these issues from the patient's perspective. Only qualitative research methods can answer some of these questions.

Aims

The aim of this study was to investigate the impact, motivations for treatment, and expectations of treatment outcome in patients with dentofacial deformity.

Subjects and methods

This was a qualitative cross-sectional study of orthognathic patients. Data were collected using one-to-one in-depth interviews, managed using a framework approach, and analysed using Critical Qualitative Theory (CQT), which is a form of theoretical qualitative analysis. Patients were eligible for inclusion if they were undergoing combined orthodontic/orthognathic treatment but who had not yet started treatment, aged 16 years or over, and able to give informed consent.

Results

In total, 18 patients were recruited and interviewed; nine females and nine males. Purposive sampling ensured that male and female patients with varying ages, ethnicities, and malocclusions were interviewed. The main themes around the areas of impact of dentofacial deformity, motivation for treatment, and expectations of treatment outcome were explored comprehensively and subthemes were identified for each main theme.

Associations and relationships between themes and subthemes were investigated and theories developed.

A new classification of impacts and motivations was developed; exclusively practical (including functional and structural), exclusively psychological (including psychosocial and aesthetic), or a combination. Different coping strategies were also identified.

The sources of motivation ranged on a spectrum between purely external and purely internal, with most subjects being between these two extremes. Participants' expectations could be divided broadly into two main categories: expectations of physical changes and expectations of non-physical changes (indirect changes due to the physical change).

In addition, a clinically-useful typology of orthognathic patients based on their expectations was observed, whereby patients could be classified as metamorphosisers, pragmatists, shedders, or evolvers, together with implications and suggestions for practice.

Conclusions

This qualitative study supports some of the existing quantitative research; however, it also challenges some widely upheld beliefs regarding the impact, motivations, and expectations of patients with dentofacial deformity. This highlights the importance of conducting robust qualitative research to compliment quantitative findings, thereby answering some previously unanswered questions and completing the cycle of evidence-based research.

2.0 Review of the literature

2.0.1 Introduction

Dentofacial deformity has been purported to be the most difficult oral condition to measure (Cohen and Jago, 1976), largely because it involves a subjective assessment of what constitutes ‘normal’ aesthetics (Esperão *et al.*, 2010). There has been a considerable body of research conducted in the past on the psychosocial issues pertaining to dentofacial deformity and orthognathic treatment. However, the vast majority of research investigating the impact of the condition and the motivations for and expectations of treatment has been quantitative, using psychometric instruments such as questionnaires. Some mixed methods research has been carried out using interviews and focus groups to inform the development of questionnaires (Cunningham *et al.*, 2000b; Travess *et al.*, 2004; Williams *et al.*, 2005; Ryan *et al.*, 2009; Lee *et al.*, 2011), but there remains a paucity of qualitative research (Morris, 2006). While quantitative approaches provide valuable information regarding the prevalence and distribution of the impact, motivations, and expectations, they cannot illuminate in depth the meaning of dentofacial deformity from the patients’ perspective. Only naturalistic enquiry in the form of pure qualitative research can provide the missing pieces in the jigsaw of how best to treat these patients using an evidence-based holistic approach.

2.0.2 The impact of dentofacial deformity

Dentofacial deformity has been explored to some extent in terms of aesthetic, functional, and psychosocial impacts (including quality of life, self-esteem, body image, social embarrassment and discomfort, and bullying) (Kiyak *et al.*, 1981, 1982a, 1982b, 1984, 1985; Kindelan *et al.*, 1998; Cunningham *et al.*, 2000a; Zhou *et al.*, 2001; Chen *et al.*, 2002; Lazaridou-Terzoudi *et al.*, 2003; Rispoli *et al.*, 2004; Modig *et al.*, 2006; Lee *et al.*, 2007a; Stirling *et al.*, 2007; Lee *et al.*, 2008; Nicodemo *et al.*, 2008a,b; Al-Ahmad *et al.*, 2009; Williams *et al.*, 2009; Burden *et al.*, 2010; Esperão *et al.*, 2010; Murphy *et al.*, 2011). However, detail regarding the true impact of dentofacial defects which can be elucidated from these studies is relatively limited. In addition, the impacts are frequently

described quantitatively in terms of degree of improvement following treatment, rather than a baseline qualitative description (Rispoli *et al.*, 2004; Al Ahmad *et al.*, 2009). From these studies valuable information can be ascertained about the average degree of change in impacts in patients following treatment, but not necessarily what the implications of living with dentofacial deformity are.

The literature pertaining to the psychological issues surrounding the impact of dentofacial deformity, such as body image, self-esteem, quality of life, anxiety, and depression, have been discussed in detail in Chapter 1 and will not be repeated here. The following is a summary of the other impacts which have been reported in the literature.

Some studies have described other impacts experienced by individuals with dentofacial discrepancy and bullying has been a dominant theme. A high proportion of Class III patients were found to experience bullying in the form of nicknames in one study. Zhou and co-workers (2001) carried out a retrospective questionnaire study involving 94 Chinese Class III patients who had received orthognathic treatment in the past. They found that 46% had been called nicknames as a result of their facial discrepancy and the majority had felt embarrassed or angry by this. However, there are possible sources of bias in this study as the questionnaires were administered many years following completion of treatment and the results are thus subject to recall bias. In addition, although the response rate was good at 68%, it is still possible that the remaining 32% of patients had different experiences as this was a self-selecting sample and consequently there may have been an element of participation bias.

Modig and colleagues (2006) carried out a longitudinal study involving thirty two orthognathic patients. The authors first reported the results of an initial study conducted between 1999 and 2001, where patients were administered a questionnaire before treatment enquiring about experiences of malocclusion and psychological effects. The results of this questionnaire revealed that 12% of participants avoided public places, 17% had problems with the opposite sex, and a quarter felt different from other people as a direct result of their dentofacial discrepancy. A second study was carried out in 2004, where the patients who had completed the questionnaire prior to treatment were again contacted and asked to participate in the second study. On this occasion,

participants were given a different questionnaire after treatment and were asked to rate the improvement in various areas: 91% said they could chew better, 72% said they felt more secure in other's company, 66% noticed an improvement in headaches, and 56% noticed a reduction in bullying. Caution must be exercised when considering these results, as some of these areas were not investigated preceding treatment as the pre- and post-treatment questionnaires were not the same. Therefore, even though a large proportion (56%) noticed a reduction in bullying, this does not mean that the remaining 44% did not notice an improvement. It may be that these individuals did not experience any bullying, and therefore, could not report a reduction. However, the impacts investigated in this study are interesting to consider and have not been widely reported before.

Lee and colleagues (2007b) considered the impact of a factor which has not previously been investigated - the stigma of dentofacial deformity. They developed a nine-item measure of stigma of deformity which investigated devaluation of ability, decreased popularity, difficulty in making friends with the opposite sex, decreased marital opportunity, bringing shame on the family, and 'bad fate' among other areas. Each statement could be graded on a five-point Likert scale and items were summed to give a global score, with higher numbers indicating that the patients felt that their deformity led to a 'bad life'. Seventy four female orthognathic patients completed the questionnaire together with 124 college students who acted as a control group. Orthognathic patients had significantly higher scores compared with controls, indicating that they experienced negative stigma as a result of their deformity. However, although statistically significant, the actual difference in mean scores was relatively small (0.36 on a five point scale) and may not be considered to be clinically relevant.

Only one purely qualitative study was found which explored issues pertaining to orthognathic patients. This study involved qualitative analysis of semi-structured interviews with seven patients who had received orthognathic treatment two to four years previously (Cadogan and Bennun, 2011). Participants reported that before treatment they felt different and had a fear of scrutiny; they also had a fear of meeting new people. Individuals recounted experiences of unwelcome attention and negative

reactions, with name-calling, prejudice, and social rejection. This study offers an interesting in-depth insight into some of the impacts of living with dentofacial deformity from the patient's perspective. However, some of the patients interviewed had congenital craniofacial defects, including cleft lip and palate and so may not be representative of the general orthognathic population. Accordingly, the findings may not be applicable to all orthognathic patients with developmental defects. In addition, patients who had a previous diagnosis of mental health problems or any psychological issues were excluded. Therefore, the results may not reflect the experiences of all individuals. Patients had also completed surgery between two and four years prior to the interviews, and hence may not accurately recall how they felt before treatment commenced.

From the available evidence, individuals with dentofacial deformity experience a wide range of negative impacts as a result of their problem. However, the majority of research has focused on quantifying the number or degree of these impacts rather than exploring the nature of them from the patient's perspective.

2.0.3 Motivation for orthognathic treatment

Motivation for orthognathic treatment has been extensively researched for over four decades and is generally well reported from a quantitative view-point. The major motivations described are aesthetic, functional, and psychosocial (Laufer *et al.*, 1976; Auerbach *et al.*, 1984; Ostler and Kiyak, 1991; Garvill *et al.*, 1992; Finlay *et al.*, 1995; Nurminen *et al.*, 1999; Rivera *et al.*, 2000; Zhou *et al.*, 2001; Vargo *et al.*, 2003; Williams *et al.*, 2005; Modig *et al.*, 2006; Palumbo *et al.*, 2006; Lee *et al.*, 2007a; Sadek and Salem, 2007; Stirling *et al.*, 2007; Espeland *et al.*, 2008; Proothi *et al.*, 2010; Rustemeyer *et al.*, 2010; Cadogan and Bennun, 2011; Øland *et al.*, 2011).

In a systematic review of the literature between 2001 and 2009, aesthetics (facial, dental, and smile) was the main motivation for seeking treatment in 30% to 96% of individuals and function (chewing, speaking, temporomandibular joint problems, and preventing future functional problems) was reported as the main motivation by 33% to 60% of individuals (Alanko *et al.*, 2010). According to the authors, psychosocial motivation (for example, improvement in self-confidence and self-esteem, ability to socialise,

popularity, and career-related issues) was not as widely reported. In the studies that did report psychosocial motivation, between 5% and 69% of individuals cited it as a motivating factor. The relative importance of functional, aesthetic, or psychosocial motivation varies in different studies.

The vast majority of research has involved using self-report questionnaires to ascertain patients' motivations, where individuals were asked to tick response options for what their main motive for treatment was or to rate their motives according to a list provided (Auerbach *et al.*, 1984; Flanary *et al.*, 1985; Ostler and Kiyak, 1991; Finlay *et al.*, 1995; Nurminen *et al.*, 1999; Espeland *et al.*, 2008; Proothi *et al.*, 2010; Rustemeyer *et al.*, 2010; Øland *et al.*, 2011). These questionnaires are generally not developed from patient-centred methods and therefore, individuals have no opportunity to offer any other response apart from those devised by the researchers. In addition, participants are often not given the opportunity to expand further on their motives. Only two studies used questionnaires with open-ended questions which allowed for elaboration on responses by participants (Rivera *et al.*, 2000; Vargo *et al.*, 2003) and only one study developed a questionnaire from focus groups with orthognathic patients (Travess *et al.*, 2004). The latter publication highlighted the importance of developing instruments using patient-centred methods as they elucidated some themes which had not been previously reported.

A minority of studies utilised interviews to ascertain patient motivation for treatment. In an early study by Garvill and co-workers (1992), a team of psychologists interviewed 27 patients two days before surgery. Most patients gave three or more reasons for treatment and the researchers found that 85% mentioned functional motives, 75% aesthetic motives, 59% cited craniomandibular symptoms, and 44% had social motivation.

Modig and colleagues (2006) conducted telephone interviews with 15 Swedish patients following treatment. The majority said that their primary motivation was functional, including difficulty chewing, frequent headaches, temporomandibular joint pain, and speech difficulty. Only one patient mentioned aesthetics as a reason for undergoing treatment. However, the interviews were conducted following treatment so there may be some recall bias or individuals' perceptions could have changed following treatment.

A mixed methods study was carried out by Stirling and co-workers in the UK (2007). They included 61 patients, of whom approximately half had not commenced treatment and half had already completed treatment. Questionnaires were administered and telephone interviews were also conducted with all participants. The interviews were analysed using thematic content analysis. Interestingly, the main motivations for treatment, as elucidated from the questionnaires, were improvement of the bite and appearance of the teeth, whereas the major motivating factor cited in the interviews was concern regarding facial appearance. The reasons for this difference in motivation in the same individuals are not clear, but it may be that the mode of data collection influenced participants' responses, where patients possibly felt that the telephone conversation was more informal and hence they were more honest.

The final study found using qualitative methods was conducted recently by Cadogan and Bennun (2011). In this study, which has previously been described, the researchers carried out semi-structured interviews with seven craniofacial patients examining different aspects of orthognathic treatment. One area covered was motivation, and participants mentioned dissatisfaction with their facial appearance as a motivating factor. However, as discussed before, these patients may not be comparable with all orthognathic patients.

It can be seen from the existing literature that individuals seeking orthognathic treatment do so for a variety of reasons, predominantly aesthetic, functional, and psychosocial. However, what are not clear are the complex reasons which influence such motivations.

2.0.4 Expectations of outcome of orthognathic treatment

Expectations of orthognathic treatment have mainly been studied in relation to their effect on satisfaction and it has been shown that poor preparation and unrealistic expectations can lead to dissatisfaction (Peterson and Topazian, 1974, 1976; Kiyak *et al.*, 1982b; Cunningham *et al.*, 1996; Chen *et al.*, 2002; Türker *et al.*, 2008). The importance of good preparation and counselling patients with regard to common side-effects following surgery, such as pain, swelling, paraesthesia, and difficulty eating, has been well documented (Olsen and Laskin, 1980; Kiyak *et al.*, 1982b; Finlay *et al.*, 1995; Chen *et al.*, 2002; Phillips *et al.*, 2007; Türker *et al.*, 2008). However, little is known

about patients' expectations of how they will feel, behave, and act following treatment and how it will affect their personal, social, and professional lives. Research into expectations of outcome has focused on assessing whether or not expectations are realistic and how they relate to satisfaction, but not what the expectations actually *are*, and again the former tend to be investigated using questionnaires (Finlay *et al.*, 1995; Nurminen *et al.*, 1999). Despite many studies alluding to expectations, little is actually known about what these expectations encompass. Despite early acknowledgement of the importance of a pre-operative interview with patients to ascertain their expectations, it is not known how widely this has been employed (Heldt *et al.*, 1982).

Summary

It can be seen that significant research has been conducted investigating the impact of dentofacial deformity and the motivation for and expectations of treatment. However, the vast majority of work has been quantitative and there is still a great deal to learn about these issues from the patient's perspective.

2.0.5 Qualitative research

Qualitative research is a type of scientific research which is difficult to define as it involves many diverse, and often conflicting, methods (Mack *et al.*, 2005). It has developed in the social research context over many years and this is reflected in the varied and changing descriptions of what it encompasses. As early as the 1600s, writers such as Francis Bacon and Sir Isaac Newton described the importance of explaining the world through direct observation instead of abstract proposals (Ritchie and Lewis, 2003).

As with all scientific research, qualitative research seeks to answer a question by systematically applying a predetermined set of procedures to gather and analyse data and formulate evidence-based conclusions and recommendations (Mack *et al.*, 2005). It is distinct from quantitative research in many ways, including the principle of exploring phenomena from the perspective of those actually being studied. It aims to provide insight into intangible constructs such as people's personal perspectives, attitudes, motivations, behaviours, experiences, and lifestyles (Spencer *et al.*, 2003). It touches the

‘human side’ of issues and explores often incorporeal concepts. Qualitative research methods, also referred to as naturalistic inquiry, are concerned with human experience (phenomenology) and theories on interpretation (hermeneutics). They include the methodical collection, organisation, and interpretation of textual material from the observation of, or interaction with, participants (Malterud, 2001).

Qualitative research is used increasingly in the fields of healthcare, social research, and public policy as it is acknowledged that biomedical resolutions are only partial remedies and a more holistic approach to answering research questions is needed. It has been said that qualitative research can ‘*reach the parts other methods cannot reach*’ (Mays and Pope, 1995, 2000, 2006; Pope and Mays, 2000; Mack *et al.*, 2005). It is widely agreed that qualitative research is a form of ‘social inquiry’ which is *interpretive* - it aims to understand the ways people interpret the world around them - and *naturalistic* - it examines phenomena in natural settings (Cohen and Crabtree, 2006). Qualitative methods are useful for the study of human and social experiences, feelings, thoughts, motivations, expectations, and attitudes – all of which are crucial to clinical knowledge (Malterud, 2001).

2.0.5.1 Characteristics of qualitative research

Although there are many different and often conflicting approaches to conducting qualitative research, there are some generally accepted methodological stances common to all (Ritchie and Lewis, 2003):

The *researcher*;

- Studies the phenomenon from the perspective of those being studied.
- Adopts a holistic approach.
- Maintains ‘empathic neutrality’ and uses personal insight while sustaining a non-judgemental position.

The research *design*;

- Is flexible and adaptive.

- Is conducted in a real world setting rather than in an experimental surrounding.

The research *methods*;

- Are flexible and sensitive to the situation.
- Involve close contact between the researcher and those being studied.
- Involve methods such as interviewing and observation.

The *analysis and output*;

- Answer questions such as what, why, how?
- Are often complex.
- Identify theories arising from the data rather than from an *a priori* hypothesis.
- Explain phenomena both within an individual and across cases studied.

2.0.5.2 Qualitative versus quantitative research

There has been much debate on the distinction between quantitative and qualitative methods in social research (Bryman, 2008). In its simplest form, quantitative methodology involves measurement (quantification) and qualitative methods do not. However the differences run deeper than that and involve fundamental diversity in theory, epistemological, and ontological orientation (Bryman, 2008).

2.0.5.3 Philosophical issues

Epistemology

Epistemology is the ‘*branch of philosophy that deals with knowledge, especially with regard to its methods, validity, and scope*’ usually in relation to the social world (Concise Oxford English Dictionary, 2008). It focuses on what we know about the social world and how we know it (Ritchie and Lewis, 2003). The two main schools of thought are *positivism* and *interpretivism*.

Positivism recognises only that which can be logically and scientifically proven and that it is appropriate to measure the social world with scientific methods. Reality is separate from those who observe it. Theory is proposed and tested in a deductive manner, where theory is deduced initially and this then guides data collection and is tested by the research methods. Deductive research is often referred to as a '*top down approach*' where the reasoning starts from the general and progresses to the more specific (<http://www.socialresearchmethods.net/kb/dedind.php>). This method adopts the natural science model where there is a reality or truth that exists independent of the researcher and of subjective interpretation. This is the model adopted in most quantitative research.

Interpretivism is the opposite stance to positivism and claims that all knowledge is open to human interpretation and that reality and the observer cannot be separated (Weber, 2004). Interpretivists believe that social phenomena need to be explored in a different manner to objects of the natural sciences and through both the research participants' and researcher's perspectives to elicit meaning. Theory is generated from the data inductively, whereby the data lead from specific observations to broader generalisations and theories in a '*bottom up approach*' (Bryman, 2008). Much of qualitative research adopts an interpretivist approach.

Ontology

Ontology is a branch of metaphysics and deals with the '*nature of being*' (Concise Oxford English Dictionary, 2008) and involves beliefs about what there is to know about the world. The main application within social research concerns whether there is a '*social reality*' which is indisputable and subject to the same universal laws as the natural world, or whether the social world is open to subjective interpretation and is a property of an individual's creation (Bryman, 2008). Again there are two main schools of thought which are *objectivism* and *constructionism* (also known as constructivism), although many other categories exist which are beyond the scope of this review. Objectivism is an ontological stance which upholds that social phenomena exist independently of us and our influences. Constructionism is the alternative ontological position which states that social reality and phenomena are constructed by our interactions and thus are constantly revised.

It is important to appreciate that this is a simplified view of a complex subject to which there are no definitive answers. The viewpoints presented represent different beliefs and perspectives on how the social world should be viewed and studied (Ritchie and Lewis, 2003). Indeed, there is also a movement towards greater pragmatism in choosing the most appropriate methods for answering specific research questions rather than focusing too much on the underlying philosophical debates. Pragmatism supports the use of transdisciplinary, multi-method research strategies and cautions against a purist philosophical stance which may undermine the ability to choose the most appropriate research method (Ritchie and Lewis, 2003). The position adopted within this research study is described in section 2.2.3.

	Quantitative	Qualitative
Epistemological orientation	Positivism	Interpretivism
Ontological orientation	Objectivism	Constructionism
General framework	<p>Seek to confirm hypotheses about phenomena (deductive)</p> <p>Instruments use more rigid style of eliciting and categorising responses to questions</p> <p>Use highly structured methods such as questionnaires, surveys, and structured observation</p>	<p>Seek to explore phenomena (inductive)</p> <p>Instruments use more flexible, iterative style of eliciting and categorising responses to questions</p> <p>Use semi-structured methods such as in-depth interviews, focus groups, and participant observation</p>
Analytical objectives	<p>To quantify variation</p> <p>To predict causal relationships</p> <p>To describe characteristics of a population</p>	<p>To describe variation</p> <p>To describe and explain relationships</p> <p>To describe individual experiences</p>
Question format	Closed-ended	Open-ended
Data format	Numerical (obtained by assigning numerical values to responses)	Textual (obtained from audiotapes, videotapes, and field notes)
Flexibility in study design	<p>Study design is stable from beginning to end</p> <p>Participant responses do not influence how and which questions researchers ask next</p> <p>Study design is subject to statistical assumptions and conditions</p>	<p>Some aspects of the study are flexible</p> <p>Participant responses affect how and which questions researchers ask next</p> <p>Study design is iterative, that is, data collection and research questions are adjusted according to what is learned</p>

Table 2.1. Comparison of quantitative and qualitative research approaches (adapted and reproduced with permission from Mack *et al.*, 2005).

In conclusion, quantitative research emphasises hypothesis testing, generalisation, and causal explanations, whereas qualitative research focuses on emerging theory and understanding concepts with, or without, particular reference to underlying philosophical beliefs. However, this distinction is not always clear cut and there can be overlap between the approaches and methods, which, most importantly, must suit the research question and the target audience (Ritchie and Lewis, 2003).

2.0.5.4 Mixed methods research

Mixed methods research combines quantitative and qualitative methods within the same study and thus can maximise the strengths of each, although this is subject to debate (Bryman, 2008). There are many different approaches to combining both types of research including Hammersley's (1996) classification of:

Triangulation - where quantitative research is used to corroborate the findings of qualitative research to improve the validity.

Facilitation – where one method is used to facilitate the use of the other method, for example, where the content analysis of qualitative interviews is used to develop a questionnaire.

Complementarity – where both methods are used so that different aspects of the study can be combined.

2.0.5.5 Conducting qualitative research

There is no single, accepted method of conducting qualitative research. How it is carried out depends on many factors including the characteristics of the research participants, the researcher's ontological (beliefs about the social world), philosophical, and epistemological (the nature of knowledge) position, the research question, and the audience (Ritchie and Lewis, 2003). The most important factor is not what method of analysis is used but rather how rigorously that method is applied.

Conducting qualitative research frequently involves seemingly unstructured methods yielding complex, detailed, and often narrative data. As discussed, it is mainly an inductive rather than deductive analytic process and it answers questions like who, what

and why (Spencer *et al.*, 2003). Methods for collecting data involve one-to-one interviews, focus groups, observation, and conversation and all methods focus on the patient. The stages are the same as for any research: design, sampling, data collection, analysis, and reporting (Spencer *et al.*, 2003). The data collected need to be analysed and summarised, and there are many different approaches to this depending on the research question. It may be necessary to assess relationships between themes or relate behaviour or biographical data to demographics such as age or gender, depending on the context of the research (Lacey and Luff, 2001).

Lacey and Luff (2001) divided the process of qualitative data analysis into the following parts, but not all may be necessary:

- I. Familiarisation with the data.
- II. Organisation and indexing of the data (coding).
- III. Anonymising sensitive data.
- IV. Identification of themes.
- V. Re-coding.
- VI. Development of provisional categories.
- VII. Exploration of relationship between categories.
- VIII. Development of theory and incorporation of pre-existing knowledge.
- IX. Testing the theory against the data.
- X. Report writing.

2.0.5.6 Sampling and sample size

The objective of sampling in qualitative research is fundamentally different to that in quantitative studies. Quantitative research usually uses probability sampling, where individuals are chosen at random and have a known probability of being selected (Ritchie and Lewis, 2003). Thus, the findings are directly applicable to the wider population as the study sample is a representative small scale version of the general population of interest. The goal in *quantitative* methods is to ensure that the sample is

statistically representative and that the findings can be applied to the general population. In *qualitative* research, non-probability sampling is favoured; this approach is concerned with understanding a certain phenomenon rather than its distribution in the whole population (Liamputtong and Ezzy, 2005). The aim of non-probability sampling is to choose information-rich cases for in-depth study.

There are many different sub-groups of non-probability sampling methods in qualitative research, including purposive sampling (which includes theoretical sampling), quota sampling, snowballing, and convenience sampling (Mack *et al.*, 2005).

Purposive sampling

Purposive sampling is a common type of sampling used in qualitative research and is exactly what it suggests; members of a sample are chosen with the purpose of representing a key characteristic which will enable the researcher to explore and understand the theories under scrutiny. Sample size is often determined by study objectives, the number of variables under investigation, time constraints and resources, and the sampling strategy is delineated prior to recruitment (Mack *et al.*, 2005). Theoretical sampling is a type of purposive sampling in which the sample is chosen on the basis of their potential contribution to the development and testing of emerging theories. The sample is chosen to ensure that as many variables as possible, which might affect variability of behaviour are considered (Mays and Pope, 2000). The process is iterative; the researcher chooses an initial sample, analyses the data, and then selects a further sample to test and refine the emerging theories. It is essential that sampling, selection, and analysis are carried out concurrently as the results of the progressive analysis determine continuing sample selection (Mack *et al.*, 2005; Luckerhoff and Guillemette, 2011). The process stops when ‘theoretical saturation’ is reached and no new data arises (Glaser and Strauss, 1967; Ritchie and Lewis, 2003; Liamputtong and Ezzy, 2005). The researcher does not know how many participants will be needed during the research, nor when sampling will be completed (Luckerhoff and Guillemette, 2011). This approach is mainly associated with the qualitative analysis technique known as grounded theory (Glaser and Strauss, 1967). Theoretical sampling may not be appropriate, realistic, or achievable for many studies. For example, if there is no

intention to build social theory, if a more targeted sample is appropriate, or if time and resource constraints mean that an open-ended approach to sample size cannot be implemented, other techniques may be more suitable. In addition, there is an argument that there are no criteria for establishing when theoretical saturation has been achieved and that it is largely subjective (Guest *et al.*, 2006; Bryman, 2008).

Quota sampling

Quota sampling is sometimes considered to be a type of purposive sampling. The sample is stratified on the basis of key factors which are considered to be important in understanding the topic under investigation, for example gender or age. The number of participants required in each group is then decided upon before recruitment begins. However, it is important to note that there still exists a degree of flexibility and these numbers may be modified as the research progresses (Mack *et al.*, 2005). The sample frame is usually drawn up in the early stages of the research. Even though it might seem that these deliberate choices may introduce bias, selection requires clear objectivity so that the theories explored have equal opportunity of being proved or disproved. It is important that the sample is as diverse as possible, within the defined parameters, to allow for the full range of factors involved in the research question, as well as their interdependence, to be identified (Ritchie and Lewis, 2003).

Snowballing

Also known as chain sampling, snowballing refers to the fact that participants are asked to refer the researcher to other members of their social network who also have the characteristics of interest. This enables contact with a sample which may not have been easily accessed otherwise (Mack *et al.*, 2005). There is the risk that the sample may lack diversity as it is partly self-selected; however, this can be minimised by specifically asking participants to identify individuals with certain characteristics and checking for the existence of these (Ritchie and Lewis, 2003). Snowballing is also a type of purposive sampling.

Convenience sampling

This technique selects individuals based on their accessibility and is a commonly used technique. It does not involve a clear sampling strategy and participants are recruited on the basis of ease of access, which has logistical benefits in terms of cost and numbers. However, the sample is prone to selection bias which can limit the generalisability and reproducibility of the results. It is a commonly upheld misunderstanding that all qualitative research involves convenience sampling (Ritchie and Lewis, 2003).

Sample size

A common question when starting qualitative research is how large should the sample be? Samples in qualitative research are usually small, and there are many reasons for this. Firstly, if the data are evaluated properly, a point of saturation is often reached where no new evidence arises, and a phenomenon only needs to appear once to be important. Secondly, in qualitative research, there is no requirement for the data to have sufficient power, as incidence and prevalence are not of concern and no statistical hypothesis is being tested. Thirdly, the material obtained is extremely data-rich and time-consuming to analyse and large samples would be unmanageable (Ritchie and Lewis, 2003). By the same token, if the sample is too small, it will not reflect the diversity of the population and will not fully explore and explain all aspects of the theories being generated. The question of whether the sample is large enough is not an easy one to answer and usually the sample achieved will allow a compromise between obtaining precise, valid results and the constraints of time and resources (Bryman, 2008).

2.0.5.7 Methods of data collection

There are different methods of collecting data in qualitative research, including field observation, focus groups, and interviews.

Field observation

Field observation involves the researchers going into a community setting and observing individuals. It involves observation, taking notes, and informal interaction to understand the perspectives of those being observed. The strength of the technique lies in the fact

that participants are observed in their own environment and this can often identify previously unknown factors. The disadvantages of this technique are that it is incredibly time consuming, the data are difficult to capture and record, and the method is inherently subjective (Mack *et al.*, 2005).

Focus groups

A focus group is a form of group interview with the emphasis on the interaction between the participants and their relative contribution to the construction of theory. The focus group is usually led by a facilitator who poses the questions and steers the conversation. Focus groups are frequently used in market research as they can yield a range of diverse perspectives that exist in a population (Mack *et al.*, 2005). The main strengths of this method of data collection are that it yields a large amount of data in a relatively short time, it also produces a wide range of opinions, and the interactive nature triggers conversations and debates. The drawbacks are that it is complicated to analyse and it is not good for exploring sensitive topics or individual perspectives (Mack *et al.*, 2005).

In-depth interviews

Interviews are one of the main techniques used in social research. It is said that '*a good interview is like a good conversation*', it is a two-way affair (Liamputtong and Ezzy, 2005). An in-depth interview is a '*conversation with a purpose*' and has the power to illuminate meaning in a way that other data collection methods cannot (Ritchie and Lewis, 2003). The key features of an in-depth interview are, firstly, that it is intended to combine structure with flexibility. The researcher has a pre-defined list of topics to cover, but should be flexible as to the order and depth of probing with each interviewee. The second feature is that the interview should be interactive in nature and the interviewer should be responsive to questions or topics raised by the interviewee. Thirdly, the interviewer should use probes to develop and explore topics where necessary. This is important in providing explanatory evidence rather than just reporting themes.

The interviewer should ask clear, short questions, avoid leading questions and jargon, and be sensitive to body language and emotion, especially when discussing personal

issues or sensitive subjects. Audio tape recording is preferable as it is less invasive and allows a verbatim record of the interview in its natural form (Ritchie and Lewis, 2003).

There are also key qualities that the in-depth interviewer should possess. First, and most important, is the ability to listen. Second is the ability to think quickly and distil the essential information, and third is the ability to develop a good rapport with the interviewee (Ritchie and Lewis, 2003).

It is crucial that the interviews are carried out to yield all the appropriate data possible as this will impact on the scope of the data, the analytical potential, and the extent to which the findings are generalisable (National Centre for Social Research, 2009a). The quality of the research and its findings are dependent on the data obtained at the interview stage. If topics are not explored or understood completely at this stage, the analysis and findings will be similarly limited. There are many techniques to increase the breadth and depth of data captured in an in-depth interview:

Active listening

Listening is not passive, the skill of active listening is about hearing, understanding, and remembering what is being said (Ritchie and Lewis, 2003). This encourages and motivates the participant to open up further, and also triggers important points which need to be covered (Ritchie and Lewis, 2003). Active listening can be communicated to the participant by appropriate eye contact and body language. In addition, allowing the interviewee time to think and respond encourages contemplation. The interviewer should resist the temptation to fill any silences as these deliberation moments are often very productive (Ritchie and Lewis, 2003).

Questioning techniques

Open questioning should be adopted where possible as this encourages more detailed responses than closed questions which only allow for dichotomous yes/no answers. The use of open questions is a real skill and one which does not come naturally to many interviewers initially as closed questions predominate much of daily social interaction (Ritchie and Lewis, 2003). This is not to say that closed questions do not have a role in

interviews, as they can be useful in ascertaining specific information and reining in the vocal or rambling respondent (Ritchie and Lewis, 2003).

Interviewers can use broad and focused questions to gain the information needed. Two types of questions have been described: Content *mapping* questions are used to introduce a topic; they are broad and are designed to map out the territory and encourage spontaneous responses. Content *mining* questions are designed to ‘*drill down*’ and amplify detail (Ritchie and Lewis, 2003; National Centre for Social Research, 2009a). The first answers tend not to yield the full explanation and probes can be utilised to explore topics further. Probes are follow-up questions or non-verbal cues (for example, a pause or raised eyebrow) which encourage more in-depth explanation.

The aim of in-depth interviews is to yield a relatively unbiased, neutral account from the perspective of those being interviewed. Leading questions, interventions, assumptions, and judgements by the interviewer can detract from this and thus decrease the validity of the findings. Leading questions can influence the response and should be avoided. The interviewer should also avoid finishing the participant’s sentences. If they struggle to finish a sentence, it may be that re-phrasing the question helps. It is easy and natural to make assumptions regarding what the participant is saying based on the researchers own views and experiences. However, these assumptions can be detrimental, as frequently what the interviewer assumes and what the interviewee mean are incongruous. Therefore, any assumptions should be verified with a question and implied meaning should always be explored (Ritchie and Lewis, 2003). Similarly, any extraneous comments such as ‘right’, ‘ok’, ‘good’ should be avoided as these may imply judgement on behalf of the interviewer. It is vitally important that the interviewer remains neutral and does not influence the participant. There is a fine balance between being empathic and influential and interviewers should refrain from being drawn upon to give their personal view or opinion. In the difficult situation where the interviewer is asked pointedly for their opinion, it is useful to suggest that they wish to focus on the participant and their perspective during the interview but offer to answer questions after the interview has ended (Ritchie and Lewis, 2003).

It is generally accepted that, by the very intimate nature of in-depth interviewing, it involves interaction and a relationship between the interviewer and interviewee, however, avoiding a biased, superficial output calls for a wide range of skills in the interviewer, many of which require practice and experience to hone.

2.0.5.8 Analysis of data

There are no clearly agreed rules for analysing qualitative data, many different approaches exist and traditionally these have been poorly described. This had led to much confusion and the commonly upheld belief that qualitative analysis methodology lacks rigour. Quality in qualitative research is gradually improving and more transparency and structure is being reported. There are many different methods of analysis, including content analysis, thematic analysis, and grounded theory (Glaser and Strauss, 1967). Content analysis involves counting how many times a theme is encountered, thereby categorising it quantitatively and then applying quantitative statistical methods to it. Thematic analysis involves coding various themes and then exploring the theme more closely, and the grounded theory approach is an inductive research method which allows social theory to be generated systematically from the data (Lacey and Luff, 2001). The choice of which method to use depends on many issues, including the research question, the depth of analysis required, and the time available.

Grounded theory

Grounded theory was first introduced by Glaser and Strauss in 1967, and it can be described as '*a theory that is inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon*' (Strauss and Corbin, 1990). According to the methods of grounded theory, concepts, categories, and themes are developed while the research is being carried out and theory is built from the '*ground up*'. This approach is particularly suited to areas of research that have not been explored previously. Central to this method is the use of constant comparison, where the data are collected and analysed concurrently. Analysis of one piece of data provides the researcher with guidelines for the collection of the next piece of data, and so on (Strauss and Corbin, 1990).

Framework analysis

The Framework method of data analysis was developed by the National Centre for Social Research (NatCen) (Ritchie and Spencer, 1994). Recently this has been renamed as Critical Qualitative Theory (CQT) to encompass the epistemological and ontological background as well as the actual method of analysis (Barnard, 2012). It is the method used in this study. It incorporates the Framework method of data management which involves summarising data from the transcripts into a framework for subsequent analysis. CQT is a type of thematic analysis which is a ‘*matrix based method for ordering and synthesising (summarising) data*’ (Ritchie and Lewis, 2003). It groups the data based on common themes and subthemes and then reduces the transcripts into a matrix or framework from which the subsequent analysis is carried out (Ritchie and Lewis, 2003). CQT involves the following stages (Ritchie and Lewis, 2003; National Centre for Social Research, 2009b; Barnard, 2012):

- I. Developing the research question
- II. Establishing the detailed objectives
- III. Building the sample frame
- IV. Writing the topic guide
- V. Conducting the in-depth interviews
- VI. Reviewing the detailed objectives
- VII. Data management
 - a. familiarisation with the data
 - b. identifying initial themes and concepts
 - c. tagging the data
 - d. sorting the data
 - e. summarising/synthesising data
 - f. testing and piloting the framework
 - g. charting the data
- VIII. Descriptive/thematic analysis
 - a. identifying elements and dimensions
 - b. constructing typologies

- IX. Explanatory analysis
 - a. detecting patterns of associations
 - b. developing explanations
 - c. seeking wider applications

These stages are described separately and in sequence but in reality there is overlap between the stages and the relationship is not linear.

I. Developing the research question

The focus of the research needs to be clearly defined prior to commencement of the study and needs to be focused and succinct.

II. Establishing the detailed objectives

The detailed objectives of the study elaborate on the principle aims of the study. This in turn informs the methodology, the choice of analysis, and the topic guide.

III. Building the sample frame

The sample frame should provide all the details required to inform recruitment and selection. It should be comprehensive and inclusive, and encompass all of the characteristics which are relevant to the research question. Knowledge of what this may entail comes from a thorough understanding of the subject. The numbers, or quota, decided upon are derived from the distribution of these characteristics in the wider population and also by practicalities such as time and resources. It is important to limit the sample frame to those characteristics which are of ultimate relevance to the question to prevent the sample becoming too large or unachievable.

IV. Writing the topic guide

A topic guide can be viewed as an *aide-mémoire* which enhances the consistency of data collection by ensuring that pertinent topics are covered systematically and homogeneously (Ritchie and Lewis, 2003). It encompasses a broad agenda of topics which need to be explored. The topic guide should not be seen as a strict prescription and should allow flexibility. What to include in the topic guide stems from the research question and detailed objectives. If more than one topic is to be explored in the

interviews, separate sections for each should be delineated, together with the aim of what information is being sought and detailed subtopics, where appropriate. It is important that the interviewer is familiar with the remit of the interviews before embarking on them, as during the interview process, it is easy to become absorbed in what is being discussed and to forget the main purpose of the interview. A topic guide is extremely useful in ensuring that consistent and focused data are obtained.

V. Conducting the in-depth interviews

The sample is recruited to satisfy the sample frame and the interviews are conducted in line with the topic guide.

VI. Reviewing the detailed objectives

As the interviews are conducted, it is important to continually refer to the detailed objectives based on the data emerging from the interviews. The objectives, and hence the topic guide, can be modified if previously unidentified but relevant topics emerge.

VII. Data management

Data management encompasses the creation and application of a thematic framework. The objective of this stage is to organise the data in the transcripts into a manageable, meaningful '*map*' which can be navigated during the analysis stages. The first stage is reading of, and familiarisation with, the transcripts. This yields recurring issues or concepts which should be noted. These are then sorted and amalgamated into higher order descriptive categories with associated sub-themes, this structure is the thematic framework. Next the transcripts are re-read and the text is tagged, or coded, as it relates to the themes and subthemes in the framework. Following this, data which have similar content and relate to particular themes are grouped together and re-read in order that the categories can be refined (Ritchie and Lewis, 2003).

Then a matrix or 'framework' is constructed in an Excel¹ spread-sheet, with a different chart, or page, representing each different major theme. The rows across the spread-sheet represent each individual interviewed and the columns represent each subtheme.

¹ Microsoft, 2007. Microsoft Excel [computer software]. Redmond, Washington: Microsoft.

The number of charts depends on the number of themes arising from the transcripts. The data from the transcripts are then summarised or ‘synthesised’ into the appropriate cells in the spread-sheet. This technique reduces the data by using summaries of the transcripts but retains links to the original data (page and line number) so it is more manageable. When entering the data into the framework, the ‘essence’ but not the detail of what the participant said should be recorded. Thus, it is important to retain the language and ‘flavour’ of what was being said but avoid too many direct quotations which complicate the framework chart. Where quotations are particularly important they can be included, if short, or a symbol and line and page number from the original transcript can be included (for example ‘Q’, page 12, line 223). The initial framework should be piloted by entering the data from two or three transcripts and then checking for any omissions and ensuring that the true meaning of the data has been conveyed. Although this stage of the process is concerned with organisation of the data and is not interpretive *per se*, it is natural that, as the researcher reads the transcripts, they will start to form preliminary theories. A separate column should be incorporated into the chart to allow for these interpretive perceptions to be recorded so that they may be explored at the analytical stage (Ritchie and Lewis, 2003).

Therefore, unlike many other analyses, CQT method uses the charts as the primary resource for the analysis and not the original transcripts and the data are arranged in a systematic way which is grounded in the accounts of the participants and yet focused on the particular research objectives. This allows the researcher to maintain an overall perspective of all of the participants together. Although this stage is extremely time consuming, it brings the researcher an intense familiarisation with the data that will yield a depth of analysis that would not otherwise be obtained (Ritchie and Lewis, 2003).

VIII. Descriptive/thematic analysis

Descriptive analysis involves an in-depth description of the issues under investigation and illuminates meaning from the perspective of the participants. It involves interpretation by the researcher of *what* is being said but does not extrapolate as to *why*.

It involves three stages which are described distinctly but generally occur concurrently: detection, categorisation, and classification (Ritchie and Lewis, 2003).

Detection involves summarising phenomena by examining the data within a theme (chart) and looking across all cases to identify the range of views, perceptions, feelings, and behaviours. The next stage is categorisation and the researcher begins to interpret the data and apply more abstract categories to distil the key dimensions. These categories can be refined as more and more data are examined but should '*stay close to the data*'. The final stage is classification and this involves conceptualising the categories, whereby the categories become more summative, abstract, and theoretical in their description. All cases must be included in the categories and it is important to appreciate that the frequency of occurrence of each category is of no importance.

On occasions, the descriptive analysis and classification will yield a number of distinct groups or 'typologies'. A typology has been described as '*the selection of a certain number or combinations of groups of variables*' (Capecchi, 1968). Typology in sociology and psychology involves classifying or analysing individuals or phenomena on the basis of similarities. Typologies have two main features; firstly, they are usually multidimensional and they combine features to convey a more succinct picture of the type. Secondly, they are mutually exclusive and exhaustive, meaning that each type is discrete and independent of each other. An individual or a feature can only fit into one type and every individual or feature must fit into a type (Ritchie and Lewis, 2003). Identifying typologies involves looking across cases within a main theme to see if there are any defining features which divide the cases. Typologies do not have to relate to an individual, although they often do, but can pertain to any phenomenon, set of beliefs, or type of experience. Typologies are powerful analytical tools which can enhance the understanding of complex social phenomena; however, they are not always present or appropriate.

IX. Explanatory analysis

The highest level of analysis involves detecting patterns of association between phenomena observed, developing explanations, and finally seeking wider applications and generalisation. Often this is done intuitively and is not obviously divided up into

distinct stages. This involves looking across the whole dataset, both within and between cases, for links between different concepts and building theories as to why these links exist.

Detecting associations involves exploring how different subthemes relate to each other and identifying linkages and patterns. A hypothesis can then be generated as to what this association is. Linkages (associations) can occur by the participant actually linking things (explicit), the researcher linking issues through the analysis (implicit), or the existing literature may already have proven it (Ritchie and Lewis, 2003).

The next stage is explaining the association. This task may be made easier by the participants offering explicit explanations during the interviews, or, more commonly, may rely on the researcher finding implicit answers within the analysis of the interviews. These answers may arise by repeated coexistence of phenomena, or by common sense assumptions or findings from other research which can then be explored by further interrogation of the data.

It is important to appreciate that it may not always be possible to develop explanations or theories for the observations from the data and even where it is possible to generate theory and explanation, these cannot be proven beyond doubt from the data from which they were induced.

The final stage of the analysis is seeking wider applications of the findings. It is possible that the research may have no application outside the population studied, but often generalisation to other populations may be possible if the research methodology has demonstrated reliability and validity. This may take the format of contributing to or substantiating existing theory, making recommendations for practice, or providing a springboard for further empirical testing.

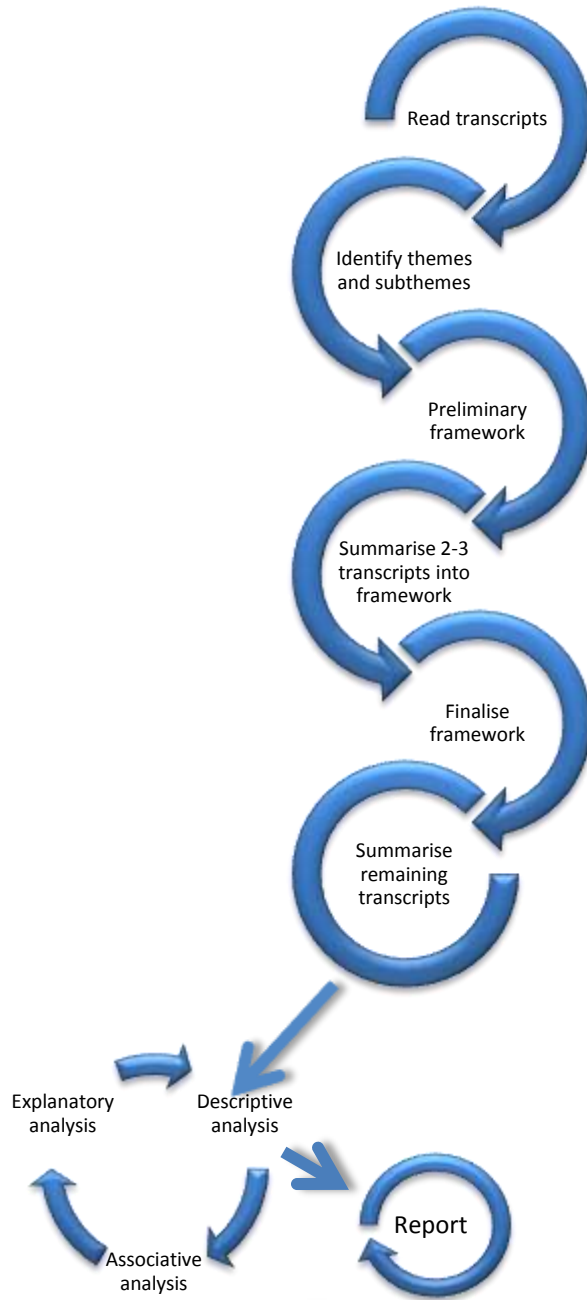


Figure 2.1. Flow diagram of the stages of CQT analysis.

2.0.5.9 Computer aided techniques

Qualitative data analysis techniques, including the Framework approach and grounded theory, can be assisted by qualitative software packages, such as N6^{®2} (QSR

² N6[®] QSR International Pty Ltd, Copyright 2003-2006.

International Pty LTD) or ATLAS.ti³, but it must be stressed that these programs do not analyse the data. They allow for more efficient management, storing, coding, and retrieval of data, and statistical counts can be performed where appropriate. However, there exists the concern that using computer packages can distance the researcher from the data (Liamputtong and Ezzy, 2005).

2.0.5.10 Quality in qualitative research

Qualitative research often comes under criticism for being ‘unscientific’ and lacking in rigour (Mays and Pope, 1995). A lack of understanding and poor reporting has led to the impression that all qualitative research is biased, subjective, and not reproducible or generalisable (Mays and Pope, 1995; Bryman, 2008). In addition, qualitative studies are often appraised using methods appropriate to quantitative research and the key differences between qualitative and quantitative research are misunderstood (Mays and Pope, 2006). Frequently qualitative samples are criticised for not meeting the criteria used in quantitative studies, for example, power, scale, and national coverage, but it must be appreciated that these qualities would contribute nothing to the robustness of a qualitative study. To complicate matters, there is no general consensus on the quality criteria that should be applied to qualitative research (Rolfe, 2006; Masood *et al.*, 2010).

There are two broad schools of thought regarding the methods of quality assessment in qualitative research, although, confusingly, this distinction is often blurred. The first group maintain that the same criteria of validity and reliability as for quantitative research apply but the second group argue that these criteria are wholly unsuitable for the assessment of qualitative research and that different standards should be set (Malterud, 2001; Ritchie and Lewis, 2003; Mays and Pope, 2006; Rolfe, 2006; Bryman, 2008; Masood *et al.*, 2010). Frustratingly, these criteria are yet to be agreed upon and are the subject of much debate.

Various checklists exist which look at aspects of the study such as design, ethics, methodology, transparency, reflexivity, neutrality, and credibility (Critical Appraisal Skills Programme (CASP) 2002; Spencer *et al.*, 2003). Recently, the National Institute

³ ATLAS.ti Scientific Software Development GmbH, Copyright 2002-2007.

for Health and Care Excellence (NICE) published guidelines on critically appraising qualitative research methodology and these have provided some consistency. However, it is important to note that not all of the guidance is suitable for all qualitative studies (NICE, 2009).

Reliability and validity

The concepts of reliability and validity were developed for the natural sciences and, in their pure form, should not be applied to qualitative research (Ritchie and Lewis, 2003). External reliability is concerned with the repeatability of a study and the consistency of the results; if the same study was repeated, would it yield the same findings? Constructionists argue that as there is no single reality to begin with and measuring reliability is a false goal (Ritchie and Lewis, 2003). In addition, social phenomena are dynamic and it is impossible to ‘freeze’ a social setting and replicate it exactly (Bryman, 2008). External reliability is rarely an aim of qualitative studies; however, transparent methodology should be reported to enable similar studies to be conducted and to ensure that claims are supported by evidence (Ritchie and Lewis, 2003). Internal reliability refers to the extent to which there is agreement between repeat measurements taken by different observers and again is of dubious relevance to qualitative research. However, an approach of transparency and detail in the reporting can demonstrate the dependability of the findings (Ritchie and Lewis, 2003).

Validity is concerned with the degree to which an instrument actually measures what it purports to measure and how precise the findings are (Streiner and Norman, 1995). External validity is the generalisability of the research results to the general population but this is often impossible to ensure in qualitative studies. Internal validity is concerned with whether we are measuring what we think is being measured, which in qualitative research relates to whether the theories derived relate to the observations from the data. In qualitative research there are ways of improving validity including:

Triangulation - this involves comparing the results from either two or more methods of data collection (for example, interviews and questionnaires), or two different samples (for example, interviews with clinicians and patients) and assessing if there is agreement to confirm or improve the clarity of the findings.

Reflexivity - this involves being aware of ways in which the data collection process, research methodology, or the researcher may have shaped or influenced the results (Mays and Pope, 1995). As the researcher is often intimately involved with the data collection and analysis process some bias may be inevitable, but recognition of this adds credibility to the results.

Respondent/member validation - this involves obtaining the participants' opinions of the results of the study and seeing if they concur.

Fair dealing - this involves ensuring that the sample includes a wide range of different perspectives so that the viewpoint of one group is not taken to be the sole truth about any situation (Mays and Pope, 2000). This should be ensured from the outset by the sample frame and recruitment.

Analogical reasoning – analogical reasoning is a form of external validity which involves applying the results of one study to other phenomena, cases, or situations that have not been studied but which display similarities with those which have been studied (Smaling, 2003).

Assessing quality in qualitative research is difficult; however, the best quality control measure is the careful, systematic planning of research design and appropriate and transparent execution of data collection, interpretation, and reporting (Mays and Pope, 2000).

2.0.5.11 Qualitative research in healthcare

From its historical beginnings of inductive reasoning in the 16th century, qualitative research has had a slow transition into mainstream science. Indeed, the corner-stone of clinical research has been, and still is, quantitative research with its emphasis on hypothesis testing and controlled experimentation (Cohen and Crabtree, 2008). It was not until the late 1960s and 1970s that sociologists and anthropologists started to introduce qualitative methods into the healthcare sciences (Cohen and Crabtree, 2008). Clinical reasoning is based, not just on experimental evidence, but largely on a subjective evaluation by the clinician which is formulated via interpretive interaction, communication, empathy, and experience (Malterud, 2001). Just because these

intangible concepts which lead to clinical decisions cannot be explained by statistical methods does not mean that they should not be studied, indeed they are every bit as important as the results of controlled clinical trials. The duty of the clinician is two-fold: to understand the disease and to understand the patient (Levenstein *et al.*, 1986). Qualitative research is increasingly being recognised as contributing to evidence-based medicine, however, despite promising calls for more qualitative research to be conducted and published, this has not materialised in the volume necessary (Horton, 1995; Malterud, 2001; McKibbon and Gadd, 2004; Yamazaki *et al.*, 2009).

Unfortunately, qualitative studies are even less common in the field of dentistry. A systematic review of qualitative dental research revealed only 49 articles published between 1999 and 2006 and found that few studies were of high quality. The authors concluded that qualitative methodology is underutilised in oral health research (Masood *et al.*, 2011). Few qualitative research publications exist in the field of orthodontics and the majority relate to dental public health, facial deformity, and cleft lip and palate and are mixed methods or questionnaire-based studies and not pure qualitative research. Thus, there is a paucity of qualitative research in this field which needs to be addressed (Phillips, 1999; Bower and Scambler, 2007; Masood *et al.*, 2010).

2.0.6 Conclusions

A relatively large body of research has been conducted on the psychosocial aspects of dentofacial deformity to date, including the impact of the problem, the motivations for, and expectations of treatment. However, the vast majority of studies have used quantitative methodology and have not explored the in-depth meaning of these issues from the patient's perspective. Evidence from well conducted experimental trials answers only part of the puzzle of how best to treat these patients. The remaining enigmas can only be answered with rigorous qualitative research methods. Despite this being widely accepted, there is a paucity of qualitative research and without this, clinicians cannot carry out the best evidence-based practice.

2.1 Aims and objectives

2.1.1 Aims

The primary aims of this qualitative study were to investigate and understand the impact of dentofacial deformity and malocclusion on people's lives, and to investigate and understand patients' motivations for, and expectations of, orthognathic treatment.

2.1.2 Objectives

Specifically, the objectives were to:

- Describe the range of impacts that dentofacial deformity has on patients' lives.
- Identify the factors that influence the impact of dentofacial deformity on patients' lives.
- Identify the motivation for electing to undergo orthognathic treatment.
- Identify what effect patients expect this treatment to have on their lives.

2.2 Subjects and methods

2.2.1 Patients and sampling

Ethical and Research and Development approval was granted by the Joint Research and Ethics Committee of University College London Hospitals Foundation Trust prior to commencement of the research (REC reference number: 09/H0719/10; Appendix 6). Potential participants were recruited as they attended a routine Orthognathic Clinic appointment and were given verbal and written information about the study. Written informed consent was obtained from all participants. All participants had been accepted for orthognathic treatment but had not yet commenced pre-surgical orthodontics. Inclusion criteria were any patient undergoing combined orthodontics/orthognathic surgery, aged 16 years and over, and able to give informed consent. Exclusion criteria were patients with congenital craniofacial anomalies, for example, syndromes or clefts of the lip and/or palate, patients with acquired facial defects, and those who had previously received orthognathic treatment.

The ability to draw wider inference from qualitative research depends largely on the nature and quality of the sampling. Quota sampling was used in this study to enable inferential generalisation to be made to other patient populations. The subgroups were chosen to reflect the possible influence of certain constructs on the factors under investigation, for example age and gender. By using this approach, all relevant groups were represented and differences and similarities within groups and between groups could be explored. The following factors were considered and included in the sample frame to aid participant selection (Table 2.2):

Gender: It was important to have both male and female participants to investigate differences between the genders.

Age: Participants in different age groups were needed so that the findings would be representative of all age-groups who receive orthognathic treatment. It was accepted that the majority would be between 16 and 25 years; however an additional age group of

those over 25 years was included for completeness. This allowed for potential exploration of how age affects impacts, motivations, and expectations.

Ethnicity: Many patients in London present from a diverse ethnic background, and accordingly a proportion of non-Caucasian, minority participants was included in the sample frame.

Malocclusion type: A wide variety of malocclusion type is represented among the patients attending for orthognathic treatment. Therefore, an attempt was made to recruit approximately equal numbers of Class II and Class III patients.

		Men	Women
Age group	16-25 years	At least 4	At least 4
	25+ years	At least 2	At least 2
Ethnicity	BME*	At least 2	At least 2
Malocclusion type	Class II	At least 3	At least 3
	Class III	At least 3	At least 3
Total		6	6

Table 2.2. The sample frame for the in-depth interviews.
[* Black and Minority Ethnic].

2.2.2 Data collection

Semi-structured in-depth one to one interviews were conducted to explore the range of issues under investigation in this study. All interviews were conducted by one researcher (FSR) and were exploratory and interactive in form. The quality and richness of the data yielded from the interviews is partly dependent on the skill of the interviewer, hence the interviewer attended courses and received intensive training in the technique by members of the National Centre for Social Research (NatCen) prior to conducting the interviews. This involved attending practical courses on the theory, techniques, and application of in-depth interviewing, followed by multiple practice sessions under the supervision of experienced colleagues.

A topic guide was devised to provide flexible direction to the interviews and acted as a reminder to ensure that all key topics were explored sufficiently (Appendix 10). This was developed following a review of the literature, informal discussions with patients and clinicians, and from the experience of the research team. However, the interviewer had freedom to explore any issue which arose and the topic guide was modified where necessary following the initial interviews. Interviews were then transcribed verbatim and the digital files erased to maintain participant confidentiality.

2.2.3 Analysis

The epistemological approach adopted in this study was one of interpretivism where understanding people's perspectives was the focus of enquiry and researcher-participant interaction was essential. However, in the context of this particular study, one of the main benefits would be in applying the results to other populations and ensuring that the findings are as generalisable as possible. Therefore, the research methodology needed to be neutral, unbiased, and able to support wider inference. The ontological stance adopted in this study lies somewhere between objectivism and constructionism, whereby it is acknowledged that a social reality exists independent of individual interpretations but that it is only accessible via individual's accounts. A largely pragmatic approach was adopted in the methodology.

A Framework approach to the data management and analysis, now called Critical Qualitative Theory (CQT), was used in this study according to the stages described in section 2.0.5.8 (Ritchie and Lewis, 2003). The analysis was undertaken by one researcher (FSR) in consultation with an expert in CQT from the National Centre for Social Research, who verified the process at all key stages (Dr Barnard, formerly Research Director, Qualitative Research Unit, NatCen).

2.3 Results

2.3.1 Subjects

In total, 18 patients were recruited for this section of the study based on the sample frame; nine males and nine females. To satisfy the sample frame, a range of age groups, ethnicities, and malocclusion types was included (Table 2.3).

		Men	Women
Age group	16-25 years	4	7
	25+ years	5	2
Ethnicity	BME	4	2
Malocclusion type	Class II	5	4
	Class III	4	5
Total		9	9

Table 2.3. Details of the participants interviewed.

2.3.2 Interview analysis

The interviews were all conducted in private by the researcher (FSR) in a non-clinical environment and interviews lasted between forty five minutes and one hour approximately. The three main themes of interest (impact, motivations, and expectations), together with associated subthemes, were analysed separately but possible associations between the themes were explored concurrently (Table 2.4). Each theme and subtheme is discussed in detail in the following sections, supported by quotations from the interviews. A quotation is attributed to a participant using the convention, P (for participant), followed by a number, denoting the participants identity, for example P1. The main themes and subthemes were used to construct the framework, within which the transcripts were summarised. A portion of the Excel spread-sheet framework can be seen in Appendix 11.

Themes →	Impact of dentofacial deformity	Motivations for treatment	Expectations of treatment outcome
Subthemes ↓	Initial awareness of the problem	Trigger for treatment now	Expected effect of treatment on life in general
	Nature of the problem	Reason for wanting treatment	Expected effect on relationships
	Impact on education	Source of motivation	Expected effect on employment
	Impact on interpersonal relationships (childhood and adult)	Importance of receiving treatment	Expected effect on confidence
	Impact on employment		When will they notice the effects
	Impact on day to day activities		Effect on lives of others
	Impact on confidence		Effect if treatment does not go according to plan
	How the problem makes them feel		Results wanted/hoped for
	Coping strategies		

Table 2.4. Data themes (top row) and subthemes (rows beneath) which arose from the analysis of the interviews.

2.3.2.1 The impact of dentofacial deformity

Participants became aware of their dentofacial deformity in a variety of ways including self-diagnosis, professional diagnosis, awareness through friends and family, and through strangers or new acquaintances. Irrespective of how they became aware of the issue, they experienced a range of psychological and practical impacts which are described in this section. To understand the impact of dentofacial deformity on people's

lives, the exact nature of the problem, the impact on interpersonal relationships and employment, the psychological impacts, and coping mechanisms were explored. Some subthemes are amalgamated during the discussion below due to considerable overlap of the issues discussed and others are not discussed further (for example, ‘impact on education’) as they did not contribute to the analysis and, upon exploration, were not relevant to the issues being studied.

Initial awareness of the problem

As described previously, there were a variety of ways in which individuals first became aware of their dentofacial discrepancy and for many individuals more than one situation was described. There was a general awareness of a problem with the teeth or face but many were not aware exactly to what the problem was attributed. A number of the patients had noticed a problem with their teeth but were not aware of the underlying skeletal discrepancy until a professional pointed it out to them. Interestingly, none of those interviewed had perceived a problem with the actual jaws themselves. While for some people a professional diagnosis simply raised their awareness of the defect, for others it led to a ‘*fixation*’ on the defect (P8, P9, P10, P13).

‘It bothers me because once you know about it you can’t help noticing it. It’s almost as when you’re having a conversation with someone and you realise they say, “oh well you know, oh well you know”, all the time then that’s all you can hear.’ P13

‘I just thought there was something about my face ... and I thought it was my nose....and then they told me that my lower jaw was growing too far forward. I then began to really look at my face and realised, hang on, no my nose is fine, it’s my lower, it’s this part of my mouth I don’t like, and then I used to take pictures of like, of the side of my face ... I charted that massively from (laughs) when I was thirteen to, well to now, and it was something that massively bothered me and it would always be something I’d look out for in pictures and it just became a kind of fixation.’ P8

The nature of the problem

The nature of the dentofacial problem is closely related to the impact of the problem but not always the same and so is discussed separately as the primary *cause* of the impacts of dentofacial deformity. Traditionally the problems associated with dentofacial deformity have been divided into three categories; aesthetic, functional, and psychosocial (Figure 2.2).

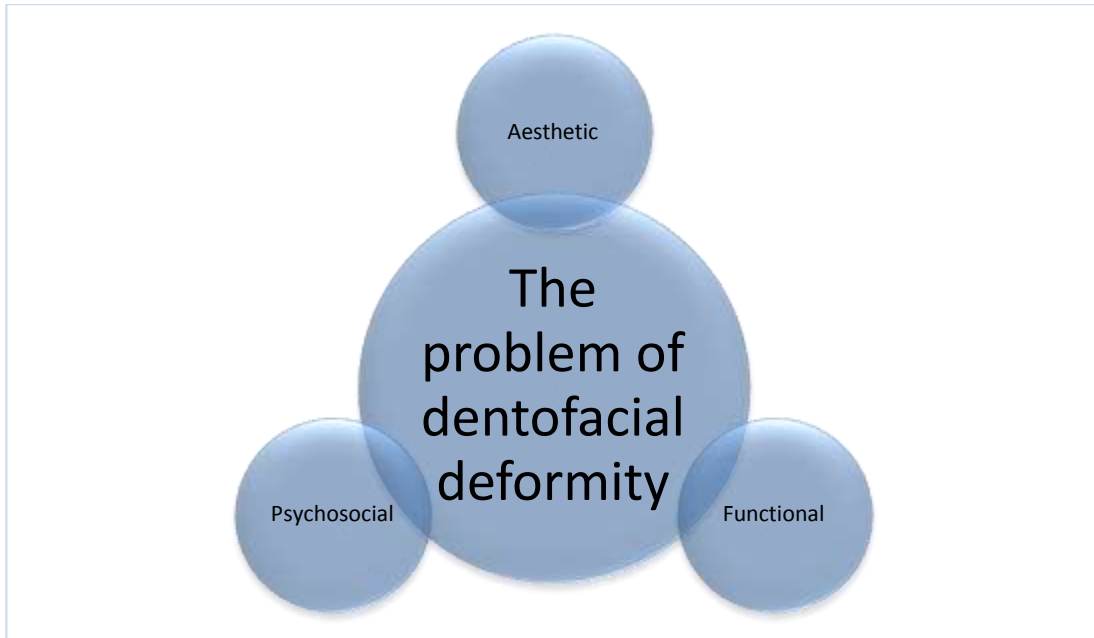


Figure 2.2. The traditional classification of the problem of dentofacial deformity.

However, this research revealed a subtly different, but important, distinction and the nature of the problem was divided into an exclusively *practical* problem (which could be functional or structural), an exclusively *psychological* problem (which included psychosocial), or a combination (Figure 2.3). This is a refinement of the traditional categorisation commonly found in the literature. The term ‘aesthetic’ is not found to be appropriate or descriptive as, although many aesthetic concerns were vocalised, it was found that these can have either practical or psychological ramifications, and therefore can have totally different impact. The same was found for the term ‘functional’, where even though the perceived initial problem was physical in nature, it could still have non-physical impacts on the individual, and thus this term was not all-encompassing or sufficiently descriptive. Similarly, the term ‘psychosocial’ was not found to be apposite.

While it is accepted that the psychosocial impacts of dentofacial deformity are far-reaching, there were other psychological impacts which do not involve social interaction and hence the overarching term *psychological* was favoured instead of psychosocial.

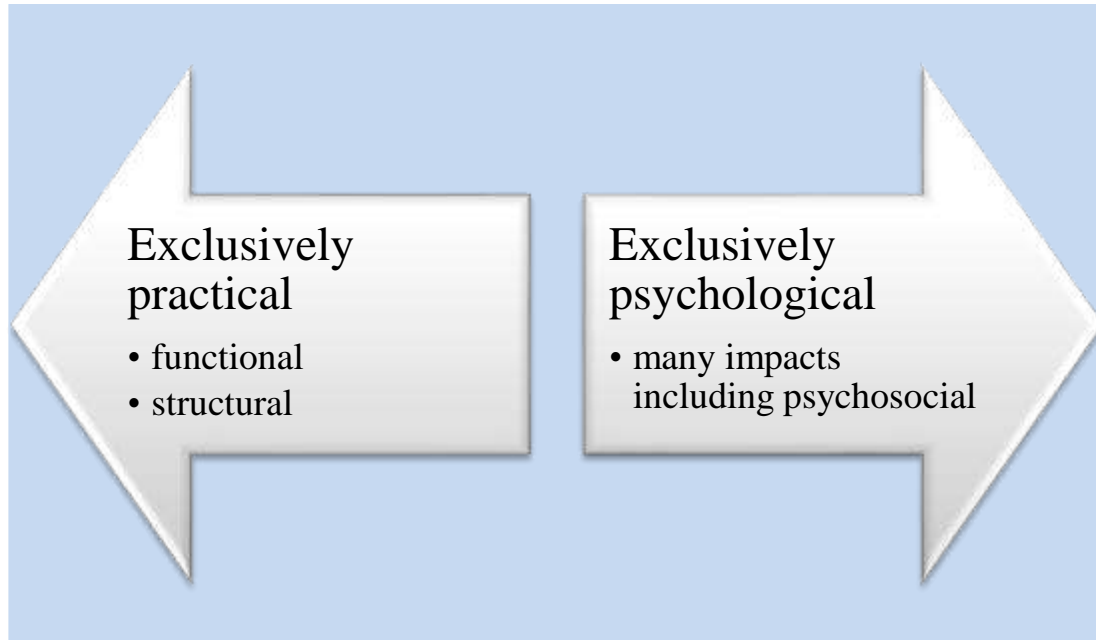


Figure 2.3. The classification of nature of the problem of dentofacial deformity used in this study.

Practical problem

The practical problem manifested itself in two main ways: a functional problem or a structural one. Practical *functional* problems included problems with eating, speech, or other activities. Examples of problems with eating included getting tired when eating (P3), only being able to bite with certain teeth (P5), not being able to eat the food they wanted or the way they liked (P15), eating taking a long time and being messy, and spitting and making noise when eating (P5, P13). Problems with speech ranged from not pronouncing certain letters clearly, to lisping when speaking or having a ‘*major*’ problem with articulation (P13). Other functional problems included not being able to bite sellotape with the front teeth (P5), the tongue getting trapped between the teeth (P8), biting the inside of the cheeks (P14), and the lower lip getting trapped under the top teeth (P17).

Practical *structural* problems involved people being objectively aware of the physical condition and where the problem was (for example a vertical gap between the front teeth or the lower jaw being longer than the upper one). In the individuals in this category, the awareness of the defect and the ‘ideal’ dental and facial appearance was purely objective, with them acknowledging the problem as a physical one only (P12, P13, P16), without any apparent psychological consequences.

‘I had kids making fun of that (my teeth), I also had kids making fun of my cast arm, I also had kids making fun of my haircuts that my mum used to make me have and to be honest, it never really bothered me because, I never let that sort of thing bother me. I’m more worried about the impact it’s going to have on my eating habits than anything else.’ P13

Psychological problem

The presence of a dentofacial deformity or malocclusion posed a psychological problem for many. Traditionally, this has been termed psychosocial to encompass the ‘*interrelation of social factors and individual thought and behaviour*’ (Concise Oxford English Dictionary, 2008). While the presence of dentofacial deformity has psychosocial impacts, it also has psychological impacts which do not relate to the social environment, for example, a feeling of victimisation or hopelessness when seeing the reflection in the mirror which is independent of negative reactions from others.

‘Sometimes I get so emotional and just sit down and look at in the mirror and I’m like what’s going on, what happened to me’. P3

Therefore, the term psychological is more appropriate as it can include purely psychological and also psychosocial issues. The nature of the psychological problem presented itself as a set of impacts and is therefore discussed in the next section on impacts.

Impacts of dentofacial deformity

The impact of living with a dentofacial deformity or malocclusion, as distinct from the *nature* of the problem, and the effects on everyday life are divided into impacts on interpersonal relationships, impacts on employment, and psychological impacts.

Impacts on interpersonal relationships

The impact of the condition on interpersonal relationships could be explained via two processes:

- Reactionary – how the participants interacted with and reacted to others in their lives.
- Provocative – how others reacted to them and the reaction it provoked from others.

Reactionary

For some people the condition had an effect on how they interacted with and reacted to others, causing them to either try to avoid mixing with others or undermining existing relationships. People described either avoiding interaction with others completely due to their condition or a negative effect on relationships, so the effects could be subdivided into effects on new or existing relationships:

New relationships: At the extreme end of the spectrum, patients avoided meeting new people completely. As children, participants had evaded making friends or meeting other children, using avoidance tactics such as staying in the library during breaks (P11).

'I just locked myself up in the library and did my own thing.' P11

As adults, some avoided socialising and had not made friends (P7). Some chose employment where they could minimise interaction with people (P7, P14).

'I've been very much controlled in what kind of job I will be doing, so I can avoid face-to-face communication with people.' P11

Others described a negative effect on new relationships attributed to their dentofacial discrepancy and feeling 'exposed' (P8, P14) or at a disadvantage when meeting strangers (P8). There was a sense of paranoia (P18), insecurity (P8, P14) and feeling defensive (P1) due to concerns that others were making judgements based on their appearance. Some were bullied as children as a result of their appearance (P11, P14). Problems forming intimate relationships were also described (P9, P14).

'I'd ... assume that that's the reason I don't have a boyfriend.' P14

Existing relationships: Some participants had been teased by siblings in childhood (P4, P6, P18) and this had led to problems with inter-family relationships due to the fact that they tended to take their frustration out on those close to them or put up barriers, such as avoiding family gatherings (P6, P7, P14, P18).

'I was teased by my brother. He said I would have to wear braces and teased me quite a bit and I started crying.' P4

There were examples of relationships that had been placed under strain because of low self-esteem associated with the problem. This issue was compounded where individuals described not wanting to talk about the problem with friends or family and getting annoyed when they tried to discuss it (P6, P18).

'I might stop being so moody with my family (after treatment) ... and giving them a hard time.' P18

Provocative

Participants also discussed the reactions of others towards them. While it was acknowledged that the condition could affect the way respondents themselves reacted to other people, not surprisingly there was also a strong perception that the condition had the effect of making it more difficult to form relationships because others assumed they were unfriendly. They also perceived that negative judgements, assumptions or comments based on their appearance had a negative effect on new relationships, even if it did not prevent them forming (P1, P3, P9, P10).

Some participants felt that existing relationships could be adversely affected but said it this was not always the case, with many saying that family and close friends accepted their appearance and did not make judgements based on it.

'I think with my family, I don't care that much. That's why I didn't consult them that much, or wait for them, for their approval, for them to give me the go-ahead. I think they already know, because I know they're my family. There is no way whereby they can reject me or insult me or anything, because I am theirs, but it's just the outsiders, like, strangers here.' P7

Impacts on employment

There were limited examples of the condition affecting employment, which means the range and diversity of impact in this area could not be fully explored, and therefore the following findings should be treated with some caution. However, for those who discussed an impact on employment, it was an important aspect of their experience of living with the condition. While participants discussed negative impacts on employment, perhaps unexpectedly some people also described positive effects. The negative effect of the condition could be a result of self-imposed restrictions or those imposed by others.

A lack of self-confidence, low self-esteem, and fear of rejection held people back from applying for jobs they wanted and was thus self-imposed.

'I'm not achieving what I should be, and that's one of the reasons, I don't like public standing up and doing public speaking, I find it difficult to voice my opinions in groups and I shouldn't do.' P14

One individual described wanting to become a teacher but, due to previous childhood experiences of being bullied by peers, felt he lacked the confidence to enter the profession. Some controlled their working environment to minimise contact with others.

'So I went to do an office job, whereby I can just be on the computer, but then I had to ... talk to everyone about the office, and I ran away from them as well. I've been very much controlled in what kind of job I will be doing, so I can avoid face-to-face communication with people. And now I've picked a very good job whereby I work at the back of the warehouse. I always had a very good salaried paid job, but I moved out from it because I was very uncomfortable along there, so now I ... work ... in the warehouse, so I'm always at the back. It's only when they need me they just call me on the phone and then I send somebody else so I'm hardly outside on the floor. I'm very controlling in the kind of job that I do pick and the kind of people I'm around with.' P7

There was a sense of being discriminated against due to the visible defect, with adverse impacts on career progression and, in these individuals; the negative effects on employment could be described as imposed by others.

'When I'm in an interview say and there's two girls and me then I'm like are they going to choose these two girls, they're not gonna choose me because of my look and people just see you as your outlook so I thought they're gonna choose that girl and they're not gonna like me. I was gonna be a presenter and they said you struggle with your talking and your look doesn't look on ... the camera basically very good so they got someone else. That was so horrible.' P3

Positive impacts of dentofacial deformity on employment were experienced by some, with one person mentioning that having a 'unique look' was an advantage in the stage acting profession.

'My teeth wouldn't affect theatres, maybe it would be a good advantage because I have a different appearance and directors always looking for different appearance style people. So that can be an advantage.' P1

Psychological impacts

It is widely recognised that malocclusion and facial deformity can have important psychological impacts on certain individuals. This research indicated that this manifested itself in six different ways:

- Self-perception and image projection.
- Concern about being misjudged.
- Impacts on self-confidence, self-image, and mood.
- Lack of control.
- Feeling of victimisation.
- Anxiety about physical impact.

Self-perception and image projection

The first way in which dentofacial defects affected people psychologically, was in a sense of dissonance between how they perceived themselves and how they felt others saw them. This could be manifested by feelings of distress and disbelief when they saw themselves on video or in a photograph, and the image they saw and felt that others saw

was different to the one they carried in their mind's eye. Another way in which this was expressed was by those who described their condition and its effects as not being part of who they really were or 'foreign' to them.

'If I see a photo of myself where I look horrendous in my eyes, everything just collapses ... immediately feeling depressed and unhappy, and there's a sort of element of shock, you know, you've got a self-image which is contradicted by that.' P14

A sense of frustration was also borne out of the fact that individuals felt they could control some elements of their appearance, such as the clothes they wore, but could not control how their teeth or face looked. One participant was particularly concerned about this because she felt it undermined her attempts to present a professional image.

'I guess when you're first meeting new colleagues ... it's all about image isn't it ... and... I try to be very well turned out ... and that (the teeth) is the one thing that I can't sort and you know, with glasses you can put contact lenses in and you can project this image of someone who's very professional and very in control and then every now and then you go "oh but maybe they're thinking about my teeth" and yeah, so it can throw you a bit.' P11

Concern about being misjudged

The second way in which the condition affected people psychologically was the anxiety it caused about being misjudged by others. There was a sense that other people would judge them based on their face or teeth and people worried that they were not projecting an accurate image of themselves and their personality as a result.

'If I'm having like a really good day and then I'll look in the mirror and I'll catch myself at a wrong angle or something, it'll knock me down and I'll feel really self-conscious, ...when you know you've got something kind of wrong with you... you feel like you haven't got a leg to stand on, ... like going out and you've got your skirt tucked into your knickers and you feel great but everyone's looking at your knickers (laughs) so you're thinking... I may feel fantastic but people are going to be looking and saying "oh but her jaw is a bit weird."' P8

There was a concern that people would assume that they were unhappy or unfriendly because they did not smile (P14, P10). There was also the worry that other people were thinking about their flaw all of the time (P18). Others felt vulnerable and exposed, that they could not stop people focusing on their defect and there was a general sense of wanting to look ‘normal’ and not stand out in the crowd (P1, P9, P13).

‘They (people) look at this part of your face when you’re speaking, it’s the most visible and apparent part of you. Sometimes I would actually like to stick a balaclava on or something like that so just my eyes were visible, then I could talk to people without being conscious of it. I’m much happier talking to people on the phone, I don’t particularly like face-to-face contact with people, I usually look away from people all the time when they look at me, which makes people think that you’re lacking in self-confidence or unfriendly or you’ve got something to hide. Yes, it’s just that really, if there’s something you don’t like about yourself, you don’t like people scrutinising it all the time, and your mouth is the... I mean, your face, it’s the focus for people isn’t it.’ P14

Impacts on self-confidence, self-image, and mood

As expected, the presence of a dentofacial discrepancy had negative impacts on self-confidence and self-image. This affected people internally (negative self-image) and in social situations, both with new people and existing acquaintances and family. Negative self-image ranged from mild dislike of the appearance of the teeth and face to a sense of self-loathing, with people using expressions such as ‘deformed’, ‘a freak’ and ‘damaged inside’. There was a sense of having something ‘wrong’ with them.

‘It’s like I’m not kind of finished yet..., it’s almost like when you have your baby teeth and you feel that you haven’t grown up yet because you haven’t got your adult teeth, it’s kind of that feeling, like I feel like I’m not done growing in a way, which feels quite weird when you’re in your twenties, like you should be kind of done.’ P8

In some individuals, the impacts on self-confidence were so strong as to lead to low mood and even depression (P6, P7, P14).

'I was quite depressed, not applying for any job for some time.' P7

Those individuals who had concerns regarding their teeth and bite alone tended not to have significant impacts on their self-confidence, whereas those whose primary concern was their facial appearance had more impacts on self-confidence and self-image. This was especially true of those whose reasons for treatment were functional instead of aesthetic. These individuals mentioned feelings of embarrassment, but did not relate the problem to their self-image or confidence (P12, P13, P15).

'I'm eating and I always have to have a napkin in my hand, it's a bit embarrassing to be honest.' P13

Lack of control

Presence of a malocclusion affected people's control over many aspects of their personality and life. Comments about the defect led to anger and conflict, with one individual worried about the repercussions of his actions.

'I get angry but I don't want to always ... have trouble, I'm a quiet guy who thinks people are human. And if I be angry, I do everything, like once a day I had a thing, the peoples in our house, I had a knife, I was cutting the bread, he made me angry, I throw it to him. Like if you angry, you lose your control, you do everything.' P1

Those with concerns regarding function felt frustrated at not having the choice of what they wanted to eat or not having control over how they ate.

'Instead of having my steak medium rare I just have it well done so it's easier to chop up and chew and ... what I find is I eat very quickly and then because I'm eating big chunks because I can't really break it down so I get full quite quickly and then about an hour later I'm hungry again.' P15

'You have front teeth, you should use them the way you want and you can't just, you know, I just don't like the fact I can't eat a carrot the way I like it because I've got this problem. It's a simple thing but if you dwell into it long enough you soon find out that these simple things are the most important ones. It's the ones

that you take for granted and suddenly when you haven't got them anymore you realise how important they are to you.' P13

Others felt that their problem affected their performance and led them to feel like they were not in control and become nervous in social situations or in groups (P14).

Feeling of victimisation

There was a feeling of 'why me', of being singled out and punished unfairly and not knowing why. People could not understand why it had happened to them and not a sibling (P3, P11, P14) and others looked for someone to blame (P14). Some expressed feeling 'let down' and 'looked down on' as a result (P6). There was a general feeling that life was more difficult and may have turned out differently if they had not been affected in this way, that they had an additional hurdle to jump or a 'millstone' around their neck (P14). Those who expressed these feelings tended to have the strongest impacts on their day to day lives.

Anxiety about physical impact

Those who had predominantly functional concerns were worried that they could not prevent damage being caused to their teeth by their bite. They were worried that their teeth would wear down prematurely and that they had not done anything to prevent it (P5, P13, P15).

'Psychological effect of me being afraid or scared ... of the implications of leaving it untreated because I'm just worried it will get worse and if it does get worse, the longer you leave it the worse I think, I'm very much a person if this is something wrong sort it out now and don't wait for tomorrow, you know. Tomorrow you might have something else to do.' P13

Figure 2.4 is a summary of the main impacts of dentofacial deformity described by the participants in this study.

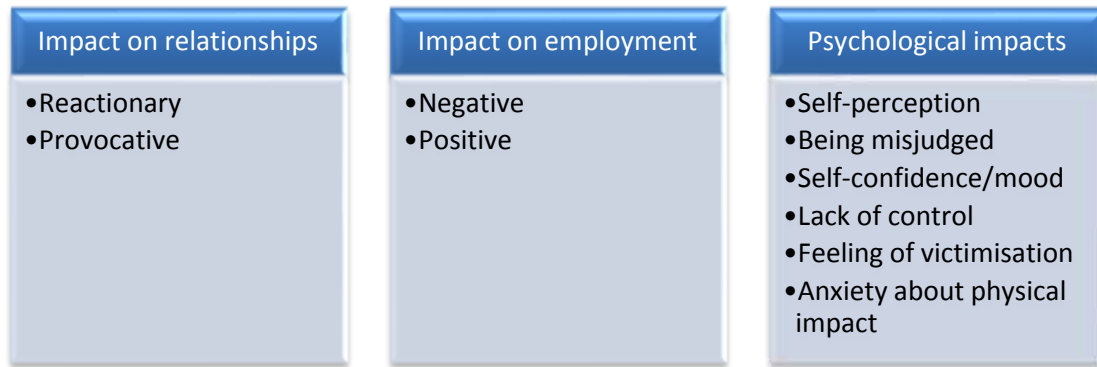


Figure 2.4. Summary of the main impacts of dentofacial deformity.

A self-perpetuating cycle

The impact of dentofacial deformity varied widely on different individuals; at one end of the spectrum, people acknowledged the impacts of the problem on their lives but were not adversely psychologically affected by it. At the other end, the problem led to psychological impacts which then led to a cycle of negativity and a self-perpetuating process, which in turn fuelled the extent of the psychological impact. For example, many felt self-conscious about the appearance of their teeth and jaw and consequently avoided smiling or talking to people. They then worried that people would think they were unfriendly or grumpy and so avoided meeting people at all to prevent others forming these opinions and this impacted further on their low self-confidence. The impact of this ranged from sufferers avoiding smiling to attempting to completely control their environment, including what type of job they did, their career progression, and their social life (P6, P7, P14). It seemed that the lower the self-esteem and the stronger the feelings of self-loathing, the more extreme the impacts on behaviour. There also appeared to be an association, which was not conclusively proven from the transcripts but which would be useful to investigate further, between those who had a strong feeling of being a victim (*'why me'*) and the extent of low self-esteem. Those who vocalised a feeling of injustice also expressed strong feelings of self-loathing: *'ridiculous'*, *'deformed'* (P6), *'a freak'*, *'damaged'* (P7, P14). This related to the extent of the impacts on their lives.

'This is stopping me from doing things and it leads to introspection, self-pity, the cycle of misery, lack of self-confidence, not doing things, getting worse.' P14

One described looking in the mirror and being ‘*put off*’ by her appearance and just staring at her reflection thinking ‘*what’s going on, what happened to me?*’ She would then get depressed and avoid going out and meeting people, which gave her more time to focus on the problem (P3). Another described becoming a ‘loner’ as a result of the negative image they had of themselves:

‘My teeth have damaged me inside. It takes me to a very bad place. You know, you feel like you’re a freak, that’s what I think. I don’t like saying it, but I do. People actually make you feel like it..... It hurts a lot. So I avoid it.’ P7

‘I think I deny myself a lot of stuff just because, well, it’s tied up, I was going to say it’s tied up with my teeth, but I don’t think it has nothing to do with my teeth any more. It’s just the confidence. I don’t have that much confidence at all.’ P7

The reason that some individuals experienced such extreme psychological impacts and others did not can only be speculated but seems to be related to a complex interaction between a person’s psychological make-up and personality, as well as past experiences.

Coping strategies

Many individuals adopted coping strategies to deal with the impact of the condition. Two types of coping mechanism were described, avoidance behaviour and altered behaviour, however a combination of both types was present in most cases. It appeared that the greater the impacts on people’s lives the more likely they were to adopt avoidance behaviours, but this cannot be proven by qualitative research and would need quantitative methodology to ascertain if a direct relationship exists.

Avoidance behaviour

This involved avoiding seeing or thinking about the defect and also avoiding others seeing it. Patterns of behaviour included not going out (P2), not socialising, not eating in front of people (P14), not having photographs taken (P14), not smiling (P4), not thinking about the problem, not allowing friends or family to discuss it, and avoiding looking in the mirror (P6).

‘I’ll avoid eating with other people as much as possible.’ P14

'So I avoid getting in any kind of photograph.' P14

'I can't look at myself in a mirror.' P6

Altered behaviour

This involved still carrying out their normal day to day activities but modifying their behaviour to minimise the impact of their condition. There was a wide range of altered behaviours, including covering the mouth to hide the teeth, not biting together to disguise the bite (P4, P10, P17), not posing for photographs straight on (P9), retracting the jaw (P14), mirror checking with posing on their best side to reassure themselves, putting the tongue under the top lip so it looked fuller (P14), moving or blinking during photographs so the photo would be ruined and would not make it to the album, posturing their jaw forward (P11), and positioning strategies so people were unable to view them in profile (P3). These were often described as sub-conscious and had become part of a learned habit.

'I ... keep my bottom jaw and my top jaw a bit open and not put them together 'cos my jaw comes out more.' P10

'Sometimes if I haven't seen my reflection for quite a while, I start to worry about my appearance and then reassure myself by looking in the... you know the mirror look, when you make yourself look the best you can (laughs), it's really sad.' P14

'I will hide my side to not let people see my jaws from this side.' P3

Summary

The evidence indicates that the presence of a dentofacial deformity may have a significant impact on a person's life. This may not be solely related to the defect itself, but possibly reflects past experiences, psychological constitution, and personality. As a result, the degree of impact is not necessarily proportionate to the extent of the deformity. Therefore, the impact of the presenting problem is more complex than may be immediately obvious to the clinician at initial consultation. The clinical relevance of understanding the impact of the deformity on patients is interwoven with an appreciation of the patient's motivation for, and expectations of, orthognathic treatment.

2.3.2.2 Motivations for orthognathic treatment

The source of motivation has been said to be associated with satisfaction with outcomes in orthognathic patients, therefore it was felt to be important to explore the full range and source of motivating factors, and the triggers for actually proceeding with treatment (Edgerton and Knorr, 1971; Peterson and Topazian, 1976; Øland *et al.*, 2011).

Range of motivating factors

In some cases there was a straightforward link between the impact of the condition and the patient's motivation for seeking treatment. The motivation could be either directly or indirectly related to the impact of the problem. Examples of motivation directly related to impact included those with problems eating or speaking who were motivated by the hope that treatment would alleviate these problems. Motivation indirectly linked to the impact of the problem involved individuals wanting to change an aspect of their lives or circumstances by correcting the physical problem. An example of this is illustrated by the following case study:

P3 was concerned about the appearance of her large lower jaw and her crooked teeth which affected her confidence. Her real motivation for treatment was to please her parents and she believed this could be achieved by improving her appearance and confidence. 'My dad especially he really wants me to look really perfect with the face 'cos he thinks as a girl like it really affects the way you look and my mum, she doesn't mind she's like, if you don't have operation I love you as you are. But my dad doesn't think like that, my dad is like "you need to have it" and I really think like my dad thinks that it affects my look and my confidence when I'm in public places so they are backing me - like they always want me to be a good girl.'

The same classification used for the range of impacts could be applied to motivating factors, namely: exclusively practical motivation (including functional and structural), exclusively psychological motivation (including psychosocial), and a combination. Often people's motivation was simply to address the problems that the deformity was directly causing but, for others, the real motivation was to bring about other secondary

changes in their lives, such as having more confidence and being able to get on with life without having to worry about the problem.

'I don't like where I'm going at the moment, and that's why I'm doing something about it, because I want my life to change, because I want to be out there, I want to be with the outside crowd, I want to go out, I want to talk to people, I want to be friendly with my colleagues and everyone. That's everything that I want to and, at the moment, the only thing that's stopping me from doing so is just my teeth.' P7

The trigger for treatment now

There were four main triggers for patients accessing treatment at a particular point in time, which were:

- Eligibility - people had presented for treatment at varying ages and many were still growing, therefore the trigger for treatment at this point was that they had stopped growing and were now suitable for treatment.
- Availability - for a variety of reasons people had become aware that this treatment was available and an option for them. Some had heard about it from friends or relatives and others were told by their dentist or orthodontist.

'From the moment I heard about it, there was some sort of a light bulb went on up there and I just was happy. It's like, you know, you having some sort of illness and finding there's a cure for it, so that's the kind of thing. I never knew there was a cure for it, so I was really, really happy about it.' P13

- Incident or experience - a particular encounter, experience, or event acted as trigger for seeking treatment.

'One of my bosses just said to me "look now is the time to get it sorted out...because you don't want to be remembered as the one with the bad teeth". And I thought 'wow' and that sort of shocked me initially and then I thought well, she's got a point and I could just sort it out.' P11

'A failed relationship (was a trigger for seeking treatment), and I thought the reasons for it were to do with my self-esteem and my behaviour related to this, and I thought I ought to do something about it.' P14

- Climax in the effects of the problem - where the problem which had been observed for a variable length of time was now becoming critical.

'I never really had a problem with it, you know, but I notice even my facial expression changed in a way because I'm not sure if my lower jaw recessed or what it was but I did notice a massive difference and when I look at the x-rays, obviously I'm a layman, I'm not a doctor but even for someone like me just looking at the gap between the lower jaw and the top jaw was a wake-up call and I thought maybe I should really do something now before this gets worse.'
P13

The source of motivation

The source of motivation for treatment has been reported to be one of the most important factors in predicting satisfaction with outcomes (Edgerton and Knorr, 1971; Peterson and Topazian, 1976; Kiyak *et al.*, 1985, 1986). Traditionally sources have been categorised as either external or internal: internal motivation stems from a long standing concern with the physical defect and a commitment to treatment to correct it. External motivation arises from a desire to please others, to either have the treatment due to pressure from others, or to lead to a change in the external environment, for example, a better job or a new relationship (Edgerton and Knorr, 1971).

This research supports this classification but suggests that motivation is a continuum rather than distinct and separate categories, with purely external motivation at one end of the spectrum and purely internal motivation at the other. It is also inextricably linked to the nature and the impact of the problem. One individual whose motivation registered on the internal end of the spectrum had become increasingly aware that he was only biting on his back teeth and had always had problems eating certain foods and wanted treatment so he could enjoy food.

‘Once it starts interfering with my eating habits, which I take religiously, I’m very serious about my, I love to eat, I eat a lot, I’m known for that and you know anything that would have an impact on that will annoy me.’ P13

Another individual, whose motivation for treatment was at the external end of the spectrum, had been told by a senior colleague that she needed to have the treatment for career progression. She admitted if she had not been told that, she probably would not have had the treatment.

Summary

The range of motivating factors, together with the triggers for wanting treatment at this time, and the source of motivation are linked to the nature and impact of the condition, either directly or indirectly. It is important to explore both the impact and motivation and recognise that in some individuals, the relationship between these may not be immediately obvious.

2.3.2.3 Expectations of treatment

It has been said that patient expectations are one of the primary determinants of satisfaction (Linder-Pelz, 1982; Kravitz, 1996) and thus interviewees were asked about their expectations of treatment, specifically what results they expected from treatment and how they thought treatment would affect their life in general.

Traditionally, expectations in relation to aesthetic surgery have been classified as realistic or unrealistic. However, this involves making a subjective judgement regarding whether or not the outcome expected by the patient is likely. This is especially true with regards to the phrase ‘unrealistic expectations’. Realistic expectations usually involve predictable, probable physical outcomes and these can be assessed objectively on the whole. However, unrealistic expectations may be better described as ‘idealistic expectations’ to encompass the fact that the individual expects the ‘perfect’ outcome but does not make an assessment of whether this is possible or not.

Another classification found in the literature subdivides patient expectations into ‘probability expectations’ and ‘value expectations’ (Uhlman *et al.*, 1984; Kravitz, 1996). Probability expectations, also known as expectancies or predicted expectations, involve

the patient's judgement of how likely an outcome will be (Dawn and Lee, 2004). They usually refer to functional outcomes and have been described as what the patient *thinks* will happen, for example, expecting the teeth to bite the correct way following surgery. Value expectations encompass patient's desires, hopes, and wishes in relation to the treatment. However, these are not always mutually exclusive categories and classification based on these terms could potentially be misleading and was not the natural taxonomy that was observed in this study.

On analysis of the transcripts it was found that participants' expectations could be broadly divided into two main categories; expectations of actual physical changes, and expectations of non-physical changes, that is, the effects that these physical changes would indirectly have. Expectations, whether they were realistic or idealistic, probability or value expectations, could be described overall as either physical or non-physical and consequently this classification is used here. This description approximately accords to the categories of probability or value expectations but is more accurate for this study population and does not involve the analyst or clinician making a subjective judgement.

Physical changes

When asked what they expected from treatment, most participants referred to the physical changes they anticipated occurring initially. Some expected changes in their overall facial appearance but most were more specific with expectations of changes in their teeth, jaws, bite, and eating. The physical changes expected could be either regarding function or appearance. The aesthetic changes anticipated were rooted in physicality and were distinct from the aesthetic changes discussed in the following section on non-physical changes, where individuals expected aesthetic changes to lead to additional psychological benefits. Those with physical expectations wanted their teeth to be straight and to bite correctly and their jaws to be a normal size and position.

'I expect my face like won't change, hopefully. I expect my teeth to bite properly and that I should be able to bite properly for the rest of my life.' (P5)

'But just to have a few bits moved around, obviously the overbite and maybe with some alteration, just a bit more tight together.' (P17)

'I just wanna have a normal jaw size and place. I don't expect so much difference, I don't but I just want to have a proper jaw that my lips are properly closing.' (P3)

Non-physical changes

Individuals did not spontaneously offer information on the expected non-physical effects when asked about their expectations, tending to focus purely on the physical changes first. When prompted to consider the effects the changes would have on life in general, the following aspects were identified; emotional effects, social effects, psychological effects, and lifestyle effects and these were inter-related in some cases.

Emotional effects

All of the expected emotional effects were positive, and included patients expecting to be happier in general, to feel more confident, and to feel more relaxed as a result of not having to worry about their dentofacial problem. The magnitude of the expected effect on emotions was variable, ranging from expecting little or no change to expectations of a very large change.

'I don't think there'll be a big change because I've never been outspoken or anything like that, I've always been quite quiet so I think it'll probably stay the same. I don't think it will have any impact on my personality or anything, it's just looks.' P16

'That will actually change my life big time... then I will be the happiest.' P6

Social effects

The expected social effects were also positive. Some participants expected these changes to be as a direct result of the treatment, but a number of participants acknowledged that accompanying psychological changes were also necessary.

'I'd understand that it wasn't to do with the teeth or my jaw, like the reason that I wasn't being more sociable, wasn't making me more friends and it was to do with the way I actually was. I guess I will try and change that, like I'd put

myself... and make more of an effort, because I do want to make more friends and be more sociable.' P10

A key expectation was that participants felt they would go out more and be more sociable, and even that they would have more successful intimate relationships. For these participants, it was not that the surgery would lead to a great change itself; rather that the surgery would remove a significant psychological barrier.

'Because the only thing that now stops me from putting myself out there is just about my teeth. So as long as they're fixed, I'll try to be more sociable and more engaging with people.' P7

'And I think I'll be more confident when I'm around them, once I get it fixed, with strangers, like, people who don't know me at all. I think I'll be more comfortable, be myself. Once I feel like that, there's no need for me to hide, for my teeth.' P7

Another anticipated effect was that surgery would mean participants would feel less defensive about their appearance. One individual thought this would mean he would be less likely to become involved in confrontations, some of which had escalated into violent interactions when out socialising.

There were two main ways in which people felt that treatment would affect their social interaction. The first was through inducing behavioural change on their part, in some cases through greater exposure to social interaction. The second was through changes in the behaviour of others.

'I feel like people will actually have more interest (in me) or you know ... because right now I feel like, looked down on in a way.' P6

The anticipated effects related predominantly to new relationships and acquaintances, however, one individual mentioned that he felt that his relations with family would improve as he would no longer be so moody.

Psychological

Expectations about changes in appearance ranged from wanting to look normal to an expectation of being perfect and unrecognisable. Having a 'normal' appearance was about *feeling* normal and the changes this would bring to their lives rather than just a physical change; thus it is classified under non-physical expectations.

Being normal was described as being 'like everybody else' and 'not standing out in the crowd'. Rather than having a particular look or appearance, normality seemed to reflect an absence of judgement about appearance. The expectation was that people who looked normal were not subjected to judgements about their appearance from either themselves or others. When probed about what 'normal' was, one patient described it as,

'Just being able to relax and forget about your appearance, it's me being happy with my appearance and saying okay, that's all okay now, I don't have to think about that, and I'll just get on with everything and be like everybody else, because I've seen what everybody else is like.' P14

'I just want it to look normal I think and not have to look in the mirror and go "ooh, that's a bit wrong isn't it" (laughs). Just, one of those faces that you don't want to feel uncomfortable to look at. I don't have massive high hopes that it's going to make me look like a complete stunning supermodel kind of person, but as long as it looked normal and didn't make me kind of go, have that moment of ugh, I'd be happy.' P8

Where the expectation was perfection, this related to more than just the teeth and jaws. There was a sense that the overall appearance would be improved and that this would lead to happiness.

Expected effects on personality ranged from participants expecting their whole personality would change as a result of treatment, to their personality improving to some extent. Those who expected their personality to change anticipated a process where they became happier with their physical appearance and so would be happier with themselves and consequently become a different person. Others expressed this expectation by

hoping that they would become a better ‘version’ of themselves. There was a sense that treatment would enable individuals to become more positive and less self-critical.

‘I won't be ... putting myself down as much as I am and stopping myself to do stuff because of my teeth. I won't be ...such ... of a critic with myself.’ P7

Others did not feel that their personality would change but rather they would now be able to ‘show’ their true personality. For some this was directly related to the physical defect. One described being a ‘smiley person’ inside but not wanting to actually smile as he did not want people to see his teeth. Thus he felt he was giving the wrong impression of his true character, which in turn was having an effect on social interaction and relationships and becoming a self-fulfilling prophecy (P7).

Other participants did not expect any changes in their psychological status or personality but just wanted to be able to forget about their defect and carry on with life. There was a sense that treatment would not improve their lives directly but would remove a negative factor and bring them to a neutral standing in life.

‘It's about me being happy with my appearance and saying okay, that's all okay now, I don't have to think about that, and I'll just get on with everything and be like everybody else.’ P14

Lifestyle effects

For some patients there was a sense that if they had the treatment, they would be able to get more pleasure out of everything else in life. They spoke about concerns and issues they had with their appearance that had prevented them from getting pleasure out of life and that after the treatment they would be more relaxed and able to embrace experiences and opportunities in a way they previously could not.

‘I think I will be, you know, happy (laughs). I would look myself maybe in the mirror, you know go out and just enjoy life like everybody else because right now it's ... just like kind of, yeah it's actually affecting my life a lot of ways.’ P6

Others expected more tangible changes to their life, such as a change in career. Some also envisaged being more successful at work because they felt that if they had more confidence, they would tend to push themselves more and achieve greater success. They

also reasoned that employers and colleagues would not discriminate against them on the basis of their physical appearance or indeed may positively favour them.

There was also a sense among some participants that being happier with their facial appearance would mean they would take more care with other aspects of their appearance such as their hair or weight.

Typology

The different expectations observed related back to the original motivation for treatment and whether the desire for treatment was for practical or psychological improvement. Those with very specific expectations of the physical outcome tended to be those whose motivation was at the purely practical end of the spectrum. Whereas those who expected more widespread and non-physical changes were those with more mixed motivation (practical and psychological). Expectations, as for motivation, were strongly influenced by the impact of the condition.

A typological classification emerged from the examination of individuals' expectations. Typology exists where people and processes can be ordered into distinct categories which combine several features to make sense of complex social phenomena (Ritchie and Lewis, 2003). Four types of patients were observed in this study based on their expectations of physical and non-physical changes (Table 2.5):

- I. Metamorphosisers
- II. Pragmatists
- III. Shedders
- IV. Evolvers

I. Metamorphosisers

These individuals have high expectations of both physical and non-physical change following treatment. They expect their physical problems to be fully corrected and to have a substantial change in physical appearance. As a direct result they anticipate life will change for the better, perhaps with resultant new relationships, more friends, or a better job. The following case study illustrates a typical 'metamorphosiser'.

P6 expects treatment to change her life 'big time' and she will look 'way better'. She will then be able to 'enjoy life, like everybody else'. People will not look down on her any more. She hopes that she will be unrecognisable after treatment as a friend of her mother's had it done and people did not recognise her. Her mother thinks this will be the case and so does she. She thinks her lips will be 'perfect' afterwards and her appearance will be 10 out of 10.

II. Pragmatists

Pragmatists have high expectations of physical change and low expectations of any non-physical changes following treatment. Their original motivation is predominantly physical with little or no emotional, social, or psychological ramifications. They expect the results of treatment to correct their physical defect but have no expectations of other associated benefits.

P15 just wants to be able to eat properly. He always noticed he could not chew well and had to chew and swallow big chunks of food. He has to have his steak well done instead of medium rare, as he prefers, so he can chew and digest it. He gets full quite quickly as he has to eat slowly but then he is hungry again an hour later. He also just bites on the back teeth and that is annoying and he worries it may wear the teeth down. He just wants his teeth to come together better and in the correct relationship. He does not expect treatment to have any change on his life in general as 'it's just teeth'.

III. Shedders

Shedders have low expectations of physical change and high expectations of non-physical change. Their main motivation is for life changes secondary to correction of the physical problem. They are looking to overcome or 'shed' the obstacles directly caused by their defect which they believe are preventing them from achieving their goals in life. They hold a strong belief that, even if the treatment does not address the physical defect completely, they will be satisfied with the outcome if they achieve the expected non-physical benefits.

P9 just wants to look 'a bit more normal'. She thinks if she has the treatment she will have more confidence and will go out more and do more things. She will be more talkative and sociable and meet new people. She feels this will really help with her career in the music industry as she will have the confidence to put herself 'out there' and will be more successful. She also thinks her jaw affects the way she sings and treatment will improve that and allow her to sing higher notes without strain. She notices the physical defect and has wondered if it makes her 'less pretty' but has come to terms with it and accepts it. However it is nice to know now that something can be done about it. She expects her jaw to be a bit more symmetrical after treatment.

IV. Evolvers

These individuals have low expectations of both physical and non-physical change. The decision to have treatment was one which they deliberated over for a long time and their current perceptions and decision to have treatment have evolved over time based on experiences and influences. They have carefully considered the pros and cons of having treatment and generally have realistic expectations. The impact of their problem is not great and the extent of the problem was usually highlighted by someone else, often the general dental practitioner. They have been influenced strongly by significant others to have the treatment.

P5 admits he probably would not have pushed for the treatment if his dentist had not motivated him. He noticed the problem in his teens when he could not bite sellotape and observed that his front teeth did not come together but it was his dentist who suggested having treatment to correct it. His mother is very keen for him to have the treatment as she has had a lot of problems with her teeth. Now that the problem has been pointed out to him, he admits it can be annoying when he cannot bite properly and now he is very motivated to have the treatment. He just wants to have 'straight teeth and bite properly'. 'I expect my face like won't change hopefully but if it makes me even more good looking I ain't gonna complain about that, I just expect my teeth to bite properly'. He gets a little frustrated when eating takes so long and finds it embarrassing sometimes in

front of others as he is messy when he is eating. He sometimes feels stupid because he cannot eat certain things. He thinks he will be a bit more confident and smile more and show his teeth after treatment. He thinks he may make a better first impression on people, for example at interviews, if his teeth and smile are nice.

Table 2.5 summarises the key features of the different typologies. The clinical implications of these different typologies are discussed in section 2.4.5.

NON-PHYSICAL CHANGES	PHYSICAL CHANGES		
		HIGH	LOW
	HIGH	<i>Metamorphosisers</i> (looking for a complete change)	<i>Shedders</i> (looking to shed old hang ups)
LOW	<i>Pragmatists</i> (looking for practical changes)	<i>Evolvers</i> (looking for a significant but small step forward)	

Table 2.5. Matrix/contingency table of expectation typologies.

2.3.3 The relationship between impact, motivations, and expectations

It is generally accepted that expectations of treatment outcome have a significant impact on satisfaction and when assessing an individual for orthognathic treatment, patient expectations have often been assessed as the sole predictor of satisfaction. However, this research has shown that it is important to also consider the impact of the dentofacial deformity on a patient's life, as well as their motivations to have treatment at this stage as these may affect satisfaction with outcome, but may not be directly related to expectations.

Two descriptive pathways leading to expectation were identified (Figures 2.5 and 2.6). In pathway one, impact and motivation were related to expectations in a simple linear pattern (Figure 2.5), whereby the impact of the problem explained the motivation, and the expectation was directly related to that motivation with no other factors involved. The following case study illustrates this linear relationship.

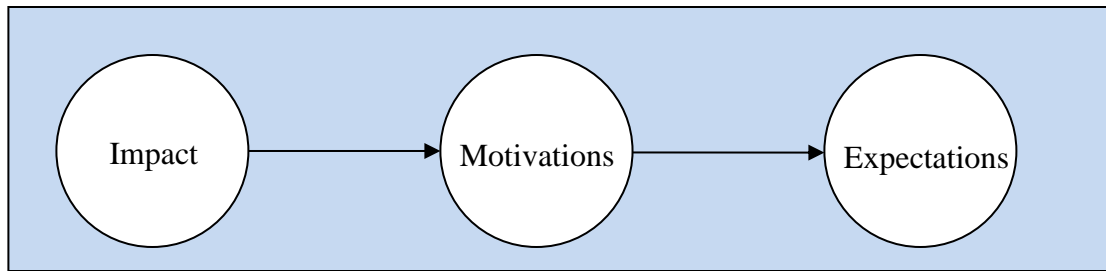


Figure 2.5. Simple linear relationship between impact, motivations, and expectations.

Case study: The impact of dentofacial deformity on P13 is purely functional and relates to eating primarily. 'Looks has never been the main thing but rather the functionality of it and once it starts interfering with my eating habits which I take religiously, I'm very serious about my, I love to eat, I eat a lot, I'm known for that and you know anything that would have an impact on that will annoy me.' His motivation for treatment is directly related to the impact of the problem on his eating habits. 'My motivation is to get my teeth fixed to a stage that I can chew properly. That's just the little things like that I, you know, it's just you almost take these little things as your own right, it's a right you have, you have front teeth you should use them the way you want and you can't just, you know, I just don't like the fact I can't eat a carrot the way I like it because I've got this problem. It's a simple thing but if you dwell into it long enough you soon find out that these simple things are the most important one'. His expectations in turn relate directly to the impact and motivation 'I have strong expectations. I don't think they're unrealistic bearing in mind what was told to me, from what was explained. My expectations are me being able to eat as I used to without having to be constantly passing food with my tongue from one side to the other in my mouth.' P13

However, in many individuals, a simple relationship did not exist between these three factors (Figure 2.6). Pathway two describes a complex relationship between impact, motivations, and expectations affected by other factors, which may not be readily identifiable or measurable. Examples of other factors with an influence on the relationship between impact, motivations, and expectations which were discussed in the interviews included parental attitudes, cultural beliefs, and childhood experiences (teasing, bullying, and career aspirations). Exploring all possible life issues which may

impact on psychological issues pertaining to orthognathic patients was beyond the scope of this study; however, it is an interesting area for further research. The following case study illustrates an example of this complex inter-relationship.

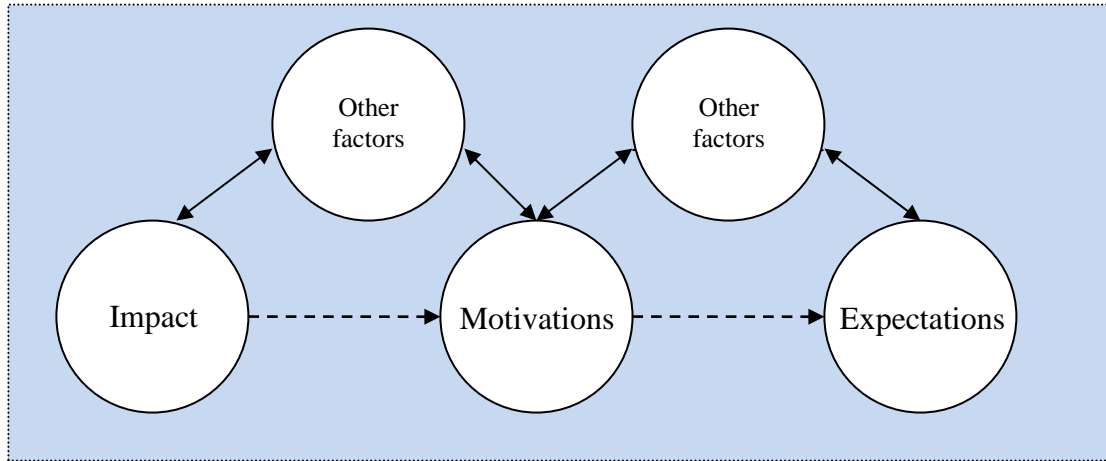


Figure 2.6. Complex relationship between impact, motivations, and expectations.

Case study: P11 was very self-conscious about her teeth and jaw as a child and was bullied as a result. She was very studious and introverted. She admits that she has largely grown out of that and her motivation is now ‘professional rather than personal’ and admits that she may not have had this treatment if a colleague had not suggested it for career progression. She expects that she will become more confident professionally when giving presentations and will not worry about what the audience is saying about her appearance. ‘I’m going to be more confident if I’m not worrying about them all the time I’m sure and professionally that’s sort of the whole point of it really that I’ll be able to stand up in front of a huge audience ... and feel like sort of I can do this without being afraid of what you’re going to say behind my back because I haven’t got bad teeth any more so that will be good.’ P11

2.3.4 Summary

Understanding patients’ expectations is widely reported to be instrumental in improving satisfaction with healthcare interventions (Chen *et al.*, 2002). In some cases, identifying patients’ expectations may be straightforward; however, in most cases it is necessary to understand the impact of the malocclusion and the motivations for treatment in order to

gain an accurate appreciation of expectations. The clinician should not underestimate the complexity of these factors or make assumptions and the emphasis should be on good communication with the patient.

The typological classification of expectations described here can be used clinically, supplemented by clinical experience, to formulate a treatment strategy for prospective patients. However, this typology is based on the findings from a small number of patients at one hospital and may not be directly applicable to other patient populations. Every effort was made through robust and transparent research methodology to make the findings generalisable but the results should still be interpreted with some caution. The clinician may never fully understand all of the possible inter-related factors which affect a patient's expectations of treatment. However, understanding the impact of the condition and the motivating factors for treatment may provide some important clues to expectations and it is vital that these are explored fully on an individual basis.

2.4 Discussion

2.4.1 Introduction

As mentioned in the Introduction (section 2.0.1), while there has been a considerable body of research investigating the psychosocial aspects of dentofacial deformity and orthognathic treatment, there remains limited qualitative data. Thus, the aim of this study was to use purely qualitative methods to elucidate the in-depth experiences of individuals with dentofacial discrepancies with respect to impact, motivations, and expectations.

2.4.2 Methodology

As previously discussed (section 2.0.5.8), there is a wide range of techniques and methods one can employ when carrying out qualitative research. When deciding on the most appropriate technique for this study, consideration was given to using grounded theory or interpretive phenomenological analysis (IPA) as used previously by this research team and in other qualitative studies in the field of dentistry or cleft and craniofacial services (Abrahamsson *et al.*, 2002; Trulsson *et al.*, 2002; Bhalla *et al.*, 2007; Hallberg and Klingberg, 2007; Ryan *et al.*, 2009; Josefsson *et al.*, 2010; Cadogan and Bennun, 2011; Lopez and Blue, 2011). However, a review of the literature and advice from experts in social research and psychology suggested that Critical Qualitative Theory, using the Framework approach, was more suitable to answering the research question. This was due to the nature of the research and the in-depth understanding that was required within the time and resource constraints. In addition, the aim of this research was to provide findings that would be generalisable and could be applied to similar cohorts of patients. Thus, a form of analysis was needed which was transparent and rigorous, carried out in as neutral and unbiased a manner as possible, with findings which were accessible and defensible and able to support wider inferences (Barnard, 2012). In addition, this technique is being used increasingly in the field of dentistry (Anderson and Thomas, 2003; Anderson, 2004; Marshman *et al.*, 2010).

Interviews were employed to collect the data, as observation or focus groups were felt to be inappropriate for exploring the potentially sensitive topics which were under investigation and could not explore in-depth individual experiences.

The patients were chosen using purposive quota sampling, as discussed in section 2.0.5.6. There is an art and a science to selecting such a sample, with the key being to obtain diversity across the sample to ensure that the range of perspectives is examined. The choice of which factors to subdivide the sample on was based on experience and knowledge of the topic under investigation. In this study age, gender, ethnicity, and type of malocclusion were considered likely to influence the experiences being explored (Table 2.2). The quota in each group was decided *a priori* to ensure diversity within the categories but also taking into consideration pragmatic factors such as knowledge of patient demographic, time and resource constraints. The sample (n=18) may be considered to be relatively small and this may have an impact on the generalisability of the findings. Nevertheless, diversity was achieved against the criteria used for sampling, and therefore the research is likely to give a good indication of the diversity in the population of patients seeking treatment for this condition.

2.4.3 Quality of this research

The quality of qualitative research can be tested in many ways including:

- assessing the appropriateness and justification of the sample,
- the method and quality of the data collection,
- the role of the researcher in data collection and analysis,
- systematic and explicit analysis,
- a range of perspectives explored and reported (including positive and negative), and
- clearly derived and defensible findings.

These factors encompass the concepts of validity and reliability as they pertain to qualitative research (NICE, 2009). Reliability is concerned with the quality of the measurement (<http://www.socialresearchmethods.net/kb/reliable.php>).

External reliability refers to the repeatability of the study and the consistency of the results, for example, would a repeat study yield the same results. Internal reliability refers to agreement between repeated measurements (Ritchie and Lewis, 2003). Some purists argue this is not relevant to qualitative research, however, in this study steps were taken to maximise reliability to enable wider inferences. These steps included using a robust sample frame to ensure a range of perspectives was explored (fair-dealing), and then utilising a robust and practiced interview technique to ensure range and depth of coverage. The interviewer (FSR) was extensively trained and maintained a neutral and unbiased position throughout to prevent influencing the participants. During the analysis, two researchers were involved in the key stages of data management, thematic, and explanatory analysis. Each stage of the analysis was transparent so that each conclusion could be traced back to the source using quotations and references to the framework and the interviews, thereby ensuring that the findings were supported by evidence.

Validity is concerned with how precise the findings are and whether they are generalisable (Streiner and Norman, 1995). External validity refers to the generalisability of the findings to the general population. No study, regardless of the methods applied, can produce findings which are universally transferable (Malterud, 2001), but qualitative research can support wider inferences through accurate and in-depth descriptions of the participants' accounts and the systematic and transparent reporting of the results as conducted in this study. Thus, analogical reasoning can be applied, whereby the results of this study can be applied to other populations with similar characteristics (Smaling, 2003).

Internal validity in qualitative research refers to whether the instrument, for example the interviews used in this study, actually measures what it purports to measure. In the context of qualitative research, it also involves whether the tools and interview technique facilitated an accurate understanding of the participant's perspective through the use of non-leading questioning, appropriate probing, and interpreting the data in an unbiased way. This is demonstrated in this study by showing that the theories and conclusions are clearly related to observations within the data including actual

comments made by participants. In addition, member checking was carried out during the interviews which involved summarising participants' accounts and asking them to confirm the validity. In order to improve validity, cross checks of the data were carried out during the interview stages, so that as theories were emerging from the interviews, the interviewer could enquire about rival explanations and counter-hypotheses.

The conflict of the researcher being a clinician regularly involved in providing orthognathic treatment (although not to any of the study participants) was considered carefully in the planning and execution of this study. The principle of reflexivity was adopted here, whereby the researcher was aware of her knowledge of this field and preconceptions were acknowledged and minimised where possible. In addition, a second researcher (MB), who is not a clinician, was involved in all stages of the analysis. Therefore, through the transparent, systematic process of conducting and reporting the findings of this study, the quality of the research has been maximised. However, as with all research, there is a limit to the effectiveness of these techniques but the aim was to reduce bias as much as possible so that readers could be as confident as possible that the findings are generalisable.

2.4.4 Research findings

The impact of dentofacial deformity

Previous research has described dentofacial deformity in relation to its impact on individuals or explored their reasons for wanting treatment rather than investigating and describing the nature and result of the problem *per se*. This research identified a possible difference between what constitutes the problem of having a dentofacial deformity and the actual impact of that problem. This is a subtle distinction but one which is important because making the assumption that the problem and the impact of that problem are the same may have implications for the management of the patient. Therefore, it is suggested that patients are asked both what the problem is in their own words and also how this impacts on their lives. This is an important part of the correct diagnosis of the issues.

Traditionally, the impact of dentofacial deformity, as reported in the literature, has focused on quality of life issues, encompassing aesthetic, functional, and psychosocial matters such as eating, social embarrassment and discomfort, self-consciousness, and bullying (Zhou *et al.*, 2001, 2002; Lazaridou-Terzoudi *et al.*, 2003; Phillips *et al.*, 2004; Rispoli *et al.*, 2004; Williams *et al.*, 2004; Williams *et al.*, 2005; Modig *et al.*, 2006; Palumbo *et al.*, 2006; Lee *et al.*, 2007a; Phillips *et al.*, 2007; Espeland *et al.*, 2008; Lee *et al.*, 2008; Al-Ahmad *et al.*, 2009; Esperão *et al.*, 2010; Murphy *et al.*, 2011).

With regards to the psychological impact of dentofacial disharmony, previous research is somewhat equivocal, but many studies have found that orthognathic patients do not appear to be more psychologically distressed than non-patients nor suffer greater anxiety or depression (Kiyak *et al.*, 1981, 1982a, 1982b, 1984, 1985; Kindelan *et al.*, 1998; Chen *et al.*, 2002; Phillips *et al.*, 2004; Rispoli *et al.*, 2004; Stirling *et al.*, 2007; Nicodemo *et al.*, 2008a; Williams *et al.*, 2009). Although one study demonstrated a significant increase in state anxiety in orthognathic patients compared with a community-based control group of non-patients (Cunningham *et al.*, 2000a).

This research suggests that the description of the impact should be replaced by a definition of what the *nature* of the problem is and this was classified as exclusively practical (encompassing functional and structural), exclusively psychological (including psychosocial), or a combination of the two. The previous classification of functional, aesthetic, and psychosocial could be seen as an over-simplification of the issue. This is because, in the classification that emerged from this study, aesthetic problems could be purely practical or purely psychological, or a combination of both, and the same applied to functional problems. While the psychological issues explored in this study related predominantly to social problems, such as lacking confidence in social situations, there were other psychological problems caused by the presence of dentofacial disharmony which were not related to social circumstances, for example hopelessness and a sense of lack of control over one's life. Hence, the reason for the different nomenclature adopted in this study.

Depending on where the patient fits into this classification, the problem then presents as a set of impacts on the individual's life. This research found that these could not easily

be classified according to the previously described system of functional, aesthetic, and psychosocial either and therefore the findings are presented in a descriptive manner. It was found that dentofacial deformity had impacts on interpersonal relationships and employment, as well as having psychological impacts. In reality, the nature of the problem and its impacts overlap considerably. Therefore, for the purposes of comparison with the rest of the literature - where the term impact is used to describe both the actual problem and its effects - the nature of the problem will be discussed as the 'impact' in subsequent sections.

The impacts on interpersonal relationships manifested themselves in two ways; by the way individuals with dentofacial deformity interacted with and reacted to others (termed reactionary impact), and also by the way others reacted to them and the reaction they provoked from others (termed provocative impact). The former caused some affected individuals to avoid meeting new people and also tended to undermine their existing relationships as they put up barriers or took out their frustration on those close to them. Problems with social interaction have been reported previously, where individuals with dentofacial discrepancies avoided public places and the opposite sex due to their problem and also found they had reduced marital opportunities (Newell and Marks, 2000; Modig *et al.*, 2006; Lee *et al.*, 2007b). This reaction may lead to individuals becoming introverted and reclusive (Newell and Marks, 2000). The impact of dentofacial discrepancy on existing relationships has not been widely reported before and is significant as it has been suggested by previous research that the support of significant others during orthognathic treatment is related to patient satisfaction with the outcome (Holman *et al.*, 1995).

Provocative impacts described how others reacted to the interviewees, whereby the participants felt that others made negative judgements of them based on their defect. This finding has been reported in research involving individuals with visible facial defects or appearance deviating from the norm. Such individuals have been judged to be less intelligent, less popular, and from a lower social class and bullying has been reported as an issue (Shaw *et al.*, 1980, 1985).

Impacts on employment described were largely negative and individuals discussed not applying for certain jobs due to the fact that they felt that their facial appearance would prevent them getting the job, or jobs in the public eye would expose them and make them a target for bullying. Others felt that they had been discriminated against at job interviews due to their dentofacial discrepancy. This sense of being disadvantaged in job selection processes has not been studied widely, but a recent study in the US found evidence that facially disfigured or stigmatised individuals are indeed discriminated against in job interviews (Madera and Hebl, 2012). Interestingly, one individual in the current study felt that having a facial appearance deviating from the norm may be an advantage in the acting profession as it could set him apart from the competition.

Psychological impacts of dentofacial deformity were widespread among the interviewees, and were manifested in a number of different ways. Individual's self-image was affected and some struggled to reconcile the image they had of themselves in their mind and that which was presented to them in the mirror or photographs. This was something which was felt to be out of their control and led to frustration. Depersonalisation, whereby an individual feels disassociated from their own physicality and experiences a lack of control, is the third most common psychological symptom after anxiety and depression and can be an indication of psychiatric disorders, such as anxiety disorder and Body Dysmorphic Disorder (American Psychiatric Association, 1994; Fuchs, 2003; Simeon, 2004). Therefore, clinicians who encounter such sentiments should be wary of the possible existence of other psychological conditions.

A sense of being misjudged was vocalised by many and has been supported by research as discussed previously (Shaw *et al.*, 1980, 1985; Newell and Marks, 2000). Negative impacts on self-confidence and self-esteem were widespread; however, pre-existing research has failed to prove this conclusively to date (Cunningham *et al.*, 2000a; Stirling *et al.*, 2007; Williams *et al.*, 2009; Burden *et al.*, 2010). This highlights the benefits of qualitative research in revealing aspects of psychological functioning which may otherwise be difficult to prove quantitatively. There is evidence from longitudinal studies that self-esteem improves following orthognathic treatment, and therefore, this finding of reduced self-esteem before treatment may be useful to clinicians and

commissioning bodies when considering treatment and allocating resources (Kiyak *et al.*, 1985; Flanary *et al.*, 1990; Hunt *et al.*, 2001).

Anxiety about the physical impact of the malocclusion was discussed and participants expressed concern that their condition would deteriorate and cause future problems with oral functioning. Other studies have found similar findings, with 69% of participants in one UK study citing a desire to prevent future dental problems (Williams *et al.*, 2005). While it is encouraging that patients are concerned about their dentition in the long-term, it is important that these concerns are realistic, as there are relatively few malocclusions which compromise the longevity of the dentition and patients should be counselled appropriately.

Many of these psychological impacts led to a cycle of negativity and a self-perpetuating process. A common example described was that individuals felt self-conscious about their facial appearance and thus avoided socialising and became more reclusive, with fewer friends, and this further impacted on their self-esteem. This ‘*self-fulfilling prophecy*’ has been noted by other researchers (Langlois and Stephan, 1981). This is of relevance to clinicians as orthognathic treatment may not be the most appropriate first line treatment for this negative cycle. Cognitive behavioural therapy has been shown to be effective in breaking this cycle and should be considered in these individuals following thorough psychological assessment by the appropriate person (Bailey, 2001).

A recurring theme which arose from the interviews when discussing the impact of the problem was the presence of coping strategies. All of the participants had adopted some form of coping strategy to help them deal with their problems, and these could be categorised in this research as either altered behaviour or avoidance behaviour. Altered behaviour involved carrying out normal day to day activities but altering situations to minimise the emphasis on the defect. Avoidance behaviour involved completely avoiding any situation that might highlight their defect. A trend was noticed, but not conclusively proven from the data, that the greater the impact of the problem on people’s lives, the more likely they were to adopt avoidance strategies rather than altered behaviour. This has not been previously reported with respect to orthognathic patients. However, coping behaviour has been described in individuals with visible

disfigurement, for example, cleft lip and palate, burns, traumatic injuries, and severe acne among other conditions (Lethem *et al.*, 1983; Newell, 1999; Rumsey and Harcourt, 2004).

Coping strategies have been described in the literature along a continuum from confrontation to avoidance (Newell and Marks, 2000). Avoidance coping mechanisms are said to be ‘maladaptive’, whereby the behaviour adopted increases stress levels and is actually a form of non-coping. Avoidance strategies tend to perpetuate the negative issues and prevent the individual dealing with the problem constructively. This avoidance is prompted by fear and anticipation of a negative outcome and leads to the individual engaging less and less in situations where they predict this happening (Newell and Marks, 2000; Rumsey and Harcourt, 2004). It has been hypothesised that this avoidance behaviour can lead to a disturbed body image (Newell, 1999). Cognitive behavioural therapy, where treatment aims to change dysfunctional and non-adaptive behaviour, has been proven to be beneficial in such situations (Taylor, 1996; Beck, 2011).

The altered behaviour noticed in the participants in this study, can be considered to be a maladaptive strategy along the spectrum towards avoidance, and may also lead to potential negative consequences, although perhaps not as severe as these individuals are still functioning socially.

Avoidance coping is thought to be widespread among individuals with facial disfigurement and this research supports that theory (Newell, 1999). The clinical significance of such findings is that individuals seeking orthognathic treatment who exhibit avoidance coping may also have body image disturbance and thus clinicians should routinely enquire about such behaviours. Indeed, elevated body image disturbance was found in a cohort of orthognathic patients assessed as part of this research programme. In addition, consideration should be given to referring any individuals who exhibit serious avoidance behaviours for psychological assessment. Alternative therapies, such as cognitive behavioural therapy, may be more appropriate in the first instance prior to embarking on orthognathic treatment.

Motivation to undergo orthognathic treatment

The motivation for choosing to undergo orthognathic treatment has been studied in the past with the main motivations being similar to the impacts of dentofacial deformity, that is aesthetic, functional, or psychosocial (Laufer *et al.*, 1976; Jensen, 1978; Heldt *et al.*, 1982; Auerbach *et al.*, 1984; Ostler and Kiyak, 1991; Garvill *et al.*, 1992; Finlay *et al.*, 1995; Cunningham *et al.*, 1996; Hoppenreijns *et al.*, 1999; Nurminen *et al.*, 1999; Bertolini *et al.*, 2000; Zhou *et al.*, 2001; Albino, 2002; Chen *et al.*, 2002; Vargo *et al.*, 2003; Williams *et al.*, 2005; Palumbo *et al.*, 2006; Lee *et al.*, 2007a; Sadek and Salem, 2007; Stirling *et al.*, 2007; Espeland *et al.*, 2008; Proothi *et al.*, 2010). The current research found that motivation could be classified in the same way as the nature of the problem, that is exclusively practical, exclusively psychological, or a combination of the two. The motivation for treatment was usually similar to the impact of the problem, although other complex issues such as family influence and career aspirations were also noted.

With regards to the source of motivation, previous research has made a distinction between internal and external motivation, where internal motivation is derived from a deep seated desire within the individual to have the treatment and external motivation indicates pressure from others (Edgerton and Knorr, 1971). This research supports this classification but found that it existed as a continuum in the population studied rather than as two distinct categories, with many individuals being motivated by both internal and external influences to differing degrees. Therefore, it cannot be assumed that if an individual cites internal motivation for treatment that they do not also have an element of external motivation. Clinicians need to explore both possibilities, as external motivation has been associated with decreased satisfaction in orthognathic patients (Kiyak *et al.*, 1982b).

Expectations of orthognathic treatment

Expectations of treatment have also been explored in the literature and reference has been made to realistic and unrealistic expectations (Chen *et al.*, 2002). However, as discussed previously, the actual expectations themselves have rarely been studied, with articles either not fully reporting the findings (Türker *et al.*, 2008) or assessing

motivation for treatment and assuming this equates to expectations (Ostler and Kiyak, 1991; Finlay *et al.*, 1995; Espeland *et al.*, 2008; Rustemeyer *et al.*, 2010). Therefore, relatively little is known about orthognathic patients' true expectations of treatment. The traditional classification of expectations as realistic or unrealistic involves making a subjective judgement as to whether those changes are likely or not and this may detract from trying to explore patients' expectations from their viewpoint. The researcher was very aware of not imposing her clinical judgement on what the participants were divulging and maintained a neutral position.

A more descriptive terminology was developed from this research to describe the expectations discussed in the interviews: physical and non-physical. Physical expectations could either be functional or aesthetic; with participants generally revealing that they expected their teeth to bite the correct way around or that they expected their face and profile to have better proportions. Non-physical expectations were not divulged spontaneously and the researcher had to probe these issues further. These encompassed effects secondary to physical changes and could be subdivided into emotional, social, psychological, and lifestyle effects.

The clinical relevance of identifying expectations is not to 'ration' treatment or to identify those who will make good or bad candidates for treatment, but to be able to offer additional support in order to improve satisfaction with the outcome. The importance of fully exploring patients' expectations has been shown to be key in improving satisfaction with the ultimate outcome of treatment (Edgerton and Knorr, 1971; Linder-Pelz, 1982; Kravitz, 1996; Chen *et al.*, 2002).

A typology arose from this research and revealed four distinct types of patient: metamorphosisers, pragmatists, shedders, and evolvers. This typology can be used to help clinicians think strategically about how to manage patients and also potentially to identify those patients who may be at risk of dissatisfaction. In addition, support mechanisms could be put in place to be available when the different types of patients are identified as discussed in the next section.

2.4.5 Clinical management of the different typologies

I. Metamorphosiser

The metamorphosiser has high expectations of both physical and non-physical changes. Therefore, these patients are potentially at high risk of being unhappy with the outcome of treatment if these expectations are not realised. Full and careful exploration of these expectations and the reasons for them is necessary. Metamorphosisers may need additional counselling and support before treatment to ensure expectations are realistic or it may be decided that the motivation for requesting treatment may be a symptom of deeper underlying issues and delaying or refusing treatment may be the most suitable line of action to take. These patients should be referred for psychological evaluation where appropriate.

II. Pragmatists

Pragmatists have high expectations of physical change and low expectations of non-physical change. Pragmatists are probably at a lower risk of being dissatisfied with treatment due to the fact that they do not expect any secondary psychological or lifestyle changes following treatment. However, their expectations of physical outcome are often high and again these individuals may need counselling to ensure their expectations are reasonable. In addition, treatment may have emotional or psychological effects that they did not expect, as orthognathic treatment is accepted to have psychological as well as physical ramifications (Cunningham and Shute, 2009). Therefore, clinicians should be careful to assess whether such effects occur after treatment and be prepared to refer patients for counselling if necessary.

III. Shedders

Shedders have the opposite expectations to pragmatists in that they have little, or no, expectations of physical change but high expectations of non-physical changes. These patients can 'slip under the radar' as being at potential risk of dissatisfaction if only physical aspects are explored. Caution must be exercised with all patients with low expectations of physical outcome as they may well be motivated by other, more complex and less realistic, expectations.

IV. Evolvers

Evolvers have low expectations of both physical and non-physical changes and may therefore be at the lowest risk of dissatisfaction. However, the risk of dissatisfaction cannot be dismissed completely as these ‘low’ expectations may be secondary to underlying low self-esteem and this needs to be evaluated. Indeed these ‘low’ expectations may be as unrealistic as high expectations as they may be lower than what can realistically be expected and may be equally inaccurate (Weiten *et al.*, 2009). In other contexts, low expectations have been shown to have a negative effect on outcome and recovery, for example, a randomised controlled trial on treatment for lower back pain showed that patients with higher expectations of recovery and improvement in symptoms post-treatment exhibited greater functional improvement (Myers *et al.*, 2008). In addition, evolvers are often strongly influenced by others to proceed with treatment, and therefore it must be established that these patients want this treatment for themselves and are not doing it predominantly for others.

2.4.6 Implications of this research

Although satisfaction with orthognathic treatment is generally high, there remains an important minority of patients who are dissatisfied with the outcome, often despite technically good results (Flanary and Alexander, 1983; Flanary *et al.*, 1985; Cunningham *et al.*, 1995; Chen *et al.*, 2002). It is possible that this may be due to inadequate patient preparation, personality characteristics, motivation, and expectations; hence why it is important to investigate these fully prior to offering treatment.

The literature has traditionally tended to classify prospective orthognathic patients into two groups where patients falling into group one are ‘good’ patients, where satisfaction is likely to be high, and those in group two are ‘bad’ patients, who are unlikely to be happy with the outcome (Table 2.6). This classification is based on clinical judgement and experience rather than scientific research (Pogrel and Scott, 1994).

	Group 1 ('good' patient)	Group 2 ('bad' patient)
Impact of the problem	Functional/Practical	Aesthetic/Psychological
Source of motivation	Internal	External
Type of motivation	Functional/Practical	Aesthetic/Psychological
Expectations	Realistic/Physical	Unrealistic/Non-physical
Satisfaction with outcome	High	Low

Table 2.6. Traditional classification of 'good' and 'bad' orthognathic patients.

2.4.7 Recommendations for future research

Ultimately, it would be interesting to examine satisfaction in orthognathic patients and assess if this relates to impact, motivation, and the different types of expectation. However, it is probable that such a relationship would be impossible to prove due to the myriad of complicating factors including childhood experiences, morals, beliefs, personality, psychological status, and other unidentified features, which are not easily measured. A possible area for further research would be to conduct a mixed methods study measuring satisfaction with outcome and evaluating if this correlates with the different typologies of expectation developed in this study.

2.4.8 Conclusions

Qualitative research has been described as an incremental science which often leads to questions as well as answers (M. Barnard, personal communication, 2009). Indeed, this research has answered previously unanswered issues, but has also invited many additional questions. An in-depth knowledge of what it is like to live with dentofacial deformity has been achieved, as well as an understanding of the range of motivating factors for choosing to undergo orthognathic treatment. In addition, a spectrum of expectations has been revealed and a clinically useful typology of patients based on these expectations has been proposed, together with implications and suggestions for practice. While much of this research supports previous findings in this field, there are

some areas that challenge widely accepted views. This highlights the need for qualitative methodology to complete the full cycle of evidence-based practice.

The commonest criticism of qualitative research is that it is not generalisable to any other population except that from which the data were derived. While the experiences described in this study pertain to a limited group of patients, by conducting this research in a rigorous, systematic, and transparent fashion, it is maintained that these findings can be applied, albeit with caution in some areas, to the majority of orthognathic patients seen on a daily basis.

Chapter 3: Social Anxiety in Orthognathic Patients



Abstract

Background

Social anxiety disorder (SAD) is one of the most prevalent mental disorders, with over one in ten individuals being affected in the UK and the condition presents as a marked fear of being evaluated negatively by others. Individuals with a visible difference in appearance often exhibit higher levels of SAD. It is possible that patients who seek orthognathic treatment to correct their dentofacial deformity may be motivated by fear of negative evaluation and have elevated levels of SAD, and this could have negative implications for satisfaction and psychological outcomes.

Aims

There were two aims of this study: (i) to establish normative general UK population values for the Brief Fear of Negative Evaluation Scale (BFNES) and (ii) to investigate SAD in orthognathic patients using the BFNES and compare these findings with the UK norms. The null hypothesis was that there was no difference in social anxiety, as measured by the BFNES, in orthognathic patients and the general UK population.

Subjects and methods

This was a cross-sectional, questionnaire study conducted in two parts. Firstly, a national survey was conducted by the Office for National Statistics (ONS) to obtain a large, representative, random sample of the general UK population. The BFNES questionnaire was administered to participants, and demographic data (including age, gender, ethnicity, regional location, level of education, general health, and socio-economic status) were also collected. Secondly, a cohort of orthognathic patients, recruited from two sites, completed the BFNES and demographic data were also obtained. The BFNES was analysed and reported in two formats; the complete original 12-item scale (O-BFNES) and a shorter 8-item version (S-BFNES).

Results

With regards to the ONS national survey, 1196 individuals participated yielding a response of 66%. Just over half were female (51.1%) and 48.9% were male. The data were weighted to correct for possible sources of bias. The mean O-BFNES score was 29.72 (SD 9.39) and for S-BFNES was 15.59 (SD 7.67). Overall, females had significantly higher scores than males ($P<0.001$). Fear of negative evaluation decreased significantly with increasing age but the degree of reduction was relatively small. There was a trend that those with more qualifications had higher BFNES scores and those who were economically inactive had lower scores. General health, ethnicity, and socio-economic status had no statistically significant effect on fear of negative evaluation.

With regards to the orthognathic sample, 61 patients were recruited with a response of 100% and the majority were female (57.4%). The mean O-BFNES score was 39.56 (SD 10.35) and the mean S-BFNES score was 24.21 (SD 8.41). Females had higher scores than males but this was not statistically significant and age had no effect on BFNES scores.

When comparing orthognathic patients with UK general population norms, multiple linear regression revealed that age, gender, and patient status were all independent predictors of BFNES scores. Orthognathic patients had significantly higher BFNES scores than the general population ($P<0.001$) and, thus, the null hypothesis was rejected.

Conclusions

According to the results of this study, it appears that orthognathic patients do experience significantly higher levels of social anxiety than the general population. This is relevant as, if patients are motivated by fear of negative evaluation, physical treatment alone may not alleviate their concerns and lead to potentially dissatisfied patients.

3.0 Review of the literature

3.0.1 Introduction

It has been estimated that approximately one in 100 people in the UK have a significant visible facial defect, and that over 400,000 people will acquire a facial disfigurement every year (Partridge and Julian, 2008). Physical appearance can be associated with anxiety in social situations, with individuals who perceive themselves as being unattractive exhibiting greater levels of social anxiety (Leary and Kowalski, 1995). Research has revealed that individuals who have a more visible condition, such as those with defects affecting the face, exhibit higher levels of psychological distress and anxiety than others, particularly in social situations (Rumsey *et al.*, 2004). This may lead to problems with social interaction, leading to lowered self-esteem and a tendency to become introverted and reclusive (Newell and Marks, 2000). In addition, in a clinical setting, individuals who seek surgical intervention to improve their dentofacial deformity may be motivated by social anxiety and this could have implications for satisfaction and psychological outcomes.

3.0.2 Social anxiety disorder

Anxiety disorders are the most prevalent class of mental disorder but, despite this, these conditions have received relatively little attention until recently (Stein and Stein, 2008). Social anxiety disorder (SAD), also known as social phobia, is the most common anxiety disorder and is defined as an enduring fear of social situations where the individual may be subject to evaluation by others (Carleton *et al.*, 2011). The condition manifests itself as a persistent and marked fear of negative evaluation by others in social circumstances (Veale, 2003). It should not be confused with normal shyness. It often has an onset in childhood and has a prevalence of 12% in the UK and up to 18% in the community in the US, with a higher prevalence observed in women (Schneier *et al.*, 1992; Offord *et al.*, 1996; Kessler *et al.*, 2005a; Ruscio *et al.*, 2008; NICE, 2013). There are insufficient data on the prevalence of SAD in Black and minority ethnic groups but

these individuals exhibit higher levels of other common mental health disorders in the UK, and accordingly may also experience higher levels of SAD (NICE, 2013).

There is some evidence that SAD is a partially heritable trait with a higher incidence in monozygotic twins, with environmental factors also contributing (Stein and Stein, 2008; NICE, 2013). Individuals with SAD tend to be shy, have low self-esteem, and are highly critical of themselves (Stein *et al.*, 2001; Cox *et al.*, 2004). SAD has been associated with sufferers having been a victim of teasing and bullying and leaving school early (Kessler *et al.*, 1994). There is considerable comorbidity with other psychiatric conditions, such as substance use disorder and depression (Schneier *et al.*, 1992; Kessler *et al.*, 1994, 2005b; Massion *et al.*, 2002; Beesdo *et al.*, 2007; NICE, 2013). In a large community based longitudinal survey of over 3000 participants conducted in Germany, 50% of participants with SAD had a depressive disorder during the 10 year prospective observation period (Beesdo *et al.*, 2007). The typical course of the condition is chronic and lifelong (Veale, 2003).

SAD has been listed among the top ten chronic disorders, including physical and mental, significantly affecting health-related quality of life (Alonso *et al.*, 2004; Saarni *et al.*, 2007). An international European epidemiological survey was conducted involving more than 21,000 adult participants from Belgium, France, Germany, Italy, the Netherlands, and Spain investigating the disability and impact of mental disorders (Alonso *et al.*, 2004). It was found that social anxiety was among the top five mental disorders which had the greatest impact on quality of life.

Social anxiety disorder often leads to significant and chronic disability with relatively low rates of remission (Massion *et al.*, 2002; Grant *et al.*, 2005; Stein and Stein, 2008). Much of the epidemiological data regarding SAD have been collected in the National Comorbidity Survey (NCS) and the later replication survey (NCS-R) conducted in the United States (Kessler *et al.*, 1994; Kessler and Merikangas, 2004). These large cross-sectional nationally representative community-based surveys were conducted in the 1990s (1990-1992) and the early part of the next decade (2001-2003) and included over 8000 participants aged between 15 and 54 years.

Interestingly, there is evidence that individuals with SAD are indeed evaluated more negatively than non-socially anxious people and the condition may invoke a self-fulfilling prophecy known as the ‘social anxiety-social rejection relationship’ (Voncken *et al.*, 2010). In this recent study, the social performance of 100 undergraduate females was assessed in a controlled experimental social encounter. Participants were asked to rate their levels of social anxiety, self-focused attention, and negative beliefs and it was found that social anxiety was increased in half of the participants during the encounter. Social rejection and performance were then rated by four trained examiners. The results revealed that social anxiety was related to increased self-focused attention and negative beliefs, and that negative beliefs, in turn, were related to relatively poor objectively rated social performance. The authors concluded that the belief of being negatively evaluated stimulated changes in behaviour which, in turn, led to poor social performance and subsequent rejection and a decreased ‘likeability’ (Voncken *et al.*, 2010).

Fear of negative evaluation is thought to be the hallmark of social anxiety, whereby this fear leads to the development of an exaggerated and illogical anxiety in social situations (Rapee and Heimberg, 1997; Weeks *et al.*, 2005). Fear of negative evaluation is thought to be central to adjustment to disfigurement, which may be a key factor in orthognathic patients (Rumsey and Harcourt, 2004).

3.0.3 Measuring social anxiety and fear of negative evaluation

The formal diagnosis of social anxiety is made on the basis of the current diagnostic criteria published in the Diagnostic and Statistical Manual of the American Psychiatric Association (American Psychiatric Association [DSM-IV-TR], 2000). These are:

- *‘A marked and persistent fear of one or more social or performance situations in which the person is exposed to unfamiliar people or to possible scrutiny by others. The individual fears that he, or she, will act in a way (or show anxiety symptoms) that will be humiliating or embarrassing.*
- *Exposure to the feared social situation almost invariably provokes anxiety, which may take the form of a situationally bound or situationally predisposed panic attack.*

- *The person recognises that the fear is excessive or unreasonable.*
- *The feared social or performance situations are avoided or else are endured with intense anxiety or distress.*
- *The avoidance, anxious anticipation, or distress in the feared social or performance situation(s) interferes significantly with the person's normal routine, occupational (academic) functioning, or social activities or relationships, or there is marked distress about having the phobia.*
- *In individuals under age 18 years, the duration is at least 6 months.*
- *The fear or avoidance is not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition and is not better accounted for by another mental disorder (e.g. Panic Disorder With or Without Agoraphobia, Separation Anxiety Disorder, Body Dysmorphic Disorder, a Pervasive Developmental Disorder, or Schizoid Personality Disorder).*
- *If a general medical condition or another mental disorder is present, the fear is unrelated to it, e.g. the fear is not of stuttering, trembling in Parkinson's disease, or exhibiting abnormal eating behaviour in Anorexia Nervosa or Bulimia Nervosa.'*

The most commonly used measures of social anxiety are interviews and questionnaires (Clark *et al.*, 1997). Interviews have many advantages, including the fact that the interviewer can elicit the level of understanding of the interviewee and adjust the questions accordingly, and the interviewer can also probe issues to investigate the depth of the problem. However, interviews require training and interviewing is costly and time consuming and not applicable for many clinical research settings. In addition, interviews are open to subjectivity and variability (Clark *et al.*, 1997). Commonly used interview schedules include the Liebowitz Social Anxiety Scale (Liebowitz, 1987) and the Anxiety Disorders Interview Schedule (DiNardo *et al.*, 1994):

- Liebowitz Social Anxiety Scale (Liebowitz, 1987): this is a clinician-administered semi-structured interview used to diagnose SAD through the assessment of fear and avoidance in social situations. The instrument comprises

24 items rating fear and avoidance, with item scores ranging between 0 and 3 (none to severe). The reliability is good although the construct validity is limited (Clark *et al.*, 1997).

- Anxiety Disorders Interview Schedule (DiNardo *et al.*, 1994): this clinician-administered structured interview assesses the presence of social anxiety based on the DSM-IV diagnostic criteria. The schedule also assesses the presence of other co-morbid conditions such as substance use disorders.

Questionnaire measures are used commonly for screening and diagnosis and have many advantages over interviews, including reduced cost and time, ease of administration, no need for training, and the ability to standardise the questions and delivery (Clark *et al.*, 1997). Examples of the most commonly used questionnaires are:

- Social Phobia and Anxiety Inventory (SPAI) (Turner *et al.*, 1989): the SPAI is a self-report questionnaire which assesses behavioural, cognitive, and physiological symptoms associated with social phobia. It comprises two subscales, the social phobia scale and the agoraphobia scale. Each item is graded on a 1-7 Likert scale. The agoraphobia scale was included to discriminate between social phobia and other anxiety disorders, specifically agoraphobia. The SPAI is a useful screening measure, with scores of over 80 on the social phobia scale alerting the clinician to the probable presence of social phobia. The psychometric properties are excellent (Clark *et al.*, 1997).
- Social Anxiety and Distress Scale (SADS) (Watson and Friend, 1969): the SADS is a 28 item inventory which assesses social avoidance and subjective distress. It was developed alongside the Fear of Negative Evaluation Scale (FNES) and both scales were established on a college student sample.
- Fear of Negative Evaluation Scale (FNES) (Watson and Friend, 1969): this is a self-report 30 item questionnaire with a true/false response format. Together with the SADS, the FNES is one of the first and most widely used measures of social anxiety. It has been used extensively and the psychometric properties are acceptable (Clark *et al.*, 2007).

- Brief Fear of Negative Evaluation Scale (BFNES) (Leary, 1983): this is a short version of the FNES which consists of 12 items. It is the measure used in the current study and is discussed in more detail in the next section.

The Brief Fear of Negative Evaluation Scale

The Fear of Negative Evaluation Scale (FNES) is a 30 item self-report questionnaire which was initially developed by Watson and Friend in 1969 to evaluate fear of negative evaluation related to social evaluative anxiety and is one of the most widely used measures of social anxiety (Collins *et al.*, 2005). It was developed and standardised on a student population in the US (Watson and Friend, 1969). The Brief Fear of Negative Evaluation Scale (BFNES) was developed by Leary (1983) in an attempt to reduce the length of the scale and make it more user-friendly (Appendix 12). The BFNES is thought to be the most commonly used measure of social anxiety used in clinical studies worldwide (Rodebaugh *et al.*, 2004; Carleton *et al.*, 2011) and consists of 12 items related to worrying or fearful cognition (Duke *et al.*, 2006). During the development of the brief version of the scale, item-total correlations were calculated for each of the 30 statements which make up the FNES and 12 of those items with a correlation of 0.50 or more were included. The format of the responses was changed from yes/no to a Likert-style response on a scale of 1 to 5, with 1 being '*not characteristic of me at all*' and 5 being '*extremely characteristic of me*'. Eight of the items are positively worded and four are negatively phrased to reduce the risk of response bias (Rodebaugh *et al.*, 2011). An example of a negatively worded item is '*I am unconcerned even if I know people are forming an unfavourable impression of me*'. The psychometric properties of the BFNES have been tested on clinical and non-clinical populations and it has been shown to have good empirical properties which are almost identical to those of the full FNES (Leary, 1983; Rodebaugh *et al.*, 2004; Collins *et al.*, 2005; Weeks *et al.*, 2005; Duke *et al.*, 2006). Total scores range from 12 to 60, there is good internal consistency (Cronbach's $\alpha=0.90$), and a high correlation between the original FNES and the BFNES ($r=0.96$). The test-retest reliability is good ($r=0.75$) when the questionnaire is re-administered at four weeks (Leary, 1983). The scale was also sensitive to treatment changes when tested on a group of patients with diagnosed social anxiety following cognitive behavioural

therapy (Collins *et al.*, 2005). The mean BFNES score was 35.7 (SD 8.1) in the general student population it was developed on (Leary, 1983).

Factor analysis of the BFNES supports either a one-factor (Leary, 1983) or a two-factor model representing positive and negative worded items (Rodebaugh *et al.*, 2004, Duke *et al.*, 2006). The positively worded items score better, perhaps due to the fact that they are less confusing than the double-negative wording of the reversed items and some authors have suggested re-wording the negative items so that they are less confusing (Collins *et al.*, 2005). The two-factor solution is thought to be due to the method variance with differently scored items rather than the measure reflecting two different underlying constructs (Rodebaugh *et al.*, 2004).

A combination of straightforward and reverse worded items was included in the original BFNES (O-BFNES) with the purpose of reducing response bias or careless responding (Rodebaugh *et al.*, 2011). However, the reverse worded items have caused some problems with the reliability and validity of the scale and therefore a number of alternatives have been suggested (Rodebaugh *et al.*, 2004; Weeks *et al.*, 2005; Duke *et al.*, 2006; Rodebaugh *et al.*, 2006; Carleton *et al.*, 2009). These alternatives include using, but not scoring, the reverse worded items, replacing them with straightforward items, or omitting them entirely. Despite the reservations mentioned, most researchers continue to use the scale in its original format. This may be because there are limited normative data available for the revised scales and this restricts their use (Rodebaugh *et al.*, 2011). Recent research supports the use of the original scale but only the inclusion of the straightforward (S-BFNES) items in calculating the total score (Carleton *et al.*, 2011; Rodebaugh *et al.*, 2011).

3.0.4 Normative data

In order to make meaningful interpretations from results of the BFNES in clinical populations, it is essential that normative community-based data, stratified on the basis of various demographic details, are available as a baseline for comparison. The BFNES has been tested in clinical and non-clinical populations and some limited normative data have been published (Weeks *et al.*, 2005; Duke *et al.*, 2006). However, the majority of these study cohorts have been either US college students or undergraduates and thus

have limited generalisability to other populations (Leary, 1983; Rodebaugh *et al.*, 2004). In addition, these norms have not been stratified on the basis of age or ethnicity (Rodebaugh *et al.*, 2011). A small number of studies have published norms established from community populations but, again, these are based in the US and Canada (Weeks *et al.*, 2005; Duke *et al.*, 2006). There are no known published normative data from the UK. The one published study involving patients with facial disfigurement from Europe (the Netherlands) used a control group recruited from general medical practitioner offices and, accordingly, these norms may not actually be representative of the general population (Versnel *et al.*, 2010). In addition, most samples have been relatively small, with limited geographical distribution (Weeks *et al.*, 2005; Collins *et al.*, 2005; Duke *et al.*, 2006). In a community US population, BFNE scores were not different across age groups but females did exhibit slightly higher scores than males (mean=33.19, SD=7.32 and mean=31.08, SD=7.23 respectively) (Duke *et al.*, 2006).

Some researchers have performed a median split on their sample total scores in order to classify individuals arbitrarily as either high or low in terms of fear of negative evaluation (Leary, 1983). A clinically useful cut-off score has recently been suggested in a clinical sample with previously diagnosed SAD compared with a group that had a negative diagnosis (Carleton *et al.*, 2011). This was on the basis of setting a cut-off point that maximised the overall sensitivity and specificity of the diagnostic decision. When scoring the eight straightforward items only, a total score of greater than 25 is suggested as diagnostic of SAD. A total score of above 38 is said to be diagnostic of SAD when using the reverse-worded items rephrased. There is no suggested diagnostic cut-off when using the original scale. Thus, it can be appreciated that there remains a need to establish general population normative values based on a large scale national random probability sample (Rodebaugh *et al.*, 2011).

3.0.5 Treatment of social anxiety

SAD is a treatable condition but, despite the considerable impairment individuals experience, only about half seek treatment, and this is usually after 15-20 years of suffering (Wang *et al.*, 2005). The British Association for Psychopharmacology have published recommendations based on the best available evidence for the treatment of

SAD (Baldwin *et al.*, 2005). These were recently superseded in May 2013 by national clinical guidelines developed by the National Institute for Health and Care Excellence (NICE, 2013).

Numerous studies and reviews have demonstrated that a range of treatments may be effective including psychological intervention, such as cognitive behavioural therapy (CBT) (Heimberg, 2002) or interpersonal psychotherapy (Stangier *et al.*, 2011), or pharmacological treatment, including selective serotonin reuptake inhibitors (SSRIs), benzodiazepines (BZDs), and monoamine oxidase inhibitors (MOIs) (Clark *et al.*, 1997; Fedoroff and Taylor, 2001; Blanco *et al.*, 2003; Stein *et al.*, 2004; Baldwin *et al.*, 2005). In a meta-analysis of 108 treatment outcome trials, pharmacotherapy was the most consistently effective treatment for social phobia, with BZDs and SSRIs being equally effective (Fedoroff and Taylor, 2001). There is some evidence that drug treatment effects may be faster but that psychotherapy interventions may be longer lasting (Heimberg *et al.*, 1998). The recent NICE guidelines (2013) have recommended offering patients CBT in the first instance, with pharmacotherapy using SSRIs as a second line of intervention. CBT in these individuals involves cognitive restructuring of negative thought processes using specific verbal techniques, together with in vivo exposure and conditioning.

3.0.6 Social anxiety and Fear of Negative Evaluation in orthognathic patients

Although there has been increased interest in social anxiety in recent years, little research has looked at its prevalence in clinical populations seeking treatment for non-anxiety-related conditions or its potential influence on clinical outcomes. If it were possible to identify in advance, those orthognathic patients who would not be happy with standard treatment alone because of underlying SAD, then these patients may be managed more appropriately. Recruiting patients into the most appropriate care pathway should have a positive impact on patient experience and well-being, resource use, and overall treatment outcomes.

Orthognathic patients have been shown to possibly suffer from higher levels of state anxiety (Cunningham *et al.*, 2000a) but there is a paucity of information regarding

social anxiety in these patients. Indeed, there is only one published study found to date assessing social anxiety in patients receiving orthognathic treatment for non-cleft or craniofacial conditions (Lovius *et al.*, 1990). These authors carried out both a cross-sectional and longitudinal study of social anxiety in orthognathic patients and found that there was a small improvement in social avoidance and distress following treatment, as measured by the Social Avoidance and Distress Scale (Watson and Friend, 1969), but no statistically significant change in fear of negative evaluation as measured by the Fear of Negative Evaluation Scale. The mean fear of negative evaluation score in the sample of 39 orthognathic patients prior to treatment was 12.7 (possible range 0-30) with a standard deviation of 6.5 and following treatment was 10.4 (SD 6.4), but this change was not statistically significant. However, no sample size calculation was reported and it is possible that the sample was not large enough to detect a statistically significant difference to support this trend of reduction in FNES score following treatment.

A small number of studies have investigated social anxiety and fear of negative evaluation in patients with orofacial clefts and other types of facial deformity (Berk *et al.*, 2001; Versnel *et al.*, 2010). Berk and colleagues conducted a cross-sectional study in China and examined the prevalence of social anxiety in 85 individuals with clefts of the lip and palate (CLP), 85 unaffected siblings, and 85 gender- and age-matched controls. They found that adults with CLP exhibited higher levels of social anxiety than unaffected groups, including those who had been raised in the same environment (Berk *et al.*, 2001). However, cultural differences may limit the generalisability of these findings to European populations as there is evidence that the expression of psychological distress manifests differently in Chinese populations compared with other cultures (Dana, 1993).

Cheung and co-workers (2006) conducted a small-scale cohort study in China investigating psychological adjustment following orthognathic treatment. They recruited nine patients with cleft lip and palate (CLP) and nine non-cleft patients who required maxillary surgery. They assessed social anxiety in these patients using a Chinese version of the Social Anxiety and Distress Scale and conversely found that the CLP patients exhibited lower levels of social anxiety than non-cleft patients before treatment (Cheung

et al., 2006). These anxiety levels reduced after conventional orthognathic treatment, but increased following distraction osteogenesis in the CLP group. Social anxiety scores remained stable in the non-CLP patients throughout treatment. Due to the small sample sizes and short follow-up (12 weeks), these results should be interpreted with caution.

Versnel and colleagues (2010) carried out a cross-sectional study in the Netherlands investigating satisfaction with facial appearance in individuals who had undergone surgery for congenital (n=59) and acquired (n=59) severe facial disfigurement and whether this satisfaction was related to demographic, physical, or psychological determinants, including fear of negative evaluation. They compared the findings with a control group (n=201) of unaffected individuals who were recruited from five general medical practitioners' offices. They found that patients with facial disfigurement had significantly higher levels of fear of negative appearance evaluation than the control group, as measured using the six item self-report Fear of Negative Appearance Evaluation Scale (Versnel *et al.*, 2010). All patients had received surgical treatment for their defect, and the degree of residual deformity was not mentioned by the authors. Therefore, the results should be interpreted with caution when extrapolating to other untreated individuals with facial disfigurement.

One other study conducted in the US investigated social anxiety and fear of negative evaluation in 30 patients with amelogenesis imperfecta (AI) compared with a control group of 29 unaffected individuals (Coffield *et al.*, 2005). The authors found that individuals with AI had significantly higher levels of social anxiety as measured by the BFNES, with a mean value of 38.7 in the patient group and 31.1 in the control group ($P=0.02$).

From the available evidence it appears that patients who are visibly different, with either acquired or congenital dentofacial defects, may exhibit higher levels of social anxiety than the general population.

3.1 Aims and objectives

3.1.1 Aims

The aim of this study was to investigate fear of negative evaluation in a randomly selected UK non-clinical sample and to compare these findings with fear of negative evaluation in a group of orthognathic patients.

3.1.2 Objectives

The objectives were to ascertain levels of fear of negative evaluation, as measured by the Brief Fear of Negative Evaluation Scale (both the original questionnaire [O-BFNES] and the straightforward version [S-BFNES]), in the general population and in a cohort of orthognathic patients.

3.1.3 Null hypothesis

The null hypothesis for this study was there is no difference in mean social anxiety, as measured by the Brief Fear of Negative Evaluation Scale, in orthognathic patients and the general UK population.

3.2 Subjects and methods

3.2.1 Normative UK sample

Ethical and Research and Development approval was granted by University College London Research Ethics Committee (UCL Ethics reference number: 2035/001, Appendix 13). In order to obtain a large, representative, random sample of the UK population, a national survey was conducted. This was done via the Office for National Statistics (ONS), which runs a monthly omnibus survey called the Opinions Survey. The ONS draws the sample from the Royal Mail's Postcode Address File, which contains the addresses for approximately 27 million private households in the UK and is updated every three months. It is the most contemporaneous and complete address database in the UK (Office for National Statistics, 2011).

Each month, 67 postal sectors are chosen and 30 addresses within each sector are randomly selected. This yields over 2000 addresses which are stratified on the basis of region, the proportion of people aged over 65 years, the proportion of households with no car, and the proportion of households where the household reference person is in the National Statistics Socio-Economic Classification (NS-SEC) categories one to three (Office for National Statistics, 2011). For this survey, an advance letter was posted explaining the nature of the survey and giving individuals the opportunity to refuse to participate. Interviewers, who were trained members of the ONS Opinions Survey team, called to the addresses in person to conduct the survey face-to-face. Up to eight attempts were made at each address at different times of the day before the address was considered a non-contact. Following the field period, attempts to contact the addresses where there had been no response were made by telephone over a four day period.

Participants were asked to complete the Brief Fear of Negative Evaluation Scale (BFNES) questions themselves following a brief description of the nature of the study (Appendix 12). Demographic data and a range of other unrelated questions from other sources were also asked during the survey (Table 3.1). The demographic data collected included age, gender, region (Government Office Region), level of education, ethnicity,

self-reported general health, long standing illness or disability, and socio-economic status (Index of Multiple Deprivation).

Demographic	Categories used
Age	Current age
Gender	Male/female
Region	Government Office Region
Level of education (highest)	Degree or equivalent Below degree level Other qualifications (including foreign qualifications below degree level) No formal qualifications
Ethnicity	Option of 18 different sub-groups
Self-reported health	Very good Good Fair Bad Very bad
Long standing illness or disability	Yes/no
Index of Multiple Deprivation	1-5 (expressed as quintiles)
Current employment (ILO classification)	In employment Unpaid family workers ILO unemployed Economically inactive

Table 3.1. Demographic details collected during ONS Omnibus survey.

Participants were asked about their highest level of education, with the options for response being degree or equivalent, below degree level, other qualifications (including foreign qualifications below degree level), and no formal qualifications.

They were asked to rate how their health was in general, with responses on a 5-point Likert scale with options for response being ‘very good’, ‘good’, ‘fair’, ‘bad’, or ‘very bad’. Participants were asked if they had a long standing illness or disability, with responses being binary, yes or no.

Respondents were asked about their current employment based on the US International Labor Organization (ILO) 1982 classification of employment: in employment (anybody who carries out at least one hours paid work in a week, or who is temporarily away from a job), unpaid family workers, ILO unemployed (those without a job, who want a job, and who have actively sought work in the last four weeks and are available to start work in the next two weeks, or out of work, have found a job and are waiting to start it in the next two weeks), and economically inactive (those who are out of work but do not meet the criteria for unemployment).

Socio-economic status was assessed using the Index of Multiple Deprivation (IMD) which takes into account income deprivation, employment deprivation, health deprivation and disability, education, skills and training deprivation, barriers to housing and services, crime, and living environment deprivation of an area. The index is commonly divided into quintiles for analytical purposes, with 1 being the most and 5 the least deprived (Department for Communities and Local Government, 2011).

3.2.2 Orthognathic cohort

Ethical and Research and Development approval was granted by the Joint Research and Ethics Committee of University College London Hospitals Foundation Trust and granted multi-site (University College London Foundation Trust and Croydon University Hospital) approval prior to commencement of the research (MREC reference number: 09/H0719/10; Appendix 6). Written informed consent was obtained from all participants. All participants had been accepted for orthognathic treatment but had not yet commenced pre-surgical orthodontics. Inclusion criteria were any patient undergoing combined orthodontics/orthognathic surgery, aged 16 years and over, and able to give informed consent. Exclusion criteria were patients with congenital craniofacial anomalies, for example, syndromes or clefts of the lip and/or palate, patients with acquired facial defects, and those who had previously received orthognathic treatment.

Potential participants were recruited as they attended a routine pre-treatment Orthognathic Clinic appointment as part of a larger study discussed in Chapter 1.

As for the normative sample, patients were given the BFNES to complete and demographic data, including age and gender, were also collected.

An *a priori* sample size calculation was performed using nQuery Advisor[®] (version 7.0; Statistical Solutions Ltd., MA, USA) using data from a similar study investigating community normative values in the US for both the O-BFNES and the S-BFNES (Rodebaugh *et al.*, 2011). The calculation assumed unequal sized groups, with an anticipated minimum of 1000 participants in the normative UK sample group. This estimate was based on the minimum average response rate for the monthly ONS Opinions surveys (Office for National Statistics, 2011). The clinically significant difference in the BFNES scores was set at 10% of the total score based on clinical experience as there was no supporting literature to guide this decision. A sample size of 31 orthognathic patients was needed to detect a difference in means of 10% on the O-BFNES scale (4.8 points) using an unpaired *t*-test with a power of 80% at the 5% level of significance. A sample size of 46 orthognathic patients was needed to detect a difference in means of 10% on the S-BFNES scale (3.2 points) using an unpaired *t*-test with a power of 80% at the 5% level of significance. Therefore, it was decided to recruit a minimum of 50 orthognathic patients to detect a clinically relevant difference for both scales allowing for some questionnaires to be incorrectly completed or not returned.

3.2.3 Statistical analysis

Statistical analysis was undertaken using the Statistical Package for Social Sciences (version 19.0; SPSS Inc., Chicago, IL, USA). Demographic data were analysed descriptively and the results from the 12-item scale (O-BFNES) and the 8-item straightforward worded scale (S-BFNES) were tested for normality. All analyses were conducted at the 0.05 level of significance. Comparisons between groups were made using Student *t*-tests and one-way Analysis of Variance (ANOVA) with Bonferroni *post-hoc* tests. Multiple linear regression was undertaken to investigate the influence of group, age, and gender on the BFNES score and to assess if there was an age/gender interaction.

The Opinions Survey data were weighted to correct for selection bias and non-response bias. These weights grossed up the data by age, gender, and region to the population control totals used in the Labour Force Survey (LFS) and this improved the precision for the variables collected (Office for National Statistics, 2011). This weighting system has been developed by the Office for National Statistics based on Census data. The sample selection is vulnerable to unequal selection due to the fact that only one adult per household was interviewed. As only one adult per household was selected, if the first person who the interviewer came into contact with was always chosen, there would be a risk that a representative range of age groups would not be obtained. For example, young people are less likely to be at home than older females and a biased sample may result. A Kish grid was used to overcome this potential source of bias (Kish, 1949). In addition, weightings were applied to the raw data to correct for response bias based on ONS complete UK Census data. For example, young males living in London are less likely to respond and therefore are assigned a higher weighting. The weighted data were used for descriptive analyses in order to estimate population parameters, whereas the unweighted data were used in the analytical statistical tests in order to compare groups. When the weights were applied in the analysis, confidence intervals are not quoted as these are only relevant to sample estimates and by applying the ONS weighting, it is assumed that the mean closely matches the true population mean and so conventional confidence intervals do not apply.

3.3 Results

3.3.1 ONS Opinions Survey of the UK general population

In total, 1196 individuals participated in the survey, yielding a response rate of 66% (Table 3.2). Results for both the O-BFNES and the S-BFNES were calculated from the BFNES responses, whereby all 12 items were summed for the O-BNFES and only the 8 straightforward worded items were summed for the S-BFNES. Summary statistics are presented for the BFNES for both the 12-item (O-BFNES) and 8-item (S-BFNES) scales, subdivided on the basis of gender, age, region (GOR), level of education, ethnicity, self-reported general health, long standing illness or disability, and quintiles of the Index of Multiple Deprivation (Table 3.7). Of the 1196 people interviewed, there were missing data for 60 individuals for the O-BFNES (5%) and 47 (4%) for the S-BFNES, yielding a total of 1,136 for the O-BFNES and 1,149 for the S-BFNES.

The gender distribution was approximately equal, with 51.1% females and 48.9% males (Table 3.3). The largest age group was 25 to 44 year olds (33.7%), with those over 75 years making up the smallest group (9.1%, Table 3.4). The mean age was 49.58 years (SD 18.92 years). The majority of respondents were from England (86.3%), followed by Scotland (8.7%) and Wales (5%). The largest proportion of individuals were resident in the South East of England (14%) (Table 3.5).

	Number	Initial sample (%)	Response (%)
Set Sample of Addresses	2010	100	
Ineligible Addresses	172	9	
Eligible Addresses	1835	91	
Eligible Households	1800		100
No interview (refusal)	477		27
Unknown Eligibility	26		1
No interview (non-contact)	101		6
Total interviews	1196		66

Table 3.2. Responses for the ONS Opinions Survey.

Gender	Unweighted count †	Weighted count ††	%
Male	542	23830309	48.9
Female	654	24951640	51.1
Total	1196	48781949	100.0

Table 3.3. Gender distribution of the ONS Opinions Survey sample.

[† Number recruited before applying weighting factor. †† Weighted to correct for selection bias and non-response bias].

Grouped Age	Unweighted count †	Weighted count ††	%
16 to 24	92	7093513	14.5
25 to 44	389	16415334	33.7
45 to 54	209	8416881	17.3
55 to 64	193	7096203	14.5
65 to 74	170	5299800	10.9
75 and over	143	4460218	9.1
Total	1196	48781949	100.0

Table 3.4. Age distribution of the ONS Opinions Survey sample.

[† Number recruited before applying weighting factor. †† Weighted to correct for selection bias and non-response bias].

GOR	Unweighted count †	Weighted count ††	%
North East	62	2108520	4.3
North West	129	5550084	11.4
Yorkshire and the Humber	123	4270160	8.8
East Midlands	96	3623025	7.4
West Midlands	105	4353772	8.9
East of England	120	4671217	9.6
London	112	6401615	13.1
South East	177	6820028	14.0
South West	128	4277079	8.8
Wales	47	2441181	5.0
Scotland	97	4265270	8.7
Total	1196	48781949	100.0

Table 3.5. Geographical distribution of the ONS Opinions Survey sample based on Government Office Region (GOR).

[† Number recruited before applying weighting factor. †† Weighted to correct for selection bias and non-response bias].

Ethnicity	Unweighted count †	Weighted count ††	%
English, Welsh, Scottish, Northern Irish, British	1040	40970747	87.0
Irish	16	648390	1.3
Gypsy or Irish Traveller	2	35946	0.2
Any other White background	32	1253202	2.7
White and Black Caribbean	6	276989	0.5
White and Black African	3	155462	0.3
White and Asian	4	237191	0.3
Any other Mixed/Multiple Ethnic background	2	152325	0.2
Indian	24	1428095	2.0
Pakistani	8	523197	0.7
Bangladeshi	3	213530	0.3
Chinese	4	163881	0.3
Any other Asian background	8	447519	0.7
African	9	341999	0.8
Caribbean	15	722666	1.3
Any other Black/African/Caribbean background	4	146748	0.3
Arab	2	110516	0.2
Any other Ethnic group	12	887966	1.0
Refusal	1		0.1
Do not know	1		0.1
Total	1196	48716368	100.0

Table 3.6. Ethnicity distribution of the ONS Opinions Survey sample.

The mean, standard deviation, and range for the O-BFNES and S-BFNES are presented in Table 3.7 (presented over 4 consecutive pages). The mean score was 29.72 (SD 9.39) for the O-BFNES and 15.59 (SD 7.67) for the S-BFNES. Results were then subdivided on the basis of gender, age group, Government Office Region (GOR), level of qualification, ethnicity, self-report general health, presence of long standing disability or illness, employment status (ILO), and socio-economic status (Index of Multiple Deprivation).

Classification	O-BFNES			S-BFNES		
	Mean	SD	Range	Mean	SD	Range
All responders	29.72	9.39	12-60	15.59	7.67	8-40
Gender						
Male	28.64	8.84	12-59	14.72	7.20	8-40
Female	30.76	9.79	12-60	16.43	8.00	8-40
Age group						
16 to 24	32.28	9.07	12-60	17.62	7.99	8-40
25 to 44	31.03	10.22	12-60	16.86	8.14	8-40
45 to 54	29.61	8.52	12-58	15.48	6.95	8-40
55 to 64	28.65	9.06	12-57	14.92	7.47	8-39
65 to 74	27.33	8.14	12-60	12.80	6.49	8-40
75 and over	25.44	7.71	12-55	12.14	5.72	8-36
Government Office Region						
North East	29.11	10.74	12-60	15.48	8.82	8-40
North West	30.52	9.51	12-59	16.40	7.77	8-39
Yorkshire and the Humber	28.22	8.76	12-57	14.79	6.47	8-40
East Midlands	32.46	9.77	13-60	17.52	7.78	8-40
West Midlands	27.06	10.48	12-52	14.79	8.27	8-39
East of England	30.08	9.21	12-55	15.36	8.21	8-38

Classification (cont.)	O-BFNES			S-BFNES		
	Mean	SD	Range	Mean	SD	Range
London	30.41	8.60	12-51	15.49	6.82	8-34
South East	30.04	8.52	13-60	15.47	7.61	8-40
South West	30.72	9.49	12-60	16.52	7.55	8-40
Wales	29.36	8.76	16-59	14.57	7.97	8-40
Scotland	28.51	9.52	12-57	14.93	7.32	8-39
Highest level of qualification						
Degree or equivalent	30.69	9.26	12-59	15.90	7.29	8-39
Below degree level	30.63	9.16	12-60	16.33	7.72	8-40
Other qualifications (inc. foreign qualifications below degree level)	28.32	8.39	12-54	14.41	6.77	8-36
None (no formal qualifications)	27.71	10.17	12-60	14.39	8.13	8-40
Ethnicity						
Combined (English, Welsh, Scottish, Northern Irish, British)	29.64	9.49	12-60	15.55	7.73	8-40
Irish	26.58	8.05	14-45	13.86	6.13	8-32
Gypsy or Irish Traveller	46.05	8.48	37-54	27.92	6.49	21-34
Any other White background	30.91	10.13	12-52	17.00	7.11	8-32
White and Black Caribbean	24.69	3.78	19-31	10.59	2.88	8-18
White and Black African	30.11	0.88	29-31	15.66	3.30	10-19
White and Asian	29.62	7.88	12-34	14.20	3.20	8-18
Any other mixed/multiple ethnic background	32.85	3.55	27-35	17.46	0.89	16-18
Indian	29.10	9.03	12-44	15.53	8.34	8-30
Pakistani	34.75	7.12	17-49	18.70	6.86	8-32
Bangladeshi	30.32	7.01	17-34	20.18	5.36	10-23
Chinese	23.53	1.31	22-25	12.48	4.69	8-19

Classification (cont.)	O-BFNES			S-BFNES		
	Mean	SD	Range	Mean	SD	Range
Any other Asian background	30.03	5.90	20-43	14.47	5.17	8-23
African	28.63	5.38	18-39	15.40	3.82	9-22
Caribbean	29.76	5.67	19-42	13.96	6.67	8-32
Any other Black/African/Caribbean background	30.81	8.65	16-42	15.57	6.91	8-25
Arab	33.51	2.50	31-36	14.52	3.50	11-18
Any other ethnic group	33.05	13.4	16-51	18.63	10.45	8-34
Refusal	34.00	*	34-34	17.00	*	17-17
Do not know	25.00	*	25-25	8.00	*	8-8
General Health (self-report)						
Very good	30.02	8.97	12-60	15.82	7.19	8-40
Good	29.48	9.30	12-60	15.29	7.71	8-40
Fair	30.01	10.24	12-60	16.01	8.21	8-40
Bad	28.74	10.04	12-58	14.88	8.48	8-38
Very bad	28.18	9.95	12-44	15.79	8.72	8-32
Long-standing illness, disability or infirmity						
Yes	29.37	10.06	12-60	15.37	8.21	8-40
No	29.91	9.02	12-60	15.71	7.37	8-40
Employment						
In employment	30.36	9.40	12-60	16.06	7.71	8-40
Unemployed	30.09	9.84	12-57	15.58	7.62	8-39
Economically inactive	28.48	9.16	12-60	14.74	7.52	8-40
Quintile of multiple deprivation						
1st quintile	31.36	9.53	12-57	16.31	8.22	8-38

Classification (cont.)	O-BFNES			S-BFNES		
	Mean	SD	Range	Mean	SD	Range
2 nd quintile	29.31	8.05	12-54	15.32	6.39	8-34
3 rd quintile	29.16	8.88	12-60	15.27	7.21	8-40
4 th quintile	29.91	10.47	12-60	15.93	8.14	8-40
5 th quintile	29.57	10.37	12-60	15.75	8.48	8-40

Table 3.7. Population weighted means, standard deviations and ranges for the original 12-item BFNES (O-BFNES) and the straightforward 8-item (S-BFNES) from the ONS Opinions Survey within major classification categories.

[*Standard deviation could not be calculated due to small sample number].

Gender

Fear of negative evaluation was higher in females than males and this was highly statistically significant ($P < 0.001$, Table 3.8, Figure 3.1).

Scale	Gender	N	Score	Mean difference	95% CI of the mean difference	P-value
O-BFNES	Male	519	28.30	-2.12	-3.22 to -1.02	<0.001
	Female	617	30.42			
S-BFNES	Male	525	14.49	-1.73	-2.61 to -0.85	<0.001
	Female	624	16.22			

Table 3.8. Comparison of BFNES scores between males and females for the original 12-item BFNES (O-BFNES) and the straightforward 8-item (S-BFNES) from the ONS Opinions Survey.

[Note: CI=confidence interval. Note: The total number of participants completing the O-BFNES was 1136 and 1149 for the S-BFNES due to missing data].

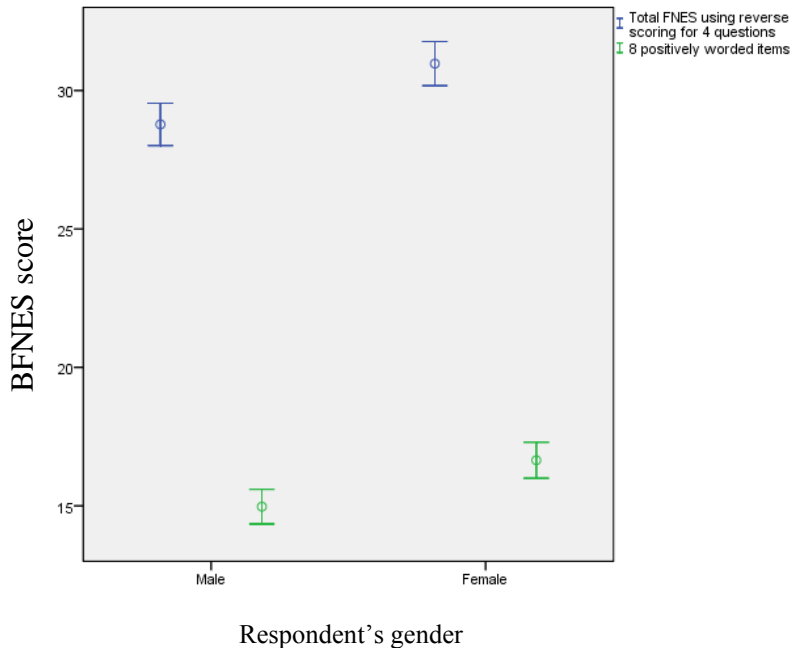


Figure 3.1. Mean and 95% confidence interval plot (error bar) showing gender differences in BFNES score when using the O-BFNES (blue) and the S-BFNES (green).

Age group

Fear of negative evaluation decreased with increasing age in males and females and a univariate linear regression model showed that for every ten year increase in age, fear of negative evaluation decreased by one point when the genders were combined. The R^2 values were 0.048 for O-BFNES, and 0.057 for S-BFNES (Figures 3.2 and 3.3, Table 3.9).

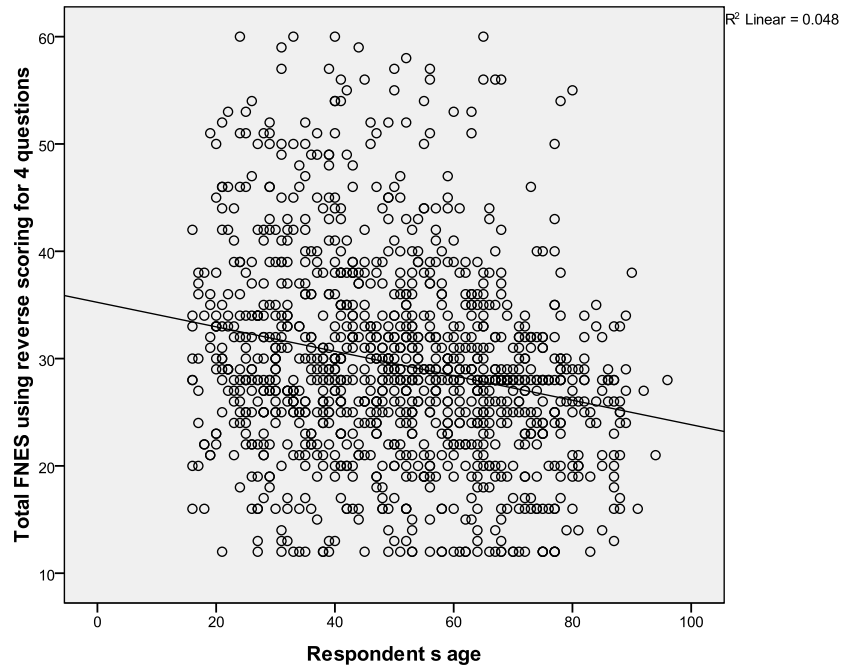


Figure 3.2. Scatter diagram showing the line of best fit with age on the X-axis and O-BFNES score on the Y-axis.

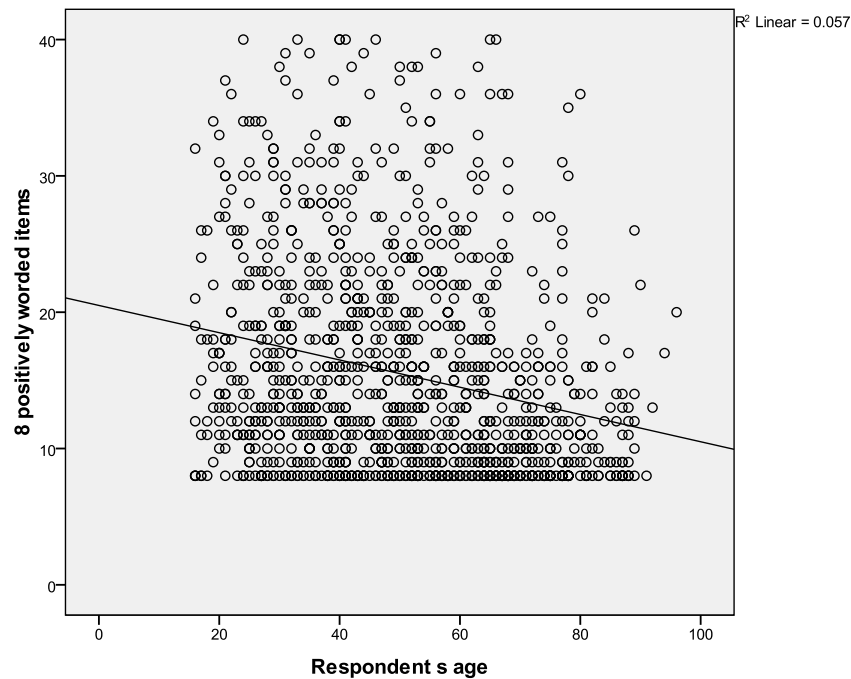


Figure 3.3. Scatter diagram showing the line of best fit with age on the X-axis and S-BFNES score on the Y-axis.

Scale	Model	R ²	Age coefficient (B)	95% Confidence interval of B	P-value
O-BFNES	(Constant)	0.048	-0.114	-0.144 to -0.084	<0.001
	Respondent's age				
S-BFNES	(Constant)	0.057	-0.100	-0.124 to -0.076	<0.001
	Respondent's age				

Table 3.9. Linear regression demonstrating effect of age on O-BFNES and S-BFNES scores.

[Note: Dependent variable: O-BFNES and S-BFNES respectively. Predictor: respondent's age.

Multiple linear regression was conducted to investigate if fear of negative evaluation scores decreased by the same amount for both genders with increasing age. The results showed that fear of negative evaluation did decrease in both genders with advancing age but not by the same amount ($P < 0.001$ for the interaction). The predicted scores decreased more in females with age (0.090 of a point reduction in BFNES score per year of age for females versus 0.063 of a point reduction per year of age for males). So, although the predicted fear of negative evaluation was on average two points higher in females than males at 18 years of age in this cross-sectional study, the gap reduced progressively among older people such that the predicted scores were equivalent between the genders among the most elderly people sampled (Figure 3.4).

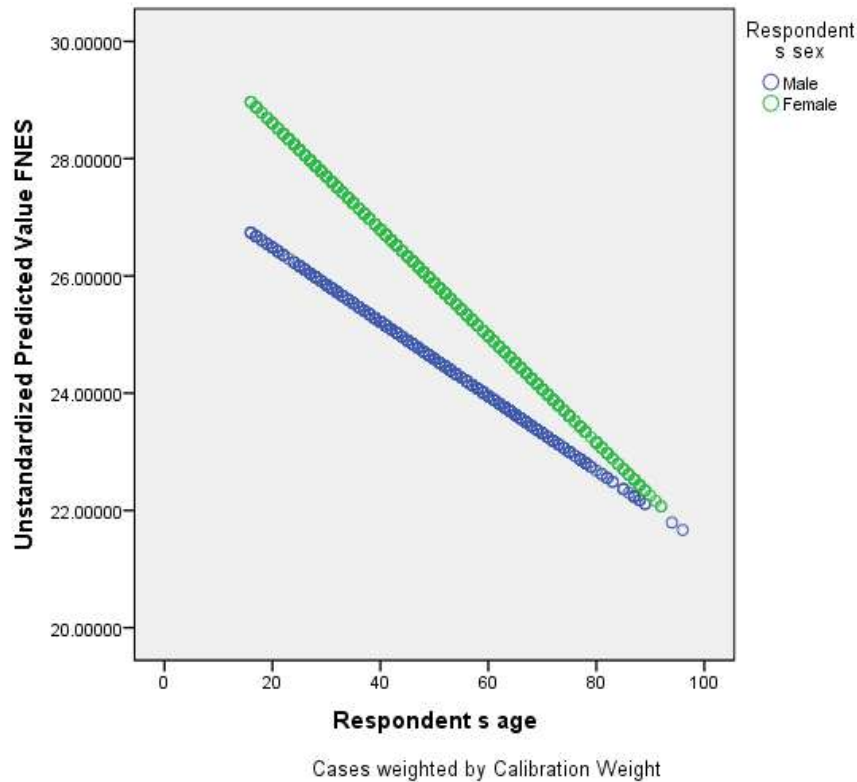


Figure 3.4. The effect of age on BFNES score for males (blue) and females (green).

Ethnicity

With regards to ethnicity, Gypsies/Irish Travellers exhibited the highest BFNES scores and Chinese the lowest (Table 3.7). However, due to the small numbers within many subgroups, statistical analysis was not possible on the basis of the 18 different subgroups of ethnicity. Therefore, the ethnicity classification was collapsed into British (n=1040) and non-British (n=154). One person answered 'don't know' and one refused to answer this section. There was no statistical difference in BFNES scores between the British and non-British groups (Table 3.10).

Scale	Ethnicity	Mean Score	Mean difference	95% CI	P-value
O-BFNES	British	29.48	0.07	-1.16 to +1.78	0.932
	Non-British	29.41			
S-BFNES	British	15.46	0.14	-1.23 to +1.51	0.843
	Non-British	15.32			

Table 3.10. Effect of ethnicity on the score for the original 12-item BFNES (O-BFNES) and the straightforward 8-item (S-BFNES) using *t*-tests.

Level of education

The majority of individuals were educated below degree level (47.4%), with 21.8% having no formal qualifications. Almost 17% had a degree or equivalent, and almost 14% had other qualifications below degree level (Table 3.11).

Level of education	Unweighted count †	Weighted count ††	Percentage
Degree or equivalent	195	8195885	16.8%
Below degree level	524	23127363	47.4%
Other qualifications (including foreign qualifications below degree level)	176	6794302	13.9%
None (no formal qualifications)	300	10627065	21.8%
Total	1195	48744616	100.0%

Table 3.11. Frequency table of the highest level of education of the participants. [Note: There were missing data for one individual. † Number recruited before applying weighting factor. †† Weighted to correct for selection bias and non-response bias].

One way Analysis of Variance (ANOVA) demonstrated a statistically significant difference between the different levels of education for both versions of the scale (O-BFNES $P < 0.001$, S-BFNES $P < 0.001$). There was a trend that those with more

qualifications exhibited higher levels of fear of negative evaluation than those with no qualifications, but not all comparisons were statistically significant.

Multiple comparisons using *t*-tests between the different subgroups and Bonferroni *post hoc* corrections revealed that, when using the 12 item O-BFNES, those with a degree or below degree level education had significantly higher scores than those with no qualifications (mean difference=3.10, $P=0.03$, confidence interval 0.75 to 5.45 and mean difference=2.99, $P<0.001$, 95% confidence interval 1.12 to 4.87 respectively). Those with below degree level education had significantly higher scores than those with ‘other’ qualifications (mean difference=2.37, $P=0.034$, 95% confidence interval 0.11 to 4.63) (Figure 3.5).

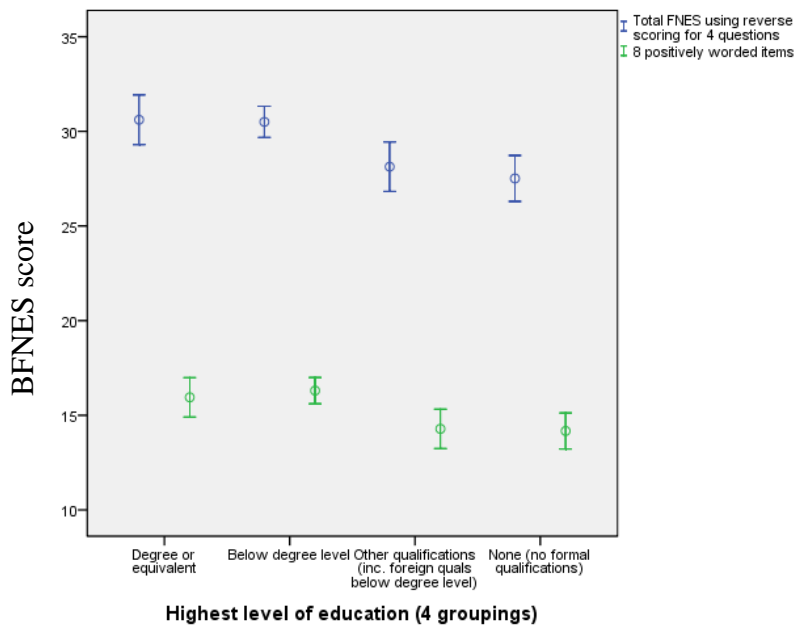


Figure 3.5. Mean and 95% confidence interval plot (error bar) showing differences in score according to level of education when using the O-BFNES (blue) and S-BFNES (green).

When examining the results of the S-BFNES, the same trend was noted, with statistically significant differences between those with below degree level qualifications and those with ‘other’ qualifications and no formal qualifications (mean difference=2.03, $P=0.020$, 95% confidence interval 0.20 to 3.85, and mean difference

1.99, $P=0.003$, 95% confidence interval 0.47 to 3.50 respectively; Figure 3.5). There were no differences between those with degree or equivalent and any other group.

General health

Participants were asked how their health was in general, with responses on a Likert scale ranging from very good to very bad. An ANOVA revealed no statistically significant differences in BFNES scores between any of the groups (Figure 3.6).

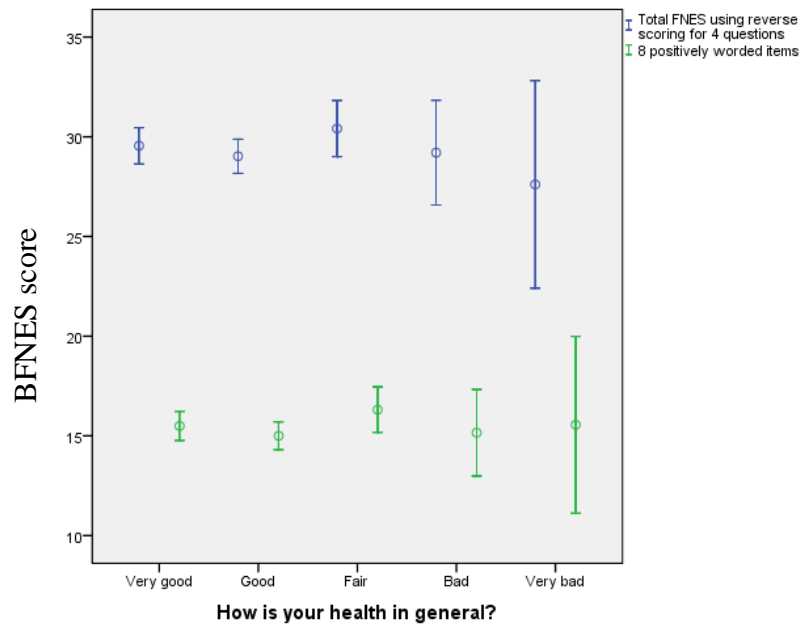


Figure 3.6. Mean and 95% confidence interval plot (error bar) showing differences in score according to general health when using the O-BFNES (blue) and S-BFNES (green).

Long standing illness

Participants were asked if they had any long standing illness or disability and an unpaired t -test revealed no statistically significant differences in BFNES scores between the two groups (Table 3.12, Figure 3.7).

Scale	Illness/disability	N	Mean Score	Mean difference	CI	P-value
O-BFNES	Yes	456	29.45	-0.01	-1.14 to +1.13	0.997
	No	680	29.46			
S-BFNES	Yes	458	15.39	-0.06	-0.98 to +0.86	0.900
	No	691	15.45			

Table 3.12. Effect of long standing illness or disability on score for the original 12-item BFNES (O-BFNES) and the straightforward 8-item (S-BFNES) as measured by unpaired *t*-tests.

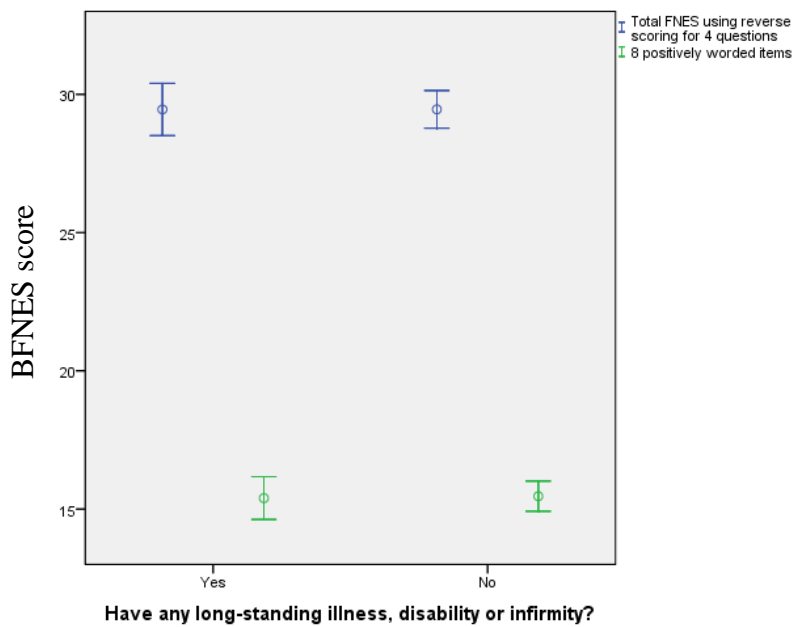


Figure 3.7. Mean and 95% confidence interval plot (error bar) showing differences in scores according to presence of long standing illness or disability when using the O-BFNES (blue) and S-BFNES (green).

Current employment

The majority of participants were in employment (59.5%), one third were economically inactive (33.8%), and 6.4% were unemployed (Table 3.13).

Employment	Unweighted count †	Weighted count ††	Percentage
In Employment (exc. unpaid family workers)	651	29014045	59.5%
Unpaid family workers	4	154257	0.3%
ILO Unemployed	63	3128397	6.4%
Economically inactive	478	16485250	33.8%
Total	1196	48781949	100%

Table 3.13. Frequency distribution of current employment of participants.

[† Number recruited before applying weighting factor. †† Weighted to correct for selection bias and non-response bias].

Those who were economically inactive had a lower fear of negative evaluation than those in employment for both scales (O-BFNES $P < 0.001$; S-BFNES $P < 0.001$). There were no statistically significant differences in BFNES scores between those who were unemployed and any other group (Figure 3.8).

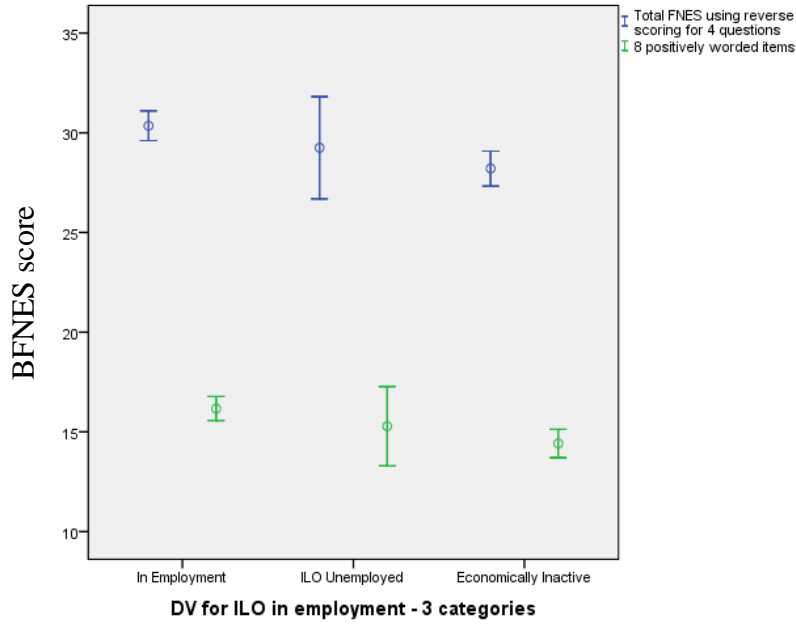


Figure 3.8. Mean and 95% confidence interval plot (error bar) showing differences in scores according to current employment for the O-BFNES (blue) and S-BFNES (green). [Note: Unpaid family workers excluded due to small numbers].

Deprivation

Relative deprivation was summarised using quintiles of the Index of Multiple Deprivation. A one way ANOVA revealed that there were no statistically significant differences in BFNES scores between the different quintiles of relative deprivation (Figure 3.9).

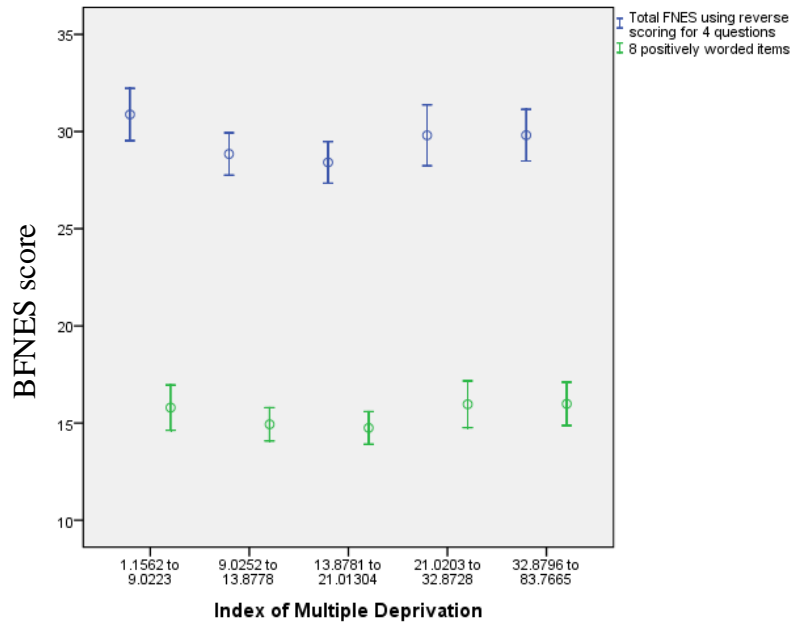


Figure 3.9. Mean and 95% confidence interval plot (error bar) showing difference in scores according to Index of Multiple Deprivation for the O-BFNES (blue) and S-BFNES (green).

Conclusions

In conclusion, in a randomly selected sample of UK individuals;

- Mean BFNES scores were 29.72 for the O-BFNES and 15.59 for the S-BFNES.
- Females had higher mean fear of negative evaluation scores than males (on average two points higher).
- Fear of negative evaluation decreased with increasing age, but the degree of reduction was greater in females so that BFNES scores approximated with advancing age.
- There was a trend that those with more qualifications exhibited higher levels of fear of negative evaluation than those with no qualifications (not all comparisons were statistically significant).
- Those who were economically inactive had lower fear of negative evaluation scores than those who were in employment.

All of these results were statistically significant. General health, the presence of a long standing illness or disability, ethnicity, and relative deprivation had no significant effect on BFNES scores.

3.3.2 Orthognathic patient data

In total, 61 orthognathic patients were recruited, 57.4% were female and 42.6% male. The response rate was 100% and there were no missing data. The majority were in the 16 to 24 age group (50.8%), followed by the 25 to 44 group (42.7%). There were no patients above the age of 64 years (Table 3.14).

Category	Number	%
Gender		
Male	26	42.6
Female	35	57.4
Age group		
16 to 24	31	50.8
25 to 44	26	42.7
45 to 54	3	4.9
55 to 64	1	1.6
65 to 74	0	0
75 and over	0	0
Total	61	100%

Table 3.14. Demographic details of the orthognathic patient cohort.

The mean O-BFNES score for the whole patient group was 39.56 (SD 10.35) and the mean S-BFNES score was 24.21 (SD 8.41) (Table 3.15).

Classification	Number	O-BFNES			S-BFNES		
		Mean	SD	Range	Mean	SD	Range
All responders	61	39.56	10.35	16-60	24.21	8.41	8-40
Gender							
Male	26	38.15	10.01	17-60	24.04	7.88	8-40
Female	35	40.60	10.63	16-59	24.34	8.90	8-39
Age group							
16 to 24	31	41.16	10.40	16-57	25.42	8.64	8-37
25 to 44	26	38.50	10.52	17-60	23.35	8.26	8-40
45 to 54	3	35.33	9.07	27-45	20.33	9.50	11-30
55 to 64	1	30.00	*	30-30	21.00	0.00	21-21

Table 3.15. Means, standard deviations and ranges for the original BFNES (O-BFNES) and the straightforward (S-BFNES) for the orthognathic patient cohort within major classification categories.

[*Standard deviation could not be calculated due to small sample number].

A one-way analysis of variance (ANOVA) revealed no evidence of a significant difference ($P=0.206$) in BFNES scores between the different age groups.

Females had higher BFNES scores than males but this was not statistically significant ($P=0.250$ for the O-BFNES and $P=0644$ for the S-BFNES) (Table 3.16).

Scale	Gender	N	Score	Mean difference	95% CI of the mean difference	P-value
O-BFNES	Male	26	38.15	-2.45	-4.70 to 4.09	0.250
	Female	35	40.60			
S-BFNES	Male	26	24.04	-0.30	-7.82 to 2.93	0.644
	Female	35	24.34			

Table 3.16. Comparison of BFNES scores between males and females for the original 12-item BFNES (O-BFNES) and the straightforward 8-item (S-BFNES) orthognathic patient data.

In conclusion, in a clinical sample of orthognathic patients:

- The mean brief fear of negative evaluation scores were 39.56 (SD 10.35) for the O-BFNES and 24.21 (SD 8.41) for the S-BFNES.
- Females had higher fear of negative evaluation scores than males but this was not statistically significant.
- There was no evidence of a difference in fear of negative evaluation score across the different age groups.

3.3.3 Comparison of the ONS UK Opinions Survey and orthognathic patient data

When comparing orthognathic patient data with the UK population norms, orthognathic patients had significantly higher fear of negative evaluation than the general population, with differences of almost 10 points for the O-BFNES and almost nine points for the S-BFNES (Table 3.17). These differences were statistically significant (Table 3.18).

Classification	O-BFNES			S-BFNES		
	Mean	SD	Range	Mean	SD	Range
Orthognathic patients	39.56	10.35	16-60	24.21	8.41	8-40
ONS survey	29.72	9.39	12-60	15.59	7.67	8-40

Table 3.17. Distribution of BFNES scores in the ONS Opinions Survey data and the orthognathic study for the original 12-item BFNES (O-BFNES) and the straightforward 8-item (S-BFNES).

Scale	Source	N	Score	Mean difference	95% CI of the mean difference	P-value
O-BFNES	ONS	1136	29.72	-9.84	-7.63 to -12.58	<0.001
	OG	61	39.56			
S-BFNES	ONS	1149	15.59	-8.62	-6.78 to -10.79	<0.001
	OG	61	24.21			

Table 3.18. Comparison of BFNES scores between the ONS Opinions Survey data (ONS) and the orthognathic patient data (OG) for the original 12-item BFNES (O-BFNES) and the straightforward 8-item (S-BFNES).

Multiple linear regression indicated that age, gender, and group (orthognathic patient or ONS survey participant) were all significant independent predictors of O-BFNES. Orthognathic patients had O-BFNES scores that were 7.33 (95% CI 4.83 to 9.84) higher on average than the general population, having controlled for age and gender. With regards to the S-BFNES, again multiple linear regression indicated that age, gender, and group were all significant independent predictors of S-BFNES. Orthognathic patients had S-BFNES scores that were 6.38 (95% CI 4.36 to 8.40) higher on average than the general population, having controlled for age and gender (Table 3.19).

Scale	Model	R ²	Coefficient (B)	95% CI of B	P-value
O-BFNES	(Constant)	0.107			
	Group		-7.33	-9.84 to -4.83	<0.001
	Respondent's age		-0.11	-0.14 to -0.09	<0.001
	Respondent's gender		2.10	1.04 to 3.16	<0.001
S-BFNES	(Constant)	0.119			
	Group		-6.38	-8.40 to -4.36	<0.001
	Respondent's age		-0.10	-0.12 to -0.08	<0.001
	Respondent's gender		1.63	0.78 to 2.49	<0.001

Table 3.19. Multiple linear regression to assess the effect of group, age, and gender on O-BFNES and S-BFNES.

[Dependent variable: O-BFNES and S-BFNES respectively. Independent variables: Group (survey participant or patient), respondent's gender, respondent's age].

Therefore, the null hypothesis that there is no difference in BFNES scores in orthognathic patients and UK population norms is rejected.

3.4 Discussion

Social anxiety disorder is the most common anxiety disorder and anxiety conditions are the most prevalent form of mental disorder (Stein and Stein, 2008). Fear of negative evaluation (FNE) is the main characteristic feature of social anxiety and is felt to be a key component in the adjustment to visible disfigurement (Rapee and Heimberg, 1997; Kent and Keohane, 2001; Rumsey and Harcourt, 2004; Weeks *et al.*, 2005). In addition, there is some evidence that fear of negative evaluation may be increased in patients with facial disfigurement (Versnel *et al.*, 2010). Despite this, the presence of FNE and the implications for clinical populations have not been thoroughly investigated in orthognathic patients to date. There is evidence that the extent of social phobia does not correlate with the severity of the craniofacial disfigurement and thus consideration should be given to carrying out psychological assessment of all patients with dentofacial deformity (Shute *et al.*, 2007). The aim of this study was to investigate fear of negative evaluation in an orthognathic patient population. To make meaningful clinical assessments, normative FNE values were needed for the general UK population for comparison. As there were no normative data for FNE in the UK, it was necessary to initially conduct a study to obtain this data.

3.4.1 Discussion of methodology

Instrument

The Brief Fear of Negative Evaluation Scale (BFNES) was used in this study (Leary, 1983). It is psychometrically robust and one of the most widely used instruments for assessing FNE, thus allowing the results of this study to be compared with many others (Rodebaugh *et al.*, 2004; Collins *et al.*, 2005). The short 12-item version of the original 30-item scale was used, which correlates well with the original scale ($r=0.96$) and has the advantage of brevity (Rodebaugh *et al.*, 2004). It has good internal consistency ($\alpha=0.90$ to 0.91) and test-retest reliability ($r=0.75$) (Leary, 1983). In addition, the response format is a Likert scale, with a choice of reply ranging from 1 to 5 rather than

yes/no. This has been proven to confer greater sensitivity in discriminating between different levels of severity of FNE (Rodebaugh *et al.*, 2004).

There has been considerable debate, and no consensus, regarding whether to use the original scale, which includes eight positively-worded items together with four negatively-worded items to reduce response bias, or whether to exclude the potentially confusing negatives statements where some contain double negatives (Rodebaugh *et al.*, 2011). The purported benefit of including reverse-worded items is to protect against careless, random responding, acquiescence bias, the responder answering the same for all items, and to act as a validity index (Rodebaugh *et al.*, 2011). However, it has been postulated that, to protect against potential responder bias, there would need to be an equal number of positive- and reverse-worded items to provide a balanced questionnaire, where the risk of answering either all positive or all negative was equal (Ray, 1983). There is evidence that including the four reverse-worded items decreases the validity of the scale, with divergent factor loadings seemingly measuring two constructs and a resultant lower internal consistency. In addition, the double negatives encourage inaccurate responses and confusion (Weeks *et al.*, 2005; Rodebaugh *et al.*, 2007; Rodebaugh *et al.*, 2011). It has been demonstrated that older individuals and those with lower levels of education show increased error variance when completing the 12-item scale due to the reverse-worded items (Rodebaugh *et al.*, 2011).

Options for overcoming these problems with validity include omitting the four reverse-worded items from the scale completely (Carleton *et al.*, 2011), rewording the reverse items so that they are positively-worded (Weeks *et al.*, 2008), or administering the scale with the reverse-worded items included but then not including them in the calculation of the total score (Rodebaugh *et al.*, 2011).

Despite the problems documented with the reverse-worded items and the recommendations to overcome these, the majority of studies still use the original form of the questionnaire. It has been suggested that this is because of the lack of normative data available for the other versions of the scale (Rodebaugh *et al.*, 2011).

In conducting this study, it was found that the reverse-worded items caused some confusion and were possibly the reason for the majority of the missing data. Five per

cent of respondents did not fully complete all items (n=60), and the data collectors from the ONS were of the subjective opinion that the negatives caused some confusion and frustration. It was felt that this led to either refusal or inability to complete the questionnaire, or respondents answering contrary to what they actually meant. Examples of comments from the data collectors included;

'Difficulty answering, knew what she wanted to say but, because of the way the questions were asked, kept giving answers contrary to her meaning then asking if she had got that right.'

'Hugely confusing, found questions repetitive and could not distinguish which end of the scale to go for. Flipping from positive statement to negative caused big problems.'

'Very difficult for a non-native speaker to understand - got half way through but we had to give up.'

In this study, the advice of Rodebaugh and colleagues (2011) based on testing the BFNES on a large US community sample was followed and the complete original scale was administered including the reverse-worded items. The results of this study were then presented in both formats (i) O-BFNES: total score of all 12 items including the four reverse-worded items, and (ii) the S-BFNES: total score of the eight straightforward items only. This gives the reader and other researchers the option of using either set of norms and to allow comparison with previous published work using both scales.

ONS Opinions Survey of the UK population

The largest non-clinical sample using the BFNES published to date is a combination of a non-randomly obtained community sample (n=489) and university students (n=4282) from the USA (Rodebaugh *et al.*, 2011). However, there are no known randomly obtained national data for any country. In order for the results of the normative study to be as widely generalisable as possible, a representative sample of the UK (excluding Northern Ireland) was sought via the Omnibus Survey conducted by the Office for National Statistics (ONS).

As discussed in section 3.2, a random stratified probability sample of the UK population was obtained, which yielded 1196 respondents. By using this method of sampling, there is an equal chance of any individual being selected and thus bias is reduced. For the BFNES questionnaire, there were missing data for 60 participants for the O-BFNES and 47 participants for the S-BFNES. Rigorous methodology was used to improve the response rate and sample size; including making up to eight attempts at participant contact at different times of the day, followed by telephone follow-up. The final response rate was 66% and this was considered acceptable as the average response rate for ONS omnibus surveys is 60% (Office for National Statistics, 2011).

The sample is susceptible to selection and response bias at different stages. Therefore, the ONS routinely applies a complex combination of weighting systems to reduce this bias. The sample selection is vulnerable to unequal selection due to the fact that only one adult per household is interviewed. As only one adult per household is selected, if the first person who the interviewer comes into contact with is always chosen, there is a risk that a representative range of age groups will not be obtained as young people are less likely to be at home than older females. Therefore, weighting accounts for issues such as this.

A Kish grid was used by ONS, which is a random number table method named after the statistician who devised it (Kish, 1949). It is a commonly used method in household sampling surveys where the interviewer ascertains the total number of individuals living in the household (even if they are not present at that time) and assigns each one a number. The youngest is always one, the next youngest is two, and so on. The Kish grid is then used for each consecutive household to determine which individual should be chosen. The grid is weighted so that it gives younger people a slightly higher chance of being chosen as they are less likely to be available for interview in the home. The data are also subsequently weighted to correct for the unequal probability of selection that occurs when only one person in a household is selected. People in smaller households are more likely to be selected and will be over-represented, because, if there is only one person in a household, there is a 100% chance that they will be selected (Office for National Statistics, 2011).

Finally, weightings are applied to the raw data to correct for response bias based on ONS complete UK Census data. For example, young males living in London are less likely to respond and therefore are assigned a higher weighting. All of the methods described ensure that the sample is as representative as possible of the general UK population and that the results are generalisable.

Clinical sample

All patients were invited to participate as they attended routine clinical appointments. This may have introduced some bias as it was a self-selecting sample. It was decided to exclude patients who had craniofacial anomalies, including clefts, and those with acquired facial defects due to the fact that these patients may be psychologically different to orthognathic patients (Versnel *et al.*, 2010). In addition, patients who had previously received orthognathic treatment were excluded as it was thought that this experience may influence the results.

3.4.2 Results

(i) ONS Opinions Survey data

Demographics

A final sample of 1196 was recruited in the Omnibus Survey. Of these, 51.1% of respondents were female and 48.9% male. This closely matches the demographics of the UK from the 2001 Census, where 51.3% of the country was female and 48.7% male (Office for National Statistics, 2005) (Table 3.20). However, it must be borne in mind that the ONS survey does not include Northern Ireland and the Census does.

The mean age of the ONS sample was 49.58 years (SD 18.92 years) which is older than the national average in 2001 which was 38.6 years. This difference is probably due to the fact that the ONS survey was restricted to individuals of 16 years and above and may, in small part, be due to increasing life expectancy over time (Leon, 2011).

With regards to ethnicity, different classifications are now used by the ONS compared with those used in the 2001 Census. However, some comparisons can be made and a very similar demographic was observed between the 2001 Census data and the ONS sample recruited in this study (Table 3.20).

Variable	ONS survey 2011	Census 2001
Gender	Male 48.9% Female 51.1%	Male 48.7% Female 51.3%
White British	87.0%	85.7%
Irish	1.3%	1.2%
White other	2.7%	5.3%
Indian	2.0%	1.8%
Pakistani	0.7%	1.3%
Chinese	0.3%	0.40%
Mixed ethnicity	0.2%	1.30%

Table 3.20. Comparison of demographic variables between ONS Survey data and the UK population Census, 2001 (Office for National Statistics, 2001).

Previous research postulated that age, gender, and ethnicity may have an influence on BFNES scores and thus these data were collected and analysed (Rodebaugh *et al.*, 2011). In addition to the standard demographic details, the ONS routinely collects information on level of education, self-reported general health, long standing illness or disability, and Index of Multiple Deprivation during each Opinions Survey. The effect of these variables on BFNES was also examined.

BFNES scores (Table 3.7)

The total mean BFNES score was 29.72 (SD 9.39) for the O-BFNES and 15.59 (SD 7.67) for the S-BFNES. The closest comparable community sample is from a US study of 489 volunteers recruited from a community volunteer registry and the local university psychology department (Rodebaugh *et al.*, 2011). That sample was divided into two groups, ages 18-59 and 60-98 years. When the two samples were combined, the total mean O-BFNES score was 30.55 and the S-BFNES was 15.91 which are similar to the results of this study and to those of a smaller scale US community study with a sample of 30, where the O-BFNES mean score was 29.2 (Collins *et al.*, 2005). Duke and co-workers (2006) observed a higher mean O-BFNES score of 32.3 (SD 7.34) in a

community sample of 355 people recruited at religious meetings and in large retail centres in the US, but the differences may be due to the more restricted sampling methodology used.

Gender (Table 3.8)

Females exhibited significantly higher BFNES scores on both scales (2.12 points on the O-BFNES and 1.73 on the S-BFNES) which is contrary to the findings of Rodebaugh and colleagues (2011) who found no statistical difference in BFNES scores between the genders. However, Duke and co-workers (2006) also found that scores were on average two points higher for females ($P < 0.05$). The finding of higher social anxiety in females is in keeping with other published literature which has found higher lifetime prevalence in females (Schneier *et al.*, 1992; Offord *et al.*, 1996; Kessler *et al.*, 2005a; Ruscio *et al.*, 2008). It must be borne in mind that the data from the Rodebaugh study was not randomly or nationally obtained and thus may not be generalisable to the whole population. In addition, females were over-represented in that study, with 72% of the sample being female.

Age (Table 3.9, Figure 3.4)

There was a trend that BFNES score decreased with increasing age in the current study, which is supported by the findings of Rodebaugh and colleagues (2011). However, the magnitude of this effect was small, with a one point BFNES decrease for every decade increase in age when the genders were combined and this is unlikely to be clinically relevant. The presence of an age/gender interaction was investigated using multiple linear regression and it was found that, although fear of negative evaluation decreased with increasing age, the change was not at the same rate for males and females. Fear of negative evaluation started higher in younger females but decreased at a more rapid rate than in males, and scores approached equivalence with advancing age (Figure 3.4). However, it must be borne in mind that these conclusions are made from cross-sectional data, and thus, it cannot necessarily be extrapolated that a particular individual's fear of negative evaluation decreases with age. Rather, it shows that fear of negative evaluation is higher in currently younger individuals than in the older population. Whilst this may mean that fear of negative evaluation does indeed decrease with age in people, it may

also mean that the current older generation exhibit lower fear of negative evaluation than the younger generation due to different past experiences, such as less presence of media and social pressures. Further longitudinal studies would be required to determine whether this is an individual or cohort effect. Interestingly, a large scale national study in the United States found that generalised social anxiety had an inverse correlation with age in males but a positive correlation with females (Wittchen and Hoyer, 2001). However, Duke and colleagues found that age did not have an effect on BFNES score (Duke *et al.*, 2006).

Ethnicity (Table 3.10)

With regards to ethnicity, it was not possible to statistically examine the effects of each different subgroup due to the small number of participants recruited in some of the 18 different subgroups. Instead, the data were categorised into British origin and non-British origin and there were no statistically significant differences between the two groups. Rodebaugh and colleagues (2011) investigated the effect of ethnicity on BFNES score in a student sample and found equivocal results, with one university sample showing no difference and another from a different university showing lowest BFNES in African-American and Hispanic groups. This is similar to the findings of a national US study on social anxiety disorders which found similar ethnic distributions (Kessler *et al.*, 2005a). Comparisons of the effect of different ethnicities on psychological variables are challenging as there are no standardised ethnic subgroups and different studies use different terminology, thus definitive conclusions are difficult to make.

Additional explanatory variables (Tables 3.11, 3.12, 3.13; Figures 3.5, 3.6, 3.7, 3.8, 3.9)

With regard to education level, there was a trend that those with more qualifications exhibited higher levels of fear of negative evaluation than those with no qualifications, but not all comparisons were statistically significant (Figure 3.5). It could be that those who have higher levels of education are more self-critical where the emphasis in education is increasingly on self-awareness and critical thinking (Pithers and Soden, 2000). However, Rodebaugh and colleagues (2011) found no differences based on years of education ($P=0.29$). Conversely, social phobia has been associated with impaired

school performance in adolescence and higher education has been found to be a predictor of satisfactory recovery for those suffering with social phobia (Davidson *et al.*, 1993).

Many of the other normative data published to date, including the sample that the BFNES was developed on, are based on college or university samples and there is evidence that these scores are higher than community samples, perhaps due to age and level of education (Leary, 1983; Collins *et al.*, 2005; Rodebaugh *et al.*, 2011). Thus, the data derived from these samples are not suitable to be used as general population norms.

In addition to the aforementioned variables, data were collected on general health, presence of a long standing illness, employment status, and socio-economic status. General health status and the presence of a long standing illness had no significant effect on FNE (Figures 3.6 and 3.7). This concurs with the findings of a large epidemiological study in the US including 3249 children with chronic illness (Cadman *et al.*, 1987). The authors found that the presence of a chronic illness (without a physical disability) conferred no increased risk of social adjustment problems.

Information on employment status was also obtained. According to the US International Labor Organisation (ILO) definitions, unemployed people are defined as '*those without a job, who want a job, who have actively sought work in the last 4 weeks and are available to start work in the next 2 weeks, or out of work, have found a job and are waiting to start it in the next 2 weeks.*' In general, anybody who carries out at least one hour paid work in a week, or who is temporarily away from a job (e.g. on holiday) is in employment. Those who are out of work but do not meet the criteria of unemployment are classified as being economically inactive (International Labor Organization, 1982).

It was found in this study that those who were economically inactive had lower BFNES scores than those who were employed (Figure 3.8). This is in contrast with the findings from another study which noted that the prevalence of mental disorders is higher in those who are economically inactive due to permanent sickness or disability (Fone *et al.*, 2007). This difference may be because the majority of those who were economically inactive in this study may have been out of choice (for example, stay-at-home parents) rather than those who were economically inactive due to ill health and thus their BFNES

scores were not adversely affected. More females were economically inactive than males in this study (43.7% opposed to 35.4%).

In the current study, there was no significant difference in BFNES score between those who were unemployed and employed. This is, again, in contrast with other UK studies which have found a significant relationship between unemployment and anxiety and depression as measured by the Hospital Anxiety and Depression Scale (Ostler *et al.*, 2001). However, FNE is a different psychological construct to anxiety and depression and consequently may not be comparable. No studies examining FNE and unemployment were found for direct comparison.

There were no significant differences in BFNES scores based on the quintiles of the Index of Multiple Deprivation in this study. Although it is generally upheld that social deprivation is associated with mental illness, the relationship is complex and controversial (Wicks *et al.*, 2005; Mensah and Hobcraft, 2008). Studies have found that socio-economic deprivation of an area is a strong predictor of depression (Ostler *et al.*, 2001), however, a recent Cochrane review found no link between childhood poverty and mental illness (Lucas *et al.*, 2008).

In conclusion, in a randomly selected sample of the general UK population;

- Mean BFNES scores were 29.72 (SD 9.39) for the O-BFNES and 15.59 (SD 7.67) for the S-BFNES.
- Females had significantly higher BFNES scores than males (on average 2 points higher).
- Fear of negative evaluation decreased with increasing age, but the degree of reduction was greater in females so that BFNES scores approximated with advancing age.
- There was a trend that those with more qualifications exhibited higher levels of fear of negative evaluation than those with no qualifications (not all comparisons were statistically significant).

- Those who were economically inactive had lower fear of negative evaluation scores than those who were in employment.

(ii) Orthognathic patient data

Demographics (Table 3.14)

Of the 61 participants, the majority of patients were female (57.4%) and this reflects the general orthognathic patient demographic, with females more likely to seek treatment than males (Proffit *et al.*, 1990; Williams *et al.*, 2005; Stirling *et al.*, 2007). However, the relatively high proportion of males compared with some other studies ensured that the male perspective was represented (Williams *et al.*, 2005). The majority of patients (50.8%) were in the 16 to 24 year age bracket, followed by 25 to 44 years (42.7%) which reflects the average age of orthognathic patients (Stirling *et al.*, 2007; O'Brien *et al.*, 2009).

BFNES scores (Table 3.15)

The mean O-BFNES score for the whole patient group was 39.56 (SD 10.35) and the mean S-BFNES score was 24.21 (SD 8.41).

Gender (Table 3.16)

In the current study, female orthognathic patients had higher BFNES scores than males but this was not statistically significant. The majority of studies examining FNE and dentofacial deformity do not supply data on the effect of age and gender on FNE, however, in the study on patients with amelogenesis imperfecta it was found that females had higher BFNES scores than males but this difference was not statistically significant (Coffield *et al.*, 2005). It may be that this current study and the one by Coffield and co-workers lacked the power to detect a significant difference between the genders if one existed.

Age

Age had no statistically significant effect on BFNES scores for the orthognathic patients and this is similar to the findings of Coffield and colleagues (2005). However, the age range in the current study was narrow, and the sample size modest. Analysis

necessitated combining the orthognathic patients into age groups and applying an ANOVA test which will have inevitably lacked sensitivity to detect differences. If there were more patients and a wider age range, such as for the respondents in the ONS survey, it would have been possible to analyse the age data using regression methods instead. However, even when regression was used to analyse the relationship between age and BFNES score in the much larger ONS Survey sample, the magnitude of the negative relationship between BFNES score and age was very small (one unit change in BFNES score per decade increase in age). It is therefore unsurprising that no statistically significant relationship between age and BFNES score could be detected within the patient sample.

(iii) Comparison of orthognathic patient data and ONS Opinions Survey data

Orthognathic patients had significantly higher BFNES scores than the normative values, with patient scores eight to nine points higher than the general population (Tables 3.17 and 3.18). The only other study assessing FNE directly in orthognathic patients found that patients had *lower* FNE than norms, however, this study used the original 30-item Fear of Negative Evaluation Scale (FNES) and thus the results are not directly comparable with those of this study (Lovius *et al.*, 1990). Those authors found that pre-treatment FNE levels (mean 13.40, SD 7.90) in orthognathic patients were lower than average normative values (mean 15.47, SD 8.62). The normative mean values they used were based on the US college sample from which the FNES was devised (Watson and Friend, 1969). There were limitations to the study on orthognathic patients by Lovius and colleagues (1990); the sample size was small (n=41) and there was no sample size calculation reported, which limits the validity of the results. In addition, the comparative normative group was not ideal to compare baseline levels with or with which to make meaningful comparisons. Finally, the pre-treatment questionnaire was distributed at varying points with some completed just prior to surgery rather than before commencement of pre-surgical orthodontics. Thus, the results should be interpreted with caution as baseline levels of FNE may be affected by commencing treatment and pre-surgical orthodontics.

Another normative UK mean has been reported to be 14.26 (SD 7.72), however, this was also based on a student population and is probably not representative of the general population (Stopa and Clark, 2001).

Patients with cleft lip and palate have been shown to have raised fear of negative evaluation compared with control groups, but although these patients also have a visible facial disfigurement, they are probably psychologically different from orthognathic patients without clefts (Berk *et al.*, 2001; Versnel *et al.*, 2010). In fact, there is some conflicting evidence to suggest that cleft patients may exhibit *lower* FNE than non-cleft orthognathic patients prior to treatment (Yu *et al.*, 2003, cited in Cheung *et al.*, 2006). This may be due to the fact that patients with clefts are aware of their defect from a very young age and have usually had multiple treatments to improve their appearance over time and may have learned to adapt. In contrast, orthognathic patients are often made aware of their defect later in life and the majority are not offered any treatment until they reach maturity and this may affect FNE levels.

Versnel and colleagues (2010) also showed that patients with congenital facial disfigurement had higher levels of fear of negative appearance evaluation (17.39, SD 6.18) than a control group (12.78, SD 6.10), as measured using the six-item self-report Fear of Negative Appearance Evaluation Scale (Thomas *et al.*, 1998). The authors recommended that all patients with facial disfigurement should be screened for low self-esteem and high fear of negative appearance evaluation and that, where screening reveals low self-esteem or high fear of negative appearance evaluation, a combination of physical and psychological treatment should be offered to improve satisfaction with treatment outcome.

In addition, patients with, what may be perceived to be milder defects of orofacial appearance, namely amelogenesis imperfecta, have also been shown to have higher levels of FNE than controls (Coffield *et al.*, 2005). In this study of 30 patients with amelogenesis imperfecta and 29 unaffected controls, patients had a mean BFNES score of 38.7 compared with a mean score of 31.1 in the control group ($P < 0.05$). The patient score in that study is comparable with the FNE levels in the orthognathic patients in the current study.

When comparing the two samples directly, multiple linear regression showed that age, gender, and whether the participant was a patient or member of the general public were all significant independent predictors of BFNES score. Orthognathic patients had a mean O-BFNES score seven points higher and mean S-BFNES score 6 points higher than the general population having controlled for age and gender (Table 3.19). Thus, we can conclude that the orthognathic patients did exhibit statistically significantly higher levels of fear of negative evaluation than the general population and there is evidence to reject the null hypothesis. The magnitude of the difference is considerable and it is likely to be clinically meaningful.

A clinically useful cut-off score using the BFNES has been suggested by Carleton and co-workers (2011) to diagnose social anxiety disorder. They examined 381 patients with diagnosed anxiety or related disorders and used receiver operating characteristic (ROC) statistical analyses to determine a cut-off score to differentiate between those individuals with social anxiety disorder and those without. ROC uses the area under a curve to determine the value for the maximum sensitivity (the percentage of people who have been diagnosed with social anxiety disorder who will be correctly classified using the associated score) and specificity (the percentage of people who do not have social anxiety disorder who will be correctly classified using the associated score) to optimise the ability to differentiate between those with and without the condition of interest. When using the S-BFNES, Carleton and co-workers (2011) found that scores of greater than 25 were indicative of social anxiety disorder. When using the 12-item scale, the cut-off score was above 38, although the authors administered the 12-item scale with the reverse-worded items, reworded positively. When applied to the current study results, considering the 12-item scale, 56% of the orthognathic patient cohort in this study met the criteria based on the cut-off score of above 38 for a positive diagnosis of social anxiety disorder as measured by the BFNES (mean 39.56). However, the range of scores reported was 16 to 60 and, thus, when examined on an individual basis, some patients did not meet the cut-off point while others had very high scores. This highlights the importance of examining each patient on an individual basis and not making assumptions based on average values. The mean score for S-BFNES in the orthognathic

patients was 24.21, which is just below the cut-off for diagnosis, with 48% of patients scoring above 25.

3.4.3 Clinical relevance

Based on the results of this study and a review of the literature, it appears that the presence of a facial disfigurement is associated with elevated FNE and orthognathic patients are at increased risk of social anxiety disorder, regardless of age, gender, and severity of the defect. Therefore, patients with facial disfigurement should be screened prior to orthognathic treatment to assess baseline FNE levels, using the BFNES, which is quick and acceptable to use chair-side. There is evidence that patients with visible facial disfigurement with high FNE want psychological assistance and surgical correction alone may not alleviate psychological symptoms (Kent and Keohane, 2001). A combination of cognitive behavioural therapy and social skills training has been suggested to enable patients to develop a satisfactory body image and deal with others' evaluations (Kent and Keohane, 2001).

3.4.4 Recommendations for future research

The orthognathic patients in this study had significantly higher FNE than the general population. What is not known is how this FNE is affected by orthognathic treatment and psychological therapy. Future longitudinal clinical trials are needed to ascertain if FNE changes following orthognathic treatment and ideally comparisons made with a similar group who are treated with psychological intervention only. In addition, similar studies should be carried out in other orthognathic units around the country to ascertain if the results are comparable.

3.4.5 Conclusions

This study has established normative values for fear of negative evaluation, as a measure of social anxiety, based on a large randomly selected general population sample which can now be used in any UK-based study requiring comparative normative data. Fear of negative evaluation in orthognathic patients was significantly higher than in the general population. From the limited evidence available, orthognathic treatment appears unlikely to improve the level of social anxiety, in particular, fear of negative evaluation

(Lovius *et al.*, 1990). Therefore, if fear of negative evaluation is a primary motivating factor in the decision to seek orthognathic treatment, this may not be alleviated by undertaking physical treatment alone and may lead to dissatisfied patients and poor treatment outcomes. Thus, psychological therapy may be more appropriate for some of these patients, either alone or in combination with orthognathic treatment.

There are also cost implications to consider as it may be more cost effective to provide psychological support where appropriate to these patients instead of orthognathic treatment. However, if both psychological support and subsequent physical treatment are indicated, this may become more costly.

Finally, the morbidity and mortality of orthognathic treatment must be considered if there is doubt regarding the potential changes in FNE resulting from physical treatment alone. These are all areas which warrant further longitudinal investigation, however, obtaining ethical approval for some elements may prove difficult. In conclusion, the presence of social anxiety disorder must be considered when assessing all potential orthognathic patients as it may have substantial ramifications.

Chapter 4: Shared decision-making in orthognathic treatment



Abstract

Background

Recently there has been increasing emphasis on shared decision-making (SDM) as the pinnacle of patient-centred care; this concept replaces paternalistic care with a mutualistic partnership between clinician and patient. SDM involves a shared process of presenting the options for treatment, together with the relative risks and benefits, clarifying the patient's preferences and values, and reaching a decision regarding treatment. There is evidence that SDM leads to improved outcomes, however, it remains to be widely adopted in healthcare to date.

Aims

The aim of this study was to measure the extent of SDM in orthognathic consultations using the OPTION scale which was devised to assess clinician involvement in SDM.

Subjects and methods

This was a cross-sectional study involving orthognathic patients and the clinicians involved in their care. Multidisciplinary orthognathic clinic consultations were audio recorded and then rated by two independent raters using the OPTION scale. The consultations were with patients who had not yet commenced active treatment.

Results

Consultations with 61 orthognathic patients were recorded; 36% were male and 64% were female. The average age was 26 years and the average consultation length was 12 minutes and 44 seconds. Three members of the orthognathic team (an orthodontist, maxillofacial surgeon, and liaison psychiatrist) were involved in each consultation and were considered as one clinician for the purposes of the assessment. Agreement between the independent raters who assessed the consultations was acceptable, with an intra-class correlation coefficient of 0.794 (95% confidence interval 0.678 to 0.871). The mean OPTION score was 22.55% (range 3-54%, SD 10.73%), indicating a low level of SDM, and the possible reasons for this are discussed.

Conclusions

The results of this study indicate that the extent of SDM in orthognathic consultations is relatively low but there are circumstances which are specific to this cohort of patients and may account for the low scores; these reasons are discussed in detail. This is the first study investigating SDM in the field of orthodontics and the results are similar to those in other disciplines. Improvements in SDM are necessary in order to ensure that patients are adequately involved in their treatment decisions.

4.0 Review of the literature

4.0.1 Introduction

There is increasing emphasis on patients as partners in their healthcare. Frequently, this balance can be difficult to achieve due to the inherent inequality of the clinician-patient relationship (Edwards and Elwyn, 2009). These encounters are often emotionally laden, with the clinician and patient coming from different perspectives and knowledge bases (Ong *et al.*, 1995). However, discussion between the healthcare professional and patient is considered to be the *'art or heart'* of medicine (Roter and Hall, 1989). Traditionally this relationship was paternalistic, where the clinician *'told'* and the patient *'did as they were told'* (Murtagh and Thorns, 2006). However, there has been a paradigm shift away from this type of encounter, and a drive towards more patient-centred care, where the patient is more empowered, informed, and autonomous (General Medical Council, 2013; Stewart, 2001).

4.0.2 Healthcare relationships

The fundamental interaction in healthcare is that between the clinician and the patient (John Hopkins Group, 2004). This unique and personal relationship is often complex due to the different positions and perspectives from which both parties arise. However, a clinician-patient consensus summit conducted in the US concluded that what patients and clinicians want from this relationship is remarkably similar (John Hopkins Group, 2004).

Four types of clinician-patient relationship have been described: default, paternalistic, consumerist, and mutualistic (Roter and Hall, 1992). Default relationships are characterised by a lack of control on both sides and are generally negative. Paternalistic relationships describe the traditional clinician-patient encounter, where the healthcare professional is dominant and decisive and the patient is passive. Consumerism is the opposite of paternalism, where the patient's rights are central and the clinician exists to fulfill these obligations. Mutuality is characterised by an egalitarian relationship and an equal process of shared decision-making and is generally felt to be the best type of

professional relationship in healthcare. The paternalistic relationship predominated healthcare until relatively recently (Murtagh and Thorns, 2006). It was felt that patient deference to medical authority was essential and that the unequal relationship was an inescapable consequence of the competency gap between the professional and the layperson (Mead and Bower, 2000). Since the 1990s, it has been recognised within healthcare policy in the UK that a more equal sharing of power and responsibility is beneficial (Department of Health, 1991; NHS Executive, 1996).

4.0.3 Patient-centred care (PCC)

The concept of patient-centred care, also known as patient-focused care, emerged in the 1950s, but only gained momentum in healthcare policy in the late 1990s (Jayadevappa and Chhatre, 2011). The term ‘patient-centred care’ was coined in 1988 by the Picker Institute (which is an international not-for-profit organisation promoting PCC) to focus clinicians on patients and their families rather than solely on biomedical parameters (<http://www.pickereurope.org>). The term signified an emphasis on the *patient’s* experience of a condition and their needs (Barry and Edgman-Levitan, 2012). PCC has been described as the clinician seeing the patient’s illness through their eyes (McWhinney, 1989) and being ‘*responsive to patients’ wants, needs, and preferences*’ (Laine and Davidoff, 1996). It encompasses a consulting style which takes into account the patient’s knowledge and experience (Byrne and Long, 1976). As the era of healthcare consumerism has dawned, PCC has gained prominence as a key aim of healthcare systems internationally (Mead and Bower, 2000; Shaller, 2007; Charmel and Frampton, 2008). There is some evidence that PCC may increase patient satisfaction, decrease the length of hospital stay, and lead to improved efficiency and effectiveness of treatments, resulting in lower costs of care provision (Stewart *et al.*, 2000; Charmel and Frampton, 2008; Meterko *et al.*, 2010; Dwamena *et al.*, 2012).

The eight core elements of patient-centred care were described by the Picker Institute, based on the findings of focus groups with patients and their families (Shaller, 2007). They are:

- Respect for patients’ values, preferences, and expressed needs.

- Coordination and integration of care.
- Information, communication and education.
- Physical comfort.
- Emotional support and alleviation of fear and anxiety.
- Involvement of family and friends.
- Transition and continuity.
- Access to care.

The Institute of Medicine in the United States stated that PCC was one of the fundamental methods of improving the quality of healthcare and that patient values should guide all clinical decisions (National Research Council, 2001). Following on from this, it has been said that the most significant characteristic of PCC is active involvement of patients in healthcare decisions (Barry and Edgman-Levitan, 2012). Research has shown that patients also have a strong personal preference for PCC (Little *et al.*, 2001). However, despite evidence that it contributes towards overall quality of care and outcomes, systems frequently fall short of delivering truly patient-centred care (Stewart, 2000; Shaller, 2007; Jayadevappa and Chhatre, 2011).

4.0.4 Shared decision-making (SDM)

Shared decision-making has been quoted as being the pinnacle of patient-centred care (Barry and Edgman-Levitan, 2012). It is said to bridge the gap between the care patients want and the care they receive (Mulley, 2011). SDM is defined as ‘*a process in which clinicians and patients work together to clarify treatment...sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of action*’ (Coulter and Collins, 2011). It is a two way process where both the patient and the clinician must share information and the responsibility for decision-making, with each respecting the other’s point of view (Coulter and Collins, 2011). It replaces the traditional situation where the healthcare professional made the decision *for* rather than *with* the patient and instead patients are seen as partners in their healthcare decisions (Légaré *et al.*, 2010). Both clinicians and patients bring different, but equally

important, expertise to the encounter. The clinician's expertise includes diagnostic skills, knowledge of aetiology, prognosis, treatment options, and outcome probabilities; whereas, the patient's expertise includes their experience of the condition, their attitude to risk, and their values and preferences (Coulter and Collins, 2011).

There is some ambiguity as to when SDM should be adopted. It has been suggested that SDM is best suited to issues involving medical uncertainty where there is more than one option for treatment (Frosch and Kaplan, 1999). Wennberg and co-workers (2002) named these conditions 'preference-sensitive conditions', where there is no clearly superior treatment choice and the different options have different risks and benefits which involve certain trade-offs and, thus, the patient's personal preferences and values should drive the treatment decision. Elwyn and coworkers described this situation as 'equipoise', where the majority of individuals would deem it reasonable to consider making a choice between competing options (Elwyn *et al.*, 2009). Others have maintained that most consultations and all treatment decisions should involve an element of SDM (Coulter and Collins, 2011). This is because most, if not all, medical decisions involve more than one reasonable approach, even if one of the choices is doing nothing (Barry and Edgman-Levitan, 2012). There has been a suggestion that SDM may be best suited to chronic, long-term conditions as there is some evidence that SDM works best in these situations (Joonsten *et al.*, 2008). Elwyn and colleagues proposed that patients should be involved to the extent to which they wish to be, regardless of the situation (Elwyn *et al.*, 2009).

SDM involves, at a minimum, the patient and the clinician and often benefits from incorporating family and friends and other healthcare professionals. SDM involves a number of essential stages during consultations, as defined by Makoul and Clayman (2006) and Stiggelbout and colleagues (2012) (Figure 4.1):

- *Define/explain the problem* – this should be in layman's terms.
- *Present the options* – this should include all options, including doing nothing or maintaining the status quo. The patient should be made aware of a position of equipoise, where there is no right or wrong decision, only a preferred choice.

- *Discuss the pros/cons (benefits/risks/costs)* – these should be explained together with the respective probabilities, where they are known, as patients often find it easier to weigh up choices they can quantify.
- *Clarify patient values/preferences* – individuals' attitudes to, concerns about, and expectations of each option should be explored.
- *Discuss patient ability/self-efficacy* – the patient should be made aware that they do not need to make this decision alone and family members and friends should be invited to participate where appropriate. Some patients do not wish to make the decision themselves and it would be counter-productive to force them to. The clinician should support the decision-making process so the patient does not feel abandoned.
- *Present what is known and make recommendations* – the clinician should present the best available evidence together with their clinical experience and counsel the patient in the shared decision-making process.
- *Check/clarify the patient's understanding* – the patient should be given the opportunity to ask questions and request more information if necessary.
- *Make or explicitly defer a decision* – some patients will make the decision at the consultation but for many others it will be appropriate to defer making this decision until they have considered the options without time pressure and consulted decision aids or significant others. A follow up appointment should be arranged in most cases.

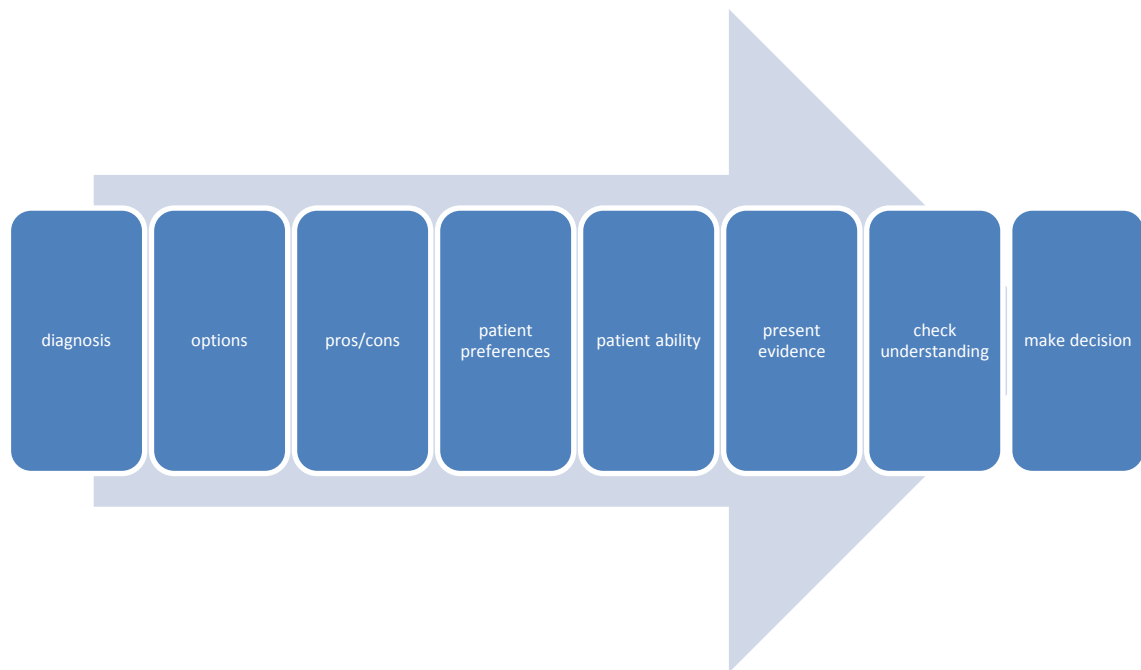


Figure 4.1. The stages of shared decision-making.

The aim of SDM is to provide healthcare that is better aligned with patients' preferences and to ensure that patients make an informed choice about their treatment options which supports them to achieve their goals (Coulter and Collins, 2011; Lee and Emanuel, 2013). Engaging in SDM is an ethical and legal imperative, supported by the General Medical Council, General Dental Council, and Government policy and legislation (Elwyn *et al.*, 2005; General Dental Council, 2005; Department of Health, 2010, 2012, 2013; General Medical Council, 2013). More importantly, it is considered to be the right thing to do for patients (Coulter and Collins, 2011). In addition, research has proven that patients generally want to be more involved in their own healthcare decisions (O'Connor *et al.*, 2003a; Kiesler and Auerbach, 2006; Chewning *et al.*, 2012) but remain unsure of how to achieve this (Couët *et al.*, 2013). Despite this, there is evidence that SDM is not widely practiced or well conducted by many clinicians (Coulter, 2010; Couët *et al.*, 2013; Lee and Emanuel, 2013).

4.0.5 How to deliver SDM

A recent inpatient NHS survey found that only 52% of patients felt they were definitely involved in decisions about their healthcare (National Inpatient Survey, 2011, cited in

Shared Decision Making Programme, 2012). Encouraging clinicians to adopt SDM has been considered as one of the biggest barriers to implementing SDM (Coulter, 2009). Studies have found that the main reasons for not practicing SDM are time constraints, lack of training, lack of supporting information technology to track patients through the SDM process, and lack of clinician-perceived patient and scenario applicability (Elwyn, 1999; Gravel *et al.*, 2006; Towle *et al.*, 2006; Caldwell, 2008; Friedberg *et al.*, 2013). Despite a marked increase in interest and research involving SDM recently, there is a lack of guidance as to how to implement it in everyday practice (Elwyn *et al.*, 2012).

Fundamentally, SDM is built on the foundations of good communication and rapport with the patient (Elwyn *et al.*, 2012). Both the clinician and the patient need to be informed, motivated, and engaged (Da Silva, 2012). Elwyn and colleagues recently proposed a simplified three-step approach for delivery of SDM: ‘*choice talk, option talk, and decision talk*’ (2012) (Figure 4.2). Choice talk involves establishing the different choices that are available. This is followed by option talk, which involves checking the patient’s knowledge, listing and describing the options, exploring preferences, discussing risks and benefits, and providing decision support. Decision talk focuses on what the patient’s preferences are and facilitates a decision being made. These stages may take place over one or more appointments and the patient may wish to obtain the opinions of significant others during their deliberation. Decision support, in the form of counselling or decision aids, is vitally important in facilitating this process and can be used at any stage (Elwyn *et al.*, 2012).

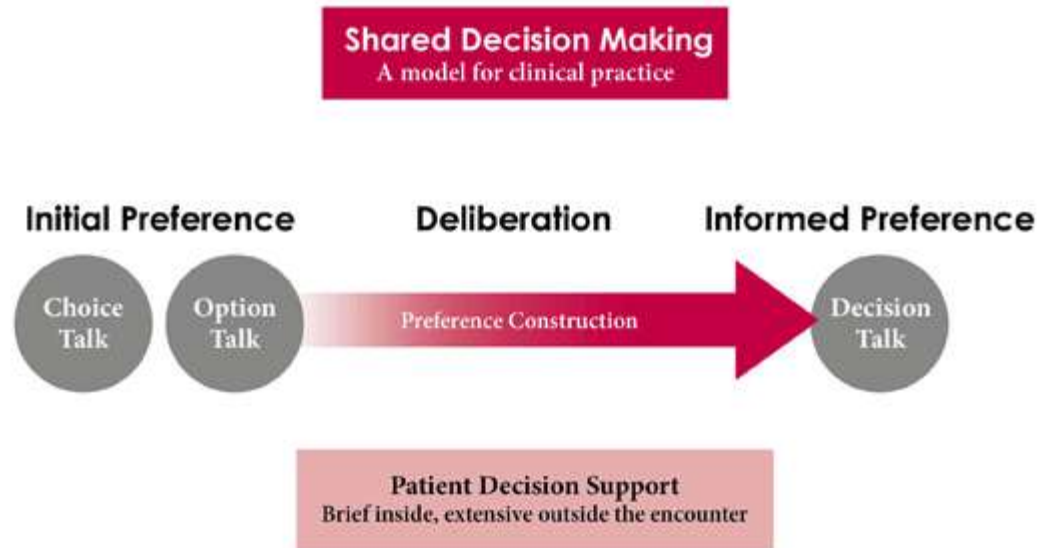


Figure 4.2. The three step process for delivering shared decision-making suggested by Elwyn and colleagues (2012).

[Reproduced from the Health Foundation (2013) (<http://www.health.org.uk/areas-of-work/programmes/shared-decision-making>)].

Lack of training has been cited as a barrier to SDM in the past and SDM is now incorporated into education at both undergraduate and postgraduate level for healthcare professionals (Elwyn, 1999; General Medical Council, 2009; Coulter and Collins, 2011; Department of Health, 2013). The Department of Health has recently commissioned the Advancing Quality Alliance (AQuA) to provide SDM training programmes (e-learning modules, training videos, and courses) to NHS providers (<http://www.advancingqualityalliance.nhs.uk/sdm/>). The Royal College of Physicians in England now offers courses and a fellowship in SDM (<http://www.rcplondon.ac.uk/update/rcp-seeks-shared-decision-making-fellow>). Nurses within the NHS have also been trained in decision coaching skills to offer telephone support for various medical conditions (<http://www.rightcare.nhs.uk/index.php/shared-decision-making/about-the-sdm-programme/>).

4.0.6 Patient decision aids (PDAs)

Healthcare decisions are rarely straightforward and can be difficult to make. This is usually because there is insufficient evidence to clearly promote one choice over another or because different individuals value risks and benefits differently (Edwards and

Elwyn, 2009). Patient decision aids, also known as patient support tools, have been developed to supplement the clinical encounter and to help patients in making treatment decisions.

PDAs are standardised, evidence-based tools developed to streamline the decision-making process as an adjunct to the patient-practitioner interaction. They provide information about the options available and their outcomes, while allowing patients to personalise this information, understand that they have a choice to make, appreciate the scientific uncertainties, clarify the personal values they place on the relative benefits versus the risks, and communicate their preferences to the clinician (Edwards and Elwyn, 2009). PDAs are different to traditional patient information materials, which generally tell patients what to do. They are also distinct from clinical guidelines, which usually exist to support practitioners rather than patients (Coulter and Collins, 2011).

PDAs can take a variety of formats, including leaflets, DVDs, and interactive websites and there is currently a shift towards internet-based PDAs (O'Connor *et al.*, 2004). Regardless of the format, three key elements should be incorporated:

- Information provision.
- Clarification of values.
- Guidance or coaching on deliberation and communication.

Information provision: for a given condition, contemporaneous, evidence-based information should be provided for each option in sufficient detail, including the risks and benefits, likely outcomes, scientific uncertainties, and probabilities. This information should be presented in a balanced manner to avoid influencing the decision.

Clarification of values: several different methods can be used to enable patients to establish their personal preferences for the different options and how they perceive the relative risks and benefits. Methods include describing what it is like to experience the physical, emotional, or social consequences of a certain harm or benefit if it occurred. Another technique is to use a balance scale to rate the relative degree of personal importance an individual would place on certain outcomes.

Guidance: PDAs are also designed to equip patients with the skills they need to communicate their preferences, uncertainties, and choices to their clinician (O'Connor *et al.*, 2004).

PDAs can be used before, during, or after an initial consultation as deemed appropriate by the clinical situation.

The number of PDAs available has increased dramatically in recent years, with the Department of Health instigating a national programme to increase SDM in the NHS. In 2012 alone, 36 new PDAs were commissioned by Right Care, which is one of the work streams commissioned by the Department of Health as part of the Quality, Innovation, Productivity and Prevention (QIPP) programme (www.rightcare.nhs.uk). Internationally, a global interest has emerged in developing and using PDAs by both not-for-profit and for-profit organisations, thus introducing variability of quality and potential conflicts of interest (Edwards and Elwyn, 2009). The quality of publicly available PDAs has been variable, and thus the need for a set of internationally accepted standards was realised. As a result of this, the International Patient Decision Aids Standards (IPDAS) Collaboration was established in 2003 and developed a quality checklist and instrument for the qualitative and quantitative assessment of PDAs (Elwyn *et al.*, 2006).

A series of Cochrane reviews demonstrated the benefits of using PDAs, including greater knowledge, more accurate risk perceptions, greater comfort with and participation in decision-making, and fewer patients choosing interventions including major and minor surgery (O'Connor *et al.*, 2001, 2003b, 2004, 2009; Stacey *et al.*, 2011). Other possible benefits which are not conclusively proven in the existing literature include reduced care and resource costs and better adherence to treatment regimens (Joosten *et al.*, 2008; Stacey *et al.*, 2011; Veroff *et al.*, 2013).

An important point to bear in mind is that, while PDAs have been proven to enhance SDM, they confer little benefit unless they are accompanied by appropriate support and encouragement on how to use them (Robertson *et al.*, 2011).

4.0.7 The benefits and limitations of SDM

The most common cause of patient dissatisfaction is not being properly informed of their illness or options for care (Grol *et al.*, 2000; Coulter and Cleary, 2001). Evidence has shown that the quality of decisions made in traditional clinical encounters is inadequate, leaving patients uninformed, unsure, and with unrealistic expectations of risks and benefits (O'Connor *et al.*, 2003a). The potential benefits of SDM are numerous and include improved patient knowledge, alignment of care with patients' values, less anxiety, improved self-esteem, improved health outcomes, reduced costs, and less variation in care (Crawford *et al.*, 2002; Légaré *et al.*, 2010; Lee and Emanuel, 2013). Using PDAs in the SDM process further increases the likelihood of obtaining these benefits (Couët *et al.*, 2013). The Health Foundation, which is an independent charity in the UK working to improve the quality of patient care, has suggested that SDM provides a wide range of mutual benefits for patients, clinicians, and organisations (Figure 4.3). In addition to the benefits discussed, advantages may include more structured, satisfying consultations, enhanced self-efficacy, better adherence to and benefits from treatment, better use of clinical skills, personal and professional development for clinicians, improved quality of care (safety, effectiveness, experience), and potentially reduced litigation (Da Silva, 2012). However, not all these benefits have been conclusively proven in all clinical settings and further research is needed (Joonsten *et al.*, 2008). A recent review of the literature commissioned by the Health Foundation suggested that the benefits of SDM have been difficult to prove conclusively to date due to the deficiencies in standardised research methods rather than the real absence of such benefits (Da Silva, 2012).

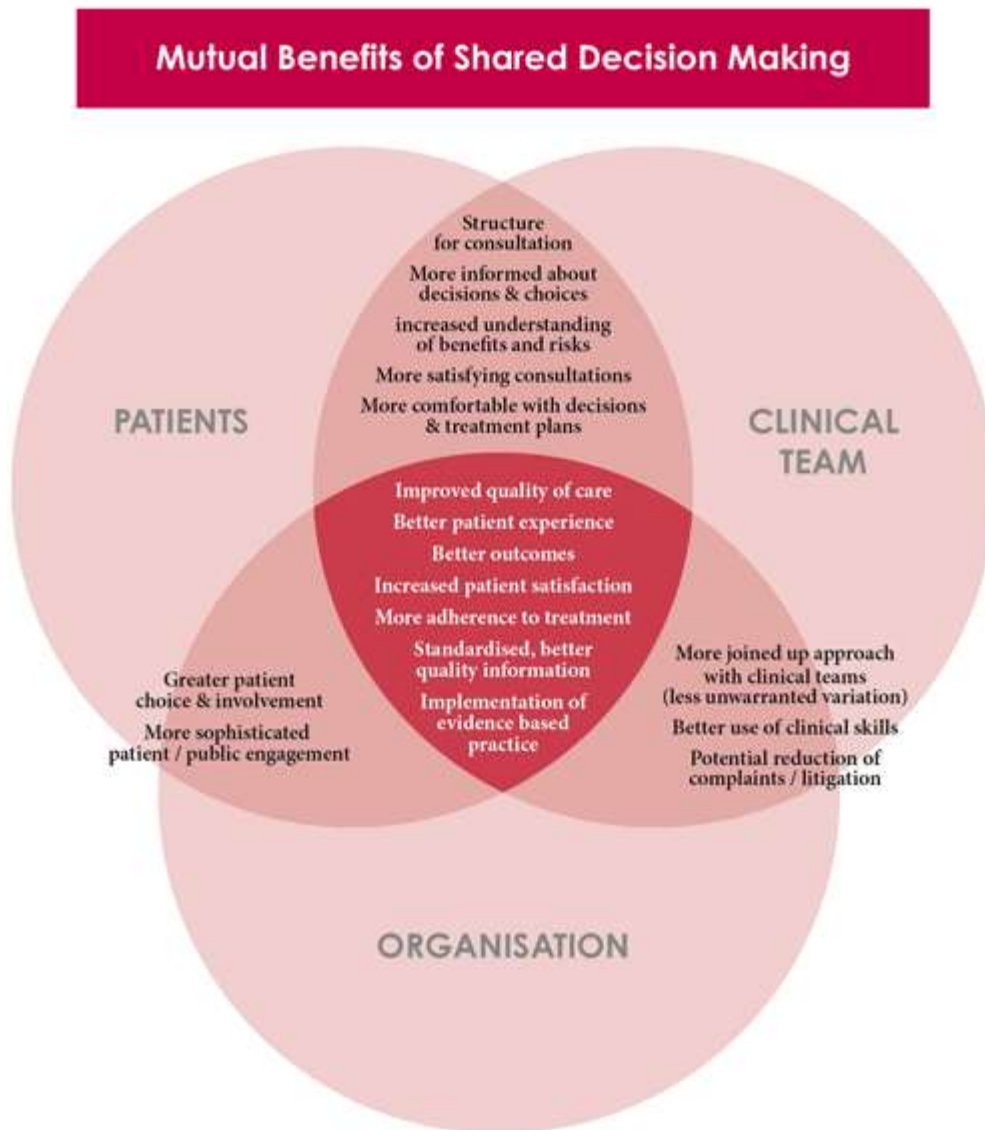


Figure 4.3. Mutual benefits of shared decision-making.

[Reproduced from the Health Foundation (2013) (<http://www.health.org.uk/areas-of-work/programmes/shared-decision-making>)].

The main drawbacks of SDM which have been suggested are that it takes more time to deliver and clinicians are already under time and economic constraints, also that not all patients are suitable for, or want, SDM (Gravel *et al.*, 2006, Légaré *et al.*, 2008). Interestingly, a recent systematic review found that there was no difference in the duration of consultations involving SDM and those which did not (Légaré *et al.*, 2010). However, this review only included two studies and, thus, further research is needed to confirm if this is the case. With regards to the applicability of SDM, clinicians have

been cautioned against screening *a priori* which patients are suitable for, or want to be involved in, SDM as clinicians are often poor judges of patients' personal values and preferences (O'Connor *et al.*, 2007). It has also been suggested that SDM can lead to patient abandonment, with the clinician deferring all responsibility for decision-making to the patient. However, Elwyn and colleagues (2000) highlighted that this should not be the case as SDM involves a partnership, with the patient and clinician jointly deciding on the best course of action. In addition, SDM does not mandate patients to make decisions, after consideration of all the facts, they are still free to defer the decision to the healthcare professional or another significant person if they feel that is appropriate. In fact, research has shown that patients who are initially reluctant to make a decision, change their minds and are happy to once they have been presented with all the options (Van Tol-Geerdink *et al.*, 2006). It is worth noting that the main drawbacks cited are usually based on clinicians' perceptions rather than an evidence base (Murray *et al.*, 2007). Despite the preponderance of benefits of SDM, many clinicians are still not routinely practicing it (Stiggelbout *et al.*, 2012).

4.0.8 How to measure SDM

There are a number of different methods and instruments used to measure SDM, including asking patients and clinicians if they have been involved in SDM, examining patient records for evidence of SDM, and observing clinical encounters to assess the extent of SDM. Due to obvious limitations of some of these methods, a number of structured tools have been developed to increase the reliability of the results (Da Silva, 2012). Scholl and co-workers (2011) carried out a recent systematic review of the instruments currently available for measuring SDM and stated that they could be broadly divided into those that were observer rated and those that were patient and/or clinician rated. Examples include:

- Decisional Conflict Scale (DCS) (O'Connor, 1995),
- OPTION (observing patient involvement) scale (Elwyn *et al.*, 2003),
- SURE (Sure of myself, Understand information, Risk/benefit ratio, Encouragement) scale (Légaré *et al.*, 2010),

- COMRADE scale (Combined Outcome Measure for Risk Communication and Treatment Decision-making Effectiveness) (Edwards *et al.*, 2003), and
- Dyadic OPTION scale (Melbourne *et al.*, 2010).

There is an increasing trend towards developing and using so-called dyadic instruments, which measure SDM from both the clinician's and patient's perspective (Scholl *et al.*, 2011). However, the most commonly used scales are the Decisional Conflict Scale and the OPTION scale (Shared Decision Making Programme, 2012). The DCS is a 16-item, patient rated scale which evaluates decisional uncertainty. Each of the items can be rated on a five-point scale and scores are rescaled to range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). It measures both the process and the outcome of the decision, including satisfaction with the decision, participation in the decision-making, and patient-clinician communication (O'Connor, 1995). However, the scale does not assess if the decision was made in line with the patient's values (Shared Decision Making Programme, 2012).

The OPTION scale is an acronym for 'observing patient involvement' and was designed to measure the extent to which clinicians involve patients in treatment decisions (Appendix 14) (Elwyn *et al.*, 2003). It utilises audio recordings of consultations to assess the clinician's skills and it was designed to assess any type of consultation for any condition, including a first encounter or a review. If there is more than one problem discussed, the rater must decide which is the *index* or main problem and limit the assessment to the rating of that. The competencies which are assessed are problem definition, explanation of choices and equipoise, portrayal of options (including the risks and benefits), and conducting a decision process. The scale includes 12 items of communication behaviour which are rated on a five-point scale (0-4), with 0 indicating that the behaviour or competence was not observed and 4 indicating that the behaviour was observed to a high standard (Table 4.2). Total scores can range from 0 to 48 and are usually standardised by converting to a scale of 0-100. The psychometric properties are acceptable with an inter-rater intra-class correlation coefficient of 0.62 and Cronbach's alpha of 0.79 (Elwyn *et al.*, 2003). Raters should be calibrated in the use of the scale prior to using it. The main drawback is that the scale does not measure the patient's

contribution to the SDM process (Elwyn *et al.*, 2005). Table 4.1 shows the 12 items in the scale and the patient-involving behaviours that they relate to.

Item	Behaviour description	Measures
1	The clinician draws attention to an identified problem as one that requires a decision-making process	Identifying problem
2	The clinician states that there is more than one way to deal with the identified problem ('equipoise')	Explaining equipoise
3	The clinician assesses patient's preferred approach to receiving information to assist decision-making (e.g. discussion in consultations, read printed material, assess graphical data, use videotapes or other media)	Assessing preferred approach
4	The clinician lists 'options', which can include the choice of 'no action'	Listing options
5	The clinician explains the pros and cons of options to the patient (taking 'no action' is an option)	Explaining pros and cons
6	The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed	Exploring expectations
7	The clinician explores the patient's concerns (fears) about how the problem(s) are to be managed	Exploring concerns
8	The clinician checks that the patient has understood the information	Checking understanding
9	The clinician offers the patient explicit opportunities to ask questions during the decision-making process	Offering opportunities for questions
10	The clinician elicits the patient's preferred level of involvement in decision-making	Eliciting preferred involvement
11	The clinician indicates the need for a decision-making (or deferring) stage	Indicating need for decision
12	The clinician indicates the need to review the decision (or deferment)	Indicating need to review/defer

Table 4.1. The competencies measured by each item in the OPTION scale (Couët *et al.*, 2013).

Scale score	Definition
0	The behaviour is not observed
1	A minimal attempt is made to exhibit the behaviour
2	The behaviour is performed at baseline skill level
3	The behaviour is performed to a good standard
4	The behaviour is performed to a high standard

Table 4.2. Scoring guidance for each of the 12 items of the OPTION scale (Elwyn *et al.*, 2005).

4.0.9 Why engage in SDM?

A global seminar was held in Salzburg in 2010 to discuss involving patients in healthcare decisions. The 58 delegates from 18 countries produced the Salzburg Statement on shared decision-making which underlined each clinician's ethical responsibility to engage their patients in shared decision-making (Salzburg Global Seminar, 2011).

Apart from being an ethical imperative, SDM now underpins government legislation. The opening paragraphs of the NHS White Paper, Equity and Excellence: Liberating the NHS (Department of Health, 2010) state that shared decision-making will become the norm in the recently redesigned NHS and the government has adopted the mantra 'no decision about me without me' to signify the importance of patient involvement in all treatment decisions. SDM is one of the core themes of the recent Health and Social Care Act which provides the legislation to allow the principles of the White Paper to be ratified (Department of Health, 2012). Therefore, SDM is now a statutory requirement for the Commissioning Board of the NHS and local Clinical Commissioning Groups (CCGs) (<http://www.rightcare.nhs.uk/index.php/shared-decision-making/>).

A number of national programmes have recently been initiated to promote SDM within healthcare and the NHS nationwide. The Department of Health initiated the Right Care programme in 2011 to maximise value within the NHS. One of the four modules within this is the national Shared Decision Making Programme, which states that SDM is ‘*essential for anyone who provides or receives health services*’ (<http://www.rightcare.nhs.uk/index.php/shared-decision-making/>). The Department of Health QIPP programme incorporates SDM and has commissioned the development of 38 PDAs and telephone support via trained decision coaches within the NHS (<http://www.totallyhealth.com/case-studies/shared-decision-making/>). The latter are NHS nurses with at least 10 years’ experience who have been trained in decision coaching and are available for telephone counselling five days a week. Additionally, MAGIC, which stands for ‘making good decisions in collaboration’, is a programme currently being run by the Health Foundation to explore how SDM can be incorporated into core clinical services (<http://www.health.org.uk/areas-of-work/programmes/shared-decision-making>).

Thus, SDM is both an ethical and a legal obligation, not only at the patient-level of delivery of care, but also at a strategic and commissioning level (<http://www.rightcare.nhs.uk/index.php/shared-decision-making/>).

4.0.10 SDM in orthodontics

The specialty of orthodontics is ideal for the use of SDM as the majority of treatment decisions are elective and involve options (Park *et al.*, 2012). Despite the increased application of SDM in medicine, dentistry has not yet followed to the same extent (Chapple *et al.*, 2003). There is a paucity of evidence of engagement in SDM in dentistry and only a small number of publications considering decision-making (Chapple *et al.*, 2003; Johnson *et al.*, 2006; Bekker *et al.*, 2010; Park *et al.*, 2012). While dentists seem to be aware of the importance of involving patients’ preferences in treatment decisions, previous research has found that dental patients are often not included in decision-making (Kay and Blinkhorn, 1996; Redford and Gift, 1997).

A cross-sectional study conducted in both a hospital and general practice setting in the UK found that dental patients preferred a collaborative decisional role, where the dentist

and the patient had equal responsibility for the decision. However, the same patients perceived themselves as having a passive role in decision-making. Lack of knowledge of dental procedures was one of the reasons given for this passive role (Chapple *et al.*, 2003). However, these publications are over a decade old and the situation may have changed since then.

A small number of PDAs have been developed for use in dentistry. Phillips and co-workers (1995) conducted a trial involving 74 orthognathic patients in which one group of patients was given a standard case presentation involving radiographs and study models and the other was given an additional video simulation prediction of the treatment outcome. A questionnaire was administered two weeks later investigating the important features in making a treatment decision. The video simulation was found to be a useful source of information but did not statistically significantly affect the decision to have surgery. Although, this study did not use a PDA according to the current definition, it did assess decision-making and was included in a recent Cochrane review of decision aids (O'Connor *et al.*, 2009).

Johnson and colleagues (2006) developed and trialled a PDA for patients choosing between endodontic treatment and extraction of a tooth. Results of a randomised controlled trial of 32 patients showed that the group that received the PDA had a small, but statistically significantly higher knowledge of the options. However, there was no difference in satisfaction with the decision-making process or anxiety in either group. Limited conclusions can be drawn from this study due to the fact that the sample was small and underpowered, however, it does highlight a potential benefit of PDAs in conferring information to patients. In addition, the PDA was developed without patient input and did not investigate patients' personal values or preferences.

Recently, Park and co-workers (2012) developed a web-based PDA for preference-sensitive treatment options for dental restorations. The authors developed a hierarchy of treatment option preferences and then developed a web-based application to enable visualisation of evidenced-based treatment options, together with preference-based weights, which included price, longevity of restoration, aesthetics, and convenience. The

PDA remains to be tested clinically, but is a potentially a very useful and novel method of enhancing SDM which could be applied to many clinical scenarios.

Three Dental Chairside Guides (DCGs), which are evidence-based clinical decisional support tools, have been developed by the American Dental Association to support the decision-making process in conjunction with decision counselling (Merijohn *et al.*, 2008). They provide decision assistance and information regarding the application of topical fluoride, the management of early enamel lesions and suspicious dental lesions, and the management of loss of attached gingiva. The effect of these PDAs has not yet been reported.

There is very little research on SDM in orthodontics and there has been a call for more research in this area (Bekker *et al.*, 2010).

4.0.11 Conclusion

It has been said that SDM is both a philosophy and a process which leads to better quality care ensuring that patients receive the ‘*care they need and no less, and the care they want and no more*’ (Mulley, 2011; Da Silva, 2012). However, currently there is minimal evidence that SDM is being routinely conducted in primary care and hospital consultations; despite the fact that healthcare professionals believe they are engaging patients in decisions (Da Silva, 2012). Research suggests that SDM does influence the way patients consider treatment decisions and may impact on outcomes. Numerous studies are currently ongoing within medicine but fewer exist within the field of dentistry and orthodontics. In keeping with the legal and ethical obligation to involve patients as partners in healthcare, it is imperative that clinicians practice shared decision-making and can provide evidence to support this.

4.1 Aims and objectives

4.1.1 Aim

The aim of this study was to measure the extent of shared decision-making in orthognathic treatment consultations.

4.1.2 Objectives

The objective was to use the OPTION scale to independently rate audio-recorded orthognathic consultations to assess the level clinicians engaged patients in healthcare decisions.

4.2 Subjects and methods

4.2.1 Subjects

Ethical and Research and Development approval were granted by the Joint Research and Ethics Committee of University College London Hospitals Foundation Trust approval prior to commencement of the research (MREC reference number: 09/H0719/10; Appendix 6). Written informed consent was obtained from all participants. All participants had been accepted for orthognathic treatment but had not yet commenced pre-surgical orthodontics. Inclusion criteria were any patient undergoing combined orthodontics/orthognathic surgery, aged 16 years and over, and able to give informed consent. Exclusion criteria were patients with congenital craniofacial anomalies, for example, syndromes or clefts of the lip and/or palate, those with acquired facial discrepancies, and patients who had previously received orthognathic treatment.

Participants had previously been seen by an orthodontic consultant within the department for triage and acceptance onto the orthognathic waiting list. Following a period of waiting, patients were allocated to a specified clinician for treatment. Patients were treated by several grades of clinician, including orthodontic trainees (specialty registrars and post-CCST trainees) and consultants. Patients were initially seen by their allocated clinician for pre-treatment records and this was usually conducted over one or two appointments. Patients then attended a group information clinic with other patients and received in-depth information on all aspects of orthognathic treatment, including orthodontics, surgery, psychosocial aspects, and diet and hygiene issues (Ryan *et al.*, 2011). One to two weeks later, patients attended an interdisciplinary orthognathic clinic for an individual consultation with all members of the orthognathic team, including the lead consultant orthodontist, maxillofacial surgeon, consultant liaison psychiatrist, and orthognathic nurse and coordinator (Figure 4.4). Potential participants were recruited for the study as they attended this pre-treatment interdisciplinary Orthognathic Clinic appointment.

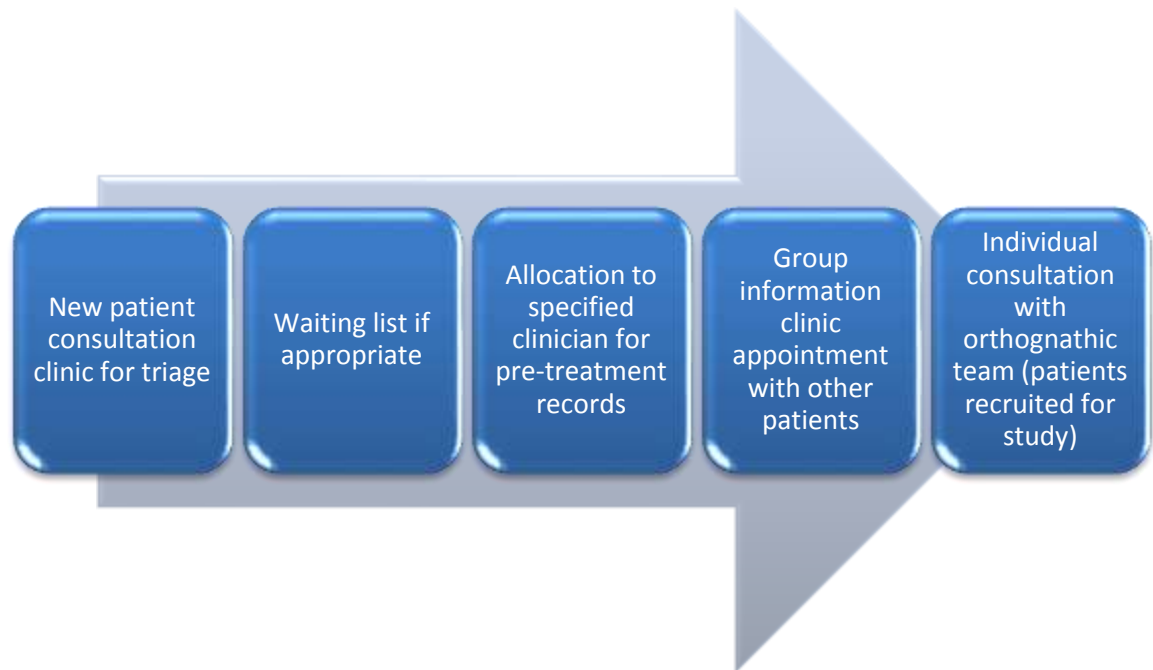


Figure 4.4. Flow diagram of the patient journey from initial assessment to multidisciplinary orthognathic team appointment where individuals were recruited for this study.

4.2.2 Methods

Following obtaining consent from the patients and clinicians involved, the entire consultation was audio recorded on a digital recorder and saved as an audio file. The instrument used to measure the extent of shared decision-making was the OPTION scale (Elwyn *et al.*, 2003). Two raters, who were calibrated and experienced in the use of the scale, independently listened to the audio files and rated the consultations. The raters were researchers involved in the regular use of the OPTION scale under the training and supervision of Professor Elwyn, who developed the scale. They were not involved in the care of any of the patients or present at the consultations and were therefore independent. Calibration involved scoring recordings of test consultations and checking the results against scores achieved by the authors of the scale.

4.2.3 Statistical analysis

Statistical analysis was undertaken using the Statistical Package for Social Sciences (version 19.0; SPSS Inc., Chicago, IL, USA). Demographic data were analysed

descriptively and the data were tested for normality. There were no missing data. All analyses were conducted at the 0.05 level of significance. For the purposes of the rating, all clinicians present at the consultation were considered as 'one' as it was not possible to rate the behaviour of one individual in a multidisciplinary consultation due to the fact that they were all giving relevant information for the same procedure. In addition, it would be difficult for the raters to distinguish between the different clinicians from the audio recording. Therefore, the rating of clinician behaviour was a composite view of all three clinicians together. Data from each of the two raters were entered into SPSS for the 12 items in the OPTION scale for each of the 61 participants. Total scores (range 0-48) from both raters for each individual consultation were summed and divided by two to produce the average score. Scores were then expressed on a scale of 0-100 by dividing by 0.48 and expressed as a percentage. The presence of systematic differences (bias) between the two sets of ratings was examined using *t*-tests. Inter-rater reliability was measured using the intra-class correlation coefficient (ICC).

4.3 Results

4.3.1 Participants and interviews

Sixty one patients consented to participate, 36% (n=22) were male and 64% (n=39) were female. The average age was 26 years. Three members of the orthognathic team were involved in each consultation – a consultant orthodontist, maxillofacial surgeon, and liaison psychiatrist. If one of the core clinicians was not present, patients were not recruited from that clinic for the study. The average consultation length was 12 minutes and 44 seconds, with a range from 2 minutes 33 seconds to 33 minutes 45 seconds.

4.3.2 OPTION scores

A one sample *t*-test of the differences in the total scores awarded by the two raters resulted in a *P*-value of 0.770, indicating no evidence of systematic differences (bias) between the two raters. Regarding random error, inter-observer agreement was reasonable, with an intra-class correlation coefficient (ICC) of 0.794 (95% confidence interval 0.678 to 0.871) between the raters for the total score indicating acceptable inter-rater reliability.

The mean OPTION composite score across the 61 consultations was 22% when converted to a percentage scale (Table 4.3). The worst consultation scored only 3% while the highest ranked consultation achieved 54%. In addition to variation in total composite scores achieved between consultations, there was also marked variation between the performance in the 12 component items, with mean scores (out of 4) ranging from 1.88 (equivalent to 47%) for item 9 down to 0.07 (i.e. 1.6%) for item 10. For all but one of the items, the minimum score was zero, implying that there was always at least one item rated as zero by both observers. The exception was item 5, for which the minimum score of 0.5 indicated that the poorest consultation in this respect was rated 0 by one of the observers and 1 by the other. Only item 9 was ever rated as 4 (the highest standard) by both raters.

Item	Measures	N	Minimum (mean score)	Maximum (mean score)	Mean	Standard deviation
1	Identifying problem	61	0	3.5	1.22	0.96
2	Explaining equipoise	61	0	3.0	0.88	0.89
3	Assessing preferred approach	61	0	1.5	0.17	0.45
4	Listing options	61	0	3.0	0.43	0.70
5	Explaining pros and cons	61	0.5	3.0	1.39	0.62
6	Exploring expectations	61	0	3.0	0.77	0.74
7	Exploring concerns	61	0	3.5	1.16	0.92
8	Checking understanding	61	0	3.5	0.52	0.75
9	Offering opportunities for questions	61	0	4.0	1.88	0.71
10	Eliciting preferred involvement	61	0	1.5	0.07	0.25
11	Indicating need for decision	61	0	3.5	1.16	0.93
12	Indicating need to review/defer	61	0	3.5	0.71	0.91
Total mean		61	1.5	26.0	10.34	5.15
Rescaled %		61	3.13	54.17	21.55	10.73

Table 4.3. Descriptive statistics for each of the OPTION items. [See Table 4.1 for description of the items].

4.4 Discussion

4.4.1 Methods

As indicated in the introduction to this chapter, shared decision-making is an increasingly topical issue in healthcare. SDM has become both an ethical and legal obligation for healthcare professionals and organisations and it is now necessary to engage patients as partners in their treatment decisions and to provide evidence that this is the norm in clinical practice. The specialty of orthodontics lends itself well to SDM as the vast majority of decisions are preference-sensitive, with at least two options available to patients, including the option of doing nothing. Therefore, the process of weighing up the relative risks and benefits is fundamentally important for these patients. With regards to orthognathic treatment, this is especially true. The benefits of orthognathic treatment are generally widespread and include enhanced oral function, better quality of life, and improved self-esteem and confidence (Kiyak *et al.*, 1982a; Hunt *et al.*, 2001; Cunningham *et al.*, 2002; Motegi *et al.*, 2003; Lee *et al.*, 2008; Alanko *et al.*, 2010; Esperão *et al.*, 2010; Murphy *et al.*, 2011; Øland *et al.*, 2011). The risks, although relatively uncommon, are potentially serious and include bleeding, infection, adverse reaction to medications, permanent paraesthesia of the areas supplied by the inferior alveolar nerve, relapse, and rarely death due to general anaesthetic complications (Teltzrow *et al.*, 2005; Kim and Park, 2007; Proffit *et al.*, 2007; Danda and Ravi, 2011; Greenlee *et al.*, 2011; Sousa and Turrini, 2012; Hwang and Choi, 2013; Ianetti *et al.*, 2013; Solano-Hernandez *et al.*, 2013). Some individuals may consider the possibility of a particular adverse consequence unacceptable, regardless of how low the likelihood. While others may consider that their condition is so debilitating, they are prepared to accept the risk. It is also pertinent to consider that facial deformity is largely subjective and the extent of the psychological distress suffered by an individual is frequently not related to the severity of the defect (Baker, 1992; Pruzinsky, 1992; Robinson, 1997, cited in Rumsey *et al.*, 2004). Therefore, the importance of ascertaining individual preferences and values is of paramount importance before deciding to embark

on a course of orthognathic treatment. Shared decision-making has not been investigated with regards to orthognathic treatment to date, thus the impetus for this study.

A number of instruments exist to assess SDM and the OPTION scale was the measure used in this study. This was because it is the most commonly used observer-rated scale and has been administered in a number of clinical situations (Couët *et al.*, 2013). It has been rigorously developed based on literature reviews, qualitative studies, and clinician and patient involvement. It has also been extensively tested and has good psychometric properties (Elwyn *et al.*, 2003). Comparative data exist for a range of clinical scenarios. Despite the fact that a number of similar instruments have been developed since the OPTION scale was first introduced, it remains the only scale to focus solely on behaviours instigated by the clinician (Couët *et al.*, 2013). Clinician behaviour was of interest in this study because this was the area which could potentially be altered in the future as it has been proven that engaging patients in healthcare is a behaviour which can be learned (Légaré *et al.*, 2010). In addition, it is argued that if healthcare professionals do not offer options and promote patient participation, SDM is unlikely to be observed (Elwyn *et al.*, 2005).

However, it is acknowledged that it may be useful in certain circumstances to measure patient participation in SDM in parallel with clinician behaviour. The OPTION scale has recently been amended to include both the patients' and clinicians' own ratings of SDM. This has been called the dyadic OPTION scale (Melbourne *et al.*, 2010). This version of the scale measures patients' and clinicians' perceptions of SDM but had not been developed and published when this study took place.

The OPTION scale was developed for use in consultations with one healthcare professional and one patient, however, it can be used for interdisciplinary consultations, where either one dominant clinician is rated or a composite view of all clinicians combined is incorporated (Edwards and Elwyn, 2009). Indeed, it has been suggested that an interdisciplinary approach to SDM has the potential to enhance the quality of the process and has been cited as the preferred method by some (Edwards and Elwyn, 2009). There has been a call for future research initiatives to explore SDM in multidisciplinary teams and an international research team has recently been introduced

to identify and test measurement tools for SDM in the inter-professional model (Edwards and Elwyn, 2009).

It was decided to involve two independent researchers in the rating of the consultations for a number of reasons. Firstly, the researchers were all members of the orthognathic team and even if they did not take part in the consultation it was felt that they may be biased with respect to the performance of their colleagues. Secondly, the OPTION scale is complex to administer and requires calibration and experience in its use. Therefore, two raters were chosen who were experienced with the scale and were supervised by the author of the scale, Professor Elwyn.

4.4.2 Results

The average length of consultations was 12 minutes 44 seconds. This is similar to the average length of consultations in other studies using the OPTION instrument, where a review of all published studies measuring SDM with the OPTION scale found the average consultation length was 14 minutes (Couët *et al.*, 2013). The majority (64%) of patients in the current study were female, which is consistent with the general demographic of orthognathic patients (O'Brien *et al.*, 2009). In addition, a recent review of studies using OPTION found that the average percentage of female patients in each study was 63%, and it has been found that gender had no effect on scores (Couët *et al.*, 2013). Two independent raters conducted the scoring of the consultations and inter-rater reliability and agreement between them was acceptable.

The average total OPTION score in this study was 21.55% (SD 10.73) (Table 4.3). No cut-off points exist to classify SDM in consultations, however, this is considered to be low, as less than a quarter of shared decision-making behaviours were noted to a good standard on average. This is, however, similar to the average score in other studies using the scale. Couët and colleagues (2013) recently carried out a systematic review of the literature including all published studies between 2001 and 2012 which used the OPTION scale. Thirty three studies met their inclusion criteria and they found an average total OPTION score of 23% (SD 14). This was for consultations where no support intervention, for example PDA, was used. One such study by McKinstry and

colleagues (2010) in the UK assessed 106 consultations conducted by 19 general practitioners covering multiple conditions. The mean OPTION score was 19% (SD 9).

The review also found that, where a support intervention was used, the average OPTION score was 34% (SD 8). A randomised controlled trial in the US comparing the use of a PDA with none assessed 44 diabetes consultations and found a mean OPTION score of 28% (SD 12) in the group who received no PDA and a score of 50% (SD 18) in the group who received the PDA (Nannenga *et al.*, 2009). The authors of the review also noted higher scores for consultations of longer duration (Couët *et al.*, 2013).

In this current study, there was large variation between the different items on the scale, with some performing well and others poorly. Item 9 (offering opportunities for questions) was consistently the item with the highest score. Couët and colleagues (2013) found that item 9 was the second highest scoring item, after item 1 (identifying the problem), and hypothesised that this was because both these behaviours apply to any patient and in any clinical context and thus are most familiar to clinicians. Item 10 (eliciting preferred involvement) and 3 (assessing preferred approach) were the lowest scored items, which is exactly the same as in other studies using the scale. Both of these items assess clinicians tailoring care towards patients' preferences and studies have shown that clinicians do not perform this well (Couët *et al.*, 2013). Eliciting patients' preferences is the crux of SDM and what separates it from traditional decision-making. It has been suggested that healthcare providers frequently misinterpret what patients want and thus it is vital that clinicians go beyond diagnosing a patient's condition and also consider their preferences (Mulley *et al.*, 2012). If patients are receiving care which is not in line with their preferences and values, this could lead to poorer adherence to treatment regimes, poorer outcomes, and reduced satisfaction.

One possible explanation for the low overall score is the unique structure of the clinics at the Eastman Dental Hospital. Immediately prior to the commencement of this study, a new protocol and style of clinic was introduced. This clinic was named the 'Group Information Clinic'. In this clinic, up to 10 patients and their family members/friends attend together and each member of the orthognathic team (orthodontist, maxillofacial surgeon, liaison psychiatrist, and dental hygienist/therapist) speaks to patients about the

different aspects of orthognathic treatment. The intention is to impart general information to the patients in a less threatening environment, where the patients are not outnumbered by clinicians. The introduction of this clinic was in response to a previous audit in the department which found that some patients were uncomfortable by the presence of so many professionals in the multidisciplinary clinic and did not feel sufficiently comfortable to ask questions (Ryan *et al.*, 2011). By introducing the Group Information Clinic, it was also hoped that patients would be more informed of the risks and benefits of treatment by receiving this information on a number of occasions, as research has found that orthodontic patients fail to recall the majority of information provided to them just ten days following consultation (Witt and Bartsch, 1993).

Patients attend the Group Information Clinic following a new patient assessment on a consultation clinic and one to two appointments for diagnostic orthodontic records (Figure 4.4). Thus, the details of orthognathic treatment have been discussed with each individual on several occasions, together with the risks and benefits. At the initial new patient consultation, the diagnosis of dentofacial deformity is discussed, together with an outline of the treatment options available, including no treatment. An overview of the orthognathic treatment process, together with the risks and benefits is given. Patients are then only placed on the waiting list if they indicate that they wish to consider orthognathic treatment. Once individuals come to the top of the waiting list they are allocated to a specified clinician for collection of pre-treatment records and at this point further details of the treatment are discussed in more detail. Patients then attend the Group Information Clinic, together with other patients, where they receive general information about pre- and post-surgical orthodontic treatment, orthognathic surgery, psychological implications, and dietary and hygiene issues. Finally, patients attend the multidisciplinary orthognathic clinic for an individual consultation with the team. If patients still wish to proceed with treatment following this pathway, they are seen by their specified clinician for the consent process.

Thus, it is possible that when patients finally came to their individual consultation with the orthognathic team, which was rated for the purposes of the study, it was assumed that they had received much of the information regarding the options, risks, and benefits,

and this was not then repeated. Also, it may have been assumed that they had already made the decision to proceed with treatment, as this was usually checked at several points prior to this stage.

To overcome this problem, the initial consultation on the new patient referral clinic could have been rated, prior to the patient being placed on the waiting list. However, this study was part of a wider research programme investigating the psychosocial aspects of orthognathic treatment, and it was only possible to recruit patients on the orthognathic clinic. In addition, when the research started, the Group Information Clinic was not in place, and thus it was assumed that the individual orthognathic consultation would be the first time the patient met the orthognathic team and was appropriate for rating.

There was also wide variation in SDM between different consultations, with some items scoring the maximum of 4 on some occasions, but scoring 0 on others. This could be related to a number of factors. SDM does not rely solely on the clinician's behaviour and patients also have a role to play. It may be that some patients did not engage in the process as readily as others despite clinicians' attempts.

Regardless of these considerations, it is reasonable to expect clinicians to demonstrate SDM skills at each consultation up until the stage that the patient makes their final decision. In fact, it could be argued that due to the fact that informed consent is an on-going procedure, a patient's knowledge and comfort with their treatment decisions should be checked on a regular basis, especially for long-term treatment or chronic conditions (General Medical Council, 2013).

It has been shown that implementation of support interventions for SDM, including patient decision aids, and training in SDM techniques improve OPTION scores (Couët *et al.*, 2013). However, no PDA currently exists for orthognathic treatment. Additional training in SDM could be provided to all members of a clinical team, especially in the area of ascertaining patient preferences.

It may be considered to be more appropriate to measure SDM from the patients' perspective rather than through an independent external rating, as, interestingly, there is evidence that there is little agreement between patients' ratings and observer ratings of SDM (Wunderlich *et al.*, 2010; Kasper *et al.*, 2011). However, although it is important

to ascertain patients' perceptions of SDM, it may not be useful on a service level as it could be considered to be less subjective and not an accurate reflection of the degree of involvement. Paradoxically, it has been found that the fewer options that are presented to patients, the more involved they feel in decision-making (Martin *et al.*, 2003).

In common with most areas of healthcare, it seems that, although the concept of SDM is feasible, it is harder to implement and truly measure in practice (Couët *et al.*, 2013).

4.4.3 Recommendations for future research

This research should be replicated in other units where there is no initial Group Information Clinic, to remove the effect of this clinic on SDM.

Ideally, this cohort of patients should be followed up prospectively to assess the effect of SDM on the treatment process and outcomes.

As administering a support tool has been proven to enhance SDM, future research should be focused on developing a PDA for orthognathic treatment. This should utilise qualitative methodology to incorporate patients' perspectives on what is important to them in making this treatment decision. Consideration should also be given to developing a condition-specific instrument for assessing SDM in orthognathic consultations.

4.4.4 Conclusions

Shared decision-making is an ethical and legal obligation for all healthcare providers in the UK. SDM has proven benefits for patients and, generally, clinicians want to engage their patients as partners in decision-making. However, there is still a chasm between the theory of SDM and actual implementation in day-to-day clinical practice, which is supported by this study. This is the first study formally investigating SDM in the field of orthodontics to the researcher's knowledge but the results are similar to those in other disciplines of healthcare. This study has highlighted the difficulty in assessing SDM in clinical care pathways, where information is often repeated numerous times. The key to improving SDM lies in training and the development of condition-specific support interventions and these are areas for future research. In order to better engage in SDM, clinicians, patients, and organisations need to be aware of their mutual responsibilities.

Shared decision-making is complex, both conceptually and in terms of implementation and research, however, it is a process that is rewarding for all involved.

Conclusions: Psychological aspects of
dentofacial discrepancy and
orthognathic treatment – conclusions
from this research



Conclusions from this research

This research project investigated a range of psychological aspects of dentofacial deformity and orthognathic treatment including pre-treatment psychological and psychosocial characteristics, impact, motivations, and expectations in relation to treatment, and orthognathic patient involvement in treatment decision-making. Both quantitative and qualitative methodologies have been utilised in order to increase the evidence base in a clinically useful manner. However, although many pertinent questions have been answered, many enigmas still remain to be resolved, including how to identify those individuals with dentofacial deformity who will not be satisfied with the results of orthognathic treatment. Longitudinal research aimed at following these patients through to completion of treatment and beyond would be useful in determining if the factors investigated in this study are pivotal to overall satisfaction with treatment outcomes. However, the answer of how to accurately predict those patients who will be satisfied may remain elusive as it is impossible to account for all possible confounding variables, even when employing the highest levels of research techniques.

It can be concluded from this research that individuals with dentofacial deformity are a distinct psychological population with significant differences from normative samples for a number of traits, including social anxiety, personality, body image, appearance related concern, and quality of life. In addition, the range of impacts, motivations, and expectations of these individuals is complex and not necessarily evident on initial examination. While clinicians cannot influence the inherent psychological characteristics of orthognathic patients or the reasons why they pursue treatment and what they hope to obtain from it, they can take steps to identify these factors and account for them in the initial treatment planning stages. Alternative management strategies to compliment, or sometimes replace, physical treatment may be beneficial, such as counselling or other forms of psychological intervention. In addition, involving patients more in the treatment decision process may improve outcomes and this research has shown that there is scope to improve this aspect of care.

Therefore, to conclude this thesis, the key to providing the best possible holistic care for orthognathic patients lies in understanding the full range of influencing factors. While it may be impossible to ever answer all the questions, it is vitally important to strive to achieve that goal and each piece of well-conducted research brings us a step closer.

Appendices

Appendix 1. Letter of funding from the British Orthodontic Society Foundation.



Appendix 2. Letter of funding from the European Orthodontic Society.



Flat 20, 49 Hallam Street
London W1W 6JN
England

Tel/Fax: +44 (0) 20 7637 0367
Fax: +44 (0) 20 7323 0410
E-mail: eoslondon@aol.com
Web: www.eoseurope.org

Dr F Ryan
Department of Orthodontics
UCL Eastman Dental Institute
256 Grays Inn Road
London WC1X 8LD

16 May 2011

Dear Dr Ryan

A COMPARISON OF FEAR OF NEGATIVE EVALUATION IN ORTHOGNATHIC PATIENTS AND THE GENERAL POPULATION

Many thanks for your recent grant submission to the European Orthodontic Society.

I am pleased to be able to inform you that your application was accepted for funding by the Grants Committee and you have been awarded a grant of £16,320.00, subject to the conditions set out in the enclosed form, which I should be grateful if you would sign and return. I should also be grateful if you would download and complete the 'Terms and Conditions of Grant Awards' from the EOS website. In accepting this offer, please can I remind you of the following clause in the agreement that you signed:

Publications:

The applicant should submit **at least one paper** related to the subject of the funded research project to the European Journal of Orthodontics. All publications resulting from research sponsored by EOS Grants shall give the credit in the Acknowledgements."

I would like to wish you all the very best with your research and we look forward to reading the results in the Journal in due course.

With very best wishes.

Yours sincerely



Susan Cunningham
Chair, EOS Grants Committee

President: Professor N Ervendi; President Elect: Professor D Suárez Quintanilla
Honorary Secretary: Dr. S Cunningham; Honorary Treasurer: Professor A Zentner

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Appendix 3. Letter of funding from the Royal College of Surgeons.



Faculty of Dental Surgery
The Royal College of Surgeons of England
35-43 Lincoln's Inn Fields
London WC2A 3PE
www.rcseng.ac.uk/fds

Ms Fiona Ryan
149 Chatsworth Court
Pembroke Road
London
W8 6DN

11 April 2011

Dear Ms Ryan

Re: Faculty of Dental Surgery Small Grant Scheme (£7,500)

I am pleased to inform you that your application for a Faculty of Dental Surgery grant has been successful.

The Small Grants Scheme is designed to meet research consumables costs for new or existing projects. The grant will be paid upon receipt of an invoice from your host institution.

Please let me know when your research will commence. The Faculty will require an end of research report when the project is finished, but we will remind you nearer the time.


Congratulations and good luck.

Yours sincerely

A black rectangular box redacting the signature of Miss Erinn Middleton.

Miss Erinn Middleton
Faculty of Dental Surgery

Appendix 6. UCLH MREC Ethical and Research and Development approval.



National Research Ethics Service

The Joint UCL/UCLH Committees on the Ethics of Human Research (Committee Alpha)

ICH R&D office, 1st Floor
3 Long Yard
London
Tel: 020 7599 4130
Fax: 020 7599 4138
Website: <http://www.nres.npsa.nhs.uk/index.htm>
WC1N 3LU

Telephone: 020 7599 4130
Facsimile: 020 7599 4138

17 April 2009

Miss Fiona Ryan
Academic Specialist Registrar/FTTA
University College London NHS Foundation Trust
Department of Orthodontics
Eastman Dental Institute
256 Gray's Inn Road
WC1X8LD

Dear Miss Ryan

Full title of study: **A longitudinal study of outcomes of orthognathic treatment**

REC reference number: **09/H0715/10**

Thank you for your letter of 10 March 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 09 April 2009. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

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

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

This Research Ethics Committee is an advisory committee to London 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

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
CV Dr Susan Cunningham		
CV Dr Justin Shute		
Questionnaire: Orthognographic Quality of life questionnaire		
Questionnaire: Derriford Appearance scale DAS 24		01 January 1996
Questionnaire: OPTION Observing patient involvement		01 June 2004
Questionnaire: Hospital anxiety and depression scale		
Summary/Synopsis		05 January 2009
Covering Letter		
Protocol	1	22 December 2008
Investigator CV		
Application		05 January 2009
Questionnaire: Satisfaction with orthognathic Surgery outcomes		
Questionnaire: BDD Interview questions		
Questionnaire: Brief fear of negative evaluation scale		01 January 1983
Questionnaire: Body dismorphic disorder modification of the Y-BOCS	Adult	01 January 1997
Response to Request for Further Information		10 March 2009
Participant Consent Form	2	10 March 2009
Participant Information Sheet: leaflet code 1		03 March 2009
Participant Information Sheet: leaflet code 2		03 March 2009
Statistician Comments		04 March 2009

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 Website > After Review

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
- 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.

09/H0715/10 Please quote this number on all correspondence

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

Yours sincerely



**Mrs Patricia Orwell
Chair**

Email: Tom.Lucas@ich.ucl.ac.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: Mr Philip Diamond
R&D office for UCLH*

The Joint UCL/UCLH Committees on the Ethics of Human Research (Committee Alpha) Attendance at Sub-Committee of the REC meeting on 09 April 2009

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Larissa Kerecuk	Paediatric Nephrologist	Yes	
Mrs Patricia Orwell		Yes	



University College London Hospitals 
NHS Foundation Trust

Joint UCLH/UCL Biomedical Research (R&D) Unit
Professor Monty Mythen

Office Location:
1st Floor Maple House
149 Tottenham Court Road
London W1T 7DN

Postal Address:
Rosenheim Wing, Ground Floor
25 Grafton Way
London, WC1E 5DB

Email: philip.diamond@uclh.nhs.uk Tel: 020 7380 9833 Fax: 020 7380 9937 Web-site: www.uclh.nhs.uk

09 March 2009

Miss F Ryan
Department of Orthodontics
EDH

Dear Miss Ryan,

Project ID: 09/0002 (*Please quote in all correspondence*)
Title: A longitudinal study of outcomes of orthognathic treatment

Thank you for registering the above study with the UCLH/UCL Biomedical Research Unit. I am pleased to give the approval of UCL Hospitals NHS Foundation Trust for the study to proceed.

You will be aware that as principal investigator you have various responsibilities under the Department of Health's *Research Governance Framework for Health and Social Care*. Please note that you are required:

- to comply with the UCLH Information Security Policy (the data protection toolkit "Consent and Security" will help you meet the requirements of the Data Protection Act and is available at <http://www.uclh.nhs.uk/services/research/>).
- to ensure that any co-investigator who is not an employee of UCLH has in place an up-to-date honorary contract.
- to keep copies of all consent forms with your project documentation. UCLH carries out audits of informed consent and if your project is selected for audit, you will need to provide access to the consent forms.
- To use an investigator file to store all the documentation relating to this research project (the attached list of headings is designed to help you assemble your investigator file).

This approval is conditional upon you having addressed any outstanding issues raised by the research ethics committee (REC) and having full ethical approval in place for the project. You should also be aware that your REC approval requires that you comply with all the requirements of the ethics committee regarding progress reports, notification of protocol amendments and adverse event reporting.

This approval is awarded on the basis of all the project documents you included in your submission to the UCLH/UCL Biomedical Research Unit, including any research agreements or contracts. In the event that the terms of any research contracts or agreements change or a new contract is issued this approval may be invalidated while the terms of the contract are negotiated.




Yours sincerely

Professor Monty Mythen
Director of R&D, UCL Hospitals NHS Foundation Trust



UCL Hospitals is an NHS Foundation Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, Hospital for Tropical Diseases, The National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.

Appendix 7. Patient information leaflets.

<p>Contact details</p> <p>Ms Fiona Ryan, Dr Susan Cunningham, Dr Justin Shute</p> <p>Tel: 020 7915 1064 Department of Orthodontics The Eastman Dental Hospital and Institute 256 Gray's Inn Road London WC1X 8LD fiona.ryan@eastman.ucl.ac.uk Website: www.ucl.nhs.uk</p> <p>UCL Hospitals cannot accept responsibility for information provided by external organisations.</p> 	<p>If you need a large print, audio or translated copy of this document, please contact us on 02079151064. We will try our best to meet your needs.</p> <p>If you wish to discuss this study with a member of the research team or an independent expert who is not part of the research team, please ask Ms Ryan or your orthodontist.</p> <p>Thank you for taking the time to read this leaflet.</p> <p><small>Publication date: 22.12.2008 Date last reviewed: 22.12.2008 Leaflet code: 1 Version number: 1 © University College London Hospitals NHS Foundation Trust</small></p>	<p>University College London Hospitals  <small>NHS Foundation Trust</small></p> <h3>A longitudinal study of outcomes of orthognathic treatment</h3> <p>Patient Information Leaflet</p> 
<p>Invitation</p> <p>You are being invited to take part in a research study. Before you decide, it is important you know why the research is being done and what it would involve from you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.</p> <p>What is the purpose of the study?</p> <ol style="list-style-type: none"> 1. You may be about to embark on a course of orthognathic treatment (braces and jaw surgery). 2. Past research has shown us that 5-10% of patients will be less than happy with the outcome of their treatment. 3. We are very interested in finding out why this is the case as there is no research to explain it clearly. 4. It may be associated with certain characteristics or personality traits and we will be investigating this. <p>Why have I been invited?</p> <p>You have been invited to participate because you have been offered orthognathic treatment to correct your bite and your jaw relationship.</p> <p>Do I have to take part?</p> <p>No. It is up to you to decide. If you do decide to participate we will ask you to sign a consent form. If you change your mind, you are free to withdraw at any time, without giving a reason. The standard of care you receive will not be affected in any way.</p> <p><small>Page 1 of 5</small></p>	<p>What will happen to me if I take part?</p> <p>We will ask you participate in an informal interview where Ms Ryan will ask you about your expectations of treatment, your motivations for having treatment, and ways in which you found out about this type of treatment and other related topics. This should take between 10-60 minutes depending on how much you wish to say. There are no right or wrong answers, we are just interested in your opinions. These will then be used to develop a questionnaire. You will not be required to do anything else.</p> <p>What are the possible disadvantages or risks of taking part?</p> <p>There are no risks anticipated. We are not expecting any of your answers to affect your treatment in any way. However, if any concerns arise we can arrange support or appropriate referral.</p> <p>What are the possible benefits?</p> <p>We cannot promise the study will help you directly but the information we get from this study will help improve treatment of other orthognathic patients. We also hope it will allow you to reflect on your own motivations for treatment and experiences.</p> <p><small>Page 2 of 5</small></p>	<p>What will happen with the results of the study?</p> <p>We hope to publish the results of the study on completion. All confidential information will be coded and you will not be identifiable in any way.</p> <p>Will my taking part in the study remain confidential?</p> <p>Yes. All information that is collected about you during the course of the research will remain strictly confidential and will be available only to the investigators named on this sheet. The safety and security of the data will be the responsibility of the principal investigator (Ms Ryan). The data held about you will include the results of the interview and also your age and gender (male or female). This information will be coded in such a way that it is completely anonymous and you cannot be individually identified in any way.</p> <p>Who has reviewed the study?</p> <p>All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Joint Research Ethics Committee. If you would like to see a summary of the findings from the study when it is completed, please tell Ms Ryan or any of the other Orthodontists involved in your treatment.</p> <p><small>Page 3 of 5</small></p>

Contact details

**Ms Fiona Ryan, Dr Susan Cunningham,
Dr Justin Shute**

Tel: 020 7915 1064
Department of Orthodontics
The Eastman Dental Hospital and Institute
256 Gray's Inn Road
London
WC1X 8LD
fiona.ryan@eastman.ucl.ac.uk
Website: www.ucl.nhs.uk

UCL Hospitals cannot accept responsibility for information provided by external organisations.

UCL HOSPITALS

If you need a large print, audio or translated copy of this document, please contact us on 02079151064. We will try our best to meet your needs.

If you wish to discuss this study with a member of the research team or an independent expert who is not part of the research team, please ask Ms Ryan or your orthodontist.

Thank you for taking the time to read this leaflet.

Publication date: 22.12.2009
Date last reviewed: 22.12.2009
Leaflet code: 2
Version number: 1

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University College London Hospitals **NHS**
NHS Foundation Trust

A longitudinal study of outcomes of orthognathic treatment
Patient Information Leaflet



Invitation

You are being invited to take part in a research study. Before you decide, it is important you know why the research is being done and what it would involve from you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

1. You may be about to embark on a course of orthognathic treatment (braces and jaw surgery)
2. Past research has shown us that 5-10% of patients will be less than completely happy with the outcome of their treatment.
3. We are very interested in finding out why this is the case as there is no research to explain it clearly.
4. It may be associated with certain characteristics or personality traits and we will be investigating this.

Why have I been invited?

You have been invited to participate because you have been offered orthognathic treatment to correct your bite and your jaw relationship.

Do I have to take part?

No. It is up to you to decide. If you do decide to participate we will ask you to sign a consent form. If you change your mind, you are free to withdraw at any time, without giving a reason. The standards of care you receive will not be affected in any way.

What will happen to me if I take part?

We will ask you to complete a series of questionnaires at 5 different time-points through-out your treatment asking about your expectations of treatment, your motivations for having treatment, and ways in which you found out about this type of treatment, how the treatment has affected you, and how you would rate the results. We will also ask specific questions about your personality traits and psychological characteristics. This should take between 40-60 minutes each time. You will not be required to do anything else.

What are the possible disadvantages or risks of taking part?

There are no risks anticipated. We are not expecting any of your answers to affect your treatment in any way. However, if any concerns arise we can arrange support or referral where needed.

What are the possible benefits?

We cannot promise the study will help you directly but the information we get from this study will help improve treatment of other orthognathic patients. We also hope it will allow you to reflect on your own motivations and experiences.

What will happen with the results of the study?

We hope to publish the results of the study on completion. All confidential information will be coded and you will not be identifiable in any way.

Will my taking part in the study remain confidential?

Yes. All information that is collected about you during the course of the research will remain strictly confidential and will be available only to the investigators named on this sheet. The safety and security of the data will be the responsibility of the principal investigator (Ms Ryan). The data held about you will include the results of the questionnaires and also your age and gender (male or female). This information will be coded in such a way that it is completely anonymous and you cannot be individually identified in any way.

Who has reviewed the study?


All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Joint Research Ethics Committee. If you would like to see a summary of the findings from the study when it is completed, please tell Ms Ryan or any of the other Orthodontists involved in your treatment.

Page 1 of 5

Page 2 of 5

Page 3 of 5

Appendix 8. Consent form.

University College London Hospitals 

NHS Foundation Trust

Department of Orthodontics
 The Eastman Dental Hospital and Institute,
 256 Gray's Inn Road, London, WC1X 8LD.
 Website: www.uclh.nhs.uk

Patient Identification Number for this study:

UCLH Project ID number:
Form version: 1 (22/12/08)

CONSENT FORM

Title of project: A longitudinal study of outcomes of orthognathic treatment.

Name of Principal investigator: Fiona Ryan

Please initial box

1. I confirm that I have read and understood the information sheet dated 22/12/2008 (version 1) for the above study and have had the opportunity to ask questions.
2. I confirm that I have had sufficient time to consider whether or not want to be included in the study.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
4. I understand that sections of any of my medical notes may be looked at by responsible individuals from the research team or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
5. I agree to take part in the above study.

Continued on next page/

Page 1 of 2

Department of Orthodontics
 The Eastman Dental Hospital and Institute,
 256 Gray's Inn Road, London, WC1X 8LD
 Website: www.uclh.nhs.uk

Patient Identification Number for this study:

UCLH Project ID number:
 Form version: 1 (22/12/08)

CONSENT FORM

Title of project: A longitudinal study of outcomes of orthognathic treatment.

Name of Principal Investigator: Fiona Ryan

 Name of patient Date Signature

 Name of Person taking consent
 (if different from researcher) Date Signature

 Researcher (to be contacted
 if there are any problems) Date Signature

Statement of interpreter (where appropriate)

I have interpreted the information above to the patient to the best of my ability and in a way in which I believe s/he can understand.

Signed Date


Name (PRINT)

Comments or concerns during the study


If you have any questions, comments, or concerns you may discuss these with a member of the research team. If you wish to talk to someone independent and who is not involved in the research, you may speak to any of the clinicians in the orthodontic department. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write to or get in touch with the Complaints Manager, UCL hospitals or the Patient Advice and Liaison Service (PALS). Please quote the UCLH project number at the top this consent form.

Appendix 9. Booklet of questionnaires used in Chapter 1.

EASTMAN DENTAL INSTITUTE AND HOSPITAL
ORTHODONTIC UNIT



Survey of Orthognathic Patients




Thank you for taking the time to fill out this questionnaire.


It is designed to find out about your personality and the factors which have motivated you to undergo this treatment.

The questionnaire is divided into 5 different sections. Each section has instructions on how to complete it. Please complete **ALL** sections fully.

Your responses are completely **confidential**. There are no right or wrong answers; we are just interested in your opinion.

Taking part in this survey will **NOT** affect your current or future care in any way.

University College London Hospitals 
NHS Foundation Trust

Mayday Healthcare 
NHS Trust

Questionnaire 1: HADS

This questionnaire is designed to help your clinician to know how you feel.

Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long, thought-out response.

I feel tense or 'wound up'

Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy

Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I can laugh and see the funny side of things

As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind

A great deal of the time
A lot of the time
Not too often
Very little

I feel cheerful

Never
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed

Definitely
Usually
Not often
Not at all

I feel as if I am slowed down

Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance

Definitely
I don't take as much care as I should
I may not take as much care
I take just as much care as ever

I feel restless as if I have to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things

As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic

Very often indeed
Quite often
Not very often
Not at all

I can enjoy a good book or radio or television programme

Often
Sometimes
Not often
Very seldom

Questionnaire 2: DAS 24

The Derriford Appearance Scale

This questionnaire is concerned with how you feel about your appearance

The first part of the scale is designed to find out if you are sensitive or self-conscious about any aspect of your appearance (even if this is not usually visible to others).

- (a) Is there any aspect of your appearance (however small) that concerns you at all?

Yes / No

If No, please turn to the next page

If Yes, please continue:

- (b) The aspect of my appearance about which I am most sensitive or self-conscious is

.....

From now on, we will refer to this aspect of your appearance as your 'feature'

- (c) The thing I don't like about my feature is

.....

- (d) If you are sensitive or concerned about any other features of your body or your appearance, please say what they are

.....

Please turn over

©1996. A.T. Carr & D.L. Harris

Instructions: The following questions are concerned with the way you feel or act. They are all simple. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (not applicable option). Don't spend long on any one question.

- a. **How confident do you feel?**
Not at all Slightly Moderately Extremely
- b. **How distressed do you get when you see yourself in the mirror/window?**
Extremely Moderately.... A Little Not at all Distressed
- c. **My self-consciousness makes me irritable at home:**
N/A Never/Almost never Sometimes Often Almost always
- d. **How hurt do you feel?**
Extremely Moderately Slightly Not at all
- e. **At present my self-consciousness has an adverse effect on my work:**
Almost always Often Sometimes Never/almost never N/A
- f. **How distressed do you get when you go to the beach?**
N/A Not at all A little Moderately Extremely
- g. **Other people mis-judge me because of my feature:**
Almost always Often Sometimes Never/almost never N/A
- h. **How feminine/masculine do you feel?**
Not at all Slightly Moderately Extremely
- i. **I am self-conscious of my feature:**
N/A Never/ Almost never Sometimes Often Almost always
- j. **How irritable do you feel?**
Not at all Slightly Moderately Extremely
- k. **I adopt certain gestures (e.g. folding my arms in front of other people, covering my mouth with my hand):**
Never/almost never Sometimes Often Almost always ...
- l. **I avoid communal changing rooms:**
Almost always Often Sometimes....Never/almost never N/A

m. **How distressed do you get by shopping in department stores/supermarkets?**

N/A Not at all Slightly Moderately Extremely

n. **How rejected do you feel?**

Not at all Slightly Moderately Extremely

o. **I avoid undressing in front of my partner:**

N/A Never/almost never Sometimes Often Almost always

p. **How distressed do you get while playing sports/games?**

Extremely Moderately Slightly Not at all N/A

q. **I close into my shell:**

Almost always Often Sometimes.... Never/Almost never

r. **How distressed are you by being unable to wear your favourite clothes?**

Extremely Moderately Slightly Not at all N/A

s. **How distressed do you get when going to social events?**

N/A Not at all Moderately A fair amount Extremely

t. **How normal do you feel?**

Not at all Slightly Moderately Extremely

u. **At present my self-consciousness has an adverse effect on my sex life:**

Almost always Often Sometimes.... Never/almost never N/A

v. **I avoid going out of the house:**

Almost always Often Sometimes.... Never/almost never

w. **How distressed do you get when other people make remarks about your feature?**

N/A Not at all Moderately A fair amount Extremely

x. **I avoid going to pubs/restaurants:**

Almost always Often Sometimes....Never/almost never N/A

y. **My feature causes me physical pain/discomfort :**

Never/almost never Sometimes Often Almost always

z. **My feature limits my physical ability to do the things I want to do:**

Almost always Often Sometimes....Never/ almost never ...

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Questionnaire 3: Neo-FFI

This questionnaire is designed to find out what type of person you are.

Instructions

Carefully read all instructions before beginning. This questionnaire contains 60 statements. Read each statement carefully. For each statement fill in the circle with the response that best represents your opinion. Make sure that your answer is in the correct box.

Circle **SD** if you strongly disagree or the statement is definitely false.

Circle **D** if you disagree or the statement is mostly false.

Circle **N** if you are neutral on the statement, if you cannot decide, or if the statement is about equally true and false.

Circle **A** if you agree or the statement is mostly true.

Circle **SA** if you strongly agree or the statement is definitely true.

For example, if you strongly disagree or believe that a statement is definitely false, you would circle **SD** for that statement.

Example

SD D N A SA

Fill in only **one** response for each statement. Respond to all of the statements, making sure that you fill in the correct response. If you need to change an answer, make an "X" through the incorrect response and then circle the correct response.

Note that the responses are numbered in *rows*.

Please turn over to continue.

1. I am not a worrier
2. I like to have a lot of people around me
3. I don't like to waste my time daydreaming
4. I try to be courteous to everyone I meet
5. I keep my belongings neat and clean

6. I often feel inferior to others
7. I laugh easily
8. Once I find the right way to do something, I stick to it
9. I often get into arguments with my family and co-workers
10. I'm pretty good about pacing myself so as to get things done on time

11. When I'm under a great deal of stress, sometimes I feel like I'm going to pieces
12. I don't consider myself especially "light-hearted"
13. I am intrigued by the patterns I find in art and nature
14. Some people think I'm selfish and egotistical
15. I am not a very methodical person

16. I rarely feel lonely or blue
17. I really enjoy talking to people
18. I believe letting students hear controversial speakers can only confuse and mislead them
19. I would rather cooperate with others than compete with them
20. I try to perform all the tasks assigned to me conscientiously

21. I often feel tense and jittery
22. I like to be where the action is
23. Poetry has little or no effect on me
24. I tend to be cynical and sceptical of others' intentions
25. I have a clear set of goals and work toward them in an orderly fashion

26. Sometimes I feel completely worthless
27. I usually prefer to do things alone
28. I often try new and foreign foods
29. I believe that most people will take advantage of you if you let them
30. I waste a lot of time before settling down to work

31. I rarely feel fearful or anxious
32. I often feel as if I'm bursting with energy
33. I seldom notice the moods of feelings that different environments produce
34. Most people I know like me
35. I work hard to accomplish my goals

36. I often get angry at the way people treat me
37. I am a cheerful, high-spirited person
38. I believe we should look to our religious authorities for decisions on moral issues
39. Some people think of me as cold and calculating
40. When I make a commitment, I can always be counted on to follow through

41. Too often, when things go wrong, I get discouraged and feel like giving up
 42. I am not a cheerful optimist
 43. Sometimes when I am reading poetry or looking at a work of art, I feel a chill or wave of excitement
 44. I'm hard-headed and tough-minded in my attitudes
 45. Sometimes I'm not as dependable or reliable as I should be
46. I am seldom sad or depressed
 47. My life is fast-paced
 48. I have little interest in speculating on the nature of the universe or the human condition
 49. I generally try to be thoughtful and considerate
 50. I am a productive person who always gets the job done
51. I often feel hopeless and want someone else to solve my problems
 52. I am a very active person
 53. I have a lot of intellectual curiosity
 54. If I don't like people, I let them know it
 55. I never seem to be able to get organized
56. At times I have been so ashamed I just wanted to hide
 57. I would rather go my own way than be a leader of others
 58. I often enjoy playing with theories and abstract ideas
 59. If necessary, I am willing to manipulate people to get what I want
 60. I strive for excellence in everything I do

Enter your responses here. Please remember to enter responses *ACROSS* the rows.

SD = Strongly Disagree, D = Disagree, N = Neutral, A = Agree, SA = Strongly Agree

1 SD D N A SA	2 SD D N A SA	3 SD D N A SA	4 SD D N A SA	5 SD D N A SA
6 SD D N A SA	7 SD D N A SA	8 SD D N A SA	9 SD D N A SA	10 SD D N A SA
11 SD D N A SA	12 SD D N A SA	13 SD D N A SA	14 SD D N A SA	15 SD D N A SA
16 SD D N A SA	17 SD D N A SA	18 SD D N A SA	19 SD D N A SA	20 SD D N A SA
21 SD D N A SA	22 SD D N A SA	23 SD D N A SA	24 SD D N A SA	25 SD D N A SA
26 SD D N A SA	27 SD D N A SA	28 SD D N A SA	29 SD D N A SA	30 SD D N A SA
31 SD D N A SA	32 SD D N A SA	33 SD D N A SA	34 SD D N A SA	35 SD D N A SA
36 SD D N A SA	37 SD D N A SA	38 SD D N A SA	39 SD D N A SA	40 SD D N A SA
41 SD D N A SA	42 SD D N A SA	43 SD D N A SA	44 SD D N A SA	45 SD D N A SA
46 SD D N A SA	47 SD D N A SA	48 SD D N A SA	49 SD D N A SA	50 SD D N A SA
51 SD D N A SA	52 SD D N A SA	53 SD D N A SA	54 SD D N A SA	55 SD D N A SA
56 SD D N A SA	57 SD D N A SA	58 SD D N A SA	59 SD D N A SA	60 SD D N A SA

Have you responded to all the statements? Yes___ No___

Have you entered your responses in the correct boxes? Yes___ No___

Have you responded accurately and honestly? Yes___ No___

Questionnaire 4: BIDQ

This questionnaire assesses concerns about physical appearance.

Please read each question carefully and circle the answer that best describes your experience. Also write in answers where indicated.

Are you concerned about the appearance of some part(s) of your body which you consider especially unattractive? (Circle the best answer)

- | | | | | |
|-------------------------|-----------------------|-------------------------|-------------------|------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all
concerned | Somewhat
concerned | Moderately
concerned | Very
concerned | Extremely
concerned |

What are these concerns? What specifically bothers you about the appearance of these body parts?

If you are at least somewhat concerned, do these concerns preoccupy you? That is, you think about them a lot and they're hard to stop thinking about? (Circle the best answer)

- | | | | | |
|---------------------------|-------------------------|---------------------------|---------------------|--------------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all
preoccupied | Somewhat
preoccupied | Moderately
preoccupied | Very
preoccupied | Extremely
preoccupied |

What effect has your preoccupation with your appearance had on your life? (Please describe):

Has your physical "defect" often caused you a lot of distress, torment, or pain? How much? (Circle the best answer)

- | | | | | |
|-------------|---------------------------------|--|--------------------------------|---------------------------|
| 1 | 2 | 3 | 4 | 5 |
| No distress | Mild, and not
too disturbing | Moderate and
disturbing but
still manageable | Severe, and
very disturbing | Extreme, and
disabling |

Has your physical “defect” caused you impairment in social, occupational or other important areas of functioning? How much? (Circle the best answer)

- | | | | | |
|---------------------------|---|---|---|--|
| 1
No limitation | 2
Mild interference
but overall
performance
not impaired | 3
Moderate, definite
interference, but
still manageable | 4
Severe, causes
substantial
impairment | 5
Extreme,
incapacitating |
|---------------------------|---|---|---|--|

Has your physical “defect” significantly interfered with your social life? How much? (Circle the best answer)

- | | | | | |
|-------------------|--------------------------|---------------------------------|-------------------|------------------------|
| 1
Never | 2
Occasionally | 3
Moderately
Often | 4
Often | 5
Very Often |
|-------------------|--------------------------|---------------------------------|-------------------|------------------------|

If so, how?

Has your physical “defect” significantly interfered with your schoolwork, your job, or your ability to function in your role? How much? (Circle the best answer)

- | | | | | |
|-------------------|--------------------------|---------------------------------|-------------------|------------------------|
| 1
Never | 2
Occasionally | 3
Moderately
Often | 4
Often | 5
Very Often |
|-------------------|--------------------------|---------------------------------|-------------------|------------------------|

If so, how?

Do you ever avoid things because of your physical “defect”? How often? (Circle the best answer)

- | | | | | |
|-------------------|--------------------------|---------------------------------|-------------------|------------------------|
| 1
Never | 2
Occasionally | 3
Moderately
Often | 4
Often | 5
Very Often |
|-------------------|--------------------------|---------------------------------|-------------------|------------------------|

If so, what do you avoid?

Questionnaire 5: OQLQ

Please read the following statements carefully. In order to find out how important each of the statements is to you, please **circle** 1, 2, 3, 4 or N/A (not applicable) where:

- 1 means it *bothers you a little*
- 4 means it *bothers you a lot*
- 2+3 lie *between these statements*
- N/A means the statement does not apply to you or does not bother you

	1	2	3	4	
	Bothers you a little			Bothers you a lot	
1. I am self-conscious about the appearance of my teeth	1	2	3	4	N/A
2. I have problems biting	1	2	3	4	N/A
3. I have problems chewing	1	2	3	4	N/A
4. There are some foods I avoid eating because the way my teeth meet makes it difficult	1	2	3	4	N/A
5. I don't like eating in public places	1	2	3	4	N/A
6. I get pains in my face or jaw	1	2	3	4	N/A
7. I don't like seeing a side view of my face (profile)	1	2	3	4	N/A
8. I spend a lot of time studying my face in the mirror	1	2	3	4	N/A
9. I spend a lot of time studying my teeth in the mirror	1	2	3	4	N/A
10. I dislike having my photograph taken	1	2	3	4	N/A
11. I dislike being seen on video	1	2	3	4	N/A
12. I often stare at other people's teeth	1	2	3	4	N/A
13. I often stare at other people's faces	1	2	3	4	N/A
14. I am self-conscious about my facial appearance	1	2	3	4	N/A
15. I try to cover my mouth when I meet people for the first time	1	2	3	4	N/A
16. I worry about meeting people for the first time	1	2	3	4	N/A
17. I worry that people will make hurtful comments about my appearance	1	2	3	4	N/A
18. I lack confidence when I am out socially	1	2	3	4	N/A
19. I do not like smiling when I meet people	1	2	3	4	N/A
20. I sometimes get depressed about my appearance	1	2	3	4	N/A
21. I sometimes think that people are staring at me	1	2	3	4	N/A
22. Comments about my appearance really upset me, even when I know people are only joking	1	2	3	4	N/A

Thank you for taking the time to complete this questionnaire. If you have any queries please contact Fiona Ryan on f.ryan@ucl.ac.uk

Please return it either in person to Fiona Ryan or by mail in the stamped addressed envelope provided to;

**Fiona Ryan,
Department of Orthodontics,
Eastman Dental Institute and Hospital,
256 Gray's Inn Road,
London, WC1X 8LD.**

Appendix 10. Topic guide for in-depth interviews.

Topic guide for in-depth interviews

Aims and objectives:

To investigate and understand the impact of dentofacial deformity and patients' motivations for and expectations of orthognathic treatment.

This will involve exploring in-depth all aspects of these factors and processes.

1. Introduction

Aim: To introduce the research and set the context for the proceeding discussion.

- Introduce self
- Introduce study: who/what it's for, what is it about
- Key points:
 - purpose of interview
 - length of interview
 - voluntary nature and right to withdraw
 - will not affect care
 - reasons for recording the interview
- Confidentiality, and how findings will be reported
- Any questions?

2. Background and personal circumstances

Aim: To introduce respondent.

- Q: What are their personal circumstances at present?
- Age, live alone, activities
- Main daytime activity, working
- What they like to do in their spare time
- Level of education

3. Impact of the problem

Aims: to investigate the nature of the problem which has prompted them to seek treatment and the effects it has on their lives.

- What is the problem in general (in their own words) PROBE FULLY
- What is the physical issue (if any)?
- Are there any other issues?
- What are any associated effects?
- How does it make them feel? PROBE FULLY
- Does it affect anyone else? (family, friends etc.)

4. Motivations for treatment

Aims: to investigate the true motivations for having treatment and to fully explore the reasons for undergoing this treatment.

- What are the reasons for undergoing treatment? (aesthetic, functional, other)
PROBE FULLY
- Whose idea was it?
- Will anyone in their life be affected by the changes?
- How would they feel if they were happy with the results but their (X) wasn't?
- How important is it to have this treatment?

5. Expectations of treatment outcome

Aims: to understand any effect they expect treatment to have on their life.

- What do they expect to get from the treatment?
- Do they expect their life to change in any way? E.g. work, relationships, successes etc. PROBE FULLY
- How will it affect their life? Eg PROBE
-function
-aesthetics
-socially
-strangers
- How soon do they expect to see any changes, if any?
- Do they expect other people to notice the difference? Who?
- How do they expect friends/family to react to the 'new them'?
- How will they feel if these things don't change/happen?
- How would they feel if the result was not what they expected?

6. Other issues

Aim: other issues which arise from interviews can be added here for future questioning if relevant.

Appendix 11. Spread-sheet of framework from analysis of interviews.

Microsoft Excel - Copy of fona framework analysis 11.02.10 appendix version (Compatibility Mode)						
A	B	C	D	E		
1	CHART 2 - IMPACT OF MALOCCLUSION ON PRED					
2	Order	2.1 Initial awareness of problem	2.2 The nature of the problem	2.3 Impact on education	2.4 Impact on relationships (childhood)	2.5
3	P6	First noticed when 12 When she was 10-12 she had problems with delayed eruption of teeth and swollen gums and thinks that may be the cause of the problem now (p3, 156). Her mother pointed this out to her as a child. Thinks the bite was ok at 12 years (p3, 121). New dentist mentioned it recently, hence referral to EDH, however, she did not mention it to her (p2, 81). She was only aware of her teeth and not her jaw being a problem (p2, 144).	The jaw "it feels like it's...pushed out" and that's what causing the teeth not to be properly (p3, 133). However she only initially noticed a problem with her top teeth (p2, 144) which she thought were too big (p3, 146). She thinks they are "sticking out" and look "ridiculous" (p4, 166) and the whole teeth look "deformed" (p4, 179).	She feels like the "mouth has it all" and someone who is good looking with bad teeth is no longer attractive (p2, 236) QQ and the mouth can really let you down. Feels like the beauty either is all in the mouth (p6, 245) QQ. Strives to use it to bring it up in arguments and call her "goody teeth" which used to make her feel hurt (p6, 274). Her mother used to mention it too and say that even though she was beautiful "inside and out" there was no denying that she had a problem with her teeth (p6, 296).	It affects the relationship with her mother and sisters as she always "has this negative sort of side" because she does not believe in herself (p6, 428).	Not disc
4	P7	First noticed when came to UK "People don't notice/care about teeth in Somalia, people 'accept you the way you are'" (p3, 115). A number of factors brought the problem to his attention, the dentist pointed it out and said he should have his teeth checked (p3, 126). Strangers noticed it and he would get funny looks in the street and friends commented on the appearance of his teeth and asked why he didn't do something about them (p3, 130).	Teeth moving forward (p2, 67). The appearance of his teeth - they are forward (p11, 529). Also wants to improve the function (biting) of the teeth but this is a secondary concern. Finds it embarrassing to eat in front of people (p12, 604) and so avoids it. Other people think he is clumsy (P15, 729) because he doesn't smile as he wants to hide his teeth. Feels he is denying himself things because of his fear of rejection and he wants to stop this. Denies himself things. Thinks this is tied up with his teeth - thinks it started with his teeth but now it's because he has lost his confidence (p14, 855) QQ. Has a very lovely life (p17, 823).	It is, as in Somalia appearance is not an issue so he has never aware of a problem with his teeth. Was outgoing before he came to UK.	Hasn't made any friends since coming to the UK because he doesn't feel good enough to be outside and socialise to make friends (p12, 593). Tends to also avoid family gatherings as gets embarrassed smiling and eating in front of people, however family tend not to take too as an answer and force him out (p12, 604) (p13, 609).	Works a lot Control people Avoids 1 Lift high But any he tough is very the kiss
5	P8	She noticed a problem with her face when she was young (12) but thought it was her nose that was the problem and she had a "background" (p1, 14).	Never liked the "place of my jaw" (p3, 140). Main motivation is she wants to change her lower jaw completely - does not like it in profile and	Doesn't feel it held her back much but perhaps had a "small" influence on relationships with boys (p12, 599). No one has ever mentioned it to her (p12, 596).	Feels like there is something wrong with her and when she meets people she hasn't got a leg to stand on and they will look at her face (p13, 516).	Not disc
1	CHART 5 - EXPECTATIONS OF TREATMENT AND OUTCOME					
2	Order	5.1 Effect of treatment on life in general	5.2 Effect of treatment on relationships (new and existing)	5.3 Effect of treatment on employment	5.4 Effect of treatment on confidence	
3	P2	Before when she had braces and her teeth were better she was a different person - more confident and would go out more, talk to more people. She "just changed for the better". She also started losing weight and became more confident (p6, 296) QQ.	Will go out more and smile more - "Thinks that treatment will improve her confidence and 'confidence from looks could give you confidence in all sorts of ways: jobs, friends, relationships'" (p8, 323).	Is hoping for a "better job, definitely" and to go on and become a vet (p8, 316).	Thinks that treatment will improve her confidence a "confidence from looks could give you confidence in all sorts of ways: jobs, friends, relationships" (p8, 323) QQ.	
4	P3	Will have more confidence (p11, 570). The way she look and talks will change (p11, 577). "It will change my life" (p13, 639). She would go out talking to people, showing herself and her hair and everything (p14, 736). Will be the same person, but more confident (p14, 756).	She would go out talking to people, showing herself and her hair and everything (p14, 736).	Doesn't expect it too have a huge impact as she is about "your technical side" (p12, 604) but it would mean that they don't judge her initially on her appearance (p12, 610). In the past she hasn't got the chance to show her skills (p12, 618).	Will have more confidence (p11, 570). She would be the "most confident person" (p14, 74).	
5	P4	Will be more confident speaking in public (p8, 351).	Doesn't like it when people stare at his teeth when he is talking - thinks it may have an effect on how women judge him (p6, 411).	Thinks will perform better in interviews if he speaks more clearly and smiles more (p8, 433).	nd	
6	P5	Thinks will be more confident and smile more and show his teeth more in photos (p7, 329).	Thinks it creates a better first impression to have nice, straight, clean teeth. It show that he looks after himself (p8, 377).	Thinks it creates a better first impression to have nice, straight, clean teeth. It show that he looks after himself (p8, 377).	Thinks will be more confident and smile more and show his teeth more in photos (p7, 329).	
7	P7	Thinks that treatment can change his personality because he will be more happy with himself (p15, 715) QQ. He can show his true personality. He is actually a very "timid" person but hides it. Hopes there will no longer be a need to hide (p15, 767) QQ. Hopes to get off the treadmill of just work home	Will try and be more sociable and more engaging with people (p15, 716).	Not discussed.	Hopes to become more outgoing. Hopes not to have to think twice about doing things. Will stop putting himself down so much (p13, 643) QQ. "Want be so much of a 'trick of myself'".	

Appendix 12. Brief Fear of Negative Evaluation Scale.

The Brief Fear of Negative Evaluation Scale

This questionnaire is designed to assess how concerned you are with what other people think of you.

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

Appendix 13. UCL ethical approval.

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE



Dr Susan Cunningham
Department of Orthodontics
UCL Eastman Dental Hospital
256 Grays Inn Road
London
WC1X 8LD

16 July 2009

Dear Dr Cunningham

Notification of Ethical Approval
Ethics Application: 2035/001: A study of fear of negative evaluation in the adult UK population

I am pleased to confirm that in my capacity as Chair of the UCL Research Ethics Committee, I have approved your project for the duration of the study i.e. until September 2010. However, I would suggest that a couple of sentences should be added to the Participant Information Sheet to explain more fully and in lay terms what fear of negative evaluation means.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events
For non-serious adverse events you will need to inform Ms Helen Dougal, Ethics Committee Administrator (h.dougal@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events
The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an

independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Yours sincerely



Sir John Birch
Chair of the UCL Research Ethics Committee


Cc: Fiona Ryan & Justin Shute, Department of Orthodontics, UCL Eastman Dental Hospital

UCL Research Ethics Committee, c/o The Graduate School, North Cloisters, Wilkins Building
University College London Gower Street London WC1E 6BT
Tel: +44 (0)20 7679 7844 Fax: +44 (0)20 7679 7043
h.dougal@ucl.ac.uk
www.ucl.ac.uk/gradschool

Appendix 14. OPTION scale.

Measuring patient involvement

3. OPTION Observing patient involvement (Research Version)



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Rater Name	Clinician Code	Date of rating	DD	MM	YY
Consultation number					
Consultation duration (m, s)					
Practitioner (M = 1, F = 2)					
Patient (M = 1, F = 2)					
New Consultation					
Review Consultation					
Cospecialist Consultation					
Description of index problem					

#	Description	0	1	2	3	4
1	The clinician draws attention to an identified problem as one that requires a decision making process.					
2	The clinician states that there is more than one way to deal with the identified problem ('equipoise').					
3	The clinician assesses the patient's preferred approach to receiving information to assist decision making (e.g. discussion, reading printed material, assessing graphical data, using videotapes or other media).					
4	The clinician lists 'options', which can include the choice of 'no action'.					
5	The clinician explains the pros and cons of options to the patient (taking 'no action' as an option).					
6	The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed.					
7	The clinician explores the patient's concerns (issues) about how problem(s) are to be managed.					
8	The clinician checks that the patient has understood the information.					
9	The clinician offers the patient explicit opportunities to ask questions during the decision making process.					
10	The clinician elicits the patient's preferred level of involvement in decision-making.					
11	The clinician indicates the need for a decision making (or delivery) stage.					
12	The clinician indicates the need to review the decision (or delivery).					

Score	Description
0	The behaviour is not observed.
1	A minimal attempt is made to exhibit the behaviour.
2	The behaviour is observed and a minimum skill level achieved.
3	The behaviour is exhibited to a good standard.
4	The behaviour is exhibited to a very high standard.

References

Abrahamsson KH , Berggren U, Hallberg L R-M, Carlsson SG (2002)

Ambivalence in Coping with Dental Fear and Avoidance: A Qualitative Study.
J Health Psychol. 7(6):653-664.

Al-Ahmad HT, Al-Sa'di WS, Al-Omari IK, Al-Bitar ZB (2009)

Condition-specific quality of life in Jordanian patients with dentofacial deformities: a comparison of generic and disease-specific measures.
Oral Surg Oral Med Oral Pathol Oral Radiol Endod. 107:49-55.

Alanko OM, Svedström-Oristo AL, Tuomisto MT (2010)

Patients' perceptions of orthognathic treatment, well-being, and psychological or psychiatric status: a systematic review.
Acta Odontol Scand. 68:249-260.

Albino JE (2002)

A psychologist's guide to oral diseases and disorders and their treatment.
Prof Psychol Res Pr. 33:176-182.

Allen PF (2003)

Assessment of oral health related quality of life.
Health Qual Life Outcomes. 1:40.

Allport GW (1961)

Pattern and growth in personality.
New York: Holt, Rinehart and Winston.

Alonso J, Angermeyer MC, Bernert S, Bruffaerts R, Brugha TS, Bryson H, de Girolamo G, Graaf R, Demyttenaere K, Gasquet I, Haro JM, Katz SJ, Kessler RC, Kovess V, Lépine JP, Ormel J, Polidori G, Russo LJ, Vilagut G, Almansa J, Arbabzadeh-Bouchez S, Autonell J, Bernal M, Buist-Bouwman MA, Codony M, Domingo-Salvany A, Ferrer M, Joo SS, Martínez-Alonso M, Matschinger H, Mazzi F, Morgan Z, Morosini P, Palacín C, Romera B, Taub N, Vollebergh WA; ESEMeD/MHEDEA 2000 Investigators, European Study of the Epidemiology of Mental Disorders (ESEMeD) Project (2004)

Disability and quality of life impact of mental disorders in Europe: results from the European Study of the Epidemiology of Mental Disorders (ESEMeD) project.
Acta Psychiatr Scand Suppl. 420:38-46.

American Psychiatric Association (1994)

Diagnostic and Statistical Manual of Mental Disorders (4th ed.).
Washington, DC: American Psychiatric Association.

American Psychiatric Association (2000)

Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.).
Washington, DC: American Psychiatric Association.

Amin K, Clarke A, Sivakumar B, Puri A, Fox Z, Brough V, Denton CP, Peter EM, Butler P (2011)

The psychological impact of facial changes in scleroderma.
Psychol Health Med. 16(3):304-312.

Anderson R (2004)

Patient expectations of emergency dental services: a qualitative interview study.
Br Dent J. 197:331-334.

Anderson R, Thomas DW (2003)

'Toothache stories': a qualitative investigation of why and how people seek emergency dental care.
Community Dent Health. 20(2):106-111.

Aouizerate B, Pujol H, Grabot D, Faytout M, Suire K, Braud C, Auriacombe M, Martin D, Baudet J, Tignol J (2003)

Body dysmorphic disorder in a sample of cosmetic surgery applicants.
Eur Psychiatry. 18:365-368.

Auerbach SM, Meredith J, Alexander JM, Mercuri LG, Brophy C (1984)

Psychological factors in adjustment to orthognathic surgery.
J Oral Maxillofac Surg. 42:435-440.

Bailey V (2001)

Cognitive-behavioural therapies for children and adolescents.
Adv Psychiatr Treat. 7:224-232.

Baker CA (1992)

Factors associated with rehabilitation in head and neck cancer.
Cancer Nurs. 15:395-400.

Baldwin DC (1980)

Appearance and aesthetics in oral health.
Community Dent Oral Epidemiol. 8:244-256.

Baldwin DS, Anderson IM, Nutt DJ, Bandelow B, Bond A, Davidson JR, den Boer JA, Fineberg NA, Knapp M, Scott J, Wittchen HU; British Association for Psychopharmacology (2005)

Evidence-based guidelines for the pharmacological treatment of anxiety disorders: recommendations from the British Association for Psychopharmacology.
J Psychopharmacol. 19(6):567-596.

Barbosa ALB, Marcantonio E, Barbosa CE de M, Gabrielli MAC (1993)

Psychological evaluation of patients scheduled for orthognathic surgery.
J Nihon Univ Sch Dent. 35:1-9.

Barnard M (2012)

Critical Qualitative Theory: Opening up the Black Box of Criminal Justice Interventions.

In: Bowen E, Brown S (editors). Perspectives on Evaluating Criminal Justice and Corrections (Advances in Program Evaluation, Volume 13).

Bingley, UK: Emerald Group Publishing Limited, pp.129-141.

Barry MJ, Edgman-Levitan S (2012)

Shared decision making - pinnacle of patient-centered care.

N Engl J Med. 366(9):780-781.

Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J (1961)

An inventory for measuring depression.

Arch Gen Psychiatry. 4(6):561-571.

Beck JS (2011)

Cognitive Therapy: Basics and Beyond.

New York, NY: The Guilford Press.

Beesdo K, Bittner A, Pine DS, Stein MB, Hofler M, Lieb R, Wittchen H-U (2007)

Incidence of social anxiety disorder and the consistent risk for secondary depression in the first three decades of life.

Arch Gen Psychiatry. 64:903-912.

Bekker HL, Luther F, Buchanan H (2010)

Developments in making patients' orthodontic choices better.

J Orthod. 37(3):217-224.

Berk NW, Cooper ME, Liu YE, Marazita ML (2001)

Social anxiety in Chinese adults with oral-facial clefts.

Cleft Palate Craniofac J. 38(2):126-133.

Bertolini F, Russo V, Sansebastiano G (2000)

Pre- and postsurgical psycho- emotional aspects of the orthognathic surgery patient. Int J Adult Orthod Orthognath Surg. 15:16-23.

Bhalla P, Major PW, Keenan L, Olson K (2007)

Qualitative analysis of the process for selecting graduate orthodontic students in Canada.

J Can Dent Assoc. 73(9):819.

Bjelland I, Dahl AA, Haug TT, Neckelmann D (2002)

The validity of the Hospital Anxiety and Depression Scale. An updated review of the literature.

J Psychosom Res. 52:69-77.

Blanco C, Raza MS, Schneier F, Liebowitz MR (2003)

The evidence based pharmacotherapy of social anxiety disorder.

Int J Neuropsychopharmacol. 6:427-442.

Bower E, Scambler S (2007)

The contributions of qualitative research towards dental public health practice.

Community Dent Oral Epidemiol 35:161-169.

British Association of Oral and Maxillofacial Surgeons (2013)

Commissioning guide for orthognathic procedures.

Retrieved from: <http://www.baoms.org.uk/file.aspx?id=570>

Accessed on: 1/07/2013

Brown L, Alexander J (1991)

Self-esteem index: Examiner's manual.

Austin, TX: Pro-Ed.

Bryman A (2008)

Social Research Methods.

New York: Oxford University Press.

Bull RHC (1990)

Society's Reactions to Facial Disfigurements.

Dent Update. 5:202-205.

Bull R, Rumsey N (1988)

The Social Psychology of Facial Appearance.

New York: Springer-Verlag.

Burden DJ, Hunt O, Johnston CD, Stevenson M, O'Neill C, Hepper P (2010)

Psychological Status of Patients Referred for Orthognathic Correction of Skeletal II and III Discrepancies.

Angle Orthod. 80:43-48.

Butcher JN, Dahlstrom WG, Graham JR, Tellegen A, Kaemmer B (1989)

Manual for the restandardized Minnesota Multiphasic Personality Inventory: MMPI-2.

Minneapolis: University of Minnesota Press.

Byrne P, Long B (1976)

Doctors Talking to Patients.

London: HMSO.

Cadman D, Boyle M, Szatmari P, Offord DR (1987)

Chronic Illness, Disability, and Mental and Social Well-Being: Findings of the Ontario Child Health Study.
Pediatrics. 79(5):805-813.

Cadogan J, Bennun I (2011)

Face value: an exploration of the psychological impact of orthognathic surgery.
Br J Oral Maxillofac Surg. 49(5):376-380.

Caldwell JG (2008)

Evaluating attitudes of first-year residents to shared decision making.
Med Educ Online. 13:10.

Capecchi V (1968)

On the definition of typology and classification in sociology.
Qual Quant. 2(1-2):9-30.

Carleton RN, Collimore KC, McCabe RE, Antony MM (2011)

Addressing revisions to the Brief Fear of Negative Evaluation scale: measuring fear of negative evaluation across anxiety and mood disorders.
J Anxiety Disord. 25(6):822-8.

Carleton RN, Collimore KC, Asmundson GJG, McCabe RE, Rowa K, Antony MM (2009)

Refining and validating the Social Interaction Anxiety Scale and the Social Phobia Scale.
Depress Anxiety. 26(2):E71-81.

Carr T, Harris D, James C (2000)

The Derriford Appearance Scale (DAS-59): A new scale to measure individual responses to living with problems of appearance.
Br J Health Psychol. 5:201-215.

Carr T, Moss T, Harris D (2005)

The DAS24: A short form of the Derriford Appearance Scale DAS59 to measure individual responses to living with problems of appearance.
Br J Health Psychol. 10:285-298.

Carver CS, Connor-Smith JK (2010)

Personality and Coping.
Annu Rev Psychol. 61:679-704.

Cash TF (2011)

Crucial considerations in the assessment of body image.

In: Cash TF, Smolak L (editors). *Body Image: A Handbook of Science, Practice, and Prevention*.

New York: Guilford Press, p129-137.

Cash TF, Grasso K (2005)

The norms and stability of new measures of the multidimensional body image construct.

Body Image. 2(2):199-203.

Cash TF, Phillips KA, Santos MT, Hrabosky JI (2004)

Measuring “negative body image”: Validation of the body image disturbance questionnaire in a non-clinical population. *Body Image*:

Int J Res. 1:363-372.

Caspi A, Roberts BW (2001)

Personality development across the life course: The argument for change and continuity.

Psychol Inq. 12:49-66.

Cattell RB, Eber HW, Tatsuoka MM (1970)

Handbook for the Sixteen Personality Factor Questionnaire.

Champaign, IL: Institute for Personality and Ability Testing.

Charmel PA, Frampton SB (2008)

Building the business case for patient-centered care.

Healthc Financ Manage. 62(3):80-85.

Chen B, Zhang ZK, Wang X (2002)

Factors influencing postoperative satisfaction of orthognathic surgery patients.

Int J Adult Orthodon Orthognath Surg. 17:217-222.

Cheung LK, Loh JS, Ho SM (2006)

The Early Psychological Adjustment of Cleft Patients after Maxillary Distraction Osteogenesis and Conventional Orthognathic Surgery: A Preliminary Study.

J Oral Maxillofac Surg. 64(1):1743-1750.

Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G (2012)

Patient preferences for shared decisions: a systematic review.

Patient Educ Couns. 86:9-18.

Choi WS, Lee S, McGrath C, Samman N (2010)

Change in quality of life after combined orthodontic-surgical treatment of dentofacial deformities.

Oral Surg Oral Med Oral Pathol Oral Radiol Endod. 109(1):46-51.

Christensen AJ, Smith TW (1995)

Personality and patient adherence: Correlates of the five-factor model in renal dialysis. *J Behav Med.* 18(3):305-313.

Clark DB, Feske U, Masia CL, Spaulding MA, Brown C, Mammen O, Shear MK (1997)

Systematic assessment of social phobia in clinical practice. *Depress Anxiety.* 6:47-61.

Clifford M, Walster E (1973)

The Effect of Physical Attractiveness on Teacher Expectations. *Sociol Educ.* 46(2):248-258.

Coffield KD, Phillips C, Brady M, Roberts MW, Strauss RP, Wright JT (2005)

The psychosocial impact of developmental dental defects in people with hereditary amelogenesis imperfecta. *J Am Dent Assoc.* 136(5):620-630.

Cohen D, Crabtree B (2006)

Qualitative Research Guidelines Project.
Retrieved from: <http://www.qualres.org/index.html>
Accessed on: 15/6/2009

Cohen DJ, Crabtree BF (2008)

Evaluative Criteria for Qualitative Research in Health Care: Controversies and Recommendations. *Ann Fam Med.* 6:331-339.

Cohen LK, Jago JD (1976)

Toward the formulation of sociodental indicators. *Int J Health Serv.* 6:681-698.

Collins KA, Westra HA, Dozois DJA, Stewart SH (2005)

The validity of the brief version of the Fear of Negative Evaluation Scale. *J Anxiety Disord.* 19:345-359.

Concise Oxford English Dictionary. 11th Edition (revised) (2008)

Oxford University Press, Oxford.

Costa PT Jr, McCrae RR (1980)

Still stable after all these years: Personality as a key to some issues in aging. In: Baltes PB, Brim OG Jr (editors). *Life-span development and behavior.* San Diego, CA: Academic Press, p65-102.

Costa PT Jr, McCrae RR (1985)

The NEO Personality Inventory manual.
Odessa, FL: Psychological Assessment Resources.

Costa PT Jr, McCrae RR (1989)

Personality continuity and the changes of adult life.
In: Storandt M, VandenBos GR (editors). The adult years: Continuity and change.
Washington, DC: American Psychological Association, p45-77.

Costa PT Jr, McCrae RR (1992)

Revised NEO Personality Inventory (NEO-PI-R) and NEO Five-Factor Inventory (NEO-FFI) manual.
Odessa, FL: Psychological Assessment Resources.

Couët N, Desroches S, Robitaille H, Vaillancourt H, Leblanc A, Turcotte S, Elwyn G, Légaré F (2013)

Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument.
Health Expect. doi: 10.1111/hex.12054. [Epub ahead of print]

Coulter A (2009)

Implementing shared decision making in the UK. A report for the Health Foundation.
Retrieved from:
http://www.health.org.uk/public/cms/75/76/1915/1522/Implementing_shared_decision_making_in_the_UK2-1.pdf?realName=U39ZtQ.pdf
Accessed on: 6/4/2013

Coulter A (2010)

Do patients want a choice and does it work?
BMJ. 341:4989.

Coulter A, Cleary PD (2001)

Patients' experiences with hospital care in five countries.
Health Aff (Millwood). 20(3):244-252.

Coulter A, Collins A (2011)

Making shared decision-making a reality. No decision about me, without me.
London: King's Fund.

Cox BJ, Fleet C, Stein MB (2004)

Self-criticism and social phobia in the US National Comorbidity Survey.
J Affect Disord. 82:227-234.

Crawford JR, Henry JD, Crombie C, Taylor EP (2001)

Normative data for the HADS from a large non-clinical sample.
Br J Clin Psychol. 40:429-434.

- Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, Tyrer P (2002)**
Systematic review of involving patients in the planning and development of health care.
BMJ. 325(7375):1263-1266.
- Crerand CE, Franklin ME, Sarwer DB (2006)**
Body dysmorphic disorder and cosmetic surgery.
Plast Reconstr Surg. 118(7):167e-180e.
- Critical Appraisal Skills Programme (CASP) (2002)**
An appraisal tool for qualitative research.
Retrieved from: <http://www.phru.nhs.uk/casp/qualitative.pdf>
Accessed on: 7/10/2009
- Cunningham SJ, Shute J (2009)**
Orthognathic treatment: see how they feel?
J Orthod. 36(1):61-66.
- Cunningham SJ, Hunt NP, Feinmann C (1995)**
Psychological aspects of orthognathic surgery: A review of the literature.
Int J Adult Orthodon Orthognath Surg. 10:159-172.
- Cunningham SJ, Hunt NP, Feinmann C (1996)**
Perceptions of outcome following orthognathic surgery.
Br J Oral Maxillofac Surg. 34:210-213.
- Cunningham SJ, Gilthorpe MS, Hunt NP (2000a)**
Are orthognathic patients different?
Eur J Orthod. 22:195-202.
- Cunningham SJ, Garratt AM, Hunt NP (2000b)**
Development of a condition-specific quality of life measure for patients with dentofacial deformity: I. Reliability of the instrument.
Community Dent Oral Epidemiol. 28(3):195-201.
- Cunningham SJ, Gilthorpe MS, Hunt NP (2001)**
Are pre-treatment psychological characteristics influenced by pre-surgical orthodontics?
Eur J Orthod. 23(6):751-758.
- Cunningham SJ, Garratt AM, Hunt NP (2002)**
Development of a condition specific quality of life measure for patients with dentofacial deformity: II. Validity and responsiveness testing.
Community Dent Oral Epidemiol. 30:81-90.

Dana RH (1993)

Multicultural Assessment Perspectives for Professional Psychology.
Boston: Allyn and Bacon.

Danda AK, Ravi P (2011)

Effectiveness of postoperative antibiotics in orthognathic surgery: a meta-analysis.
J Oral Maxillofac Surg. 69(10):2650-2656.

Da Silva D (2012)

Evidence: Helping people share decision making A review of evidence considering whether shared decision making is worthwhile.
London: The Health Foundation.

Davidson JRT, Hughes DL, George LK, Blazer DG (1993)

The epidemiology of social phobia: findings from the Duke Epidemiological Catchment Area Study.
Psychol Med. 23:709-718.

Dawn AG, Lee PP (2004)

Patient Expectations for Medical and Surgical Care: A Review of the Literature and Applications to Ophthalmology.
Surv Ophthalmol. 49(5):513-524.

Department for Communities and Local Government (2011)

English Indices of Deprivation 2010: Guidance document.

Retrieved from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6222/1871538.pdf

Accessed on: 3/5/2012

Department of Health (1991)

The patients' charter.

London: HMSO.

Department of Health (2010)

Equity and Excellence: Liberating the NHS.

London: Department of Health.

Retrieved from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/135875/dh_117794.pdf.pdf

Accessed on: 7/4/2013

Department of Health (2012)

Health and Social Care Act.

London: Department of Health.

Retrieved from: <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

Accessed on: 6/6/2013

Department of Health (2013)

The NHS constitution.

London: Department of Health.

Retrieved from:

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf>

Accessed on: 20/5/2013

Derogatis LR, Rickels K, Rock AF (1976)

The SCL-90 and the MMPI: a step in the validation of a new self-report scale.

Br J Psychiatry. 128:280-289.

Deshpande PR, Rajan S, Sudeepthi BL, Abdul Nazir CP (2011)

Patient-reported outcomes: A new era in clinical research.

Perspect Clin Res. 2(4):137-144.

Devlin NJ, J Appleby (2010)

Getting the most out of proms. Putting health outcomes at the heart of NHS decision-making.

London: The Kings Fund, 2010.

Retrieved from:

<https://www.kingsfund.org.uk/sites/files/kf/Getting-the-most-out-of-PROMs-Nancy-Devlin-John-Appleby-Kings-Fund-March-2010.pdf>

Accessed on: 21/3/2013

DiMatteo MR, Lepper HS, Croghan TW (2000)

Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence.

Arch Intern Med. 160(14):2101-2107.

DiNardo PA, Brown TA, Barlow DH (1994)

Anxiety Interview Schedule for DSM-IV (ADIS-IV).

Albany, NY: Greywind Publications.

Dion K, Berscheid E, Walster E (1972)

What is beautiful is good.

J Pers Social Psychol. 24:285-290.

Dufresne RG, Phillips KA, Vittorio CC, Wilkel CS (2001)

A screening questionnaire for body dysmorphic disorder in a cosmetic dermatologic surgery practice.

Dermatol Surg. 27:457-462.

Duke D, Krishnan M, Faith M, Storch EA (2006)

The psychometric properties of the Brief Fear of Negative Evaluation Scale.

J Anxiety Disord. 20(6):807-17.

Dwamena F, Holmes-Rovner M, Gauden CM, Jorgenson S, Sadigh G, Sikorskii A, Lewin S, Smith RC, Coffey J, Olomu A (2012)

Interventions for providers to promote a patient-centred approach in clinical consultations.

Cochrane Database Syst Rev. 12:CD003267.

Eagly AH, Ashmore RD, Makhijani MG, Longo LC (1991)

What is beautiful is good, but...: A meta-analytic review of research on the physical attractiveness stereotype.

Psychol Bull. 110:109-28.

Edgerton MT, Knorr NJ (1971)

Motivational patterns of patients seeking cosmetic (esthetic) surgery.

Plast Recon Surg. 48:551-557.

Edwards A, Elwyn G (2009)

Shared decision-making in health care. Achieving evidence-based patient choice.

Oxford: Oxford University Press.

Edwards A, Elwyn G, Hood K, Robling M, Atwell C, Holmes-Rovner M, Kinnersley P, Houston H, Russell I (2003)

The development of COMRADE- A patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations.

Patient Educ Couns. 50(3):311-322.

Efrain MG, Patterson EWJ (1974)

Voters vote beautiful: The effect of physical appearance on a national election.

Can J Behav Sci. 6(4):352-356.

Efran G (1974)

The effect of physical appearance on the judgment of guilt, interpersonal attraction, and severity of recommended punishment in a simulated jury task.

J Res Pers. 8:45-54.

Elwyn G (1999)

Towards a feasible model for shared decision making: focus group study with general practice registrars.

BMJ. 319:753.

Elwyn G, Frosch D, Rollnick S (2009)

Dual equipoise shared decision making: definitions for decision and behaviour support interventions.

Implement Sci. 4:75.

Elwyn G, Edwards A, Kinnersley P, Grol R (2000)

Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices.

Br J Gen Pract. 50:892-897.

Elwyn G, Edwards A, Wensing M, Grol R (2005)

Shared decision making. Measurement using the OPTION instrument.

Wales: Cardiff University.

Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R (2003)

Shared decision making: developing the OPTION scale for measuring patient involvement.

Qual Saf Health Care. 12:93-99.

Elwyn G, Frosch D, Thompson R, Joseph-Williams N, Lloyd A, Kinnersley P, Cording E, Tomson D, Dodd C, Rollnick S, Edwards A, Barry M (2012)

Shared decision making: a model for clinical practice.

J Gen Intern Med. 27(10):1361-1367.

Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, Thomson R, Barratt A, Barry M, Bernstein S, Butow P, Clarke A, Entwistle V, Feldman-Stewart D, Holmes-Rovner M, Llewellyn-Thomas H, Mounjid N, Mulley A, Ruland C, Sepucha K, Skyes A, Whelan T: International Patient Decision Aids Standards (IPDAS) Collaboration (2006)

Developing a quality criteria framework for patient decision aids: online international Delphi consensus process.

BMJ. 333(7565):417.

Espeland L, Hogevoid HE, Stenvik A (2008)

A 3-year patient centred follow-up of 516 consecutively treated orthognathic surgery patients.

Eur J Orthod. 30:24-30.

Esperão PTG, de Oliveira BH, de Oliveira Almeida MA, Kiyak HA, Miguel JAM (2010)

Oral health-related quality of life in orthognathic surgery patients.
Am J Orthod Dentofacial Orthop. 137:790-795.

Eysenck HJ, Eysenck SBG (1975)

Manual of the Eysenck Personality Questionnaire.
London: Hodder and Stoughton.

Faravelli C, Salvatori S, Galassi F, Aiazzi L, Drei C, Cabras P (1997)

Epidemiology of somatoform disorders: a community survey in Florence.
Soc Psychiatry Psychiatr Epidemiol. 32:24-29.

Fedoroff IC, Taylor S (2001)

Psychological and pharmacological treatments of social phobia: a meta-analysis.
J Clin Psychopharmacol. 21:311-324.

Finlay PM, Atkinson JM, Moos KF (1995)

Orthognathic surgery: patient expectations; psychological profile and satisfaction with outcome.
Br J Oral Maxillofac Surg. 33:9-14.

Flanary CM, Alexander JM (1983)

Patient response to orthognathic experience: Factors leading to dissatisfaction.
J Oral Maxillofac Surg. 41:770-774.

Flanary CM, Barnwell GM, Alexander JM (1985)

Patient perceptions of orthognathic surgery.
Am J Orthod. 88:137-145.

Flanary CM, Barnwell GM, Van Sickels JE, Littlefield JH, Rugh AL (1990)

Impact of orthognathic surgery on normal and abnormal personality dimensions: a two-year follow up study of 61 patients.
Am J Orthod Dentofacial Orthop. 98:313-322.

Fone DL, Dunstan F, John A, Lloyd K (2007)

Associations between common mental disorders and the Mental Illness Needs Index in community settings. Multilevel analysis.
Br J Psychiatry. 191:158-163.

- Friedberg MW, Van Busum K, Wexler R, Bowen M, Schneider EC (2013)**
A demonstration of shared decision making in primary care highlights barriers to adoption and potential remedies.
Health Aff (Millwood). 32(2):268-275.
- Foster G, Ysseldyke J (1976)**
Expectancy and halo effects as a result of artificially induced teacher bias.
Contemp Educ Psychol. 1:37-45.
- Frosch DL, Kaplan RM (1999)**
Shared Decision Making in Clinical Medicine: Past Research and Future Directions.
Am J Prev Med. 7(4):285-294.
- Fuchs T (2003)**
The Phenomenology of Shame, Guilt and the Body in Body Dysmorphic Disorder and Depression.
J Phenomenol Psychol. 33:2.
- Garvill J, Garvill H, Kahnberg K-E, Lundgren S (1992)**
Psychological factors in orthognathic surgery.
J CranioMaxilloFac Surg. 20:28-33.
- General Dental Council (2005)**
Standards for Dental Professionals.
London: General Dental Council.
Retrieved from:
<http://www.gdc-uk.org/Newsandpublications/Publications/Publications/StandardsforDentalProfessionals%5B1%5D.pdf>
Accessed on: 2/5/13
- General Medical Council (2009)**
Patient and public involvement in undergraduate medical education.
London: General Medical Council
Retrieved from:
http://www.gmc-uk.org/Patient_and_public_web.pdf_40939542.pdf
Accessed on: 5/5/2013
- General Medical Council (2013)**
Good Medical Practice.
London: General Medical Council.
Retrieved from:
http://www.gmc-uk.org/guidance/good_medical_practice/partnerships.asp
Accessed on: 2/5/13

Gerrig RJ, Zimbardo PG (2002)

Psychology and Life.
Boston: Allyn and Bacon.

Glaser BG, Strauss A (1967)

The Discovery of Grounded Theory: Strategies for Qualitative Research.
Chicago, IL: Aldine Publishing Co.

Goldberg LR (1990)

An alternative description of personality: The big-five factor structure.
J Pers Soc Psychol. 59(6):1216-1229.

Grant BF, Hasin DS, Stinson FS, Dawson DA, Patricia Chou S, June Ruan W, Huang B (2005)

Co-occurrence of 12-month mood and anxiety disorders and personality disorders in the US: results from the national epidemiologic survey on alcohol and related conditions.
J Psychiatr Res. 39:1-9.

Gravel K, Légaré F, Graham ID (2006)

Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions.
Implement Sci. 1:16.

Greenlee GM, Huang GJ, Chen SS, Chen J, Koepsell T, Hujoel P (2011)

Stability of treatment for anterior open-bite malocclusion: a meta-analysis.
Am J Orthod Dentofac Orthop. 139(2):154-169.

Grol R, Wensing M, Mainz J, Jung HP, Ferreira P, Hearnshaw H, Hjortdahl P, Olesen F, Reis S, Ribacke M, Szecsenyi J; European Task Force on Patient Evaluations of General Practice Care (EUROPEP) (2000)

Patients in Europe evaluate general practice care: an international comparison.
Br J Gen Pract. 50:882-887.

Guest G, Bunce A, Johnson L (2006)

How many interviews are enough? An experiment with data saturation and variability.
Field Methods.18(1):59-82.

Gutiérrez-Lobos K, Scherer M, Anderer P, Katschnig H (2002)

The influence of age on the female/male ratio of treated incidence rates in depression.
BMC Psychiatry. 2:3.

Hallberg U, Klingberg G (2007)

Giving low priority to oral health care. Voices from people with disabilities in a grounded theory study.
Acta Odontol Scand. 65(5):265-270.

Hammersley M (1996)

The relationship between qualitative and quantitative research: paradigm loyalty versus methodological eclecticism.

In: Richardson JTE (editor). Handbook of research methods for psychology and the social sciences.

Leicester: BPS Books.

Harris DL, Carr AT (2001)

Prevalence of concern about physical appearance in the general population.

Br J Plast Surg. 54:223-226.

Heimberg RG (2002)

Cognitive-behavioral therapy for social anxiety disorder: current status and future directions.

Biol Psychiatry. 51:101-108.

Heimberg RG, Liebowitz MR, Hope DA, Schneier FR, Holt CS, Welkowitz LA, Juster HR, Campeas R, Bruch MA, Cloitre M, Fallon B, Klein DF (1998)

Cognitive behavioural group therapy vs phenelzine therapy for social phobia: 12-week outcome.

Arch Gen Psychiatry. 55:1133-1141.

Heldt L, Haffke EA, Davis LF (1982)

The psychological and social aspects of orthognathic treatment.

Am J Orthod. 4:318-328.

Hepburn S, Cunningham S (2006)

Body Dysmorphic disorder in adult orthodontic patients.

Am J Orthod Dentofacial Orthop. 130:569-574.

Herrmann C (1997)

International experiences with the Hospital Anxiety and Depression Scale-a review of validation data and clinical results.

J Psychosom Res. 42:17-41.

Holman AR, Brumer S, Ware WH, Pasta DJ (1995)

The impact of interpersonal support on patient satisfaction with orthognathic surgery.

J Oral Maxillofac Surg. 53(11):1289-1297.

Honigman RJ, Jackson AC, Dowling NA (2011)

The PreFACE: A preoperative psychosocial screen for elective facial cosmetic surgery and cosmetic dentistry patients.

Ann Plast Surg. 66(1):16-23.

Hoppenreijns TJ, Hakman EC, van't Hof MA, Stoelinga PJW, Tuinzing DB, Freihofer HP (1999)

Psychologic implications of surgicalorthodontic treatment in patients with anterior open bite.

Int J Adult Orthod Orthognath Surg. 14:101-112.

Horton R (1995)

The interpretive turn.

Lancet. 346(8966):3.

Hunt OT, Hepper PG, Burden DJ (2001)

The psychosocial impact of orthognathic surgery: A systematic review.

Am J Orthod Dentofacial Orthop. 120:490-497.

Hwang K, Choi Y-B (2013)

Postoperative Monitoring Following Jaw Surgery Is Essential.

Arch Plast Surg. 40(1):66-67.

Iannetti G, Fadda TM, Riccardi E, Mitro V, Filiaci F (2013)

Our experience in complications of orthognathic surgery: a retrospective study on 3236 patients.

Eur Rev Med Pharmacol Sci. 17(3):379-384.

International Labor Organization (1982)

Resolution concerning statistics of the economically active population, employment, unemployment, and underemployment, adopted by the Thirteenth International Conference of Labor Statisticians.

Retrieved from:

<http://www.ilo.org/public/english/bureau/stat/download/res/ecacpop.pdf>

Accessed on: 25/1/2012

Jayadevappa R, Chhatre S (2011)

Patient Centered Care - A Conceptual Model and Review of the State of the Art.

Open Health Serv Policy J. 4:15-25.

Jensen SH (1978)

The psycho-social dimensions of oral and maxillofacial surgery: a critical review of the literature.

J Oral Surg. 36:447-453.

John Hopkins Group (2004)

Defining the Patient-Physician Relationship for the 21st Century: 3rd Annual Disease Management Outcomes Summit.

Retrieved via: <http://www.cardiophonics.com/PatientPhysician.pdf>

Accessed on: 15/5/2013

Johnson BR, Schwartz A, Goldberg J, Koerber A (2006)

A Chairsides Aid for Shared Decision Making in Dentistry: A Randomized Controlled Trial.

J Dent Educ. 70(2):133-141.

Joosten EA, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CP, de Jong CA (2008)

Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status.

Psychother Psychosom. 77(4):219-226.

Josefsson E, Lindsten R, Hallberg LR (2010)

A qualitative study of the influence of poor dental aesthetics on the lives of young adults.

Acta Odontol Scand. 68(1):19-26.

Kasper J, Heesen C, Köpke S, Fulcher G, Geiger F (2011)

Patients' and observers' perceptions of involvement differ. Validation study on inter-relating measures for shared decision making.

PLoS One. 6(10):e26255.

Katon W, Russo J (1989)

Somatic symptoms and depression.

J Fam Pract. 29(1):65-69.

Kay EJ, Blinkhorn AS (1996)

A qualitative investigation of factors governing dentists' treatment philosophies.

Br Dent J. 180:171-176.

Kent G, Keohane S (2001)

Social anxiety and disfigurement: The moderating effects of fear of negative evaluation and past experience.

Br J Clin Psychol. 40:23-34.

Kessler RC, Merikangas KR (2004)

The National Comorbidity Survey Replication (NCS-R): background and aims.

Int J Methods Psychiatr Res. 13:60-68.

Kessler RC, Chiu WT, Demler O, Walters EE (2005a)

Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication.

Arch Gen Psychiatry. 62:617-627.

- Kessler RC, Berglund P, Demler O, Jin R, Merikangas KR, Walters EE (2005b)**
Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication.
Arch Gen Psychiatry. 62:593-603.
- Kessler RC, McGonagle KA, Zhao S, Nelson CB, Hughes M, Eshleman S, Wittchen H-U, Kendler KS (1994)**
Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States.
Arch Gen Psychiatry. 51:8-19.
- Kiesler DJ, Auerbach SM (2006)**
Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions.
Patient Educ Couns. 61(3):319-341.
- Kim S-G, Park S-S (2007)**
Incidence of Complications and Problems Related to Orthognathic Surgery.
J Oral Maxillofac Surg. 65:2438-2444.
- Kim SJ, Kim MR, Shin SW, Chun YS, Kim EJ (2009)**
Evaluation on the psychosocial status of orthognathic surgery patients.
Oral Surg Oral Med Oral Pathol Oral Radiol Endod. 108(6):828-832.
- Kindelan JD, Sheard CE, Nashed RR (1998)**
A comparison of patients requiring orthognathic treatment who subsequently refused or accepted surgery.
Int J Adult Orthod Orthognath Surg. 13:115-118.
- Kish L (1949)**
A Procedure for Objective Respondent Selection within the Household.
J Am Stat Assoc. 44(247):380-387.
- Kiyak HA (2008)**
Does orthodontic treatment affect patients' quality of life?
J Dent Educ. 72(8):886-894.
- Kiyak HA, McNeill RW, West RA (1985)**
The emotional impact of orthognathic surgery and conventional orthodontics.
Am J Orthod. 88:224-234.
- Kiyak HA, West RA, Hohl T, McNeill RW (1982a)**
The psychological impact of orthognathic surgery: a 9-month follow-up.
Am J Orthod. 81:404-412.

- Kiyak HA, Hohl T, West RA, McNeill RW (1984)**
Psychologic changes in orthognathic surgery patients: a 24-month follow-up.
J Oral Maxillofac Surg. 42:506-512.
- Kiyak HA, McNeill RW, West RA, Hohl T, Heaton PJ (1986)**
Personality characteristics as predictors and sequelae of surgical and conventional orthodontics.
Am J Orthod. 89(5):383-392.
- Kiyak HA, Hohl T, Sherrick P, West RA, McNeil RW, Bucher F (1981)**
Sex differences in motives for and outcomes of orthognathic surgery.
J Oral Surg. 39:757-764.
- Kiyak HA, McNeill RW, West RA, Hohl T, Bucher F, Sherrick P (1982b)**
Predicting psychologic responses to orthognathic surgery.
J Oral Surg. 40:150-155.
- Koo J, Young J (2002)**
Body image issues in dermatology.
In: Cash TF, Pruzinsky T (editors). Body image: A Handbook of Theory, Research and Clinical Practice.
New York: Guildford Press.
- Kosowski TR, McCarthy C, Reavy PL, Scott AM, Wilkins EG, Cano SJ, Klassen AF, Carr N, Cordiero PG, Pusic AL (2009)**
A systematic review of patient-reported outcome measures after facial cosmetic surgery and/or nonsurgical facial rejuvenation.
Plast Reconstr Surg. 123(6):1819-1827.
- Kovalenko A, Slabkovskaya A, Drobysheva N, Persin L, Drobyshev A, Maddalone M (2012)**
The association between the psychological status and the severity of facial deformity in orthognathic patients.
Angle Orthod. 82:396-402.
- Kravitz RL (1996)**
Patients' Expectations for Medical Care: An Expanded Formulation Based on Review of the Literature.
Med Care Res Rev. 53(1):3-27.
- Lacey A, Luff D (2001)**
Qualitative data analysis.
Retrieved from:
http://research.familymed.ubc.ca/files/2012/03/Trent_Universtiy_Qualitative_Analysis7800.pdf
Accessed on: 20/11/2009

Laine C, Davidoff F (1996)

Patient-centered medicine: a professional evolution.
JAMA. 275:152-156.

Langlois JH, Stephan C (1981)

Beauty and the beast: The role of physical attractiveness in the development of peer relations and social behavior.
In: Brehm SS, Kass SM, Gibbons FX (editors). Developmental Social Psychology: Theory and Research.
New York: Oxford University Press, p152-168.

Langlois JH, Kalakanis L, Rubenstein AJ, Larson A, Hallam M, Smoot M (2000)

Maxims or myths of beauty? A meta-analytic and theoretical review.
Psychol Bull. 126:390-423.

Laufer D, Glick D, Gutman D, Sharon A (1976)

Patient motivation and response to surgical correction of prognathism.
Oral Surg Oral Med Oral Pathol. 41:309-313.

Lazaridou-Terzoudi T, Kiyak HA, Moore R, Athanasiou AE, Melsen B (2003)

Long-term assessment of psychologic outcomes of orthognathic surgery.
J Oral Maxillofac Surg. 61:545-552.

Leary MR (1983)

A brief version of the Fear of Negative Evaluation Scale.
Pers Soc Psychol Bull. 9:371-375.

Leary MR, Kowalski RM (1995)

Social anxiety.
New York: Guilford Press.

Lee EG, Ryan FS, Shute J, Cunningham SJ (2011)

The impact of altered sensation affecting the lower lip after orthognathic treatment.
J Oral Maxillofac Surg. 69(11):e431-445.

Lee EO, Emanuel EJ (2013)

Shared Decision Making to Improve Care and Reduce Costs.
N Engl J Med. 368(1):6-8.

Lee LW, Chen SH, Yu CC, Lo LJ, Lee SR, Chen YR (2007a)

Stigma, body image, and quality of life in women seeking orthognathic surgery.
Plast Reconstr Surg. 120:225-231.

Lee S, McGrath C, Samman N (2007b)

Quality of life in patients with dentofacial deformity: a comparison of measurement approaches.

Int J Oral Maxillofac Surg. 36:488-492.

Lee S, McGrath C, Samman N (2008)

Impact of orthognathic surgery on quality of life.

J Oral Maxillofac Surg. 66:1194-1199.

Légaré F, Ratté S, Gravel K, Graham ID (2008)

Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions.

Patient Educ Couns. 73(3):526-535.

Légaré F, Kearing S, Clay K, Gagnon S, D'Amours D, Rousseau M, O'Connor A (2010)

Are you SURE?: Assessing patient decisional conflict with a 4-item screening test.

Can Fam Physician. 56(8):e308-314.

Leon DA (2011)

Trends in European life expectancy: a salutary view.

Int J Epidemiol. 40(2):271-277.

Lethem J, Slade PT, Troup JD, Bentley G (1983)

Outline of a fear-avoidance model of exaggerated pain perception. I.

Behav Res Ther. 21(4):401-408.

Levenstein JH, McCracken EC, McWhinney IR, Stewart MA, Brown JBB (1986)

The patient-centred clinical method: 1 A model for the doctor-patient interaction in family medicine.

Fam Pract. 3:24-30.

Liamputtong P, Ezzy D (2005)

Qualitative research methods.

Oxford: Oxford University Press.

Liebowitz MR (1987)

Social phobia. Modern Problems.

Pharmacopsych. 22:141-173.

Linder-Pelz SU (1982)

Toward a theory of patient satisfaction.

Soc Sci Med. 16(5):577-582.

Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, Payne S (2001)

Preferences of patients for patient centred approach to consultation in primary care: observational study.
BMJ. 322(7284):468-472.

Lopez N, Blue CM (2011)

Socialization of new dental therapists on entering the profession.
J Dent Educ. 75(5):626-632.

Lorenzo GL, Biesanz JC, Human LJ (2010)

What is beautiful is good and more accurately understood. Physical attractiveness and accuracy in first impressions of personality.
Psychol Sci. 21(12):1777-1782.

Lovius BB, Jones RB, Pospisil OA, Reid D, Slade PD, Wynne TH (1990)

The specific psychosocial effects of orthognathic surgery.
J Craniomaxillofac Surg. 18(8):339-342.

Lucas PJ, McIntosh K, Petticrew M, Roberts H, Shiell A (2008)

Financial benefits for child health and well-being in low income or socially disadvantaged families in developed world countries.
Cochrane Database Syst Rev. 16(2):CD006358.

Luckerhoff J, Guillemette F (2011)

The Conflicts between Grounded Theory Requirements and Institutional Requirements for Scientific Research.
Qual Rep. 16(2):396-414.

Macgregor FC (1979)

After plastic surgery: adaptation and adjustment.
New York: Praeger Publishers.

Macgregor FC (1981)

Patient dissatisfaction with results of technically satisfactory surgery.
Aesthetic Plast Surg. 5:27-32.

Macgregor FC (1989)

Social, psychological, and cultural dimensions of cosmetic and reconstructive plastic surgery.
Aesthetic Plast Surg. 13:1-8.

Macgregor FC (1990)

Facial disfigurement: problems and management of social interaction and implications for mental health.
Aesthetic Plast Surg. 14:249-257.

Mack N, Woodsong C, MacQueen KM, Guest G, Namey E (2005)

Qualitative Research Methods: A data collector's field guide.
Research Triangle Park, NC: Family Health International.

Madera JM, Hebl, MR (2012)

Discrimination against facially stigmatized applicants in interviews: An eye-tracking and face-to-face investigation.
J Appl Psychol. 97(2):317-330.

Makoul G, Clayman ML (2006)

An integrative model of shared decision making in medical encounters.
Patient Educ Couns. 60(3):301-312.

Malterud K (2001)

The art and science of clinical knowledge: evidence beyond measures and numbers.
Lancet. 358:397-400.

Mangione TW (1995)

Mail Surveys: Improving the quality.
California: Thousand Oaks.

Marshman Z, Gibson BJ, Benson PE (2010)

Is the short-form Child Perceptions Questionnaire meaningful and relevant to children with malocclusion in the UK?
J Orthod. 37(1):29-36.

Martin LR, Jahng KH, Golin CE, DiMatteo MR (2003)

Physician facilitation of patient involvement in care: correspondence between patient and observer reports.
Behav Med. 28:159-164.

Massion AO, Dyck I, Shea MT, Phillips KA, Warshaw MG, Keller MB (2002)

Personality disorders and time to remission in generalized anxiety disorder, social phobia, and panic disorder.
Arch Gen Psychiatry. 59:434-440.

Masood M, Masood Y, Newton TJ (2010)

Methods of Qualitative Research in Dentistry: A Review.
Dent Update. 37:326-336.

Masood M, Thaliath ET, Bower EJ, Newton JT (2011)

An appraisal of the quality of published qualitative dental research.
Community Dent Oral Epidemiol. 39:193-203.

Mays N, Pope C (1995)

Rigour in qualitative research.
Br Med J. 311:109-112.

Mays N, Pope C (2000)

Assessing quality in qualitative research.
BMJ. 320(7226):50-52.

Mays N, Pope C (2006)

Qualitative Research in Health Care.
London: Blackwell BMJ books.

McCrae RR, Costa PT (1990)

Personality in adulthood.
New York: Guilford Press.

McCrae RR, John OP (1992)

An introduction to the five-factor model and its applications.
J Pers. 60(2):175-215.

McCrae RR, Costa PT Jr (1999)

A five-factor theory of personality.
In: Pervin LA, John OP (editors). Handbook of personality: Theory and research (2nd ed.).
New York: The Guilford Press.

McCrae RR, Costa PT Jr (2004)

A contemplated revision of the NEO five-factor inventory.
Pers Individ Diff. 36:587-596.

McHorney CA (1999)

Health status assessment methods for adults: past accomplishments and future directions.
Annual Rev Public Health. 20:309-335.

McKibbin KA, Gadd CS (2004)

A quantitative analysis of qualitative studies in clinical journals for the 2000 publishing year.
BMC Med Inform Decis Mak. 22(4):11.

McKinstry B, Hammersley V, Burton C, Pinnock H, Elton R, Dowell J, Sawdon N, Heaney D, Elwyn G, Sheikh A (2010)

The quality, safety and content of telephone and face-to-face consultations: a comparative study.
Qual Saf Health Care. 19(4):298-303.

McWhinney I (1989)

The need for a transformed clinical method.

In: Stewart M, Roter D (editors). *Communicating with medical patients*.

London: Sage.

Mead N, Bower P (2000)

Patient-centredness: a conceptual framework and review of the empirical literature.

Soc Sci Med. 51(7):1087-1110.

Melbourne E, Sinclair K, Durand M-A, Légaré F, Elwyn G (2010)

Developing a dyadic OPTION scale to measure perceptions of shared decision making.

Patient Educ Couns. 78:177-183.

Mensah FK, Hobcraft J (2008)

Childhood deprivation, health and development: associations with adult health in the 1958 and 1970 British prospective birth cohort studies.

J Epidemiol Community Health. 62(7):599-606.

Merijohn GK, Bader JD, Frantsve-Hawley J, Aravamudhan K (2008)

Clinical decision support chairside tools for evidence-based dental practice.

J Evid Based Dent Pract. 8(3):119-132.

Meterko M, Wright S, Lin H, Lowy E, Cleary PD (2010)

Mortality among patients with acute myocardial infarction: the influences of patient-centered care and evidence-based medicine.

Health Serv Res. 45(5):1188-1204.

Michopoulos I, Douzenis A, Kalkavoura C, Christodoulou C, Michalopoulou P, Kalemi G, Fineti K, Patapis P, Protopapas K, Lykouras L (2008)

Hospital Anxiety and Depression Scale (HADS): validation in a Greek general hospital sample.

Ann Gen Psychiatry. 7:4.

Modig M, Andersson L, Wårdh I (2006)

Patients' perception of improvement after orthognathic surgery: pilot study.

Br J Oral Maxillofac Surg. 44:24-27.

Moles DR, Cunningham SJ (2009)

A national review of mandibular orthognathic surgery activity in the National Health Service in England over a nine year period: Part 1 - Service factors.

Br J Oral Maxillofac Surg. 47:268-273.

Morris D (2006)

Improving standards in orthognathic care: the bigger picture (a national and international perspective).

J Orthod. 33(3):149-151.

Mosby's Dental Dictionary (2007)

London: Mosby.

Moss TP, Harris D, Carr T (2004)

Manual for the Derriford Appearance Scale 24 (DAS24).
Bradford on Avon: Muskateer Press.

Motegi E, Hatch JP, Rugh JD, Yamaguchi H (2003)

Health-related quality of life and psychosocial function 5 years after orthognathic surgery.
Am J Orthod Dentofacial Orthop. 124(2):138-43.

Muldoon MF, Barger SD, Flory JD, Manuck SB (1998)

What are quality of life measurements measuring?
Br Med J. 316:542-545.

Mulley A (2011)

Learning from variations to increase value for money in the NHS (Web log post).
Retrieved from:
<http://www.kingsfund.org.uk/blog/2011/07/learning-variations-increase-value-money-nhs>
Accessed on: 5/4/2013

Mulley AG, Trimble C, Elwyn G (2012)

Stop the silent misdiagnosis: patients' preferences matter.
BMJ. 345:e6572–e6575.

Murphy C, Kearns G, Sleeman D, Cronin M, Allen PF (2011)

The clinical relevance of orthognathic surgery on quality of life.
Int J Oral Maxillofac Surg. 40(9):926-930.

Murray E, Pollack L, White M, Lo B (2007)

Clinical decision-making: physicians' preferences and experiences.
BMC Fam Pract. 8:10.

Murtagh FEM, Thorns A (2006)

Evaluations and ethical review of a tool to explore patient preferences for information and involvement in decision making.
J Med Ethics. 32:439-446.

Myers SS, Phillips RS, Davis RB, Cherkin DC, Legedza A, Kaptchuk TJ, Hrbek A, Buring JE, Post D, Connelly MT, Eisenberg DM (2008)

Patient expectations as predictors of outcome in patients with acute low back pain.
J Gen Intern Med. 23(2):148-153.

Nannenga MR, Montori VM, Weymiller AJ, Smith SA, Christianson TJ, Bryant SC, Gafni A, Charles C, Mullan RJ, Jones LA, Bolona ER, Guyatt GH (2009)
A treatment decision aid may increase patient trust in the diabetes specialist. The Statin Choice randomized trial.
Health Expect. 12(1):38-44.

Nardi P, Acocella A, Tedesco A, Rispoli A, Giacomelli E (2003)
Psychological aspects in orthognathic surgery. Body image and quality of life in postsurgical assessment.
Minerva Stomatol. 52(4):145-152, 152– 155.

National Centre for Health and Care Excellence (2013)
Social anxiety disorder: recognition, assessment and treatment. NICE clinical guideline 159.
Retrieved from: <http://www.nice.org.uk/nicemedia/live/14168/63868/63868.pdf>
Accessed on: 30/6/2013

National Centre for Social Research (2009a)
Course manual: In-depth interviews.
London: NatCen.

National Centre for Social Research (2009b)
Course manual: Analysis of qualitative data.
London: NatCen.

National Health Service (2012)
Support planning 2013/2014 for clinical commissioning groups.
Retrieved from:
<http://www.england.nhs.uk/wp-content/uploads/2012/12/support-planning-ccg.pdf>
Accessed on: 23/5/2012

National Health Service Executive (1996)
Patient partnership: building a collaborative strategy.
Leeds: NHS Executive.

National Institute for Health and Clinical Excellence (2009)
The guidelines manual.
London: National Institute for Health and Clinical Excellence.
Retrieved from: www.nice.org.uk.
Accessed: 25/5/2012

National Research Council (2001)
Crossing the quality chasm: a new health system for the 21st century.
Washington, DC: National Academies Press.

Newell RJ (1999)

Altered body image: a fear-avoidance model of psycho-social difficulties following disfigurement.

J Adv Nurs. 30(5):1230–1238.

Newell R, Marks I (2000)

Phobic nature of social difficulty in facially disfigured people.

Br J Psychiatry. 176:177–181.

Nicodemo D, Pereira MD, Ferreira LM (2008a)

Self-esteem and depression in patients presenting angle class III malocclusion submitted for orthognathic surgery.

Med Oral Pathol Oral Cir Bucal. 13(1):E48-51.

Nicodemo D, Pereira MD, Ferreira LM (2008b)

Effect of orthognathic surgery for class III correction on quality of life as measured by SF-36.

Int J Oral Maxillofac Surg. 37:131-134.

Nikbakht A (2012)

Analysis of Personality Traits of Applicants for Cosmetic Surgery.

J. Life Sci. Biomed. 2(6):283-286.

Nurminen L, Pietila T, Vinkka-Puhakka H (1999)

Motivation for and satisfaction with orthodontic-surgical treatment: a retrospective study of 28 patients.

Eur J Orthod. 21:79-87.

O'Brien K, Wright J, Conboy F, Appelbe P, Bearn D, Caldwell S, Harrison J, Hussain J, Lewis D, Littlewood S, Mandall N, Morris T, Murray A, Oskouei M, Rudge S, Sandler J, Thiruvengkatachari B, Walsh T, Turbill E (2009)

Prospective, multi-center study of the effectiveness of orthodontic/orthognathic surgery care in the United Kingdom.

Am J Orthod Dentofacial Orthop. 135(6):709-714.

O'Connor AM (1995)

Validation of a Decisional Conflict Scale.

Med Decis Making. 15:25-30.

O'Connor AM, Llewellyn-Thomas HA, Flood AB (2004)

Modifying Unwarranted Variations in Health Care: Shared Decision Making Using Patient Decision Aids. A review of the evidence base for shared decision making.

Retrieved from:

http://geiselmed.dartmouth.edu/cfm/education/PDF/shared_decision_making.pdf

Accessed on: 20/4/2013.

- O'Connor AM, Drake E, Wells G, Tugwell P, Laupacis A, Elmslie T (2003a)**
A survey of the decision-making needs of Canadians faced with complex health decisions.
Health Expect. 6(2):1-13.
- O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR, Sodano AG, King JS (2007)**
Toward the 'tipping point': decision aids and informed patient choice.
Health Aff (Millwood). 26(3):716-725.
- O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M, Jones J (2003b)**
Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. (2):CD001431.
- O'Connor AM, Stacey D, Rovner D, Holmes-Rovner M, Tetroe J, Llewellyn-Thomas H, Entwistle V, Rostom A, Fiset V, Barry M, Jones J (2001)**
Decision aids for people facing health treatment or screening decisions.
Cochrane Database Syst Rev. (3):CD001431.
- O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, Entwistle VA, Fiset V, Holmes-Rovner M, Khangura S, Llewellyn-Thomas H, Rovner D (2009)**
Decision aids for people facing health treatment or screening decisions.
Cochrane Database Syst Rev. (3):CD001431
- Office for National Statistics (2001)**
Census: UK Data Service Census Support.
Retrieved from: <http://casweb.mimas.ac.uk>
Accessed on: 13/4/2011
- Office for National Statistics (2011)**
Opinions (Omnibus) Survey Information Guide.
London: Office for National Statistics.
- Offord DR, Boyle MH, Campbell DC, Goering P, Lin E, Wong M, Racine YA (1996)**
One-year prevalence of psychiatric disorders in Ontarians 15 to 64 years of age.
Can J Psychiatry. 41:559-563.
- Øland J, John Jensen, Ask Elklit, Birte Melsen (2011)**
Motives for Surgical-Orthodontic Treatment and Effect of Treatment on Psychosocial Well-Being and Satisfaction: A Prospective Study of 118 Patients.
J Oral Maxillofac Surg. 69:104-113.

Olsen RE, Laskin DM (1980)

Expectations of patients from orthognathic surgery.
J Oral Surg. 38:283-285.

Ong L, Dehaes J, Hoos A, Lammes FB (1995)

Doctor-patient communication - A review of the literature.
Soc Sci Med. 40:903-918.

Ostler S, Kiyak HA (1991)

Treatment expectations versus outcomes among orthognathic surgery patients.
Int J Adult Orthod Orthognathic Surg. 6:247-255.

Ostler K, Thompson C, Kinmonth AL, Peveler RC, Stevens L, Stevens A (2001)

Influence of socio-economic deprivation on the prevalence and outcome of depression in primary care: the Hampshire Depression Project.
Br J Psychiatry. 178(1):12-17.

Otto MW, Wilhelm S, Cohen LS, Harlow BL (2001)

Prevalence of body dysmorphic disorder in a community sample of women.
Am J Psychiatry. 158:2061-2063.

Ouellette PL (1978)

Psychological ramifications of facial change in relation to orthodontic treatment and orthognathic surgery.
J Oral Surg. 36:787-790.

Palumbo B, Cassese R, Fusetti S, Tartaro GP (2006)

Psychological aspects of orthognathic treatment.
Minerva Stomatol. 55:33-42.

Park SG, Lee S, Kim M-K, Kim H-G (2012)

Shared decision support system on dental restoration.
Expert Syst Appl. 39:11775-11781.

Partridge J, Julian D (2008)

The incidence and prevalence of disfigurement.
London: Changing Faces.

Peterson LJ, Topazian RG (1974)

The preoperative interview and psychological evaluation of the orthognathic surgery patient.
J Oral Surg. 32:583-588.

Peterson LJ, Topazian RG (1976)

Psychological considerations in corrective maxillary and midface surgery.
J Oral Surg. 34:157-164.

Phillips C (1999)

Patient-Centered Outcomes in Surgical and Orthodontic Treatment.
Semin Orthod. 5:223-230.

Phillips C, Hill BJ, Cannac C (1995)

The influence of video imaging on patients' perceptions and expectations.
Angle Orthod. 65(4):263-270.

Phillips C, Bennett ME, Broder HL (1998)

Dentofacial disharmony: Psychological status of patients seeking treatment consultation.
Angle Orthod. 68:547-556.

Phillips C, Kiyak HA, Bloomquist D, Turvey TA (2004)

Perceptions of recovery and satisfaction in the short term after orthognathic surgery.
J Oral Maxillofac Surg. 62:535-544.

Phillips C, Essick G, Blakey G 3rd, Tucker M (2007)

Relationship between patients' perceptions of postsurgical sequelae and altered sensations after bilateral sagittal split osteotomy.
J Oral Maxillofac Surg. 65:597-607.

Phillips KA (1996)

The broken mirror.
New York: Oxford University Press.

Phillips KA, Dufresne Jr RG, Wilkel CS, Vittorio CC (2000)

Rate of body dysmorphic disorder in dermatology patients.
J Am Acad Dermatol. 42:436-441.

Pithers RT, Soden R (2000)

Critical thinking in education: a review.
J Educ Res. 42(3):237-249.

Pogrel MA, Scott P (1994)

Is it possible to identify the psychologically "bad risk" orthognathic surgery patient preoperatively?
Int J Adult Orthodon Orthognath Surg. 9(2):105-110.

Pope C, Mays N (2000)

Analysing qualitative data.
BMJ. 320(7227):114-116.

Proffit WR, White RP Jr (1991)

The need for surgical-orthodontic treatment.

In: Proffit WR, White RP (editors). Surgical-Orthodontic Treatment. St. Louis: Mosby, p2-23.

Proffit WR, Phillips C, Dann C 4th (1990)

Who seeks surgical-orthodontic treatment?

Int J Adult Orthodon Orthognath Surg. 5(3):153-160.

Proffit WR, Turvey TA, Phillips C (2007)

The hierarchy of stability and predictability in orthognathic surgery with rigid fixation: an update and extension.

Head Face Med. 3:21.

Proothi M, Drew SJ, Sachs SA (2010)

Motivating factors for patients undergoing orthognathic surgery evaluation.

J Oral Maxillofac Surg. 68:1555-1558.

Pruzinsky T (1992)

Social and psychological effects of major craniofacial deformity.

Cleft Palate Craniofac J. 6:578-583.

Rapee RM, Heimberg RG (1997)

A cognitive-behavioral model of anxiety in social phobia.

Behav Res Ther. 35:741-756.

Ray JJ (1983)

Reviving the problem of acquiescent response bias.

J Soc Psychol. 121:81-96.

Redford M, Gift HC (1997)

Dentist-patient interactions in treatment decision making: a qualitative study.

J Dent Educ. 61:16-21.

Richman L (1978)

The effects of facial disfigurement on teachers' perception of ability in cleft palate children.

Cleft Palate J. 15:155-160.

Rief W, Buhlmann U, Wilhelm S, Borkenhagen A, Brähler E (2006)

The prevalence of body dysmorphic disorder: a population-based survey.

Psychol Med. 36:877-885.

Rispoli A, Acocella A, Pavone I, Tedesco A, Giacomelli E, Ortiz L, Scott AA (2004)
Psychoemotional assessment changes in patients treated with orthognathic surgery: pre- and postsurgery report.
World J Orthod. 5:48-53.

Ritchie J, Spencer L (1994)
Qualitative data analysis for applied policy research.
In: Bryman A, Burgess RG (editors). Analyzing Qualitative Data.
London: Routledge.

Ritchie J, Lewis J (2003)
Qualitative Research Practice: A Guide for Social Science Students and Researchers.
London: Sage Publications Ltd.

Rivera SM, Hatch JP, Dolce C, Bays RA, Van Sickels JE, Rugh JD (2000)
Patients' own reasons and patient-perceived recommendations for orthognathic surgery.
Am J Orthod Dentofacial Orthop. 118(2),134-140.

Robertson M, Moir J, Skelton J, Dowell J, Cowan S (2011)
When the business of sharing treatment decisions is not the same as shared decision making: A discourse analysis of decision sharing in general practice.
Health (London). 15(1):78-95.

Robinson E (1997)
Psychological research on visible difference disfigurement.
In: Landsdown R, Rumsey N, Bradbury E, Carr A, Partridge J (editors). Visibly Different: Coping with Disfigurement.
London: Butterworth-Heinmann, p102-111.

Rodebaugh TL, Woods CM, Heimberg RG (2007)
The reverse of social anxiety is not always the opposite: the reverse-scored items of the Social Interaction Anxiety Scale do not belong.
Behav Ther. 38(2):192-206.

Rodebaugh TL, Woods CM, Heimberg RG, Liebowitz MR, Schneier FR (2006)
The factor structure and screening utility of the Social Interaction Anxiety Scale.
Psychol Assess. 18:231-237.

Rodebaugh TL, Woods CM, Thissen DM, Heimberg RG, Chambless DL, Rapee RM (2004)
More information from fewer questions: the factor structure and item properties of the original and Brief Fear of Negative Evaluation scale.
Psychol Assess. 16:169-181.

Rodebaugh TL, Heimberg RG, Brown PJ, Fernandez KC, Blanco C, Schneier FR, Liebowitz MR (2011)

More reasons to be straightforward: Findings and norms for two scales relevant to social anxiety.

J Anxiety Disord. 25:623-630.

Rolfe G (2006)

Validity, trustworthiness and rigour: quality and the idea of qualitative research.

J Adv Nurs. 53(3):304-310.

Rosen JC, Reiter J (1996)

Development of the body dysmorphic disorder examination.

Behav Res Ther. 34(9):755-766.

Rosenberg M (1965)

Society and the adolescent self-image.

Princeton, NJ: Princeton University Press.

Rosenthal R, Jacobsen CF (1968)

Pygmalion in the classroom: Teacher expectations and pupils' intellectual development.

New York: Holt, Pinehart and Winston, p3-31.

Roter DL, Hall JA (1989)

Studies of doctor-patient interaction.

Annu Rev Public Health. 10:163-180.

Roter D, Hall J (1992)

Doctors talking with patients/Patients talking with doctors.

Westport: Connecticut Auburn House.

Rumsey N, Harcourt D (2004)

Body image and disfigurement: issues and interventions.

Body Image. 1(1):83-97.

Rumsey N, Bull R, Gahagan D (1982)

The effect of facial disfigurement on the proxemic behaviour of the general public.

J Appl Soc Psychol. 12:137-150.

Rumsey N, Byron-Daniel J, Charlton R, Clarke A, Clarke S-A, Harcourt D, James H, Jenkinson E, Lindenmeyer A, Moss T, Newell R, Newman S, Saul K, Thompson A, Walsh E, White P, Williams E (2012)

Identifying the psychosocial factors and processes contributing to successful adjustment to disfiguring condition.

Retrieved from:

<http://www.thehealingfoundation.org.uk/thf2008/images08/media/ARCFinalReport.pdf>

Accessed on: 22/5/2012

Rusanen J, Lahti S, Tolvanen M, Pirttiniemi P (2010)

Quality of life in patients with severe malocclusion before treatment.
Eur J Orthod. 32(1):43-48.

Ruscio AM, Brown TA, Chiu WT, Sareen J, Stein MB, Kessler RC (2008)

Social fears and social phobia in the USA: results from the National Comorbidity Survey Replication.
Psychol Med. 35:15-28.

Rustemeyer J, Eke Z, Bremerich A (2010)

Perception of improvement after orthognathic surgery: the important variables affecting patient satisfaction.
Oral Maxillofac Surg. 14:155-162.

Ryan FS, Shute J, Cunningham SJ (2009)

A qualitative study of orthognathic patients' perceptions of referral to a mental health professional: part 1 - questionnaire development.
J Orthod. 36(2):85-92.

Ryan FS, Barnard M, Cunningham SJ (2012)

What Are Orthognathic Patients' Expectations of Treatment Outcome - A Qualitative Study.
J Oral Maxillofac Surg. 70:2648-2655.

Ryan FS, Shute J, Cedro M, Singh J, Lee E, Lee S, Lloyd TW, Robinson A, Gill D, Hunt NP, Cunningham SJ (2011)

A new style of orthognathic clinic.
J Orthod. 38(2):124-133.

Saarni SI, Suvisaari J, Sintonen H, Pirkola S, Koskinen S, Aromaa A, Lönnqvist J (2007)

Impact of psychiatric disorders on health-related quality of life.
Br J Psychiatry. 190:326-332.

Sadek H, Salem G (2007)

Psychological aspects of orthognathic surgery and its effect on quality of life in Egyptian patients.
East Mediterr Health J. 13:150-159.

Salzburg Global Seminar (2011)

Salzburg statement on shared decision making
BMJ. 342:d1745.

Sandy JR, Irvine GH, Leach A (2001)

Update on orthognathic surgery.
Dent Update 28:337-342 344-345.

Sarwer D, Crerand C (2002)

Psychological issues in patient outcomes.
Facial Plast Surg. 18:125-133.

Sarwer DB, Wadden TA, Whitaker LA (2002)

An investigation of changes in body image following cosmetic surgery.
Plast Reconstr Surg. 109(1):363-369.

Saucier G, Goldberg LR (1998)

What is beyond the Big Five?
J Pers. 66:495-524.

Schneier FR, Johnson J, Hornig CD, Liebowitz MR, Weissman MM (1992)

Social phobia: Comorbidity and morbidity in an epidemiological sample.
Arch Gen Psychiatry. 49:282-291.

Scholl I, Koelewijn-van Loon M, Sepucha K, Elwyn G, Légaré F, Härter M, Dirmaier J (2011)

Measurement of shared decision making – a review of instruments.
Z Evid Fortbild Qual Gesundheitswes. 105(4):313-324.

Shaller D (2007)

Patient-Centered Care: What does it take?
London: The Commonwealth Fund.

Retrieved via:

http://www.commonwealthfund.org/usr_doc/Shaller_patientcenteredcarewhatdoesittake_1067.pdf

Accessed on: 12/4/2013

Shared Decision Making Programme (2012)

Measuring shared decision making. A review of research evidence.

Retrieved from:

http://www.rightcare.nhs.uk/wp-content/uploads/2012/12/Measuring_Shared_Decision_Making_Dec12.pdf

Accessed on: 25/5/2013

Shaw WC (1981)

The influence of children's dentofacial appearance on their social attractiveness as judged by peers and lay adults.

Am J Orthod. 79:399-413.

Shaw WC, Humphreys S (1982)

Influence of children's dentofacial appearance on teacher expectations.

Community Dentist Oral Epidemiol. 10:313-319.

Shaw WC, Meek SC, Jones DS (1980)

Nicknames, teasing, harrassment and the salience of dental features among school children.

Br J Orthod. 7:75-80.

Shaw WC, Rees G, Dawe M, Charles CR (1985)

The influence of dentofacial appearance on the social attractiveness of young adults.

Am J Orthod. 87:21-26.

Shelton CI (2004)

Diagnosis and management of anxiety disorders.

J Am Osteopath Assoc. 104(3 Suppl 1) S2-S5.

Shute R, McCarthy KR, Roberts R (2007)

Predictors of social competence in young adolescents with craniofacial anomalies.

Int J Clin Health Psychol. 7(3):595-613.

Simeon D (2004)

Depersonalisation Disorder: A Contemporary Overview.

CNS Drugs. 18(6):343-354.

Slade GD (2012)

Oral health-related quality of life is important for patients, but what about populations?

Community Dent Oral Epidemiol. 40(Suppl 2):39-43.

Slade PD, Dewey ME, Newton T, Brodie D, Kiemle G (1990)

Development of the body satisfaction scale (BSS).

Psychol Health. 4:213-226.

Smaling A (2003)

Inductive, analogical, and communicative generalization.

Int J Qual Method. 2(1):1.

Smith ER, Mackie DM (2007)

Social Psychology.

New York: Psychology Press.

Snaith RP, Zigmond AS (1994)

The Hospital Anxiety and Depression Scale and The-Irritability Depression-Anxiety Scale and The Leeds Situational Anxiety Scale.

Windsor, Berkshire: NFER-NELSON Publishing Company Ltd.

Solano-Hernandez B, Antonarakis GS, Scolozzi P, Kiliaridis S (2013)

Combined orthodontic and orthognathic surgical treatment for the correction of skeletal anterior open-bite malocclusion: a systematic review on vertical stability.

J Oral Maxillofac Surg. 71(1):98-109.

Sousa CS, Turrini RN (2012)

Complications in orthognathic surgery: A comprehensive review.
J Oral Maxillofac Surg Med Pathol. 24:67-74.

Specht J, Egloff B, Schmukle SC (2011)

Stability and change of personality across the life course: the impact of age and major life events on mean-level and rank-order stability of the Big Five.
J Pers Soc Psychol. 101(4):862-882.

Spencer L, Ritchie J, Lewis J, Dillon L (2003)

Quality in Qualitative Evaluation: A Framework for Assessing Research Evidences.
London: Government Chief Social Research's Office.
Retrieved from: www.strategy.gov.uk/downloads/su/qual/downloads/qqe_rep.pdf
Accessed on: 2/9/2010

Spielberger CD, Gorsuch RL, Lushene R, Vagg PR, Jacobs, GA (1983)

Manual for the State-Trait Anxiety Inventory.
Palo Alto, CA: Consulting Psychologists Press.

Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F, Thomson R (2011)

Decision aids for people facing health treatment or screening decisions.
Cochrane Database Syst Rev. (10):CD001431.

Stangier U, Schramm E, Heidenreich T, Berger M, Clark DM (2011)

Cognitive therapy vs interpersonal psychotherapy in social anxiety disorder: a randomized controlled trial.
Arch Gen Psychiatry. 68(7):692-700.

Stein MB, Stein DJ (2008)

Social Anxiety Disorder.
Lancet. 371(9618):1115-1125.

Stein DJ, Ipser JC, Balkom AJ (2004)

Pharmacotherapy for social phobia.
Cochrane Database Syst Rev. 18(4):CD001206.

Stein MB, Fuetsch M, Müller N, Höfler M, Lieb R, Wittchen H-U (2001)

Social anxiety disorder and the risk of depression: a prospective community study of adolescents and young adults.
Arch Gen Psychiatry. 58(3):251-256.

Stewart M (2001)

Towards a global definition of patient centred care. The patient should be the judge of patient centred care.
BMJ. 322(7284):444-445.

Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J (2000)

The impact of patient-centered care on outcomes.

J Fam Pract. 49(9):796-804.

Stiggelbout AM, Van der Weijden T, De Wit MP, Frosch D, Légaré F, Montori VM, Trevena L, Elwyn G (2012)

Shared decision making: really putting patients at the centre of healthcare.

BMJ. 344:e256.

Stirling J, Latchford G, Morris DO, Kindelan J, Spencer RJ, Bekker HL (2007)

Elective orthognathic treatment decision making: a survey of patient reasons and experiences.

J Orthod. 34(2):113-127.

Stopa L, Clark DM (2001)

Social phobia: Comments on the viability of an analogue research strategy and British norms for the fear of negative evaluation questionnaire.

Behav Cogn Psychother. 29:423-430.

Strauss A, Corbin J (1990)

Basics of qualitative research: Grounded theory procedures and techniques.

Newbury Park, CA: Sage Publications, Inc.

Streiner DL, Norman GR (1995)

Health measurement scales: a practical guide to their development and use.

Oxford: Oxford University Press.

Taylor S (1996)

Meta-analysis of cognitive-behavioral treatments for social phobia.

J Behav Ther Exp Psychiatry. 27:1-9.

Teltzrow T, Kramer F-J, Schulze A, Baethge C, Brachvogel P (2005)

Perioperative complications following sagittal split osteotomy of the mandible.

J Cranio-Maxillofac Surg. 33:307-313.

Thomas CM, Keery H, Williams R, Thompson JK (1998)

The fear of negative appearance evaluation scale: Development and preliminary validation. Paper presented at the annual meeting of the Association for the Advancement of Behavior Therapy, Washington, DC.

Towle A, Godolphin W, Grams G, Lamarre A (2006)

Putting informed and shared decision making into practice.

Health Expect. 9(4):321-332.

Travess HC, Newton JT, Sandy JR, Williams AC (2004)

The development of a patient-centered measure of the process and outcome of combined orthodontic and orthognathic treatment.

J Orthod. 31(3):220-234.

Trulsson U, Strandmark M, Mohlin B, Berggren U (2002)

A qualitative study of teenagers' decisions to undergo orthodontic treatment with fixed appliance.

J Orthod. 29(3):197-204.

Türker N, Varol A, Ogel K, Basa S (2008)

Perceptions of preoperative expectations and postoperative outcomes from orthognathic surgery: part I: Turkish female patients.

Int J Oral Maxillofac Surg. 37(8):710-715.

Turner SM, Beidel DC, Dancu CV, Stanley MA (1989)

An empirically derived inventory to measure social fears and anxiety: The Social Phobia and Anxiety Inventory.

Psychol Assessment. 1:35-40.

Uhlman RF, Inui TS, Carter WB (1984)

Patient requests and expectations. Definitions and clinical applications.

Med Care. 22:681-685.

van Steenberg E, Litt MD, Nanda R (1996)

Presurgical satisfaction with facial appearance in orthognathic surgery patients.

Am J Orthod Dentofacial Orthop. 110(6):653-659.

Van Tol-Geerdink JJ, Stalmeier PF, van Lin EN, Schimmel EC, Huizenga H, van Daal WA, Leer JW (2006)

Do prostate cancer patients want to choose their own radiation treatment?

Int J Radiat Oncol Biol Phys. 66:1105-1111.

Vargo JK, Gladwin M, Ngan P (2003)

Association between ratings of facial attractiveness and patients' motivation for orthognathic surgery.

Orthod Craniofac Res. 6:63-71.

Veale D (2000)

Outcome of cosmetic surgery and "DIY" surgery in patients with body dysmorphic disorder.

Psychiatr Bull. 24:218-221.

Veale D (2003)

Treatment of social phobia.

Adv Psychiatr Treat. 9:258-264.

Veale D (2004)

Body Dysmorphic Disorder.
Postgrad Med J. 80:67-71.

Veroff D, Marr A, Wennberg DE (2013)

Enhanced Support For Shared Decision Making Reduced Costs Of Care For Patients With Preference-Sensitive Conditions.
Health Aff. 32(2):285-293.

Versnel SL, Duivenvoorden HJ, Passchier J, Mathijssen IM (2010)

Satisfaction with facial appearance and its determinants in adults with severe congenital facial disfigurement: a case-referent study.
J Plast Reconstr Aesthet Surg. 63(10):1642-1649.

Vindigni V (2002)

The importance of recognizing body dysmorphic disorder in cosmetic surgery patients: do our patients need a preoperative psychiatric evaluation?
Eur J Plast Surg. 25:305-308.

Voncken MJ, Dijk C, deJong PJ, Roelofs J (2010)

Not self-focused attention but negative beliefs affect poor social performance in social anxiety: An investigation of pathways in the social anxiety-social rejection relationship.
Behav Res Ther. 48:984-991.

Vulink NCC, Rosenberg JM, Plooij R, Koole R, Bergé SJ, Denys D (2008)

Body dysmorphic disorder screening in maxillofacial outpatients presenting for orthognathic surgery.
Int J Oral Maxillofac Surg. 37:985-991.

Wang PS, Lane M, Olfson M, Pincus HA, Wells KB, Kessler RC (2005)

Twelve-month use of mental health services in the United States: results from the National Comorbidity Survey Replication.
Arch Gen Psychiatry. 62:629-640.

Ware JE, Sherbourne CD (1992)

The MOS 36-Item Short-Form Health Survey (SF-36[®]): I. Conceptual framework and item selection.
Med Care. 30(6):473-483.

Watkins LM, Johnston L (2000)

Screening Job Applicants: The Impact of Physical Attractiveness and Application Quality.
Int J Select Assess. 8(2):76-84.

Watson D, Friend R (1969)

Measurement of social-evaluative anxiety.
J Consult Clin Psychol. 33:448-457.

Weber R (2004)

The Rhetoric of Positivism Versus Interpretivism: A Personal View.
MIS Quart. 28(1):3-12.

Weeks JW, Heimberg RG, Fresco DM, Hart TA, Turk CL, Schneier FR, Liebowitz MR (2005)

Empirical validation and psychometric evaluation of the Brief Fear of Negative Evaluation Scale in patients with social anxiety disorder.
Psychol Assess. 17:179-190.

Weeks JW, Heimberg RG, Rodebaugh TL, Norton PJ (2008)

Exploring the relationship between fear of positive evaluation and social anxiety.
J Anxiety Disord. 22(3):386-400.

Weiten W, Lloyd MA, Dunn DS, Hammer EY (2009)

Psychology Applied to Modern Life: Adjustment in the 21st Century.
Belmont, CA, Wadsworth: Cengage Publishing.

Wennberg JE, Fisher ES, Skinner JS (2002)

Geography and the Debate over Medicare Reform.

Retrieved from:

http://www.econ.canterbury.ac.nz/personal_pages/john_fountain/teaching/HealthEcon/reading/HAgeographyWennberg.pdf

Accessed on: 4/5/2013

Wicks S, Hjern A, Gunnell D, Lewis G, Dalman C (2005)

Social adversity in childhood and the risk of developing psychosis: a national cohort study.

Am J Psychiatry. 162(9):1652-1657.

Williams RW, Travess HC, Williams AC (2004)

Patients' experiences after undergoing orthognathic surgery at NHS hospitals in the south west of England.

Br J Oral Maxillofac Surg. 42:419-431.

Williams AC, Shah H, Sandy JR, Travess HC (2005)

Patients' motivations for treatment and their experiences of orthodontic preparation for orthognathic surgery.

J Orthod. 32:191-202.

Williams DM, Bentley R, Cobourne MT, Gibilaro A, Good S, Huppa C, Matthews NS, O'Higgins E, Patel S, Newton JT (2009)

Psychological characteristics of women who require orthognathic surgery: comparison with untreated controls.

Br J Oral Maxillofac Surg. 47:191-195.

Witt E, Bartsch A (1993)

The effect of information and communication in the orthodontic consultation. Part 1: The imparting of information.

Fortschr Kieferorthop. 54(5):187-195.

Wittchen HU, Hoyer J (2001)

Generalized anxiety disorder: Nature and course.

J Clin Psychiatry. 62:15-21.

World Health Organisation (1946)

Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no.2, p100) and entered into force on 7 April 1948.

Retrieved from: <http://www.who.int/about/definition/en/print.html>

Accessed on: 14/3/2012

Wunderlich T, Cooper G, Divine G, Flocke S, Oja-Tebbe N, Stange K, Lafata JE (2010)

Inconsistencies in patient perceptions and observer ratings of shared decision making: the case of colorectal cancer screening.

Patient Educ Couns. 80(3):358-363.

Yamazaki H, Slingsby BT, Takahashi M, Hayashi Y, Sugimori H, Nakayama T (2009)

Characteristics of qualitative studies in influential journals of general medicine: a critical review.

BioScience Trends. 3(6):202-209.

Yu S, Zhang Y, Luo A (2003)

Counseling model of medical students [Chinese].

Chin Psychiatr J. 7:219.

Zhou YH, Hägg U, Rabie AB (2001)

Patient satisfaction following orthognathic surgical correction of skeletal Class III malocclusion.

Int J Adult Orthodon Orthognath Surg. 16:99-107.

Zhou Y, Hägg U, Rabie AB (2002)

Severity of dentofacial deformity, the motivations and the outcome of surgery in skeletal Class III patients.

Chin Med J. 115:1031-1034.

Zigmond AS, Snaith RP (1983)

The Hospital Anxiety and Depression Scale.

Acta Psychiatr Scand. 67(6):361-370.

Zojaji R, Javanbakht M, Ghanadan A, Hosien H, Sadeghi H (2007)

High prevalence of personality abnormalities in patients seeking rhinoplasty.

Otolaryngol Head Neck Surg. 137(1):83-87.