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Does the British Orthodontic Society orthognathic DVD aid a prospective patient's decision making? A qualitative study

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Abstract

Objectives: To explore the views of potential orthognathic patients concerning the influence of the BOS Orthognathic DVD in their decision making process.

Design: Qualitative, cross sectional study

Setting: A UK dental teaching hospital

Participants: Patients considering orthognathic treatment

Methods: New patients were recruited from orthognathic clinics following an initial consultation. After an appropriate time to view the DVD, in-depth interviews were conducted with 10 patients (aged 16–48yrs) in their homes. Interviews explored the attitudes and perceptions that influenced the decisions about surgery, with a focus on the role of the DVD in this process. The interviews were transcribed and a framework analysis was undertaken.

Results: The main themes identified were the participants' perceptions on the patient stories, use of images, the nature of the DVD itself and its usefulness in the decision making process. Participants reported they were heavily influenced by the patient stories. Virtual animations of surgery were seen as useful; whereas the before and after images of surgery were found to be disorientating. The design of the menu resulted in confusion or information being missed. The DVD was seen as a trusted resource, whereas the Internet was seen as biased, general and sensationalistic.

Conclusions: The DVD gives trusted information that patients cannot obtain or process from professional sources or the Internet. If used properly it can have a role in the decision making process, but should be seen within the context of other influences on the patient. This research has highlighted some aspects of the DVD that could be improved upon.

KEYWORDS: Consent, Decision making, Patient information, Orthognathic

Introduction

The decision to undergo orthognathic treatment is a complex one for patients, who must understand the potential risks, as well as benefits, before deciding to proceed. Although satisfaction rates following orthognathic treatment are generally high, patients with unrealistic expectations are more likely to be unhappy with their treatment.¹ Despite the best efforts of clinicians to impart information to patients to allow them to make informed decisions about their treatment, patient drop outs vary from 7-28%.^{2, 3} The most common reason given by patients for dropping out was satisfaction with the presurgical orthodontic result.^{2,3}

Qualitative research has highlighted the complex decision making process patients must go through when considering orthognathic treatment. Broder⁴ found most prospective patients confirmed that the decision to have surgery was their own, but they discussed it with close family and friends in order to gain endorsement for their decision and good doctor-patient communication was essential.

Other studies have examined the retention of patient knowledge about orthognathic treatment. Stirling et al⁵ found that the risks of treatment were poorly understood. The majority of patients in the study (73%) were under the impression that orthognathic treatment was their only option and almost half (46%) were unhappy with aspects of information delivery. Some cited staff communication as responsible for making them feel worse. This may have implications in the decision making process.

Orthognathic decision making involves patients processing information from many sources, including clinical consultations, specifically designed information leaflets and even the Internet. Recent research has looked into the validity of Internet resources using the DISCERN tool. This highlighted the fact that few websites hold the correct amount of valid information to be of use to patients.⁶ A DVD was produced by the British Orthodontic Society (BOS) in 2007 to aid patients understanding about orthognathic treatment.⁷ It was developed by a group of clinicians, including an orthodontist who had undergone orthognathic treatment; however little research has been carried out to assess what prospective orthognathic patients think about the usefulness and effectiveness of this DVD.

The aim of this project was to explore, using qualitative methods, the role of the BOS DVD in the decision making process of patients considering orthognathic treatment. The specific research questions were:

- What are the opinions of patients about the BOS Orthognathic DVD as they decide whether or not to undergo surgery?
- Does the DVD aid the decision making process?

The findings of this study are important to understand the use of the DVD in clinical practice and to consider the need for further resources to improve decision making.

Participants and methods

This was a prospective cross-sectional qualitative study. Ethical approval was obtained from Yorkshire and the Humber Research Ethics Committee (Ref 08/H1308/228; September 2011). Research governance approval was obtained from Doncaster and Bassetlaw Hospitals NHS Foundation Trust (the sponsor for the study) and Sheffield Teaching Hospitals NHS Foundation Trust, where the research was undertaken.

Participants were recruited from joint orthodontic/orthognathic clinics undertaken in the Orthodontic Department of the Charles Clifford Dental Hospital, Sheffield. Purposive sampling was undertaken to include patients, of any ethnic origin, who were considering, but had not undergone, orthognathic treatment to address skeletal discrepancy. Sampling was based on a sampling framework including age, gender and skeletal discrepancy. There was no upper age limit for inclusion, but teenage patients had to be developmentally ready for surgery. Patients were not approached if they were under 16 years old, had a craniofacial syndrome (including cleft lip and/or palate), complex medical histories, were considering re-operation following a previous osteotomy or trauma, or were unable to fluently communicate in English.

Potential participants were approached by a senior clinician when they attended the joint clinic, were given a brief explanation of the study and then asked if they wished to take part. If they showed interest in the research they were provided with an information leaflet about the study and consent form, as well as a copy of the BOS orthognathic DVD to view at their leisure. The BOS orthognathic DVD is given routinely to all patients following their attendance at the joint clinic. After a period of two weeks the patient was contacted and asked if they would agree to be

interviewed. The timings of interviews were considered important, as the aim was to obtain participants' views after their first joint orthognathic clinic meeting and when they had had sufficient time to view and contemplate the DVD. It was hoped to capture participants in the 'decision making process' in order to gain understanding about how they weighed-up the information they had been given, the nature of their skeletal discrepancy, and the role of the DVD.

Interviews were undertaken in the participant's home to ensure they were as relaxed as possible and more likely to respond naturally.⁸ Before the start of the interview written consent was obtained and participants were asked for a pseudonym to ensure anonymity. The interviews were semi-structured and a topic guide (see appendix), based on a review of the literature (Stirling et al 2007) and informal discussions with patients, was used to ensure all key areas of interest were covered. However the nature of the interview allowed the phrasing of the questions to be adapted for each participant and an exploration of new relevant themes that arose. The interviewer (AF), received theoretical and practical training from an experienced researcher before commencing the interviews. All interviews were recorded digitally, and transcribed verbatim by the researcher who conducted the interviews.

Data analysis

The approach to analysis was based on framework analysis.⁹ The first step included familiarisation with the data. Key themes were identified and referenced in the participants' responses. The production of thematic frameworks was initially drawn from the original objectives of the project. As data analysis continued new themes emerged from recurring points of view or experiences found in the data. Data collection stopped when saturation was reached and no new themes emerged. Two senior researchers (ZM, MH) then reviewed the transcripts and discussion took place to refine the key themes.

Results

Recruitment occurred between October 2011 and March 2012. A total of 18 patients, who were considering undergoing orthodontic treatment and orthognathic surgery, were invited to take part. Of these sixteen patients were contacted and four refused to take part. Ten interviews were undertaken. After 10 interviews it was decided that further interviews would provide little additional information. The two remaining

patients who were interested in participating were then contacted to thank them for their interest and to tell them their participation was no longer required. Four males and six females were interviewed, with ages ranging from 16 to 48 years. Interviews lasted between 12 and 52 minutes. All participants were White British and a range of malocclusions were presented in the individuals interviewed (Table 1).

Four themes were identified regarding the influence of the DVD on the decision about whether or not to undergo orthognathic surgery (Figure 1).

- Patient stories
 - Value
 - Problems
- Use of images
 - Surgery animations
 - Before and after pictures
- Nature of the DVD
 - Structure
 - Use
- Usefulness in the decision making process
 - Opinion of the DVD
 - Comparison to other sources of information

Theme 1 – Patient stories

Participants immediately focused on the patient stories as an overwhelming gain from the DVD. Patient stories are interspersed between each information section presented by the narrator, on the DVD.

Value

Participants valued the patient stories in terms of understanding what they may experience, both the positive and negative aspects. To some it appeared to establish the reality of the decision under consideration. The stories appeared balanced and credible to the viewers.

"It was quite useful cos....obviously they weren't actors....they explained their concerns and things they found difficult about it." (Jane 16yrs old)

"I could see these people had been transformed, y'know it's only 10 mm in some direction." (Paul, 38yrs old)

"It terrified me to be honest the DVD, more than the surgeon." "After watching the DVD it did sink in." "It kinda made you realise it's real." "It's easy sitting in a room with a gentlemen explaining what they're going to do..."

"But it was more the patient stories that put me off really." (In relation to the patients on the DVD talking about the surgery and post-operative recovery) (Laura 27yrs old)

Being able to see a patient wearing orthodontic appliances was also valued:

"It was good to see someone that still had the braces still on cos I could see sort what they looked like.....I haven't had them before, it's hard to visualise. (Paul S, 19yrs old)

Problems

Although the patient stories were valued they were not without some problems. Younger participants interviewed commented that they did not relate to the patients due to their age. Participants aged in the late teens commented that patients on the DVD were likely to be unaware of peer pressure, the stress of exams and schooling and the concerns of juggling university entry with a decision to undergo surgery. One participant commented upon the isolation she felt after watching the patient stories (Figure 2).

"The people that were interviewed, were all a lot older than I am....I wanted someone's opinion who was more my age...I felt like I was the only one this young probably." (Amy, 16yrs old)

Other patients found it a little difficult to relate to the patients, as they didn't describe their motivations for surgery.

"There wasn't a bit...where the patient said what was wrong with them before." (Barry 19yrs old)

Some felt that the DVD could be improved if the patients interviewed would have suggested tips and hints about recovery after the surgery, but that this was not discussed.

Theme 2 – Use of images

The second theme to emerge from the data was participant perspectives on the use of images. Within this theme were the subthemes of the surgery animation and the before and after pictures. The surgery animation accompanies each surgical operation explanation. Before and after pictures accompany each patient story.

Surgery animations

Accounts suggested that the virtual animations used to explain the surgery also improved the participants understanding of what surgery involved. Patients commented that the moving images were better than the explanation in the joint clinic. Viewers were relieved to find that no actual images of surgery were on the DVD.

"They helped you to picture it better than just talk about it. You can see what they've done." (Amy 16yrs old)

"The graphics and descriptions of the operations were done in a very good way I thought." (Paul, 38yrs old)

Before and after pictures

Interviewees commented on wanting to see the changes that surgery can provide. The DVD does have images of patient's before and after surgery, but respondents indicated that they found these confusing. The 'before' pictures were of the patients in profile, but the 'after' pictures were a still image taken from the front (Figure 3). This made it difficult to see the facial changes surgery could provide, as the photos were not comparing like with like.

"I think the only improvement would be the before and after pictures, cos I'd think it would have been better if you'd shown 2 pictures of the side

view and the front view instead of one of each, cos you couldn't really tell the difference." (Jane, 16yrs old)

Participants commented on wanting to see the effect surgery would have on the appearance and bite of the teeth. Some commented they wanted to see the changes of the face also, but this seemed less important than the tooth-related changes that may occur. Some patients, during their consultation, had been shown a full set of before and after images from an orthodontic imaging programme and commented that these were better than the ones on the DVD.

"I'd already had pictures shown to me at the Dentist as well. So I've already seen before and after photos....I asked for them because I think that they are really helpful." (Jane P, 19yrs old)

"The ones at the hospital were better to be honest with you because it showed you the teeth inside, it showed you the profile as well as face front." (Paul, 38yrs old)

Theme 3 – Nature of the DVD

The third theme related to the structure of the DVD and how it was used.

Structure

Although participants mentioned that they liked the DVD menu, the array of titles to click on did result in confusion or information being missed. The interactive menu led to, in some cases, participants avoiding certain sections of the DVD they did not deem relevant or were frightened of, for example the 'surgery section'. Some viewers commented that they avoided the surgery section for fear of seeing pictures of real surgery. One person had been told by their dentist that there were real videos of surgery being performed.

"My dentist told me that the operation would be on the DVD...but not to watch it if I didn't want to!" (Jane P, 16yrs old)

Other participants were not told at their consultation what type of surgery was being provisionally planned. This led to, in some cases, patients watching the entire surgery section of all the orthognathic operations.

*"It was very long, a lot of duplication between the different sections."
(Sarah, 48yrs old)*

Linked to this, although not exclusively, some participants complained that the DVD was too long, repetitive or 'long-winded'. The editing of the DVD results in the beginning of each surgery section being exactly the same.

"I wasn't sure whether, cos of the edit...whether what I was watching, I'd watched before or not!" (Paul, 38yrs old)

Use

Participants commonly stated that they watched the DVD only once completely. There appeared to be an initial reluctance by most to watch the DVD straight away after receiving it from the consultation clinic. Some watched most of the DVD once and then went back to other sections they were interested in later.

*"I watched all of it, just once." (alone) "I went to the most interesting bit first like the surgery...then went back and watched the other bits."
(Barry, 19yrs old)*

Participants watched the DVD by themselves or with one or two close family members. Partners and parents were the most commonly quoted people with which to watch the DVD. This was to help to understand the language used in the DVD.

"I watched it alone, and then I had to watch it with him (husband) so twice...cos a few words I didn't understand really...but (he) explained them." (Laura, 27yrs old)

Other viewers found it useful to watch it with close family members to engender discussion.

"I watched it about 3 (times), I watched it all apart from the surgery part." "I'm quite busy so I've watched it in chunks..but I liked watching it in chunks...you can really look at each stage a bit." "I watched it a bit...then you (mum) watched it with me....I need to learn about things myself and make up my mind." (Jane P, 27yrs old)

Some patients excused themselves only viewing it once by saying that watching the DVD was not a priority in their busy lives.

"Only the once...my husband watched it with me....I'll probably watch it another day, it's just time." (Sarah, 48yrs old)

Despite only reportedly watching the DVD once, all participants wanted to keep their copy of DVD rather than return it to the hospital.

The feeling from most people interviewed was that the DVD was important to watch before coming to a decision about surgery, because participants felt they gained knowledge and information that they did not gain from the clinical consultations or other sources.

During one of the early interviews a participant commented upon the use of an online resource as well as the DVD.

"Maybe if there was an online element so you could view all that information before going to the hospital.(For consultation)" (Barry, 19yrs old)

The use of online resources was explored further in subsequent interviews as a complement to or a replacement for the DVD. Opinions were mixed on whether replacement of the DVD was prudent at this time; however, some interesting ideas were discussed that may warrant further discussion among professionals at a later date.

"You could sort of log in or whatever, on website and have all the information that's both generic and specific that's relevant to that person...and somewhere where you could talk to the surgeon or someone on a consultation...like a mini forum....clips on the DVD could quite easily be put on a network."

"(Add) various different bits about aftercare, it would be slightly more user friendly...cos DVD's are easier to lose. "(Paul S, 19yrs old)

Theme 4 – Usefulness in the decision making process

The final theme focused on the overall usefulness of the DVD in the decision making process.

Opinion of the DVD

Participants reported a range of views on the construction of the DVD to their decision making.

"I thought it was good. It wasn't too sort of pressurised, it was relaxed and, just simple and explained it to you.....and after the DVD I have, sort of, made my decision.....I think everyone who's considering it (surgery) should watch it definitely."(Jane, 16yrs old)

"I mean when it comes to further down the line and having the DVD, that's something that's more detailed and would help you make a decision. I think I do have enough information to come to a decision." (Paul S, 19yrs old)

"Before I watched it I wasn't too sure what I wanted to do...after, I had a better idea that I'd rather have the operation." "I thought the DVD was enough." (Amy, 16yrs old)

Others said it was a useful resource that gave them information they did not know, but it did not change their decision to opt for surgery.

*"I did probably need to watch it before but it hasn't affected my decision...or influenced it that much really. But it has helped inform me."
(Paul, 38yrs old)*

"The DVD just confirmed it for me." (Sarah, 48yrs old)

Due to the format, some did not find the DVD useful at all, and seemed to gain little from the experience. The array of titles to click on did result in confusion or information being missed. Duplication of introductions in the editing process left other feeling disorientated.

"I skipped some bits 'cos I was getting a bit bored." (Lucy, 17yrs old)

"I wasn't sure whether, cos of the edit...whether what I was watching, I'd watched before or not!" (Paul, 38yrs old)

Comparison to other sources of information

Other sources of information cited included a BOS leaflet and the Internet.

Use of the Internet was confined to searching keywords through search engines such as Google, going on encyclopaedia sites like 'Wikipedia' or searching orthognathic blogs or forums. The risk of seeing graphic surgical pictures or finding unhelpful biased views and general information put participants off from using the Internet.

"I was apprehensive to Google it cos I didn't know what would come up, sort of thing....I don't like blood and stuff. I didn't know if that would put me off." (Jane, 16yrs old)

"I don't want to be tied to the computer when I come home from work in the evenings." (Sarah, 48yrs old)

"I had a look on the internet....the internet is just kinda biased.....negative isn't it.....It's all sensationalistic now...no one wants to read a little mundane report." (Paul, 38yrs old)

"I know the information at the consultation was specific to me...if I go somewhere else I could get the wrong information." "...I appreciate anyone and everyone is allowed to post things on the Internet." (Paul S, 19yrs old)

These comments would suggest that, in contrast to the Internet, the DVD is a trusted resource.

"I think the DVD is more specific to me...this is what you're having done, this is what's going to happen...the Internet is just hearsay isn't it really?" (Laura, 27yrs old)

Discussion

This qualitative study investigated the views of patients about the BOS orthognathic DVD and suggests that it is a valuable resource available to patients considering orthognathic surgery. It was felt by some participants that the DVD did help in the decision making process.

The most important gain from the DVD for participants was hearing about orthognathic surgery, from the point of view of previous patients. This gave the information a unique perspective from which the viewer could learn. The images on the DVD also helped participants understand surgery and the possible gains from surgery.

The DVD was seen as a trusted resource, which for some patients influenced their decision making process. This was because of the negative and unhelpful information some found on the Internet, the lack of any other real resources and the fact that the DVD is given out by consultants at the hospital. For others it confirmed their initial feelings about treatment, but for some it had no effect.

The interviews revealed that the DVD is not without some flaws and could be improved. A problem highlighted with the DVD was the format and inclusion of

before and after pictures. The intra oral photos were seldom related to the facial pictures. A complete set of pictures was also rarely seen making it difficult for participants to orientate themselves to see the changes surgery could bring to the face and teeth. It would be prudent to have a complete set of photos to allow patients to compare the changes.

Use of the DVD should continue, but clinicians should be aware some aspects need to be addressed or missing information needs to be covered elsewhere. It would be interesting to discover how the DVD prepared patients for surgery.

Following on from this research, and to ensure proper use of the DVD, below are some recommendations and suggested improvements to the DVD:

DVD Recommendations

Use of the DVD

1. For the DVD to be of most benefit to patients they need to know beforehand what type of surgery is being offered to them, so they can watch the relevant sections.
2. The DVD should be provided as soon as possible after the first consultation. This would allow for longer contemplation and review of the DVD for patients, as the data shows there is an initial reluctance before first viewing of the DVD.
3. It appeared that the younger interviewees were less engaged by the DVD. This could be down to the format (the problem of no young patients interviewed on the DVD) or more of a reluctance to open-up during interview.

Suggested improvements from participants to the DVD

1. Improve the format and content of before and after surgery photos.
2. The DVD should include interviews of younger people. It was interesting to find so many middle-aged patients on the DVD, as it has been well documented that most orthognathic patients are aged around late teenage to early twenties.¹⁰
3. Development of the DVD to become an online resource hosted by a website trusted by patients. This would allow for regular updating of the material and

monitoring of access. The information could be formatted to become more of a decision aid. This would include alternatives to surgery, something the DVD does not have.

Limitations of the Research

Sampling

A purposive sample was collected and aimed to be a heterogeneous sample. It was hoped this would gain a wide range of views to questions posed; however, no patients from black or minority ethnic groups were interviewed. It is not known what proportion of black or minority ethnic patients undergo orthognathic surgery in the UK.

Translation to the whole population

The qualitative nature of this research means that the results of this study may not be transferrable to the population as a whole. Most of the patients used in the stories on the DVD were White British, from the Yorkshire area and were treated in the same unit so these stories may be most relevant to the local group of patients interviewed in this research. The views expressed may therefore represent a ‘Yorkshire bias’; however, it is interesting to see that the use of the DVD and some of the opinions surrounding it were similar to an unpublished audit by Ryan et al.¹¹

Impact of the researcher

As part of reflexivity the influence of the primary researcher was considered when analysing the data. The interviewer, who was an orthodontist, took the role of researcher to reduce the risk of participants giving perceived ‘correct’ answers to questioning. The participants were not made aware of his profession. The interviewer himself underwent orthognathic surgery in 2009 and the potential for this to bias the study was considered at every stage in the study design, data collection, analysis and reporting.

Influence of the research

It is possible the participants who agreed to take part in the study may have done so because they had strong feelings about the DVD; however, this is unlikely, as a range of views was obtained.

This research highlights the fact that, although useful, the DVD could be improved. The study gives clinicians a clearer understanding of how the DVD is used by patients and areas where the DVD may not deliver to the patient a complete understanding of orthognathic surgery.

Recently, particularly in medical care that involves patients making life-changing decisions, decision aids have been developed to help patients resolve their treatment choice. A decision aid helps map out all of the options, benefits and risks to the patient, with statistics used where appropriate. By reviewing all relevant information, independent of the clinician, the decision aid should reduce the risk of memory bias¹² and external factors. These factors have been shown to influence the decision of the patient and forcing them into a choice through unrealistic expectations, which has been highlighted in qualitative research.¹³

In a recent Cochrane review on decision aids,¹⁴ 55 high-quality randomized control trials were identified, but only two were from the field of dentistry.^{15, 16} One dealt with the decision about how to best treat a heavily decayed tooth. The other used visual predictions of the outcome of orthognathic surgery as a decision making aid for patients. Accordingly, dental professionals have few true decision aids to help patients make sound decision about their treatment.

Further consideration should be given to the need for a patient decision aid for orthognathic surgery.

Conclusions

- The DVD was seen as a trusted resource, giving a range of views about undergoing surgery.
- The DVD made the decision process and surgery 'real' for viewers. For some viewers it helped with their decision making.
- DVD gives information that patients cannot get or process from professional or external sources (e.g. Internet). Therefore, if used properly it has a role in the decision making process.

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Tables

Table 1; Skeletal Class and malocclusion of participants questioned.

Skeletal 2; Class II div 1 Incisors	Skeletal 2 Class II div 1 Incisors with AOB	Skeletal 2;, Class II div 2 Incisors	Skeletal 3; Class III Incisors
2	3	1	4

Figure Legends (See attached files)

Figure 1; Diagrammatic representation of themes identified through interviews

Figure 2; Screen captures showing the faces of patients who took part in the orthognathic DVD (Reproduced by kind permission from the BOS).

Figure 3; Screen capture of one patient from the orthognathic DVD with before (left) and after surgery (right) images (Reproduced by kind permission from the BOS). Study participants found it difficult to see the changes from these two different views.

Figure Legends

Figure 1; Diagrammatic representation of themes identified through interviews

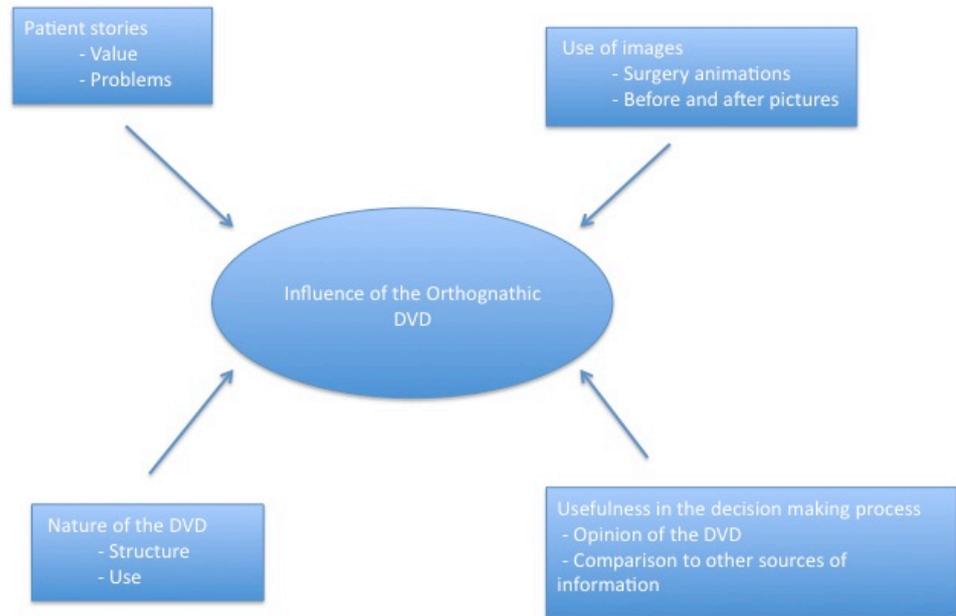


Figure 2; Screen captures showing the faces of patients who took part in the orthognathic DVD (Reproduced by kind permission from the BOS).



Figure 3; Screen capture of one patient from the orthognathic DVD with before (left) and after surgery (right) images (Reproduced by kind permission from the BOS). Study participants found it difficult to see the changes from these two different views.



Appendices

Topic guide for semi structured interviews

1. Why were you referred to the surgical orthodontic clinic?

Prompt: What motivated you to attend; what was the reason?

Prompt: Who 1st identified the problem?

Prompt: What was the problem?

2. What did you think about the consultation?

Prompt: What did you know about orthognathic surgery before the appointment?

Prompt: What did you gain from the appointment?

Prompt: What was unhelpful during the appointment?

3. Tell me what you felt when watching the DVD?

Prompt: What aspects of it were good?

Prompt: What aspects of it were bad?

Prompt: What has helped you in coming to a decision about treatment?

Prompt: What are the alternatives to treatment/surgery?

Prompt: What do you understand the benefits of treatment are?

Prompt: What do you understand the risks of treatment are?

Prompt: How much of the DVD did you watch?

4. Who decides what treatment should be performed?

Prompt: How involved do you feel in the decision?

5. Has anything/anyone influenced you in reaching a decision?

Prompt: Television, Internet, family, friends, others you know who have had treatment?

6. Could you suggest any improvements to aid your decision making?

Prompt: To the DVD

Prompt: To the other information given

Prompt: Tips for the Orthodontists and Oral Surgeon

Prompt: Overall experience