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SECTION

# Elective orthognathic treatment decision making: a survey of patient reasons and experiences

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*Objective:* Few studies have explored decisions about orthognathic treatment (OGT) from the patient's perspective. This study describes the factors associated with the patient's decision to have or not have orthognathic treatment, and assesses whether the process can be considered to be informed decision making.

*Design:* A cross-sectional survey employing both interview and questionnaire methods, conducted in four OGT services in Yorkshire.

*Sample:* Participants were patients aged over 16 years, either making an OGT decision over a 6-month period or had made their treatment choice 18–42 months prior to the study start date in 2003.

*Measures:* Questionnaires assessed patient demographics, dental history and psychopathology (anxiety, satisfaction with self, body satisfaction, facial appearance); interviews explored patients' reasons for, and experiences of, orthognathic treatment.

*Results:* Of 138 patients approached, 61 participated (mean age 25 years, 66% female). Psychopathology scores were within the normal range. The thematic content analysis of interview transcripts found: reasons given for having OGT were to improve the 'bite', as well as gaining a more normal facial appearance; most patients reported the service information was satisfactory, but about half made negative comments, with some reporting staff communications made them feel worse; knowledge of OGT risks and benefits was poor; patients had strong emotions about their facial appearance and the orthognathic treatment they received, which did not seem to be addressed by current practice.

*Conclusions:* Some OGT patients do not appear to be making informed decisions about their treatment. They seem to have unmet needs in relation to support for their decision making, and managing the emotional effects of undergoing and adjusting to treatment. The implications for information provision, assessment and support during treatment are discussed.

*Key words:* Informed choice, orthodontics, attitudes, treatment decisions, orthognathic surgery

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## Introduction

Enabling patients to make informed decisions about elective treatments is a key health policy objective.<sup>1</sup> As well as the ethical imperative that patients are aware of any risks associated with treatment, research indicates that patients tend to be more satisfied when involved in decision making about treatment, for example in

orthopaedic surgery.<sup>2</sup> An informed decision is one made prior to treatment following the patient's evaluation of the risks and benefits of all treatment options, in accord with their beliefs.<sup>3</sup> We know, however, that individuals tend not to make treatment decisions very systematically.<sup>4</sup> Instead, they often employ a range of strategies to make the decision 'easier', such as 'screening out' information that is worrying, does not appeal or relies

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on contextual cues, such as a friend's recommendation. Using these simpler strategies increases the likelihood of more 'wrong' choices being made, and feelings of regret and dissatisfaction,<sup>5</sup> particularly when the decision consequences are serious.

The main treatment option for patients with facial deformity, where there is a significant discrepancy in the position or size of the maxilla or mandible, is orthognathic treatment (OGT). This elective treatment, though, has significant consequences. On average treatment takes place over a two-year period, requiring both orthodontic appliances and surgery.<sup>6-8</sup> Most research on this topic focuses on identifying the psychosocial and clinical factors that may predict uptake of surgery<sup>8-17</sup> and/or post-surgical outcomes.<sup>8,13,15,18</sup> This literature suggests that patient choices about OGT are influenced by their perceptions of their facial form,<sup>19</sup> and not by anxiety, stress, self-esteem, introspection or extraversion, expectations or body satisfaction. Interestingly, it is also not associated with clinician evaluations of facial disharmony.<sup>14,19</sup>

Studies to date have focused on the positive and negative consequences of treatment itself. The former includes improved chewing ability and jaw function, increased self-esteem, straighter teeth and more attractive physical appearance. The latter includes post-operative numbness, pain and surgical or hospital costs.<sup>7,18-22</sup> However, few studies have explored patients' involvement in decision making about OGT from their own perspective. What evidence there is suggests it is unlikely that patients are making informed choices about OGT as their knowledge about the possible consequences of treatment is poor.<sup>10</sup> In addition, in orthodontics, it appears that patients are relying on conversations with peers to make treatment choices, rather than evaluations of accurate information about the risks and benefits of treatment options.<sup>23</sup> Poor knowledge about OGT may be attributable to patient factors, such as information processing biases and memory loss, but there is also evidence that information provision by professionals is of variable, often sub-optimal, quality.<sup>8</sup>

This study attempts to explore the process of decision making by OGT patients in more detail. It aims to describe the factors identified by patients as influencing their decision to have or not have OGT, and ascertain whether this process can be considered to be informed decision making.

## Method

### *Design*

This was a cross-sectional survey utilizing mixed methods. Semi-structured telephone interviews were

employed to elicit patients' reasons for and experiences of OGT. Patient questionnaires were used to record data about patients' demographic characteristics and levels of psychopathology that could be used to compare with the sample characteristics of participants in prior and future research. Clinician questionnaires were used to obtain clinical details and clinicians' expert ratings of severity of patients' facial disfigurements.

### *Sample and setting*

Patients over 16 years old diagnosed with skeletal anomalies of the mandible and maxilla during early childhood, and who were making (or had previously made) choices about OGT were eligible to participate. Patients who were experiencing active psychiatric problems or whose facial deformities were due to trauma were excluded from study participation. All four clinics providing OGT services to North and West Yorkshire agreed to participate. As one of the clinics provided services to two different regions, ethics approval was sought and granted from five committees in 2002.

### *Sample selection*

Purposive, heterogeneous sampling was used to identify patients with a broad range of views and experiences about OGT choices.<sup>24,25</sup> It is likely that those who have undergone decision making about treatment will have a different range of experiences and recall different information as being important in their decision making than those currently facing the decision to undergo treatment. In order to develop a broad understanding, it was decided to include a prospective and retrospective sample. The prospective sample was recruited from all patients accessing OGT services for the first time over a consecutive, eight-month period. The retrospective sample was recruited from all patients who had made choices about OGT 18-42 months prior to the study start date. This time frame meant that all patients who had accessed the newly-structured OGT services were included and also allowed those who had undergone OGT sufficient time to adjust to the impact of invasive procedures. The sample heterogeneity was further enhanced by involving patients from four different clinics; patients accessing different clinics and resources may have received different advice and/or information, and have different views and experiences.

### *Sample size*

There is no algorithm to calculate sample size for qualitative data. The sample size depends on the study

aim, nature of the topic, quality of the data elicited, study scope and the method of analysis employed; sample size can range from 1–50.<sup>24,25</sup> Clinic data showed there to be 67 patients eligible for the prospective sample and 71 for the retrospective sample. The disparity in these figures is illustrative of changes to service provision, as formalized OGT services were newly established and growing. To meet ethical requirements, patients were contacted about the study by post. As response rates for postal surveys can range from 80% to below 40%,<sup>26</sup> all eligible patients were approached and all those agreeing to participate were interviewed.

### Materials

All participants were given a study information sheet, consent form and a patient questionnaire. Consultants were also asked to complete a brief questionnaire for each patient participating in the study. These materials, together with the interview schedule and thematic coding frame, are discussed below.

### Patient questionnaires

The questionnaire purpose was to elicit data to describe the sample in terms of demographic and clinical variables thought by *a priori* research to be potentially important, such as age, orthognathic history, perceived facial attractiveness and standardized measures to assess psychopathology. The patient questionnaires were piloted on a sample of orthognathic patients and assessed for acceptability and wording; the wording was altered accordingly for retrospective and prospective samples. The following variables were assessed:

- Demographic details (age, sex, ethnic origin, highest level of educational attainment) and medical history (orthodontic symptoms, diagnosis, and orthodontic and orthognathic treatments) were assessed using a measure designed for the study.
- Affect (state anxiety levels) was assessed using the State–Trait Anxiety Inventory (STAI: Y-6 item).<sup>27</sup>
- Satisfaction with self may influence perceived attractiveness or desire to change appearance and was assessed in two ways: global self-esteem was assessed using the Rosenberg Self-Esteem Scale (RSES),<sup>28</sup> a widely used 10-item self-report measure; satisfaction with the body was measured using the Body Satisfaction Scale (BSS),<sup>29</sup> a popular self-report measure designed to assess dissatisfaction or satisfaction with a total of 16 body parts, and giving subscale scores for head and body.
- Perceived facial attractiveness was assessed with a study specific measure using two Likert-scale items:

‘compared to others (the general population) my facial appearance is’ (Better–Worse; 1–7) and ‘How would you rate your facial appearance (compared to the general population)’ (very good–very poor; 1–7).<sup>30</sup>

### Consultant questionnaire

The purpose of the questionnaire was to record clinically relevant details from the patient's notes (medical history, diagnosis, recommended treatment) and elicit an expert rating of the patient's perceived facial attractiveness using a modified version of the patient measure described above (‘the patient's facial appearance’, rather than ‘my facial appearance’). This measure provides an estimate of clinical severity and allows a comparison to be made between patient and clinician perceptions of facial attractiveness.<sup>30</sup>

### Interview schedule

Questions were derived from a review of the literature and covered the following areas (Appendix 1):

- reasons for choosing to seek treatment;
- experiences of services and information provided;
- perceived advantages and disadvantages of having and not having OGT;
- consequences of the decision (for the retrospective sample only).

Interview schedule questions were piloted with four clinical psychology trainees and five patients across two different clinics. Because the participants were geographically spread, a telephone interview format was adopted, a viable alternative to face to face interviews.<sup>25,31</sup> The interviewer wrote down participants' responses to questions during the interview. Where necessary, participants were asked to pause to enable accurate documentation of the participant's views.<sup>31</sup> The interviews did not have a time limit.

### Coding frame

This was developed following guidelines for thematic content analysis of transcript data.<sup>25,26</sup> The purpose of the coding frame was to classify patients' utterances into categories that enabled interpretation about the main issues for patients such as accessing services, experiences of decision making about treatment options, views about treatment and the service received, beliefs about their problem, and emotions experienced throughout the process. The final coding frame (Appendix 2) was applied to each patient record of the telephone

interview. The steps used to move from the patient's utterances to themes are described in more detail below:

- One investigator (JS) read over the verbatim notes made during the telephone interview several times and split the text into meaningful units—a word, phrase, sentence or paragraph that imparted a discrete piece of information with one overall meaning.
- Meaningful units were grouped into loose categories in order to identify those items with different or similar meanings. These initial classifications were discussed with HLB and GL and several revisions were made.
- These loose grouping categories made up the preliminary coding frame, which was applied systematically to data from three retrospective and three prospective participants. Where necessary, grouping categories were either collapsed, added to or further divided.
- Discussions took place between JS, HLB and GL relating the grouping categories with the literature on effective decision making, impact of hospital treatment and satisfaction with service delivery. This allowed the identification of broader, conceptual themes. The resulting themes and sub-categories formed the coding frame's final structure.
- The coding frame was applied to all transcripts, so classifying patients' utterances. To check the reliability of the coding frame, JS and a colleague experienced in content analysis independently coded four transcripts and the results were compared, producing a Kappa coefficient for themes of 0.90 (excellent).
- Nineteen themes were generated, including: information about patients' decisions and experiences of OGT, quality of information provided time given to make decision, reason for referral, positive consequences of orthognathic treatment, negative consequences of orthognathic treatment, alternatives to orthognathic treatment, no treatment option, orthodontic treatment offered, other people involved in reaching decision, factors involved in decision, affect raised about decision and treatment.

#### *Procedure – prospective patients*

Patients were sent information about the study before their first orthognathic clinic consultation and approached by JS on arrival at clinic. Patients who agreed to participate provided written consent, completed the questionnaire after their consultation and made arrangements with JS to conduct a telephone interview after four weeks. Participants'

consultant orthodontists completed their brief questionnaire at the point of a patient's written consent.

#### *Procedure – retrospective patients*

Retrospective patients were sent study information, a consent form, questionnaire and pre-paid return envelope. If no reply was received within two weeks, an identical reminder was sent. Upon receipt of completed forms, participants were contacted and the telephone interview was carried out. Participants' consultant orthodontists completed a questionnaire at the point of receiving the patient's written consent.

#### *Data analysis*

The questionnaire data analyses were carried out to:

- provide a description of the participant characteristics;
- assess differences in patient characteristics between the retrospective and prospective group (ANOVA or Chi-square);
- assess differences in patient characteristics with population norms, using data provided in the manuals of the measures used (*t*-tests).

The analyses of the qualitative data were carried out to integrate the findings in such a way as to meet the aims of the study and address the following issues: motives for seeking orthognathic treatment, whether the information provision was sufficient to enable informed decision making; whether patients were making reasoned decisions about treatment, who influenced the decision, affect associated with orthognathic treatment choices. Frequency data were generated from the qualitative analysis and used to illustrate the number of patient's referring to each theme. Frequency data are common in thematic content analysis, but the figures are purely descriptive and should not be used to support patient quotes; using these data statistically is meaningless. The patients' quotes are identified by a participant study number, which relates to the total number approached to take part in the study (range: 1–138).

## **Results**

#### *Quantitative data*

Forty-four per cent of those approached agreed to participate; 31 (46%) prospective patients and 30 (42%) retrospective patients. Those taking part were older (25 years) than those who declined (19 years;  $f=4.21$ ;  $df=1$ ;  $P>0.05$ ).

Two-thirds of participants were female, most were Caucasian and had at least GCSE qualifications (Table 1). There were no differences in demographic details by sample group (Table 1). Analysis of the psychometric measures showed scores were similar for both groups, other than the prospective group having higher dissatisfaction on the head (BSS) subscale ( $f=32.0$ ;  $P<0.01$ ). As a consequence, the analyses suggest the two patient samples were sufficiently homogenous on these measures to be analysed together.

#### Representativeness of sample: psychopathology

Orthognathic patients do not differ from the general population in terms of anxiety, self-esteem or body satisfaction when compared to population norms taken from manuals and key papers reporting the measures' psychometric qualities<sup>27-29</sup> (Table 2).

#### Consistency between consultant and patient ratings

Consultants rated patients' facial appearance 'more severe' than patients' on both items: facial appearance

compared to others ( $t=-4.5$ ,  $P<0.001$ ); rating of facial appearance ( $t=-5.9$ ,  $P=<0.001$ ) (Table 3).

#### Orthognathic history and treatment decision

Although patients talked about their condition with their dentist ( $n=48$ ; 79%), orthodontist ( $n=26$ ; 43%) and/or general medical practitioner ( $n=6$ ; 10%), the clinic appointment was the first time most patients (54/61; 89%) had been referred to orthognathic services. However, in the prospective group, only a quarter (8/31) were undecided about whether or not to have treatment prior to this appointment. In total, only four of the 61 patients chose not to have treatment, one retrospective and three prospective. The main reasons cited for referral to orthognathic services were problems with bite and appearance of teeth (Table 4).

#### Qualitative data

The following section describes the analysis of interviews conducted with 59 participants (29 retrospective, 30 prospective). One prospective participant could not

**Table 1** Demographic characteristics of participants.

		Total ( $n=61$ ) $n$ (%)	Retrospective ( $n=30$ ) $n$ (%)	Prospective ( $n=31$ ) $n$ (%)
Sex	Female	40 (66%)	19 (63%)	21 (68%)
	Male	21 (34%)	11 (37%)	10 (32%)
Ethnic background	White	56 (91%)	29 (97%)	27 (87%)
	South Asian	4 (7%)	1 (3%)	3 (10%)
	Chinese	1 (2%)	0	1 (3%)
Educational level	no formal education	1 (2%)	0	1 (3%)
	GCSE equivalent	26 (42%)	11 (36%)	15 (48%)
	A level or equivalent	14 (23%)	8 (27%)	6 (19%)
	Degree	16 (26%)	9 (30%)	7 (23%)
	professional training	4 (7%)	2 (7%)	2 (7%)

**Table 2** Comparison of standardized psychopathology measures between study and population norms.

Scale		Study mean (SD)	Population mean (SD)
STAI: Y-6 item (low-high anxiety; 20-80)		37 (14)	36 (10)
Rosenberg self-esteem scale (high-low esteem; 10-40)		31 (5)	35 (5)
Body Satisfaction Scale (low-high dissatisfaction; 7-49)	Head dissatisfaction	20 (8)	18 (7)
	Body dissatisfaction	16 (7)	22 (8)

**Table 3** Comparison of patient and consultant rating of participant's facial attractiveness ( $n=59$ ).

	Participant rating mean (CI)	Consultant rating mean (CI)	$t$	Sig.
Facial appearance compared to others (better-worse; 0-6)	4.7 (4.3-5.1)	5.6 (5.4-5.8)	-4.5	<0.001
Rating of facial appearance (better-worse; 0-6)	4.6 (4.3-4.9)	5.6 (5.4-5.8)	-5.9	<0.001

be contacted on the pre-arranged dates after completion of the questionnaire and one retrospective participant was unavailable on both occasions that an appointment had been arranged. A second retrospective participant terminated two telephone calls and the interview was not completed. However, qualitative information from this participant was included because s/he wrote extensively on the returned questionnaire.

#### *Motives for seeking orthognathic treatment (OGT)*

Patients stated in the questionnaires that the most common reasons for referral were problems with their bite and the appearance of their teeth. However, during the interview, patients expressed concerns that their abnormal facial appearance was also a significant reason for seeking treatment. Patients were aware that they looked different from others, that this appearance did affect their behaviour and self-esteem, and that they wanted to look 'more normal':

*I wanted to be able to laugh without covering my mouth and I thought others were talking about my teeth. (patient 58)*

*I always blamed everything on the fact I looked funny. I suppose it's only part of the picture. (patient 84)*

*Facial appearance has been there always really ... in my teens it was a big thing, I hated it. (patient 62)*

*I was teased quite a lot when I was younger over my jaw, [it] quite affected me. (patient 82)*

*It sounds a bit odd but it would be nice to blend into the background a bit more. (patient 100)*

Although patients were comfortable using the functional terminology of bite and teeth alignment to describe their clinical problem, it seemed that professionals' clinical use of these terms could increase

patients' perceived severity of their condition and exacerbate feelings about 'difference':

*When I was told about it at the clinic I started noticing how far back my jaw was. (patient 65)*

*Didn't notice the problem with my bite [until I went to clinic] because I am used to it. (patient 66)*

*I am doing it more [not letting people look at the profile of my face] since the clinic it made me worse, more aware. (patient 103)*

#### *Was the information provision sufficient to enable informed choice?*

When asked explicitly, 78% of patients stated that staff provided information verbally about OGT; 63% of patients also reported receiving written information from the clinic. Few patients (3%) pro-actively sought information despite staff encouraging them to do so and only 10% sought information from other patients. Positive comments about information were provided by 90% of patients:

*When you are at the clinic you forget to ask important information but it is all explained in the leaflets. (patient 8)*

*The literature helped me to find questions which I could then ask about. (patient 52)*

About half (46%) stated that they were unhappy with aspects of the information such as difficulty in understanding the content, variability in quality across the service, and timing:

*Need things simplified so that I can understand ... [they] talk in medical terms. (patient 75)*

*I did not know about the operation until about a year into treatment. (patient 35)*

**Table 4** Patients' reasons for referral to orthognathic services.

	Total (n=61) n (%)	Retrospective (n=30) n (%)	Prospective (n=31) n (%)
Appearance of teeth	44 (72%)	22 (73%)	22 (71%)
Bite problems	43 (71%)	20 (68%)	23 (74%)
General appearance problems	32 (53%)	16 (53%)	16 (52%)
Self-esteem	23 (38%)	14 (47%)	9 (29%)
Chewing and eating problems	16 (26%)	8 (27%)	8 (26%)
Pain in joints of lower jaw	12 (20%)	3 (10%)	9 (29%)
Socializing problems	10 (16%)	6 (20%)	4 (13%)
Speech problems	7 (12%)	5 (17%)	2 (7%)
Headaches	3 (5%)	0	3 (10%)
General health problems	2 (3%)	1 (3%)	1 (3%)

*The stuff I got before the operation was more useful than the stuff I got originally. (patient 15)*

*If I was told at the start that it would of have been two years, I would have been mentally prepared for it ... (patient 73)*

*The information was more about what it would look like after but not about the process of treatment. (patient 28).*

These comments do suggest that not all patients had access to accurate and complete information prior to making their choices. However, some statements also suggest that patients chose not to attend to information that was presented:

*I tried not to think about the bad things they said ... I just wanted it [surgery] done. (patient 12)*

*I didn't want to know the ins and outs [of surgery] I just wanted to do it. (patient 28)*

*Did patients make reasoned choices about the treatment options?*

The statements made by patients suggest that most (66%) were making trade-offs between the pros and cons of having OGT:

*I'm prepared to go through the pain if it makes me feel better about myself. (patient 75)*

*Always thinking about it ... playing it over in my mind. (patient 14)*

*Feel I made the right decision for where I am in life. (patient 10)*

Most patients stated that the benefits of treatment were both functional and appearance, in that they were

'more normal' (Table 5). Improved well-being was also mentioned as positive consequences of treatment:

*Now I look normal. That's quite important as it is not cosmetic surgery. As the aim was not to look beautiful just normal. (patient 84)*

*I think it increased my self-esteem, not that I realized before the operation that I was conscious of my appearance. (patient 94)*

The negative consequences of treatment fell into three categories: issues around the procedure, post-operative recovery and long-term impact (Table 5). The main concerns about the procedure were pain and the treatment not working in terms of feeling or looking any different:

*Worried that I will look better after surgery but I'll still feel the same. (patient 100)*

*I may come out looking worse than I did before or just the same, I'd go through all that pain and just look as peculiar. (patient 100)*

Most patients stated nerve damage as a risk specific to OGT, and general anaesthetics a risk of operations in general. Patients seldom mentioned actual figures for likelihood of occurrence and, in general, negative consequences were mentioned by very few patients (Table 5):

*They didn't put it across as a risk but when putting the break in the jaw to move it about, it may split into more pieces. (patient 48)*

*General anaesthetics [that's] dodgy. (patient 1)*

Most patients (73%) perceived OGT as the only real option available and that once treatment started they

**Table 5** Patients' perception of the positive and negative consequences of orthognathic surgery ( $n=59$ ).

		n (%)
Positive consequences	Appearance	43 (73%)
	Feeling better emotionally	34 (58%)
	Physical benefits, e.g. bite	35 (59%)
Negative consequences – short term	Risks associated with surgical procedures	27 (46%)
	Damage to nerves	41 (69%)
	Infection/problems with blood	7 (12%)
Negative consequences – post operative	Acute pain	14 (24%)
	Appearance	10 (17%)
	Weight loss	6 (10%)
Negative consequences – long term	Appearance	9 (16%)
	Continued problems	4 (7%)
	Chronic pain	5 (8%)

felt there was no stopping; continuing without treatment was not perceived as an option:

*I didn't feel I was given an option ... (patient 3)*

*Long-winded process because once started hard to stop. (patient 12)*

In addition, some patients felt that not having OGT would compromise both their emotional and physical health:

*Yes [risk of no treatment], to my sanity. It would have got me down eventually. (patient 58)*

*It could cause premature ageing. (patient 65)*

A third of patients (37%) discussed some consequences of having orthodontic treatment without surgery. The main advantages were seen as having straighter teeth (22%) and avoiding surgery (7%); the main disadvantages were beliefs that the change would not be permanent (31%) and they would still not look normal (19%):

*They said if I took the brace off it would go back to before. (patient 18)*

*They said it would make my nose look huge as my bottom jaw is too small. (patient 8)*

*Who influenced the choices about orthognathic treatment (OGT)?*

About half (54%) stated that the decision to have treatment was their own. Two-thirds stated that both the dental professionals and family were involved in the decision making; both in terms of support and expressing their opinion on the right choice. Friends were not described as being influential in the decision:

*As a child, it was my parents' decision, I had to accept it. (patient 84)*

*My dentist said he always regretted not having treatment when he was younger, this influenced me to go from 90% sure to 100% sure to have treatment. (patient 51)*

*Did it for me and for my children so they are not embarrassed in the future by me. (patient 84)*

*What affect (emotion) was associated with patients' orthognathic treatment (OGT) choices?*

Most patients expressed quite strong emotions: difficulty and uncertainty in making the decision (25%); guilt about the condition's cause (12%); worry about the

outcome of treatment (34%); frustration at delays in having treatment once the choices had been made (54%):

*Difficult [decision] as neither consultant gave a definite opinion whether I should have it. (patient 90)*

*I don't know. I thought it was my own fault for not wearing the first brace and I thought it was my own fault because of brace ... (patient 69)*

*About a week before the operation it had to be cancelled [due to abscess] and it was put back a year. I was devastated and almost dropped out but I decided to go on. (patient 28)*

## Discussion

This study is one of the first to explore, in detail, the process of decision making about orthognathic treatment (OGT) from the patient's perspective. The study used mixed methods: questionnaires provided data on patients' demographic characteristics, OGT details and psychopathology, semi-structured telephone interviews elicited data about patients' views and experiences of making the decision to have or not to have OGT, in their own words. The findings are summarized under two broad themes, issues pertaining to decision making about OGT, and areas of adjustment to facial anomalies and OGT.

It is unlikely that all patients made truly informed decisions about OGT as patients' choices were not based on evaluations of the advantages and disadvantages of the available treatments options. Functional problems of bite and teeth alignment played a role in patients' OGT decisions, but achieving a normal facial appearance was a key motivation. Furthermore, although patients made statements suggesting some evaluation of treatment attributes (e.g. trading off pain with improvements in appearance), OGT was perceived as the only option; no examples were given to demonstrate patients traded off the positive and negative attributes of the treatment option with the no treatment alternative. Awareness of the risks of OGT was poor and few details about other treatment options were forthcoming. In addition, even though most had made their treatment decision before speaking with the experts, and half identified limitations with service information provision, patients did not seek information about treatment options from other sources.

The findings highlight that living with facial skeletal anomalies, and deciding about and adjusting to treatment, is emotionally demanding. However, these data indicate that patients were not suffering from any type



of body image psychopathology. Indeed, the expert ratings of patients' facial appearance suggest patients had realistic, if not slightly positive, evaluations of their facial appearance. The differences in BSS head subscale ratings between retrospective and prospective patients suggests that the latter group perceived their facial appearance to improve after treatment, i.e. an appropriate evaluation of facial appearance and change. The patients' quotes illustrate that their skeletal anomalies make them functionally and observably different from the normal population, affecting how others behave toward them and how they perceive themselves. Patients see OGT as an option to 'make them normal', a view seemingly endorsed by their family and health professionals. It is understandable that some see withholding or delaying OGT as detrimental to their well-being. Many patients found the decision to undertake OGT difficult and were worried about aspects of OGT. For some patients, there were such strong, unresolved feelings about their treatment experiences that they were unable to engage with the research despite agreeing to participate.

We can have some confidence in the validity of these findings. First, the quality of measures employed were valid and reliable: the psychopathology measures were standardized and/or used in similar samples by *a priori* research;<sup>9,11,14-16,19-21</sup> the coding frame developed to classify the telephone-interview transcripts demonstrated good inter-rater reliability.<sup>24-26</sup> Second, some findings in this study replicate those from other studies with similar populations:

- OGT patients are as psychologically stable as the general population;<sup>7-11,14-16</sup>
- reasons for referral;<sup>12,17,19,23</sup>
- insufficient information provision;<sup>10,11</sup>
- differences in ratings of facial appearance between patients and professionals.<sup>25</sup>

Third, the study recruited a modest-sized sample of patients from four different clinics across Yorkshire with a range of OGT decisions and experiences. It is likely that the findings do represent the views of patients making such treatment choices, suggesting the findings may be generalizable to other OGT service providers.

However, there are some methodological considerations to take into account when interpreting these findings. First, the non-participation rate was 56%. This recruitment rate was in line with expectations for the use of postal methods for approaching participants. Also, it is feasible that the attrition rate was affected by the patient group being young and, therefore, more likely to have moved away from the original contact addresses, e.g. to university. However, it is always

possible that the experiences of those who chose not to take part differed from the study participants. Indeed, it seems fair to suggest that some non-participants had strong negative or unresolved issues about OGT that are not represented amongst these data. On the other hand, other non-responders may have been entirely happy with their OGT experience. Second, this was a cross-sectional design—a 'snapshot' of patients' experiences at either the beginning or end of the OGT decision-making journey. As this treatment can take two years to complete, it is possible that the experiences and views important to patients at different stages were not identified because of memory limitations and recall bias. For example, what were patients' views and experiences half-way through their treatment when the pre-surgical orthodontics may have worsened their facial appearance due to 'decompensation' factors, as well as the physical presence of fixed stainless steel orthodontic appliances on their teeth? Third, the study did not objectively assess the quality of both verbal and written information provided to patients in the four clinics. It is not clear what clinical information was provided to patients. Therefore, it is difficult to ascertain whether limitations in patients' knowledge about the advantages or disadvantages of OGT was attributable to the patients' own processing and recall of information, or due to limitations in service delivery and resources within each of the participating units.

This study has several implications for services providing OGT. First, measures of psychopathology and beliefs about abnormal perceptions of appearance do not explain patients' reasons for undertaking OGT and are unlikely, by themselves, to be useful as part of the assessment or evaluation of treatment. As patients' reasons for having treatment are realistic, i.e. to look normal, rather than beautiful and to improve functionality, future service indicators should involve comprehensive measures of patient well-being. Second, patients do have fears and worries about the consequences of treatment, its effect on their appearance and adjustment post-treatment. Some patients also reported feeling worse after conversations with staff and it was clear some had strong needs that were unmet by current service provision. It is likely that the use of psychological services to assess patient need and deliver treatment to assist patients' adjustment to invasive treatments, and significant changes in their facial appearance would address these issues. Third, some patients were not making informed decisions about OGT. In emotionally demanding or difficult treatment contexts, patients will be reluctant to evaluate systematically information about all the treatment options;<sup>4</sup> they will rely on a simpler strategy to justify their choice,

such as the desire to be more normal. However, there is evidence that, if patients are encouraged to evaluate the advantages and disadvantages of all treatment options, and how they would feel about the associated consequences, they will be better prepared for procedures, experience less distress about decision making and have more realistic expectations of treatment outcomes.<sup>4,33</sup>

This study provides a snapshot of the experiences of OGT patients from four clinics within one region in the UK. What is evident is that facial anomalies and associated OGT have an impact on patients' physical, emotional and social well-being. This study's findings suggest that current OGT services may not be fully meeting the needs of all their patients. This is, in part, attributable to organizational changes, service limitations and issues pertaining to body image psychopathology.<sup>32</sup> As a result, research is required to ascertain the effectiveness of interventions to support patients in making these difficult treatment decisions.

## Conclusion

These findings suggest that there are a number of options that could enhance OGT services and these are summarized below:

- Decision aids to support patients in making informed choices about orthognathic treatment.<sup>3,4,33</sup> As treatment is lengthy, it is feasible that a set of decision aid interventions may be useful in enabling patient involvement at different stages of the two-year treatment process.
- Consideration should be given for ways of ameliorating the normal reactions of those contemplating or undergoing the invasive procedures that typify orthognathic treatment: *information aids* increase knowledge and satisfaction about treatment and procedures, reduce anxiety, and prepare patients for procedures;<sup>34</sup> *one-to-one counselling* helps patients adjust to the physical and emotional changes as a result of treatment and the secondary impact of hospitalization and surgery.
- Services should adopt more comprehensive measures of well-being rather than focusing on psychopathology;<sup>18,35,36</sup> for example, measures assessing the efficacy of services<sup>37</sup> to improve patients' emotional, social and functional well-being.
- Consideration should be given towards developing a UK-wide protocol to standardize the information patients receive during their orthognathic treatment 'journey', i.e. a formal care pathway and, ideally, the way in which this should be delivered.

## Contributors

This study was carried out as part of Jackie Stirling's professional training in Clinical Psychology. Hilary Bekker was the lead academic supervisor, Gary Latchford was the course supervisor, and Jay Kindelan, James Spencer and David Morris were the clinical expert supervisors. All authors contributed to study research aim, design, evaluation of measures, intellectual content of the paper, and approval of the final version of the paper. Jackie Stirling was responsible for: submitting applications for ethical approval (overseen by Jay Kindelan, James Spencer and David Morris); analysing the data and writing up the thesis (overseen by Hilary Bekker and Gary Latchford); providing a first draft of the current paper and coordinating responses from other authors. Hilary Bekker has been responsible for subsequent revisions. Hilary Bekker is the guarantor.

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## References

1. Department of Health. *The NHS improvement plan: putting people at the heart of public services*. London: Department of Health; 2004. Available at: <http://www.dh.gov.uk/assetRoot/04/08/45/22/04084522.pdf> (accessed 19 December 2006).
2. Farley F, Weinstein S. The case for patient-centered care in orthopaedics. *J Am Acad Orthop Surg* 2006; **14**: 447–51.
3. Bekker H, Thornton JG, Airey CM, *et al.* Informed decision-making: an annotated bibliography and systematic review. *Health Technol Assess*, **3**: 1–156.
4. Bekker HL. Genetic screening: facilitating informed choices. In D. N. Cooper, ed. *Nature encyclopedia of the human genome*. London: Nature, 2003; 926–30.
5. Baron J. *Thinking and Deciding*, 2nd edn. Cambridge: Cambridge University Press; 1994.
6. Lovius BB, Jones RB, Pospisil OA, Reid D, Slade PD, Wynne TH. The specific psychological effects of orthognathic surgery. *J Craniomaxillofac Surg* 1990; **18**: 339–42.

7. Harris M, Reynolds I. *Fundamentals of orthognathic surgery*. London: WB Saunders, 1991.
8. Hoppenreijts TJ, Hakman EC, van't Hof MA, Stoelinga PJ, Tuinzing DB, Freihofer HPM. Psychological implications of surgical-orthodontic treatment in patients with anterior open bite. *Int J Adult Orthodont Orthognath Surg* 1999; **14**: 101–12.
9. Kiyak HA, McNeill RW, West RA, Hohl T, Heaton PJ. Personality characteristics as predictors and sequelae of surgical and conventional orthodontics. *Am J Orthod* 1986; **89**: 383–92.
10. Kiyak HA. Psychological aspects of orthognathic surgery. *Psychol Health* 1993; **8**: 197–21.
11. Finlay PM, Atkinson JM, Moos KF. Orthognathic surgery: patient expectations; psychological profile and satisfaction with outcome. *Br J Oral Maxillofac Surg* 1995; **33**: 9–14.
12. Forssell H, Finne K, Forssell K, Panula K, Blinnikka L. Expectations and perceptions regarding treatment: A prospective study of patients undergoing orthognathic surgery. *Int J Adult Orthodont Orthognath Surg* 1998; **13**: 107–13.
13. Tucker MR. Orthognathic surgery versus orthodontic camouflage in the treatment of mandibular deficiency. *J Oral Maxillofac Surg* 1995; **53**: 572–78.
14. Scott AA, Hatch JP, Rugh JD, et al. Psychosocial predictors of high-risk patients undergoing orthognathic surgery. *Int J Adult Orthodont Orthognath Surg* 1999; **14**: 113–24.
15. Scott AA, Hatch JP, Rugh JD, et al. Psychosocial predictors of satisfaction among orthognathic surgery patients. *Int J Adult Orthodont Orthognath Surg* 2000; **15**: 7–15.
16. Cunningham SJ, Gilthorpe MS, Hunt NP. Are orthognathic patients different? *Eur J Orthod* 2000; **22**: 195–202.
17. Rivera SM, Hatch JP, Dolce C, Bays RA, Van Sickels JE, Rugh JD. Patients' own reasons and patient-perceived recommendations for orthognathic surgery. *Am J Orthod Dentofacial Orthop* 2000; **118**: 134–40.
18. Cunningham SJ, Hunt NP. Quality of life and its importance in orthodontics. *J Orthod* 2001; **28**: 152–58.
19. Bell R, Kiyak HA, Joondeph DR, McNeill RW, Wallen TR. Perceptions of facial profile and their influence on the decision to undergo orthognathic surgery. *Am J Orthod* 1985; **88**: 323–32.
20. Kindelan JD, Sheard CE, Nashed RR. A comparison of patients requiring orthognathic treatment who subsequently refused or accepted surgery. *Int J Adult Orthodont Orthognath Surg* 1998; **13**: 115–18.
21. O'Brien K, Kay L, Fox D, Mandall N. Assessing oral health outcomes for orthodontics – measuring health status and quality of life. *Community Dent Health* 1998; **15**: 22–26.
22. Ronis DL, Callan MA, Vig KW, Vig PS, McNamara JA Jr. Developing measures of patients' perceptions of orthognathic surgery. *Int J Adult Orthodont Orthognath Surg* 1994; **9**: 87–94.
23. Trulsson U, Strandmark M, Mohlin B, Berggren U. A qualitative study of teenagers' decisions to undergo orthodontic treatment with fixed appliances. *J Orthod* 2002; **29**: 197–204.
24. Ritchie J, Lewis J, eds. *Qualitative research practice: a guide for social science students and researchers*. London: Sage, 2005.
25. Robson C. *Real world research: a resource for social scientists and practitioner-researchers*, 2nd edn. Oxford: Blackwell, 2002.
26. Breakwell GM, Hammond S, Fife-Schaw C, eds. *Research methods in psychology*. London: Sage, 1995.
27. Marteau TM, Bekker H. The development of a six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory (STAI). *Br J Clin Psychol* 1992; **31**: 301–6.
28. Rosenberg M. *Society and the adolescent self-image*, rev edn. Middletown: Wesleyan University Press, 1989.
29. Slade PD, Dewey ME, Newton T, Brodie D, Kiemle G. Development and preliminary validation of the body satisfaction scale (BSS). *Psychol Health* 1990; **4**: 213–20.
30. Dunlevy HA, White RP Jr, Proffit WR, Turvey TA. Professional and lay judgement of facial esthetic changes following orthognathic surgery. *Int J Adult Orthodont Orthognath Surg* 1987; **2**: 151–58.
31. Sturges JE, Hanrahan KJ. Comparing telephone and face-to-face qualitative interviewing: a research note. *Qual Res* 2004; **4**: 107–18.
32. Morris DO. Improving standards in orthognathic care: the bigger picture (a national and international perspective). *J Orthod* 2006; **33**: 149–51.
33. O'Connor AM, Stacey D, Entwistle V, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2003; **2**: CD001431, review.
34. Ley P, Llewellyn S. Improving patients' understanding, recall, satisfaction and compliance. In Broome A, Llewellyn S, eds, *Health psychology: processes and applications*, 2nd edn. London: Chapman & Hall, 1995; 75–98.
35. Gregory J, Gibson B, Robinson PG. Variation and change in the meaning of oral health related quality of life: a 'grounded' systems approach. *Soc Sci Med* 2005; **60**: 1859–68.
36. Juggins KJ, Feinmann C, Shute J, Cunningham SJ. Psychological support for orthognathic patients – what do orthodontists want? *J Orthod* 2006; **33**: 107–15.
37. Travess HC, Newton JT, Sandy JR, Williams AC. The development of a patient-centered measure of the process and outcome of combined orthodontic and orthognathic treatment. *J Orthod* 2004; **31**: 220–34.

## **Appendix 1: semi-structured interview schedule**

- 1. Why were you referred to the combined surgical orthodontic clinic?**
  - Prompt: what were your physical symptoms?
  - Prompt: other than physical symptoms what other problems did your jaw and teeth cause you?
- 2. Please describe your experience of the combined surgical orthodontic clinic, from the point that you were referred to the point when a decision was made whether to go forward for treatment or not?**
  - Prompt: what did you know about combined surgical orthodontic treatment before you were referred?
  - Prompt: who advised you to seek a consultation with combined surgical orthodontic treatment?
- 3. How did you come to a decision?**
  - Prompt: what influenced your decision?
  - Prompt: what were the alternatives to surgery?
  - Prompt: how involved were your family and friends in making the decision?
- 4. What information did you access to inform you about combined surgical orthodontic treatment?**
  - Prompt: where did you access this information?
  - Prompt: how useful was this information?
- 5. What were the benefits of having surgery?**
- 6. What were the risks of having surgery?**
- 7. What were the benefits of other treatments?**
- 8. What were the risks of other treatments?**
- 9. How do you feel about your decision now?**

## Appendix 2: final thematic coding frame to classify patient responses

<b>Behaviour</b>	Actual	Had	
		Did not have	
	Intention	Yes	
		No	
Uncertain			
<b>Who Advised referral</b>	Self		
	Dentist		
	Practical		
	No knowledge		
<b>Reason For Referral</b>	Eating/Chewing		
	Pain		
	Dental problems		
	Bite		
	Breathing Difficulties		
	No Physical Problems		
	Appearance		
	Emotional impact		
	Investigating Options		
	Memory of Reason for Referral		
	Speech		
<b>Referred in the Past</b>	Yes		
	No		

<b>Prior Expectations/Experiences</b>			
<b>Previous Knowledge</b>	None		
	Who got information from	Work	
		Dental professional	
		Family/friends experience	
Some knowledge			
<b>Who Provided the Information</b>	Clinic	Leaflets	
		Staff	
		Photographs/Models	
		Clinic wall	
		Past patients	
	Self-sought	None	
		Internet	
		Books	
		Magazines	
		Radio	
		Television	
	Timing of information		
<b>Quality of Information</b>	Positive statement		
	Negative statement		
	Content of Information		

<b>Process of Treatment</b>				
<b>Positive Consequences of Orthognathic Treatment</b>	Appearance			
	Concept of being 'normal'			
	Emotional consequences			
	Physical			
	None			
<b>Negative Consequences of Orthognathic Surgery</b>	General Risks of surgery			
	Specific Risks of surgery	Uncertainty about procedure		
		Anaesthetic		
		Blood		
		Problems in the operation		
		Damage to Nerve		
	Immediately post-op	Infection		
		Acute Pain		
		Diet/weight loss		
		Appearance		
	Long-term problems	Emotional consequence		
		Chronic Pain		
		Emotional Consequence		
		Continued bone growth		
	Appearance			
Orthodontics				
Knowledge of % chance of consequence occurring				
Practical	Time to get back to normal			
Not remember/unsure				
<b>Alternatives to orthognathic surgery</b>	Orthodontics only			
	No treatment			
<b>No treatment</b>	Positive consequences	Don't know		
		None		
		Avoid negative consequences of surgery		
	Negative consequences	No change		
		Increase in problems		
None				
<b>Orthodontic Treatment Only</b>	Positive Consequences	Avoid negative consequences of surgery		
		Unsure		
		Straight teeth		
		Length of time		
		Physical		
	Negative Consequences	Permanence/Extent of change		
		Physical		
Emotional				

<b>Orthodontic Treatment Only</b>	Negative Consequences	Cost	
		Appearance	
		None	
		Unsure	
		Length of time	

<b>People involved in decision</b>	Dental professional		
	Family and friends	No involvement	
		Concordant	
		Discordant	
<b>Factors Involved in Decision</b>	Physical		
	Own		
	Experience of others		
	Expertise of surgeons		
	Appearance		
	Emotional		
	Avoiding regret		
	Information		
	Time		
	Evaluation		
	No alternative		
	None		
	Cost		
<b>Time for decision</b>			
<b>Emotions</b>	Positive	Positive	
		Relief	
	Negative	Bad	
		Frustration	
		Fear/Worry	
Ambiguous/Uncertain			
<b>Experience of clinic</b>	Positive		
	Neutral		
	Negative		
<b>No further comment</b>			