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The Orthognathic Surgery Patient's Experience – a Grounded Theory study

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ABSTRACT

Objective: Facial visible difference has a range of impacts not only functional and aesthetic but also in terms of the emotional and social wellbeing of patients. The aim of the study is to develop a theory that explains a person's experience of the orthognathic treatment.

Methods: The study was a qualitative cross-sectional grounded theory study. Semi-structured interviews were used to explore the experience of orthognathic patients undergoing treatment in a NHS hospital in the UK. Face to face interviews with 22 orthognathic patients (4 male and 18 female; age range 18-66 years) were conducted. Of these, 12 participants had had surgery six-eight weeks prior to the interview, six were in the decision making phase for orthognathic treatment and four participants had had the surgery one-two years prior to the interview. Further theoretical sampling and data collection was carried out from online blogs and forums on orthognathic treatment. Grounded theory methodology was used for the analysis of the data collected.

Results: Analysis of the interviews indicated that during the process of orthognathic surgery, patients go through a status passage of 'normal facing'. Orthognathic patients were inducted into this passage through their dentists, peer influence in the form of teasing and bullying about facial appearance, knowledge of orthodontic treatment gained from peers and their own perceptions of self-image. Decision making for orthognathic treatment influenced this status passage of 'normal facing', which, in turn, was influenced both positively and negatively by external factors. Temporality played a key role in normal facing. The factors that influenced the shape of this passage were the patient's social support system, post-surgery recovery, quality of care, age of the patient, patient's own life priorities, the preparedness of the patients in the form of information about the treatment, and the role of professionals involved in care provision. 'Normal facing' appeared to positively influence the patient's coping behaviour and self-perception.

Conclusions: Orthognathic patients undergo a scheduled status passage of 'normal facing', which appears to be influenced by various clinical, demographic and psychosocial factors. This status passage consequently influenced the person's self-perception.

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ABBREVIATIONS

AOB – Anterior Open Bite

BDD – Body Dysmorphic Disorder

CLP – Cleft Lip and Palate

GT – Grounded Theory

HRQoL - Health Related Quality of Life

OQLQ- Orthognathic Quality of Life Questionnaire

OHSQ - Oral Health Status Questionnaire

OHQoL- Oral Health related Quality of Life

OHIP- Oral Health Impact Profile

POMS – Profile of Moods States

QoL- Quality of Life

SF- 36 – Short Form Health Survey

Chapter One: Introduction

The experience and treatment of facial differences has been, until relatively recently, studied from different perspectives. There is the perspective of the patient, the perspective of the public and the perspective of the clinician who treats facial difference. As we shall see, these perspectives have more or less remained separate, operating with different concepts and ideas and developing different languages to communicate about facial differences. It is only relatively recently with the advent of psychological and sociological interest in facial difference that the boundaries of these perspectives have been gradually eroded.

Nevertheless, this process has been painfully slow, but it is now starting to promise significant gains for patients and individuals who live with visible differences. This thesis seeks to track the different perspectives within which people with facial differences are viewed. It begins with a review of the different literatures on facial difference. In this review we will discover how different literatures (and languages) about facial difference exist and how these differences point towards the separation of the phenomenon of facial difference into separate realities.

You would think that surgery as dramatic and extensive as orthognathic surgery would be supported by detailed empirical evidence and extensive research informed by patients themselves. In fact this is simply not the case. This thesis seeks to correct the historical biases in current research on orthognathic surgery by beginning to build knowledge from within the perspective of patients themselves.

Facial discrepancies have a range of impacts including not only function and aesthetics but also on emotional and social well-being of people. Orthognathic surgery is an elective facial surgery procedure to correct facial discrepancies and hence improve function and aesthetics. To date, there has been very little qualitative research investigating the psychological impact of orthognathic surgery on the life of patients. Very little theoretical work has been carried out in orthognathic surgery. The aim of this project is to explore the experience of orthognathic surgery patients and to build a theory that seeks to explain what is going on in their experiences. Grounded theory (GT) methodology was employed to develop a theory that helps explain what is happening to orthognathic patients before, during and after their treatment journey.

This entailed collecting data from patients in various stages of orthognathic treatment. These patients were interviewed to understand their experiences, decision making process, concerns, expectations, coping mechanisms and recommendations. Patients were interviewed mainly after the surgery (six-eight weeks post-surgery) when they were being discharged from their Oral and Maxillofacial Surgery clinics. A few patients were also interviewed one to two years after orthognathic surgery, as well as some patients who were in the decision-making phase about orthognathic treatment. Therefore, data was obtained at three different time points along the orthognathic treatment pathway. Further, data was collected from online forums and blogs to account for the world-wide variations or similarities of orthognathic patient experiences. In order to add value to the theory, data collected from a questionnaire based quantitative study examining the psychological aspects and quality of life of patients was also used in this research. The knowledge, which has been gained from this research will hopefully contribute to a better understanding of the psychosocial concerns of patients who seek orthognathic surgery and the impact of orthognathic surgery on the life of patients. The study will also help inform and develop orthodontic-orthognathic services so that they can better meet the needs of patients deciding whether or not to undergo such surgery.

The thesis is structured as follows:

Chapter Two: is the narrative review of the literature on orthognathic treatment, decision-making process, visible difference, coping with visible difference and impact of orthognathic treatment. It details the orthognathic surgery treatment pathway based on recent guidelines developed in the UK. The decision-making process is detailed from a general perspective and current understanding of decision making in orthognathic surgery is elaborated upon. Further, the psychological impact of visible difference is considered in depth leading to differences in how individuals cope with visible differences. Finally, the impact of orthognathic surgery on individuals is also detailed. This leads to the aim of the study and the objectives of the research.

Chapter Three: describes the Grounded Theory methodology used in this study. The materials and methods are described along with details of the data analysis and theory generation.

Chapter Four: presents the results of the study including the presentation of the final theory using the literature to introduce the reader to a well-known formal theory called status passage.

Chapter Five: discusses the research findings along with limitations and strengths of the theory that has been developed.

Chapter Six: draws light on the major conclusions from the research. It also summarises recommendations for future policy and research.

Chapter Two: Literature review

2.1. Orthognathic surgery

2.1.1 Definition

Orthognathic surgery in its simplest definition refers to “alignment of the jaws” (Dimitroulis et al., 1994, p.8). Orthognathic surgery is the surgical procedure to correct abnormalities of the jaws (American Association of Oral and Maxillofacial Surgeons, 2012). It describes a number of surgical procedures that can be carried out on either one or both the upper and lower jaws to bring the jaws into a more acceptable or functional relationship (Royal College of Surgeons of England, 2013). The end result of the surgery should be a more harmonious jaw structure. Orthognathic surgery is an elective surgery performed only when indicated on the basis of functional and morphological criteria. The decision to undergo orthognathic surgery is influenced by patients’ perceptions and the impact of the abnormalities of the jaws on a patient’s life (Bock et al., 2009).

2.1.2. Prevalence of orthognathic surgery

Dentofacial deformities¹ have been described as deformities that primarily affect the jaws and dentition, hence causing an effect on the mid and lower part of the face. They could be limited to one jaw or extend to multiple craniofacial structures such as in the case of cleft lip or palate (Ong, 2004, p.239). Dentofacial deformities are developmental problems frequently resulting from a complex interaction among multiple factors that influence growth and development (Proffit and White, 1991). The occurrence of dentofacial deformities has been reported to be approximately 20% within the population (Kerawala and Newlands, 2009, Wolford and Fields, 2000). More recently, one study has suggested that approximately 250,000 people in the UK may require orthognathic treatment (Kumar et al., 2008).

A substantial rise has been found in the number of orthognathic surgeries performed per year in the UK. (Travess et al., 2004) suggested that this rise in the number of orthognathic surgeries could be attributed to advancements in the field of orthodontics and oral surgery improving the accessibility for individuals seeking orthognathic treatment. A recent report showed that 2,718 orthognathic surgeries were carried out

¹ The terminology used differs in the clinical literature compared to that in the psychology literature. The differing definitions will be discussed in Section 2.3.

in the UK in 2012 (Royal College of Surgeons of England, 2013). However, it also reported that there were wide variations in the number of cases carried out in various parts of the country. A nine year study carried out between 1997 and 2006 within the NHS (England) reported that 8,941 patients underwent mandibular orthognathic surgery (Cunningham and Moles, 2009). These data were extracted from NHS Hospital Episode Statistics. Although this study considered only mandibular orthognathic procedures, it was reported that of these, 88% of patients also had maxillary surgery as an additional procedure. Hence, this study sample could represent the orthognathic surgery cases in the UK during the 9-year period of the study. The mean age of the patients in this study sample was 24 years. The male to female ratio was reported to be 1:1.7 (Cunningham and Moles, 2009).

In the year 2008, 10,345 patients were reported to have been hospitalised for orthognathic surgery in all of the United States of America (Venugoplan et al., 2012). These data were obtained from the Nationwide Inpatient Sample for year 2008 and the procedure was identified in the database using the *International Classification of Disease, Ninth revision, Clinical Modification*. Among these 10,345 patients, 56.2% of them were females. The mean age of the patients who underwent orthognathic surgery in the USA in 2008 was reported to be 26.7 years (Venugoplan et al., 2012). The reason for a larger number of patients undergoing orthognathic surgery in the USA as compared to the number of patients in UK who underwent orthognathic surgery in 2012 (Royal College of Surgeons of England, 2013) could be attributed to the difference in the size of these countries.

A study from China, which lasted for 15 years (1990- 2004), reported that 2,910 orthognathic procedures were carried out in 1,294 patients in Hong Kong (Chow et al., 2007). Of these, 62% were females and 38% were males. The mean age of the patients in this sample was 24.1 years and the range were between 16 to 54 years of age. However, a study conducted in New Zealand with an aim of describing the demographic characteristics of patients undergoing orthognathic surgery in Otago concluded that the mean age of patients undergoing orthognathic surgery increased every year (Parton et al., 2011). This study was conducted over a period of nine years (2001-2009) and 91 patients were included. The male to female ratio in this sample was 1:1.6. It was observed that the mean age of the patients increased by approximately 5 years during the period of study. Between 2001 and 2003 while the

mean age was 22.1 (SD, 9.4) it increased to 27.7 (SD, 11.4) between 2007 and 2009. This suggested that the age of patients undergoing orthognathic surgery had been increasing in more recent years.

The aforementioned study samples from UK, USA, China and New Zealand suggested that females tend to have orthognathic treatment more frequently than males. Similarly, another study in the UK also reported that females underwent orthognathic surgery more often than males (O'Brien et al., 2009). O'Brien and colleagues (2009) studied 131 orthognathic patients in the North-West region of England to evaluate the effectiveness of the treatment. Among these 131 patients, 47 were males (35.9%) and 84 were females (64.1%). Another study from Cairo, Egypt, carried out between 1998 and 2004 also showed that more females underwent orthognathic surgery than males (Sadek and Salem, 2007). Sadek and Salem (2007) assessed the motivation for orthognathic surgery, satisfaction with treatment and its effect on quality of life. In their study of 120 patients, 48 were male and 72 were female patients. These studies all show that more women than men undergo orthognathic surgery. However, in one earlier study that examined gender differences and motivations for orthognathic surgery it was found that both male and females were equally concerned about their appearance and other concerns such as mastication and speech difficulties which motivated them towards orthognathic surgery (Kiyak et al., 1981). This increase in the number of female orthognathic surgery patients in recent years may be also a part of the changing beauty trends in the world.

2.1.3. Indications for orthognathic surgery

A recent commissioning guide published by the Royal College of Surgeons of England (2013; p.2) for orthognathic procedures included the following conditions under the dentofacial deformities that can be treated by orthognathic surgery;

- Post-traumatic jaw deformities and malocclusions
- Cleft lip and palate
- Obstructive sleep apnoea
- Hemi-facial microsomia
- Condylar hyperplasia

- Patients with significant jaw deformities, which results in functional and psycho-social disadvantage.

The main indications that are relevant to the participants in this study and are prescribed by the commissioning guide for orthognathic surgery will be discussed in the following sections. However, before discussing the indications of orthognathic surgery, the basic concepts of malocclusion need to be understood.

The teeth and the relationship of jaws significantly influence the facial structure. The jaws grow continuously as a child grows. The age at which a girl completes growth is between 14-16 years and for a boy between 15-18 years of age (Hall and Lorenz, 2012). Until this age, there is scope for continuous change in dentofacial appearance. It is the size and shape of the permanent teeth in relation to the growing jaw that determines the dentofacial appearance in adolescents. The occlusion of teeth depends upon the relationship of the maxilla and mandible, and the upper and lower teeth set in them. Depending on an individual's growth pattern, various types of malocclusions can occur.

2.1.3.1. Types of Malocclusion

For many years, clinicians have used a classification to group these malocclusions called the Angle's classification of malocclusion. There are three types (Figure 1):

- i) Class I (Neutroclusion) where the first molar teeth are in position described as normal in occlusion, leaving other teeth in malocclusion but there is a harmonious skeletal relationship between the upper and lower jaws;
- ii) Class II (Distocclusion or retrognathic) where the lower first molar is placed behind the upper first molar when in occlusion and/or the maxilla is placed forward to the mandible (Class II division 1 with labioversion of the maxillary incision teeth and Class II division 2 with linguoversion of the maxillary central incisor teeth);
- iii) Class III (Mesioclusion or prognathic) where the lower first molar is placed forward to the upper first molar and/or the mandible is placed forward to the maxilla (Angle, 1899).

Figure 1: Types of malocclusion



Class I Malocclusion



Class II division 1 Malocclusion



Class – III division 2 Malocclusion



Class- III Malocclusion

Malposition of teeth or malocclusion can be easily identified by individuals and can seek treatment from an orthodontist to improve tooth alignment, function and facial appearance (Reyneke, 2010). However, malocclusions of class II or class III types that include more severe skeletal discrepancies may require surgical intervention along with orthodontics. Such dentofacial deformities are the major indication for orthognathic surgery, otherwise known as combined orthodontic and surgical correction (Royal College of Surgeons of England, 2013).

2.1.3.2. Functional concerns

Dentofacial deformities can hamper physical function in many ways. Basic function such as chewing could be affected (Kiyak et al., 1982a). Malocclusions of all types have been found to negatively affect the chewing ability of individuals (English et al., 2002). Similarly, individuals with discrepancies in the jaws have also been found to have difficulties in mastication (chewing) (Choi et al., 2015, Picinato-Pirola et al., 2012, Zarrinkelk et al., 1995, Tate et al., 1994). Tate et al. (1994) stated that improvement of masticatory function was a main aim of orthognathic surgery. They analysed the masticatory function of pre-orthognathic surgery patients and compared it with a control group with normal occlusion. The study found that pre-orthognathic surgery patients had lower levels of masticatory function than the controls. It was also concluded that occlusion influenced masticatory efficacy more than force of mastication determined by the muscle activity. Nevertheless, a recent study among 42 participants including people who needed no treatment, needing orthodontics and those needing orthognathic surgery concluded that mild masticatory impairment allowed satisfactory adaptation to function and therefore emphasised the need for objective evaluation of masticatory function to discern treatment need (Bourdiol et al., 2017).

An abnormal relationship between the jaws cause the upper and lower sets of teeth to not meet in normal occlusion. People who have such malocclusions often have issues such as difficulty in biting (Rusanen et al., 2010, Nurminen et al., 1999). One such common abnormal relationship between the jaws is the anterior open bite (AOB) which requires treatment (Figure – 2). Anterior open bite, defined as no contact or overlap between the maxillary and mandibular incisors, present with a gap between the upper and lower front teeth (Proffit et al., 2007). The incidence of AOB varies between races and with dental age, ranging from 1.5% to 11% within the population

(Ng et al., 2008). The most common reason for AOB was stated as the downward-backward rotation of mandible and the over eruption of posterior teeth (Kuroda et al., 2004, Proffit et al., 2000). However, AOB has also been reported to being caused by other dental, soft tissue, skeletal and habitual (digit sucking) factors (Lin et al., 2013).

Various treatment approaches have been advocated depending on the cause and the age of the patient such as functional appliances that modify growth in younger patients, fixed orthodontic treatment for mild cases of AOB, orthodontics using skeletal anchorage devices and orthognathic surgery for more severe cases of AOB (Lin et al., 2013). The most debated treatment options for severe AOB have been orthognathic surgery versus orthodontics using skeletal anchorage devices (Bisase et al., 2010, Kuroda et al., 2007). The stability of the treatment against relapse was most often addressed when considering the advantages of either of these treatments for AOB. A recent meta-analysis by Greenlee et al. (2011) to compile evidence for the stability of orthognathic surgery and orthodontic skeletal anchorage treatment found that both treatments had more than 75% stability. It also stated that the assumption that non-surgical treatments were less stable than surgical needs to be confirmed with higher level controlled studies. However, Bisase et al. (2010) stated that anterior open bite is a common orthognathic indication and was a challenging dentofacial deformity to treat.

Figure 2: Anterior open bite



The positioning of the teeth act as a guide for tongue and help in speech. Hence, dentofacial deformities can cause difficulty in speech (Ambrozic et al., 2015, Soh and Narayanan, 2013, Ryan et al., 2012b). However, Public Health England (2013) in its

interim clinical commissioning policy for orthognathic surgery stated that orthognathic surgery should be of low priority for patients with speech problems and temporomandibular jaw pain since there is little evidence of functional improvement reported in these cases. While these are the functional concerns that dentofacial deformities cause for patients, it is very rarely separate from the appearance concerns (Reyneke, 2010).

2.1.3.3. Aesthetic and psychosocial concerns

Dentofacial deformities including skeletal discrepancy often worsens facial aesthetics and can negatively impact on the quality of life of the affected individuals (Kovalenko et al., 2012, Zhang et al., 2006). A study by Johnston et al. (2010) about patients' perception of facial attractiveness reported that orthognathic surgery patients were unhappier about their facial and dental appearance than the others who did not seek orthognathic surgery and older female patients seemed to have greater unhappiness with their appearance. The authors also concluded that patients with class two malocclusion were keener on changing their overall facial appearance than patients with class three malocclusion. Finlay et al. (1995) reported that 52% patients in the study cited appearance concerns as the reason for seeking orthognathic surgery while 31% cited functional concerns. The perception of an individual's own appearance, particularly of the face, was found to influence mental health and social interactions of individuals (Berscheid and Gangestad, 1982, Peck and Peck, 1970).

People with dentofacial deformities exhibit higher levels of psychological stress in social situations than those without any deformities (Rumsey and Harcourt, 2004). This has been well recognised by clinicians and the psychological impact of dentofacial deformities is considered before treatment planning for orthognathic surgery (Rustemeyer et al., 2010). Kavalenko et al. (2012) in a study on the association between psychological status and severity of facial deformity concluded that patients with different degrees of facial deformity have different psychological profiles. Patients with severe facial deformity show higher prevalence of anxiety, emotional instability and unsociability (Kovalenko et al., 2012). Alanko and colleagues (2010) from a systematic review of the literature on the psychosocial well-being of orthognathic surgery patients concluded that although these patients did not experience psychiatric problems, many patients experienced problems such as anxiety and depression. Hence, the orthognathic commissioning guide also stated that patients

who have significant psychological concerns due to facial deformities could be treated with orthognathic surgery (Royal College of Surgeons of England, 2013).

2.1.3.4. Other indications

Cleft lip and palate (CLP), a congenital or birth defect of dentofacial development (Proffit and White, 1991), benefitted from orthognathic surgery as part of a treatment involving a multidisciplinary team from infancy until adulthood (Royal College of Surgeons of England, 2013, Daskalogiannakis and Mehta, 2009, DeLuke et al., 1997, Ross, 1986). Yet another indication for orthognathic surgery is Obstructive Sleep Apnoea (OSA), characterised by a recurrent collapse of the upper airway causing frequent awakening from sleep (Lye et al., 2008, Waite et al., 1989). While many other treatment methods including continuous positive airway pressure (CPAP), Uvulopalatopharyngoplasty i.e., resection of uvula and excess soft tissue of the soft palate (Malhotra and White, 2002) and tracheostomy were considered effective in treating OSA, since the 1980's orthognathic treatment was found to be useful in treating OSA. Lasting effectiveness of mandibular advancement and bi-maxillary advancement on OSA has been reported (Marcussen et al., 2017, Vigneron et al., 2017, Zaghi et al., 2016, Islam et al., 2014, Gokce et al., 2012). The current study excluded participants with CLP and OSA.

Some effect on TMJ function has been reported as a result of orthognathic surgery (Dujoncquoy et al., 2010, Panula et al., 2000, Rivera et al., 2000, De Clercq et al., 1998). The relationship between Temporomandibular Joint (TMJ) dysfunction and malocclusion is much debated in the medical literature (O'Ryan, 1995). While some believe that there is a close relationship between malocclusion and TMJ symptoms, others believe there is no such relationship. Similarly, many controversies exist regarding the effect of orthognathic surgery on TMJ dysfunction (Nale, 2014). Some studies have found that there was no improvement or rather worsening of signs and symptoms of TMJ dysfunction (Oland et al., 2010a, Wolford et al., 2003, Onizawa et al., 1995, O'Ryan and Epker, 1983); whilst other studies have reported various levels of improvement (Dujoncquoy et al., 2010, Panula et al., 2000, Rivera et al., 2000, De Clercq et al., 1998, Magnusson et al., 1990).

However, findings from the studies discussed above on orthognathic surgery have made it clear that the most common indications for orthognathic surgery are

malocclusions that cannot be managed by orthodontic treatment alone. The remainder of the conditions included in the commissioning guide are quite infrequent in occurrence but can have serious negative effects on the patients' quality of life.

2.1.4. Clinical pathway

Given the three major types of malocclusion (see Section 2.1.3.1.) the treatment plan and pathway varies for each type of malocclusion. The treatment plan also varies according to the age at which the individual is referred;

- i) growth modification (in growing children dentofacial orthopaedics can alter growth expression to some extent),
- ii) orthodontic camouflage (repositioning of teeth to compensate for jaw discrepancy) and
- iii) combination of orthodontic and surgery or orthognathic surgery in individuals after growth completion (Reyneke, 2010, Bailey et al., 2000).

It is necessary that orthognathic surgery is customised for each patient according to the growth pattern. However, prediction of growth following surgery is difficult. Nonetheless, orthognathic surgery can be done during two phases depending on stage of growth;

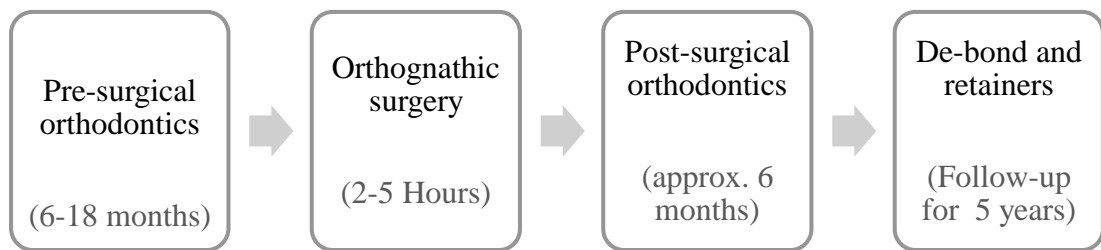
- i) interceptive surgery - undertaken when the individual is still growing so as to modify selective unfavourable (both psychological and structural) growth patterns , and
- ii) definitive surgery - performed after the completion of growth (Dimitroulis et al., 1994).

The age at which orthognathic surgery can be carried out is often during late adolescence and early adult life for definitive surgery and during the early adolescence if interceptive surgery is intended. However, the vast majority of orthognathic surgery is carried out on young adults (after completion of growth) with a few on older adults (Soh and Narayanan, 2013).

Traditionally, orthognathic surgery aims to achieve a more harmonious relationship between the upper and the lower jaws and also to improve the occlusal function (Alanko et al., 2010). The treatment required a phase of orthodontic treatment along with the surgical treatment to produce the desired results. A variable period of

orthodontic treatment precedes and follows the surgery (See Figure 3). Then again, a recent study from Finland, on the length of time taken for conventional orthognathic treatment concluded that extraction of teeth (excluding third molars) included in pre-surgical orthodontic treatment prolonged treatment time by an average of 8-9 months (Paunonen et al., 2017). A clear understanding of the aesthetic and functional goals and close working relationship between the orthodontist and surgeon have been shown to be vital for a successful orthognathic treatment outcome (Kerawala and Newlands, 2009). Initial assessment of the patient is done in a joint clinic by orthodontists and the oral surgeon, where the patient expectations and motivations are used to determine the treatment plan with the backing of clinical tools for assessment of what can be realistically attained.

Figure 3: Clinical pathway

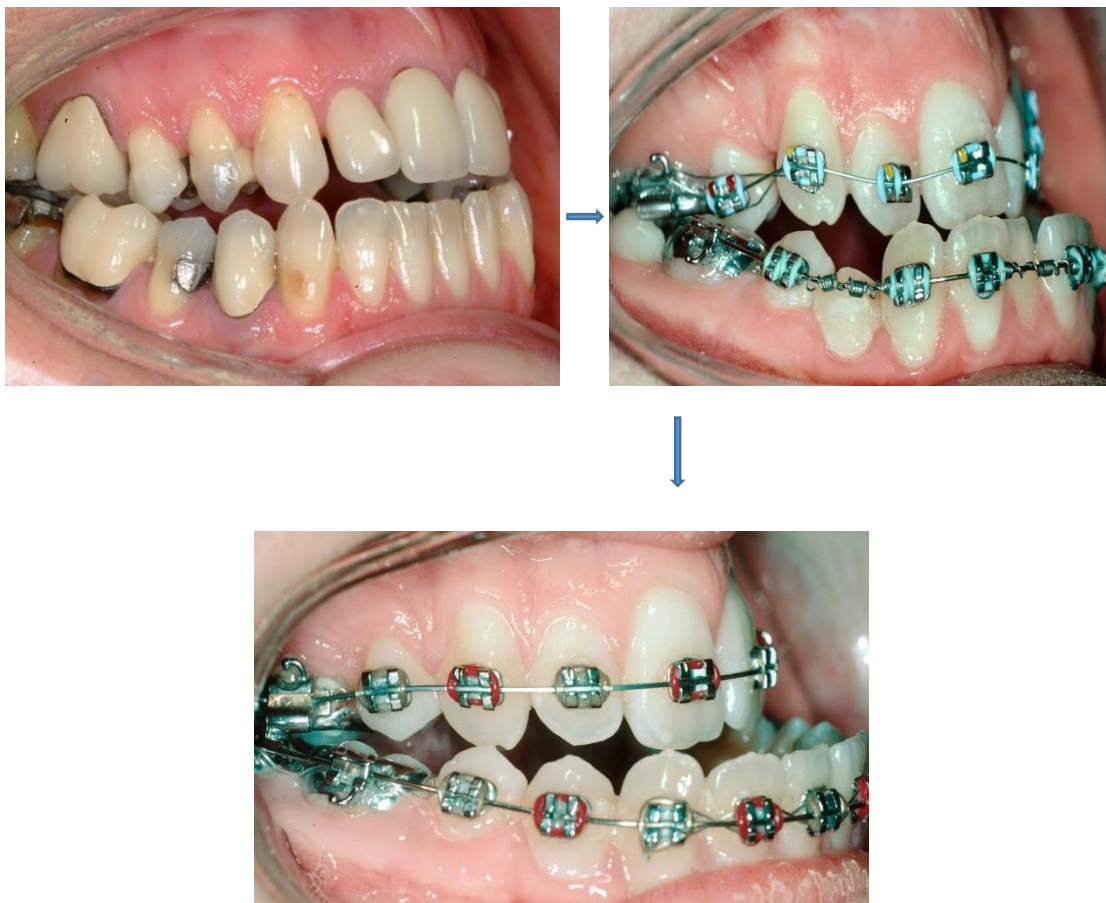


2.1.4.1. Pre-surgical orthodontics

Once appropriate initial assessment has been carried out, the orthodontist and surgeon planned the treatment in agreement with the patient's own wishes. The pre-surgical orthodontic treatment variably lasted between 18-24 months depending on the age of the patient, type of malocclusion and the treatment plan (Royal College of Surgeons of England, 2013, Kerawala and Newlands, 2009, Harris and Reynolds, 1991). It has also been recommended in the commissioning guide for orthognathic surgery (2013) that pre-surgical orthodontic appointments are made every four to six weeks. The aim of orthodontic treatment at this period of time was to reverse any dental compensation and reveal the true jaw discrepancy (See Figure 4). It has been shown to facilitate orthognathic surgery by aligning the arches by eliminating crowding, spacing and cross-bites; alteration and co-ordination of arches, and de-compensation by movement of upper and lower incisors to reverse any camouflage masking the underlying jaw discrepancy (Kerawala and Newlands, 2009, Wolford and Fields, 2000, Harris and Reynolds, 1991). However, in recent years, research has identified the surgery first

approach to orthognathic treatment (where orthognathic surgery is done without any pre-surgical orthodontics) as opposed to conventional orthognathic treatment with pre and post-surgical orthodontics (Jeong et al., 2017, Peiro-Guijarro et al., 2016, Wang et al., 2016). In conventional orthognathic treatment, primarily, fixed appliances are used although removable appliances maybe used early in the treatment. The type of tooth movement, duration and the end result targeted varied depending on the type of dento-facial defect and the treatment plan made. Towards the end of the pre-surgical phase or orthodontic treatment the patient was prepped for surgery and anchorages for internal fixation (use of soft elastics) of the jaws are also placed according to need after surgery (Kerawala and Newlands, 2009).

Figure 4: Dental de-compensation



Before the surgery, new records must be taken and re-evaluated to determine the progress and readiness for surgery. Face bow² recordings are taken if both the jaws are going to be repositioned during surgery. Acrylic occlusal wafers are then constructed and these wafers act as a guide plane for aligning the jaws during the surgery. The patient's general health and psychological stability (Harris and Reynolds, 1991) also have to be checked before surgery. It is essential that the patient is provided with information to understand and are realistic about what to expect post-surgically including the periods of pain, swelling and variable periods of numbness of the lips (Chen et al., 2002). While reassurance from the surgeon can benefit the anxious patient, it cannot discount the graveness of the recovery period that lies ahead. During hospital admission, it is important that the patient received good social support. However, if social support is unavailable, additional care and support are required from the nursing staff (Cunningham, 2008). As with every other surgery, pre-surgery procedures such as haematological tests, prophylactic antibiotics and systemic steroids need to be provided and tailored to the medical needs of the patient.

2.1.4.2. Orthognathic surgery

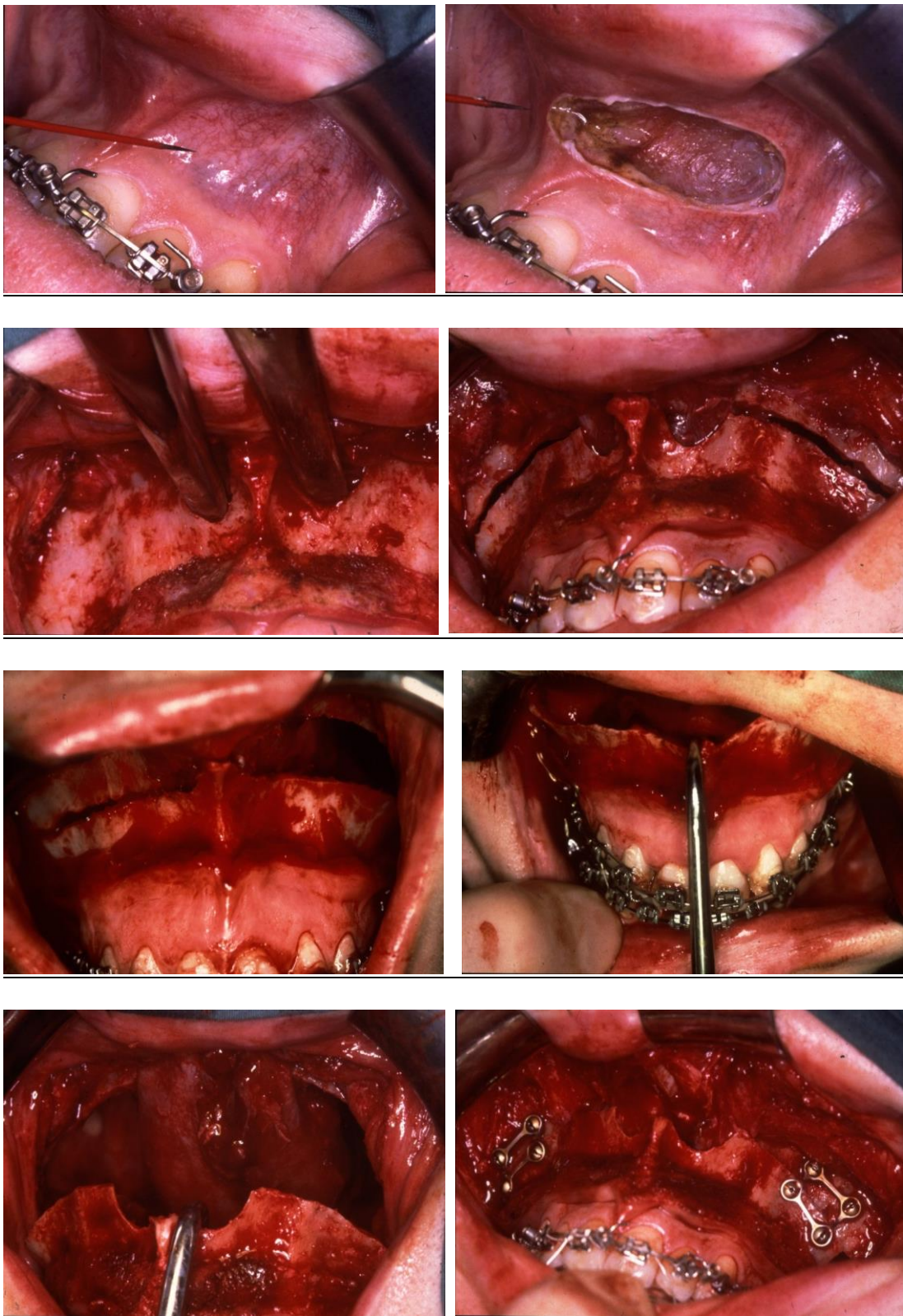
A two-jaw surgery usually takes between four and six hours depending on the planned jaw movements. Depending on the type of jaw movement, advancement or retraction, bone may be added or removed respectively. If advancement is planned, bone grafts generally derive from the patient's rib or iliac crest (hip). Generally, all the incisions to access the surgical sites are placed intra-orally and leaving no visible scarring. The bone cuts are made to carefully avoid the roots of the teeth and minimise damage to the teeth. In the lower jaw, removal of impacted third molar teeth, which are usually lying in the site of the planned osteotomy, is generally carried out 9-12 months prior to the surgery. This allows good bone healing and avoids complications during the osteotomy. Once the desired surgical movements have been made, the jaws are fixed using bone plates in the new jaw positions (See Figure 5). The use of mini plates for fixation in orthognathic surgery has now enabled the infrequent use of inter-maxillary fixation which is now only used for short periods post-operatively (Kerawala and Newlands, 2009). This reduces the post-operative discomfort and care made much

² Face bow is a calliper like device used to record the relationship of the jaws to the temporomandibular joints

easier. However, light elastics may be advocated by surgeons for inter-maxillary fixation despite the use of mini plates.

The period of hospitalisation following surgery varies depending on the type of surgery and the surgeon's assessment of the patient. Previously an average of 2-5 days of hospitalisation were expected after the surgery (Harris and Reynolds, 1991), but currently patients only stay in hospital for one or two nights. Immediately following surgery, swelling, discomfort, pain and numbness in the lower face was common. However, post-surgical intensive care is rarely indicated (Royal College of Surgeons of England, 2013). Nutrition becomes a pressing concern in the days after surgery as patients struggle to eat and drink and hence a good amount of social support becomes vital (Kerawala and Newlands, 2009). Maintenance of oral hygiene is essential. Patients are reviewed on a regular basis in the weeks after surgery. Six to eight weeks after surgery, the patients start the post-surgical phase of their orthodontics that may last 3-6 months. This will make the final minor adjustments to the teeth position to ensure a stable occlusion.

Figure 5: Stepwise Maxillary orthognathic surgical procedure



2.1.4.3. Post - surgical orthodontics

The commissioning guide for orthognathic surgery suggested that the postoperative recovery period for single jaw surgery was typically two weeks but for a bimaxillary osteotomy (upper and lower jaw) procedure the recovery period was three weeks (Royal College of Surgeons of England, 2013). The actual orthodontic procedures do not usually commence until six to eight weeks after the surgery, although the decision about post-surgical orthodontics was shortly after the surgery (Wolford and Fields, 2000). Initially, since the bone healing is not complete, the tooth movements can be very rapid, and therefore the orthodontists could only place light forces and also review the patient at closer intervals. Once the healing was complete, the orthodontic reviews were spaced as recommended by the commissioning guide. The final tooth positioning could be attained in three to 12 months.

2.1.4.4. Orthodontic bracket debond and retention

After the fixed orthodontic appliances are removed there is a need to place a fixed or removal type of retainer after debonding of orthodontic brackets for a variable period of time in order to prevent relapse. It is recommended that the patients are reviewed for at least five years following removal of orthodontic appliance involving two to three appointments (Royal College of Surgeons of England, 2013). The final post-surgical healing including settling down of soft tissue swelling and numbness is expected to take between nine to 12 months (Wolford and Fields, 2000). This is the final clinical procedure in orthognathic treatment. However, whether or not it marks the end of treatment from the patient's perspective is yet to be researched.

2.1.5. Perceived severity

Perceived severity, as defined by Witte (1992) is the individual's belief about the seriousness or magnitude of a health threat. It refers to the degree to which an individual deems a particular disease or condition to be serious (Logan et al., 2010). Janz and Becker (1984) stated that perceived severity included the evaluation of both clinical (e.g. disability, pain etc.) and social consequences (e.g. work life, family life, social relationships etc.) of the health condition. It was also stated that perceived severity varied from individual to individual (Janz and Becker, 1984). Perceived severity was reported to be independently associated with the perceived need for treatment in a study about need for medication to prevent bone fracture (Schousboe et al., 2011).

In the case of the orthognathic patients, the degree and severity of the condition is assessed differently by patients and clinicians. From a patient's perspective, the severity of the condition depends on the functional, aesthetic and psychological concerns that the dentofacial deformity may cause in their day-to-day life. Although the degree of severity of the condition may be assessed differently by clinicians and patients, the patient's functional, aesthetic and psychological concerns should be taken into account by the clinicians when planning for the orthognathic surgery (Alanko et al., 2010, Cunningham et al., 2001). It has been found that the use of technical terminologies by professionals to describe functional problems of the patients in clinics was found to increase patient's perceived severity of their condition. For example, a recent study by Stirling and colleagues (2007) aimed at understanding the orthognathic decision-making process through telephonic interviews of 59 orthognathic patients. From the interviews, it was found that patients understood the use of terminologies to describe their functional problems in clinics. However, the professional's use of these terminologies in clinics increased patient's feelings about their 'difference' and their perceived severity of the condition.

Maxwell and Kiyak (1991) stated that the patient's own perception of their facial appearance was important in determining their willingness to seek treatment. A group of 35 orthognathic surgery patients were asked to self-rate their facial appearance before treatment. It was reported that the patients' perception of their facial image was not associated with the actual objective measures of the dentofacial defect such as the cephalometric measures. Hence, patients' perception of the dentofacial defect differed from the objectively determined defect, but it had an influence on the patients' perception about need for orthognathic treatment.

Naini and colleagues (2012) studied the influence of severity of facial asymmetry on perception of attractiveness and hence the desire for surgical correction. In this study, 185 observers rated frontal facial images with asymmetries of 0-25mm on a 7-point Likert scale. Images of both a male and a female face with vertical, horizontal and combined vertical and horizontal asymmetries were used for rating. The perceived need for orthognathic surgery was found to increase among individuals with an increase in severity of asymmetries. Asymmetries over 10mm were rated by observers to have an increased need for surgery (Naini et al., 2012). Further, de Almeida and Vieira Bittencourt (2009) studied the association between the

anteroposterior position of the mandible and the perceived need for orthognathic surgery. Twenty-eight faces, with variations made in the anteroposterior position of the jaw, of two females (one black and one white) and two males (one black and one white), were evaluated by eighty observers including orthodontists, oral surgeons, artists and lay persons. It was reported that the facial convexity strongly influenced the perceived need for surgery. In another study undertaken to examine the perceived need for orthognathic treatment by patients and clinicians it was found that both surgeons and orthodontists rated a greater degree of need for overall treatment as compared to patients (Juggins et al., 2005). However, the perception of severity of the dentofacial deformity varies between individuals and also so do the motivations and expectations of orthognathic surgery patients.

2.1.6. Motivations and expectations

Various studies in the past have considered motivation for patients to undergo orthognathic surgery in detail (e.g. Oland et al., 2011a, Proothi et al., 2010, Modig et al., 2006). These questionnaire based studies identified functional concerns, primarily masticatory difficulty as the main motivation for orthognathic surgery along with other concerns such as speech and pain from trauma (Soh and Narayanan, 2013). Many other quantitative studies that have included motivation of patients for surgery have also come to similar conclusions where functional concerns were the main motivation (Proothi et al., 2010, Wong et al., 2002, Garvill et al., 1992, Forssell et al., 1998). For example, Proothi et al. (2010) reviewed 501 patients between 1990 and 2006 using questionnaires. The results of the study stated that of the many complaints patients had due to the poor relationship between the maxilla and mandible, it was the bite/function that was the primary motivation to seek treatment. Only 15% of the patient sample included in the study stated that appearance concerns were their primary motivation to seek surgery although 76% of them had stated that they had appearance concerns due to the dentofacial deformity. However, none of these studies were able to obtain the patient's perspective by allowing them to use their own words to describe their motivations and expectations.

There have been various other studies that have reported appearance or aesthetic concerns as the primary motivation for many orthognathic surgery patients (Sadek and Salem, 2007, Finlay et al., 1995, Shalhoub, 1994, Kiyak et al., 1986b, Bell et al., 1985, Proothi et al., 2010). For example, Sadek and Salem (2007) conducted a study

among 120 Egyptian orthognathic surgery patients between 1998 and 2004 using standardised questionnaires. Aesthetic reasons were stated as the primary motivation for seeking orthognathic surgery among 95% of the patients in the study. The remaining 5% had cited functional problems such as mastication and speech concerns in addition to aesthetic concerns as the reason for seeking treatment.

In recent years, some other quantitative studies focused on orthognathic surgery have found that patients seek surgery for both functional and aesthetic improvements (Cunningham et al., 2000c, Cunningham et al., 1995). Although psychosocial concerns have been well recognised as a concern for orthognathic treatment, it has not been reported as the primary motivation for seeking care (Rustemeyer et al., 2010, Lee et al., 2007, Auerbach et al., 1984). Interestingly, all these studies have used quantitative methods using standardised or validated questionnaires to study the motivating factors for seeking orthognathic treatment. Therefore, the voices of the patients were only partially heard since the patients were given a set number of options to choose from when expressing their views, rather than being interviewed on their experiences.

Motivation for surgeries have been found to be many and varied. Edgerton and Knorr (1971) classified them into two forms:

- (i) External motivation – patients seek treatment because they have ‘paranoid’ ideas that changing their physical appearance will improve their social circumstances or with a need to please others and;
- (ii) Internal motivation - patients seek treatment because of a long standing functional or appearance problem and they have strong internal feelings about wanting to improve appearance.

It has been suggested that it is the internally motivated patients who form ‘better’ orthognathic surgery patients (Cunningham et al., 1996b). This may be because externally motivated factors may be more difficult to gratify as a result of surgery (Philips and Bennette, 2000). It is therefore important that the clinicians are well aware of how realistic and attainable patients’ aspirations are before progressing with treatment.

Ryan et al. (2012a) in a cross-sectional qualitative study explored the motivation for orthognathic treatment along with impact of dentofacial deformity on these patients.

In-depth interviews of 18 patients were conducted. As a result of the study it was suggested that the traditional classification of internal and external motivation was treated as a continuum by the researchers, with purely external on one end of the spectrum and purely internal on the other. Similarly, the three main categories of motivation for treatment; functional, aesthetic and psychosocial were re-classified as exclusively practical (including functional and structural concerns), exclusively psychological (including psychological and aesthetic) and a combination of both as a result of this study. Again, these categories of motivation were suggested to be a spectrum rather than distinct categories. It is likely that most patients would fall somewhere in between while a few will fall on either of the extreme ends of the spectrum. This is important because, in an attempt to perfect patient selection for orthognathic surgery, many studies have strived to define the type of patient expectations and motivations which lead to improved patient satisfaction following surgery (Forssell et al., 1998).

Expectations of patients before undergoing orthognathic surgery can be realistic or unrealistic and this has been deemed important in relation to obtaining a satisfactory outcome. Various studies have looked into the relationship between expectations of patients and their satisfaction with the surgical outcome (Espeland et al., 2008, Chen et al., 2002, Bertolini et al., 2000, Kiyak et al., 1988) Clinicians found that people with realistic expectations before the surgery tend to be more satisfied with the surgical outcomes (Chen et al., 2002). Chen et al. (2002) stated that patients with more severe dentofacial deformities were more satisfied with the surgical outcome. This was attributed to such patients having more realistic expectations and so it was easier to achieve their desired aesthetic and functional improvement through orthognathic surgery. Two suggestions were made by the authors, one, the patient must be able to clearly state what they seek to correct, and secondly, doctors must clearly explain to patients realistically that orthognathic surgery can improve function and aesthetic but not total correction. However, for these suggestions to be practical there is a need to build knowledge from the perspective of the patient, which would in turn enable clinicians to manage the expectations of patients more realistically.

It can be concluded that the type of motivation orthognathic patients have influences their expectations from the surgery. Similarly, the motivations of the patient can

influence the decision to have orthognathic surgery. Further details about how and why motivations influence the decision to have orthognathic surgery is explored in the following section.

2.2. Decision Making and Orthognathic Surgery

2.2.1. Definition of decision-making:

Samuel Eilon (1969), in a paper about decisions in management, stated that the definition of a decision is most often taken for granted and is associated with making a choice between alternative courses of action (p. B172).

Within his paper, the definition of decision making varies greatly both within and across disciplines. For example, in management, a common definition is “decision making involves the selection of a course of action from among two or more possible alternatives in order to arrive at a solution for a given problem” (Trewartha and Newport, 1982, p. 148). In psychology, “decision making refers to the entire process of choosing a course of action” (Hastie, 2001, p.657).

In the field of medicine, a number of definitions of decision making have been found. For example, decision making has been defined as a deliberate mental choice in which the decision maker chooses between two or more options and then takes committed action based on the evidence (Matteson and Hawkins, 1990). Focusing on decision making in a clinical setting, clinical decision making was defined as “a contextual, continuous, and evolving process, where data are gathered, interpreted, and evaluated in order to select an evidence-based choice of action” (Tiffen et al., 2014, p. 401).

It can be seen from these definitions that the key components of decision making within medicine are information gathering, weighing the decision’s risks and consequences and finally the choice of best course of action. Similarly, when reviewing what a good decision is, again within medicine, Ratliff et al. (1999) described a good decision as one that is made when the decision maker is well informed and also reflects personal preferences. Marteau et al. (2001) linked good decision with ‘informed choice’ and stated that it was based on relevant knowledge or information and on individual’s values. Elwyn and Miron-Shatz (2010) described a good decision as one based on phases in decision making. They proposed that the act of decision making comprises of a pre-decisional deliberation phase (process of

arriving at a decision mainly based on the information gathered and considered) and decision determination phase (the decision taken by integrating deliberation inputs).

In all these various definitions, two aspects of decision making appeared to be common; one aspect was the information or knowledge about the options and the other was the individual's perspective. In the subsequent sections the role of both of these aspects in decision making will be explored further.

2.2.2. What influences decision making?

Decision making is not just about how the decision is made but also what influences the decision. In medical decision making, apart from medical factors (nature of medical issue), many non-medical factors and the social context have been found to influence the decision making process (Clark et al., 1991, Askham, 1982, Eisenberg, 1979). These factors were identified and grouped into three categories: (i) Characteristics of patients – such as; age, sex, socio economic status (SES), race, ethnicity and individual factors like assertive personality and physical attractiveness; (ii) Characteristics of the doctor - including; medical speciality, level of training, length of clinical experience, geographical location, age, sex, race and ethnicity; (iii) features of practice such as; type of organisation (fee paying or not) and form of doctors' compensation (salaried or entrepreneurial) (McKinlay et al., 1996). Therefore, in any medical decision the influence of individual factors, characteristics of the medical professional and the nature of the care quality facility was identified to influence the person's decision making. However, the influence of these factors on decision making in orthognathic surgery needs to be further explored.

2.2.3. Decision making in orthognathic surgery

Depending on the severity of the dentofacial deformity, orthognathic patients were provided with various treatment options by the clinicians, which is dependent on the nature and severity of the deformity. As discussed in Section 2.1.4, these treatment options may range from simple growth modification treatment to complex treatment such as orthognathic surgery. Inclusion of patients in the decision making process has been deemed to be important and it has been reported that this may improve patients' awareness and acceptance of the final result of orthognathic surgery (Bailey et al., 1999). Depending on the severity of jaw discrepancies, treatment modalities varied between patients. Patients with mild jaw discrepancies could be treated with

orthodontics alone to camouflage the discrepancies. On the other hand, patients with severe discrepancies in their jaw relation required surgery along with orthodontics for treatment (Sabri, 2006).

In a study focusing on the issues in the decision making process of orthognathic surgery, Broder et al. (2000) randomly categorised factors influencing the decision making process into concrete and subtle factors. Social issues, psychological well-being, social support, self-worth, expectation for self and future and patient- clinician interaction were the subtle factors that influenced decision making. The concrete factors that were found to influence decision making were financial resources, health care provider, time availability, morphological findings and physical problems. However, understanding patients' decision making process was stated to be very difficult since there were complex processes such as the individual identifying the problem, sensing a need to make a change leading to them seeking treatment. This was the only study which identified an internal process within the individual that commenced prior to patient's seeking orthognathic treatment. However, this internal process was not explored in detail.

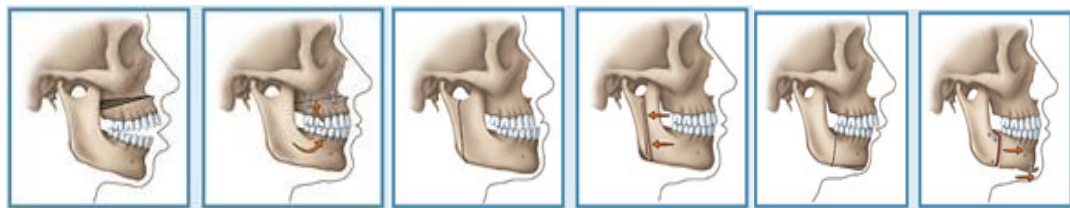
An online literature search for papers in English on decision making in orthognathic surgery between 1864 and 2014 was conducted using databases like Web of Science, Google scholar, PubMed and Scopus. Only four studies were found which focused entirely on patients' decision making in orthognathic surgery (Flett et al., 2014, Hågensli et al., 2014, Stirling et al., 2007, Broder et al., 2000). However, 57 papers were found that mentioned decision making in relation to orthognathic surgery. Among these 57 papers there were some that addressed the decision making process in orthognathic surgery as a secondary research question (Ryan et al., 2011; Rivera et al., 2000, Philips et al., 1995; Garvill et al 1992, Jacobson, 1984). The remainder had simply mentioned 'decision making' passively in relation to orthognathic surgery without actually having studied the process. For example; Tompach et al. (1995) stated that it was important for oral surgeons to understand the orthodontic decision making process so as to improve inter-professional communication in orthognathic treatment. Sabri (2006) stated that patients had to be provided with the information they needed to be part of the decision making process in orthognathic surgery. Such studies do not add much to the knowledge regarding decision making in orthognathic surgery.

2.2.4. Decision making about type of treatment

The decision making process appears to be a difficult process not only for the patients but also for the clinicians. There have been few studies in the past that have looked into the clinicians; both orthodontists and oral surgeons' choice of treatment along with a layperson's perspective other than the patients themselves. For example, studies by Benyahia et al., 2011, Fabre et al., 2010 and Broder et al., 2000, looked into which treatment option in orthodontic treatment alone: combined orthodontic and orthognathic treatment, or other treatment, best suits the patient. Each of these studies looked into different aspects of decision making about type of treatment.

Fabre et al. (2010) studied the difference in the decision making process between clinicians and people about different types of orthognathic surgery itself. The different types of surgery were: surgery including both the jaws and surgery of either one of the jaws; in upward, forward, downward or backward direction (See Figure 6).

Figure 6: Jaw movements through orthognathic surgery



Maxillary Osteotomy³

Mandibular set back⁴

Mandibular advancement⁵

Purely from a clinical perspective, taking into account the Class III type of malocclusions, Fabre et al. (2010) evaluated the difference in the predicted outcome of three different treatment options for 18 patients among orthodontists, maxillofacial surgeons and laypersons. The three surgical options considered in the study were mandibular setback, Le Fort I⁶ advancement and Bimaxillary surgery⁷. Predicted profile photographs of all 18 patients from all three different surgeries were evaluated. This evaluation was done by placing a mark on a 10-Graded Visual

³ Maxillary osteotomy is the surgery of the maxilla (upper jaw) and move it into a new desired position.

⁴ Mandibular set back refers to surgery of the mandible (lower jaw) to slide it back in relation to its original position.

⁵ Mandibular advancement refers to surgery of the mandible (lower jaw) to slide it forward in relation to its original position.

⁶ Le Fort I is a type of maxillary osteotomy where the bone cuts are place below the level of the nose.

⁷ Bimaxillary surgery refers to the surgery of both upper and lower jaws together.

Analogue Scale (ranging from 0 to 10) where 0 represented 'very unattractive profile' and 10 represented 'very attractive profile'. Evaluation was done by 521 maxillofacial surgeons, 78 orthodontists and 61 laypersons. It was found that for the majority of the patients there was a general agreement about the preferred treatment option. Overjet, nasofacial and nasomental angles were important in decision making between mandibular setback and Le fort I option (The more negative the overjet, the larger the nasofacial angle, the smaller the nasomental angle, the greater the preference for Le Fort I surgical option). Wits appraisal⁸ seemed to be important in decision making between mandibular setback and bimaxillary option. The more negative the wits appraisal the greater the preference for bimaxillary surgery. While this study is very detailed from a clinician's perspective and also takes into consideration the view of laypeople, the research failed to consider the point of view of the orthognathic patients themselves.

Benyahia and colleagues aimed to devise a guide model that would enable clinicians to make a good decision about the treatment for Class III malocclusions (2011). This study focused on helping orthodontists decide between two possible treatment options for class III malocclusions - orthognathic surgery and orthodontic camouflage. Orthodontic camouflage used orthodontic treatment alone to realign teeth in the jaws such that the underlying skeletal discrepancy is masked. In this paper it was stated that, especially in borderline cases the clinicians' clinical experience was most important in making a choice between orthodontic camouflage and orthognathic surgery. Lateral headfilms of 47 adult patients were analysed and 22 patients were undergoing orthodontic camouflage treatment and 25 orthognathic surgery. Various measurements and analyses were used to analyse cases and the model was devised. For example, *Holdaway angle*⁹ was used to differentiate between patients prior to treatment. It was reported that the developed model enabled correct classification of 87.2% of patients in the study to a treatment option which was appropriate for the patients. While, the study reported the appropriateness of a

⁸ Wits appraisal of jaw disharmony is a simple method to measure the severity or degree of anteroposterior jaw dysplasia on a lateral cephalometric head film. Jacobson, A. (1975). The "wits" appraisal of jaw disharmony. *Am J Orthod*, 67, 125-38.

⁹ Holdaway angle was defined as the angle of soft-tissue nasion to soft-tissue pogonion to labrale superius. Johnston, C., Burden, D., Kennedy, D., Harradine, N. & Stevenson, M. (2006). Class iii surgical-orthodontic treatment: A cephalometric study. *Am J Orthod Dentofacial Orthop*, 130, 300-9.

treatment option for patients, this was decided purely from the perspective of the clinician and the patient's perspective was not sought.

The study by Broder et al. (2000) compared the treatment decision of patients about type of treatment from patient records. As can be seen in Section 2.8., medical records of 118 patients from two sites in North Carolina, USA who were referred for orthognathic treatment were studied. Of those patients, 60% chose orthognathic surgery, 30% chose orthodontics alone and 10% were undecided. However, since these data were derived from patient records and not directly from patients, one cannot be sure about the decision being made entirely by the patients themselves.

The studies discussed above have considered the decision making about choice between orthognathic surgery and orthodontics. ***There has been no study, to date, which has focused on the patient's choice about the type of orthognathic surgery.***

It could be argued that clinicians are the experts in making a decision about the type of surgery that will provide best clinical results for the patient. However, in the era of patient centred care and treatment, future studies may explore the role of patients in decision making in orthognathic care, choice of treatment, the factors which influence decision making in this field. In addition, what impact patient involvement may have on the outcome of the treatment both in terms of clinical and psychosocial outcomes could potentially be explored.

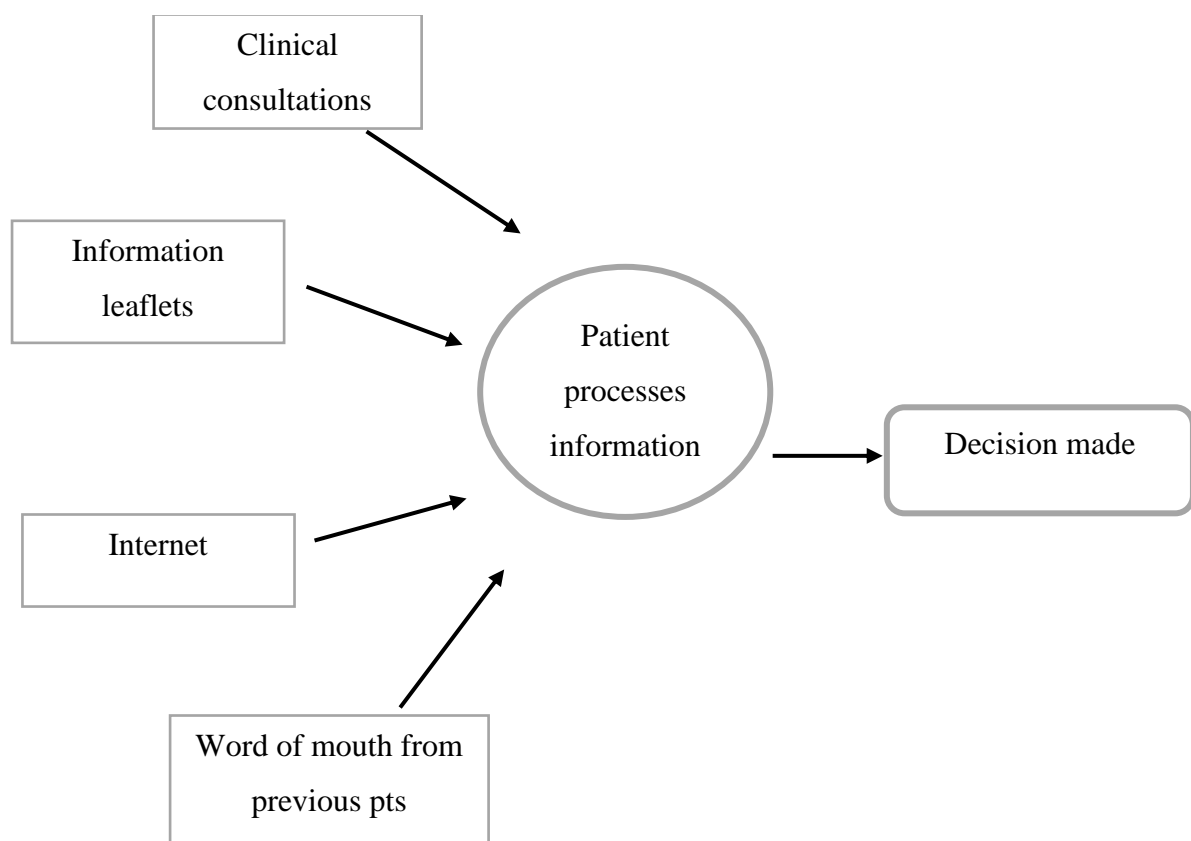
Orthognathic surgery, as mentioned earlier, is an elective surgery and the decision to undergo surgery is influenced by the patients' own perception of need (Bock et al., 2009). However, in most cases, the age at which patients are referred to hospitals for orthognathic surgery is late adolescence to early adult-hood (See age range in Table 5). Therefore, decision making involves patient, clinician and most likely the parents. When the number of people involved in decision making increases, the complexity of any approach in clinical decision making increases. For example; in an informed decision making approach, where the patient plays a proactive role and the clinician acts as an agent to provide information, the role of the parent becomes ill defined and can also contradict or coincide with the role of the patient. However, these are, currently, grey areas in orthognathic decision making because of a clear lack of research.

2.2.5. Aids in decision making

The information provided to patients plays a major role in the decision making process about orthognathic surgery. The information about the treatment procedure is available for patients through various sources such as clinical consultations, information leaflets on orthognathic surgery and the internet (Flett et al., 2014). Patients are also given the opportunity to talk to other individuals who have undergone similar types of orthognathic surgery in the past (Heliotis, 2014). However, a Cochrane review on decision aids used in the clinical decision making process concluded that little is known about the degree of detail that decision aids need in order to have a positive effect on attributes of the choice made or the decision-making process (Stacey et al., 2014)

Patients were referred to orthodontists by their dentist to seek treatment for the various occlusal and functional problems they experience. Orthodontists provide patients with treatment options that were viable for them. Orthognathic patients in England were initially seen at joint clinics in the presence of the orthodontist and oral surgeon (Heliotis, 2014). The consultants discussed and agreed on the possible treatment plans which were then discussed with patients and families (Royal College of Surgeons of England, 2013). Hospitals also handed out patient information leaflets for patients to understand the treatment better (British-Orthodontic-Society, 2012b). Patients get the opportunity to think about their options and make a decision. To further assist patients with decision making, patients were given a DVD that has various sections included in it about the surgery, the DVD was developed by Orthodontists who had themselves received orthognathic treatment and so had some insight into the process themselves (British-Orthodontic-Society, 2012a). Patients were also offered an opportunity to talk to other people who have had the surgery in private (Heliotis, 2014). Apart from the various types of information patients can obtain at the consultation clinics, there is a wide range of information about orthognathic surgery that is available to patients on the internet these days (Aldairy et al., 2012). Figure 7 summarises the influence of information on decision making for orthognathic surgery.

Figure 7: Influence of information in decision making process



The effectiveness of the DVD as a decision making aid for orthognathic surgery in the UK was studied by Flett et al. (2014). Ten patients were interviewed after they viewed the DVD and before starting their treatment. One of the problems pointed out about the DVD was that the ages of the patients shown in the DVD were much older than the usual young adults who underwent the surgery. Hence, it was harder for them to relate to the patient stories as shown in the DVD. Another problem of the DVD that was reported was the structure of the DVD, with the menu having many titles to click which led to missing out information and confusion. Some participants avoided watching some sections of the DVD, deeming them as less relevant or frightening to watch. It was reported that the surgery section was avoided out of fear to watch a real surgery. The DVD did not influence everybody's decision to have the surgery uniformly. For example, some patients had made the decision to undergo surgery prior to watching the DVD; whilst others made the decision after watching the DVD. However, when compared to internet sources, Flett and colleagues did find

that patients found the DVD a more trusted source of information. Nevertheless, one other study which evaluated the validity of information available on the internet about orthognathic surgery, had concluded that the information on the internet was valid (Aldairy et al., 2012). Similarly, a recent study that evaluated the patient's perception of online information resource about orthognathic surgery on the British Orthodontic Society website found that patients found it to be helpful and reassuring (Kettle et al., 2017).

Previous studies have examined the effectiveness of visual aids used in patient consultation clinics in supporting patients' decision making. For example, the use of videos in providing orthognathic patients with information about the surgery has been reported in past studies as an effective method of increasing interpersonal communication between patients and clinicians (Phillips, 1999, Phillips et al., 1995). On the other hand, one latest study investigated the content of YouTube videos related to orthognathic surgery and concluded that the video contents were substandard and patients should be advised to view it with caution (Hegarty et al., 2017). The study reported that only 9.17% of 60 videos analysed were classified as having excellent general information.

Broder et al. (2000) reported that several of the young participants were impressed with the visual presentation such as the treatment simulation, and the before and after slides of orthognathic surgery. This study is detailed further in the subsequent section. However, apart from these physical tools, Broder et al., (2000) also found ease of access to care, and social support, as two factors that aided the decision making process in the American population that was studied. But, there seems to be a clear lack of research exploring these areas of intangible decision aids. Flett et al. (2014) concluded that the DVD is an effective tool in the decision making process but "should be seen within the context of other influences on the patient" (p.88). These 'other influences' that the patient might have was a key area that needed to be further explored to understand this complex decision making process for orthognathic surgery.

2.2.6. Factors that facilitate or obstruct decision making for orthognathic surgery

There are three potential questions patients ask themselves before surgery; these are; “Should I have any treatment?”, “Which treatment should I have?” and “When should I have treatment?” (Broder et al., 2000, p.249). Multiple needs and motives of the patients influence the answers to these questions which in turn influences the treatment decision of the patient (Broder et al., 2000, Rivera et al., 2000). The process is often difficult to explore because of the range and complexity of the factors involved. It is further complicated by the complex pathway that ultimately leads to seeking treatment for facial deformity. This pathway begins from identifying or knowing that there is a problem to finally seeking treatment (Broder et al., 2000). This has been the only study to date that has identified that the pathway of orthognathic treatment begins with the individuals identification of the problem, which occurred prior to the actual commence of treatment.

To date, two studies have explored the factors that influence decision making for orthognathic surgery. These were from two different perspectives; Broder et al. (2000) considered patients’ reasons and issues in deciding to have orthognathic surgery over orthodontics, whilst Stirling et al. (2007) explored the process of decision making from the patients perspective by identifying factors that influenced decision making.

Broder et al. (2000) studied a sample of 118 patients from two university based dentofacial centres for 2 years in New Jersey, USA. Phone call interviews were conducted along with chart audits to obtain information about demographics, reasons for seeking treatment as well as treatment decision. It was reported that the mean age of the patients in both sites were 24.6 and 24.2 years. Among the 118 patients, there were more females than males.

The factors that influence or hinder decision making were classified in three ways; i) Intrapersonal factors, ii) Interpersonal factors and iii) specific health care delivery system factors (Broder et al., 2000). Among the intrapersonal factors that facilitated or acted as a barrier in decision making; stress, health attitudes and social support were found to have major influence. Communication between doctor and patient was the most important interpersonal factor. Physical environment and access to care was

the major specific health care delivery system that influenced decision making. In short, it was concluded that multiple issues impacted patients seeking treatment for facial discrepancies and diverse patient needs, education, health values and backgrounds impacted on their decision making (See Table 1).

Table 1: Facilitators or barriers regarding decision making for orthognathic treatment

Intrapersonal Issues	Health attitudes	Knowledge, Attitude towards health providers
	Family stress	School/Job, Business, Divorce, Child birth
	Social support	Child care, Social support
Interpersonal communication	Doctor- patient communication	Dentist/staff behaviour, Educating the patient/family
Specific health care delivery system factors	Access to care	Cost, Transport
	Facility/ Physical environment	Cleanliness
	Logistics/Quality of care	Waiting period, Prior orthodontic experience

(Broder et al., 2000, p. 254)

Stirling et al (2007) conducted a mixed method study with the aim to describe the factors influencing patients' decision to have or not to have orthognathic treatment

and to determine if this process was an informed decision. This study was conducted in four clinics providing orthognathic treatment in the North and West Yorkshire region of England in the year 2003. A total of 61 patients, who had had (30) and those who were about to undergo orthognathic surgery (31) were included in the quantitative questionnaire based study. In the qualitative study, there were 30 patients who were going to have surgery and 29 patients who had had surgery (two participants were not available for the telephonic interview). The mean age of the participants was 25 years and 66% of the participants in the study were females. All patients completed a questionnaire assessing demographics such as age, sex, ethnicity, highest level of education, state anxiety levels, self-esteem, body satisfaction and perceived facial attractiveness. There were no statistical differences in levels of anxiety, self-esteem and body satisfaction between patients and population norms suggesting that orthognathic patients do not have greater levels of anxiety or worse self-esteem than the general population. The population norms were derived from previous studies (Marteau and Bekker, 1992, Slade et al., 1990, Rosenberg, 1965). In addition, all patients were interviewed over the telephone and their experiences and reasons for orthognathic treatment discussed. From these, the patients reported that the major reason for referral to orthognathic clinics were because of problems with bite and appearance, a finding consistent with other studies (Hågensli et al., 2014, Forssell et al., 1998, Bell et al., 1985). In addition, it was found that patients' concerns about their 'abnormal' facial appearance were also a major reason for seeking treatment. However, their expectations from the surgery were found to be realistic because patients wanted to appear 'normal' and not beautiful. About half of the patients interviewed stated that it was their own decision to have the surgery, two-thirds stated that both dental professionals and family had supported and expressed their opinion about surgery as the right choice of treatment for them.

This study also identified a number of emotions associated with the treatment decision as listed in Table 2. As can be seen from Table 2, the most prevalent emotion was 'worry' and 'frustration'. In terms of the patients understanding of the pros and cons of orthognathic surgery over orthodontics, it was found that 31% of people from the sample believed that the change obtained from orthodontics would not be permanent and 19% thought that it would still not make them look 'normal'. The main concerns raised about orthognathic surgery were pain, and treatment failing in

terms of looking and feeling no better. However, there was no differentiation made between the findings from the group of participants who had had surgery and who were going to have surgery.

Table 2: Emotions associated with orthognathic treatment choice

Type of emotions	Percentage of patients
Difficulty and uncertainty in making the decision	25%
Guilt about the condition's cause	12%
Worry about the outcome of treatment	34%
Frustration in delay in treatment after the choice was made	54%

(Stirling et al., 2007)

It was found that about 46% of the patients were unhappy about some aspects of the information provided to them about the surgery. It was also observed that 73% of the patients thought that orthognathic surgery was their only option and treatment could not be discontinued once commenced. Hence, Stirling et al. (2007) concluded that some orthognathic surgery patients were not making informed decisions about their treatment. It was also concluded that patients required more support in decision making and in managing the emotional effects of the treatment. There was a strong recommendation made for improving the quality of the decision making aids for patients contemplating orthognathic surgery.

Although Stirling et al. (2007) outlined patients' perspective of orthognathic treatment and difficulties surrounding the decision making process, there is little detail on the factors that influence patients' decision to have or not to have orthognathic treatment. While this study was able to identify and list a number of concerns patients had during the decision making process for orthognathic surgery, it failed to investigate the relationship between these concerns and the patients' decision making process. The study had aimed at describing the factors identified by patients influencing their decision about orthognathic surgery, but only various

difficulties patients encountered during the decision making process were identified. The study failed to identify the factors that influenced decision making. This was because individual characteristics of the patient such as; age, sex, ethnicity, highest level of education and medical history including orthodontic symptoms, diagnosis, and orthodontic and orthognathic treatments, were only used to describe the sample, rather than be subject to any analysis. Yet, McKinlay and colleagues (1996), in earlier research, had identified these individual characteristics as key influencers on decision making. Further, the study did not explore the patients' perspective as to the factors helping them make a better decision about having or not having orthognathic surgery. The paper lacks clarity in defining the few factors that were identified as influencing or not influencing decision making such as anxiety, self-esteem and body satisfaction, patients' perceived facial attractiveness, emotions related to the decision making process, understanding of the pros and cons of treatment and motivation for seeking orthognathic treatment. Even though the study had the potential to compare the concerns and perspectives of patients who had surgery with patients who were going to have surgery, Stirling et al. (2007) did not make this comparison. This might be because the authors derived their approach from existing psychological questionnaires; thus, one solution to this would be to simply begin with the patients' views themselves and *build theory and knowledge from within their perspective*.

2.2.6.1. Perception of facial profile and influence on decision making

Other work that has been carried out investigating factors influencing decision making included a US study by Bell and colleagues (1985). This study took into account only the aesthetic concerns of the patient influencing their decision making and found a strong relationship between patients' own perception of facial profile and decisions about orthognathic surgery. Eighty patients who were previously seen by orthodontists and oral surgeons for orthognathic treatment consultation were included in the study. There were 58 females and 22 males. Their age ranged from 16 to 54 years. Forty of these patients had decided to undergo surgery, while forty had decided against having surgery. The participants were asked to rate their own facial profile by comparing this with four profile drawings on a questionnaire, which acted as rating scales. These questionnaires, along with unidentified pre-treatment photographs of patients, were also sent to 43 laypersons, 46 orthodontists and 37 oral surgeons in various states of USA. Each of these evaluators were asked to compare

the patient profile from the photograph to the drawings of facial profile on the questionnaire and record the number of the one that most resembled the patient profile. From this questionnaire study, it was found that all four groups; the patients themselves, oral surgeons, orthodontists and laypersons, decision or recommendation to go for orthognathic surgery depended on the individuals' perception of their facial profile. Hence, the study concluded that patients' self-perception of facial profile played an important role in the decision to have orthognathic surgery. This would suggest once again that perhaps we should begin from the point of view of patients themselves when we seek to understand the decision to undertake orthognathic surgery.

Bell et al. (1985) also concluded that while orthodontists and oral surgeons evaluated the facial profile similarly, the oral surgeons seemed to favour orthognathic surgery more than the orthodontist. Again, it was found that the people who opted to not undergo surgery had a facial profile that was evaluated by lay people to be closer to the ideal. It may be because, in line with the finding of this study, laypersons are more likely to evaluate a facial profile as closer to normal profile than any dental specialist. Therefore, there is a need for knowledge about the patient perspective about their treatment need rather than accumulating more understanding from the clinician's perspective. Indeed, Bell et al. (1985) strongly recommended that the patient's perception of facial aesthetics and need for treatment should be of primary concern when facial aesthetics are considered. However, this study does not take into account the psychological aspects of the patient such as body dysmorphic disorder (BDD) which has been discussed in the more recent years (Cunningham and Feinmann, 1998). However, Bell et al. (1985) discussed the possibility of other influences on the patients' decision about orthognathic surgery as has been identified by previous studies. For example; Broder et al. (2000) and Kiyak and Beach (1984) found significant influence of friends, family and other relatives on patients' decision about orthognathic surgery.

To date, the study by Bell and colleagues is the only one that has investigated the direct influence of perception of facial profile on patients' decision about orthognathic surgery. Other factors have been identified, however, and these are outlined in the following section.

2.2.6.2. Factors related to decision making process for orthognathic surgery

As mentioned in the preceding section, few studies to date have explored the decision making process for orthognathic surgery. However, a handful of studies have identified different factors that influence people's decision making (See Table 3). The primary aim of studies considered in this section was not about exploring different factors that influenced people's decision about orthognathic surgery. However, these studies were able to identify factors that influence the decision making process without placing them in any particular order. Nevertheless, those factors considered in previous literature can be grouped into motivation for treatment, psychological aspects of individuals and facial, dental morphological features and information about orthognathic treatment. These are summarised in Table 3.

Table 3: Factors related to orthognathic decision making

Factor(s) influencing decision making	Author and Date	Country	No. of participants (age range)	Design of study	Key findings
Motivation for treatment	Phillips et al., 1997	USA	135 (unknown)	Questionnaire study	16% -primarily a self-image motivation. 4% - oral function motivation, 6% - strong dual self-image/oral function motivations
	Forssell et al., 1998	Finland	100 (unknown)	Semi structured Interviews	Functional issues motivated treatment more than aesthetic issues.
	Rivera et al., 2000	USA	143 (14-56 years)	Open ended questionnaire study	Improve aesthetics; function and TMJ disorders were main reason for patients' decision to undergo surgery.

	Williams et al., 2005	UK	559 (16-63)	Retrospective questionnaire survey	Main motives for patients were to straighten teeth, prevent further dental problems and improve self-confidence.
	Proothi et al., 2010	USA	501 (12-45 years)	Survey	The primary motivation for orthognathic surgery was bite/function and not appearance.
	Jacobson, 1984	USA	50 (unknown)	Survey	The main motivation for treatment was reported as: 76% - desired improvement in facial appearance 70% improvement in jaw function.

Psychological aspects	Kiyak et al., 1986	USA	90 (14-43 years)	Longitudinal questionnaire study	Positive effect of treatment on body-image was a motivator for surgery. Neuroticism correlated with satisfaction with surgery.
	Kiyak, 1993	USA	90 (14-43 years)	Review of two longitudinal studies	Psychological profile of patients seeking orthognathic surgery was within normal range and had more psychological gains than only orthodontic treatment.
	Kindelan et al., 1998	UK	44 (unknown)	Questionnaire study.	No significant differences in psychological profiles; including stress, body satisfaction, self-esteem and introspectiveness among

					people who opted and refused surgery
	Cunningham et al., 2000	UK	176 (unknown)	Questionnaire based study with controls	Orthognathic patients showed higher state anxiety, lower self-esteem, body and facial body image.

Facial and dental morphology	Bell et al., 1985a	USA	80 patients 37 oral surgeons 46 orthodontists 43 lay persons 80 facial profiles	Questionnaire study	Self-perception of facial profile was more important in making decision for surgery. Lay people are more likely to rate profile as normal as compared to surgeons and orthodontists
	Squire et al., 2006	USA	28 orthodontists 30 dental models	Observational study	A positive overjet of > 8mm, negative overjet of > -4mm and transverse discrepancy more

					than 3mm needed orthognathic surgery.
	Oland et al., 2011a	Denmark	66 (17-33 years)	Questionnaires study	Facial profile type had very little influence on motives for surgery. Overall treatment satisfaction was related to any type of profile change after surgery.

Information about orthognathic treatment	Stirling et al., 2007	UK	61 (mean age = 25 years)	Mixed methods cross sectional survey.	Many patient's had not made an informed decision to have orthognathic surgery.
	Flett et al., 2014	UK	10 (16-48 years)	Semi- structured interviews	The DVD about orthognathic surgery was a useful decision making aid for orthognathic surgery.

From the table above, it can be seen that the motivating factors that influenced decision making of patients have been identified as; improvement in function such as chewing and biting (Rivera et al., 2000, Forssell et al., 1998, Phillips et al., 1997), self – confidence (Williams et al., 2005), self-image (Phillips et al., 1997) and aesthetics (Narayanan et al., 2008, Williams et al., 2005, Rivera et al., 2000, Jacobson, 1984). Some studies concluded that aesthetic improvement was a major motivator for deciding to undergo orthognathic surgery (Williams et al., 2005, Williams et al., 2009, Jacobson, 1984, Rivera et al., 2000).

Jacobson (1984) addressed decision making in orthognathic surgery as the second part of his research question. The first part of this study aimed at examining effect of physical appearance on social interactions. It involved a post-treatment survey of fifty orthognathic surgery patients in the USA to understand the emotional needs and reaction of patients to orthognathic surgery. The ratio of females to males was 2:1 (34 females and 16 males). It was found that participants listed more than one reason for motivation to undergo surgery. However, the most common motivation was to improve facial appearance (76% - improve facial appearance, 70% - improve jaw function). The author, commenting about number of females being more than men in the sample, stated that females were less inhibited to act upon their desire to improve appearance than men. This was the case even if both men and women alike desired to improve aesthetics. However, Jacobson (1984) did not consider the application of this reasoning in participants' motivation for surgery. Since the number of females was twice the number of males in this sample, the finding reported can be argued to be representative of the major motivator for female participants more than the male.

Rivera and colleagues examined patients' reasons to undergo orthognathic surgery and compared it with the orthodontist's reason for recommendation for surgery in the USA (2000). Patients' reason for seeking orthognathic surgery was asked to be listed on an open ended questionnaire by 105 females and 38 males prior to surgery. It was found that 71% reported aesthetic motives, 47% functional motives and 28% TMJ improvements acted as motives for surgery. Again, in this study the number of female participants was more than three times that of male participants. Considering the reason given by Jacobson (1984) about women having less inhibition about acting on desire to improve aesthetics, this sample could also be skewed due to the large number of female participants. Rivera et al. (2000) also found that there was no influence of

age on motivation for treatment. In contrast to previous findings (Garvill et al., 1992) aesthetic motivation was not only common among the young patients but also the older patients. Rivera et al. (2000) interprets this difference observed, suggesting that in the recent years the society has become more accepting of cosmetic procedures, particularly relating to aging. While, in the earlier years, older people who sought aesthetic improvements were considered to be psychologically disturbed or self-centred, in the present era such notions ceased to exist.

A questionnaire study conducted in thirteen UK NHS orthodontic centres among 326 patients (58% response) also concluded that aesthetic improvement in the form of straighter teeth was the major motivation for seeking orthognathic surgery (Williams et al., 2005). It was reported that 74% of the respondents were females. Similarly, Narayanan et al. (2007) conducted a study in a relatively small Indian sample of fifty patients (21 patients were used as controls who did not undergo surgery) found that aesthetic improvement was the key motivator for surgery.

In contrast to the already described studies, Forssell et al. (1998) in a study conducted among one hundred orthognathic patients in Finland concluded that functional issues majorly motivated the decision to have surgery. The authors stated that, this difference in the finding compared to previous studies could be attributed to the sociocultural difference in the population studied. For example, sociocultural factors such as media, family setup and peers in each population studies varied from the other. Another study which found that functional improvement motivated orthognathic treatment decision more than aesthetic improvement was by Proothi et al. (2010). A very large sample of 501 US participants took part in this survey based study. The gender distribution was 43% male and 57% female. It was reported that most common motivator for surgery was improvement in function. It was found that while 37% reported improvement in bite as a motivator, 36% had not answered the question at all. Even so, the authors justified this difference in the findings from the ones that reported aesthetic improvement as the key reason by pointing out the relatively small sample size used in those studies. However, studies such as Williams et al. (2005) had used large enough sample and yet had found aesthetics as the major motivator. Forssell et al. (1998) observed that along with aesthetic and functional motivations, psychological aspects also were an important motivation to decide for orthognathic surgery. This

also indicates that patients are aware of a positive psychological impact orthognathic surgery can have while deciding to have the surgery.

The various psychological aspects and personality profiles that may influence decision making for orthognathic surgery have been found to be body image (Cunningham et al., 2000a, Kiyak et al., 1986), state anxiety and facial body-image (Cunningham et al., 2000a). In addition, Kindelan and colleagues also considered other factors such as stress, introspectiveness and body-satisfaction in relation to decision making. They found that these factors had no significant influence on decision making (Kindelan et al., 1998).

Apart from Bell et al. (1985) there was one another study in the past that looked into the influence of facial profile on seeking orthognathic surgery (Oland et al., 2011b). The primary aim of the study was to assess influence of patient's facial profile on their motivation to seeking change in their appearance. Although this study did not directly address the influence of facial profile on decision making, it related facial profile to motivation to seek surgery. While Bell et al. (1985) concluded that self-perception of facial profile had a greater influence on people deciding about surgery; Oland et al. (2011b) found no influence of facial profile on patients' motivation for seeking surgery. The reason for this was pointed out as facial profile being just one of the aspects of patients' facial appearance hence not influencing patients' motivation. But Bell et al. (1985) had considered the patients' perception of their facial profile over the perception of the orthodontists about patients profile unlike in the study by Oland et al. (2011b). Another study aimed at identifying patients who would need orthognathic surgery depending on the type of dental or morphological measures (Squire et al., 2006). It concluded that patients with more than 8mm overjet, -4mm or greater reverse overjet and transvers discrepancy of more than 3mm needed orthognathic surgery. This study was conducted in America mainly to help insurance providers decide on funding orthognathic surgery.

Information provided to patients are discussed in Section 2.2.5. Apart from these decision aid studies mentioned in Section 2.2.5, Jacobson (1984) reported about the information provided to patients prior to surgery. It was found that only 4% of the 50 participants in the study reported the information provided prior to surgery as inadequate. Broder et al. (2000) also reported the usefulness of video imaging of

patients' current image and simulated after surgery image. Despite all the decision making aids and information provided to patients, Stirling et al. (2007) concluded that many patients were not making informed decision about orthognathic surgery. However, it must be acknowledged that, in the NHS, the DVD was introduced followed by the recommendation from Stirling and colleagues (2007) about the need for better decision making support. The DVD was produced in the year 2007 by orthodontists who had undergone orthognathic surgery themselves (British-Orthodontic-Society, 2012). While Stirling et al. (2007) started their cross sectional survey in 2003. This indicates the need for further studies to evaluate the effectiveness of information provided to the patients prior to surgery including all forms of information available to the patients.

2.2.7. Time taken for decision making

Awareness of the presence of a problem in the dentofacial appearance is the first step leading an individual to orthognathic treatment. While some people become aware of the problem themselves, for some others this awareness may be imparted on them by friends, family or health professionals. Time taken for decision making to have treatment can extend from the time when the person was first aware of the problem until the final consent for treatment is given to the clinician. However, in the case of elective surgeries such as orthognathic surgery the time taken for decision making is from the time when the patient was referred to the hospital (joint clinics with orthodontist and oral surgeons) to discuss treatment options to the signing of the consent form which is most often immediately before the surgery (Meredith, 1993).

Broder et al. (2000) as mentioned in section 2.2.6, studied a sample of 118 patients from New Jersey, USA. The mean age of the patients were approximately 24-25 years of age. Within the sample there were more female than male patients. It was found that more than 50% of patients were aware of their problem for a long period of time. Most patients reported awareness of the problem for the first time during early adolescence.

A longitudinal qualitative study was conducted among 27 orthognathic surgery patients in Sweden in 1987 (Garvill et al., 1992). This study aimed at exploring the factors governing patients' decision to undergo orthognathic surgery and to evaluate their overall satisfaction with the quality of life after treatment. Each of these 27

patients (10 male; 17 female; median age: 28 years) were interviewed five times, once before the surgery and four times up to 18 months after surgery. The interviews were conducted by psychologists 2 days before surgery, 2 days after surgery and 2,6 and 8 months after surgery. It was found that the possibility of surgical treatment had been known to patients for 1-30 years before they commenced treatment and that, on average, four years was taken to make a decision to have orthognathic surgery (Garvill et al., 1992). However, this study also found that half of the patients were influenced by their family or dentist before they made their decision. This study also explored the reasons, in the patient's opinion, for having surgery, the authors found that 63% of the patients in the study had negative influence of their facial appearance on their personal life and 44% on their social life. The study concluded that the improvements in patient's facial features following surgery had a beneficial influence on their personal and social life situations. Nevertheless, the study used a structured interview design which included questions with 'yes' or 'no' answers and used ratings on quantitative scales. This could have limited the patient's autonomy to direct the interview towards their core concerns. Further, the time of the first interviews were arguably very close to the date of the surgery which may have biased their responses owing to emotional and physical distress leading up to and following from the surgery respectively.

There seems to be very little research that has explored decision making time for orthognathic surgery. However, this could possibly be attributed to the variable amount of time taken for the pre-surgical orthodontic procedures that patients undergo before orthognathic surgery. Unlike other surgeries, elective or not, orthognathic surgery is performed only after a substantial period of pre-surgical orthodontics. This provides the patient with time to make or change their decision about the surgery.

2.2.8. Decision against orthognathic surgery

Orthognathic surgery being an elective procedure, information is provided to patients about the surgery and alternative options of having only orthodontics or having no treatment are given. Research has been conducted among both groups of people who have chosen to have the surgery and not to have the surgery (Hågensli et al., 2014, Bailey et al., 2001, Kindelan et al., 1998, Kiyak et al., 1986). Bailey et al. (2001) in an attempt to understand who seeks orthognathic surgery, studied medical records of more than 2,000 cases of referrals for orthognathic surgery in University of North

Carolina. The female to male ratio in the sample studied was 2:1. Majority of the patients referred for orthognathic surgery were of white skin colour. However an increase in patients, especially Hispanic and Asians were reported after 1995. Ten per cent of the sample studied were African Americans. From the records, it was concluded that although individuals with facial asymmetries were referred for surgery, it did not appear to influence their decision to opt for surgery. It was observed that the skeletal and dental patterns of individuals who had surgery and declined surgery were not very different. Hence, Bailey et al. (2001) concluded that perhaps the decision to undergo surgical treatment may be influenced by factors other than clinical characteristics such as skeletal patterns.

An earlier study in England investigated the psychological characteristics of 44 patients who were referred for orthognathic surgery (Kindelan et al., 1998). Psychological aspects such as stress, self-esteem, introspectiveness and body-satisfaction were assessed by pre-validated questionnaires. Of the 44 patients, 30 patients underwent surgery and 14 opted out. The findings indicated that there was no significant difference in the psychological profile between both groups of patients. This result however cannot rule out the role of psychological profile in the difference in decision making for orthognathic surgery given the small sample size and key psychological aspects not included. For example, Kiyak et al. (1986), studied other aspects including body-image and neuroticism in orthognathic patients. They studied 90 patients who had surgery and 33 patients who did not have surgery, along with 33 patients who had only orthodontic treatment. It was concluded that the positive effect of seeking treatment on body-image motivated patients to have the treatment. It was also observed that neurotic patients were less satisfied with treatment than the others.

A very recent study from Norway aimed at examining the factors that influenced patients decision to refuse orthognathic surgery (Hågensli et al., 2014). Patients who refused surgery and had surgery after being referred to University of Oslo for treatment were included in the study. Of the 470 people referred for treatment, 160 refused surgery and 236 underwent surgery. Un-operated patients were mailed questionnaires addressing their reasons for not opting for surgery, satisfaction with the information provided during consultation and opinion about their oral function and appearance. The questionnaire was designed to be comparable with the questionnaire already used among patients undergoing operation. The most prevalent reasons for declining

surgery were identified as risks of surgery (especially nerve injury), lack of severity of functional problem, burden of care and general reluctance to have surgery. It was found that most of the patients were happy with the information provided (very good =34.3%, good =50.5% and insufficient =15.2%). This study also concluded that the dentofacial characteristics were quite similar among people who declined and opted for surgery. This conclusion further suggests the importance of non-clinical factors influencing decision making for orthognathic surgery as noted above (Broder et al., 2000). Hågensli et al. (2014) also concluded that informed consent for orthognathic surgery was a challenge for both patients and clinicians and information provided during consultation should include the actual risks and benefits of treatment.

2.2.11. Summary

Of those studies in the literature, only four were clearly aimed at studying the decision making process in relation to orthognathic surgery (Flett et al., 2014, Hågensli et al., 2014, Stirling et al., 2007, Broder et al., 2000). Of these four, Flett et al. (2014) and Hågensli et al. (2014) focused purely on the effectiveness of decision making aids - orthognathic surgery DVD and information available to patients on the internet respectively. Stirling et al. (2014) failed to address the main aim of the study, to describe the factors that influenced decision making for orthognathic surgery. Further, the study lacked the methodological rigour to differentiate between the factors that influenced the decision for orthognathic surgery among the patients who had surgery from the patients who were going to have surgery.

Studies which have identified factors influencing decision making, as seen in Table 3, have only been able to list these factors without being able to place them in any particular order. Such a list is of little value if it is not placed in order or with a particular context. The use of a theoretical framework would be able to add more value to such a list of factors influencing decision making by possibly ordering these factors based on priority. Further, the use of theory could help in understanding the effectiveness and mechanism of existing systems in place for decision making. The use of such theory driven research have been well debated in social sciences and many researchers have concluded that theory driven research can be used to replicate desirable outcomes, identify attributes for failure – be it mechanism failure or failure of theory itself (Coryn et al., 2011). Similarly, the application of this theory driven approach in orthognathic decision making could potentially help identify failures in

delivery of decision making aids, replicate good outcomes of decision making and possibly help identify theories that are effective in orthognathic decision making.

The importance of information provided to patients in supporting the decision making process has been well recognised. However, there has still been a lack of research in identifying the use of information in the decision making process for orthognathic surgery. For instance, Flett et al. (2014) studied only one format of the decision making tools, a DVD. It was reported that watching the DVD did not alter every patients' decision about orthognathic surgery. Hence, there appears to be a need to study the actual usefulness of these aids designed to support patients' decision making process. Yet another area, which requires further research, is in the impact of decision aids apart from information aids such as leaflets and audio-visual media, on orthognathic surgery outcomes. Apart from the information aids, some of the other environmental factors that influenced decision making were social support and access to care. However, only one study was found to have accounted for these factors like social support and access to care (Broder et al., 2000).

Further, the psychological aspects that have been considered in relation to decision making in the existing literature are self-esteem, body- image, body –satisfaction, anxiety, depression, and neuroticism. However, other psychological aspects such as resilience and coping abilities, which could influence decision making processes have not been addressed.

In sum, decision making in orthognathic surgery is a complex multifactorial process. There is a need for further research to identify the major factors that influence decision making (including patients psychological and environmental factors), describe the actual decision making process using a theoretical framework and to assess the effectiveness of existing decision making aids.

2.3. Visible difference and psychological impact

In the previous sections, the clinical aspects of orthognathic surgery and the perspective of the clinicians have been reviewed at length. In this section, the patient perspective of their appearance and its psychological impact is reviewed. There is a difference in the language used in this section as compared to the previous, especially because of the difference in the perspectives of the patients and the clinicians. The most important difference is how the physical difference in the patient's jaw structure

is described by clinicians and the patients themselves. We have seen that ‘deformity’, ‘discrepancies’ and ‘disfigurements’ have been used to describe the physical difference in appearance as expressed from a clinical perspective. However, patients do not tend to call themselves ‘deformed’. Further, Rumsey and Harcourt (2007) argued against the use of such negatively framed words and suggested the use of the word ‘visible difference’. Therefore, in this section the term ‘visible difference’ will be used to refer to facial or any other disfigurement.

In the preceding sections it has been established that aesthetic improvement is one of the many reasons why individuals decide to have orthognathic surgery. It has also been established in Section 2.1.3 that various visible differences, including cleft lip as well as plate and facial asymmetries, are indications for seeking orthognathic surgery. Therefore, it is evident that individuals seeking orthognathic surgery have lived with a visible difference and the concerns caused by it have warranted surgical treatment. The concerns caused by the visible differences are largely psychological (Rumsey and Harcourt, 2007, Rumsey and Harcourt, 2004) and understanding these psychological impacts is of central importance for this research. This is because if we are to better manage facial difference we need to fully grasp the impact of such differences on individuals. One way to do this is to ask patients themselves and listen.

The majority of previous studies on visible difference have demonstrated that individuals experience psychological distress as a result of visible difference (Rumsey et al., 2004). It has been acknowledged that this was largely because for centuries the society in which we live has been inclined in favour of beauty and attractiveness (Rumsey and Harcourt, 2005). Various studies in the past have reported that people with an attractive appearance have had preferential social treatment in the form of employment opportunities (Stevenage and McKay, 1999, Dipboye et al., 1975), academic achievements (Clifford, 1975, Ross and Salvia, 1975, Clifford and Walster, 1973, Dion, 1972), relationship prospects (Fisman et al., 2006, Stewart et al., 2000, Krebs and Adinolfi, 1975), persuasive power (Sigall and Aronson, 1969) and in criminal justice (Spira et al., 1966). Other studies, for example, Bull and Rumsey (1988) have critiqued these findings by pointing out the lack of ecological validity of most of these studies. Many of the studies used photographs of individuals with various appearance differences to evaluate the response of assessors based on attractiveness. Therefore, it was suggested that findings from these hypothetical

situations may be misleading. Nonetheless, it is evident from the literature that physical attractiveness may provide individuals with social and other ‘benefits’ intra- and inter-personally.

In order to explore the psychological impacts of visible difference, a deeper understanding of visible difference and its implications becomes necessary. In the following section, the meaning and implications of visible difference will be discussed with special focus on facial visible difference.

2.3.1. Visible difference

Rumsey and Harcourt (2005) stated that it was difficult to define a disfigurement (visible difference) since there was no defined range of ‘normal’ and ‘abnormal’. However, the most common definition used states that disfigurement is “a difference from a culturally defined norm which is visible to others” (Rumsey and Harcourt, 2005.p.88). Rumsey and Harcourt (2005) also emphasised the importance of ‘visible to others’ in the definition so as to clearly exclude conditions such as Body Dysmorphic Disorder (BDD); an anxiety disorder where an individual is preoccupied with imagined defects in their physical appearance or a gross exaggeration of a slight physical anomaly (American Psychiatric Association, 1994).

Although visible differences could affect any visible part of the body, facial visible difference was found to be integral in the literature on visible difference. The face is an integral part of a person’s identity (Rumsey and Harcourt, 2005). The face is synonymous with the person in all human relationships (Macgregor, 1990).The importance of the face in everyday life was further emphasised through the verbal expressions in our language such as ‘face-to-face’, ‘losing face’, ‘facing up to something’, ‘two faced’ etc. (Hughes, 1998a). Facial appearance was stated to have a strong impact on social interactions (Masnari et al., 2012).

Aspects of facial appearance such as symmetry and averageness of faces have been defined and its deviance have also been studied in the past (Komori et al., 2009, Rhodes, 2006). Averageness referred to “the degree to which a given face resembles a majority of faces in a given population” (Komori et al., 2009, p. 136). Symmetry referred to “the extent to which one half of the face is similar to the other half” (Komori et al., 2009, p.136). A young (age 18-26 years) Japanese sample of 48 males and 48 females rated the symmetry of 96 photographs of faces and 114 (age 18-68 years)

participants rated the averageness of faces in the same photos. It was found that averageness alone affected the females' thoughts about facial attractiveness while for males both averageness and symmetry affected facial attractiveness positively (Komori et al., 2009). Similar findings about the positive influence of symmetry and averageness of the face have also been reported in other studies (Fink et al., 2006, Baudouin and Tiberghien, 2004). Interestingly, facial symmetry has been associated with coping abilities of individuals (Fink et al., 2006), personality characteristics (Fink et al., 2006) and perceived health (Rhodes, 2006). However, deviance or differences in these attractiveness traits were perceived negatively by observers. For example, asymmetry and distinctiveness were related to anxiety (Fink et al., 2006) and ill-health (Rhodes et al., 2001). It was not only the facial differences but also any physical visible differences were found to be negatively perceived for very many years (Gething, 1992, Dimitroulis et al., 1994, Cogswell, 1968). Following this understanding, several researchers have studied the impact and differences in the influence of various visible differences on the response from others.

Visible differences can be either congenital or acquired (Rumsey and Harcourt, 2005). Congenital visible differences are present from birth such as, craniofacial anomalies (e.g. Crouzon syndrome, Apert's syndrome etc.), cleft lip and palate, birthmarks or vascular malformations (e.g. Port wine stain) and syndactyly or webbing (incomplete separation of fingers or toes). Acquired visible difference develops later in life such as those resulting from accidents, for example burns, road traffic accidents, dog bites etc. or through the treatment of diseases such as cancer resections, scars etc. It was also found that congenital visible differences caused a more negative response from others than those that were acquired and temporary disfigurement (such as scars from traumatic injuries or burns) (Rumsey et al., 1982). However, the aetiology and severity of the visible difference were found to have different responses from members of the general public and it also affected the social interactions of the individual (Cochrane and Slade, 1999).

2.3.2. The psychological impact of visible difference on individuals

There is growing amount of literature that has established just how severe the psychological impact of visible differences can be on individuals. This literature will now be reviewed in this section. The literature on the impact of visible difference draws attention to three main issues, namely; body image, lower self-esteem and social

interaction (Rumsey and Harcourt, 2005). These have, however, been shown to have different impacts across points in the life course, particularly in relation to whether congenital or acquired. While acquired visible differences impact on the life of individuals from the time when it first arises, congenital visible differences, such as cleft lip and palate and other craniofacial anomalies, impact on the life of individuals from birth and throughout their life at various times. Various issues have been identified in relation to the developmental stages of individuals with congenital visible difference (Rumsey and Harcourt, 2005).

The development of self-concept and self-esteem initiates during the early childhood and is greatly influenced by the role played by important people in the child's life (Roberts, 2006). Self-concept refers to "the individual's belief about himself or herself, including the person's attributes and who and what the self is" (Baumeister, 1999, p.13). Apart from the influence of important people, it has also been well established that self-concept and appearance are closely related (Gorgan, 1999, Harter, 1999). Although self-esteem and self-concept are often used interchangeably, Harter (1999) stated that self-esteem refers to overall evaluation of oneself, including feelings of general happiness and satisfaction. However, the visible difference in children caused them to be at a greater risk of poor perception of self and lower self-esteem (Rumsey and Harcourt, 2005).

Endriga and Kapp-Simon (1999), in their review of psychological literature on cleft lip and palate and other craniofacial anomalies found that 30-40% children with congenital visible difference experienced behaviour disorders such as internalising problems (shyness, depression and somaticizing) and externalising problems (aggression, disobedience, impulsivity). Apart from these, it was also found that children with visible difference experienced learning disorders and difficulties related to social competence. It was recognised from various studies that social withdrawal fewer friends and issues in peer relationships were common among children with visible difference (Endriga and Kapp-Simon, 1999, Pope and Ward, 1997). While Kapp-Simon and McGuire (1997) reported that children with visible difference initiated and received fewer social approaches, Endriga and Kapp-Simon (1999) pointed out that these children avoided social interactions and were socially withdrawn so as to avoid peer rejection and uncertainties in social interactions.

Children with visible differences are also faced with difficult responses from others. Teasing and appearance related bullying were commonly reported among children with visible differences (Rumsey and Harcourt, 2005). In a cross-sectional study of 160 children with CLP (mean age 13.6 years) and 113 children without any clefts (mean age 13.0 years) who acted as controls, Hunt et al. (2006) reported that 62% of participants with CLP had been teased. Teasing and bullying were reported as physical, verbal or emotional in nature from the semi structured interviews conducted. The major reason for teasing was reported to be due to appearance (among 55% of CLP participants who were teased). Yet another major reason for teasing was found to be related to speech (34%). Similarly, another study among adolescents (aged 11-19.5 years) which investigated the appearance related concerns also found that 75% of the 190 adolescents stated that they were teased or bullied based on appearance and this caused great distress (Lovegrove and Rumsey, 2005).

Various studies among orthognathic surgery patients have also reported a significant amount of bullying in the form of teasing and being called nicknames (Modig et al., 2006, Williams et al., 2005, Zhou et al., 2002, Zhou et al., 2001). For example; Williams et al. (2005) reported that 61% of the 190 patients in the study had been teased about their appearance. One out of two patients reported being called a nickname because of their appearance in the study by Zhou et al. (2002, 2001).

Adolescence is considered as the time when visible difference caused or exacerbated existing issues of self-consciousness and self-esteem (Rumsey and Harcourt, 2005). Appearance played a major role in dating and hence adolescents with visible difference lacked the confidence to make initial moves fearing the shortcoming of their visible difference (Rumsey and Harcourt, 2005). Turner et al. (1997) from 242 interviews of 112 CLP patients (age 1- 20 years) found that 60% of patients were teased about their speech or appearance. The 15-20-year-old CLP patients in the sample reported a negative effect on self-confidence due to their CLP. Another interesting finding in this study was a minor yet significant 23% (n=7) of 15-year-old CLP patients in the sample expressed feelings of being excluded from the treatment planning decision making because they felt that the clinicians and parents made the final decision about their treatment. Nevertheless, adolescents with visible differences face up to various difficulties in their day-to-day life.

The psychological impacts on adults with visible differences were predominantly due to difficulties in social encounters and negative emotions and self-perceptions (Rumsey and Harcourt, 2005). Many studies in the past have established that issues in social interaction were a pressing concern for individuals with visible differences (Rumsey et al., 2004, Pope and Ward, 1997, Kapp-Simon, 1986, Shaw et al., 1980). Macgregor (1990) stated that the hurtful responses of the ‘non-disfigured’ strangers in everyday social encounters in life (e.g. while travelling to work, shopping etc.) were more distressing than the hurt to their self-esteem on seeing their visibly different appearance in a mirror. Furthermore, the individuals with visible differences are denied the privacy or ‘civil inattention’ (Goffman, 1963b) which is normal for individuals with no visible differences (Macgregor, 1990). Various reactions of strangers to individuals with visible differences have been identified by Macgregor (1990) such as, naked stares, startled reactions, furtive looks, curiosity, personal questions, whispering, aversion, laughter, ridicule and avoidance (p.250). These responses in turn created psychological impact on the victims such as shame, anger, impotence and humiliation (Macgregor, 1990). Therefore, unsurprisingly, individuals with visible difference show more inhibition in social behaviour, withdraw from peers and adopt different coping behaviours to hide their visible difference (van den Elzen et al., 2012). The behaviour to hide the visible difference was succinctly described by Erwin Goffman in his literature on Stigma in which he called the “management of undisclosed discrediting information” about one-self as ‘passing’ (1963b, p.42).

Face-to-face encounters of individuals with visible differences showed more negative responses from others than other forms of social encounters (Rumsey et al., 1986). Rumsey et al. (1986) found that fewer people agreed to take part in market research when market researchers with visible difference approached them as opposed to ones without any visible difference. On the other hand, when the face-to-face interaction was avoided, people were equally helpful to individuals with and without visible difference. Similarly, Rumsey et al. (1982) showed in their study that people preferred to interact closely (proxemics) with individuals with no visible difference than with individuals who had a visible difference (see Section 2.3.1.). Rumsey et al (1986) used the example of posting ‘lost’ application forms completed with a passport size photograph of the individual and studying the response rate of people. This study showed that visible differences on a photograph did not affect the response rate from

others. Thus, they justified the effect of avoiding face-to-face contact. However, the reasons for people avoiding encounters with individuals having a visible difference were found to vary. Some of the reasons cited were due to lack of knowledge, avoiding anything contagious and due to uncertainty about how to behave when encountering a person with visible difference (Bull and Rumsey, 1988).

The victims of negative responses and reactions in social encounters have shown difference in their own behaviour in the form of aversive emotional responses, social anxiety, lower self-esteem, negative body image and certain behaviour patterns like social avoidance (Rumsey and Harcourt, 2005). However, Macgregor (1990) stated that sometimes the avoidance and rejection of individuals with visible differences may be overstated because these individuals were made highly sensitive and aware of negative responses by others. Therefore, what others may regard as unimportant or behaviour with no consequence, an individual with a visible difference may not feel likewise (Macgregor, 1990). Rumsey and Harcourt (2005) stated that this hypersensitivity caused individuals with visible differences to have poor interaction styles ranging from complete social avoidance to shyness including awkwardness, embarrassments, defensiveness and hostility to others. The body language used during social interactions was also different from people with no visible difference. For example, Adachi et al. (2003) studied the head and face body language of CLP patients using video recording and observed that CLP patients displayed significantly lower head nods and fewer smiles as compared to others.

Apart from difficulties in interaction with strangers, individuals with visible differences were also found to have issues in long-term relationships. Porter et al. (1990) studied the effect of vitiligo, an acquired skin condition, on the sexual relationships of affected individuals. Fifty-percent of the participants in the study stated that there was a reduction in their sexual activity mainly due to their own anxiety and discomfort since the occurrence of vitiligo. Similar findings were also reported in a study among head and neck cancer survivors. Gamba et al. (1992) interviewed 66 patients, between six months and eight years after surgical treatment for head and neck cancer. Physicians had grouped 36% of these patients as having minor facial disfigurement and 24% as having extensive facial disfigurement. The result of this study showed a higher impact on patients with extensive facial disfigurement in the form of worsened relationship with partners (27%), reduced sexuality (74%) and

increased social isolation (36%), as opposed to lower impacts on patients with minor facial disfigurement. Fifty-seven percent of patients with extensive facial disfigurement have experienced a change in their self-image. However, other studies have also considered the psychological impact of severity of visible difference in various contexts including response from others.

The severity of visible differences was found to influence the responses of others (general public) (Cochrane and Slade, 1999). It was found that the negative responses of other to individuals with severe, mild or moderate disfigurements varied depending on the severity of the visible differences (Macgregor, 1979). Corresponding to this, it was also found that predictability and consistency of others' response to different degree of severity of visible differences play a significant role in individual's adjustment to their appearance (Lansdown et al., 1991, Macgregor, 1990). Therefore, individuals with severe disfigurements were reported to have lower negative adjustments such as anxiety, since the response of others to the visible difference was consistent and more predictable. However, there are other studies which have reported contrary findings to the abovementioned (e.g. Pruzinsky, 1992).

Pruzinsky (1992) discussed the psychological and social experiences of individuals with severe forms of craniofacial deformity (visible difference of head and face). It was concluded that individuals with more severe craniofacial deformity was at greater risk of experiencing social and psychological stresses. It was also concluded that much of the stress in individuals' experiences were due to the responses of others to their visible differences. The visible differences also negatively impacted on quality of life of the individuals. Pruzinsky (1992) stated that many of these individuals with severe visible differences did not develop 'psychopathology' because of the influence of intervening personality and familial influences, which mitigated the negative social responses.

To summarise, visible differences cause many negative psychological impacts on individuals. Studies on visible differences have reported the negative psychological impacts of living with visible differences such as lowered self-esteem, anxiety, depression and difficulties in social situation, for example: Rumsey and Harcourt, (2004); Rumsey et al., (2004); Kent and Thompson, (2002). While many studies have found that there is a significant negative impact on body-image and self-esteem of

individuals, the negative responses from various forms of social interactions play a major role in causing lowered self-esteem and negative change in body image. The influence of social support, especially from the family, ameliorated the negative impacts. Interestingly, through adjustment and adaptation to visible difference, participants in a few studies have reported some positive impacts of visible differences, which will be discussed in the subsequent section.

2.3.2.1. Positive impact of visible difference

Despite reports of negative psychological impacts, it has been observed that many individuals who live with a visible difference do not report psychological distress. Rumsey et al. (2004) conducted a cross-sectional survey among 458 participants from London and Bristol to study the psychosocial needs for patient with conditions causing visible differences by using both quantitative and qualitative methods. It was found that 48% and 27.5% of this sample had shown definitive or borderline anxiety and depression respectively. It was also found that 50% of this sample had scored lower than the normative levels on psychological domains. However, the other 50% and more people who participated in the study and lived with a visible difference showed no such concerns.

The role of friendship and acceptance was studied in Norway in relation to self-perception of appearance and depressive symptoms (Feragen et al., 2010). In this study, adolescents with a visible difference such as visible cleft lip or complete cleft lip and palate (n= 196) were compared with adolescents with no visible cleft such as only cleft palate (n = 93) and also with a comparison group with no anomalies (n = 1832). Outcome variables such as depressive symptoms, friendship and social acceptance, and self- perception of physical appearance were assessed using questionnaires. It was found that physical appearance mediated the association between social acceptance and emotional distress among all the three groups in the study. Furthermore, boys with visible differences reported less depressive symptoms and also had significantly more positive perception of friendships. Thus, this study reported another positive consequence of visible difference among young people.

Griffiths et al. (2012), studied the impact of visible difference on the romantic relationships of adolescents (age 13-20 years) in the UK using mixed methods including an online survey with open-ended questions. The sample consisted of 22

males and 18 females. It was found that 73% of the 40 participants had experienced a romantic relationship and 23% were at that time in an active romantic relationship. Although 43% reported concerns about their current or future romantic relationships due to the visible difference, majority of the sample, 58%, reported to be confident in romantic relationships. Interestingly, among the 58% (n =23) 19 participants had cleft lip and palate repair and four had some form of skin conditions causing visible differences. Nonetheless, it was observed that a large proportion of adolescents with visible differences had positive experiences of romantic relationships. The major part of the study was focused on the positive adjustments made by these adolescents and will be discussed in Section 2.5. However, before discussing the positive adjustments with visible differences and treatment, it is necessary to focus on the outcome and impact of orthognathic surgery. This will further enable better understanding of coping with both the visible difference that necessitated orthognathic surgery and impact of orthognathic surgery itself.

2.4. Impact of orthognathic surgery

In this section, the impact orthognathic surgery has on the patients is detailed. Here we will see that the perspective of the patients intersects with that of the clinicians'. This is because the impact of the surgery can be assessed only by taking into account the perspective of the patient themselves regarding the impact. Therefore, we see that the language of this section integrates both the clinical and patient perspectives.

Orthognathic surgery and its impact on individuals has been studied for years in relation to surgical techniques (Hernandez-Alfaro et al., 2014, Guglielmi et al., 2013, de Paula et al., 2013, Donatsky et al., 2011, Bryan and Hunt, 1993), surgical outcomes (Bryan and Hunt, 1993), functional correction, TMJ function and patient satisfaction (Kuroda et al., 2007; Pahkala and Kellokoski, 2007; vanSteenbergen et al., 1996; Kiyak et al., 1988). Since the 1980s there has been an active interest in exploring the impact of orthognathic surgery on the psychosocial well-being and quality of life of individuals (e.g. Rustemeyer and Gregersen, 2012; Pavone et al., 2005; Hunt et al., 2001, Kiyak et al., 1984). More explicit and repeated studies have shown a positive impact of orthognathic surgery on function, aesthetics, psychosocial aspects and hence the quality of life of the individual (e.g. Espeland et al., 2008, Sadek and Salem, 2007). These various aspects which are impacted upon by orthognathic surgery are discussed in detail in the following sections.

2.4.1. Functional impact

Many studies in the past have reported a significant impact on masticatory function following orthognathic surgery (Yamashita et al., 2011, Iwase et al., 2006, Pahkala and Kellokoski, 2007, Zarrinkelk et al., 1995, Proffit et al., 1989, Nagamine et al., 1986). Researchers have found improvement in masticatory function such as chewing and biting among patients post-orthognathic surgery (Piancino et al., 2013, Trovik et al., 2012, van den Braber et al., 2006, Nurminen et al., 1999, Cunningham et al., 1996a). For example, van den Braber et al. (2006) studied the chewing performance and maximum bite force of 12 patients with Class III malocclusion before and after orthognathic surgery in Netherlands. While the bite force was tested on the first molars, the chewing performance was tested with sieving method after 15 strokes of chewing on an artificial test food. The results of this study showed that five years post-surgery there was significant improvement in chewing performance from pre-surgical measure, provided the patient had poor chewing performance. Nevertheless, improvement in maximum biting force could not be shown even five years after orthognathic surgery. While this study clinically measured change in chewing and biting abilities of patients, Trovik et al. (2012) used questionnaires to study the patients' perception of improvement in function following orthognathic surgery. In this study, seven oral health related questions were rated on visual analogue scales by 36 participants (age range 29-62 years) in Norway. The most significant change was found in chewing ability. However, not all studies have reported positive improvement in masticatory function (e.g. Zarrinkelk et al., 1995). For example, Proffit et al. (1989) used transducers to measure the biting forces of 70 orthognathic patients following surgery in USA and compared it with before surgery biting forces. The biting force was measured on the right first molar of all patients. Various types of change in biting force were observed among patients who had maxillary osteotomy, mandibular setback, and mandibular advancements (See Table 4). The study concluded that orthognathic surgery produced large changes in occlusal or biting forces but it was not related to change in morphology or altered geometry after surgery. This study strongly recommended seeking further explanation about the cause for such variable changes in occlusal forces following orthognathic surgery.

Table 4: Change in occlusal forces post -orthognathic surgery

Type of surgery (n)	>20% improvement in occlusal force	Little or no change in occlusal force	>20% decline in occlusal function
Maxillary osteotomy (15)	N= 10	N= 3	N= 2
Mandibular advancement (34)	N= 11	N=11	N= 12
Mandibular setback (21)	N= 6	N= 9	N= 6

(Proffit et al., 1989)

Many researchers in the past have shown that patients with TMJ dysfunction benefit from orthognathic surgery (e.g. Martin, 2011, Dujoncquoy et al., 2010, Lai et al., 2002, Wolford et al., 2002, Panula et al., 2000, Moenning et al., 1997). For example; Panula et al. (2000), in a prospective follow-up study of 60 patients, showed that there was a 60% reduction in TMJ symptoms following orthognathic surgery. Helkimo's Anamnestic and Dysfunction Indices were used once pre-surgery and twice post-surgery (average follow up four years after initial assessment). A control group of 20 patients with similar type of deformity and symptoms, but did not want to undergo orthognathic surgery, were also assessed. While a majority of patients (73.3%) showed TMJ dysfunction in the initial pre-surgery assessment, there was a significant improvement in symptoms observed in 60% of the sample during the final assessment. A significant reduction in headache due to TMJ dysfunction was also observed (Initial assessment n= 38, final assessment n= 15). On the contrary, there have also been other studies that have shown no improvement or rather acceleration in the TMJ symptoms following orthognathic surgery (Wolford et al., 2003, Hori et al., 1999, Crawford et al., 1994, Sanroman et al., 1997, Moore et al., 1991). However, there are also studies that have found variable response in TMJ symptoms as an outcome of orthognathic surgery (e.g. Onizawa et al., 1995, O'Ryan, 1995) and concluded that the alteration in TMJ symptoms following orthognathic surgery was not attributed to the correction in malocclusion.

The role of orthognathic surgery in improving speech difficulties due to malocclusion has been long debated. As mentioned earlier in section 2.1.3.2, the orthognathic

commissioning guide (Royal College of Surgeons of England, 2013) stated that little evidence was available about the benefits of orthognathic surgery to improve speech. However, some studies have reported substantial amount of improvement in the speech of patients with prior speech difficulties following orthognathic surgery (e.g. Murphy et al., 2011, Bertolini et al., 2000, Vallino, 1990). Murphy et al. (2011) in a questionnaire study among 62 orthognathic patients found that 32% patients reported improvements in speech following orthognathic surgery. Nevertheless, there have also been studies that reported no change in speech following orthognathic surgery, but if any there was only deterioration in speech immediately following surgery (e.g. Dalston and Vig, 1984, Garber et al., 1981).

In the current literature, a significant impact on the functional outcome of orthognathic surgery was evident (Martin, 2011, Oland et al., 2010a, Phillips et al., 2004, Hatch et al., 1998, Auerbach et al., 1984). Many of these studies found a positive correlation between patients' perception of functional outcome and satisfaction with the treatment obtained (Martin, 2011, Oland et al., 2010b). Philips et al. (2004) observed that patients who had higher functional burden before the surgery were less satisfied with the functional outcome of orthognathic surgery. Then again, Rustemeyer and Gregersen (2012) found that aesthetic and psychological outcome had a greater impact on the life of orthognathic patients than functional outcomes.

2.4.2. Aesthetic impact

Aesthetics or appearance concerns of orthognathic patients has been well documented in existing literature (e.g. Johnston et al., 2010, Espeland et al., 2008, Cheng et al., 1998, Garvill et al., 1992, Athanasiou et al., 1989). The impact of these aesthetic concerns on affected individuals has already been discussed in sections 2.1.3.3 and 2.3.1. Facial appearance played an important role in individuals' social and personal life (Grammer et al., 2003). Similarly, it also correlated with many positive personality traits (Dion et al., 1972). Many studies on orthognathic surgery have considered the impact of change in facial aesthetics following surgery (e.g. Jesani et al., 2014, Sinko et al., 2012, Rustemeyer et al., 2010). For example; Sinko et al. (2012), analysed the effect of facial aesthetics and certain personality traits of orthognathic patients on others' (with no appearance difference) perception. The pre and post-surgery facial profile photographs of eight skeletal class III and eight skeletal class II malocclusion patients along with eight skeletal class I occlusion individuals, who served as controls,

were assessed by 92 volunteers on a computer-assisted test battery. The assessors marked facial aesthetics on a 7-point Likert scale and also assigned personality traits such as unintelligent, brutal, aggressive and inhibited. Their results of the study showed that the photographs of the two patient groups were marked less attractive and unintelligent as compared to the control group. Both the patient groups benefited strongly from the surgery, with respect to intelligence and aesthetics. However, the class III malocclusion group seemed to be rated more strongly in relation to personality traits as compared to other groups. Therefore, it is evident that others can make judgment not only about the facial appearance but can also assign a personality trait using profile photographs. These judgments were found to be altered following orthognathic surgery.

It was not only others who were influenced by the facial appearance but individuals themselves who require orthognathic surgery were also affected by their facial appearance (Johnston et al., 2010). Johnston et al. (2010), tested the hypothesis – ‘perception of dental and facial attractiveness of orthognathic patients were similar to non-patients’, among 162 patients and 157 non-patients who acted as controls. Happiness with dental and facial appearance was accessed from questionnaires using visual analogue scales as well as binary and open response data. The results of this study showed that orthognathic patients were less happy with their facial appearance than the controls. Women and older patients were much less happy with their facial appearance. Patients with class II malocclusions were more eager to change their facial appearance than patients with Class III malocclusions. Therefore, the study rejected the hypothesis they tested. However, similar findings about female orthognathic patients being unhappy about their facial aesthetics than males have also been reported in other studies (e.g. Jacobson, 1984).

Various studies have reported significant improvement in facial appearance following orthognathic surgery (e.g. Murphy et al., 2011, Rustemeyer et al., 2010, Pahkala and Kellokoski, 2007, Ostler and Kiyak, 1991). For example; Murphy et al. (2011) studied the clinical relevance of orthognathic surgery among 62 patients (age range 18-38 years), 27 male and 35 females. The study used an orthognathic quality of life questionnaire and visual analogue scale to assess the impact of orthognathic surgery. It was found that 93% of the participants reported moderate to large improvement in facial aesthetics following orthognathic surgery. However, 64% also reported

improvement in ability to chew and 32% reported improvement in speech. More importantly the study found the largest clinical relevance of orthognathic surgery to be in facial aesthetics. Similar findings about patient satisfaction with the aesthetic improvement following orthognathic surgery was also reported in a study evaluating the treatment outcomes of bilateral sagittal split osteotomy (a type of mandibular orthognathic surgery) (Pahkala and Kellokoski, 2007). Improvements in facial appearance were reported among 82% of the 82 patients included in the study. Another study with a larger sample of 583 patients, 83% improvement in aesthetics and 81% improvement in function (chewing) was reported in a 3-year follow-up questionnaire based study (Espeland et al., 2008). Therefore, it is now evident that orthognathic surgery has a positive impact on the facial aesthetics of individuals.

However, the improvement in facial appearance or aesthetics following orthognathic surgery was associated with similar improvement in the quality of life and the psychological profile of the patients (Sadek and Salem, 2007). This leads on to discussing the psychological impact and the impact on quality of life of orthognathic patients.

2.4.3. Psychological impact

Orthognathic patients, who live with a visible difference, as established from earlier sections, experience various psychological stresses in life (e.g. Frejman et al., 2013, Cunningham et al., 2000b, Phillips et al., 1998, vanSteenbergen et al., 1996). For example; Cunningham et al. (2000b) conducted a longitudinal study of the psychological profile of 81 orthognathic patients in UK and compared it with non-patient control group. The questionnaire measured various psychological components such as anxiety, depression, perceived social support, body-image and self-esteem. The questionnaire was completed by participants before the start of orthodontics leading to orthognathic surgery. The results of the study showed that the orthognathic patients showed an average of 3.2 times higher levels of state anxiety, higher social support network, less satisfaction with overall body-image particularly facial body image and slightly lower self-esteem than the control group. Comparing the findings from the orthognathic patient group with the socio-demographics, it was observed that with every 10 years increase in age, there was a 1.3 point reduction in satisfaction with facial body image. Based on the gender, males reported fewer individuals for social support, higher self-esteem and greater satisfaction with both overall and facial body

image as compared to females. On comparing the ethnicity of patients, minority ethnic groups like South Asians reported larger social support while Caucasians reporting the lowest social support. Then again, minority ethnic groups also reported fewer concerns about body-image and facial body-image as compared to whites. Cunningham et al. (2000b) concluded that there were differences in the psychological profile of orthognathic patients compared to the non-patients in the form of higher anxiety, higher social support (in numbers), lower body image and facial body image and, to a less significant extent, lower self-esteem.

Similarly, another study from the USA among 194 patients with dentofacial disharmony needing orthognathic surgery found that these patients experienced psychological distress (Phillips et al., 1998). In this questionnaire based study, Symptoms check list -90 -R (SCL-90-R) was used to measure the levels of psychological distress prior to orthognathic surgery. The values obtained from the questionnaire were compared with the population norms of males and females. It was found that orthognathic patients had scored higher in interpersonal sensitivity, psychoticism and obsessive-compulsive dimensions on the SCL-90-R as compared to the population norms. However, this study, unlike Cunningham et al. (2000b), found no difference by age or gender. But then again, this study looked into psychological distress aspects rather than the normal psychological profile aspects studied by Cunningham et al. (2000b). Interestingly, Philips et al. (1998) also reported that 24.7% of the study sample qualified positively for a psychotic disorder. Hence, they concluded that a large number of patients who seek orthognathic surgery experience high levels of psychological distress that calls for intervention. Likewise, another recent study also reported dental anxiety and post-traumatic stress disorder (PTSD) among orthognathic patients through a case control study of 39 'pre -surgery', 39 'post-surgery' and 39 'control' subjects (Al-Bitar and Al-Ahmad, 2017). The study concluded that better communication between the patients and treatment team was especially necessary during the assessment of the emotional status of the patient pre-operatively. The need to discuss the psychological issues and psychosocial treatment implications was also emphasised. Similarly, a study by Ryan and colleagues (2016) in the UK, compared Social Anxiety Disorder in orthognathic patients with the general population and concluded that the 61 orthognathic sample showed higher levels of social anxiety than 1196 participants from the general population.

The current literature on orthognathic surgery has a large number of studies that have focused on the psychological aspects of orthognathic surgery (e.g. Jesani et al., 2014, Cadogan and Bennun, 2011, Rustemeyer et al., 2010, Nardi et al., 2003, Hunt et al., 2001, Bertolini et al., 2000, Hatch et al., 1999, Kiyak et al., 1985, Auerbach et al., 1984, Kiyak et al., 1982b). One of the earliest studies which is most cited in this field of research is by Kiyak et al. (1982b, 1984) who studied the psychological outcomes and self-reported oral function status of 82 patients undergoing orthognathic surgery in Washington, USA. Questionnaires were administered to the participants five times; initially at least 2 days before surgery, then 1-2 days post-surgery, 3-4 weeks post-surgery, 3-4 months post-surgery and finally 9 months post-surgery. The questionnaires administered at each time point varied slightly in the aspects that were assessed. However, in general all the questionnaires assessed function (e.g. mastication, speech, TMJ), personality (e.g. self-esteem, body image, locus of control), social network (e.g. involvement of others) and outcomes including expectation and motivations. The study concluded that most patients experienced high levels of satisfaction with the psychological outcomes and oral function following orthognathic surgery. However, the study noticed a decline in the self-esteem of patients 9 months after surgery and a similar reduction in satisfaction with the facial body image was noticed at 9 months post-surgery. Kiyak et al. (1982b) attributed this decline to patients' adaptation with the new appearance and increased awareness of individual facial features. Finally, the study concluded that patients reported increases satisfaction with orthognathic surgery and showed interest in recommending the surgery to others.

The authors followed up the patients 24 months post-surgery to assess the same outcome measures used in the previous study (Kiyak et al., 1984). It was observed that self-esteem rose significantly from nine to 24 months post-surgery but was not as high as pre-surgery scores. Similarly, the body image scores also rose significantly from nine to 24 months after surgery and this score was found to be higher than pre-surgery scores. The transient decline in the psychological aspects measured was ascribed to the period of orthodontic treatment after surgery. Therefore, the authors strongly recommended continuous follow-up of orthognathic patients for at least two years after orthognathic surgery. Many studies since then have also reported improvement in the psychological functioning of orthognathic patients 2 years after surgery. Since

this study there has been many studies that have looked into various psychological aspects of patients following orthognathic surgery (e.g. Auerbach et al., 1984, Kiyak et al., 1985, Flanary et al., 1990); all of which have reported a significant impact of orthognathic surgery on psychological aspects.

A systematic review of studies from 1981 to 2000 detailed the psychosocial impact of orthognathic surgery (Hunt et al., 2001). They found 29 studies that were relevant and included in the systematic review. From these studies that included both prospective and retrospective studies, it was concluded that orthognathic patients experienced psychosocial benefits in the form of improved self-confidence, body and facial image and better social adjustments. However, the lack of consistency in the measures and designs used in the 29 studies reviewed, made it difficult for the authors to assess the extent and duration of the psychological benefits of orthognathic surgery. Studies that accessed psychological outcomes of orthognathic surgery have used various pre-validated psychological measures. However, each of these aspects have shown a significant change following orthognathic surgery in most of these studies. Studies have also shown a significant impact of psychological outcomes on the quality of life of patients following orthognathic surgery (Miguel et al., 2014, Soh and Narayanan, 2013). Nonetheless, Hunt et al. (2001) recommended the need for more qualitative studies to understand the patients' perceptive in relation to the quality of life following orthognathic surgery.

Interestingly, a rather recent systematic review on the psychosocial well-being of orthognathic patients found that orthognathic patients did not experience any psychiatric problems related to their dentofacial appearance (Alanko et al., 2010). Thirty-five relevant studies from 2001 to 2009 were included in the review. The main psychological aspects that were reviewed from the studies included in the systematic review were psychological distress and BDD, self-esteem and self-confidence, body image and everyday satisfaction in life (social issues). The results are summarised in Table 5. Unlike this systematic review, a newer study reported that the weighted prevalence of BDD in orthognathic surgery was 11.2% (Veale et al., 2016). However, this review made an interesting conclusion about the reporting of psychological problems such as anxiety and depression among sub-groups of patients. The authors stated that this was because most studies reported the mean problem score of the patients and compared it with population norms. This systematic review recommended

the need for more prospective studies and assessment methods focusing on day-to-day changes in attitude of patients.

Table 5: Psychological aspects of orthognathic patients

Psychological dimension	Key findings
Psychological distress	Orthognathic patients were not psychologically distressed or have BDD as compared to the general population. Patients reported depression and anxiety.
Self-esteem and self –confidence	Pre-surgery, no difference in self-esteem between patients and non-patients. Improvement in self-esteem and self-confidence following surgery.
Body image	Pre-surgery, patients were less satisfied with body image than non-patients. Post-surgery there was an improvement in satisfaction with body image.
Everyday life satisfaction	There were few studies regarding these issues. Patients experienced problems with eating and bullying pre-surgery. Social issues improved following surgery.

(Alanko et al., 2010, p. 257)

In summary: Various studies have examined the psychological impact of orthognathic surgery both longitudinally and retrospectively after surgery and concluded that there is an impact on psychological aspects of the patient. These studies have addressed various psychological dimensions and have used different instruments to assess these which make it hard to compare across studies.

Orthognathic studies have most often compared the mean scores on such psychological constructs with the population norm. The various psychological aspects that have been studied in the past include self-esteem, self-confidence, self-concept, body image, facial body image, anxiety and depression, locus of control, personality type and social support. Aesthetic and psychological outcomes of orthognathic surgery have been found to influence quality of life of the individual. Hence it becomes

necessary to understand the concept of quality of life and how this is influenced by orthognathic surgery.

2.2.4. Impact on quality of life

2.2.4.1. What is quality of life?

The World Health Organisation (WHO, 1995, p.1405) defined quality of life (QoL) as “an individual’s perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.”

The abovementioned definition of quality of life will be used in this research since this is the commonly used and most standardised definition of quality of life. The practical application of this concept of QoL becomes possible through the use of various measures of quality of life.

Health related quality of life (HRQoL) provides a way to measure the person’s experience of health and illness and its various impacts on their quality of life. Among the various definitions of HRQoL, one of the most useful is:

“Health-related quality of life is the value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy” (Patrick and Erickson, 1993, p 22).

More specific to the substantive area in this study, is Oral Health related Quality of Life (OHQoL) which describes QoL in relation to a person’s oral health. The most current definition of OHQoL is:

“the impact of oral disorders on aspects of everyday life that are important to patients and persons, with those impacts being of sufficient magnitude, whether in terms of severity, frequency or duration, to affect an individual’s perception of their life overall” (Locker and Allen, 2007, p.409).

For many years, the quality of life of orthognathic patients has been assessed in studies using different measures including various pre-validated questionnaires of psychological aspects like self-esteem (e.g. Cunningham et al., 1996b, Bertolini et al., 2000), anxiety and depression (e.g. Cunningham et al., 1996b), body-image (e.g.

Bertolini et al., 2000, Nardi et al., 2003), and health related measures such as Health Related Quality of Life- HRQoL (e.g. Bennett and Phillips, 1999), Sickness Impact Factor (e.g. Scott et al., 1999, Hatch et al., 1998) and Oral Health Status Questionnaire –OHSQ (e.g. Motegi et al., 2003, Scott et al., 1999, Hatch et al., 1998). However, these measures were not condition specific to patients with dentofacial deformities and require orthognathic surgery (Kanatas and Rogers, 2010).

Cunningham et al. (2002, 2000c) developed a condition specific QoL measure to investigate outcomes of orthognathic surgery called the Orthognathic Quality of Life questionnaire (OQLQ). Since then, a vast majority of the studies on quality of life outcomes of orthognathic surgery have been using OQLQ (e.g. Alanko et al., 2014, Khadka et al., 2011, Murphy et al., 2011).

2.4.4.2. Orthognathic surgery and health related quality of life

Orthognathic surgery patients experience poorer quality of life before orthognathic surgery because of their dentofacial concerns (Bock et al., 2009, Bennett and Phillips, 1999). For example; Bock et al. (2009) studied the functional, aesthetic and psychosocial aspects of patients with dentofacial deformity among 50 Germans (25 males, 25 females) using the translation of OQLQ. The participants reported functional restrictions (50.4%), aesthetic impairment (43%) and reduction in quality of life due to social aspects to a lesser extent (42%). These findings were similar to the study by Cunningham et al (2000c) which aimed to develop the Orthognathic quality of life questionnaire.

Evidence also suggests that orthognathic surgery has a positive outcome on quality of life of individuals (e.g. Goelzer et al., 2014, Kavin et al., 2012, Khadka et al., 2011, Choi et al., 2010, Garcia Esperao et al., 2010, Lee et al., 2008, Hatch et al., 1998). For example; Lee et al. (2008) evaluated the change in QoL of 36 (age range 16- 30 years) patients from Hong Kong, China with dentofacial deformities following orthognathic surgery. The Short form health survey measure; SF-36, Short form oral health impact measure; OHIP-14 and OQLQ were used. While SF-36 measure focused on the impact of physical and mental health status of the individual on OHQoL, OHIP-14 focused on the impact of the individuals' oral health condition on OHQoL and OQLQ focused on the impact of dentofacial deformity on QoL of the individual. Each of these questionnaires were administered to patients at baseline (before surgery but

after pre-surgical orthodontics), 6 weeks post-operatively and then again six months post-operatively. Deterioration in SF-36 (physical and mental health status) was noticed six weeks post-operatively while there was no change in the OHIP-14 (oral health condition) and OQLQ (dentofacial deformity). However, at six months post-operatively the SF-36 returned to normal and significant improvement in the OHIP-14 and OQLQ ($P, 0.01$) was observed. Thus, the study concluded that significant improvement in QoL occurred following orthognathic surgery despite a transient deterioration in general health and wellbeing immediately following the surgery.

Garcia Esperao et al. (2010) unlike Lee et al. (2008) studied the impact of how Oral Health related to quality of life (OHQoL) on orthognathic patients by comparing scores of the measure pre-treatment (even before pre-surgical orthodontics) to pre-surgery and then post-surgery. A total of 117 patients were recruited in Brazil, 20 in the pre-treatment phase, 70 in the pre-surgical phase and 27 in the post-surgical phase. The OHIP-14 was administered to all the participants. The scores obtained were compared with each other. It was found that patients who needed orthognathic surgery and were in pre-treatment phase were 6.48 times more likely to experience negative impact of the condition as compared to the slightly lower 3.14 times negative impact of patients in the pre-surgery phase. Therefore, the study concluded that orthognathic surgery positively impacted on the OHQoL of patients. However, it is worth taking into account that this study did not follow up patients longitudinally, instead patients at different phases of treatment were all assessed at different times. Nonetheless, according to this study's findings, the baseline data collected pre-surgically on OHQoL would then represent a considerably lower impact on OHQoL than the actual impact dentofacial deformity had caused to the OHQoL of the individual pre-treatment. Contrary to this, the psychological aspects considered longitudinally by Cunningham et al. (2001), as mentioned in Section 4.3, were found to have very little change in the pre-treatment to pre-surgery phase.

Rustemeyer and Gregersen (2012) in their study identified the difference in each individual factor that affected the QoL of individuals following orthognathic surgery using OHIP-14 measure. Fifty patients (age range 18-52 years) were asked to fill the OHIP-14 approximately nine months before surgery (before bonding orthodontic brackets) and then again approximately 12 months after surgery (after orthodontic appliance was removed). This study found that although there was no significant

change in the scores that described the physical pain, disability and chewing function, there was a significant positive change in scores describing psychological discomfort, social disability and aesthetics. It was also found that the self-confidence (OH-5) score was the most significant indicator of improvement in QoL post-surgically. It was thus concluded that psychological and aesthetic factors influenced the QoL of orthognathic patients strongly as compared to the functional aspects. This finding is of great significance for this research since it emphasises the importance of psychological and aesthetic perception of change when studying the quality of life of orthognathic patients.

To sum up the findings from various studies on QoL of orthognathic patients, a rather recent systematic review (2001- 2012) evaluated the benefits of orthognathic surgery on QoL of individuals (Soh and Narayanan, 2013). 21 relevant studies were included in the systematic review. On comparing these studied which had used OQLQ, OHIP and SF- 36 to measure QoL, Soh and Narayanan (2013) concluded that QoL was improved in patients following orthognathic surgery. The use of validated instruments to measure outcomes was recommended by the authors to help quantify results of the study. This review also recommended the necessity to quantify the changes in QoL among different type of dentofacial deformity and types of surgeries. This indicated that there was a necessity to firstly understand the reason for differences in the QoL of individuals with various types of visible difference or dentofacial deformities.

2.5. Individual differences in coping with and treatment of visible difference

Another aspect of research that demonstrates the overlapping nature of the clinical and patient perspectives is how the study of coping and adaptation has been applied to the challenges faced by orthognathic patients. Individuals are shaped by the social system they live in through multiple forms of influences (Lazarus and Folkman, 1984). As discussed earlier, within the context of appearance psychology, the societal views of an acceptable appearance influence the individual's perception of one's own appearance. Then again each individual has unique experiences and biological makeup (i.e. physical appearance, in the context of this study) which causes them to act accordingly to their social and individual destinies. This juxtaposition of individual

and social identities caused some degree of disparity between the individual and society and also within the individual, causing 'stress' (Lazarus and Folkman, 1984).

The usage of the word 'stress' captured a field which, before the introduction of the word, was shared by a number of other concepts (Cofer and Appley, 1964) such as anxiety, conflicts, frustrations, emotional disturbances and alienation and isolation (Lazarus and Folkman, 1984). Hence, Lazarus (1966) suggested that stress be treated as an organising concept for understanding a wide range of phenomena of great importance in human and animal adaptation. However, Lazarus and Folkman (1984) stated that stress is often defined as either a stimulus (events in the environment such as natural disasters) or response (reacting to stress). Another definition of stress found in the literature states that "stress is a negative experience associated with threat, harm or demand" (Baum, 1990). It can be seen from these definitions that stress is influenced by the characteristics of the person as well as the nature of the environmental event.

Lazarus and Folkman (1984) observed that since the 1960s it was recognised that although stress is an inevitable aspect of human condition, it is coping that altered adaptation outcome of individuals. Researchers have reported influence of individual factors and socio-environmental factors on the way people cope. For example, in recent years, studies have reported various positive ways of coping with visible differences (Feragen et al., 2009, Strauss and Fenson, 2005). Strauss and Fenson (2005) through a qualitative approach, examined the contents of fiction, non-fiction, web sites and first-person accounts to understand how quality was built into the lives of individuals with visible difference due to craniofacial anomalies. Three main domains identified were;

- i) personality and psychological domain,
- ii) family, work and social interactive domain and
- iii) cultural and societal domain.

Within each of these domains, various themes were identified and these are listed in Table 6. By using the strategy of downward comparison, individuals were found to feel 'lucky' or 'fortunate' about their lives compared to the less fortunate. It was also found that individuals were able to learn from their experience of being 'different' and have realisations which would not have been possible without having faced with the

adversity of visible difference. Resilience, “the individual capacity to meet challenges with flexibility” was reported to be integral for a good life with visible difference. Further, focusing on other aspects of life, humour and spirituality or faith was reported to be a source of comfort for individuals with craniofacial anomalies. Supportive responses of their family about the visible difference, social support as well as social contacts, contributed to positive adaptation and better quality of life of individuals. Similarly, other studies have reported positive impact of social support in the form of satisfaction with appearance among patients with head and neck cancer treated surgical (Hassanein et al., 2001) and orthognathic surgery patients (Holman et al., 1995).

Table 6: Themes identifying how QoL was built into the lives of individuals with craniofacial anomalies.

Domain	Themes
Personality and psychological domain	<ol style="list-style-type: none"> 1. Downward comparison/feeling fortunate 2. Placing the condition into a greater context of learning 3. Resilience 4. Focusing on other aspects of life apart from face 5. Humour 6. Faith, belief and inner spiritual strength
Family, work and social interaction domain	<ol style="list-style-type: none"> 1. Family capacity and supportive response 2. Social support systems and social interactions
Cultural and societal domain	<ol style="list-style-type: none"> 1. Media and public culture 2. Socio-political declarations of differences

(Strauss and Fenson, 2005, p.14)

Among orthognathic patients, there is a paucity of research on the effect of coping strategies on the stresses caused by the visible difference and treatment itself. However, before discussing coping in orthognathic patients, it is necessary to better understand the concept of coping.

2.5.1. Coping

2.5.1.1 Definition of coping

The widely used definition of coping in psychology literature is,

“constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.”

(Lazarus and Folkman, 1984, p.141)

2.5.1.2. Ways of coping

In response to stress, people cope in two basic forms: avoidance, and approach coping (Roth and Cohen, 1986). Approach, and avoidance coping, refer to cognitive and emotional activities oriented either towards or away from the threat respectively. Approach coping involves confronting the problem, gathering information and taking direct action. Hence, approach coping is generally seen as adaptive coping (Baker et al., 2009) and associated with making good adjustments with stress (Holahan and Moos, 1987). In contrast, avoidance coping involves avoiding, denying or minimising the importance of the stressful event or stressor (Ogden, 2007, Penley et al., 2002) and is seen as maladaptive coping. Nevertheless, the effect of either of these types of coping varied according to the nature of the stressor. For example, avoidance coping was seen as more effective in coping with distress due to pain (McCaul and Malott, 1984) while approach coping was more useful in coping with stress caused due to illnesses like cancer (e.g. Roesch et al., 2005, Roesch and Weiner, 2001).

In the coping literature, various theoretical approaches to coping have been used (e.g. repression- sensitization coping, avoidance- vigilance coping, denial- intrusion etc.). Roth and Cohen (1986) stated that the concept of approach and avoidance coping bring about the personality or individual difference of all these other approaches to coping. Therefore, in this research the focus will be on the approach and avoidance style of coping. Additionally, to understand how people cope, it is necessary to identify the internal and external factors that help in coping.

2.5.1.3. Coping Resources

Lazarus and Folkman (1984) stated that the ways people cope were largely dependent on the resources that are available to them and also factors that inhibit the use of these resources. Unlike Antonovsky (1979), who viewed coping itself as a resource that could resist stress, Lazarus and Folkman (1984) viewed coping as a process that evolves from resources so as to mitigate the existing stress. Numerous resources used for coping were grouped into resources that are properties of individuals and environmental resources including social and material resources (See Table 7) (Lazarus and Folkman, 1984). It is beyond the scope of this research to address each of these coping resources. However, selected few resources that are applicable to this research in orthognathic patients will be further discussed.

Table 7: Coping Resources

Group of Resources	Type of Resource	Example coping strategy
Resources that are primarily properties of the person	Health and energy	Physical well-being
	Positive beliefs	Hope Faith or Spirituality Optimism Control – internal locus of control Self –esteem Mastery
	Problem solving skills	Search for information, analyse situation, identify problem, generate and choose alternate course of action
	Social Skills	Communication skills Behavioural skills
Environmental Resources	Social Support	Emotional, informational and/ or tangible support from people
	Material resources	Monetary resources

(Lazarus and Folkman, 1984)

Self-esteem, defined as a favourable or unfavourable attitude towards the self (Rosenberg, 1965, p.15), was another coping resource to manage stressful events (Taylor and Stanton, 2007). Positive self-esteem has been tied to better psychological well-being (Paradise and Kernis, 2002). In the stress-coping literature, it has been shown that individuals with high self-esteem adopt active coping strategies as opposed to individuals with lower self-esteem who opt for passive avoidant coping strategies (Dumont and Provost, 1999, Thoits, 1995). Self –esteem was often studied in orthognathic literature in relation to its impact on the psychological outcome following orthognathic surgery (e.g. Lazaridou-Terzoudi et al., 2003, Cunningham et al., 2001, Bertolini et al., 2000, Cunningham et al., 2000b, Kiyak et al., 1986a). Nonetheless,

many of these studies in the literature have not considered self-esteem as a coping resource in orthognathic surgery.

Social support, simply defined “as whom we can rely, people who let us know that they care about, value, and love us” (Sarason et al., 1983, p.127), is another significant coping resource. Schaefer et al. (1981) identified three types of functions of social support that helped individuals cope with stress. These consist of emotional support, which provides the feeling of being loved and cared about; tangible support, involving direct aid and service; and informational support, consisting of advice and feedback. Researchers have suggested that the presence of or the perception of presence of social support helps individuals to cope with stressful situations (e.g. Ogden, 2007). Many different reasons were identified by various researchers about the positive influence of social support on coping with stress. One of the explanations was based on social comparison theory which suggests that individuals under stress choose an appropriate coping strategy by comparing themselves with other individuals in their social circle (Ogden, 2007). Another reason for this was stated to be due to the increased sense of being valued by the person with good social support, which in turn helped individuals to cope better (Baumeister and Leary, 1995). However, many researchers have found positive outcomes of good social support in individuals dealing with stresses related to appearance concerns (e.g. Holman et al., 1995, Baker, 1992, Blakeney et al., 1990, Orr et al., 1989). Influence of social support has also been studied in relation to orthognathic surgery in the recent years and all the studies consistently found a positive influence of social support on the outcome of orthognathic surgery (Cadogan and Bennun, 2011, Cunningham et al., 2000b, Holman et al., 1995).

2.5.1.4. Coping and orthognathic surgery

An online literature search for words ‘coping’ and ‘orthognathic surgery’ (along with ‘cope’ and ‘orthodontic surgery’) using databases like Web of Science, Google scholar, Scopus and PubMed was conducted between 1864 and 2014. Nine relevant papers in English were found that had considered psychological coping in orthognathic patients. However, only one study in 1988 had used coping as the framework for the study – Kiyak et al. (1988). The other studies, among the nine, had acknowledged the influence of psychological coping on orthognathic patients. Details of these studies are discussed below.

Kiyak et al. (1988) tested the hypothesis – vigilant ‘copers’ would have better orthognathic outcomes than avoidant ‘copers’ by studying 114 orthognathic patients. The questionnaires used in the study focused on pre-surgical expectations, post-surgical problems mood states and satisfaction with outcomes. Patients completed questionnaires six-eight months before surgery and five more times in the course of three to five years post-surgery. The hypothesis was dis-proved, and it was found that avoidant ‘copers’ (who anticipant fewer problems) had better psychological outcomes of orthognathic surgery than vigilant ‘copers’ (who anticipated many problems). However, this study did not use any pre-validated questionnaires apart from the profile of mood states (POMS; Lorr and McNair, 1971) and thus questioning the validity and reproducibility of the test. Additionally, this study did not use any measure to directly access coping strategies but instead had to rely on responses to expectations from surgery, causing the findings, about type of coping strategies used by patients and its relationship with outcomes, questionable. However, the main focus of the study was the psychological outcome of orthognathic patients and not the coping strategies of the patients. Coping strategies of the patients were accessed with the view of finding its relationship with psychological outcome following orthognathic surgery.

Two recent qualitative studies have acknowledged the role of coping strategies in orthognathic patients from the interviews (Ryan et al., 2012a, Cadogan and Bennun, 2011). Ryan et al. (2012a) sort to understand reasons for dissatisfaction with outcome of orthognathic surgery in a small minority of patients. Semi structured interviews of 18 patients from London, UK explored the impact of dentofacial deformity and expectations and motivations of the patients. Two types of coping mechanism were described by participants – avoidance coping and altered coping. While the avoidance ‘copers’ avoided thinking about, seeing or showing the deformity, the altered ‘copers’ continued normal life by altering their behaviour to show less of their deformity (Ryan et al., 2012a). However, the study did not draw any further light on the coping strategies used by orthognathic patients. Similarly, Cadogan and Bennun (2011) from their qualitative research (using semi structured interview) among seven participants from UK, concluded that factors such as social support, sense of humour, coping strategies and cognitive behavioural skills provided orthognathic patients with resiliency. Nevertheless, no further light was drawn on type of coping strategies used by orthognathic patients.

Stricker et al. (1979) stated that poorer satisfaction with facial appearance was not only related to facial disharmony but also had a relation with other social elements. Further, various research has shown that different people cope differently with appearance differences (e.g. Secord and Backman, 1959). Resting on these considerations, van Steenbergen et al. (1996) strongly recommended a need for future studies that examined coping strategies of orthognathic patients, therefore, test social coping theory and account for satisfaction with facial appearance. However, there is no evidence of any study that have examined coping strategies of orthognathic patients to account for patient satisfaction in the current literature.

2.6. Summary

Orthognathic surgery is an elective surgical procedure to align the upper and lower jaws in a more favourable relation. Dentofacial deformities that may require orthognathic surgery was reported to be found in 20% of the population. Orthognathic surgery is indicated for correction of severe skeletal malocclusions, jaw deformities due to trauma, cleft lip and palate, condylar hyperplasia, facial symmetries, obstructive sleep apnoea and severe jaw deformities that cause functional and psychosocial concerns. The treatment itself involves a period of pre-surgical orthodontics followed by the surgery and a further period of orthodontics to align the teeth in the new jaw position. Therefore, orthognathic treatment takes about 18-24 months to be completed.

The decision to undergo such an extensive treatment can be challenging for patients and few studies have explored the decision-making process for orthognathic surgery. Studies like Broder et al (2000) identified the influence of motivation and decision to have orthognathic surgery. Information about the treatment provided or accessible for patients was also found to influence decision making (Flett et al., 2014). While many studies have tried to identify the factors that influence decision making for orthognathic surgery, none have provided a comprehensive list of factors that influence the decision. However, a list of factors would be of little value with any particular order or being placed within a context. Developing a theory in orthognathic decision making would add value to the list of factors that influence decision making. However, no such theory was developed to date.

In the literature review, numerous different voices using various languages about orthognathic surgery have been identified. In the first few sections, the clinical aspects

of orthognathic surgery were central and therefore a more medical language was used in the studies. However, within the psychological research based on visible difference, the language changed to being more of a layperson's. This change also indicated the voice of the patient being heard.

As part of incorporating more of the patient's voice in orthognathic surgery research, psychosocial aspects of orthognathic surgery have been studied in the recent years. Most of these researches have been questionnaire based studies and there is a paucity of qualitative research.

Studies in the past have explored various aspects of orthognathic treatment such as motivations and expectations, outcomes of treatment, quality of life of patients etc. However, the entire patient experience of orthognathic treatment has never been studied as a whole. Furthermore, many of the social psychological factors associated with good outcomes are taken out of context and studied independently of one another. For example, studies have identified an improvement in the self-esteem of patients who have undergone orthognathic surgery and this good outcome has been studied independently without considering the overall effect of such a positive change within the patient's experience. One way to resolve the fragmented nature of the research is to provide a theory that is grounded in patient experience and which explores the whole orthognathic journey from before, to during, and again after orthognathic surgery.

This leads to the aim of the current study.

2.7. Aim

The aim of the study is to develop a theory that explains a person's experience of the orthognathic treatment.

2.8. Objectives

The research objectives are to:

- Map the experiences of a person prior to commence of orthognathic treatment, along the course of treatment and following the completion of treatment.

- Develop a theory that best explains what is happening to a person through the process of orthognathic treatment and which is based on their own views of what is going on.
- Explore the motivations, expectations and patient's experience of surgery and patient's opinions on the outcome of the treatment.

Chapter Three: Methodology and Methods

3.1. Overview

This study uses Grounded Theory (GT) methodology. As in any GT study, data were obtained using various methods of which semi-structured interviews contributed the largest amount of data collected. Other sources of data were also used to add value to the theory. These were online blogs and forums, and secondary sources such as data reported by others. For example; data in the form of a clinician's account of one of their patient's experience of orthognathic surgery was included as secondary source of data in this study. Each of these will be detailed in Section 3.4. Firstly, grounded theory methodology is detailed.

3.2. Grounded Theory

Grounded theory is one of the most popular qualitative research methods in the world (Birks and Mills, 2011). It is developed as a general method for comparative analysis for the generation theory from empirical data (Glaser and Strauss, 1967, p.1). Before going any further into the details of GT, it is essential to define 'theory' within the context of GT.

3.2.1. Defining theory:

The word theory, within the context of GT, has been defined in different ways in the literature. Glaser and Strauss (1967) defined theory as that which has explanatory or predictive ability. According to Charmaz (2006), the positivists defined theory in terms of explanatory relationships between concepts. In contrast, interpretivists view theory in a more abstract and indeterminate way. However, the more recent definition of theory by Birks and Mills (2011) states that it is an explanatory scheme comprising a set of concepts related to each other through logical patterns of connectivity (Birks and Mills, 2011, p. 113).

3.2.2. What is Grounded Theory?

Grounded theory is a research method that was first described within sociology. It later found its application in other disciplines such as anthropology, philosophy, medicine, psychology, education, architecture and marketing. The original text, *The Discovery of Grounded Theory*, by Glaser and Strauss (1967), was written in response to a long lasting gap between theory and empirical research in sociology during the 1950s and

1960s. GT was developed as a new approach for doing research which was concerned with using the data obtained from empirical research in the discovery of theory (Gibson and Hartman, 2014).

GT was meant for discovery rather than justification (Glaser and Strauss, 1967). GT, as opposed to other research methodologies, is seen as a form of knowledge generation rather than hypothesis testing (Gibson and Hartman, 2014, Glaser and Strauss, 1967). Whilst most of the research from any discipline are hypothesis testing research, GT is an emergent research which aims at understanding the research situation. Glaser (1978) stated that GT aims to discover the theory implicit in the data. Hence the relationship between data and ideas are more relaxed in GT (Gibson and Hartman, 2014). Another difference between hypothesis testing research and GT is based on the rigour of the research. In hypothesis testing research, the rigour is based on narrow criteria, which holds good only for the methodology developed in that research. On the other hand, GT has its own source of rigour. For example; check the theory generated against the participant's understanding of the phenomena, delineate the scope of the research, describe the relationship of the literature to each category that emerged in the theory etc. (Chiovitti and Piran, 2003). Having established that GT is different from hypothesis testing research, it is now essential to understand the characteristics of GT.

Gibson and Hartman (2014), in their book *Rediscovering Grounded Theory*, described five core aspects of GT. They are; i) openness, ii) explanatory power, iii) difference between generation and justification, iv) theory structure and v) research process. Openness and flexibility are two terms that are used to describe GT in the literature. This simply means that the researcher should not allow their preconceived ideas about the research field to dominate their approach to generating theory whilst doing GT. Secondly, the theory generated through GT must have the explanatory power as to answer what is going on and explain how the problem studied can be resolved. Furthermore, as established earlier in this chapter, GT is meant for discovery and no attempts are made to verify or justify the theory. Fourthly, the theory structure of GT is centred on a 'core category' which is the core problem addressed in the theory. Corbin and Strauss (1990) defined the core category as 'the central phenomenon around which all the other categories and their sub-categories are integrated' (p. 116). Hence the resultant theory should be able to explain the relationship of the core

category with the setting or the role or group of people studied. This relationship becomes the common factor between the core category and all the other sub-categories identified in the theory. Finally, the research process of GT is an interactive process because data are collected and analysed and furthermore, data are collected to build the evolving theory (Gibson and Hartman, 2014). These core aspects of GT are summarised in Table – 8.

Table 8: Core aspects of GT

Core aspects of GT	Implications
Openness	- Research question should be kept open
	- Data collection must be open to explore new areas and kept neutral.
	- Data analysis must not be influenced by preconceived ideas.
Explanatory power	- Must be able to explain how to resolve the problem addressed and what is going on.
	- It must fit the data and be modifiable to new information.
Discovery versus justification	- It is meant for discovery and not justification.
	- Theory is adjusted to accommodate new information rather than justify the theory developed.
Theory structure	- The theory is organised around a core category.
	- The theory related the core category to the sub-core categories which is developed through theoretical coding.
Research process	- It is an interactive process.
	- Process of truth tracking.

(Gibson and Hartman, 2014)

3.2.3. Basic procedures in doing GT

The importance of openness and flexibility in GT has been emphasised already in the above section. However, these characteristics extend to the procedure of doing grounded research as well. Gibson and Hartman (2014), while detailing the techniques for doing GT, stated that ‘we do not want to over prescribe but to offer some advice on how to approach the process of doing grounded theory’ in order to preserve the openness and flexibility of grounded theory (Gibson and Hartman, 2014, p. 139).

The first and foremost step for starting out a GT was exploring the area of interest of the substantive field of study with a view to developing a research question. The research question needs to be open since one cannot predetermine what are the relevant concerns for the participants in the study (Strauss and Corbin 1998). In this study, the patients’ experience of orthognathic surgery was the area of interest. The research question addressed in this study was what is the experience of the patients though the orthognathic journey?

As in any other research, the next step was sampling and recruitment of participants. In GT, ‘everything begins with data’ (Wasserman et al., 2009, p. 358) and ‘all is data’ (Glaser, 1978; p. 8). As mentioned earlier, GT is all about understanding the core concerns of the people in the particular research field. Hence sampling and recruitment were undertaken with a view to obtain diverse and wide variety of data to have different perspective of people’s concerns in the research field. Theoretical sampling is an approach for data collection in GT which is further detailed in section 3.3.2. However, it is a way of thinking that enables sampling for the purpose of developing an appropriate theory.

Theoretical sampling follows on from theoretical sensitivity (Gibson and Hartman, 2014). The researcher needs to be able to tease out elements from the data that are relevant for the theory from the data. This ability of the researcher was referred to as theoretical sensitivity (Birks and Mills, 2011; p. 59). Gibson and Hartman (2014) stated that theoretical sensitivity is important because it links the spirit of discovering theory from data to a series of attitudes and procedures that the researcher should develop. One of the techniques identified to raise theoretical sensitivity was the use of literature (Strauss and Corbin, 1998, Strauss and Corbin, 1990). Birks and Mills (2011) justified the use of literature, without forcing ideas into the theory, through the

comparison of theoretical concepts in the literature with the coded data. Hence the literature can potentially become a source of data. Some of the other ‘analytical tools’ that are used to develop theoretical sensitivity are – making comparisons, use of questioning, using the flip-flop technique, looking at the language, looking for negative cases etc. (Corbin and Strauss, 2008).

There are many sources for data collection in GT. However, participant interviews, which are later transcribed, are the most common source of data (Birks and Mills, 2011). The other types of data can be from observations, documentary evidence, literature, questionnaires, photographic images, artwork, field notes etc. (Holton and Walsh, 2017, Gibson and Hartman, 2014, Birks and Mills, 2011). Hence diverse type of data collection methods can be used in GT. However, the nature of GT ensures that a close relationship is maintained with the data throughout the study rather than an isolated task of data collection (Birks and Mills, 2011).

Data analysis in GT comprises of coding (grouping of data under codes), theoretical coding (specification of the type of theory and elaboration of its key relationships) and saturation (filling out categories with memos that capture all ideas in the data such that further sampling and data collection will yield little new findings) (Gibson and Hartman, 2014). At this stage the research needs to pace between sampling, data collection and coding it. Coding for as much variability and variety in the emerging theory as possible is important. Table 9 shows an example of coding. Initial coding/open coding are based on the core concerns of the participants and how they are resolved. Once this is decided on the process of intermediate coding/selective coding begins. The primary task of this stage is to fill out the core category and focus on how to integrate and organise the emerging theory. The aim of this stage is saturation. According to Holton and Walsh (2017) theoretical saturation refers to the constant comparison of conceptual indicators in the data to the point where additional indicators yield no further theoretical specification or elaboration (p.103). Glaser (2001) described theoretical saturation as “intense property development” (p.191) that lifts the theory above description enabling its integration as an abstract conceptual theory (Holton, 2007). Thus the categories will be saturated and they can be linked together into a fully integrated theory.

Table 9: Example of open coding

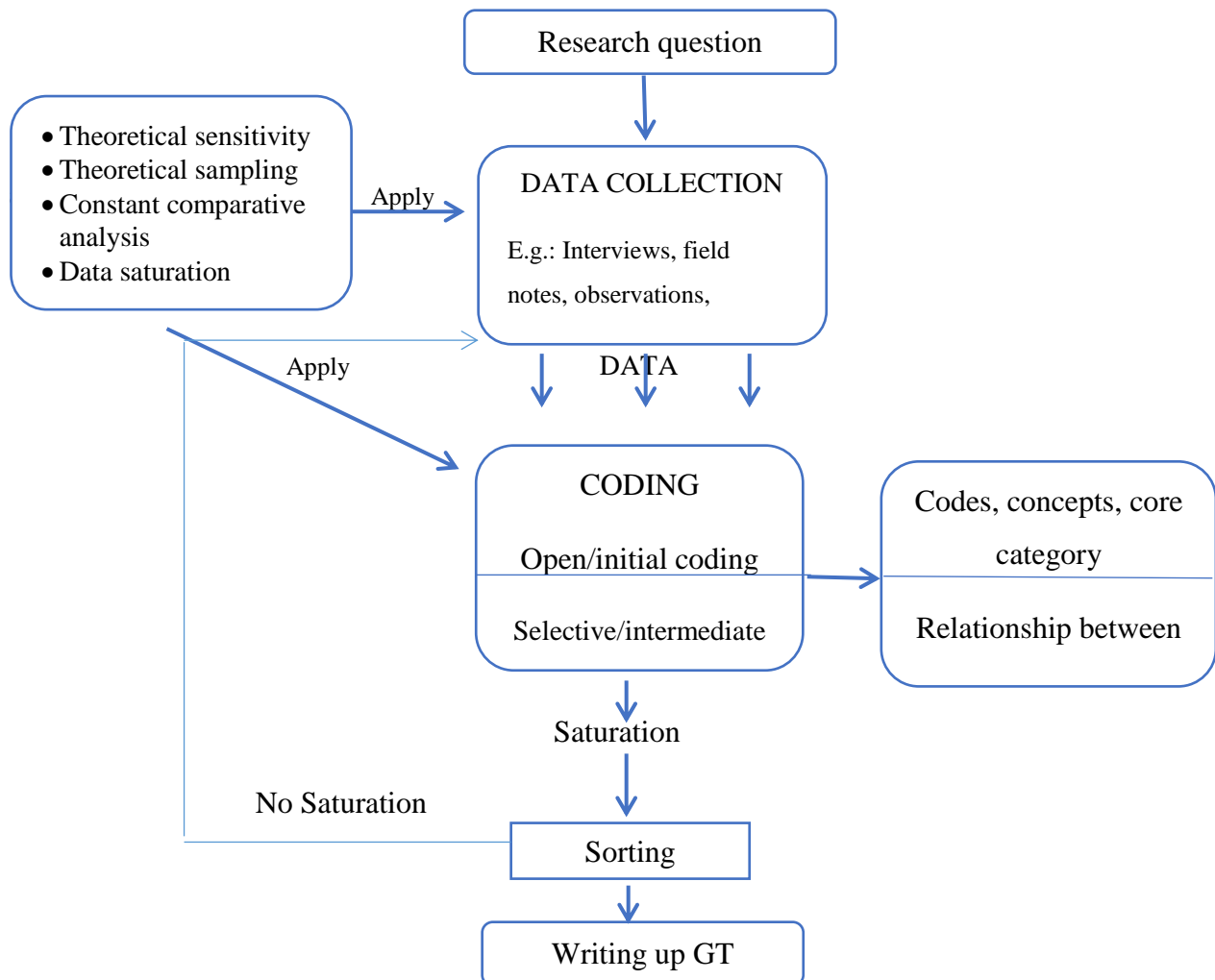
Transcript	Coding
<p><i>Q: Can you tell me how did you come to realise that there was a problem with your jaws?</i></p> <p>Well as a teenager, I wore a brace on, on the top teeth. But as soon as the treatment was finished, my top teeth started to protrude again, but ... so I always knew I had got an abnormal... to me abnormal looking jaw. I knew it was smaller than it should be, compared to everybody else and I always felt very self-conscious of it and I was very shy as a young person. Umm and I used to get teased a lot at school. Partly boys. Umm so that was ... that was hard at the time.</p>	<ul style="list-style-type: none"> - Teenage years - Previous orthodontic treatment - Abnormal jaws – this is interesting to know what normal and abnormal was - Abnormal as compared to everybody else – comparison with others! - Self- conscious - Teasing by boys - Hard time – acknowledgement of emotional difficulty
<p><i>Q: Can you tell me how did you get through those difficult times?</i></p> <p>I don't know... I think I always have very supportive family and a very good network of friends... umm and work colleagues so Plus I really love my job. So I have had a lot of positive moves in my life and I suppose I think that nothing's ever really gone wrong for me. I met my husband, we got married and got 2 lovely daughters so you know... and he's never talked of me as looking any different to anybody else... I suppose. But he knows how much it means to me to have a normal profile... you know... to face. So, yeah so he has always been very supportive.</p>	<ul style="list-style-type: none"> - Social support – support from family, colleagues and friends - Enjoy job - Meeting a good partner - Support and understanding from partner – husband talking about her profile matters to her! - Partner understanding her feelings about her appearance

Writing up is the last stage in GT research. Gibson and Hartman (2014) stated that researcher becomes ready for writing up only when they are sure what the GT is saying

and knows what its main contribution to the field of research is (p. 148). They have also emphasised the importance of writing about the major impact of the phenomenon on the people in the study and also writing about the different aspects of the emergent theory.

To summarise, the process of doing GT is not based on a rigid set of rules. Openness and flexibility of GT extends into the process of doing GT. The procedures of sampling, data collection and data analysis, these tripartite processes are often found together in GT. These processes are iterative and carried out as required for specific research. GT involves constant comparative analysis of the data. Figure 8 shows the procedures involved in GT. In the following sections, each of the procedures mentioned above will be discussed in relation to this study.

Figure 8: Procedures involved in GT



3.3. Qualitative interviews

3.3.1. Overview

Semi-structured interviews were conducted with participants at different stages of orthognathic treatment. During the initial phase of the data collection, participants were recruited for semi-structured interviews from among the patients, currently six to eight weeks following their orthognathic surgery. Based on the findings of the data obtained in this phase, further theoretical sampling was done among patients in the decision-making phase about orthognathic treatment and from patients who completed orthognathic treatment one to two years ago (who were in long term follow up care at the hospital). The aim of this part of the study was to generate a theory that would explain what the concerns of orthognathic surgery patients were and how their concerns were resolved through surgery.

3.3.2. Sampling and recruitment

Sampling for participants interviews was not based on any set criteria since the methodology used for the study is GT. As mentioned earlier, GT uses theoretical sampling which is an evolving strategy according to the needs of the study. It ensures that only data that are relevant is sought and is relevant to clarify the relationship between emerging categories (Glaser, 1998). Glaser and Strauss (1967) defined theoretical sampling as:

“the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (Glaser and Strauss, 1967, p.45).

Hence, theoretical sampling is an ongoing process in GT research as is data collection, coding and analysis. This process terminates when no new information emerges from the data, i.e. saturation. Therefore, it was impractical to decide the number of participants required for this study at its beginning.

At the beginning of the study, there are no clues from the evolving theory to guide sampling. Birks and Mills (2011) argued that it is possible to apply theoretical sampling from the outset of the study since the concepts and patterns can be seen at the beginning stages of the research. On the contrary, Charmaz (1994) had stated that a researcher could use purposive sampling at the beginning of the research and this

would be acceptable for GT research. More recently, Gibson and Hartman (2014), also argued that the use of preconceived ideas for sampling in the initial stages of research was unproblematic as long as the research remained open to what emerged in the data and that the researcher engaged in further sampling as it was required by the emerging theory. Therefore, in the initial stages of this study, purposive sampling technique was used.

Patients who had completed orthognathic surgery were in a better position to provide a first-hand account of their experience of the treatment. There were two contradicting factors that needed to be considered in order to decide on the time point at which an orthognathic surgery patient can be approached so as to be able to obtain a comprehensive account of their experience of orthognathic treatment. Firstly, orthognathic surgery is a major surgical procedure which takes approximately six hours to be completed. This leaves the patients sore and swollen for a considerably long period of time. Hence, collecting data from patients in the days immediately following the surgery would not be appropriate. Secondly, orthognathic treatment, as described in chapter two, is an ongoing process for up to 18 months following surgery in the form of post-surgical orthodontics. When data are collected from patients who have recovered fully from the surgery, this could potential cause a recall bias in the data provided by the participants in the research. Therefore, it was decided that participants in the initial part of the study would be recruited from among the patients who were not immediately post- surgery and were finishing their orthodontic treatment as part of the orthognathic treatment. After consulting with clinicians it was decided that 6-8 weeks post –surgery would be appropriate time to interview participants as they were no longer being regularly reviewed in the Oral and Maxillofacial Surgery (OMFS) clinics. I recruited these participants from the Oral and Maxillofacial Surgery clinics on the day when they were being discharged from the clinics and would continue treatment with the orthodontic clinics alone until completion of treatment. However, these participants were approached for the first time with information about the study in the OMFS clinics during the patient’s 4-6 weeks post-surgery follow- up appointments. Thus, they were given enough time to think about if they wanted to participate in the study, before they were approached again in their 6-8 weeks post-surgery appointment to obtain consent and interview them for the study.

The data obtained from the early interviews conducted among six to eight weeks post-surgery patients made it evident that interviewing two other groups of patients would add to the knowledge base of this study. This was because data obtained revealed the importance of the pre-surgery experience, decision making and patients hope for further change in the following months to come. This suggested that interviewing only those straight after surgery would limit our understanding of the whole patient journey. Consequently, I included patients who were in the decision-making phase for orthognathic treatment. It was found that valuable information could be obtained from interviewing this group of patients about factors that facilitate and act as barriers in decision making. Additionally, it would be a good opportunity to understand why some patients decided not to undergo orthognathic surgery. The second group were the patients who were in the long term follow-up phase after orthognathic surgery, i.e. 12 months or longer after surgery. This group of patients were a potential source of information about patients' experience in the long term following surgery with the settled new jaw position. Hence, patients from the earliest phase of decision making to patients in long term follow up after orthognathic treatment were included in the research. The addition of these two groups of patients also supplemented the sampling variation that was valuable for GT research.

Although there was no requirement to set any inclusion or exclusion criteria in patient recruitment into the study, to comply with the NHS ethics, some exclusion criteria were adhered to in this study. Only English speaking participants were recruited. Patients with cleft lip and cleft palate and patients suffering from obstructive sleep apnoea were excluded from the study. These groups were excluded to ensure that the patients in the study were referred to orthognathic treatment purely as an elective surgical procedure rather than as part of an ongoing treatment for a health condition.

3.3.2.1. Procedure for recruitment

Participants were recruited from the Oral and Maxillofacial Surgery Department of Charles Clifford Dental Hospital, Sheffield. Patients were contacted in advance based on the information about the patient available from the relevant clinics. This contact was made either directly during a clinical appointment or via post. During the initial sampling, patients six to eight weeks post-surgery were contacted in clinics when they attended for making surgical wafers one to two weeks prior to the surgery. A Patient Information Leaflet (See Appendix A) was given to the patient along with a verbal

briefing about the study and what was expected from the participants. The other two sets of patients – in the decision-making phase and the long term follow-up, were contacted via post one to three weeks prior to their standard clinical appointment. A cover letter (See Appendix B) and the Patient Information Leaflet were included in the post.

On the day of the clinical appointment, these patients were approached and confirmation for willingness to take part in the study was confirmed verbally. The Participant Consent Form (See appendix C) was given to the patient to sign and date. The Interviewer counter signed this. Following this, the patient was taken to a spare room in the clinic or in the dental school to conduct the face-to-face interview.

All the participants in the study were recruited and interviewed by the author herself. In order to be able to approach the patients in the clinics for recruitment into the study, the author had to approach the Clinical Research Office of the Sheffield Teaching Hospital to be granted permission to access clinics. The author also had to obtain Disclosure and Barring Services (DBS) clearance before approaching patients for recruitment into the study.

3.3.2.2. *Sample size*

A total of 22 patients were interviewed for this study. Table 10 shows the number of patients recruited within each phase.

Table 10: Sample size distribution

Phase	Description	No. of Participants (Male: Female)	Total
One	6-8 weeks post – surgery	12 (M=2, F=10)	Total number of participants = 22 Age range 18 - 66 years.
Two	In decision making phase for surgery	6 (M=2, F= 4)	
Three	1-2 years post - surgery	4 (M=0, F= 4)	

3.3.3. Data collection

Data collection for GT research can be done through various methods of which interviews are the most popular (Gibson and Hartman, 2014). Semi-structured interviews were used for data collection in this study. From the initial purposive sampling, the patients who had completed orthognathic surgery and were being discharged from the oral and maxillofacial clinics were interviewed. However, as the study progressed, based on the emerging theory, further data collection could be done from a different sample of participants and using other methods of data collection (Gibson and Hartman, 2014; Charmaz, 1994). Therefore, the use of field notes and medical records/clinical data form, were also a source of data in this study. In any case, the aim of data collection in GT was to collect data that are as diverse and varied as possible and for the purposes of building theory (Gibson and Hartman, 2014). This also justified reviewing the relevant literature before the study commenced to develop theoretical sensitivity and also to generate data that could help with constant comparison for the development of the emerging theory. Literature, especially from the field of appearance psychology, as observed from the literature review, added great value to the data used in this study. This is because the various psychological elements related to appearance explored in the interviews was compared and verified against the findings in the literature. Hence, literature became a great source for data enabling constant comparison for the emerging theory.

Although an unstructured interview would have been able to obtain an in-depth understanding of the participants concerns (Mason, 2002), a semi structured interview method was used in this study. Hence, the interviews followed a set topic guide for the initial interviews (See Appendix -D). The topic guide was devised such that the patient was given every opportunity to talk about their story of orthognathic treatment freely. Other questions included in the interview were to highlight any concerns participants would have had before seeking orthognathic treatment particularly focusing on psychosocial concerns, motivations and expectations of the patients, decision making process for orthognathic treatment, psychological resilience and coping of the participants. Each of these interviews took approximately 30 – 45 minutes. The interviews were conducted in a closed room within the dental hospital or in the adjoining dental school according to availability on the day of the interview. These interviews were recorded on a digital voice recorder.

Field notes were made immediately following the interview. These field notes constituted the interviewer's observations of the participant's responses to the questions asked in the interview. For example; if a particular question made the participant distressed or anxious, or if a patient looked very emotional while recollecting some past experiences. Hence, the field notes also became a useful source of data in this GT research.

3.3.4. Data management

The data obtained through the interviews, which are recorded on a digital voice recorder were transcribed for use in the study. The interviews were transcribed by the author herself using MS word computer programme. The transcripts also made note of laughter, crying, long pauses, sighs and emphasis of words. The field notes of the corresponding participants were also stored along with the transcripts. Both the transcripts and the interviews were stored in encrypted format on password protected computers at the University of Sheffield.

MS word computer programme was further used for coding and categorising the data. These aspects of data analysis will be discussed further in the following sections.

3.3.5. Data analysis

3.3.5.1. Coding and theoretical coding

Coding is the mechanism used for categorisation of data in GT. Different approaches to coding data have been discussed in the literature (Holton and Walsh, 2017, Gibson and Hartman, 2014). However, before discussing coding it is worthwhile to know what a code is. Birks and Mills (2011) stated that codes are a form of shorthand that researchers repeatedly use to identify conceptual reoccurrences and similarities in the patterns of participants' experiences. Further, groups of codes representing a high-level concept form a category (p. 93).

Glaser (1978) provided specifications of coding procedures that were designed to develop the theory from data. Here, coding was aimed at generating categories and their relationships. Whereas theoretical coding was a way to delineate the range of relationships found between categories in a theory. However, there have been several discontinuities in the process of coding in the later texts on GT. Gibson and Hartman (2014) clarified all discontinuities that appeared in the literature on coding in GT and simplified the goal of coding in GT to perform two functions; i) produce categories

that have to express what the theory is about and ii) have to express how they relate to each other (p. 98).

Some authors like Birks and Mills (2011) have used separate stages in coding while some other have used less clear separation between these stages. For example, Glaser (1978) used 'initial coding' and 'selective coding' which Birks and Mills (2011) divided clearly into two phases called 'initial coding' and 'intermediate coding'. However, in this study, 'open coding' phase and 'selective coding' phase were both used, which is in agreement with Gibson and Hartman (2014).

Open coding aims at discovering what the main concerns of the participants were and hence identify the core category of the theory. However, Gibson and Hartman (2014) emphasised the importance of the researcher being able to identify what is counted as data in their study. Open coding is often undertaken by analysing the transcripts line by line (Glaser, 1978) and developing codes from them. By taking larger slices of data and paying attention to the reach of the data helps in improving the impact and scope of the codes in the developing theory (Gibson and Hartman, 2014). The use of comparisons and data slicing (taking the incident observed and thinking 'where else can this happen?') can help in exploring the general relevance of the emerging categories.

Selective coding is the phase in which the researcher focuses on analysis and coding to increasingly specify and develop the categories of the developing theory. The identified core category should relate to many other categories developing in the theory and should dominate the theory. Therefore, the core category should recur frequently in the data. It should be highly modifiable and have a grasp in other disciplines as well. The key aspect that enables the generalizability of the emerging theory is by selectively coding for the applicability of the core category (Gibson and Hartman, 2014).

In this research, open coding was done on transcripts from interviews and field notes. An example of coding and developing categories is shown in Table 11. Codes identified were marked next to the line on the transcript as a comment using the 'review' function of MS Word document. These codes were later analysed further to develop categories. These were made note of on index cards and organised into their respective categories. These categories were then analysed to identify the core

category and data slicing was done to study the generalizability of the core category. Simultaneously theoretical memos were written which is discussed in the next section.

Table 11: Example of developing categories from codes

Transcript	Codes	Categories
<p><i>Q: Can you tell me how did you come to realise that there was a problem with your jaws?</i></p> <p>Well as a teenager, I wore a brace on, on the top teeth. But as soon as the treatment was finished, my top teeth started to protrude again, but ... so I always knew I had got an abnormal... to me abnormal looking jaw. I knew it was smaller than it should be, compared to everybody else and I always felt very self-conscious of it and I was very shy as a young person. Umm and I used to get teased a lot at school. Partly boys. Umm so that was ... that was hard at the time.</p>	<ul style="list-style-type: none"> - Teenage years - Previous orthodontic treatment - Abnormal jaws - Abnormal as compared to everybody else - Self- conscious - Teasing by boys - Hard time 	<div style="display: flex; flex-direction: column; align-items: center;"> <div style="display: flex; align-items: center; margin-bottom: 10px;"> <div style="border-left: 1px solid black; border-right: 1px solid black; height: 40px; margin-right: 5px;"></div> <div style="font-size: 2em; margin-right: 5px;">}</div> <div style="text-align: left; padding-left: 10px;">Seeking normalcy</div> </div> <div style="display: flex; align-items: center;"> <div style="border-left: 1px solid black; border-right: 1px solid black; height: 40px; margin-right: 5px;"></div> <div style="font-size: 2em; margin-right: 5px;">}</div> <div style="text-align: left; padding-left: 10px;">Acknowledgement of emotional difficulties</div> </div> </div>

<p><i>Q: Can you tell me how did you get through those difficult times?</i></p> <p>I don't know... I think I always have very supportive family and a very good network of friends... umm and work colleagues so plus I really love my job. So I have had a lot of positive moves in my life and I suppose I think that nothing's ever really gone wrong for me. I met my husband, we got married and got 2 lovely daughters so you know... and he's never talked of me as looking any different to anybody else... I suppose. But he knows how much it means to me to have a normal profile... you know... to face. So, yeah so he has always been very supportive</p>	<ul style="list-style-type: none"> - Social support – support from family, colleagues and friends - Enjoy job - Meeting a good partner - Support and understanding from partner - Partner understanding her feelings about her appearance 	<p>Social support</p>
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3.3.5.2. Memos

Glaser (1978) stated that “memos are the theorizing write up of ideas about codes and their relationships as they strike the analyst while coding” (p. 83). Hence while writing theoretical codes, the researcher writes their own ideas about the codes they are developing and their relationship with each other. Thinking and writing theoretically is essential all throughout GT, and the way to do this is using theoretical memos. Hence in the memos, the researcher needs to make comparisons and think in terms of the theory that is emerging (Glaser and Strauss, 1967).

Gibson and Hartman (2014) stated that it is crucial to write memos throughout the GT that may be quite descriptive or focus on the variations between categories. However,

Glaser (1978) suggested that the memos written should not be re-written but the researcher should move forward continuously by adding to the memos through further coding and comparison of data. Thus the memo becomes more theoretical, conceptual and dense (Raphael, 2008). Writing memos about the core category and its specifications leads to development of the key concepts of the theory (Gibson and Hartman, 2104).

The three keys aspects Gibson and Hartman (2014) stated about how to write a memo were; flexibility, modifiability and a degree of freedom. These memos must be able to be edited and updated. They also need to be held in such a way as to be able to sort them. The goal of this process of writing memos is to produce a ‘memo fund’ that can be used in the next stage of GT –sorting.

An example of the memo written in this research is shown in the Table 12. In this research, memos will be written on index cards and were stored categorically in an index card box. Larger memos were written using MS word and these documents were stored in named computer folders.

Table 12: Example of writing memo

Transcript	Categories	Memo
<p><i>Q: Can you tell me how did you get through those difficult times?</i></p> <p>I don't know... I think I always have very supportive family and a very good network of friends... umm and work colleagues so plus I really love my job. So I have had a lot of positive moves in my life and I suppose I think that nothing's ever really gone wrong for me. I met my husband, we got married and got 2 lovely daughters so you know... and he's never talked of me as looking any different to anybody else... I suppose. But he knows how much it means to me to have a normal profile... you know... to face. So, yeah so he has always been very supportive</p>	<p>Social support</p>	<p>It looks like she was trying to seek comfort in all the good things that happened in her life in order for her to get through difficulties. Two major areas of her life she finds particularly positive were her professional life and her family life. While she enjoyed the company of her work colleagues, it was important to her that she 'loved' her job as well. In her family life, finding her husband and he being understanding and supportive matters to her. On the whole for her what mattered the most, all had went well (nothing went wrong). To me it seems like good social support from people who matter the most helped her.</p>

3.3.5.3. Sorting and Writing up

Sorting is the next stage in the GT research process. It is a technique that further enables conceptual thinking about the emergent theory. Although Glaser (1978) emphasised the importance of sorting in GT methodology, many of the later literature in GT limited the emphasis of sorting to a technique of putting the theory together (For example; Birks and Mills, 2011; Charmaz, 2006). According to Gibson and Hartman (2014), sorting is a complicated procedure and is done differently for a PhD research, a book, scholarly journal and a lecture.

This is a PhD research in the Faculty of Medicine, Dentistry and Health sciences and hence the sorting for this will be considered further. Some of the key issues that can arise when using GT research for a PhD research have been discussed by Gibson and Hartman (2014). They suggested addressing these concerns during sorting and integrating the theory before writing up. One of the major concerns addressed was the importance of the study making an ‘addition to knowledge’ in a PhD. Although Glaser (1978) argued that GT will produce self-evident knowledge and there is no need for further justification, Gibson and Hartman (2014) stressed the importance of explicitly writing about what the developed GT adds to the literature.

Secondly, the structure of the thesis accepted in the Faculty of Medicine, Dentistry and Health sciences follows a set pattern including a literature review, methodology, materials and methods, results and discussions. However, for a GT research, a literature review is generally considered as not being the appropriate way to initiate research. But, for the purpose of a PhD, a literature review may be necessary (Raphael, 2008). Additionally, many GT experts have supported the use of a literature review as data and acknowledged the need for a literature review in many studies for purposes such as funding (Andrews, 2006, McCallin, 2003, Glaser, 1998). Further, Gibson and Hartman (2014) suggested the addition of a concluding section to outline what the theory added to knowledge without having to disrupt the integration of the theory. In the case of the current study, this will be done through writing about the ‘implications for practice’ as a result of the theory. Other ways to enhance findings of the research during sorting is to consider general implications of the theory and by considering if the theory relates to a common sense understanding of the problem (Gibson and Hartman, 2014).

Having considered these issues that may arise while writing up a PhD thesis; one has to go beyond guidelines given by Glaser (1978) and provide additional information (such as a literature review) and justification for the theory in the writing up of this GT.

3.4. Other methods of data collection

3.4.1. Online blogs and forums

In GT, 'all is data' (Glaser, 1978; p. 8). Therefore, every account of a person who underwent, is undergoing or considering undergoing orthognathic surgery was useful data for this study.

In the modern times of technology, many people use online blogs and forums for self-expression and to share their thoughts about various things they think are important (Yu et al., 2013). According to O'Sullivan (2005), contemporary pen and paper diaries are being fast replaced by electronic sources such as 'blogs' or 'live journals'. Blogs are web based journals containing posts of users in a reverse chronological order. When these blogs are focused on a particular topic which is of interest to a target audience, the viewers of the blog can discuss the topic in depth and they have an opportunity to learn from each other (McAndrew and Johnston, 2012). Hence blogs are a good source of day- to- day reporting of people's experience.

Blogs are a form of narrative. However, they differ from other narratives since these blog posts are told in brief episodes with each posts having a beginning and an end (Rettberg, 2008). In such blogs the readers are given an active role to participate by asking questions or posting comments about the post (Rettberg, 2008). On the other hand, within online forums or discussion boards, any member is not only allowed to ask questions or comment on the topic written, but they are allowed to start a discussion about a new topic. Online discussion forums were found to be a great source of social support for many health related conditions (Kummervold et al., 2002, Loader et al., 2002).

There are many such blogs and open forums of orthognathic patients. These blogs were written in great detail. For example, most of the orthognathic surgery blogs talk about the day-by-day experience of recovery following the surgery, while some of the blogs also posted pictures of how they looked on each day following the surgery (e.g. Oliveira, 2014). Hence these blogs can provide useful data for this study.

Blogs and forums were identified through the Google search engine and randomly selected for GT analysis. Examples of such orthognathic blogs and forums are listed in Table 13. However, only blogs and forums which were open to public use without having to sign up or register for, were used for analysis in order to comply with ethical use of online data. Blogs that were not in the English language were excluded from the study. The data from these blogs were analysed using the GT method as described in the previous section.

Table 13: Examples of orthognathic surgery blogs and forums online

<u>Blogs</u>	<u>Forums</u>
http://steffies-orthognathic-surgery.blogspot.co.uk/	http://www.jawsurgeryforums.com/
http://mymilliondollarsmilee.blogspot.co.uk/	http://www.archwired.com/phpbb2/viewforum.php?f=15
http://www.jawsurgeryblog.com/	http://www.realself.com/forum/the-orthognathic-surgery-community
https://roxsjawsurgery.wordpress.com/	http://forums.digitalspy.co.uk/showthread.php?t=1992993
http://awimpsguidetoorthognathicsurgery.blogspot.co.uk/	http://www.thestudentroom.co.uk/showthread.php?t=1603029
http://jawsmylife.blogspot.co.uk/	
http://theteethofsteph.blogspot.co.uk/	

The use of data from online blogs and forums provided a variety of data since these online sources provided accounts of the experience of patients across the globe. Thus, a wider range or comparison was facilitated for developing the GT. For example, it was possible to obtain data about patients who were not satisfied with the outcome of orthognathic surgery, unlike the patients who were interviewed in the hospital. Such data allowed constant comparison and filled gaps in the theory developed. Interestingly, the data from orthognathic blogs have never been analysed before in this manner although they are such a rich source of data.

3.4.2. Secondary sources of data

In a GT study, as mentioned previously, ‘all is data’. Therefore, it was possible to include data relating to various patient experiences of orthognathic surgery in the analysis of this study. The early authors of GT methodology included secondary datasets as an appropriate source of data for GT (Glaser 1998, Glaser and Staruss, 1967), but secondary data sources were rarely used by grounded theorists (Birks and Mills, 2011). In recent years, use of secondary datasets has increased in research (Rubin and Babbie, 2008). Similarly, secondary data were successfully used in GT research (Whiteside et al., 2012).

The sources of data discussed above – qualitative interviews and online blogs and forums - were primary sources of data because the patients themselves reported their experience of orthognathic surgery. However, data regarding patient experiences were also obtained from reporting of patient experiences by dental professionals who treated these patients and friends and family members of these patients. These were a secondary source of data since they were analysed and reported by someone other than the researcher themselves (Rubin and Babbie, 2008). However, since these secondary data were only case reporting rather than a full research analysis, the data were considered appropriate for use in GT as reported in past GT studies (Andrews et al., 2012 and Whiteside et al., 2012). Such data were obtained from attending various multidisciplinary team meetings, conferences, attending joint clinics for discussing patient care, speaking to people interested in the substantive area of study and from various sources of literature about the substantive area. The clinical records of the patients were also accessed to obtain relevant data.

3.5. Previous GT studies in orthognathics

In the literature, it was found that there was one study in the past which has applied GT methodology within the substantive area of orthognathics. It is important that this study is explored in detail since the aim and methodology were very closely related to this current study. Sadat-Marashi et al. (2015) in a qualitative study explored the perceptions and values of patients who underwent orthognathic treatment one to three years ago. Data was collected from five women and five men, between 20-25 years of age, through open, in-depth interviews. The data collected was analysed using the GT approach. The aim of this study was to explore the individuals’ subjective perception and values having gone through orthognathic surgery to resolve their ‘dentofacial

deformity' (Sadat-Marashi et al., 2015, p. 2392). Only French speaking patients treated in the University Hospital of Geneva were included who did not have CLP, facial trauma, TMJ disorders, hypodontia, previous orthodontics and facial plastic surgery.

During the interviews, six themes were covered including; individual motivation, satisfaction, pain, social interactions, impact with regard to school, work and daily life and outlook towards future. The study identified the core category that described the participants' satisfaction with treatment outcomes despite their difficult experiences during orthognathic treatment. One of the other categories that was identified was related to the information available to the patients prior to the surgery and stated that information in the form of experience shared by those already having undergone similar treatment would have been more valid. However, the authors failed to identify this category as an aid in decision making and failed to explore it any further. Yet another category identified was the shock for family and friends at the hospital which was due to the post-surgical swelling. It was stated that family and friends worried that this was because of a mistake during the surgery. The authors did not, however, identify this as a lack of preparedness of the friends and families along with the patients.

A great deal of emphasis was placed on physical discomfort along with its impact and this was described in relation to pain causing difficulty in eating, pain of prolonged orthodontics and swelling following surgery. However, the authors chose to describe these aspects as separate categories that influenced the core category. Smiling with self-confidence was described as a category which was central to the participants' everyday experience. It was stated that the reason why patients underwent orthognathic surgery was to have a self-confident smile. Before surgery, patients adopted habits to hide smile such as putting hand in front of mouth, putting tongue between teeth, keeping lips closed while smiling, avoiding smiling altogether and placing facial emphasis elsewhere by applying large amount of makeup around eyes or with noticeable hairstyles. However, after orthognathic treatment, patients were reported to be more self-confident and socially comfortable.

This study was not devoid of methodological weaknesses. Firstly, the selection criteria for sampling was very rigid and a variety of data were not collected to allow

comparison and hence develop a more generalizable theory. The young population who spoke French alone were included. All participants had completed orthognathic surgery at least one year ago and there was the potential of recall bias. This also prevented the detailed exploration of issues of decision making and participants' perceptions prior to surgery, which led to surgery and resolution of concerns regarding 'dentofacial deformity'. The findings of the study remained centred on the physical aspects of recovery following surgery and patient satisfaction attained as a result being able to smile with self- confidence. This seemed to suggest that the motivation for orthognathic surgery was to improve smile and self-confidence while as we have seen in chapter two, reasons why patients opt for orthognathic surgery is not only for smile improvement. Overall, this theory lacked robustness to provide deeper understanding of the patient perceptions and values having undergone orthognathic surgery.

3.6. Ethics Approval

Ethical approval was granted for this study from the London Stanmore Research Ethics Committee (See Appendix E). The Research ethics reference number is 14/LO/1488.

Ethics approval was granted for a previous protocol of the study which was a mixed methods study. However, one year into the study, the sample size proved to be too large to meet within the time scale of this PhD. Therefore, the study design was altered to limit it to just the qualitative component. A substantial amendment to this effect was submitted to the research ethics committee and was approved.

3.6.1. Ethical considerations in Qualitative research such as grounded theory

In qualitative research, the researchers are often required to clarify their role in the research process (DeWalt and DeWalt, 2010). The researcher is involved in all stages of a qualitative research process starting from defining the concept to design, interview, transcription, analysis verification and reporting of the concepts and themes. Therefore, the researcher is an integral part of the research process (Fink, 2000).

Similarly, the researcher – participant relationship in qualitative studies can raise a range of different ethical concerns (Ramos, 1989, Warusznski, 2002). The patient's willingness to participate in the study, their compliance with the research and the depth and validity of the data obtained are, to a large extent, based on the trust and co-

operation engendered between the researcher and the participant (Firby, 1995). In the current study, the researcher obtained data from the participants through face to face interviews. Participants were aware that the researcher was not part of the clinical care team and were assured that any information they shared with the researcher would not affect any further treatment they received at the hospital. This information and all information about the study was given to the participants through an information sheet about the study.

The relationship between the researcher and the participant begins with the information sheet, which is constructed to be motivating, informative and open, and to disclose something about the background of the researcher in order to foster trust (Kylmä et al., 1999). A brief background of who the researcher is and all the contact information of the research was provided on the information sheet for this study. The participants were invited to speak to the researcher for any clarification and further information regarding the study. It was also made clear that it was absolutely acceptable for the patients to decline taking part in the study. Therefore the ethical principle of making a voluntary choice to part take in the study was ensured.

Informed consent is an explicit agreement between the participant and the researcher to participate in the research process, which has two components - information (information and comprehension) and consent (voluntariness and competence) (Nusbaum, and Chenitz, 1990). Both of these components of informed consent were adhered to in this study by allowing participants every opportunity to seek further information and ensuring that they were competent to give consent voluntarily. Written consent was obtained 2-4 weeks after the information sheet was made available to all participants. It cannot be assumed that consent at one stage of the research is still valid at another stage (Holloway and Wheeler, 1996). Therefore, further verbal consent was obtained from the participant just before starting the interview and this consent was also recorded on the voice recorder.

Anonymity and confidentiality along with informed consent were listed as the core ethical concerns in any qualitative study (Richards and Schwartz, 2002). For health care professionals, confidentiality means no personal information is revealed but for researchers the meaning of confidentiality is less clear and involves elaboration of the form of outcome that might be expected from the study (Richards and Schwartz,

2002). Anonymity of participants during data analysis is protected by using pseudonyms or numbers on tapes, and in notes and transcriptions (Holloway and Wheeler, 1996). However, this study maintained anonymity and confidentiality of all participants at all stages of the study. In order to ensure this all patients were given a pseudonyms and the researcher adhered to maintaining confidentiality at all times regarding any patient information. Furthermore, all physical data collected were stored safely in a locked cupboard at the dental school, while all digital data was stored on secure and password protected computers only accessible to the researcher.

Participants revealed personal and sometimes emotionally upsetting details of their past experiences in the interviews. This nature of information was anticipated to be obtained from the interviews and therefore, a clinical health psychologist was included in the team of researchers in the study so that help could be offered to participants if they needed it. However, none of the participants expressed an interest in consulting the health psychologist during the course of the study. Further, the interviewer ensured that participants who were upset during the interview were given time to recompose, checked if they wanted to discontinue the interview and gained verbal consent again to continue with the interview if they so wished.

Chapter Four: Results

4.1. Introduction

The aim of this study was to develop a theory that explains what happens to patients¹⁰ who undergo orthognathic surgery. This chapter will detail the findings of the study. The results of a qualitative study can be best explained using quotations from the data and describing the analysis that led to the results. The first section of this chapter will include three vignettes. These three vignettes are chosen because they are the accounts of the various experiences of three individuals who were at different stages of orthognathic treatment when interviewed. Further, these vignettes have three main purposes. Firstly, these vignettes will set the scene for the results of this research. Secondly, they will serve to introduce the reader to the findings related to patient experiences from a holistic point of view. Finally, like their traditional purpose, vignettes will be used to explore what is going on within the context of the research. This is done by asking questions based on the vignettes. The answers to these questions helps in developing the GT.

Vignettes have been used frequently in qualitative research (for example; Jackson et al., 2015, Hughes and Huby, 2002, Hughes, 1998b). The most common use of vignettes in research has been to help in asking questions to the participants involved in the research (Barter and Renold, 2000). Here vignettes were used slightly differently to aid in the presentation of the results of the study. The author invites the readers to start asking questions about what is happening to patients who undergo orthognathic treatment based on the vignettes detailed below. In the subsequent sections of the chapter, the findings of the study will be discussed leading to the presentation of the GT.

¹⁰ All the individuals recruited into this study are 'participants'/ a person. However, since all the participants also held the status of being patients at the hospital, these participants are addressed as patients more often in this study.

Vignette -1: The Experience of a patient who had undergone orthognathic surgery 12 weeks previously

Marie is a 66-year-old retired nurse who had had concerns about her appearance and problems with biting, chewing and eating for a very long time. She has a very supportive husband, two daughters and grandchildren. It was these concerns about her appearance and difficulties with eating that had led her to seek combined orthodontic and orthognathic surgery treatment. Marie had bi-maxillary (upper and lower jaw) osteotomy 3 months ago.

When talking about the concerns about her appearance, Marie recounted that she was made aware of her appearance at a very early age in her life by schoolmates who teased her and called her names like ‘goofy’. Marie had a recessive lower jaw with an overjet of 16 mm. She said she was often stared at and asked questions about her jaws. Marie recalled and laughed about her grandchild asking her if she had a chin. Although this recent remark by her grandchild did not upset her, the constant teasing and name calling during her teenage years left her with an emotional scar that made her cry even today.

The psychological impact that Marie had because of her appearance where huge. She explained that she was very shy young girl. She did not like to meet new people, never liked to be the centre of attention and was generally very self-conscious. This, she said, affected her job as a registered nurse because she was never confident enough to give presentations or go to meetings and talk to new people. Marie confined herself to a group of close friends during all such social or professional events. Marie told me: “when looking in the mirror I didn’t look normal, I didn’t feel normal”. It was this feeling of not being ‘normal’ that had bothered Marie all her life although she was very happy with her life in terms of her job, her supportive husband, family and friends who did not think she looked different in anyway.

The functional problems caused by her 16 mm overbite added to Marie’s psychosocial concerns. She was extremely self-conscious while eating in public places such as restaurants and felt as if everyone was looking at her. Marie always found it hard to chew on hard foods like steak but learnt to deal with it. The bite marks that appeared when she bit into an apple bothered her and she said “The teeth marks on the apple

was very different because my top teeth were prominent and my lower teeth were really far back so it looked odd". Reflecting on her functional problem Marie said that "I never had a proper bite but I suppose that it was the bite is all I had for all those years so it was something that I got used, just learnt to live with it. But now I realise, now that I have got a normal bite and mainly a normal appearance".

It was not just her bite that she got used to and coped with, but also her appearance and all the associated emotional concerns she had about it. Marie said that as an adult she had learnt to brush off people's comments and questions about her jaw, which is something she could not do as a teenager. Marie had turned to her mother and confided in her during her teenage years about her troubles with being teased and called names at school. She spoke with pride about how she had never been depressed in her life or had to seek professional counselling. However, she also acknowledged the support she had received from her family, particularly her mother as a teenager, from her close friends during her working life and from her husband ever since she got married, in coping with her insecurities associated with her abnormal jaws - as she calls it.

Marie enjoyed working as a registered nurse very much. She explained that as part of her job she had to meet new people every day but that did not make herself conscious unlike meeting new people outside of work.

"As I said before, meeting new people I used to be self-conscious. But then again, particularly if that was a patient or their family that was coming, that was totally different because they were in a more vulnerable position than...I mean I was the professional going to help them so that was totally different. [] Meeting new work colleagues or going to bigger groups of professionals, I can't think of an occasion where I felt intimidated but it's only when people are quite overpowering". (Semi structured interview)

Prior to her surgery Marie avoided situations where she felt vulnerable and exposed. In large professional meetings, she sat with her close friends and did not socialise with new people. She told me that she would ask her colleagues to present work at meetings instead of doing it herself, as she felt very nervous if she had to present something and it affected how she spoke.

“When I feel confident I feel my speech is quite normal but if I felt nervous I mumble. I used to put that somehow down to how I looked. [] audience watching me present, what your impression would be of me, of my facial appearance”.

Marie’s concern about her appearance affected her in many ways. Although she said nothing that really went wrong in her life, she had a wonderful husband, a job she loved and two lovey daughters she always wanted “to look normal, to have a normal smile a nice smile, a normal chin and a normal bottom jaw.” This was what motivated her to seek medical help. Marie had orthodontic treatment as a teenager but the treatment failed to give her desired results. Later in her mid-thirties she had been seen at the hospital for an assessment but no further follow up was arranged by the hospital nor were they forthcoming about what could be done for her. She had to leave behind her desire to get treatment until she retired because of her work commitments.

It was at a lecture by an oral and maxillofacial surgeon that Marie attended, while she was still working as a nurse, that she first heard about orthognathic surgery as a treatment option to correct jaw abnormalities. Three years ago, she asked her own dentist about possible treatment for her jaws and she was referred to the Dental Hospital in Sheffield where orthognathic surgery was suggested to her as the best treatment option for her. Speaking about the decision making to have the surgery Marie said, “It’s not something to be taken lightly. I really got to weigh up the pros and cons of having it done”. While her husband, children, orthodontist and oral and maxillofacial surgeon had all helped her to make the decision she never once thought that they tried to persuade her either way regarding the decision she made. Marie was given lots of written information backed up with verbal information during her clinical appointments, which made her feel well informed. However, she did feel apprehensive about having the surgery because of the fear of the unknown. “Although you are given all the information, you don’t know what is going to be your actual experience.”

For Marie personally, this treatment to correct her smile and appearance was something she always wanted and when she was offered an opportunity, she felt at her age, it was a one-time chance or live with lifelong regret of not having it done. Marie was also given ample time to make the decision because of the gaps between clinical appointments for the various assessments. Once the decision was made to have the surgery the next step was starting the treatment process.

Marie was made well aware that the treatment was a time consuming process. She was scheduled to go through 18 months of pre-surgical orthodontics but there was an unforeseen eight months delay for the surgery, which Marie said, was a difficult waiting period for her. Marie thought the surgery went very well and the first 24 hours following the surgery was brilliant. However, once the wafer was fitted to stabilise the jaws in their new position, Marie was very scared because she was nauseous and worried how she would manage if she was sick when her mouth was wired shut. But then she was very pleased with caring attention and useful information provided by the hospital staff which put her worried mind at ease. Marie went home from hospital 48 hours after the surgery. She had the wafer removed 4 days after it was fitted and then followed the soft diet regime she was given to aid her recovery. During her post-surgery days, Marie said;

“There were only a few days where I felt, oh dear what have I done? But as soon as I looked at myself in the mirror, I knew I had done the right thing and why. Because it had really altered my appearance”.

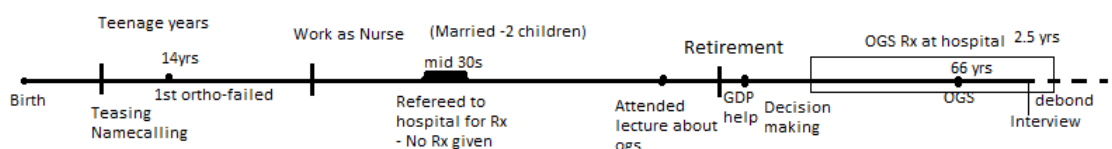
Now nearly 12 weeks after the surgery, Marie is absolutely pleased with the results and it was exactly what she had hoped for from the treatment. She now feels that she has a normal smile and a normal appearance. Sometimes her jaws do feel a bit unnatural and she thinks it is because her jaws have moved position but she is now getting used to it. She is able to chew better these days and all she needs to do now is work on her mouth opening a bit more.

Marie said that she had been to a restaurant with her friend two days ago and was self-conscious this time for a whole different reason. She still has some numbness in her lower lips, which made her conscious if she was dribbling while eating. Apart from that she said she was now alright eating in a public place unlike before her surgery. From the appearance perspective, Marie is absolutely pleased with the results of the surgery and said she would go for it again if she had to. She has no regrets whatsoever about the surgery she has had. However, she is still waiting for the sensation to her lower lips and her mouth opening to return to normal, and for the debond (removal) of the orthodontic brackets after the completion of the post-surgical orthodontics.

The observational analysis and interview outcomes of Marie’s experience of orthognathic surgery treatment can be summed up in the vignette above. This vignette tells us a lot about the experience of a patient undergoing orthognathic surgery from their perspective. It also invites us to ask more questions.

Firstly, the structure of the vignette shows what happens to a patient who undergoes orthognathic surgery and this can be plotted on a timeline (See Figure 9). The experiences Marie had to share were all a sequential set of incidents that occurred throughout the course of her life, which influenced her experience of orthognathic surgery. On this timeline, the major event that occurred and marked a significant change is the orthognathic surgery itself. Since Marie is an older adult (66 years old), her timeline is much longer before the significant life event unlike younger adults who undergo orthognathic surgery in their late teens or early twenties. However, from the analysis of all the data obtained in this study, the length of the timeline prior to the significant event (orthognathic surgery) and the impact it has on the person is particular to the individual’s experience and their own psychological makeup. This will be discussed in detail later on in this chapter.

Figure 9: Timeline of Marie’s orthognathic treatment experience



Secondly, although the vignette concludes on a positive note about how pleased Marie is with the outcome of the surgery, she is still waiting for more changes to occur with regard to her face. Marie was interviewed fairly soon (3 months) after the bi-maxillary osteotomy and the post-surgical orthodontic treatment was ongoing. This finding from the analysis suggested that the completion of the change, which patients anticipated the orthognathic surgery (significant event) would bring about, did not always happen immediately following the surgery. From Marie’s account, removal of the orthodontic brackets post orthognathic treatment seemed to mark a milestone and was indicative

of the completion of change. We can only be certain about when the change was completed by collecting data from patients who had gone past the final milestone, whatever that might be.

We will now look into another vignette detailing the experience of an individual who had orthognathic surgery two years before the interview with orthodontic brackets having been removed over a year and a half ago.

Vignette – 2: Lisa two year post double jaw surgery

Lisa is a 22 year old and she had double jaw surgery 2 years ago. She was told she would need jaw surgery when she was hospitalised at the age of 14 for removing an infected tooth. She was told that her jaws were growing the ‘wrong way around’. This the first time Lisa realised that there was a problem with her jaw that needed to be addressed. She was annoyed with that knowledge because she thought all she needed was braces like her friends had and her teeth would be straightened out. At the age of 15 years she was told she would need to wait until she was 17 years and facial growth had slowed to actually have the jaw surgery.

Lisa initially rejected the idea of having jaw surgery because of her fear of hospitals and dentists. However, by the age of 17 years, she decided to go ahead with jaw surgery and at the age of 19 years, she was operated upon.

Lisa recalled that since her problem was an increased lower facial height, with just one appointment at the orthodontist it was made clear that she had only two options to sort her jaw out. One was to have the jaw surgery and the other was to do nothing. Although her initial reaction was to reject surgery as she became 16 years of age she started noticing her appearance more and felt like she did not look normal.

“when I was 15, I was still very young and very terrified of hospitals and dentists ...and anything to do with that umm but then when you are 15 -16 you start noticing your appearance more and it starts to really get to you that you don’t look normal, because you are being told that there is something different about you. But I kinda knew that there was something different...”

By then, it was not only the appearance that was bothering her, but she said it was getting difficult to eat and even speak because of her under bite. So she was seen at the hospital a couple of times to decide if surgery was really needed or, like she had hoped, if orthodontics alone could have been a suitable option for her. At the hospital she was told that she could decide to have only the orthodontics, however that would only make her teeth straight and would do nothing to correct the increased lower facial height. Lisa said that it was all very clearly explained to her so she knew from the start what would happen if she did not go ahead with the surgery and why the surgery was needed.

It was knowledge of how much time the treatment would take to get done was what made Lisa annoyed at that time. However, at the time of the interview, when she reflected upon the experience, she felt that it was not that bad because she knew why it needed that much time to be done and also when she compared her ‘perfect teeth and jaws’ with her friends who have had movement of their teeth following orthodontics, she felt that her double jaw surgery has definitely benefited her.

When Lisa was asked about her reasons for seeking jaw surgery, she said “I was referred into orthognathic surgery, I didn’t ask for it”. However, once she was introduced to orthognathic surgery she said she realised that some of the problems she had with her speaking – like pronouncing ‘s’ properly, eating – biting into an apple, could be ‘fixed’ if she had the surgery. Apart from these functional concerns she said she did not like to smile or laugh and when she did smile she would always cover her face with her hand because she knew that there was a visible gap between her upper and lower set of teeth. She said she was very withdrawn when meeting new people. Lisa hated having her picture taken because she said “my side profile was horrible and the older I got the more obvious it got”.

Lisa said she did not eat a lot. “It became very frustrating when you can’t eat an apple or eat a sandwich very well, and then you get very worried that people are looking at you because you are eating with the side of your mouth instead of at the front, so it did effect you in a lot more ways than you think it does.”

The concerns Lisa had about her appearance also affected her on an emotional level. She said was not a confident person when growing up. She recalled being a very quiet person who had difficulty meeting new people or going out with friends. She said she

did not eat very well and so was very thin. This also affected her self-confidence. Lisa never spoke about these emotional problems to anyone and she said this was because she was very withdrawn and kept everything to herself. However, she felt comforted when she started seeking treatment. Lisa said;

“In my head I knew I was doing something about it, so I hoped that it would change and so I wouldn’t have to be so paranoid about it. [] So I was seeking treatment by then and so I felt kinda better once the braces was on so then you are part of every one else and everyone else has had braces, now it’s your turn and even if they notice something to do with your jaw, they will also notice the braces and the fact that it’s going to change and it’s not permanent.”

Speaking about decision making to have the surgery, Lisa said she was positively motivated by her parents because they saw how it would benefit her and at the same time was sensitive about Lisa’s fears about hospitalisation. Lisa recollected the appointments with her dentist, orthodontist and surgeon prior to the decision being made being very informative and not prescriptive. She was pleased that she was given a few years to think about having the surgery and she was given enough time leading up to the surgery to say no to the surgery. Further, she spoke highly about the help that came from seeing and talking to her cousin who had jaw surgery 9 years before her and how it helped her decide about the surgery. Lisa compared the information she got from the orthognathic DVD given to her from the hospital and said although the DVD gives a lot of information, it was talking to a person who has previously had the surgery that felt more useful for her. By speaking to a person, Lisa said, you could speak about your personal situation with the treatment and share relevant experiences and she added:

“...whereas in the DVD you don’t know what has been edited out. (Laughs)”

Lisa felt that seeing a professionally taken before and after picture of her cousin who had jaw surgery very useful for her to clearly visualise what the surgery could give her. Along with seeing the picture, her cousin also told her about how much of a difference the surgery had made in her ability for bite and chew food. This, Lisa said persuaded her to go ahead and have the surgery. Apart from this, she built her trust in the operating surgeon and her team by having spoken to a friend, an anaesthetist, who

knew the operating team very well. She said the reassurance she got from this friend eased her fears and worries about the surgery itself to a large extent.

When Lisa made the decision to have the surgery at the age of 17 years, she expected to look prettier, be able to eat – bite and chew her food better and be more self-confident to meet new people and go out with her friends. Today when she reflects on her expectations she feels that she was not left disappointed.

“ I mean, now I am moving to Japan, I don’t think I would have done, had I not had the surgery and been happy with myself and my face and my ability to eat and speak and you know...it is little things but it does make a big difference.”

Reflecting upon how the experience of orthognathic surgery had influenced her coping abilities with difficult situations in life, Lisa said that having gone through the surgery she learnt to see the light at the end of the tunnel. Citing an example she said a year and half after her surgery during her final year of her degree she had financial difficulties and problems with accommodation during her university term time. She coped with the situation with her confidence gained from her experience of orthognathic surgery. The experience of coping with orthognathic surgery showed Lisa the light at the end of the tunnel in the form of an appearance she liked and was proud of. Similarly, she believed that at the end of the ordeal of completing the degree withstanding the difficulties she was facing would lead her to the light at the end of the tunnel in the form of working in Japan. Lisa felt that her experience of going through orthognathic surgery has changed her abilities to cope with difficulties in life positively.

“Like little things ... If I wanted ear piercing ... if I can go through that surgery, I can have my ears pierced. If I can survive what was a very scary time of my life like going to the dentist, all invasive treatment, if I can do that, I can come out at the top. I can tackle anything!”

For Lisa, her friends and family were a great support in getting through the tough times of having orthognathic surgery. She vaguely recollected her post-operative period when her mother had been by her side when she had difficulty eating, sleeping and talking and also her friends learning more sign language to help her communicate with them. However, what she had to say about her post- operative period was very little possibly because of the time that has lapsed since then.

Now, 2 years post-surgery Lisa felt very self-confident and happy about herself. She felt more confident in social situations and easily made new friends as compared to how she was prior to the surgery.

“I probably wouldn’t have talked to you before I had surgery like this... I feel proud of my teeth and you sort of want to brush your teeth more, otherwise you sort of lose interest if they don’t look good. So now I am making sure that they are clean and taking care of them. Whereas before I was bit like umm I can’t be bothered. I feel like it’s an asset now... I can use it. I can use my smile.”

Lisa said that she could see the difference in her appearance within a few weeks after the surgery. She thought that she now looked more like her mother and her teeth were straighter. But it was after her braces were removed that she felt her change was complete and her appearance was final.

“That was it I am done. There was a little bit of swelling to go but that was my teeth. That was it. And I think on some level you want to show them off while smiling and talking and meeting people and on some level it did boost my confidence”.

Lisa’s friends told her that now when they look at her she looks like seeing a baby grow to being an adult, meaning she looks like her old self in some level but not exactly like how she used to look before the surgery. For her personally, she felt very happy about her appearance now, and would definitely make the decision to have surgery again if she had to.

Vignette -2 sums up the experiences of Lisa, a young lady who underwent orthognathic surgery two years prior to the interview (See Figure 10). Carrying on from the analysis of Vignette -1, the completion of the change, which Lisa anticipated from her treatment, is clearly evident in Vignette -2. Lisa felt that all she hoped for the treatment was achieved once the post-surgical orthodontic brackets were removed. Lisa felt certain that there was nothing more that would change since there were no more external forces acting on her facial skeleton or her teeth. Therefore, like Marie anticipated, removal of the orthodontic bracket seemed to be a key milestone in the experience of patients who undergo orthognathic surgery. Although different people perceive and acknowledge the completion of the anticipated change at different stages

post- surgery, removal of orthodontic braces post-surgery still remained as a mile stone for most patients.

Figure 10: Timeline of Lisa’s experience of orthognathic surgery



When comparing Lisa’s account with that of Marie’s, it is apparent that Marie had a lot more to speak about the actual day-to-day experience of visiting the hospital for appointments and her post –surgery period than Lisa. On the other hand, Lisa seemed to reflect more about how her life changed following orthognathic treatment. This reflection included going back to explore her decision making as a turning point in her life. However, within Lisa’s account, the decision-making process appeared to be an event that occurred a long time ago, the details of which were vague yet important to Lisa. Therefore, it is worth exploring the decision making process for orthognathic treatment in further detail. The best way to do this is by drawing on an account of someone who was interviewed whilst in the decision making phase for orthognathic treatment.

Vignette -3: Sandra’s decision about orthognathic surgery

Sandra is a 24 year old healthcare professional. She was referred to the hospital to consider orthognathic surgery as a treatment option for her in order to correct her jaw position. She had a facial asymmetry and a class III skeletal relationship. She was told that she could either have orthognathic surgery or have no treatment at all with regard to her jaw position because orthodontics alone could not correct her concerns. Sandra was referred into the treatment pathway not long ago and was still deciding if she wanted the surgery done or not. She had met the orthodontist and surgeon at joint clinics in the Dental Hospital a few times and was given information about the surgery. However, she had not yet decided if she was going to have orthognathic surgery.

Reflecting on the reason why she sought help with regard to her jaw and teeth Sandra said, although she was aware of a problem with her jaws, it was only when her friends and college classmates made comments about her facial appearance that she was made increasingly conscious of her facial appearance.

“I think in the back of my mind I was always aware of it, but I kind of just got on with it because I didn’t think there was anything out there. Because I have seen people whose jaws are more out there than mine, so obviously I dint think anything could be done with that. Probably accept that my face was slightly disfigure, not disfigured but slightly not normal. [] So it was always in the back of my mind but when people start picking on it you realise it more.”

Speaking more about the remarks and comments made by her fellow classmates and people in the group, not her friends, she said:

“People at school and college, more from the wider group said things like oh you are lopsided! We were playing cricket when we were in college and one of the boys or girls made a remark about maybe hitting my face with the bat and maybe correct that side”

Sandra said that these remarks and comments made her feel awful. Although initially she bottled all her feelings, when she approached her parents with her concerns they were very supportive and helped her to let things go and get past it.

Around the similar age, 18 years, she also noticed that her jaw clicked and it bothered her. When she asked her regular dentist about it, Sandra said no helpful solution was given to her. The lack of a supportive response was frustrating for Sandra and she decided to change her general dentist.

Sandra said she was absolutely certain that she was going ahead with the surgery when she left from the hospital during her previous joint clinic appointment. However, she went home and watched the orthognathic surgery DVD that was given to her. On watching that and also after doing some more research on her own she felt that although all the feedback seemed positive, she noticed that all of the people who were operated on had more severe problems with their jaws than what she perceived as her problem. This feeling made her rethink about her decision again. It was the understanding of what was going to be done during the surgery that bothered Sandra

more while the process of orthodontics did not bother her at all. So it was very difficult for Sandra to make a decision about having the surgery.

Sandra's positive inclination towards having the surgery during her previous hospital appointment, she said, was because she simply thought the surgery would change her appearance without giving much thought about what was involved in the surgery. She said at that point she was not aware of it taking three years for completion of treatment and what was involved during these three years. However, during the appointment she was told to go watch the DVD and do some of her own research, which made her more aware of what was involved as part of the treatment process.

The research Sandra did in order to gain more information was through the internet. She looked into YouTube videos, read about people's experiences following surgery on Google and also saw before and after pictures of orthognathic patients. Through this, she learned that the days immediately following the surgery were the most difficult with the swelling and pain. Although the end result was obviously good she said. She also learnt about the risk of losing sensation on various parts of the face and jaw. Sandra said that the DVD and her own research on the internet gave her a very clear picture of what was involved in the orthognathic treatment process. Apart from these the hospital had also given her information leaflets about the surgery but Sandra did not think they were particularly useful. It was the DVD she preferred better because it made her more aware of the treatment process. However, it also made her more worried about having the treatment. Sandra said it would have been useful to be directed to a specific useful website because when she did random searches all sorts of negative and positive stories appeared which confused her decision.

“And then when I watched the DVD, which was really helpful, it kinda gave me the feeling that I want to get it done, but when I kinda did a bit more research into it, although most of it was positive, but a lot of people who had it done had a lot more kind of ...theirs (jaws) was more stuck out than mine. I don't know then if I have gotten used to mine, it is just kind of I think... the surgery is making me a bit uncomfortable about the whole thing... coz I have seen kinda what will be done, for me that's what's worrying me, the braces don't bother me.”

Despite her understanding of what to expect from and during the treatment process Sandra was undecided because of a few concerns she had. Firstly, she did not think that her “jaws stuck out a lot” unlike the people on the internet or the DVD who had gone through the surgery. This made her unsure if surgery was necessary for her. Secondly, she was concerned if it was the right time in life for her to use three years to correct her facial appearance. This was because she had just started a new job and was focusing on progressing in her career. Sandra said at her age it is a difficult decision to make and if she was younger, say around 18, she would not think much and would have had the surgery. Thirdly, she had seen that a lot of people were struggling while they were going through the treatment process. Therefore, knowing both the positive outcomes and the negatives of having the surgery in relation to her life made Sandra undecided.

“I am very close to my parents so they are very much, they are kind of, obviously they said to me that the decision at the end is yours but they kind tell me what they feel about it as well. Umm my sister, I am very close to my sister. That’s it really. My friends, to an extent my friends are not really a massive influence, it’s more my parents and my sister I guess”.

Sandra’s parents and her sister were also included in her decision making process. Her parents were supportive of whatever Sandra decided to do regarding the surgery. But her sister thought that she should not be having the surgery. Sandra on the other hand could not decide if she wanted it done she said that she was not always the most decisive person however she was not too bad either. It was her mother she would often turn to whenever she had to make a difficult decision.

Sandra wished that her dentist would have picked up her problems with the jaw earlier and referred her to the specialist earlier. That way she would probably have been offered this treatment option at a younger age. Today she said she keeps thinking,

“It will take me six months to come back, it’s quite a long time coming back and that comes as another impact on decision making because I keep thinking well if I come back in six months from there on it is a three year process after that. If I say no then I have to go through this whole process again and that’s kinda makes it a bit difficult”.

Talking about the time that was given to her for making the decision, she thought that the time that was given to her was both good and bad. Since she was now undecided

the orthognathic team giving her more time to decide was a good thing. However, the time between the appointments was very long and therefore Sandra thought that the length of time played a lot on her mind and made her undecided today. She thinks if there was a lesser gap between the appointments during the decision making process, it would have helped her decide faster. Sandra said any time longer than three months between appointments was too long during decision-making time.

“I think every time I come, I leave feeling more confident that I want to get it done. I think they (dental care team) influence me but not in a bad way... they influence you in a good way that they reassure you in all the stuff that I worry about”.

Every time Sandra saw the orthognathic team at the hospital she felt more reassured about having the surgery. So she felt that the dental care team has influenced her in decision making in a positive manner. This was because Sandra trusted them to have the most knowledge and experience about orthognathic treatment and what it involves. She felt that what she read on the internet was not always right but on the other hand what the orthognathic dental care team said was more accurate because of their expertise. Sandra said they were very reassuring and whenever Sandra would panic about making a decision they would comfort her by giving her more time to think about it and then make a decision.

“So for me it’s the fear that somethings going to go wrong and my face will have permanent damage. So that’s something that do influence my decision.”

Sandra feared that it was her face and whatever was done to the face through the surgery would remain permanent on her face. She feared what if something went wrong, although she trusted the abilities of the surgeon. According to Sandra breaking something that is natural and putting it back together would mean the risk of things going wrong in the long run is greater because whatever was man-made was never as good as natural. She also feared the surgery itself because for her it was a big operation and was unsure if it was all worth it. The other fear she has was about the time factor- both the time taken for orthognathic treatment and the time of the treatment in relation to her life priorities such as her career.

In order to deal with these fears, Sandra tried to talk herself through her fears and looked into the various possibilities that could happen. She also spoke to her mum and her friends about it. However, she said, she would constantly be worried until the

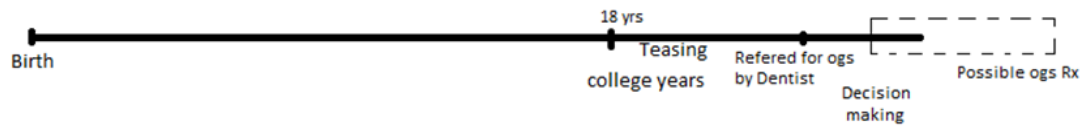
problem was sorted or in this case until the decision was made and the treatment was completed.

Speaking further about how support from her family and friends helped her in decision making, Sandra said that she felt more encouraged and sure if her family said it was a decision they approved of. On the other hand if they said it was something they thought that was not good then Sandra would not feel comfortable with the decision and would worry if it was really a good decision. She felt more confident in her decisions if her parents were agreeing with her about the decision. But in the case of orthognathic decision making, Sandra felt that since it was her face and her body that was being operated on, at the end if something went wrong it would her only be that would be affected and so she could not leave that decision to her parents or anyone else for that matter. She also said that if the problem she had was very severe and if surgery was the only option she would have gladly gone ahead and done it even if her parents did not approve of it. Even if they had supported her decision for surgery, they would not always be there to deal with problems say at the work place or when Sandra was alone. Sandra knew that she had to deal with it on her own since it was her face and her life.

Sandra strongly recommended that if the dental professionals could direct patients to specific dental websites that would provide good information about orthognathic treatment that would be very useful for people who are making a decision about orthognathic surgery.

The above vignette details the experiences of 24-year-old Sandra who was in the middle of making her decision about whether or not to go for orthognathic treatment (See Figure 11). Since Sandra had not yet entered the active treatment pathway, i.e. she had not started with even the pre surgical orthodontic treatment, the decision making process was identified as one of the early milestones in the orthognathic treatment experience of patients.

Figure 11: Timeline of Sandra's orthognathic treatment experience



Now that we have three vignettes about the experiences of three different individuals at three different phases of orthognathic experience, these vignettes can be used to study patient experiences from a neutral perspective. These vignettes can also be used to explore what is going on within the context of the research. The author invites the readers to start asking questions about the orthognathic experience of patients based on the three vignettes detailed above.

From the vignettes, one can positively identify two milestones in the orthognathic experience of patients. From Vignettes 1 and 2 we can see that patients looked forward to the completion of change in their facial appearance. This 'completion of change' is therefore a key milestone in the experience of patients undergoing orthognathic surgery. Another milestone was mainly detailed in Vignette 3 - initiation of change, i.e. through decision making to have orthognathic treatment. These milestones raise several additional questions.

The first set of questions is about the milestones in the experience of patients currently undergoing orthognathic treatment. Some of these questions are: What do these milestones stand for? Are these the only milestones within the treatment experience of these patients? What happens between these milestones? The second set of questions are about the 'change', which the patients hope for and possibly attain as a result of the orthognathic treatment. The most important question is: what is the change that orthognathic patients want? Is it just the superficial change in facial appearance or more? Secondly, will the pathway of orthognathic treatment sum up and map the pathway of this change, which is so central to the experiences of patients undergoing orthognathic surgery? Or is the change something over and above this

change? Finally, what is really happening to patients undergoing orthognathic treatment as a result of this change which they hope for from the surgery?

Whilst there are multiple factors shaping and affecting each patient experience detailed in the vignettes there are some salient characteristics that are common between each. One such finding is the presence of a sequential timeline in each of the accounts with orthognathic surgery being perhaps ‘the’ significant event on the timeline. While the clinical phase of their experience only begins with the involvement of clinicians in the hospital, for Marie, Lisa and Sandra their experience of active treatment pathway began much earlier and extended beyond their time at the hospital. This is clearly made evident on the three timelines shown in Figures 9, 10 and 11.

Secondly, the awareness of a problem with their jaw structure occurred much earlier during their life time. Marie lived with that awareness for 62 years before seeking orthognathic surgery, while Lisa was made aware of it at the age of 14 years and not long after at the age of 15 years she was told she could have the surgery in two years. Sandra on the other hand was made increasingly conscious of her problems during her late teens and was still contemplating orthognathic treatment. Apart from the time at which these individuals were first made aware of their jaw structure, the source which made them aware was also different. For Marie and Sandra it was their classmates and peers, while for Lisa it was the dentist at the hospital. Nonetheless, the awareness of having a problem with the jaw structure led these individuals eventually into orthognathic treatment.

Thirdly, from the three vignettes it is seen that the dental professionals play a major role in the patient’s experience of orthognathic treatment. As seen in Lisa’s account, dental professionals played a major role in making her aware of the underlying problem with her jaws. It was also seen that the dental professionals were a trusted source of information for all patients during decision making. The care provided in the hospital following the surgery was a major part of Marie’s orthognathic experience. Overall, dental professionals appeared to play a pivotal role in the experience of patients in the active treatment pathway.

Fourthly, the experiences these individuals had prior to actual referral into orthognathic care pathway had an influence on their experience of the orthognathic treatment itself. Their first experiences, in the form of bullying, teasing, name calling

or lack of self -confidence, were reflected on by all three individuals. However, the response of each of the three individuals to their early experiences was very different.

From the three vignettes, we saw individuals who were in different phases of their lives and had different priorities. But, they had similar experiences in relation to their jaw function and appearance. The manner in which these individuals responded to the difficulties they came across due to their facial appearance and jaw function suggested that they may have adopted different coping strategies. Although at this stage of the presentation of results it remains unclear the degree to which positive coping mechanisms have been used, one element that appeared to be common throughout the interviews was the role of family and friends. The support Marie, Lisa and Sandra received from family and friends helped them both before entering into the active treatment pathway and also during the days post-surgery. Therefore, in this early stage of the results we can see that social support appears to play a positive role in helping patients cope with orthognathic treatment.

Lastly and most importantly, one common finding in the three vignettes was the expectation of Marie, Lisa and Sandra to 'be normal' as a result of orthognathic surgery. These individuals had used the word 'normal' in terms of facial appearance, ability to chew and bite and also simply in 'feeling normal'. It was also evident that these individuals spoke about 'being normal' in comparison with the vast majority of the others in their narratives who were presented as already 'normal'.

From the analysis so far, we can see that there are many factors that influence a patient's orthognathic treatment journey starting from their awareness of the problem until the change is completed. These factors include whether or not treatment is resolved according to the patients expectations. As identified from the vignettes, there were many more problems in the journeys these patients underwent. These will be discussed in the following sections in a sequential manner using the support of more data from the research. The sequence of events in the orthognathic journey as indicated by the data suggested that orthognathic treatment was not a single event but a process or a phase of life that an individual passed through. With this understanding, we can move on the next section where the GT will be introduced and the core category of the GT described.

As this is a GT study, the results of the study will be presented and placed along with the current knowledge of each of the relevant substantive areas under consideration. The following sections therefore present detailed results along with an integrated discussion. This chapter will however be followed by a more general discussion to place the theory in overall context.

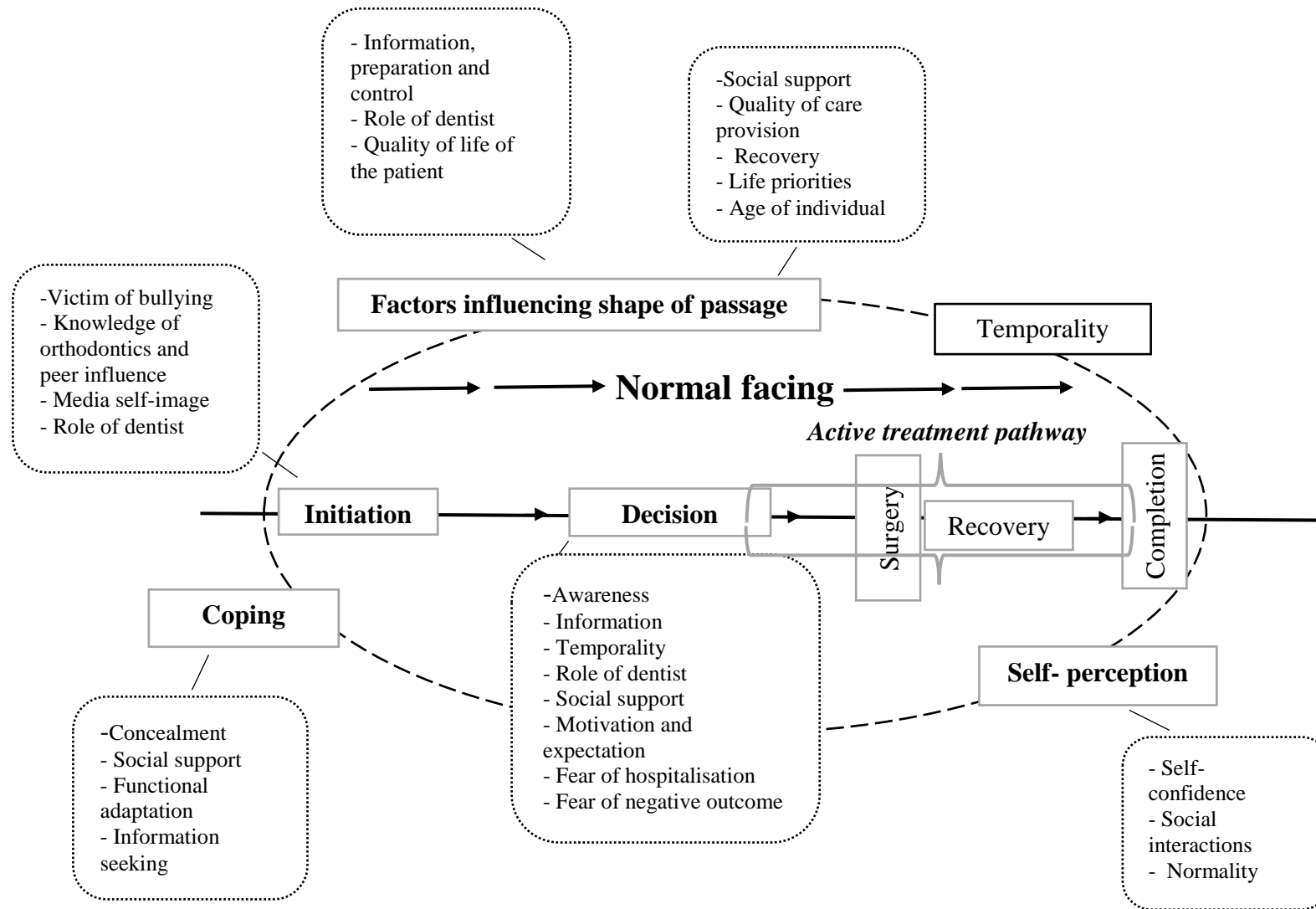
4.2. Introduction to the GT

In the methodology chapter (Chapter Four) it was explained how GT is generated by identifying categories within the data and eventually establishing the core category (Corbin and Strauss, 1990). The categories that go to make a GT are theoretical representations of participant's actions that are, in turn, aimed at resolving the main concern of the participants in a particular substantive area. The most central category in GT analysis is called the core category and is central because it helps to organise the rest of the theory. It is also central because all of the other categories have some relationship with the core category and with each other (Gibson and Hartman, 2014). This is the nature of GT, which generates dense theory that is integrated rather than a set of loosely associated themes.

This study identified the core concern of patients who underwent orthognathic surgery to be their need to fit in to society. Prior to the surgery, these individuals felt that either their appearance or ability to eat, chew or talk were different from that of others. Therefore, they sought orthognathic treatment in order to 'fix the problem' they had with their jaw structure and hence fit in better with the rest of society. In the study, the participants were found to use the words 'normal' and 'being normal' to describe their need to 'fit into' society.

This section introduces the GT through the description of the core category. Figure 12 summaries the whole theory.

Figure 12: Normal Facing theory

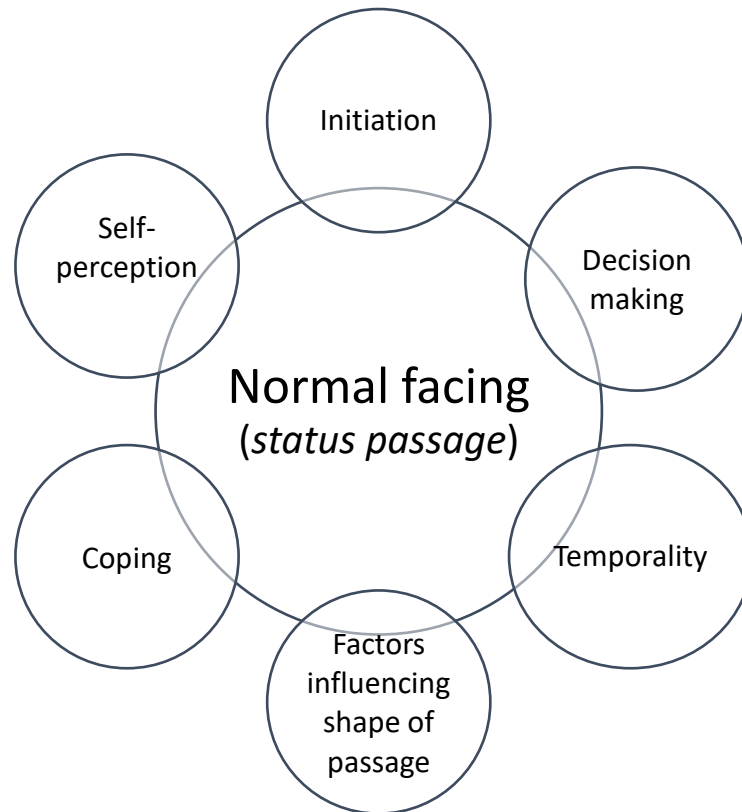


While Figure 12 is based on a timeline that should be read from left to right, it shows the various categories that influenced the core category. The categories identified in the study are written in bold along and around the time line. The other boxes indicate the milestones along the timeline. The concepts that influenced the categories are listed in the large boxes that feed into the categories. All the different categories along with their interrelationships identified in this GT will be further detailed in subsequent sections. Figure 13, shows the close association between the core category and the other categories identified in this GT.

What is happening to a patient who undergoes orthognathic treatment? This GT discovered that normal facing is what happens to the patient who undergoes orthognathic treatment. This core category explains how the main concerns of orthognathic patients were continually resolved through their interactions with friends, family and dental care. It was also discovered that normal facing is a type of status passage - a formal theory within the substantive area of orthognathics.

Through the vignettes we have seen that the experiences of individuals who undergo orthognathic treatment can be mapped onto a timeline. This suggests that the orthognathic journey was a phase of their life, which had a certain beginning and an end. Patients passed through this phase to attain a change in their facial appearance, to bite better, speak more clearly and to be free from pain. Social scientists, Glaser and Strauss, called this type of passage from one phase in life to another as a status passage (Glaser and Strauss, 1971). For example, a change of status from being single to being married, being a student to a graduate, becoming a mother etc. Similarly, a status change occurred in the participants of this study. However, to attain complete understanding of the nature of the status passage that occurred by undergoing orthognathic treatment, it is key to identify what is the change that occurred through orthognathic treatment. Status passage and its discovery in orthognathic treatment will be detailed further in subsequent sections in this chapter.

Figure 13: Normal facing core category and categories



4.3. Normal Facing

The data obtained in the study revealed the desire of the individuals in the orthognathic pathway to be less excluded from others and obtain a sense of normality. Below are a few quotes from the study that exemplify the various ways in which normality was discussed by participants in the study:

“I don’t think I have ever eaten in a normal way. I have never just bite an apple or bit a sandwich. I eat anything like this (action to back of teeth)... or I chop it up and then eat it. I have never, I suppose in my opinion eaten in a normal way. I can never pick something up and bite it. And I suppose it has always been like that. And I don’t know if it’s just a genetic thing and that’s the way my jaw have always been but it’s got more noticeable ...” (Mia, 28 year old, Female)

“In the first week I didn’t want it but then I thought like it would be a lot better for me and then when I was like looking in the mirror I was

yeah I wish I could have like a normal face so I think that's what made me do it." (Jen, Female, 18 years).

"N: How do u feel now, that you are done with the surgery?

K: yeah it's fine. I just get on with everything now and just be like normal, get on with everything as normal.

N: when u say normal ... can u explain to me?

K: I just like to go out drinking and socialising with my friends and not too bad... not drinking all the time but ... like seeing my friends like majority of the times, like going on holiday and things like that.

N: was that different before you had the surgery?

K: well it's like, I didn't... I didn't have the confidence to really go out and socialise as much coz I was always covering my mouth and those things... I didn't really want to show my mouth...but... that did not work. But now that's all fine." (Interview between Author and Kenny, Male, 19 years).

In the above quotes, all three participants had very different reasons why orthognathic treatment potentially could or had brought about a change in their lives. Mia's core concern was **functional normality**, which she felt could be attained through surgical correction of her jaws. For Jen it was an **appearance related normality**, which inspired her to go through orthognathic treatment. In contrast, Kenny's concern was **psychological normality** that was to be attained through orthognathic treatment. The concept of **normality** in normal facing, then, had a physical, tangible, bodily dimension and another less visible, psychological, non-tangible dimension. While the appearance and functional ability of a person are both visible, physical and tangible, the psychological aspect of normality has much more to do with a person's own perception. However, these examples also showed that facial appearance, the ability to chew, bite, speak and feel confident were all equally important for every individual.

The concept of 'normal' was found to be subjective to an individual's perception of what is normal for them and was compared with 'others'.

“I so much wanted to be like everybody else. It was my dream really.”
(Kathy, 54 years, Female)

There are many debates about ‘what is normal’. Indeed, there are very dense and complex sociological theories, mainly centred on disability studies, about normality. However, the author would like to emphasise that within this GT the concept of normality was explored simply within the context of patient perception in relation to orthognathic treatment. It is the author’s view that any debates regarding the link of normality in the context of orthognathics and disability is beyond the scope of this study. It should form the basis of ongoing work involving a much more critical disability studies approach to GT in this context.

Visible difference, as described in the literature review, is directly related to what is normal and abnormal culturally and is visible to others (Rumsey and Harcourt, 2005). In the case of patients undergoing orthognathic treatment, the difference in jaw structure and functional concerns are both visible to ‘others’ because it is part of their facial features. Ramsay and Harcourt (2005) stated that the face is an integral part of a person’s identity. Therefore, it is understandable that patients who underwent orthognathic treatment entered the status passage to ‘normal facing’ to ensure that their face became closer to what was culturally considered ‘normal’. It is for this reason that the core category of this GT was conceptualised as ‘normal facing’.

Definition of Normal Facing: Normal facing is the clinical and psychosocial process in which an individual’s face, a major part of one’s identity, and self-perception moves closer to being what is considered as ‘normal’.

Figure 14: Normal facing

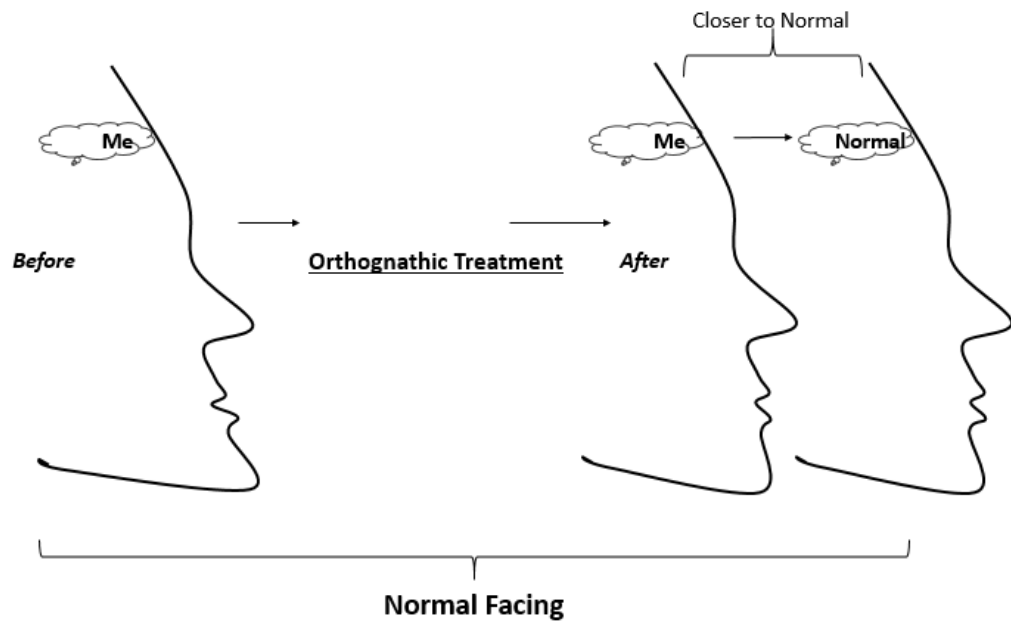


Figure 14 explains the meaning of normal facing pictorially. Starting from the left, the outline of the face shows the profile of the patient's face before and after orthognathic treatment and the far right profile is what is culturally and clinically considered a normal profile. The distance between the far left and the far right profile shows the degree of deviance from what is considered 'normal'. The degree of deviance hold good in terms of clinical measures as well as the self-perception of the patient. The thought bubble placed within the profile represents the self-perception of the patient regarding each of the respective facial profiles. Normal facing is therefore a homonym.

A homonym is a single phrase, which has two separate meanings. For example; wife beater is a homonym. Wife beater is a type of sleeveless shirt. The other meaning of wife-beater is someone who hits his wife (Source: www.dictionary.com). Similarly, normal facing can also have two different meanings.

The first meaning of normal facing is concerned with the change in the patient's facial profile. The patient's face before surgery changes through orthognathic treatment to a

new face, which is much closer to what appears as a ‘normal face’ both in clinical and cultural terms. Hence, through orthognathic treatment, patients change from the status of having a less normal facial profile to the status of having a facial profile that is closer to ‘normal’.

Clinically, Angle’s class I jaw relation was considered ‘normal’ and the facial profile was straight, unlike the convex profile for class II and concave profile for Class III jaw relations (Angle, 1899). Dental professionals use this as guidance in orthognathic treatment and strive to change the patient’s profile to a ‘normal’ profile. This clinical classification of profile was derived from the cultural or societal norms because only 5% of the population did not have a normal jaw relationship (Posnick, 2014). Therefore, culturally as well, a person with a straight facial profile was considered to have a normal facial appearance.

The second meaning of ‘normal facing’ is the patient’s perception of facing normality possibly through undergoing orthognathic treatment. However not everyone chose orthognathic surgery for normal facing and therefore normal facing was not only attained through orthognathic surgery. It was seen that the patient’s perception of themselves changed from being deviant to being normal. This was not only in terms of facial appearance but also in relation to functional abilities and psychological perception. Therefore, the experience of treatment through the active treatment pathway involved a status passage to ‘normal facing’. This second meaning of normal facing indicates that there are deeper psychosocial implications arising out of the experience.

The active treatment pathway, beginning from the patient’s entry into the hospital system - either self-referred or through professional referral - to the surgery, recovery and discharge from the hospital after clinical completion of treatment is also identified as another closely related status passage to that of normal facing. At the beginning of the pathway, he or she is simply a person who suspects that they do not have a ‘normal’ jaw structure or appearance. As they enter into the pathway, they assume the status of a patient – a patient who is undergoing orthognathic treatment. Once they have been discharged from the clinical care pathway they lose the status of being a patient and become a person who hopefully has a jaw structure closer to normal. This clinical

pathway is conceptualised here as a separate status passage embedded within the broader status passage of ‘normal facing’. The status passage through the orthognathic clinical pathway is represented and labelled as the ‘active treatment pathway’ in Figure 12. Since this GT is from the patient perspective, normal facing was identified as the more comprehensive theory encapsulating the person’s journey from initiation into the passage to completion.

In the clinical sense orthognathic treatment was completed when the patient was discharged from the hospital. However, the completion of this status passage, in the patient perspective, was dependent on their satisfaction with the completion of treatment and the time it took for patients to accept their new face as part of their self-identity. Data obtained from the semi-structured interviews revealed 100% patient satisfaction among those who had undergone surgery. However, this is certainly not the case from the analysis of blogs and online forums. For example, a 26-year-old female from Huston, USA, 3 months after surgery wrote;

“I'm so depressed. This is affecting my life so much. I cannot identify with this person I see in the mirror. I preferred my old face than this. I feel like I lost my hereditary looks as well. I used to be told I look like my mom and I don't anymore. He should have moved my upper forward only about 4mm and my lower back about 2mm. It frustrates me so much to think that I waited for this all my life, all the money I spent, the torture of braces twice, and the torture post op and to be this unhappy. [] My features just don't look normal. I preferred my face before surgery. [] I just cannot identify myself with this person I see in the mirror. I used to be told I looked like my mom and now I don't. It makes me so sad!” (Pinkyy05, Female, 26 years, online)

This example suggests that completion of the active treatment phase does not imply the completion of the status passage. Pinkyy05’s inability to relate to her new face suggested that although clinically she would have obtained a normal jaw relation, her perception of what normal was remained unmet. As we can see from this example, completion of the status passage does not always coincide with completion of active

orthognathic treatment in the hospital. The status passage towards normal facing is only completed when the person's self-perception of their changing face is closer to what they thought was 'normal' and when their new face becomes integrated into their self-identity.

"It takes a while to get used to the fact that you're different now. I remember thinking it was instant, but it wasn't. It took me a good few months after (the surgery) to get used to the fact that this is me! [] it was round about the time just before the brace came off and after they came off." (Lola, 21 years, Female)

"I would say a year to 18 months after the surgery. I looked a lot different, just getting used to it I suppose, sometimes I would see my reflection and it was hard to absorb, take a step back sometimes. My face was quite numb after the surgery as well, so getting used to feeling, getting used to moving, talking sometimes my lip moving, my jaw it was all getting used to it and so...like sometimes I would think this is how I am going to be felling for the rest of my life and I would get some more feeling back somewhere else (on the face) and then that out keep happening. Yeah but I would say a year to year and a half. To get used to recognising myself and this is how I would look for the rest of my life." (Becky, Female, 22 years)

These quotations illustrate that the completion of status passage did not correspond with completion of surgery or completion of orthodontic treatment. It was the patients' acceptance of their new face and integration of that into their self-identity that was fundamental to the completion of this status passage. The acceptance of completion of status passage occurred following the restoration of function, sensation, mouth opening, pain relief and reversal of all swelling. Once all these occur patients stopped expecting any further changes to happen to their facial appearance and dental occlusion enabling them to accept completion of status passage. (See Figure 15 which shows the difference in the appearance following orthognathic treatment)

Figure 15: Change in facial appearance following orthognathic treatment



Person before treatment



Same person after treatment

Completion of status passage occurred even in patients who were not happy with the outcome of orthognathic treatment. Some patients who were unhappy with the results of treatment attempted to proceed with a second surgery to try and obtain favourable results through repeating the process of ‘the active treatment phase’. After the second orthognathic treatment passage these patients may be happy with the outcome and complete the status passage. If they remain unhappy, a compromised acceptance of completion of the status passage is made by the patient. However, none of the patients interviewed had a bad outcome; although many such examples were obtained from the online blogs and forums.

A popular, young, female blogger about orthognathic surgery writes about the chronic pain, which was an after effect of her orthognathic treatment that was carried out 4 years ago as follows:

“Unfortunately, for thousands of people all over the world, pain is a constant and daily battle. One that you cannot often see being fought. People often make jokes about my weakness and limitations but it is a reality for me. I would love to be NORMAL. And even typing this now, my eyes are filling with tears. I feel so flawed as a human being. This article isn’t supposed to be a woe is me moment, it is supposed to help you understand what chronic pain patients go through.” (Stefanie

Grant, Female, online (<http://steffies-orthognathic-surgery.blogspot.co.uk/>).

The above quote clearly indicated the sorry state of the patient including their sense of self-doubt, self-pity and acceptance of reality. The reference to ‘being normal’ with regard to the feeling of pain was noted within her text. According to her, being normal meant being pain free in this context. However, the text also suggested that she had accepted the reality of her status, which included the chronic pain. This implied that for her the status passage was complete although the status she attained through orthognathic treatment was not what she had expected.

On the other hand, people who do not accept the reality of their status after having got an unfavourable or unexpected outcome are the ones that struggle to cope with life after treatment. First-hand data were difficult to obtain from patients who had not accepted the status they attained. However, two instances of such non-acceptance and its consequences were obtained in this study from secondary sources. An oral surgeon at the Charles Clifford Dental Hospital presented a case of one of his patients who could not accept the new face she had following orthognathic treatment for a long time after surgery. She, in the clinician’s opinion, had a perfect clinical outcome to 1 mm perfection. However, the patient kept coming back to the hospital with trouble accepting the change. Clinically, the oral surgeon said, there was nothing more that could be done for her. Finally, this patient was found to have thrown herself in front of the train with the view to ending her life. Such a drastic measure was done because she could not accept the change in facial appearance. This was an extreme example of a person for whom the status passage failed to complete by accepting the outcome of orthognathic treatment. Nevertheless, the status passage ultimately completed by ending in her death. A similar occurrence of suicide was reported about an engineering student, in India, following the completion of orthognathic treatment. These data were also obtained from secondary sources.

Lastly, completion of the status passage occurred, not only for patients who decided to go ahead with orthognathic treatment, but also for those who opted to not have orthognathic treatment. These patients either decided to do nothing and eventually accepted their facial appearance as normal or underwent orthodontics. The definition

of normal facing does not revolve around orthognathic treatment. It revolves around the person's perception of attaining normality and can happen without actually entering the active treatment pathway. However, in this study, no data were obtained first hand from people who refused orthognathic treatment to be able to describe the exact process of the status passage leading to completion. The theory therefore could be subject to further modification (Glaser, 1978).

In Figure 13 the theory of normal facing was shown to be influenced by the categories such as awareness, decision making, temporality, factors influencing the shape of the passage which included controlling agents, coping and self-perception. The figure represents the relationship between all the categories and the core category. The initial awareness of the patient about their concerns influenced the initiation into normal facing status passage. Decision-making was a key milestone that entered the patient into the active treatment phase leading to normal facing. The experiences of the patient or the shape of the passage of normal facing was determined by the various controlling agents and the balance of control maintained between the patient and the dental professionals. Temporality was shown to play a continuous role in normal facing. Patients' coping behaviour influenced the status passage leading to acceptance, which was also influenced by the patients' self-perception. These categories will be detailed further in subsequent sections.

One other way of representing normal facing is as a linear process or a timeline centring the significant event of the status passage - which is orthognathic surgery. See Figure 16.

Figure 16: Normal Facing theory in linear representation

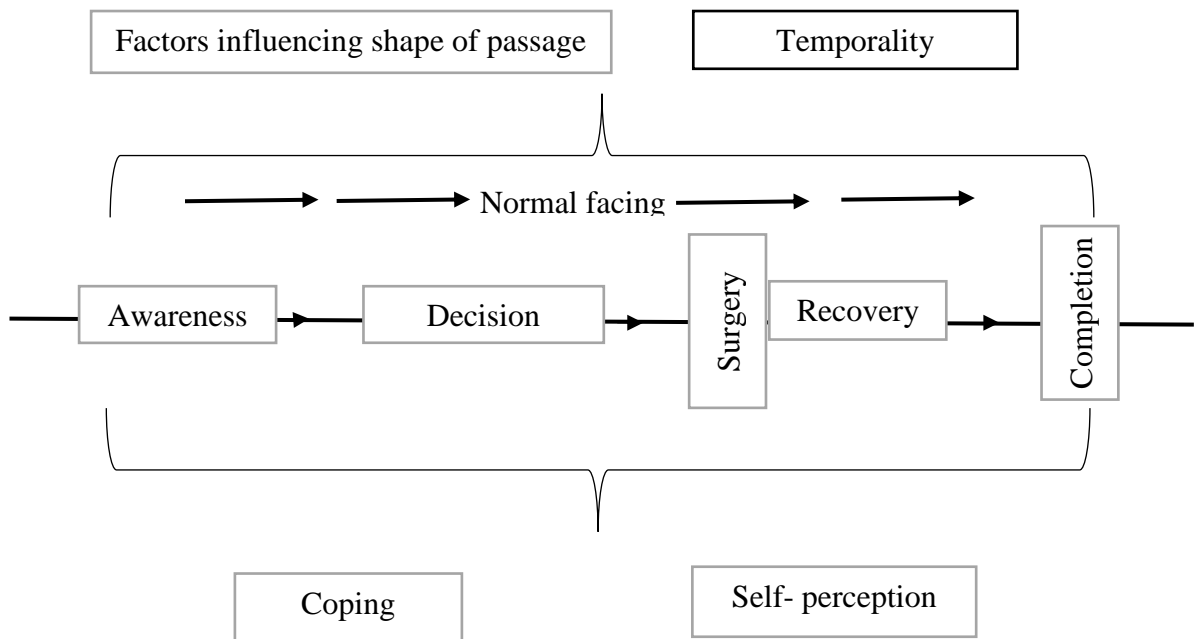


Figure 16 is the linear representation of the theory ‘normal facing’. The solid line is the time line of the patient’s orthognathic passage. The first point of entry into the passage occurs at the stage of awareness. As time proceeds, patients reach the stage of decision making for orthognathic surgery. Once the decision to have the surgery is made, the patient starts active orthognathic treatment and has surgery on a set day. This day was usually referred to as Day 0 in most blogs written by patients signifying the importance of the next day - Day 1 as a new beginning for these patients in some ways. For example see blog: <https://roxsjawsurgery.wordpress.com/2013/03/05/day-1-measure-twice-cut-once-2/>

Immediately following the surgery begins the phase of recovery. The period of recovery varies from patient to patient on the time line. Nonetheless, the passage attains completion by the patient’s acceptance of having completed the passage.

All along this passage, factors such as patient’s coping behaviour and self-perception during each stage hugely influences the status passage. These are examples of two patient-related internal factors that can be seen to influence normal facing. The status

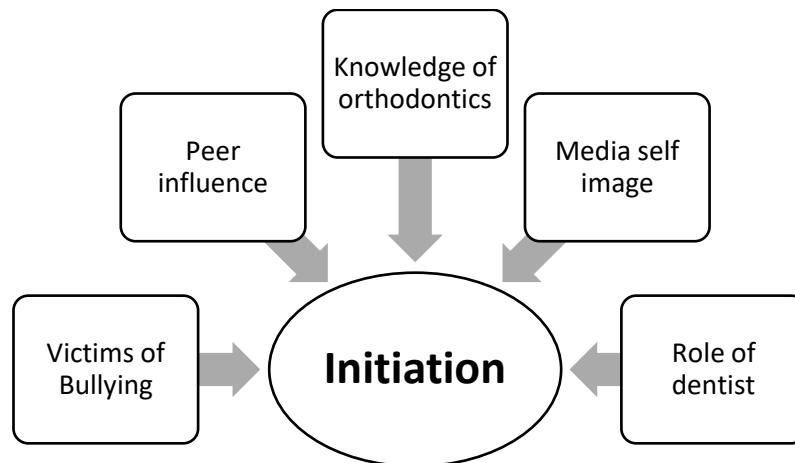
passage – normal facing, attains completion when the patient accepts their new face and integrates it to their identity. It also marks their perceived integration into what they perceive as ‘normal’ within their social context. Therefore, this linear diagram summarises the GT developed in this study. As mentioned earlier, all the categories will be discussed in detail in the subsequent sections based on this linear representation of the theory.

4.4. Initiation into normal facing

In the vignettes, we presented how all three individuals described their experiences in a chronological order and their experiences were all mapped on a timeline. On these timelines, the actual period in which they were having active orthognathic treatment was marked using a rectangular box. However, when they spoke their reflections were not limited to the active treatment phase. When detailing their experience of the orthognathic journey, most patients started their account from the time when they first realised about the problem with their jaw structure. This indicated that from the patient’s perspective their journey through orthognathic treatment initiated well before the active phase of treatment at the hospital usually from the time when they were first made aware of their problem. Therefore, the initiation of the normal facing was found to occur at a different time point from the beginning of the active orthognathic treatment.

This category of initiation was found to have a single dimension – awareness. A person’s awareness of the problem was found to be the first step into the initiation of the orthognathic journey. However, this awareness, arguably, was what Glaser and Strauss (1996) called suspicion awareness. Suspicion awareness, they said, was a situation where the patients suspected what others knew and therefore attempted to confirm or invalidate his/ her suspicion (Glaser and Strauss, 1966, p. 11). This suspicion was later transformed to open awareness and patients were inducted into the status passage. During this phase of the patients’ orthognathic treatment journey, they were made aware of structural issues concerning their jaws through various means. These means of awareness leading to initiation were identified as the sub categories in this category. The sub categories are as shown in Figure 17

Figure 17: Factors influencing initiation



Awareness played a role all along the course of the patient’s experience of orthognathic treatment. However, considering the active treatment phase, at different stages of the treatment, patient’s awareness was about different aspects involved depending on the phase of the treatment they were in. For example:

“I think I just, I knew I'd regret it if I didn't so it was quite an easy decision for me to make, I wasn't worried about it hurting because I knew it would only hurt for a short period of time, so once the, my dentist had sort of suggested it I decided then and there and she sent it though and, so it wasn't something I thought about and had to go away and weigh up, I just jumped on it.” (Emma, 26 years, Female)

Emma was well aware about what to expect during the course of treatment and this awareness came in handy for her during the decision making phase. Awareness played a role in decision-making and details of this are discussed in Section 4.5.1.

“I knew that it would take time, it's all been explained really well from the beginning so I knew it would take years... and lots and lots of appointments and . Umm...[] so yeah it's taken 3 and a half years or so but I knew it would take a while.... So I was prepared.” (Suzie, 38 years, Female).

Similarly, Suzie was also well aware of the length of the treatment when she commenced treatment and was prepared to accept what was going on. Suzie’s awareness of the recovery period made her more prepared for the process. The awareness of their current stage, within their orthognathic experience, was constantly

present beginning at the initiation phase and ultimately terminating in their awareness and acceptance of completion of change.

4.4.1. Victims of bullying and the initiation into normal facing

The majority of the patients who were interviewed in this study were victims of bullying during the early years of their life because of a visible difference caused by their jaw structure. Current literature also shows that orthognathic patients were victims of bullying in the past (Alanko et al., 2014). Bullying included being teased and name-calling. Through these early childhood experiences of being victims of bullying, these young individuals were made aware of themselves being ‘deviant’ in some way and hence being inducted into normal facing.

“I think because my jaw, I was bullied quite a lot at school and part of it was around the appearance of my teeth...” (Emma, 26 years, Female)

“Commonly I was called ‘goofy’ umm...and I suppose that used to hurt” (Marie, Female, 66 years)

“It were like ... you know like saying ‘goofy’ and like teeth stick out and things like that” (Kenny, 17 years, Male)

“I was bullied in primary school, probably after the accident, probably about 6 or 7 years old, so I was bullied from then right up until I left high school... throughout that period for the way that my jaw looked and the way that my teeth were at the time. [] specifically name calling, umm about my appearance I used to be called ‘beaver’ quite a lot because my teeth used to stick out quite badly that was the main one.” (Mia, Female, 28 years).

Name-calling was mainly through the use of words like goofy, bugs’ bunny, beaver etc. It was most common during school years. However, patients were still emotional when speaking about these early experiences even years after their occurrence.

“Umm you get bullied a lot if you look different ... it stays with you... (cries)”(Lola, 21 years, Female)

This indicated the lasting scars such childhood experiences left on these individuals. Many of the participants in the study stated that they had poor self –confidence because of the past bullying experiences. This effect of bullying on the person’s self-confidence is detailed further in later sections.

Nevertheless, similar findings have been reported in past studies about stigma and facial visible differences. For example, Masnari et al. (2012) reported that a majority of individuals with facial visible difference experienced various forms of stigma and one quarter of these individuals were teased about their facial appearance. Similarly, Strauss et al. (2007) also reported that majority of people with facial visible difference experienced stigma in various forms. Concurrently, studies among orthognathic patients have also reported high incidence of bullying prior to treatment (Alanko, 2010, Williams et al., 2005, Zhou et al., 2002, Zhou et al., 2001).

4.4.2. Peer influence, knowledge of orthodontics and the initiation into normal facing

Friends and peer groups of young individuals played a major role in their lives (Eccles, 1999). This is perhaps unsurprising considering the amount of time they spend together. The influence of peers in the initiation of normal facing was either directly by a friend pointing out there was something wrong with their jaw structure or, indirectly when the individual themselves compared their teeth and jaws with that of their friends. For example:

“It was pointed out by a friend like took you know like took a micky sometimes it were like... in a joke way but u could tell that there was something wrong with your teeth” (Kenny, 17 years, Male)

Often, children went through orthodontics during their adolescence in order to ‘fix crooked teeth’. From the analysis of the interview data, it appeared that most young adults accepted orthodontics as a relatively common and straight forward solution for treating appearance related problems with their teeth. They also saw that many of their peers had their crooked teeth straightened and the appearance of their teeth improved through orthodontic treatment.

“It was something I expected because a lot of teenagers have orthodontic work anyway and I wanted straighter teeth anyway” (Millie, 17 years, Female).

“I wanted braces, because a lot of my friends had them and they had perfectly straight teeth. And I thought that will correct my overbite” (Roz, 23years, Female)

While some of the young people thought it was orthodontics alone that they needed, some others noticed more problems with their jaw by themselves. The degree and severity of the skeletal discrepancies vary from individual to individual and therefore the degree to which friends and peers influence the process will also vary.

“I would have been about 13 or 14 so early 2000s. I think I had braces for about 3 years that time as well. I think I had fixed and then I had removable one as well. I also had the head gear with the metal outside and it all came out side and all hooked on. , I was really happy with the way it looked and then over time because it had not been followed up correctly, it obviously just regressed back to where it was, and that was quite upsetting.” (Mia, 28 years, Female).

It was also found that many of these patients had had orthodontics once in the past, which did not give the desired results and so they eventually decided to go through orthognathic treatment. The failure of the first round of orthodontic treatment, possibly due to any unfavourable growth after completion of orthodontics, was found to act as a driver into the orthognathic treatment.

4.4.3. Media self-image and the initiation into normal facing

In this study, photographs were found to be a major influence on patient’s perception of their facial appearance. Patients very often said that they avoided being photographed and hated seeing themselves in any photographs in the past. For some people it was one such photograph that made them aware of their jaw related problem.

“And then a few years ago I went for passport photo, the first one I had done, and they said could you umm make sure your lips are closed and I couldn’t close them over my teeth. Which upset me. So I went

back to my dentist and said I had noticed this...” (Mia, 28 years, Female).

There was no mention of videography impacting on their awareness. However, looking into ones image in the mirror was cited as being traumatic for some:

“I can remember going into changing rooms to try on bikinis and there were mirrors all over the wall and I looked and when most women are looking at their bodies and conscious about how their bodies look, I just looked at my face and it like reflected it so I could see it from the side and I just bust out crying because I thought I looked awful”. (Ester, 20 years, Female).

Although, in the above example, awareness was triggered from the information given to the patient from a dental professional.

4.4.4. The role of dentists and the initiation into normal facing

The dentists, usually the patient’s general dental practitioner, was found to play a role in confirming the suspicion awareness into complete awareness about the underlying skeletal discrepancies of the jaws. However, a final diagnosis was typically made by the orthodontist to whom the dentist referred these patients. By this phase in the orthognathic journey, patients were well aware of their jaw related concerns.

In some instances, it was found that patients’ awareness was shaped directly by their dentist without any suspicious awareness phase. For example:

“I guess it was my normal dentist who said you should think about orthodontic work” (Millie, 17 years, Female).

Patients often were aware that their teeth needed straightening and expected to have orthodontic treatment, which would fix their teeth in a few years. However, it was the dentists or the orthodontists who made them aware for the first time that they need surgery along with orthodontics.

“No.. no when they mentioned that the jaw was out and that I needed some form of surgery that was when I noticed it. [...] They said something about the bite which was a bit daunting because I was there

thinking of having a brace, may be have it for two years. But surgery...” (April, 19 years, Female)

The dentist or the orthodontist played a crucial role in inducting the patient into the active treatment pathway. It is, therefore, important how the dentist and orthodontists introduce the patient to the need for orthognathic treatment. This is because of two reasons as seen in the above quote. Firstly, surgery was a scary thought for most people, especially young adults who formed the majority of people who underwent orthognathic treatment. Secondly, patients who were unaware of the severity of their skeletal discrepancies were sometimes made aware of it by their dentist. In this situation, when something about their face was being pointed out to them, it was found to impact greatly:

“My orthodontist was off sick and it was a locum orthodontist that pointed it out and she didn’t do it very nice, and she just bluntly said your lower jaw is further back than your top jaw and that was it, and then she said you’ll probably have to have surgery and that was it. I didn’t know until then. So I went home and I was looking in all the mirrors and I was thinking oh my gosh I look awful from the side and I just got really self-conscious about it.” (Ester, 20 years, Female)

The findings of the study clearly indicated that dental professionals played a major role in making patients aware of the physical status of their jaw. Along with that came a large responsibility for the dental professionals in ensuring that the information was smoothly passed on to the patients. Following the development of a complete awareness context came the next milestone, which was the decision to proceed with orthognathic treatment. Decision making about orthognathic treatment was another category that was identified in this GT study and the section below will discuss this in detail.

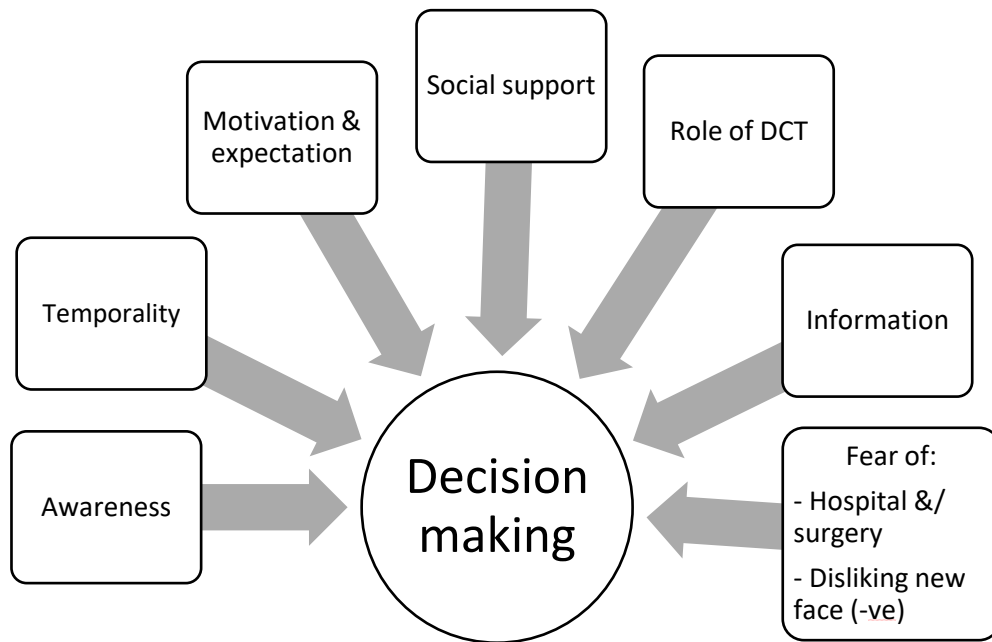
4.5. Decision making and the active treatment pathway of normal facing

In the previous section, we have seen that patients had a suspicion awareness about their jaw related issues that later became an open awareness by the intervention of

their general dentist, who referred them to an orthodontist. The orthodontist identified the need for orthognathic treatment and directed the patients to the surgery. However, an oral and maxillofacial surgeon was also involved in discussing the possibility of orthognathic treatment with the patient. A combined assessment of the patient by the orthodontist and the oral and maxillofacial surgeon was carried out. Once the orthodontist and oral and maxillofacial surgeon had come to an understanding that orthognathic treatment was the best treatment option for the patient, the patient was informed and was given the opportunity to decide if he/she wanted to proceed with the treatment.

The decision making process for orthognathic surgery was identified as an important category that played a major role in the patient's experience of orthognathic treatment. The importance of the decision making process was made clear during the semi-structured interviews for this study when patients one or two years post-surgery also reflected upon their decision making. This was often done with a view to reflecting upon the appropriateness of their decision to undergo orthognathic treatment. However, decision making for orthognathic treatment was a complex process like any other decision making process (Wang and Ruhe, 2007). Data from this study showed that the decision making process for orthognathic treatment was influenced by various factors (See Figure 18), which were identified as sub categories of this category – decision making. They are each discussed in detail in the subsequent part of this section.

Figure 18: Factors influencing decision-making



4.5.1. Awareness and decision making in normal facing

Being a GT, as stated earlier, the categories are interrelated and subcategories overlap with each other. Therefore this subcategory – awareness - is directly related to the previous category but bears a slightly different meaning within the context of decision making. Here, the concept of awareness deals with two aspects, namely (i) patient’s awareness of their jaw related concerns and (ii) patient’s awareness of their treatment options including orthognathic surgery.

The decision making process was directly influenced by the context of patient’s awareness of their jaw related concerns. Although the means by which the patient was made aware of the problem did not hugely impact on decision making, the psychosocial impact of that awareness on them influenced the patient’s decision making process. For example, patients who were hugely influenced by name calling, teasing and bullying were found to readily make a decision to undergo orthognathic treatment without much indecisiveness.

“Right it was pointed out to me by a friend who like taking a mickey sometimes at me... it was in a joke way but you could tell that there was something wrong with your teeth. So I did [orthognathic surgery] it for myself, like to do the operation and sort it out!Yeah yeah the teasing triggered the decision probably. If it wouldn’t I would have

had it myself. I would have known it a bit later that I need straighter teeth and get better looking” (Kenny, 18 years, Male)

“Obviously I looked very different, I was bullied a lot as a child for the way it looked umm so I have always been aware of it.” (Mia, 28 years, Female)

Then again, patients who were influenced by bullying did not always actively seek orthognathic treatment for many reasons. They were found to prioritise their life events over orthognathic treatment at times. For example, Marie was very much bothered by the childhood teasing and bullying as we saw in Vignette 1. However, she did not seek orthognathic treatment until she retired from her job as a nurse although she was aware of orthognathic surgery as a treatment option for her concerns about the appearance of her jaws. This was clearly because her priority for her professional life was more than her appearance concerns. Yet her concern about her facial appearance was large enough for her to have sought orthognathic treatment at the age of 66 years. This concept of a patient’s life priorities will be discussed further in subsequent sections.

Among the various agencies that lead to awareness and initiation into normal facing, no difference was found on how various agencies influenced the decision making process. Most patients highlighted bullying and teasing since it left a lasting scar on their emotional status as described in the previous section.

Patient’s awareness of the options available to them for dealing with their concerns with their jaw structure also influenced their decision making process. As discussed in Chapter Two, three treatment options were usually made available to patients during the decision making process, namely orthodontic treatment alone, combined orthodontic and orthognathic treatment, and other treatments such as growth modification (Benyahia et al., 2011, Fabre et al., 2010, Broder et al., 2000). From the interviews in this study, it was evident that patients were also given the option to do nothing.

“I found it quite umm clear... umm everything was umm well explained , it was very clear what my choices were and it was left to me to make that decision”(April,19 years, Female)

Most often all these options were made available to all patients who were referred to the hospital for orthognathic treatment consultation. However, some patients were aware of their options even before they were referred. This was often the case with patients who were mature adults. For example Marie was made aware of the option of orthognathic treatment during her 30's when she attended a lecture by an oral and maxillofacial surgeon. This was 30 years before she was referred to the hospital for treatment. In some other cases, patients become aware of the option to have orthognathic treatment for concerns they have and then actively seek an agent (a dental professional) who can induct them into the treatment pathway or sought advice for finding insurance funding for the treatment.

Hi, I am looking for reputable maxillo surgeons within England. I need double jaw surgery due to my overbite. The NHS I feel are messing me about so I have decided to look privately. Grateful for anybody who could give me names of surgeons they have had surgery with or know of through reputation. (silo2015, 29 years, Male, online: <https://www.realself.com/review/orthognathic-surgery-29-year-male-overbite-england>)

During the decision-making process patient's awareness of the alternative options also greatly influenced their decision-making. All the participants in this study were aware that doing nothing about their concerns was also a possible option. All the possible options were given to the patients during their early visits to the hospital to consult the orthodontist and the oral and maxillofacial surgeon. Awareness about all the treatment options was an essential part of informed decision-making (General Dental Council, 2009). Understandably, patient's awareness of the treatment options was gained from the information provided to the patients by the dental professionals. Information provided to patients is another sub category that will be detailed in the next section on decision-making.

4.5.2. Information available for decision making

Information made available to patients who are considering undergoing orthognathic surgery was found to play a vital role in the decision making process. This sub category, as seen previously, has a close relationship with the patient's own awareness about the need for orthognathic treatment. However, this sub category represents the

knowledge the patient acquires pertaining to the various options available to treat their dentofacial concerns. Patients obtain information regarding treatment options by the dental professionals, often without coercion, and from various other sources. The information the patient had about their treatment options was found to play a pivotal role in the decision-making process.

In a blog titled 'Deciding against orthognathic surgery' it was found that the lack of information provided to the patients by their orthodontists and oral surgeons was a key reason for patient's decision against surgery. A 33-year-old female who wrote that she was coercively referred for orthognathic surgery (despite only wanting to ensure that her teeth would remain healthy in the long run despite her bite related issues) wrote:

"I guess I was expecting more comprehensive support throughout this process. So far it seems like I have to ask all the questions, and that no information is volunteered or presented in any way other than verbally. I'm such a novice in this process, and it's been exhausting to ask question after question and have to dig for information. My mind set alone has shifted on several points since getting serious about braces just over a month ago." (Gabriella36, 33years, Female, online: <http://www.archwired.com/phpbb2/viewtopic.php?t=48706>)

On the other hand, patients who received information with clarity and no perceived coercion where found to benefit more in the decision making process:

"I found it quite clear, everything was umm well explained, it was very clear what my choices were umm and it was left to me to make that decision coz obviously it's me that has to go, had to go through the treatment. Umm I didn't feel like there was any pressure to do or anything that I didn't want to do. [] Well everything was dealt with really well. Everyone I spoke to were very clear, yeah I think I found that (decision making) process the simpler part as it were." (Mia, 28 years, Female)

Some patients received too much information and found this intimidating by what was involved in the surgery. Speaking about the information made available on information leaflets at the hospital one of the participants in the study in his decision making phase said:

“I think it is good idea, it outlines a lot of the key things, but I think it can also be... for someone who doesn't need extensive surgeries it could be slightly intimidating as well. I was... I think I was okay with it, but I was slightly intimidated by the materials on there, some of the possible surgeries more the major ones which they were showing which I am not quite sure where mine would range on the spectrum of ...” (Will, 21 years, Male).

“I felt the less I knew about things the better.... Because I think if you overload yourself with information you are always gonna talk yourself out of it.” (Lola, 21 years, Female)

This implied that there needs to be a right balance of how much information is provided to patients about treatment during the decision making phase. It also indicates that inappropriate information can be obtained as well. Patients were found to often obtain information not only from the health care professionals but also from various other internet sources (Aldairy et al., 2012). Therefore, it would not be realistically possible to control the amount of information available to the patients regarding orthognathic treatment. But, as Aldairy and colleagues (2012) concluded, patients could find accurate information on appropriate websites if they were directed to those websites by key professionals.

Provision of alternative treatment options was also found to be an important aspect of informed decision-making process. All the participants in the semi-structured interviews in the study stated that they were well informed about their alternative options including no treatment as an option as well. This finding was in line with current literature which identifies the need for providing patients with all available treatment options to aid in decision making (Flett et al., 2014). While this study found that most participants in the semi-structured interviews made a well informed decision about orthognathic treatment, one past study in the UK about decision making in orthognathic treatment concluded otherwise (Stirling et al., 2007).

Various information aids were used by dental professionals in the current study to provide patients with information about treatment. Patients were given information leaflets (British Orthodontic society patient Information leaflet on orthognathic surgery), a DVD by the British orthodontic society on orthognathic surgery and they

were directed to online information about orthognathic surgery including blogs and support forms. Apart from this, patients were told what to expect by the orthodontists and the oral and maxillofacial surgeons treating them. Some patients were also given the opportunity to meet other patients who have had surgery in the hospital in the recent past.

Among the different sources of information, the dental team was the most trusted. While most patients thought that all the information aids were helpful, it was the leaflets that were found to be less useful than other sources. About the DVD, while many patients found it very useful, younger patients said that the age of the people filmed was not something they could relate to since they were much older. Therefore, the information provided to the patients was found to be useful for them only if it was relevant to their own need. Some patients did not watch the DVD because they did not want to pay and rent it.

Most of the younger patients were self-motivated to seek more information online. While others were happy with the information they obtained from the hospital. The online blogs were found to be of good use to many patients when deciding about orthognathic treatment. On these blogs and forums people shared their experiences and asked questions of each other which helped them decide about the treatment and gain information about what to expect in each stage of the treatment. These blogs and forums provided a wide choice of varied information from which, each individual could choose the most appropriate for them, unlike what the DVD offered. Reading blogs was also found to make people change their mind and decide to go ahead and have surgery.

“Do I think getting this surgery done could make me happier, yes, do I think going through with it for what might be minor issues is worth all the craziness it entails, I’m not sure. Your blog helped open my eyes to what one goes through with this surgery and it is for that reason that I posted this long message seeking your input on what u would do, knowing what you know from going through it, if you were me? I know it’s my decision ultimately, just feel at this point, hearing from someone whose been there, done that, would be insanely

helpful.” (Stacey, 30 years, Female, online: <https://roxsjawsurgery.wordpress.com/decision/>)

The most preferred source of information was first-hand information from a person who had had orthognathic treatment in the past for a concern that was similar to theirs.

“I think it’s one of the most useful things being able to talk to people who have gone through it. I think that was what I found most useful. I had one of my friends who had had the surgery, I spoke to her and also I spoke to a lot of people through the blog I wrote online.” (Roxy, 22 years, Female)

A past study has recognised the need for effective decision aids for patients deciding about orthognathic treatment (Flett et al., 2014). Other studies have pointed out the importance of the information provided to the patients in helping with decision making for orthognathic treatment (Stirling et al., 2007, Broder et al., 2000, Cunningham et al., 1996a). However, this study, for the first time, has been able to throw some light on patient preferences about the type of information that aids in decision making in orthognathic surgery.

4.5.3. Temporality

Temporality was another concept found to influence decision making of the patients. The concept of temporality deals with the three aspects; (i) time at which orthognathic treatment had been offered to the patient in relation to their life events (ii) time given for decision making and (iii) time taken for the completion of the treatment itself.

In the previous section on awareness, it was noted that patients defer orthognathic treatment in order to make time for other life priorities. Time at which orthognathic treatment is offered to the patient in relation to other important life events played a major role in a patient’s decision about orthognathic treatment. For example, many of the patients undergoing orthognathic surgery were young adults doing their A levels or entering university and they preferred to defer orthognathic treatment such that it would not interfere with their education and careers. Priorities for people vary at different stages of life and having orthognathic treatment was one among the many priorities they had. Family and work commitments were the other key life priorities identified in this study which outweighed orthognathic treatment.

“I think it was ... I had my children and I think there was quite a bit of pain side of it (laughs) got used to the pain side of it, not thinking of any more children now so sorting myself out ...in a way.” (Suzie, Female 38 years).

When there were many other priorities in a person’s life, they were found to struggle in making a decision about orthognathic surgery. This was seen in Sandra’s experience as illustrated in Vignette 3 where she said it was a bad timing with her career just taking off and she wished the treatment was offered to her when she was younger and in university. Prioritising other life events or other status passages before normal facing is what was done by Sandra. This sort of behaviour was also reported in another study about complete tooth loss (Gibson et al., 2016) and in their investigation of the rank order of tooth loss as a status passage among other passages, it was found that in the olden times other passages such as marriage was scheduled after complete tooth loss. Unlike, this rank order, in the current study for some older patients, normal facing had a lower rank as compared to other passages such as career, marriage, education etc.

The second aspect of temporality was the time given for decision making itself. All the participants in the interviews reported that they were given enough time to think and make a decision to undergo orthognathic treatment. However, some patients stated that the time gap between the appointments were a bit too long and so more time than needed which, in turn, delayed starting the treatment and completing it.

“I think having time to make a decision is good. However the time that lapses between the appointments , that time can be quite long , like from now it’s gonna be 2-3 months before I can get other appointments then to make decision . Been 8 months since I had my last one to make this one. So it’s been quite a long time to get the next appointment that’s more to do with the surgery being booked up.” (Will, 21 years, Male)

The final aspect of temporality in decision-making was the patient’s understanding of the time taken for completion of the treatment. Orthognathic treatment takes 18-24 months (excluding time taken for use of retention appliances) of active clinical treatment time until discharge (The Royal College of Surgeons of England, 2013). In

this study, it was found that most patients knew that the treatment would take two to three years for completion. This knowledge nudged them to weigh their decision to have the surgery against any possible other important life priorities within that time scale.

“I think my difficulties in making the decision were really the extent of the treatment needed, the length of time taken and the impact it had on my life especially since I have only couple of years left in university and then treatment would still be ongoing when I am trying to find a job on the graduate scheme and into obviously that process.” (Will, 21 years, Male).

Therefore, time- i.e., time when treatment was offered, time given for decision making and patient’s understanding of the time taken for completion of treatment - were all found to have a major influence on the decision making process. There have been no previous studies that have looked into all these aspects of temporality in relation to decision making in orthognathic treatment. Past studies, such as Garvill et al. (1992), concluded that a long time of 4 years was given to the patients in their study to decide about orthognathic treatment. Further a UK based study by Garg et al. (2010) provided nation benchmarks for the time taken for osteotomies, for the orthognathic surgery itself and the number of days of hospital stay following surgery. The authors did not, however, consider the length of orthognathic treatment as a whole. The findings of this study suggested that a clear understanding of the temporality of orthognathic treatment would benefit patients during their decision making process.

4.5.4. Motivation and expectations

Most patients who underwent orthognathic treatment were internally motivated. This had a direct relationship with decision making and who was involved in decision making. All the participants in the semi-structured interviews stated that it was ultimately their own decision to undergo the surgery. This decision was made as a result of internal motivations to improve their appearance or functional abilities. It was not possible to exclude any external influence on the patients’ motivation for orthognathic treatment.

Many patients made reference to ‘being normal’ when they were asked what did they expect from the surgery.

“Umm.. just to look normal. To... have a normal smile and a nice smile... a normal chin, a normal bottom jaw. [] normal as anyone.”(Marie, 66 years, Female)

This clearly suggested an external influence on the motivation of the patient because they were evidence of patient’s comparison of oneself with others who were considered normal within society. Therefore, the type of motivation orthognathic patients have when entering treatment appears to be a mix of strong internal motivation marginally influenced by what was considered, by them, to be societal norms.

Expectations from the surgery were found to be a mixture of functional correction, appearance changes and psychological improvements.

“Leading up to the surgery I was still having speech difficulties, I could speak clearly, annunciating was a problem, I was seeing a speech therapist so I was expecting that would improve. Confidence was the main one really, I just didn’t...I would shy away from myself and just didn’t want to draw attention to myself.” (Becky, 22 years, Female)

From the semi-structured interviews in this study, it was found that appearance concerns were the major reason why patients wanted orthognathic treatment. This was congruent to some of the studies in the past (Sadek and Salem, 2007, Finlay et al., 1995, Shalhoub, 1994, Kiyak et al., 1986, Bell et al., 1985, Proothi et al., 2010) and opposed other studies which stated functional concerns were the most common reason (Proothi et al., 2010, Wong et al., 2002, Garvill et al., 1992, Forssell et al., 1998). Here, psychosocial and functional concerns were equally found to be a reason for opting for orthognathic treatment.

4.5.5. Social support

Social support was a sub category that influenced decision making in two different ways. Firstly, support from family and friends – social support - influenced the patient’s decision to have or not to have surgery. Secondly, support available from friends and family to help with other social roles such as caretaker of a young one influenced the decision about timing of the surgery.

It was found that most often patients themselves were the main decision makers about undergoing orthognathic surgery. However, patients tended to consult with their family and friends for their opinion before finalising the decision regarding the surgery. Many patients stated that it was an important life changing decision and wanted the support and understanding from their nearest and dearest ones regarding their decision.

“Deciding to go through with the treatment (braces, surgery, etc.) is a major decision to make. Not just financially, but emotionally. Surgery can change our appearance and improve the quality of our lives. It comes with the possibility of risks & rewards. It's a big decision and we want support and understanding. [] When it comes down to it we want everyone in our lives to be 100% supportive of what we are going through. Thankfully most of the people in my life are, but there are those that doubt the necessity of the surgery.”
(KaylaChristine, Female,

online: <http://www.archwired.com/phpbb2/viewtopic.php?t=48459>)

It was observed that the information leaflets given to patients also stated that there was a need for support from family and friends especially during the post-surgery recovery period. Knowledge of this need for support following surgery also influenced patients' decision-making based on their available provision for support.

The availability of support for carrying out the patient's roles of responsibility also influenced the decision regarding the patient's thoughts on appropriate time to undergo surgery. Young patients undergoing orthognathic treatment usually had a social role as a student and support was needed from the dental care team to time the surgery during term breaks or summer holidays and avoid periods of school examinations. Young working patients required the surgeries to be timed around their provision for leave of absence from work. On the other hand, patients who had a social role as a caretaker of a child/children needed support from family and friends to provision child care. Therefore, they required the surgeries to be scheduled when social support was available to take over their role of care providers.

“We talked about it, he is quite happy easy going and just –like get it done! And ... I knew he would be there to help and support me.[]

umm just being there for child care really. Plus I knew that there was a lot of appointments and being able to have that help was good and obviously when I had the operation, whole family having time of work and coming round and stuff.”(Suzie, 38 years, Female)

These findings about the influence of social support on decision making about orthognathic surgery are in line with past studies on orthognathic decision making. For example, Broder et al. (2000) identified social support along with financial support as an enabling resource in the decision making to undergo orthognathic surgery. Holman et al. (1995) tested and verified the hypothesis that perceived support for patient decision to undergo orthognathic surgery would affect patient satisfaction as a function of who was providing support to the patient. In the UK, Stirling et al. (2007) reported that of the 61 participants in the study, two thirds stated that their family members were involved in the decision making process in terms of support and expressing their opinion on the right choice. However, friends were not found to have influenced the decision-making. They did report, however, that the dental professionals who they consulted also played a role in the decision making process (Stirling et al., 2007).

4.5.6. Role of dental care professionals in decision making

Dental care professionals play a major role as a support for patients who undergo orthognathic treatment. Their role of support, as seen in the preceding section, were sometimes simply to be understanding about the patient’s other social roles and accommodate the treatment stages accordingly or in other times to be there to provide professional help in getting through pain, fear and distress. However, in the decision making phase, the role of the dental care professionals were mainly to provide all the necessary information and support in making a decision about their treatment plan.

Trust in the surgeon was another great influence on patients’ decision-making process. Patients trust in the abilities, experience and skills of the dental treatment team helped build confidence in their opinion about orthognathic treatment as the best option for them.

“Yeah definitely (the dental care professionals influenced my decision) because they were so natural and I felt like they had such experience in the field and they have done so many surgeries

successfully before and I guess I had such good confidence in them and ultimately it came down to if they think I was a valid case for them, then I am gonna go with that and I am gonna trust their opinion. Because I trusted them so much it wasn't really an issue for me to trust them or to go ahead with the surgery.” (Roz, 23 years, Female).

“I just put my trust in them (orthodontist and oral surgeon)... you know you are the expert” (Lola, 21 years, Female)

The trust was built based on the record of accomplishment of successful surgeries, approach and communication with the patients. However the approach and support from the orthodontist and their general dentist also played a role in the decision making process.

“Each dentist that I have been to, I have mentioned it but they said it's extreme to go for the surgery so... more or less put me off it and then I moved to (Name of town) and then the dentist at (Name of another town) suggested it coz he had got people that had it done, sent before for it and it was something he would recommend. So... basically swapping dentists made me have it (orthognathic surgery) done.” (Suzie, 38 years, Female).

The general dentist often played a major role in the NHS system with regard to patient care. They were the first point of a patient's entry into the system of care. For example, it was usually the general dentist who referred the patients to orthodontics and orthognathic services provided in secondary or private care sectors. If the general dentist missed mentioning surgery, it was the orthodontist's role to make appropriate referral for surgical intervention. Further, patients developed a rapport with the dentists and orthodontists because of the frequency with which they see the patient.

“My dentist, not within the Charles Clifford, my own dentist, she is quite pushy, quite fiery and she was quite pushy about saying well why, why don't you get it done again, not in a negative way but yeah she seemed quite enthusiastic about me going back and getting it sorted.” (Emma, 26 years, Female).

Patients often referred to their general dentist and orthodontist as ‘my own dentist’ and ‘my own orthodontist’ emphasising the relationship they had with them. This emphasis on the doctor-patient- relationship also emphasises the degree of influence these dental care professionals have on the patient’s decision making for orthognathic treatment. The role of dental care professionals is not limited to just decision-making but they also play a major role in the whole orthognathic treatment experience of the patient. This will be discussed further in the subsequent section.

4.5.7. Fear of the patient – hospitalisation and negative results from surgery

This is a subcategory which illustrates the single most common reason which negatively impacted on patient’s decision making to undergo orthognathic treatment. Like in any decision, the reservations which patients have regarding undergoing the treatment pertain to their various fears. Fears of four different aspects were identified in this study, which appeared to influence patients to decide against surgery. They were i) Fear of hospitalisation and surgery itself, ii) Fear about the recovery period especially about the anticipated pain following surgery, iii) Fear of negative outcomes of the surgery including the possibility of them disliking their new facial appearance and iv) Fear of orthognathic treatment interfering with day to day affairs since it is an elective procedure.

“Umm having a stay in the hospital is obviously a big negative ... the time it would take and the discomfort as well. Umm obviously it’s one night. Also having surgery itself in the first place is scary. I have never had surgery before so that also comes in.” (Will, 21 years, Male)

The above quote is an example illustrating the person’s hesitation to decide about having orthognathic surgery due to their fear of being hospitalised and having a general anaesthetic for the surgery itself. Indeed, this was often the case for young healthy adults who had never been hospitalised for a surgery. Therefore, the hesitation in decision-making was due to the fear of the unknown. While for others the hesitation was due to an unpleasant experience they had had in the past and for them it was a scary decision to make. Nonetheless, patient’s fear about being hospitalised and having the surgery steered them away from deciding to have the surgery at least briefly as a part of their orthognathic experience.

“I was feeling scared at first but then I know it’s probably the best thing for me. [] Its just before being told ...having surgery and having my jaw broke... [Scared me]” (Ria, 16 years, Female)

The second fear patients reported was the fear of the recovery period following the surgery. All patients had an understanding that the early days of the recovery would be painful. However, some patients feared the recovery period more than others. Partially this was because the patients were given a detailed vision of what to expect during each day following surgery. This vision was made clearer from the various online blogs with day-by-day entries of patient experiences following surgery, which many young patients read.

Below is a quote of what a blogger wrote about reading online blogs before deciding to have surgery:

“In retrospect, I think I filtered out the negative when I read other jaw surgery blogs, in denial! If you showed this blog to your caretaker before surgery, would they let you go through with it?” (R., Female, online , <https://roxsjawsurgery.wordpress.com/>)

It was found that detailed information about the recovery following surgery could negatively influence the patient’s decision about surgery. This was because details regarding the possible complications that could be expected during recovery could instil fear in patients. When speaking about the recovery most patients were concerned with the pain and swelling during recovery time. Less commonly, patients expressed a fear of weight loss following surgery during the recovery period.

“I knew about the weight loss... how much will I lose... because I wasn’t a big person anyway. Umm even though my husband was doing very high calorie foods it wasn’t so much how much weight I lost, I probably lost $\frac{3}{4}$ of a stone but it was the body mass I lost, my clothes were out here (showing action) and umm for about 3-4 months I was like that, you really don’t realise how much weight loss you do with that. That was one of my fears.” (Kathy, 52 years, Female)

Online blogs also showed that patients were concerned about the lasting numbness on various parts of their face and considered themselves to be recovering until the

numbness wore off completely. This information of the possibility of losing sensation over part of the face following surgery and not knowing clearly about when the sensation would return back to their face was a scary information for patients. This leads us to the third fear of the patients considering orthognathic surgery.

Patients feared the negative outcomes of surgery that mainly included fear of disliking the new facial appearance and long lasting numbness or paraesthesia of different parts of the face. During the decision making phase patients were given an idea of how their jaw structure would change causing a change in their facial appearance. However since this was only a rough estimate patients feared if they would be able to accept and like their new facial appearance.

“My first orthognathic surgeon for a consultation, he informed me that there is a risk of permanent loss of sensation on and around the tip of the middle of my lower lip. Since there is a nerve that goes through the bone of my lower jaw, the cutting, opening, and repositioning of that bone might damage the nerve in a way that it won't be able to grow back. I would still be able to move it just fine, but he said it would feel numb permanently. This worried me so I asked him more about it, and he said that nationwide (USA) percentage of that happening is around 10%. This eased my worries for a while, I guess. [] But the more I think about it, the more it worries me. I've felt that numbness in my lips from injections from my dentist, and it's quite uncomfortable. I don't think I can live with that feeling for my entire life. I also want to be able to feel everything when I kiss my girlfriend, but I guess that's a bit selfish of me.”
(Gunsandroseschild, 19years, Male, online <http://www.archwired.com/phpbb2/viewtopic.php?t=11574>)

The last type of fear was the fear of surgery interfering with their daily affairs since orthognathic treatment was an elective procedure. This fear was often projected in patients who were not internally motivated for surgery and had a lower degree of functional and appearance concern. For example, a 40-year-old female patient with mild aesthetic concerns and no functional impairment wrote on a forum;

“And some other reasons to choose the nonsurgical route (at least for now) are that I have a small child to care for (not nice if mummy can't care for you for weeks after surgery for something mainly cosmetic....) and my pregnancy wish in the near future, if life would give it to me....” (Anna, 40 years, Female, online-
<http://www.archwired.com/phpbb2/viewtopic.php?t=44099>).

This type of fear was also seen in the case of Sandra in vignette 3 who had mild appearance concerns while deciding about orthognathic treatment. She stated that her career was only taking off and a three-year commitment for orthognathic treatment was a major concern for her. This meant she was undecided about orthognathic treatment.

To summarise, decision-making was found to be a very crucial part of the patient's experience of orthognathic treatment, which was often taken after careful consideration. A shared decision was made between the patient, doctors (oral and maxillofacial surgeon and orthodontist) and the patient's support group. This is contrary to other findings about decision making from the UK which reported that most patients did not make an informed decision about orthognathic surgery (Stirling et al., 2007). They found that most of the patients failed to make choices based on the evaluation of the pros and cons of all the available treatment options. In the present study, patients reflected on the decision they made even years after the treatment was completed with no regret, showing the importance of the decision making phase of orthognathic treatment.

The next category identified during the discovery of normal facing is 'factors influencing the shape of the passage'. In Figure 12 (page 141), the category 'factors influencing shape of the passage' is placed alongside the circle that encapsulates the timeline of normal facing. This is because the concept of shape of the passage did not have a role limited to a certain point on the timeline but had a continuous relationship with normal facing. However, the category – shape of the passage - was conceptualised based on the discovery of normal facing as a status passage. In order to better understand this category, a basic understanding of the formal theory of status passage and its properties would be imperative. The next section provides a basic introduction to status passage and draws light on the discovery of status passage in the experiences

of patients who entered the active treatment pathway. Following this, the remaining categories in the GT will be detailed.

4.6. Status passage and its discovery in patients' experience of orthognathic treatment

“I mean, now I am moving to Japan, I don't think I would have done that, had I not had the surgery and been happy with myself and my face and my ability to eat and speak and you know...it is little things but it does make a big difference. [] I probably wouldn't have talked to you before I had surgery like this... I feel proud of my teeth and you sort of want to brush your teeth more, otherwise you sort of loose interest if they don't look good. So now I am making sure that they are clean and taking care of them. Whereas before I was bit like umm I can't be bothered. I feel like it's an asset now... I can use it. I can use my smile.”(Lisa, 22 years, Female)

“I wanted to feel better in myself and I think the only way I could feel that was if I had some it was always my dream I suppose , I wanted to be like everybody else to close my mouth and I thought I can't no matter how much I forced it I couldn't close it, and I so much wanted to be like everybody else that way. And it's kind of a dream really, and I obviously got my dream. (Laughs)” (Kathy, 52 years, Female)

In the above quotations, it is clear that both Lisa and Kathy have had a major change in their life and are very pleased with this change. Lisa, makes two sets of comparisons between herself before and after 'the surgery'. She refers to her boost in self-confidence when she said she would not have moved to Japan if she had not had the surgery. Her perception of improvement in her facial appearance and functional abilities seemed to be what increased her self-confidence. The second aspect that seems to have changed in Lisa after experiencing orthognathic treatment is her self-worth. She now values her teeth and her smile while she did not see them as an asset before having the surgery. On the other hand, for Kathy her dream of being like everyone else had come true through her experience of orthognathic treatment. Her self-perception improved and she was feeling better in herself, this was her dream.

These examples clearly suggested that people who entered the pathway of orthognathic treatment experienced a change and moved from a lower to an improved self-perception. According to Glaser and Strauss (1971, p.2), status passages “may entail movement into a different part of a social structure; or a loss or gain of privilege, influence or power, and a changed identity and sense of self, as well as changed behaviour”. This understanding of status passage can be seen as directly related to the change experienced by Lisa and Kathy. They both experienced a change in their sense of self and also changed behaviour as a result of their orthognathic treatment experience. This change in identity enabled them to move within the social structure from being partially an ‘outsider’ i.e., being treated differently by others, to being an ‘insider’ who received acceptance. This change in self-perception resulting from the change in facial appearance and functional abilities was a common finding in the data. Therefore, it was found that patients who experienced the orthognathic treatment went through a status passage which brought about a change in the individuals sense of self and behaviour. In order to explore the status passage that occurred in individual’s who experienced orthognathic treatment, the properties of status passage described by Glaser and Strauss (1971) were studied in relation to the data. Being a GT study, the author was cautious not to force the data to fit evolving theory. However, for the purpose of presentation in this thesis, the properties of status passage that are relevant to this substantive case will be described followed by relevant examples from the study.

The key characteristics of most status passages that have been studied by sociologists and anthropologists are – scheduling (when change in status should be made, by whom and whose agency), regularisation (regularised actions by various participants for completion of the status passage) and prescription (prescribed sequence of steps for completion of status passage). However, Glaser and Strauss argued that these three characteristics may be absent or present in some status passages only to some degree (Glaser and Strauss, 1971, p.3). The characteristics of status passage are therefore considered with reference to six principal considerations; namely Reversibility, Temporality, Shape, Desirability, Circumstantiality and Multiple Status Passages (Glaser and Strauss, 1971). Like many studies in the past (Tolhurst and Kingston, 2013, Vickers, 2010, Larsson et al., 2003 and Lewis, 1999), in the following sections these six principal considerations listed by Glaser and Strauss in their book *Status*

passage: a formal theory, will be used to present the results of the study and illustrate the common features of orthognathic treatment as a status passage.

a) Reversibility:

Status passage is dynamic and constantly in motion. Therefore, the passagee and the agents involved in the status passage were often found to be concerned about the reversibility of the status passage. Reversibility included considerations such as direction of the passage, repeatability, inevitability, preventability and if the passage can be arrested or not (Glaser and Strauss, 1971). This characteristic of status passage indicates the direction of the passage i.e. if the passage is moving forward or if it reverses based on all the other considerations mentioned previously. These considerations of status passage can be better understood using some of the commonly cited examples of status passage.

Age related change in life status such as transition from childhood to adulthood is a very commonly cited status passage (Heinz, 1991, Glaser and Strauss, 1971). This is an irreversible, not preventable, inevitable, non-repeatable, unidirectional and cannot be arrested type of status passage. Glaser and Strauss stated that non reversibility of a status passage is determined by inevitability and non-preventability of the direction of that status passage (1971). Aging is a classic example of non-reversible status passage. Yet another example of status passage is status of being employed. Status passage of being employed is reversible, preventable, not inevitable, multi-directional and can be arrested by the passagee or agents at any time. Similarly, all the identified status passages can be described in relation to these characteristics of reversibility.

Orthognathic treatment is an irreversible status passage simply because once the surgery was undertaken, the status of having gone through the surgery cannot be undone. It is however completely elective and patients can stop proceeding with the set treatment plan at any point during the course of orthognathic treatment until the actual surgery itself. For the aforementioned reasons, orthognathic treatment is multi directional, whereby patients can choose to complete the treatment, get a desirable or undesirable outcome, and patients can also choose to not complete the treatment and continue with their original status in relation to their jaw structure before surgery.

In this way, reversibility does not depend purely on the physical nature of the patient's jaw structure. According to Glaser and Strauss, reversibility depends on structural

conditions including situational and contextual conditions and on the personal condition of the passagee (1971). An orthognathic relapse (the new position of the jaw and teeth following surgery are not retained and moves back to the original position for clinical reasons), although not very common (Bailey et al., 2004), it would class as reversal of the status passage. On the other hand, if a patient decides to have a second surgery to reverse the outcome of the previous orthognathic surgery, then it would class as reversal of the status due to a personal condition. Despite these reversals the status of having gone through the surgery cannot be undone.

b)Temporality

As established already, status passage is in constant motion and the direction of the status passage can be reversible or non-reversible. Concerns about the direction of the passage are closely linked with concerns about its diverse temporal dimensions. Most often participants involved in the status passage are interested to know about the temporal expectations from the passage (Glaser and Strauss, 1971, p.33). In the context of orthognathic treatment, this would mean a set of questions regarding the time taken for the treatment and recovery. Another question that accompanies this would be who decides on how long each stage of treatment should take. Glaser and Strauss called this legitimatising the temporality of the status passage (1971, p.34). It was discovered that dental professionals are the agents who legitimatised the temporality of orthognathic treatment. Patients were interested in knowing the actual time taken for pre- surgery orthodontic period and post-surgery recovery periods (Luther et al., 2003). The dental professionals were able to provide the patients with this information about the expected time taken for each phase of the treatment.

The rate and pace of the passage was yet another consideration of the status passage. People involved in the status passage were not only concerned about where they were going (direction) through the passage but they also wanted to know how soon they would get there (Glaser and Strauss, 1971). Therefore, the rate at which the passage progressed and the pace at which the prescribed steps in the passage advanced was of concern to the passage.

“I think my difficulties in making the decision were really the extent of the treatment needed, the length of time taken and the impact it had on my life especially since I have only couple of years left in university

and then treatment would still be ongoing when I am trying to find a job”(Will, 20 years, Male).

In the context of orthognathic treatment, it was found that most of the patients had a major concern about the temporal dimension of the treatment passage. In the above example, Will was interviewed during his decision-making phase expressed obvious concerns about the timing aspect of the treatment pathway. The time taken for the pre-surgical orthodontics and post-surgical recovery were the most commonly mentioned factors that affected the rate of progress of the treatment. On the other hand, most patients thought that the pace of the treatment was determined by the frequency and length of the hospital appointments to see dental professionals and advance to the next phase of the treatment.

“It (timing) could have done with being shorter but there’s nothing you can do about it. Fairly tedious having to come every sort of about 6 weeks I think it was, that was one of the reasons why it’s took sort of 3-4 years.[] so it obviously pushed it on 12 months by missing that one appointment which annoyed me. [] So the timeframe and the ability to be flexible on some of it has been a bit awkward, and self-employed, especially when you come to appointments and you end up sat in the waiting room, I think the longest I waited was an hour and a half in the waiting room, I can accept a delay but when you're on a parking meter with 2 hours on the meter yeah you can do with things going a little more smoothly, especially when you're trying to get work done..” (Rob, 30 years, Male).

In the above quote, Rob expresses concern over the timeframe of the treatment pathway and how it affected his everyday routine. Here, Rob is purely concerned about the temporality of the active orthognathic treatment phase. However, other people in the study have expressed concerns about the temporality of when they were initiated into the treatment pathway. For example, Marie, in Vignette 1 had to wait until she was retired to be able to start active treatment phase. In either of these cases temporality was determined largely by the institution of dentistry and to a small extent by themselves. Rob’s concern about the pace of the treatment and its associated

waiting time showed that dental professionals or the institution of dentistry is the agent who controlled the pace of the pathway.

Like, Rob, 18 year old Jen also found the temporal aspect of the treatment pathway unfavourable.

“I’m not having it [orthognathic surgery] because I had so many exams to get in to university and everything and I knew it would be a lot of time spent going to hospital so I was like worried about that, affecting my education and everything” (Jen, 18 years, Female).

In the above quote, Jen spoke about the orthognathic treatment interfering with career and education. This indicated that there are other status passages that occurred along with orthognathic treatment and this patient gave more priority to her education and career or work over the orthognathic treatment. Glaser and Strauss called this ‘temporal articulation’ and stated that temporal articulation typically reflects the general priority of work over the sentimental order of a passage (Glaser and Strauss, 1971, p.53). However, most people tend to alleviate their sentiments towards work as part of the temporal articulation. In this case the change the orthognathic treatment would bring formed part of the sentimental order of the status passage and progressing through mainstream education was the work. The agent who legitimatised the temporality of orthognathic treatment i.e. the dental professionals had a central role in this temporal articulation. For example, surgeons rescheduled orthognathic surgery to allow time for university exams. Temporal articulation was therefore found to be a key area of discussion in this study and will be detailed further in subsequent sections.

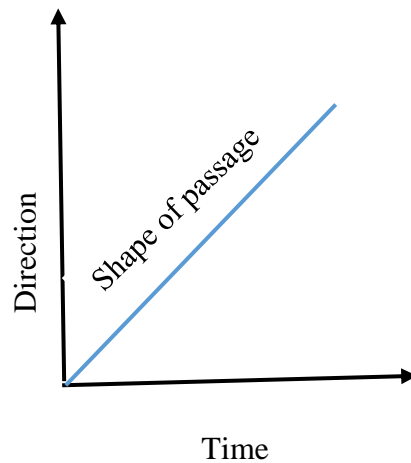
Glaser and Strauss pointed out that if the direction of the status passage was plotted against time then the resultant graph would represent the shape of the passage (1971). In the following section, the shape of the passage will be discussed in relation to orthognathic treatment.

c) Shape of the passage

The shape of the passage can be plotted graphically on the two axes of direction and time. The resultant line that is drawn on the graph represents the shape of the passage (See Figure- 19). The temporality and the direction of the passage, which has been

detailed so far, has an impact on the shape of the passage (Glaser and Strauss, 1971). However, there were other factors that can influence the shape of the status passage.

Figure 19: Shape of an ideal passage



When a person attempts to shape the passage according to their desire – to move it forward or make it standstill, that person makes some conscious efforts to do so. The passagee is not always able to be in sole control of the shape of the passage. There are other means of control. Glaser and Strauss stated that the control of the status passage varied according to three conditions – shaping the passage as it exists (e.g. aging, schooling), is generated (e.g. marriage, elective treatment) or is discovered (e.g. acute or chronic illness). Means of control and balance of control are the two identified factors that also control the shape of the passage (Glaser and Strauss, 1971). A deeper understanding of these factors is relevant to a better understanding of the status passage being undertaken during orthognathic treatment as we shall see in the next sections.

Means of control and normal facing:

One of the simplest means to control normal facing as a status passage is by prescribing the direction and schedule or temporality of the passage. When these are controlled, the shape of the passage is predictable with a greater degree of certainty. This is often seen in large organisations, institutions and services. However, when the direction and temporality of a status passage is unknown, for example, in the case of

terminal illness, flexible prescription is used to control the shape of the passage. This means agents resort to using measures that maintain the shape of the status passage within a certain acceptable limit.

Yet another means of controlling the shape of the passage is by means of prescribing the type of people suitable for the passage. For example, recruiting people who are medically fit for the defence services of a country. With respect to orthognathic treatment, in the literature, it was found that prescribing the type of people who entered the passage was advocated. For example, within the literature, a number of studies centre on how to identify and exclude individuals with body dysmorphic disorder from orthognathic treatment (Rispoli et al., 2004, Cunningham and Feinmann, 1998). BDD is one of the ways in which patient selection is done in the active treatment pathway.

In relation to control over normal facing status passage, both the passagee and various agents can be seen to exercise control. This type of control is predominantly seen in cases of non-institutionalised and less prescribed status-passages. In such passages, the passagee is said to not have an agent for the passage unless they recruit an agent themselves. For example, when a married person decides to get divorced, he/she does not have an agent/ divorce lawyer who would enable his/her status passage to becoming divorced unless he/she recruits an agent him/herself. Therefore, here the passagee (person getting divorced) also has a means of control over the passage (legal divorce) as does the agent (divorce lawyer).

When this understanding was applied to the case of orthognathic treatment, it was found that orthognathic treatment, which is an elective procedure, was non-institutionalised and less prescribed in nature. The individual recruited a team of dental professionals to enable the status passage. The temporality of that recruitment of agents gave more control to the passagee, which in turn depended on the individual identifying a need to have orthognathic treatment. Glaser and Strauss (1971, p. 61), stated that most often the recruitment of agents in the higher socially ranked levels such as doctors, lawyers, accountants, surgeons, consultants, stock brokers etc. is done on a trust basis because they do not like being compared on criteria such as quality and fees.

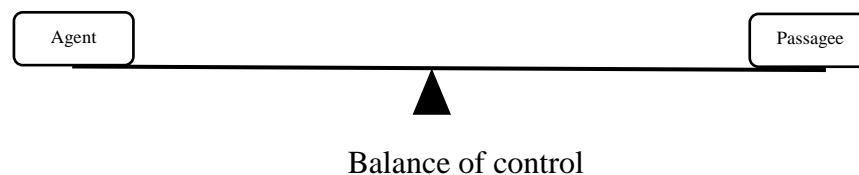
Once the passage has been well established, then different and well known means for shaping the passage manifest themselves. The agent draws on the knowledge they have

attained from training to shape the passage and the agents and the passagee work together to shape and negotiate the shape of the passage. In the case of normal facing and active treatment pathway, the patients help shape the passage through treatment compliance and the dental professionals provide treatment and both schedule the pace of the passage. This negotiation between the agent and the passagee results in a balance of control in shaping the passage.

Balance of control and normal facing

The balance of control between the agent and the passagee needs to be maintained in the shaping of the passage (See Figure 20). However, if there is a shift in this balance either towards the agent or the passagee then the shape of the passage is likely to shift.

Figure 20: Balance of control



In most professional and client relationships, the control is with the professional. Traditionally, professionals used the best of their knowledge and judgement to ensure the expected shape of the passage while the client, the passagee, was in a weaker position of control. Then, if the client tended to exert more control then the balance was lost and the shape of the passage was likely to deviate and become more challenging. In case of orthognathic treatment, there was a professional–client relationship between dental professionals and the patient. The weaker control, which the patient had, was in the form of compliance with the treatment. For example, a patient attending for appointments on a regular basis was important for the passage to be on schedule.

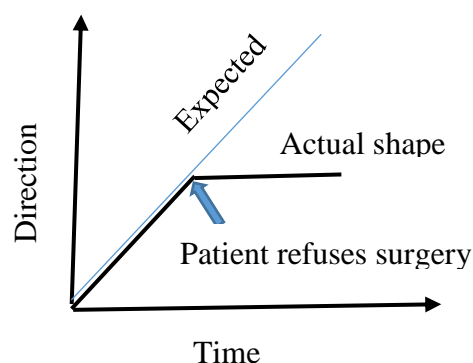
Sometimes the passagee may refuse to complete the passage. This may be because they felt more comfortable within the passage than what lay ahead after completing the passage. Glaser and Strauss (1971, p.64) gave the example of a student who avoids the completion of course work deliberately due to the fear of completing graduation. In this study, we have seen that orthognathic treatment was in itself a status passage

which lay embedded in normal facing, a wider psychosocial status passage. However, some individuals chose to stay within the active treatment pathway due to the fear of what lay ahead on completion of the passage. For example, one of the male oral surgeons at the hospital reported the following about one of the patients he had seen at the hospital in the past. Please note that this data were a form of secondary data, since it was reported to the researcher by the clinician (not from an interview) during a routine visit to the joint clinics where field notes were being made during patient consultations.

He stated that he had a patient who was from a minority community. She completed her pre- surgical orthodontics and whenever the clinical team scheduled a date for the surgery, she would go through till the last moment and then refused to go ahead with the surgery. This happened on many occasions. He recollected the patient telling him the reason why her parents wanted her to have the surgery was so that she could be ‘married off’ in the traditional manner. But she did not want to get married like that and so she kept avoiding the surgery.

In this case, the passagee avoided a significant part of the treatment and hindered the scheduling of the passage so as to avoid what lay ahead following the completion of the surgery. This is a classic example of how the balance of control can influence the shape of the passage (See Figure- 21). However, a similar shift in the shape of the normal facing status passage occurs when the person refuses to enter the active treatment pathway and continues with normal facing. The shape of that passage would be difficult to describe based on this study since no data were obtained from people who refused orthognathic treatment. Nevertheless, the shape of such a normal facing status passage would look different from the shape of the passage identified in this study.

Figure 21: Shape of passage when balance of control shift



Glaser and Strauss (1971) list different types of shift in balance of control that can affect the shape of the passage. A complex interrelationship between the agent and the passagee was identified. It could be either mutual (where both agent and passagee needed each other to proceed), contingent (either could go on without the other), or intersecting (where both agent and passagee could go on with the passage without the other). Intersecting type of interdependence has been found to be more prevalent in the client –expert relationship (Glaser and Strauss, 1971, p.71). The relationship between orthognathic patients and dental professionals had a potential intersecting interdependence because the patients could seek a different surgeon or orthodontist (dental professionals) at any time and the dental professionals could function independently as agents for other patients in the orthognathic treatment. However, in the context of orthognathic treatment the shift in balance of control was minimal since the agent i.e. the dental professional was more in control than the passagee – the patient. The dentist was known to have more knowledge about the passage and so the passagee had less control.

Sometimes mild deviances in the shape of the passage do occur as the passage is in constant motion (Glaser and Strauss, 1971). These deviances result in changes in the shape of the passage. Such deviances are corrected by making the passagee or agent; whoever led to the deviance, aware of the problem and rectifying it. For example, following orthognathic surgery, some patients fail to comply with inter maxillary rigid fixation (IRF) due to fear of choking, swelling etc. This may led to increased periods of hospitalisation or removal of the IRF sooner than planned.

“I spent another 24 hours in the hospital, and in hind sight I had a little bit longer because the day I came home I felt quite nauseous and with and I had been [].... The anaesthetic was still wearing off and I felt quite nauseous and that was quite scary. Because I was worried that if I was going to be sick, how would I be sick with the wafer and the elastics. So I didn’t actually manage to keep the wafer in for the full week. I had to come back here on day 4 I think it was and have the wafer removed because I was just so worried about being sick”(Marie, 62 years, Female)

In this section on the shape of the passage, we have identified only the dental professionals as the agent involved in the status passage along with the passagee – the

patient undergoing orthognathic surgery. This was because they seemed to be the most obvious agents involved in the passage. However, from the study it was found that since most of the patients identified for orthognathic treatment were young adults, the parents or the family members also played a role in facilitating the passage. Even in grown adult patients, it was found that the convincing of the partner or other family members was vital in the shaping of the passage.

“My partner did a lot of reading and tried worrying me I think, she couldn’t understand why I wasn’t bothered or phased by the fact that I was going in to hospital and having the work done that I was having done. I think she was probably more worried about it than me”. (Rob, 30 years, Male)

Therefore, the control exerted by various means and the balance maintained between the different controlling parties involved in the status passage played a vital role in the shape of the passage (Lewis, 1999). The relationship between the properties of status passage and the experiences of patients who undergo orthognathic treatment, will be elaborated upon as the theory unfolds in the coming sections.

d) Desirability

The desirability of the passage is yet another characteristic of status passage. The desirability of the passage by both the passagee and the agents help in shaping the passage itself (Glaser and Strauss, 1971). One could argue that the active treatment pathway – part of the normal facing was a rather desirable passage for patients. These adults had to consent for the treatment before entering the process and if it were not desirable for them, they were unlikely to consent to the treatment. However, degree of desirability was subject to change as the passage progressed (Glaser and Strauss, 1971, p. 89). A few examples for this change in desirability of orthognathic treatment status passage was found in this study. Patients often reported self-doubting their decision to go ahead with orthognathic treatment during the decompensation movement of teeth in the pre-surgery orthodontic phase, a phase where the bite and face appearance was made worse.

“Umm and I think it’s worse before the surgery because they make your teeth look a lot worse. Umm... and it just made me a lot more

conscious. So that was the worst part for me. That it made you look a lot worse” (Sonia, 26 years, Female)

Further, during the second day of recovery, often patients had facial swelling and pain. This stage of the treatment was found to very challenging for most patients and the desirability of the treatment was reduced.

“I went to the toilet after I'd woke up and I had my drains and everything with me and I looked in the mirror, I was trying not to but I couldn't resist looking in the mirror and I just burst out crying. I thought my face had been ruined.” (Ester, 20 years, Female)

Change in the degree of desirability was not unusual. This sort of change in desirability can also be seen in pregnancy. When the early stages of pregnancy were found to be very desirable for the new mum, the later stages became uncomfortable and less desirable (Glaser and Strauss, 1971). At this point, it is only the passagee who feels a reduction in the desirability of the passage because of her own discomfort; other agents involved in the passage may feel differently.

Similarly, in the orthognathic treatment status passage, the degree of desirability of the patient may not always coincide with other agents involved in the process. Dental professionals often are given the choice for case selection; they therefore choose the individuals they think that they can treat effectively and elect them to enter the treatment pathway. Within the sample that was recruited in this study, all the dental professionals agreed that orthognathic treatment was a desired passage for their patients. However, other agents such as family members or partners of patients did not necessarily have the same desire for the passage as the patient did. This possibly was because they, unlike the dental professionals, saw the active treatment pathway as a separate part of the wider normal facing status passage which the individual was going through.

*“From my parents: "You look fine! Why do you need jaw surgery?"
Mom bursts into tears "WHY ARE YOU WILLINGLY GOING UNDER THE KNIFE?!" Dad says "You have a chewing problems? You never said anything about that?! We couldn't tell!" Basically, my mom never got that it was a quality of life issue, and my dad*

thinks that I eat too much possibly?? (Ahhhh, Asian parents...) Also, as a young adult (and now a not as young adult), who talks to their parents about how they can only chew on one side of their mouth? That seems like a fun conversation at the dinner table..."
(Deathorglory – blog comment, Online:
<http://www.archwired.com/phpbb2/viewtopic.php?t=48459>)

In the quote above, it was the degree of desirability of the passage that drove the passage to completion or prolonged the passage. Glaser and Strauss (1971) stated that there was need for agreement on the degree of desirability of the passage between the agents and the passagee in order to maintain the cooperation between them until the completion of the passage. Ceremonies may occur at the end of a passage to mark its closure and this depends on the desirability of the passage to the passagee and the agents. A classic example for this is a graduation ceremony that is scheduled ahead of time and lures the student to not prolong the student years and make a transition into working life by temporally and clearly shaping the passage. With respect to orthognathic treatment, no such ceremonies were found. However, this was largely nothing to do with the desirability of the passage but because of the nature of the clinical treatments being undertaken.

The degree of desirability depends on the social circumstances of the person (Tolhurst and Kingston, 2013). Glaser and Strauss stated that the “degree of desirability of a status passage depends both on the degree to which a man [sic] is socially integrated into the groups and on the social circumstances that provide such desirable passages” (Glaser and Strauss, 1971, p. 92). The underlying desire for social integration was evident in patients undergoing the orthognathic treatment in this study although this operated at different levels. It was seen that most patients in the active treatment pathway chose to enter the orthognathic treatment passage was to better ‘integrate’ with wider society. This aspect was detailed in Section 4.3 (page 143) elaborating how patients sought to be ‘normal’ and better integrate with the society. However, patients in the active treatment pathway desired to socially integrate with others who were similarly in the active treatment pathway.

“I think it’s one of the most useful things being able to talk to people who have gone through it. I think that was what I found most useful. I had one of my friends who had had the surgery, I spoke to her and also I spoke to a lot of people through the blog I wrote online.” (Roxy, 22 years, Female).

The above example suggested that the active treatment pathway and the wider normal facing status passage were lonely passages and individuals desired company to share their respective passages. When individuals entered the active treatment pathway within the normal facing status passage, it was possible for the individuals to integrate with others who shared the passage. Roxy was able to speak to many others in similar status passage as her through online blogs. While there are blogs for people who undergo or are considering orthognathic treatment, there are no means of social integration with the others in normal facing without entering active treatment pathway. Therefore, the degree of desirability was influenced by the degree to which the people shared the status passage.

The patients who were interviewed in the study also showed a keen interest in meeting and speaking to other patients who received orthognathic treatment in the hospital and if possible to form a social network with them.

“Part of me wants to go in every Monday and every Thursdays and say hello to people who have had it [orthognathic surgery] done and say like it will be okay, it will be fine.”(Lisa, 22 years, Female)

“The blogs definitely (were most useful) , particularly the people who’d had upper and lower jaw surgery because it was the first time I’d ever seen people who’d felt the way I’d felt about their jaws so its kind of nice to see that actually they’d felt awful about the way they looked when they were younger as well and then seeing how happy they were, it was a really good thing and I was able to get my mum and dad to have a look at the blogs as well so they could have an idea of what was going on.”(Emma, 26 years, Female)

Desirable status passages are subject to recapitulation by the passagee and the agents. Glaser and Strauss (1971, p. 97) stated that this could be either because they wanted to revisit the sentimental journey through the passage or in order to control the forward

shape of the passage or a new passage. Normal facing was definitely a sentimental journey focusing on the psychosocial changes but this status passage was centred on orthognathic treatment passage in this study. Through the interviews for this study, the participants revisited their experiences through the passage. For some this revisiting and sharing was more emotional than for others.

Many people also wrote online blogs and replied to other people's comments and questions online about their orthognathic experience. This could be seen as a means of mere reflection or also as a means of control over the shape of their passage into the future. For example, patients especially from the American subcontinent often wrote and discussed about insurance coverage for the surgery. They took ideas from others and shared experiences about how the financial cost of the treatment could be managed in the future. Below are quotes from a thread on a forum

Q: "The big thing I want covered here is the bi-maxillary advancement. My insurance is Blue Cross/Blue Shield PPO. I called and my health insurance does indeed cover jaw surgery if it is medically necessary. I would like all of yours' s opinion on whether or not my case has a chance of being covered? I have difficulty breathing through my nose, it has forced me to breathe through my mouth most of my life. I am getting checked out for Sleep Apnoea. I am constantly tired and anxious. I have jaw pain. I grind my teeth TERRIBLY at night." (Nate92)

A: "I also have BCBS and I believe my case is approved based on skeletal deformity. I don't really have a severe "functional problem" (i.e. I can chew food fine) but my surgeon did say he considers my case as medically necessary because my jaws aren't where they are supposed to be. Your case sounds a lot worse than mine with the jaw pain and sleep apnoea. I think you already have a good insurance, so it's all up to how the surgeon classify your case. GL!"

(Alicia0913,

Online:

<http://www.archwired.com/phpbb2/viewtopic.php?t=44710>)

The passagee may experience social isolation if the passage is desirable only to the agents and the passagee themselves (Glaser and Strauss, 1971). However, in the case of the active treatment pathway, all of the patients interviewed had a good social support system and were not socially isolated. Online blogs and forums that have been included are also a testimony for the social interactions that were possible between patients within the treatment pathway.

e) Circumstantiality

Circumstantiality stands for whether the passage is made by one person alone or in aggregation or collectively. The social nature of status passage means that it is unlikely that a passage will be undertaken in isolation (Tolhurst and Kingston, 2013, p. 188). Glaser and Strauss highlighted that:

“Among the structural conditions that profoundly affect the nature and consequences of status passages are those pertaining to the number of agents and passagees, in combination with the respective relationships of all concerned” (Glaser and Strauss, 1971, p. 116).

This characteristic of status passage considers the social relationship between the passagee and the agents. The journey through the passage for both the passagee and the agents could be alone or accompanied by others. Glaser and Strauss classified it as:

Passagee	Agent
Alone	Alone
Member of a group with collective characters	Member of collectivities
Member of aggregate with minimal collective character	Member of aggregate

(Glaser and Strauss, 1971, p. 116)

There are various, precisely nine possibilities of social relationship between the agent and the passagee. For example, it could be collective and collective like a faculty in a

department and a class of students whereby a collective group of staff members are agents for a number of students in the class to complete the passage of education in that class. Here the status passage of all the students occur simultaneously and not in succession. This type of agent passagee relationship is often seen in institutional settings. On the other hand aggregate passages, which also occurs in institutional settings, can consist of a number of different individuals whose passages are managed either simultaneously or successively (or both) by the agent group (Glaser and Strauss, 1971, p.118).

The possible combination of agent passagee relationships are; collective- aggregate, aggregate – collective, aggregate – aggregate, aggregate - solo, collective – solo, solo – aggregate, solo- collective and solo – solo. Each of these relationships has its own contingent issues (Glaser and Strauss, 1971).

A range of factors will shape the social relations of a passage, and the nature of a health condition may have an impact on the passage (Tolhurst and Kingston, 2013 p.188). Patients' experience of normal facing varies in its social relations depending on individuals and their particular circumstances. As mentioned earlier normal facing can be a solo or lonely passage if these individuals do not connect with others in similar passage. However, in a general sense considering the active treatment pathway, patients are members of an aggregate group whereby each individual patient undergoes treatment either simultaneously or in succession. Patients in the active treatment pathway do not experience a collective passage since the clinical and personal perception of their condition varies from person to person or case to case. It is possible that this isolation in the status passage is what leads them to online blogs and forums, seek others for support and build a collective status passage.

For example, online blogs and forums invite people with similar type of jaw concerns to share their experiences with others. They compare and contrast their experiences on these platforms. It was also seen that people with different experiences try to get involved in these discussions for mutual support.

“Heya, I didn't have surgery for an overbite but I did have it for an underbite, which is a pretty similar-ish procedure (braces, operation, recovery, liquid diet etc!) [] f there's anything you want to know about the recovery/liquid diet/surgery part I can tell you as much as I can!”

I know it's a slightly different op, but it's similar recoveries/preparation etc.” (Liv1204, Online: <https://www.thestudentroom.co.uk/showthread.php?t=1603029>)

The agents involved in the orthognathic treatment are a multidisciplinary team of dental professionals. This includes orthodontists, oral and maxillofacial surgeons and other dental care professionals like dental hygienists, nurses and general dentist. Within NHS hospitals, it was found that the treatment team was a collective team where the orthodontist and oral and maxillofacial surgeons worked together at different stages of the treatment process to enable completion of the passage. However, in various private health care systems the agent’s social structure was seen as part of an aggregate where the orthodontists complete their role as caregiver and transfer the patient to the surgeon. The surgeons then completed the surgery and then sent the patient back to the orthodontist for completion of post-surgical orthodontics. Therefore, the circumstantiality of orthognathic treatment as a status passage was complex and varied according to the individual circumstances of the patient and the type of care system. Nonetheless, the social relation between the passagee and the agents in the active treatment pathway fitted the characteristic of circumstantiality which is an important feature of status passage.

f) Multiple status passages

People go through more than one passage at a time. Multiplicity of status passages can cause issues depending on the relationship between the passages. Glaser and Strauss stated that among the multiple status passages, some could be relatively independent of each other while some others may compete with each other for time and energy causing a lot of strain on the person (Glaser and Strauss, 1971, p. 142). However, some other passages may be relatively supportive for another passage making life easier for the person. But then one of the main concerns of multiplicity of status passages, identified by Glaser and Strauss (1971), was the need for prioritising one over the other. Hence, the key phenomenon associated with multiplicity of status passage was priority, competition, support and interdependence. It was important that the agent and the passagee were able to articulate the phenomena of multiple passages (Glaser and Strauss, 1971).

Most people in modern society need to juggle multiple status passages by making decisions using strategies, tactics and help of appropriate agents.

“These status passages are influenced by variable such as whether the passages are voluntary or involuntary, expected or unexpected, desirable or undesirable of short or long duration” (Glaser and Strauss, 1971, p.143).

When more than one status passage exists, they may vary in their degree of interdependence from being completely independent to highly interdependent. Interdependence between status passages involves varying degree of completion, priority and support either mutually between two passages or favouring at least one passage (Glaser and Strauss, 1971).

An extremely competitive passage claims priority over all other co-existing passages. An example cited by Glaser and Strauss for such an extremely competitive passage was ‘crises’.

“Crises tend to ‘flood’ the lives of the passagee so that virtually all other passages may have to be temporarily ‘frozen’ or even permanently abandoned”. (Glaser and Strauss, 1971, p. 144)

Tolhurst and Kingston (2013) concluded that dementia was a passage that was comparable to crisis because it subsumes all other co-existing passages. However this does not mean that the other passages would have to be abandoned instead they are sustained with the priority being given to the ‘crises’ –in this case dementia. The tactics that are used to slow down or reverse the course of the crises interferes with the course of other passages.

Crises were differentiated from its ‘near relative’ – emergency. Glaser and Strauss stated that an emergency was relatively expected and hence can be planned for although cannot be prevented (1971, p.146). In the case of orthognathic treatment emergencies can be expected in the form of infection of the plates used to screw the jaw bones during surgery. Although they are a possible risk, the exact time of occurrence is often not predictable. However, when such an emergency occurred, the course of action was usually pre-determined and hence the duration of the emergency was also known.

“My operation took place in November 2010. [] All seemed to go O.K. until a few months later when I started getting infection after infection I was referred back to hospital and had the left plate removed. This was in April 2011 [] I am home now. Cannot do much though. I look like the terminator”. (Tinkybell – online)

Less dramatic than crisis or emergencies are situations when multiple status passages become extremely competitive causing stress on the individual passagee. In such situations the individual needs to go through a phase of learning, experimenting with tactics and developing strategies which will enable them to not abandon any passage or at least choose the most desirable passage (Glaser and Strauss 1971). This was evident in Vignette 1 where Marie prioritised her career and family life over her strong desire for seeking orthognathic treatment which she put off until she retired from her working life. Similarly, edentulous patients in New Zealand were found to have valued the status passage into complete tooth loss less than other status passages such as marriage or staying at home to contribute to the household economy (Gibson et al., 2016).

Sometimes these multiple status passages also provide mutual support. This requires working out the articulation necessary to a more vital passage and thus phasing out the passage becomes of utmost importance. In such instances, conventional modes of scheduling eases off the juggling of phases. Going back to the previous example, the student can easily articulate the dates set for the orthognathic surgery and the schedule of A level examinations because of their predetermined nature. In this respect, a student’s passage through the education system can support an orthognathic treatment passage by enabling clearer scheduling for the passage.

However, such mutually supportive passages may require management of disruptive circumstances. Temporal management also becomes crucial where status passages are mutually supportive. A classic example for this was found in the experience of Jen

“Because of exams and everything because I had my last exam like two days between that and the surgery so it was just like everything went so quick and .. affected my exam like focussing and everything so that’s why I was worried about it and like I got a bit grumpy about it affecting my exam [] I had my English exam in the morning and then I had like

afternoon appointment here at the Dental Hospital so that was on my mind in the morning [] but I thought it was like bad timing really”.
(Jen, 18 years, Female)

In this study, the importance of multiple status passages co-existed with orthognathic treatment and this was of central importance to the study. Further details of this will be discussed in Section 4.7.

Multiple status passages was the final aspect or characteristic of status passage listed by Glaser and Strauss (1971). By using the characteristics or properties of status passage, as described by Glaser and Strauss (1971), in presenting the analysis so far, the author has only intended to show how orthognathic treatment is a status passage. However as Gibson et al (2016) rightly pointed out these characteristics of status passage do not discuss the social conditions that result in the complexity of the status passage, nor the extent to which this might be a central feature of modern life. Characteristic of multiple status passage did not discuss the possibility that some status passages lend their meaning to other status passages. In the following sections, by detailing the findings of the study further, the author will elaborate the social context and the meaning rendered by orthognathic treatment –as a status passage - to other status passages.

In the aforementioned section, it has been established that the active treatment pathway is a status passage. From this section and from section 4.3 it has also been established that patients who enter the active treatment pathway go through a wider psychosocial status passage which was discovered in this study and named as normal facing. The different characteristics of status passage have been used to draw light on the nature of the active treatment pathway embedded in normal facing and it can be safely concluded that the active treatment pathway is a scheduled, preventable and irreversible status passage which co-exists with multiple status passages. In the following sections, the next category – temporality - followed by factors influencing the shape of the passage will be detailed.

4.7. Temporality

A key aspect of the change that patients underwent in this study was how time was organised. Time here stands for clock time and within normal facing it is represented on the graph as time in days. On the other hand, temporality, a key characteristic of

the status passage represented how time was organised by the person during the passage. Therefore, temporality is critical for the shape of the passage; the patient's perceptions of their appearance being the other parameter. Temporality is very important because it helps us see how various turning points and therefore various agents can affect the progress of the status passage. Whilst the horizontal shape of the status passage happened over different time periods, the patient's perception of facial appearance also changed accordingly. It was found that there were two important factors related to temporality in the shaping of the passage namely i) scheduling factors and ii) time taken for the natural process involving recovery.

Given that orthognathic treatment is an elective procedure, many aspects of timing the active treatment pathway were predictable and controllable. This, in turn, influenced the shape of the wider normal facing status passage. However since the data in this study was obtained from the patients in the active treatment pathway it was found that the patient themselves enabled the scheduling of the passage in the form of time taken for decision making, time taken off from work or school and other social commitments.

“I was doing my accounts while I was in the hospital. That’s why I had to go back to work so early, it had to be done so for work is was bad timing but that was never going to be ideal. But for my sporting it was essentially perfect timing.” (Rob, Male, 30 years).

Similarly, the clinical institutions (hospitals and practices) handled the scheduling of the passage in the form of scheduling between hospital appointments and scheduling a suitable date for the surgery. Nevertheless, the control over scheduling the shape of the passage was unbalanced during the occurrence of unforeseen circumstances during the process. For example, unexpected pregnancy during the course of pre-surgical orthodontics. This would warrant the passage to cease temporarily or permanently depending on the patient's decision and allow priority for another status passage involving pregnancy. This circumstance is also discussed further in a later subcategory; that of life priorities.

“Well I am 18 and umm I was young a fit for operation. Umm I think that’s one of the reasons why I recovered so well after it. Well.. I had my operation on 27th of April and I went back to work by like about

mid- May. So I were only off for like 2- 3 weeks. [] Well I knew this girl and she had the same operation what I was going to have and she said like there... it look her longer to recover because she was older, which she said it took around 4 weeks, I said that was long, and I said if it took 4 weeks.”(Kenny, 18 years, Male).

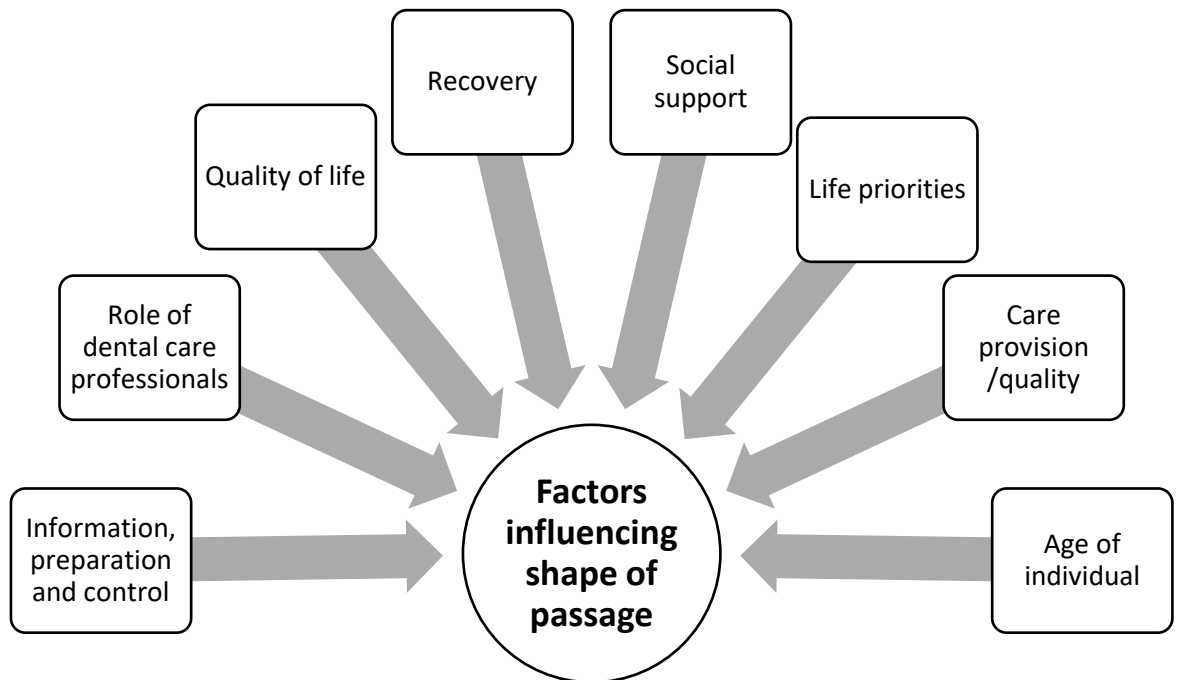
The second factor of time taken for the natural process of recovery included clinical aspects of time taken for adequate results from the pre-surgical orthodontics, recovery time taken following surgery and the time taken for desired results from post-surgical orthodontics. All of these aspects were based on the natural recovery time and varied from person to person. Kenny’s comparison about himself and the girl he spoke to shows the difference in the recovery time between patients. This variation was also true in terms of time taken for pre- and post-surgical orthodontics. Among the participants in the study who were interviewed, no two patients were found to have had the same amount of time taken for pre-surgical orthodontics, post-surgical orthodontics or recovery following the surgery. This clearly showed that the recovery process varied from person to person.

In this section, it has been shown how temporality played a major role in normal facing. Time, we have seen in Section 4.6, is an important parameter along which the shape of the status passage was shaped. The horizontal axis of the graph representing shape of the passage represents time (in days or years). While time is the medium in which normal facing occurs, there are other factors that can influence the shape of passage. These factors were identified in this study as the next major category and are detailed below.

4.8. Factors influencing the shape of the passage

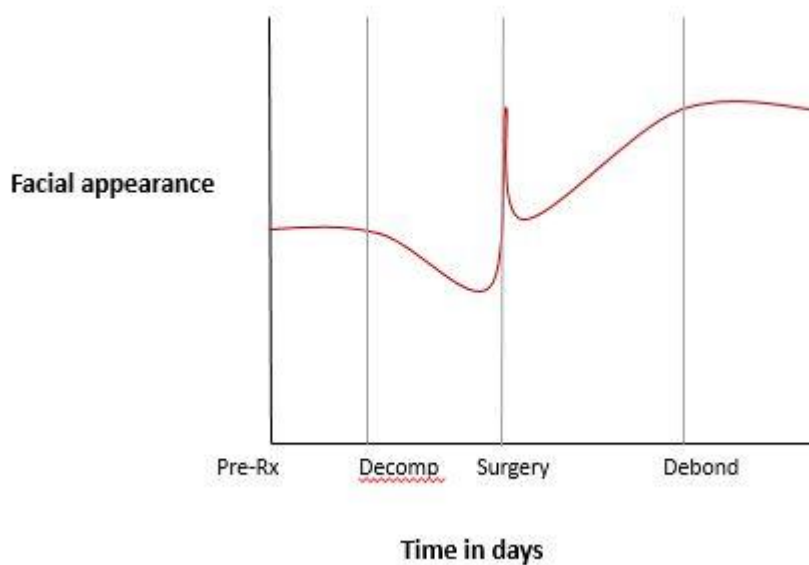
It has been established in Section 4.6 that the shape of the passage is influenced by various controlling factors and the balance of control over the passage. We have seen that the horizontal parameter on which the shape of the passage is plotted is time. This parameter of time and organising of time has been discussed in the previous section. The data obtained in this study revealed that the shape of the passage was influenced by various factors as showed in Figure 22.

Figure 22: Factors influencing the shape of passage



The data revealed that the shape of the passage through orthognathic treatment had a couple of peaks and valleys. The x-axis of the graph shows the time taken for the status passage to complete in days and the y-axis of the graph shows the direction of the status passage, which is called facial appearance. Facial appearance is an umbrella term used to include all the facial changes including dental, skeletal and soft tissue changes that occurred through the process of orthognathic treatment.

Figure 23: Graph of shape of passage of a patient's orthognathic experience



The shape of the passage is a peak and valley graph (See Figure 23). When the patient entered the status passage their perception of their facial appearance/normality of appearance and function were at a certain point between the least and the best outcome. This continued to flat line until treatment began in the form of decompensation teeth movement through pre-surgical orthodontics. During this phase, the concerns of the patient in terms of both function and appearance dropped down further.

“My bite got extremely difficult towards the op, you could noticeably tell that things were increasingly difficult to eat, just because of the way that the teeth had been positioned into to ultimately then get moved.” (Rob, 30 years, Male)

However, patients reported that their psychosocial concerns did not worsen because they felt like people would understand that at least he/she is doing something about it.

“So I was seeking treatment by then and so I felt kinda better once the braces was on so then you are part of every one else and everyone else has had braces, now it's your turn and even if they notice something to do with your jaw, they will also notice the braces and the fact that it's going to change and it's not permanent.” (Lisa, 22 years, Female).

The above quotation appeared to be of significance for two reasons. It showed how Lisa had psychological satisfaction of having dealt with her facial appearance concerns and the braces on her teeth would testify to the world about it. The second and major significance rests in the way Lisa who started her sentence referring to herself as 'I', an isolated individual, and then as soon as she states the braces are on, she refers to herself as 'you' - a second person reference. This clearly suggested the change Lisa felt - including herself as part of the 'rest'. This observation pointed in the direction of a status passage that occurred along the process leading up to orthognathic surgery and further.

Following the orthodontic decompensation, on the day of the surgery, the perception of facial appearance raises to a point higher than where it started off. This is plotted as a peak in the shape of the passage because the swelling and bruising does not occur until the following day after surgery (Laskin, 1985). The height of the peak should correlate with the patient's perception of improvement in facial appearance, functional ability and self-perception. However, the patient is often under the influence of general anaesthetic on the day of the surgery and may not necessarily have any perception regarding the facial appearance. It was often cited that a next of kin or a friend took photographs of the patient on the day of the surgery after the surgery.

“My children actually took a photo of when I was kinda around... I didn't go down well, mid- afternoon, so I wasn't coming around properly until after early hours of the following morning , my daughter took a photo when I was still coming out of the anaesthetic and I was .. I wasn't swollen at all, I was just normal.” (Kathy, 52 years, Female).

Following the day when the patient was fully awake and alert, the swelling and bruising would have occurred. The swelling was found to maximise during 24 – 48 hours post-surgery. Hence, there was a step fall in the facial appearance and function. It was on this day most patients were fitted with a wafer or elastic bands to secure the maxilla and mandible in their new position.

“I have got bands and everything like locked together and you can't talk that's things were you struggle.” (Kenny, 19 years, Male)

The intermaxillary fixation tend to be removed after one week. Participants reported better recovery after this point and as a consequence the graph is drawn to illustrate a gradual raise in how they rated their facial appearance and function. The raise finally reaching the same level as on the day of the surgery. Very often this corresponded with the time of debonding the orthodontic brackets and the time when all the swelling and bruising has subsided.

“It wasn’t until the swelling went down (the new appearance sinking in)” (Kathy, 52 years, Female)

Finally, the graph plateaued without bringing about any further change in the person’s facial appearance or functional abilities. The plateau nonetheless would appear to continue until the patient accepts the change and completion of status passage is acknowledged by the person. The time at which completion of status passage occurs was found to be different across individuals. Consequently, the shape of the normal facing status passage depended largely on the patient’s expectation and acceptance of change unlike the status passage that corresponds to the active treatment pathway, which begins and ends with the hospital appointments.

The shape of the passage was subject to changes based on various factors that controlled it and also based on the balance of control maintained between the passagee (the patient) and the agents (dental care professionals and social support). In the following section, all the factors that influence the shape of the passage and the agents that control the passage will be detailed; explained using quotations from the data.

4.8.1. Recovery

The recovery period of the patient following orthognathic treatment was found to influence the patient experience of normal facing and the shape of the passage. Referring back to Figure 12, ‘Recovery’ is an important milestone in the normal facing timeline because of the pivotal role it plays in governing patient’s experience of normal facing. In the previous section 4.7, we have seen how the temporal element of recovery influenced the shape of the passage. The other dimension of recovery that influenced the shape of the passage was the patient’s perception of recovery as compared to what they expected. .

Patients had a basic understanding of what to expect during the recovery period in terms of pain and discomfort. This was discussed briefly in Section 4.5. However, the

actual period of recovery dealing with the physical and functional discomfort was found to greatly influence patient experience. The day following the surgery was identified as the worst day of recovery and we have seen how the shape of the passage took a steep dip due to this in Section 4.6.

“The recovery isn't nice, but it really really is worth it. There was a lot of swelling for the first couple of weeks, but obviously it goes down so if you do decide to have it don't worry too much about that! The liquid diet is really frustrating (especially when your friends and family sit and eat in front of you >.<), I had my jaw surgery in mid-November and started eating proper meals again the week of Christmas, so about 4 weeks I guess. You kinda live off soup and build-up milkshakes for a while (and even soups were too thick for me at first >.<), but I definitely wouldn't change it because it was worth it.” (Liv1204, online, <https://www.thestudentroom.co.uk/showthread.php?t=1603029>)

It was found that majority of the patients reported that they were happy about having orthognathic surgery when they reflected upon the experience leading to normal facing. However, during the days of initial recovery many patients reported to have questioned their decision and regretted it simply because of the pain and discomfort they suffered. The pain and discomfort they went through had a direct impact on their quality of life.

Well I had pain where I had like tube things out of the side of my neck, after I had surgery done and when they were pulling them out I was like oh I regret this and then the pain afterwards I didn't know the extent of how painful it was. There were a lot of times when I was like I wish I hadn't had this done because of the pain. When I got back from hospital, the first week of eating as well I was just like I regret this. I had so much medicine as well, I was taking like four doses a day of three different things so that was horrible. I was regretting it then as well, but as the pains gone down I don't really regret it anymore. (Jen, 18 year, Female).

Jen was interviewed 8 weeks post-surgery and had not completed her post- surgery orthodontic treatment. She had a clear recollection of her recovery period and was able to compare her expectations of the recovery period to what she experienced. For the same reason, it was also found that among the three different groups of people who were interviewed in this study the short-term follow-up patients who were 8-12 weeks post- surgery were the ones who discussed the recovery period at length. In contrast, the long term follow- up patients or the 1-2 years post-surgery patients did not highlight the recovery period as much.

This finding was similar to the patients who wrote blogs very promptly updating their clinical recovery and emotions about recovery on the blog.

Here is a post on a blog by a patient 3 years post-surgery:

“I am so sorry it’s taken so long to post an update. But please look at it this way: life does go on after double jaw surgery. It’s not perfect... but you don’t think about it enough to update your blog! For a couple years I was responding to every comment and then, I got a new phone, didn’t download the Wordpress app, didn’t get the notifications for new blog comments and just forgot.” (R., Female, Online: <https://roxsjawsurgery.wordpress.com/> , almost 3 years later!)

Now, below is a post by this very same girl on Day 18 following her surgery and her posts were very continuous until day 15, which is the previous post, mentioned in the quote:

“My swelling is pretty much the same now as when I last posted. I guess from here on it’s going to be very slow progress. I still have about 10% of swelling left but as you can see [photo attached to the post], nothing anyone would notice. But I can feel it. It’s very thick around my nose, upper lip and chin, in the jowls and beneath my jaw. But I look good enough to be out in public and my bruising is all gone.” (R., Female, online: <https://roxsjawsurgery.wordpress.com/2013/03/23/day-18-rox-the-great-and-powerful/>)

It was not only R.'s recovery that was slowing but also the frequency of her update on the blogs. This implied that as the pace of the recovery slowed down and recovery was nearing completion, patients felt less of a need to talk about it. The importance of the recovery phase in their lives seems to fade away. Whilst the recovery was directly related to the active clinical active treatment pathway, completion of recovery also implied completion of normal facing. The reduction in the frequency of discussing the experience of the passage suggested completion or acceptance of the change. Similar findings was also found in other status passages. For example, becoming a new mother has been well recognised as a status passage (Fenwick et al., 2009). We have seen that there are a number of local support groups, online websites and support forums for new mothers to discuss their experiences and concerns (e.g. Netmums.com, momsupport.org, postpartumprogress.com etc.). However, once the new mothers settle in to their new status of being a mother, they slowly became less involved in discussions and support groups. Likewise, people in the normal facing status passage also wean off from taking part in the active discussion forums as they settle in and accept the change that occurred through the status passage.

It was also observed that people discussed and sought advice from others whilst they were in the active treatment phase of the status passage in order to seek support from others in similar status passages. New mothers sought support from one another, likewise, patients who were recovering from orthognathic treatment sought support from others who also were in the treatment pathway. This indicated that social support also played a role in recovery and in turn it helped shape the passage. Social support played a major role in normal facing status passage and it is detailed further in the coming section.

4.8.2. Social support

“I never actually had any counselling (about bullying) or you know never sought any professional help at all. But just to talked to my mother.” (Marie, Female, 66 years)

In this example, we can see that Marie despite suffering from bullying did not receive any formal support. She relied heavily on the support of her mother. This indicates the centrality of social support in the experience of the condition. This social support was

also found to influence the patient's passage through orthognathic treatment not just during the active treatment phase but also much before and much later after the completion of the active treatment. The support patients received from friends and family helped them cope with the harsh experiences of being bullied as children due to their visible difference.

The support and reassurance they received help counter act the negative emotional effect of bullying. On the other hand, people who lacked adequate social support were found to have emotional scars that reflected poor self-confidence.

"I was not the most confident person as a child" (Mia, 28 years, Female)

Social support was found to play a determinant role all throughout the normal facing - status passage. We have already seen the influence of social support in decision making for orthognathic surgery. Further patients have reported the positive influence of social support during the periods of recovery. This indicated that social support played a central role in the status passage and it was one of the controlling agents in the shape of the passage.

"My advice to anyone considering orthognathic surgery is make sure you have a good support group behind you so that when you are going through those first few days they are there to lift you up and take your mind off things for a while and also to bully you into going for walks, going into public. I could not have done this without the support of my family. Walking was very good as it eased the tightness around my face and made me feel more normal. Also, drink lots. I started off with a straw but found this incredibly difficult and so soon just started drinking straight from the cup. Messy but easier! Go into this operation with a positive attitude and expect it to be hard. You will come out the other side and the more positive you are the quicker you will get back to normal." (metalmouthedmedic – 18 years, Female, <http://www.archwired.com/phpbb2/viewtopic.php?t=33682>)

From the above quote, it was clear that orthognathic patients valued the support they received during recovery so much that they wanted to recommend having a support group to future patients. This knowledge of necessity of social support while going

through orthognathic surgery is so well established that most information leaflets given to patients emphasises the need for social support when deciding about orthognathic treatment (British Orthodontic Society). The results of the present study were in line with the existing knowledge.

One of the patients in the long term follow up after surgery group said:

“My friends told me that when they saw me it was like seeing a child grown to an adult because I looked like before in some ways but still not the same” (Lisa, 22 years, Female).

On completion of treatment, patients were found to seek the opinions of their friends and family about their new face. The above quote shows that the approval and recognition of their original identity by their social group is important to them. Whilst the expectation of the patients entering the normal facing status passage was to have an improved facial appearance, function and self-perception, they also did not want to lose their self –identity because of the active treatment pathway. Patients turned to their social support system to ensure that their identity was preserved and their expectations were met as a result of the treatment. These finding from the study clearly showed that the patients perceived changes are more than what was clinically seen and a broader change certainly happened beyond the active treatment pathway.

4.8.3. Role of dental care professionals

Dental care professionals included orthodontists, oral and maxillofacial surgeons and the patient’s own dentist. They were found to play a major role in enabling the active treatment pathway. The active treatment pathway entailed a great deal of doctor patient relationship, very often the agent – dental care professionals controlled the passage more than the patients themselves did. Then again, as mentioned many times earlier, active treatment pathway is a status passage which only a part of the broader normal facing status passage.

*“They are the expert so I have listened to everything they have said.”
(Millie, 17 years, Female)*

In the above quote, Millie’s acceptance of the dental care professionals as the experts in the field and willingness to comply with their decisions for her clearly indicated the doctor- patient power relationship. Therefore, dental care professionals were a

controlling agent of the active treatment pathway and hence influenced the shape of normal facing status passage.

In the earlier sections on awareness and decision-making, we have already seen how the role of dental care professionals influenced normal facing. All of the factors above directly or indirectly influence the shape of the normal facing status passage. However, one needs to acknowledge that the role of dental care professionals became crucial to shaping the normal facing status passage only when the patient decided to enter the active treatment pathway during the course of normal facing. In the case of a person who refused orthognathic treatment or any other alternative treatment and proceeds with normal facing, dental care professional do not act as a controlling agent.

"I don't exactly have an underbite... my teeth meet exactly. Looking at my profile, I could benefit from orthognathic surgery (the very suggestion made me put off visiting another orthodontist for 18 years!) But I'm not going with the surgery.. [] The jaw change from surgery would really be very minimal, and I don't really want an Extreme Makeover. Has anyone else decided "no, thanks... surgery's not for me and I'll just go with the straight teeth, thanks!" (Valster, online: <http://www.archwired.com/phpbb2/viewtopic.php?t=15100>)

In the above example, Valster refused surgery and said that he can live without undergoing orthognathic surgery. In this case, the only role of the dental care professional was in giving the option of orthognathic surgery as a treatment option and not a direct role in the shaping of the normal facing status passage.

Apart from these factors, the other major concern patients raised in this study was about how the system within which the dental care professionals worked had influenced their orthognathic status passage.

"I feel sad that it was not picked up earlier by my dentist. If I was told then and given that opportunity to have surgery when I was younger I would have gone with it when I was younger" (Kathy, 54 years, Female)

"In my early teens is when I originally had my brace on. For few years then, umm went through all that... surgery was mentioned but was

never really pushed. Umm had all the treatment umm unfortunately I was passed from person to person and was not dealt with properly. And the treatment kept going back and forth and it wasn't progressing. So it wasn't dealt with correctly.” (Emma, 26 years, Female).

It was found that many patients complained about being lost in the system. Especially older patients who expressed concerns about how they were not offered orthognathic treatment earlier when they would have clearly benefited from a smoother recovery and lesser number of years with the face they wanted to improve. In vignette 1- we saw that Marie was seen in the hospital in her thirties for a possible orthognathic treatment. However, the hospital failed to get back to her and commence treatment. Instead, she had to wait for another 30 more years to finally get her jaw concerns corrected. These findings clearly indicated that in the past the role of the institution of dentistry and dental care professionals played an active role in determining the beginning of the active treatment pathway.

4.8.4. Information, preparation and control

We have seen the role of information in decision making in the category – decision making. Information about the treatment and what was involved during each stage of the treatment played a major role in shaping the passage through orthognathic treatment. Information enabled the preparation of patient expectations concerning certain occurrences during the course of the normal facing. However, in this study most of the data obtained about information and patient preparation was pertaining to the active treatment pathway. The presentation and interpretation of information affected how prepared the patient was. How prepared they were depended on how informed the patient was at the time of an occurrence. It was found that patients felt more in control of the situation when they were more prepared. In the following example, we can see how Ester felt a lack of control as a result of not being prepared.

“When I woke up from surgery I knew I'd been sick and I was sick loads of blood and I was terrified because I thought I didn't know where this blood was coming from, I thought I was dying because I was being sick blood and I couldn't ask anybody because it was just coming out and then they said afterwards oh it's just normal it's the

blood that you've swallowed in surgery and I just thought why didn't someone tell me that before I had the surgery because when it actually happened and I was sick loads of blood I didn't know what was going on I thought I were dying and I just thought someone could have at least told me that that's what happens" (Ester, 19 years, Female) .

A sense of being in control greatly influences the patients' experience of orthognathic status passage. Similar findings about "psychological preparedness" and sense of control has been reported in the field of psychology and post-traumatic stress (Basoglu et al., 1997), child birth (Kimber et al., 2008) etc. Within orthognathic surgery literature, the role of information has been reported in relation to decision- making for surgery (Flett et al., 2014, Stirling et al., 2007).

The online forums and blogs on orthognathic surgery were found as a testimony for the importance of information needed by the patients during orthognathic treatment. People asked questions to others who have had surgery and are going through the treatment process to seek more information about what to expect and verify if what they are experiencing is unusual.

4.8.5. Impact of orthognathic surgery, quality of life and shape of the passage

The impact of orthognathic surgery was found to be a major sub-category that influenced the shape of the passage. Different types of impacts of orthognathic treatment were identified in this study. They are broadly classified to functional impacts, appearance related impacts and psychological impacts.

For example, Rob a 30-year-old male found the pre-surgery orthodontics to have negatively impacted on his functional abilities.

"My bite got extremely difficult towards the op, you could noticeably tell that things were increasingly difficult to eat, just because of the way that the teeth had been positioned into to ultimately then get moved." (Rob, 30 years, Male).

Similarly, patients also suffered from negative psychological influences as a result of the pain and discomfort during the orthodontic treatment before and after the orthognathic surgery.

“The pain from wearing the brace ... things like when it cut your cheeks and small things... Sometimes when it’s been going on for a while you get a little bit fed up and sometimes u think oh did I do the right thing ... deciding to wear it again but you know in the end that...”
(Mia, 28 years, Female)

It was not always a negative impact, which patients perceived as a result of orthognathic treatment. It was found that the interim negative impacts of the treatment process was acceptable for the patients because they saw the light at the end of the tunnel in the form of a positive outcome of the treatment process. It was found that most patients mentioned “all that was totally worth it!” when asked how do they feel after having completed treatment.

“I’d been focussed on my appearance and I didn’t realise how much of a difference it would make to how I feel in general, I’m much more confident, more confident at work and much happier, my face now resting seems smiling so I don’t feel self-conscious about that.” (Emma, 26 years, Female).

In the above example, Emma speaks about the appearance related impact and its indirect psychological impact she experienced following the treatment.

It was found that the various types of impacts orthognathic treatment ultimately influenced the quality of life of the patient during the course of their normal facing status passage. Nevertheless, quality of life being a latent construct, it was not something patients spoke of directly while in the active treatment phase. Therefore, no reference to the quality of life was obtained from the semi structured interviews. Conversely, reference to quality of life was used in the written language of these patients who underwent orthognathic treatment which was obtained in the online data.

“This surgery has improved my quality of life in a few ways I expected but also in a lot of ways I didn’t expect. Those mysterious ear aches I got before surgery? Haven’t had one since. Used to be that cold or hot wind caused an ear ache and I haven’t had that since. My neck feels more relaxed at night when I lay my head on my pillow. I didn’t realize that my neck could be affected by the structure of my face! Also, I am enjoying biting into things I never dared to before with my

open bite. Here are just a few of the things I can bite into that I had to cut into small pieces before surgery.” (R. online, <https://roxsjawsurgery.wordpress.com/>, day 365).

In the above quote, we see that unexpected changes that occurred as a result of the orthognathic surgery positively influenced R’s quality of life. It was not only the psychological perception of the patient which made unexpected positive changes but unexpected clinical outcomes also made a positive influence on patient’s quality of life. We also notice that R does not fail to recognise and use the phrase ‘quality of life’ to describe the positive impact of orthognathic treatment.

In this study it was found that the a positive impact and the latent better quality of life reflected as a peak in the graph showing the shape of the passage and a negative impact and poorer quality of life caused a dip in the graph. In Figure 23, the sharp dip in the graph on the day following surgery corresponds to the negative impact of surgery in the form of hospitalisation, pain, swelling, discomfort and inability to eat causing reduced quality of life. On the other hand the peak on the graph around the time of debond represents positive appearance related, functional and or psychological impact that improved the patient’s perception of their quality of life. Orthognathic surgery and its related quality of life has been widely studied in the past and these will be discussed further in the next chapter.

4.8.6. Life priorities and its influence on the shape of the passage

The life priorities of the patient have already been discussed in a couple of previous categories. Life priorities were seen to influence the decision-making process with regard to the patient awareness and temporality of the decision. Life priorities were also found to have a role in controlling the shape of orthognathic status passage. The patient’s life priorities were found to influence the time dimension of the shape of the status passage more than the vertical direction of the passage.

For example, Jen spoke about declining the first date she was offered for her orthognathic surgery and postponing the surgery. In the following quote she gives a reason relating to her life priorities

“I thought I’m not having it because I had so many exams to get in to university and everything and I knew it would be a lot of time spent

going to hospital so I was like worried about that, affecting my education and everything.” (Jen, 18 years, Female).

Jen, a young student aspiring to study at a university prioritised her education over completing orthognathic surgery. By declining the surgery on the first date provided she essentially increased the time taken for completing orthognathic treatment. Her decision to prioritise her exams over surgery extended the horizontal x-axis representing time on the shape of status passage graph.

It was also found that some life priorities make patients call off orthognathic treatment for an indefinite time and get back on the status passage at a later time. This was discussed in reference to unforeseen circumstances in the Section 4.7. One such example was found in an online forum discussing unexpected pregnancy during the course of orthognathic treatment.

“This is why I had to call off jaw surgery... Twice! You will have to stop breastfeeding for at least a few weeks so for that reason my surgeon did not want me to have the surgery until the baby was at least a year old. Now my youngest is 17 months old so I am considering surgery again. (Stargirlxx, online, <http://www.archwired.com/phpbb2/viewtopic.php?t=44240>)

The effect of such life events are unpredictable on the shape of orthognathic status passage. However, it was certain that these life priorities majorly influenced the time dimension of the shape of orthognathic status passage.

4.8.7. Quality of care provision and shape of the passage

Individuals in the active treatment pathway received care from the hospital approximately for 18-24 months during orthognathic treatment and then for less frequent follow –up appointments. It was found that the quality of care provision influenced the shape of the normal facing status passage by directly influencing the active orthognathic treatment status passage. The various aspects which contributed to the quality of care provision were: i) hospital personnel, ii) information and support provision, iii) schedule of appointments a recall and iv) additional support such as dietitian and counselling services.

The approach and type of care provided by hospital personnel not only during the in-patient stay but also during each orthodontic or oral surgery appointment was important to how the patients experienced orthognathic treatment. The rapport patients build with the hospital staff enables to them to build trust which gave them a sense of “being in it together” as Becky, a 22 year old female patient, said in her interview during a long term follow-up appointment at the hospital.

“Everybody I met in Charles Clifford has been lovely and kind” (Roz, 23 years, Female)

The quality of care provision was not separate from the information provision, which patients expected from their care provider. In the previous chapters, we have discussed the importance of this information for patients undergoing orthognathic treatment. However, it was the information, which was given to them by the care provider that was most trusted, and the support received from them made the status passage easier.

The support given by the care provider in the form of help and understanding of the patient’s personal circumstances in scheduling the appointments and recall for hospital care determined the patient’s perception of quality of care provision.

“I think like at first it (date of surgery) was meant to be earlier on in the year but then that would have got in the way with College and everything so they changed it so, now if I get in to University it will be a lot better because I’ve had time to recover over the holiday” (Jen, 18 years, Female).

The participants in the semi-structured interview all stated that they benefited from the provision of having a dietitian who advised them before the surgery about the diet they could be on following the surgery. However, there was no provision for a psychologist or psychiatrist available at the time on a routine basis. During a multidisciplinary team meeting, the orthodontists and oral surgeons in Sheffield had agreed that there was a need for a psychologist to be on the team to help patients who required support.

4.8.8. Individual’s age and its influence on the shape of the passage

Participants in the semi-structured interviews identified the advantages and disadvantages of having orthognathic treatment in relation to their own age.

“Someone said it will be alright, but a lot of them said it was all difficult but I was thinking is it because they had a longer recovery... and that... because they are older that they struggled to cope with operation and majority of young ones I watched, they recovered quickly... so I thought because I am younger I did recover quickly as well. So it made me decide that I wanted to do it.” (Kenny, 18 year, Male)

An age related connection was made as to when would it be best to have the surgery. For the younger patients it was because they could recover faster and it was acceptable to have orthodontics when they were young. On the other hand for the older patients, it was because they had more time in hand and got all that was important to be done out of the way.

“Because that was something that I always wanted doing. Umm and once I knew it could be done, then... I felt yeah I ... I have got only this one chance and at my age, if I had decided no ...then that would be... I could have been living with a regret so umm because I felt I wanted umm you know they are not going to offer it to me again, so if I said no at that stage then I would not have another chance to have it done.” (Marie, 66 years, Female)

But in the case of Marie, for her it seemed to be the last chance to get what she always wanted. Now that she was retired and had so much time, Marie stated it was a good time for her to get it done although she acknowledges her age being a risk factor for such a surgery.

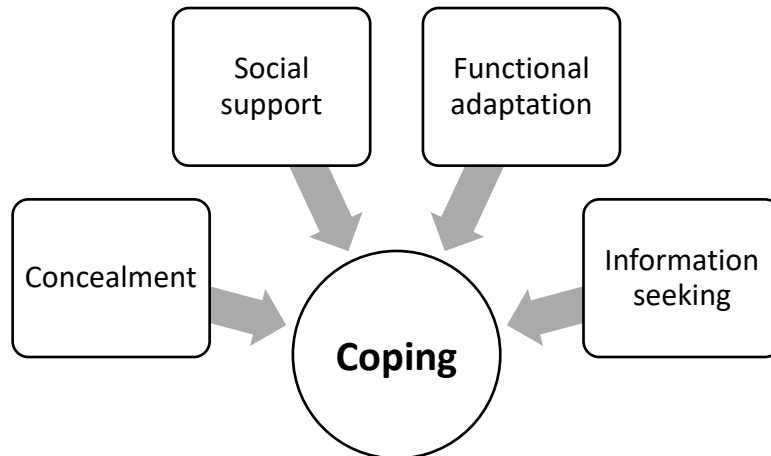
This sub category – age of the patient - also very closely related to the sub category life priorities because these are greatly dependent on the patient’s age. For example, for a younger patient, life priorities usually are education, exams, career and university admission; whilst for a middle aged person it may be work, family life and children.

4.9. Coping behaviours in normal facing

Patients who underwent orthognathic treatment, as established previously, were faced with many adverse life situations starting from childhood bullying to recovery from

major surgery. Coping was found to be a behavioural response of patients to such adverse life situations. Therefore, this category on coping was identified to have an influence on orthognathic treatment experience of the patient. Various internal and external factors helped shape patients' coping behaviour. Figure 24 shows the coping behaviours that helped patients cope during their orthognathic treatment passage.

Figure 24: Coping behaviours



4.9.1. Concealment as a means of coping

Concealment was identified as a behaviour adopted by people to cope with the jaw structure related concerns. People were found to use various means to mask their concerns regarding their jaw structure. Behaviours were adopted to conceal both functional and appearance concerns. To mask appearance females adopted methods such as wearing heavy makeup and hairstyling such that the jaws were concealed. Males might wear a baseball cap and males and females alike covered their mouth with a hand while smiling or laughing, or avoided smiling and laughing in public.

“I had driving lessons at the time and I always used to make sure that my hair was down because he always used to be looking at me from the side to see that I was checking my mirrors and everything when I was driving, I hated it so I used to have... I had a fringe and I made sure that my hair was down covering that side of my face that he was looking at and he noticed, he said why have you always got your hair covering your face, is it because you're not checking your mirrors properly and you don't want me to notice?” (Ester, 20 years, Female)

“I'd cover my mouth quite often when I smiled or talked, I'd make sure I could only be photographed from certain angles [] I avoided lots of social situations” (Emma, 26 years, Female)

“I didn't like really anybody come too close to me coz I was very embarrassed and always had my hand over my mouth.”(Kathy, 52 years, Female).

Functional concerns were mainly eating – chewing and biting and some speech difficulties. It was found that people often avoided eating in public places like restaurants since they were very self-conscious about eating in front of others. The masking behaviour most people adopted especially if they had an anterior open bite was to cut food that were required to be bitten into like sandwiches or apples into small pieces and chewed it with their back teeth. Others who had difficulty chewing covered their mouth with their hand while chewing.

For example, Mike, a very shy man who had decided to undergo orthognathic surgery, stated that he avoided going to any restaurant. Below is a segment of his interview:

N: can u think u of a particularly difficult situation and how do you deal with it?

M: probably something like... going to a restaurant maybe?

N: you wouldn't go out to a restaurant? Never?

M: I did go when I was younger not anymore

N: so if somebody asked you to go out for socialising or so how do you cope?

M: probably make an excuse yeah” (Mike, 28 years, Male)

Mike adopted an avoidance type of coping mechanism to deal with the difficulty he had in chewing which was a functional concern.

Actively concealing the areas of concern, be it appearance or function, was a behaviour adopted by most patients in their pre- surgery days. However, the exact opposite behaviour was seen in these patients after the completion of the status passage. Patients who did not bother with personal grooming especially style and makeup were

found to pay more attention to these. For example, a 38-year-old female participant stated that she took more interest in grooming herself after completing the treatment.

“I take more interest in my appearance now. I never used to wear any make up on...I haven't got any on today... but I now take more pride in doing that. That sort of daft stuff (laughs). While before I thought I am not going to take any pictures coz I will not smile, so I will not bother doing this stuff”. (Suzie, 38 years, Female)

It was not only make up but also general personal grooming that people were found to take active interest in following the completion change they expected to obtain through orthognathic treatment. Likewise, in Vignette 2, the 22-year-old Lisa, had found that her life positively changed a lot when her facial appearance changed as a result of the surgery. She had stated that since the surgery she paid more attention to keep her teeth clean and healthy while before the surgery she did not bother to do so with the view that they were already not looking great so why bother. Therefore, as result of the status passage – normal facing, it was seen that people did not conceal their dental and facial features but instead they highlighted them and projected them more in their daily lives.

4.9.2. Functional adaptation as a coping behaviour

Functional adaptation was another subcategory that was identified to influence the patient's coping behaviour and was very closely related to the previous sub category – concealment. While concealment dealt with masking patient's concerns, functional adaptation was a behaviour learned by the patient in order to make the best use of their altered jaw structure. In the previous subcategory, behaviour of the patients such as cutting food that required biting into and chewing with the back teeth was discussed as a masking behaviour. However, such behaviours were adopted by patients not only to conceal their functional impairment from society, but also as a behaviour they had to adopt in order to carry out the function of chewing and biting effectively.

It was also found that very often patients were unaware of the different functional adaptations they had done before completion of treatment to be able to chew, bite, and speak efficiently. Sometimes patients themselves were aware that they had made a functional adaptation to their jaw and teeth structure.

“Not that I have noticed [any problems with chewing and biting] but it is probably because I learnt to bite a certain way because of the way my teeth are.” (Will, 20 years, Male)

Patients with temporomandibular joint disorders that caused pain and dislocation of the joint adopted palliative measures, as advised by their dentists. These palliative measures were also functional adaptations made by the patients in order to retain function and prevent pain from the temporomandibular joint.

Functional adaptations do not limit to the period before surgery but patients were found to make different functional adaptations following the surgery during the recovery period as well. Since some functional impairments are predictable as a result of swelling and bruising following the surgery, the surgical team advises an appointment with a dietician to guide them on nutritional requirements immediately after surgery. The dietitian also provides the patients advice regarding what type and consistency of food they can be having while their jaws are wired shut during the one week after surgery. This was often liquid diet and soft food in the subsequent days. This dietary adjustment was also a form of functional adaptation made by the patient.

The role of functional adaptation continues all through the process of patients recovery from the surgery because the patient now had to adapt to a new jaw position and structure and learn to function using them. Therefore, functional adaptation was found to be a coping behaviour that played a key role in the patient’s experience of orthognathic treatment.

4.9.3. Social support to aid coping

This sub category on social support has a great influence on the patients coping behaviour. Social support has already been discussed as a sub category that influences decision making and acts as a controlling agent in the status passage. The influence of social support on coping with orthognathic passage was identified at the very beginning of the passage – when bullying made them aware of an underlying visible difference.

“I wouldn’t have dealt with it half as well as I did if my mum was not with me, I am from a pretty close knit family” (Lola, 21 years, Female).

People were reliant on their support system to a large extent to cope with difficult situations and the above quote clearly shows the importance of family for coping with stress. For some people the social support also came from friends who were with them through the time of recovery, help them communicate when their face was swollen shut and could not talk and be there to get through recovery.

“I got support from everybody actually. It was good to know that people were there supporting me. And after surgery as well.” (Kathy, 54 years, Female)

Nevertheless, support received from near and dear ones provided patients with a ‘good feeling’ even when they were going through a scary surgery which would change their face –their identity.

4.9.4. Information seeking to enable coping

Orthognathic surgery patients were often found to seek information from various sources as a method of coping with the various worries and concerns they encountered. This was identified as a type of problem solving behaviour. One of the classic examples of information seeking behaviour was numerous blogs and forums available online on orthognathic treatment. These were made of vast number of patients to obtain more information about their concerns, share and obtain answers for their questions.

Yet another source for information seeking was directly from the dental care professionals.

“Definitely talk to your ortho about it. If I were you, I would already tell your ortho this afternoon because it may reassure you to know what solutions there are.” (Anna5, online <http://www.archwired.com/phpbb2/viewtopic.php?t=44240>)

The information obtained from the orthodontist and oral surgeon was trusted and this information enabled patients to cope with the situation. However, many patients still coped by means of information gathered from other people’s experience of orthognathic treatment. As mentioned earlier, the online forums and blogs are a testimony for this type of coping behaviour.

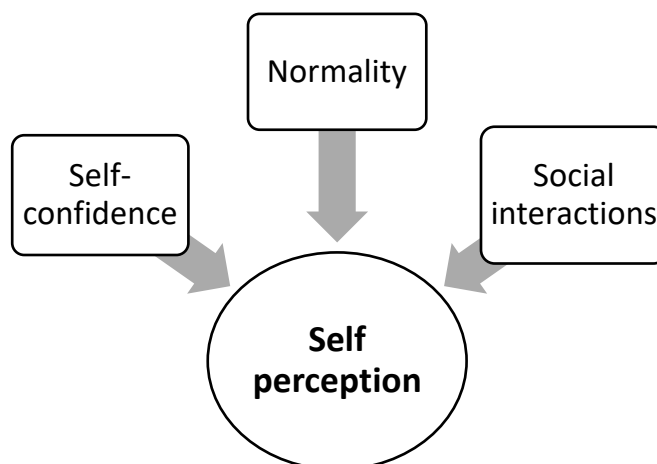
In summary, orthognathic patients adopted various coping behaviours to deal with the facial visible difference, the treatment process and also the outcome of the treatment. This was not a new finding and was consistent with some of the earlier studies in the field of orthognathic surgery (Alanko et al., 2014).

4.10. Self- perception

Self-perception was found to be the ultimate category, which determined the effect of the orthognathic treatment passage. Self-perception was the umbrella term used to represent all the feelings about ‘self’ which the patient had all throughout the status passage. This included self-confidence, self-esteem, self-worth and self-image. However, being a GT, as part of conceptualising findings from data, the best fitting concept was named as the category, which was self-perception. Patient satisfaction was found to be directly related to the patient’s self-perception at the end of the treatment. Patients expected the orthognathic surgery to: “fix my face”, “change my life” “be able to smile” etc. as found in the data. All these expectations were not quantifiable but were determined based on their own perceptions. Therefore, patient satisfaction would come from their perception of their expectations being met. After having gone through 3 years of treatment, patient satisfaction was a very important and well-deserved outcome for orthognathic patients. However, orthognathic treatment was meaningful for patients only if patients’ perception of their-self had improved.

Figure 25 shows the various aspects that were found to form a part of patient’s self-perception and factors that influence it.

Figure 25: Self – perception



4.10.1. Self- confidence

The data obtained in this study showed that self-confidence was a concept that was very often referred to by the patients when asked about their self-perception, expectation and outcome of the treatment. It was also found that early childhood experiences especially bullying greatly affected the self-confidence and self-esteem of many of these patients.

*“I felt very less confident, low self-esteem which I still have... (crying)
I am not the most confident person because of it (bullying)” (Mia, 28
years, Female).*

The effects of bullying has already been discussed in Section 4.4.1 (page 156). However, the lack of self-confidence instilled in these young minds was found to last for a very long time. This finding is consistent with previous studies in relation to visible difference (Rumsey and Harcourt, 2005).

*“Confidence was the main one really, I just didn’t...I would shy away
from myself and just didn’t want to draw attention to myself. It was
just self-doubt. I thought the people were just not looking at me but
my teeth. That was my focus point. And I was like... obviously I didn’t
want people looking at it wasn’t a pretty sight. [] after surgery my
confidence has improved a lot” (Becky, 22 years, Female)*

The main motivation and expectation of many patients who underwent orthognathic treatment was to become more self- confident and get over all their self-doubt and self- worth issues. While some patients did not realise that was a possible outcome of orthognathic treatment, they were positively surprised to find how much more confident they were after the treatment. Here is a quote about it;

*“I didn’t realise it would just make me feel much happier and more
confident in general, I’d not thought about that side of things, I’d been
focussed on my appearance and I didn’t realise how much of a
difference it would make to how I feel in general, I’m much more
confident, more confident at work and much happier, my face now
resting seems smiling so I don’t feel self-conscious about
that.”(Emma, 26 years, Female)*

Self-confidence was a positive treatment outcome for many patients who underwent orthognathic surgery.

“My name is xxx and I am 21 years old, I was 18 when I had surgery. I am a student now which is something I would not have had the confidence to do if I hadn’t had the surgery” (Lola, 21 years, Female)

This opening line in an interview clearly showed the impact of improved self-confidence in this young lady which was a result of successful orthognathic treatment. While for others, being a student would have been absolutely a ‘normal’ affair, for Lola it was not. She was able to do something which was so ‘normal’ for others only because of the confidence she gained after completing orthognathic treatment.

Self- confidence was found to be improved in all the patients interviewed in this study. Improvement in self confidence and self-esteem were also reported by Alanko and colleagues (2010).

4.10.2. Social interactions

‘A man is known by the company he keeps’ - but what if the man feels like a misfit in any company?

“It was like pretty hard getting friends, it looks like I'm really standoffish, I don’t know. It seemed as if I wasn’t interested in taking but sometimes I think, I don’t know I just felt so self-conscious about everything about my mouth, so that made me struggle making friends.” (Jen, 18 years, Female)

Social interactions were a major part of psychological wellbeing and therefore the need to belong was extremely powerful and persuasive motive for people (Baumeister and Leary, 1995). Lack of good social interactions also affected the person’s self-perception and personality traits like shyness was often reported by patients.

“Really self-conscious, particularly it was more noticeable in photos rather than the mirror for me but it was really off to one side of my profile but my jaw was quite far forward and when I smiled there was a lot of gum at the top so I'd just avoid photos being taken, I'd feel really anxious, I'd feel sick if someone else had a camera, if say I'd been on a night out and I'd log on to Facebook the next day and

someone had uploaded some pictures and tagged me in them, before even seeing them I'd start to get sort of sweaty and panicky and just feel dreadful. “ (Emma, 26 years, Female)

In the present times, social media is a large part of people's social life. The concerns which Emma had regarding her photos and being seen on social media was not only her concerns with the media self- image but it also stems from her difficulties in social interactions. Emma stated that her image in the mirror did not bother her but it was the photos. Photos are seen by 'others' when posted on social media but when it was her image in the mirror it was only her and her closest people who saw her image. However, direct and online social interactions were found to be difficult for many patients in the orthognathic status passage.

4.10.3. Normality

The patient's perception of what is 'normal' or normality had an influence on their self-perception. In this context, 'normal' stands for facial appearance, ability to chew or bite and feel similar to the rest of the society. Therefore, normality had a functional, appearance and psychosocial dimension to it.

“I always knew I had got an abnormal... to me abnormal looking jaw. I knew it was smaller than it should be, compared to everybody else. [] I just felt umm you know... looking in the mirror I didn't look normal, didn't feel normal.” (Marie, Female, 66 years).

After having the surgery she said about what she expected from the surgery;

“Well mainly the appearance, I mean the... I never had a proper bite, umm but I suppose that bite is all I had for all those years so it was something that I got used to. Just learnt to live with. But that now I realise, now that I have got a normal bite, and mainly a normal appearance...normal as anyone.” (Marie, Female, 66 years).

The above quote told a lot about Marie's self-perception. She strongly relates her self-perception to what was considered 'normal' and makes a direct comparison with others around her by saying "normal as anyone". This implied that normality was a relative term used by patients when they compared themselves with what was the cultural norm or what majority of the society considered normal. This understanding

takes us back to the role of expectations and motivations discussed in section 4.5.4 (page 170), where it was found that the motivation and expectations of patients were a blur between being internal and externally motivated because of the strong external influence of social norms on patient's expectations and motivations. Here we also see that social norms have an influence on the patient's self-perception.

Normality is a vast topic within the literature however within orthognathic literature reference to normal was often seen in relation to a population which did not require orthognathic treatment especially in comparative studies (Sinko et al., 2012, Rusanen et al., 2010, Williams et al., 2009). However, no studies to date have discussed the influence of normality in relation to orthognathic treatment. This is probably because normality is a complex and highly volatile concept within the social world.

The implications of the findings of this study will be discussed at length in the next chapter.

Chapter Five: Discussion

5.1. Introduction

This study explored the experience of individuals who underwent orthognathic treatment and developed a theory based on their perspectives on what is going on in this treatment pathway. Data were collected from face-to-face semi-structured interviews and from online blogs and forums written by patients. Data collection was done over the course of a year. GT methodology was used to analyse the data. The theory developed from this study was called normal facing and it was identified as the core category. Normal facing is a status passage experienced by a person who undergoes orthognathic treatment. The actual successful completion of normal facing was based on the individual's perception of change and acceptance of their face into their self-identity. The six other categories which were identified to have a direct relationship with normal facing were; initiation, decision making, temporality, factors influencing shape of passage, self-perception and coping (See Figure 12, Page 141). It was identified that the active treatment pathway is also a status passage embedded within the larger normal facing status passage. Therefore, the study identified that the completion of active treatment pathway does not coincide with the completion of normal facing.

The discussions about the findings of this study will be based on the GT and how it adds to the existing literature. Section 5.2 will discuss normal facing as a new theory in orthognathics. It will also discuss normal facing in relation to pre-orthognathic experiences of patients, decision making and impact of orthognathic treatment. Finally, Section 5.3 will discuss the various limitations of this study.

5.2. Normal facing – a new theory in orthognathics

This study aimed to develop a theory regarding what happens to patients who undergo orthognathic treatment. The current study was the first of its kind and is the second study in the orthognathic literature that used ground theory methodology for theory generation. The only other study that used GT methodology was by Sadat-Marashi and colleagues (2015), which explored the subjective perceptions and values of people who underwent orthognathic treatment in the past to resolve their visible difference. The core category identified was defined as the satisfaction of the participants with the treatment outcome despite their difficulties during the treatment. Unlike this

previous study, the current study explores the entire experience of individuals that entered orthognathic treatment pathway, beginning from the time of initial awareness of facial visible difference through the acceptance of changed facial appearance.

Normal facing was identified as the core category in this study, which was defined as the clinical and psychosocial process in which an individual's face, a major part of one's identity and self-perception, moves closer to being what they consider as 'normal'. This core category answered the research question – what happens to patients who undergo orthognathic treatment? In the past, various studies have explored the reasons why people opted for orthognathic treatment (Proothi et al., 2010, Brons et al., 2009, Rivera et al., 2000, Nurminen et al., 1999) and other studies have focused on the outcomes of orthognathic treatment – functional (e.g. Martin, 2011, Yamashita et al., 2011, Oland et al., 2010a, Pahkala and Kellokoski, 2007, Iwase et al., 2006, Phillips et al., 2004, Wolford et al., 2002, Panula et al., 2000, Hatch et al., 1998, Zarrinkelk et al., 1995, Proffit et al., 1989, Auerbach et al., 1984), aesthetic (e.g. Jesani et al., 2014, Sinko et al., 2012, Rustemeyer et al., 2010) and psychological impacts (e.g. Jesani et al., 2014, Cadogan and Bennun, 2011, Rustemeyer et al., 2010, Nardi et al., 2003, Hunt et al., 2001, Bertolini et al., 2000, Hatch et al., 1999, Kiyak et al., 1985, Auerbach et al., 1984, Kiyak et al., 1982b). While, these studies have been successful in recognising segmental information regarding patients' motivations and treatment outcomes, the current study, for the first time, was able to identify the core change that happens to individuals who undergo orthognathic treatment (normal facing).

As described in Section 4.3 and illustrated in Figure 14, normal facing is centred on the desire of the individual to attain 'normality' in physical appearance and thereby their psychological perception of the self. Studies in the past have reported to have obtained data relating to patients' desire for normality (Sadat-Marashi et al., 2015, Cadogan and Bennun, 2011). However, it has not been identified as the central motive for seeking orthognathic surgery. Then again, Cadogan and Bennun (2011), discussed the role of social comparison theory, and stated that patients undergoing orthognathic surgery engaged in upward comparison as they tended to compare themselves negatively with others. This finding was true in the current research, as a result of which patients desired to look and feel 'normal' in comparison with others by undergoing orthognathic surgery.

Further, this study also recognised normal facing was a status passage, which could also attain completion without entering active orthognathic treatment. A quantitative study among 105 patients who declined surgery found that these patients were equally dissatisfied with their masticatory function and dentofacial appearance as the patients who were operated (Hagensli et al., 2014). However, 23.8% of the people who decided not to have surgery, found it easy to decline surgery. In the current study, although no primary data were obtained from people who declined orthognathic treatment, from the data obtained it was inferred that normal facing status passage attained completion even among people who declined surgery, by their acceptance of their self-perception as ‘normal’ for them. Nevertheless, it would be worthwhile to explore further the experiences of people who decline orthognathic surgery to understand their pathway through the status passage in greater detail.

a) Other status passages that bear resemblance to normal facing

This is the first study that identified the orthognathic treatment experience of patients as a status passage and named the theory – normal facing. However, in dentistry, there has been one other study which identified a similar status passage relating to complete tooth loss (Gibson et al., 2016). In a GT study, data were collected from 20 edentulous people in New Zealand and analysed the social factors leading to tooth loss and their subsequent experiences of being edentulous. The experience for patients which led to complete tooth loss and becoming denture wearers was described as a status passage. This study revealed the importance of scheduling, prescribing, social factors, reversibility and awareness context of status passage into complete tooth loss. Similarly, in the current study, normal facing theory also describes the importance of scheduling, temporality, awareness of patients and the influence of social factors on the status passage in orthognathic treatment.

Studies from other disciplines have also discovered theories that are similar to normal facing theory and identified status passage in experiences of people in various walks of life (Tolhurst and Kingston, 2013, Fenwick et al., 2009)

Whilst normal facing theory is centred on the patient’s self-perception of normality, another study which identified a status passage bearing close association with a person’s sense of normality was among women who underwent a caesarean section during child birth (Fenwick et al., 2009). The core category identified was called

‘achieving normality’ after caesarean section and it was stated that all participants strove to achieve normality in different ways. This study also highlighted the relevance of the temporal dimension of status passage because of the choices and decisions of the mothers for caesarean section during child birth. These findings are found to be very similar to the current study, which also identified the relevance of temporality, patients’ desire to attain normality in the current theory. Interestingly, this was the only other study that has been found, which identified the role of obtaining normality as part of a status passage through medical intervention.

b) Active treatment pathway embedded in normal facing

In Section 4.3 and Figure 12, the ‘active treatment pathway’ was identified and represented as embedded in ‘normal facing’. The active treatment pathway in itself is a status passage where the person enters the passage as a patient, undergoes treatment and exits the passage by being discharged from the hospital, hence losing the status of being a patient. However, this status change did not always coincide with the completion of normal facing. Studies in the past have explored stability of treatment outcome (Farronato et al., 2015, Jakobsone et al., 2011, Kanno et al., 2008), patient satisfaction and quality of life, by means of long term follow-up beyond the active treatment pathway (Toviket et al., 2012, Espeland et al., 2008, Pahkala and Kellokoski 2007, Mihalik et al., 2003). However, the majority of studies in the past have been centred on the active treatment pathway. Similarly, in the current study, the majority of the data collection occurred during the active treatment pathway and few during long term follow up. This was justified because accessibility of data from orthognathic surgery patients is most practical when they are seen in the hospital for treatment appointments. This is the reason why most studies have also focused on the active treatment pathway.

Normal facing extends before and beyond the active treatment pathway. In the case of patients who decided not to undergo orthognathic treatment, normal facing occurs without the active treatment pathway. Hence, the current study, for the first time, recognised that going through the active treatment pathway is not always necessary for people with jaw related visible differences to attain normal facing in their own way. However, the details of what is involved in this type of normal facing needs to

be further explored. Details of the implication of normal facing in decision making will be detailed further in Section 5.2.2.

c) What normal facing theory adds to current knowledge?

This is the first study, which identified and developed a theory which details what happens to patients who undergo orthognathic surgery. Normal facing theory, for the first time, identified the actual change which orthognathic patients attain by passing through orthognathic treatment is being closer to what is considered ‘normal’. The theory of normal facing places emphasis on the perceptions of physical appearance and how these are judged to relate to ‘normality’. This ‘normality’ can be clinically measured and observed, although this thesis demonstrates that it can also be analysed from the patient’s perspective. The theory values and emphasises the patient’s self-perceptions. While studies in the past have identified the role of many psychological factors such as self-esteem, self-concept, body-image etc., this is the first study to have explored the role of patients’ perception of the self as being abnormal in orthognathic treatment.

Normal facing theory is a status passage, which is a formal theory (Glaser and Strauss, 1964). Normal facing theory states that, by undergoing orthognathic treatment, the person changes their status of being less than normal (based on facial appearance and their own self-perception of being normal) to being closer to normal. Therefore, normal facing theory is a status passage similar to getting married. While, on the wedding day the person’s marital status changes from being unmarried to married, through undergoing orthognathic surgery, the person changes from being less than normal to being normal (as perceived by the individual). However, this change does not occur immediately after the day of the surgery. Since the recovery period varies between patients, the time taken for completion of change as perceived by the patient also varies between patients. A recent study by Bhamrah and colleagues (2015) identified that the expected and actual end of treatment changes occurred at different times. However, they failed to underpin the reason for this and supported the finding by stating that patients required variable amounts of time to adjust to the change that occurred through orthognathic treatment. Unlike Bhamrah and colleagues (2015), the current study identified the role of self-perception in the patient’s acceptance of change, marking the end of treatment changes.

Figure 23, shows the graphical representation of the shape of normal facing as a status passage. It is evident that the shape of the status passage was not linear and it corresponded to the patient's facial appearance and their self-perception in relation to what was considered as 'normal'. The graphical representation also showed the importance of time since the changes occurred over a period of time. It was also recognised that the horizontal length and vertical peaks of the graph would vary from individual to individual because of the non-linearity and time. However, the key finding is that the shape of normal facing involved peaks and troughs which finally plateaued out most often at the higher point than where the graph began. This finding coincides with the past studies which concluded that there was a positive impact of orthognathic surgery on the lives of people who undergo this treatment (e.g. Rustemeyer and Gregersen, 2012, Murphy et al., 2011, Espeland et al., 2008, Sadek and Salem, 2007, Hunt et al., 2001 etc.).

The trough and peak has been found in relation to the psychological impact of orthognathic surgery in a series of papers based on a long-term follow-up study in the United States of America (Kiyak et al., 1984 and Kiyak et al., 1982b). As described in Section 2.4.3, a decline in the patient's self-esteem was noticed during the nine month follow-up period following surgery and the authors had attributed this to the period of post-surgery orthodontic treatment. However, the self-esteem and body image of the patients were found to have increased at the 24-month follow up. The common aspect of the findings of Kiyak and colleagues and the current study is the identification of the role of psychological factors in causing a transient trough or reduction in the perception of outcome of the treatment during the follow-up period. Therefore, as Kiyak and colleagues (1984) recommended, the current literature supports the need for continuous follow-up appointments with professionals for a prolonged period of time until the self-perception of the patient has adapted to the change following surgery.

It has been mentioned that normal facing theory commences way before the active treatment pathway. The initiation into the normal facing trajectory variably occurs at a younger age and many studies have explored the after effects of the initiation into normal facing. For example; studies in the past have found patients who underwent orthognathic surgery to have been past victims of bullying, name calling and teasing (Alanko et al., 2010, Modig et al., 2006, Williams et al., 2005, Zhou et al., 2002, Zhou

et al., 2001). While the current study also found the participants to have been victims of bullying, it also, for the first time, identified that many of these individuals were inducted into normal facing by the experience of being bullied. The experiences of the patients during the initiation into normal facing and leading up to the active treatment pathway will be discussed further in the next section.

5.2.1. Visible difference and initiation into normal facing

In the previous section, the normal facing theory has been discussed and placed within the current orthognathic literature. It was also established that the active treatment pathway is a status passage embedded in and playing a major role in the normal facing theory. Most of the data obtained in this study and the past studies have been greatly centred on the active treatment pathway. Nevertheless, normal facing theory identified that the status passage initiated much, prior to the beginning of active treatment pathway at the hospital. In this section, the experiences and psychosocial events that lead to the active treatment pathway will be discussed.

a) Experiences of people with facial visible difference

Stigmatisation of people with visible difference has been well established in the literature (Masnari et al., 2012, Lee et al., 2007, Strauss et al., 2007, Strauss et al., 2001, Goffman, 1963a). Reports of stigmatisations in the form of staring, teasing, bullying and name-calling are often experienced by these people (Masnari et al., 2012, Strauss et al., 2007). Patients who underwent orthognathic surgery have also reported similar experiences of being bullied, teased and called names (Alanko, 2010, Lee et al., 2007, Williams et al., 2005, Zhou et al., 2002, Zhou et al., 2001). The current study, in agreement with the literature, also found that most patients who entered the active treatment pathway have had early life experiences of being teased and name called and sometimes bullied regarding their facial visible difference. It was also found that these early experiences of being victims of bullying, teasing and name-calling impact on them on an emotional level which, potentially, lasted for a very long time.

b) Initiation of normal facing

The awareness of the facial visible difference was found to be the precursor of initiation into normal facing. As detailed earlier in Section 4.4 and Section 4.5.1, stages of awareness, as identified by Glaser and Strauss (1964), included suspicion

awareness and open awareness. However, awareness leading to initiation into normal facing or active treatment pathway has never been explored before.

Awareness of the facial visible difference did not directly cause the initiation of the pathway as discussed in Section 4.4. The first and major factors that lead to initiation of normal facing were identified in this study. One of the major factors identified was being a victim of bullying, teasing and name calling. It was found that peer influence and knowledge of orthodontics lead patients to initiation of the passage. This finding was consistent with a study by Burden (1995) who reported that uptake of orthodontic treatment by peers had a great influence on a person's decision to embark on orthodontic treatment. However, the current study, for the first time, identified the influence of peers having orthodontic treatment on the person's initiation in to the orthognathic journey.

The other factors that were found to play a role in the initiation of normal facing was the person's media self-image and the pivotal role played by the dentist. Participants in the study stated that seeing photographs of their face and image of their face as seen in the mirror had an influence in initiating normal facing. Studies in the orthognathic field have used photographs to assess people's perceptions of facial attractiveness (Knight and Keith, 2005) and change in appearance following surgery (Sinko et al., 2012). Nevertheless, the role of mirrors, photographs and imaging techniques in initiating the person's journey into orthognathics was not identified before this current study. Similarly, the role of dentists in making people aware and initiating normal facing has not been identified previously.

c) Role of perceived severity

Patients' perceived severity of their visible difference was not identified as a main category in this grounded theory study. However, in relation to patients understanding medical language, Sterling and colleagues (2010) had stated that patients understood the terminologies used by the professionals and this increases their feeling about their 'difference' and hence their perceived severity of the condition. Similarly, the current study also found that most patients understood the medical language used by the professionals to a certain extend and expressed an opinion of being made more self-conscious about their 'flaws' by talking about it in front of them.

5.2.2. Decision making

The decision-making phase was a very crucial phase within the normal facing status passage. During this phase, people in the normal facing status passage were divided into two groups; people who proceeded to the active treatment pathway and those who proceeded with normal facing without entering the active treatment pathway. There is currently a lack of data regarding the detailed experiences of patients who do not proceed with treatment. A study in the past compared the psychological profiles of patients who refused surgery with those who accepted surgery and found no difference (Kindelan et al., 1998). Hagensil and colleagues (2014) listed the factors associated with patients' decisions to refuse surgery and also found that patients who refused surgery were unhappy with the masticatory function and dentofacial appearance. No other studies have explored the experiences of those patients who refused surgery.

Factors influencing decision making

A number of factors were identified to have a direct influence on the decision making (See Section 4.5) and shown in Figure 18. These factors will be discussed in the following subsection. Among these factors; information given to the patients, motivation and expectations of the patients and fear of negative outcomes of the treatment were previously identified to have an association with patients' decisions to have orthognathic treatment (Stirling et al., 2010). On the other hand, Broder and colleagues (2000) identified the role of social support, doctor – patient relationship and access to care to have influenced decision making. The compatibility of these findings with that of the current study will be discussed.

a) Awareness

Patients' awareness about their facial visible difference and also about the options available was found to influence decision making for orthognathic treatment. As discussed earlier, awareness of their facial visible difference initiated patients into normal facing. Additionally, awareness of the various possible treatment options, including no treatment as an option, that are available in normal facing also hugely influence a patient's decision. The decision-making process used by patients is multifaceted (Broder et al., 2000) and the three questions addressed are "Should I have any treatment?", "Which treatment should I have?" and "When should I have treatment?". It was possible for the patient to answer the first question only if the

patient was aware of their visible difference and aware about availability of treatment. Therefore, the findings of the current study is in line with Broder and colleagues (2000).

b) Information

The second question addressed by patients during decision making, as stated by Broder and colleagues (2000) is, “What treatment should I have?”. The answer to this question comes from the information made available to the patients regarding their treatment options. The current study found that patients were provided with information by the dental care professionals in the form of verbal information, DVDs, and leaflets; and they also obtained information from online sources and by talking to friends and acquaintances. Any particular source of information was not strongly favoured over the other. However, most people expressed an opinion of benefiting from speaking to somebody of their own age group who had previously had similar surgery. Congruent with this finding, Broder and colleagues (2000) found that the patient knowing someone who had completed treatment at their hospital was a significant facilitator for decision making. A recent study of internet forums as an information and support resource for orthognathic patients also strongly supported the need for establishing a formal mechanism in patient care service to allow patients to talk to other patients who have had similar treatment. They also concluded that there was a gap in the provision of information regarding proposed treatment, which was one reason for patients turning to internet sources (Bhamrah et al., 2014). These authors, in line with the findings of the current study, also state that patients used internet forums to seek information support and reassurance from peers undergoing similar treatment.

Flett and colleagues (2014) studied the DVD as an information aid for orthognathic patients and concluded that it was a trusted source of information which could be improved by including interviews of younger people since they constituted the majority of patients who undergo orthognathic surgery. Accordingly, this study also found that younger people expressed an interest in obtaining information from people of their age. Further, while Stirling and colleagues (2010) stated that orthognathic patients did not make an informed decision about their treatment, the data from this

study showed that most patients did make informed decisions about orthognathic treatment.

c) Temporality

The third question addressed by patients were “When should I have treatment?” (Broder et al., 2000). This question addressed the temporal aspect of their decision making. It also highlighted the elective nature of the treatment because of which patients could choose when to have the treatment. This study found that the time at which orthognathic treatment was offered to patients impacted on their decision. This was found to be related to scheduling the treatment in relation to other concurrent status passages within their life and the rank order of each of these. Similar findings were reported by Broder and colleagues (2000) who found 15% of orthognathic patients chose to have treatment at that particular time based on their schedule flexibility and financial security. Apart from this, the other aspects of temporality that influenced the decision making were the length of time taken for treatment and the amount of time given for decision making itself. All patients stated that sufficient time was given for decision making but most people found that the treatment took too long to complete. These two temporal aspects were not reported in any previous study.

d) Social support and role of dental care professionals

Social support was a key factor that not only influenced patients’ decisions to undergo orthognathic treatment, but also played a major role during patients’ recovery from surgery and acceptance of the new face leading to completion of normal facing. The importance of the role of social support in decision making and during post-surgery periods with respect to patient satisfaction was reported many years ago by Holman and colleagues (1995). Social support was identified as a resource along with finances/insurance, which enabled positive decision making for patients to undergo orthognathic surgery (Broder et al., 2000). Similarly, Bhamrah and colleagues (2015) also concluded that peer support available from online resources was useful for patients in the decision-making stage and helped them prepare well to cope with surgery.

The role of dental care professionals in the decision-making stage of orthognathic treatment was found to be of a trust relationship and the rapport patients established with these professionals. Broder and colleagues (2000) stated that doctor-patient

communication in the form of rapport and understanding, played a major role in decision making for orthognathic treatment. However, no other studies in orthognathics have identified trust in the dental care team as a factor that influenced decision making, although trust in the information provided by dental care professionals has been reported (Flett et al., 2014).

e) Fears making the individuals refrain from orthognathic treatment

Fear of hospitalisation, fear of the surgery and fear of the negative impacts of orthognathic treatment were found to be the reasons that negatively influenced decision making. These findings were partly similar to the findings by Hagensli and colleagues (2014) who concluded that risk of side effects, burden of care and general reluctance to being operated on were the reasons why people refused to undergo orthognathic surgery.

f) Motivation and expectations of the person

Motivations and expectations have been studied in the past in relation to assessing patient satisfaction with orthognathic treatment (e.g. Oland et al., 2011a, Proothi et al., 2010, Modig et al., 2006). In this study we identified the motivations and expectations of patients as a factor that influences their decision to have orthognathic surgery. As detailed in section 4.5.4 (page 170), concerns over appearance were a major motivating factor for patients to decide to undergo orthognathic treatment and their expectation for this was to be more ‘normal’.

This demonstrates an internal motivation (for example: patients themselves desired a change in their facial appearance making them freely opt for orthognathic surgery) with some external influences which made them desire ‘normality’. Therefore, internally motivated patients were found to be better orthognathic patients (Cunningham et al., 1996b), the current sample were likely to be more satisfied with orthognathic treatment.

5.2.3. Impact of orthognathic treatment

The single most important outcome of orthognathic treatment for patients was found to be attaining normality. Although the study did also highlight additional outcomes in line with previous work; Paesthetic e.g. Jesani et al., 2014, Sinko et al., 2012, Rustemeyer et al., 2010), functional (e.g. Piancino et al., 2013, Trovik et al., 2012,

Cunningham et al., 1996a) and psychological impacts (e.g. Ryan et al., 2016, Jesani et al., 2014, Cunningham et al., 2000b).

Impact of orthognathic treatment and patient satisfaction

In line with current literature (e.g. Sadat-Marashi et al., 2015, Rayan et al., 2012, Alanko et al., 2010, Cunningham et al., 1996), this study also found that the majority of patients who undergo orthognathic treatment were satisfied with the outcome. However, the theory of normal facing also recognises that the complete satisfaction of the treatment came with the acceptance of change and incorporation of the changed facial appearance into their perception of self. While past studies have identified that treatment outcomes had periods of upheaval in levels of patient satisfaction and psychological impact (Kiyak, 1984, Kiyak, 1982), this was due to patients desiring to complete post-surgical orthodontics. Conversely, the theory of normal facing identifies the reason for the decrease in patients' psychological impact and quality of life as a response to swelling, bruising, pain and paraesthesia following surgery. These impacts gradually improved as the patient recovered from the effects of the surgery itself. A similar improvement in psychological impact over time has also been reported by Barbosa and colleagues (1993) and Jacobson (1984).

Satisfaction with orthognathic treatment was reported with variable intensity at different stages of post-surgery follow up appointments. Although patients stated that they were happy with the outcome of surgery during a six to eight weeks post-surgery appointment, they also included statements of hope for further improvements. This suggested that patients were further awaiting completion of change. Indeed, satisfaction following surgery increased over time. This was consistent with the findings of a study which explored the factors that effected post-surgery patient satisfaction, which also reported an increase in patients' satisfaction with time (Chen et al., 2002). They also reported that people who had severe facial 'deformities' and were more educated were more satisfied with the treatment. On the other hand, patients who did not have social support and accepted surgery passively were more dissatisfied. In the current study, there was no data available to confirm reasons for dissatisfaction. However, it was found that patients with severe facial visible differences were more satisfied with the outcome of the surgery.

The opinions of a person's friends and family regarding the outcome of treatment played a role in their acceptance and satisfaction of the treatment outcome. Similar findings about the role of responses from other people influencing the patients' perception of treatment outcome has been reported in past studies (Chen et al., 2012, Holman, 1995). Holman et al. (1995) concluded that the social support available prior to surgery influenced the patients' immediate post-surgery satisfaction. However, post-surgery pain, swelling and loss of sensation, did not seem to influence the long term patient satisfaction with treatment obtained. However, patients reported dissatisfaction with treatment immediately post-surgery. This is concurrent with the findings of Chen and colleagues (2002) who stated that post-surgery swelling and pain influenced patient satisfaction.

Integrating the change into self-perception

The ultimate test of the patients' perception of outcome of orthognathic treatment was found to be dependent on the person's acceptance of the change and integrating that change into their self-perception. Broder et al. (2000) in a qualitative study identified patients' 'readiness to change' as a theme that influenced patient's decision to undergo orthognathic treatment. They went ahead to state that the issue of thinking about and knowledge were the prerequisites for change. Consequently, all patients who opted into the active treatment pathway (orthognathic treatment), have accepted the upcoming change to a certain extent even before the outcome of the treatment is seen. It is here realistic and unrealistic expectations plays a role in enabling acceptance of the change. In this study, most participants were found to have realistic expectations of the treatment. Similar findings have been reported by Chen and colleagues (2002). However, studies in the past have identified patients with unrealistic expectations from orthognathic treatment who struggled to be satisfied with the outcomes (Williams et al., 2005, Finlay et al., 1995, Barbosa et al., 1993).

The time taken for identifying the completion of change as a result of orthognathic treatment varied from person to person. Furthermore, the acceptance of change also occurred at a later time following completion of active treatment pathway. Data obtained in the study by Bhamrah and colleagues (2014) showed that patients acceptance of change and recognising their face as being normal happened a long time after completion of active treatment.

The self-perception of the person was found to be very important in determining the acceptance of change and hence the completion of normal facing. Since the face is synonymous with all human relationships (Macgregor, 1990), a change in the face would have a huge impact on the person's relationship with others and with their own self-perception. While many studies in the past have identified the improvements in psychosocial aspects of a patient who underwent orthognathic treatment such as self-esteem, body-image (e.g. Alanko et al., 2014, Lazaridou-Terzoudi, 2003, Kiyak et al., 1986) and self-confidence (e.g. Rustemeyer and Gregersen, 2012, Alanko et al., 2010, Derwent et al., 2002); self-perception has been often discussed conjunction with aesthetic aspects such as facial profile and body-image (Johnston et al., 2010, Rispoli et al., 2004, Nardi et al, 2003, Bell at al., 1985). Similarly, the current study considered self-perception in conjunction with the person's facial aesthetics following treatment. However, patients took time to cope with the change and accept the completion of normal facing.

5.2.4. Coping behaviours in normal facing

The current study identified coping as a major category that influenced the normal facing theory. Coping behaviour was adopted by individuals through all phases of normal facing starting from coping with pre-treatment visible difference, coping with active treatment pathway and finally coping with post-treatment change. The various coping resources identified are discussed below in relation to the listed three phases of normal facing.

a) Coping by concealment and functional adaptation

Concealment was a coping behaviour adopted to cope with pre-treatment visible difference and the appearance and functional concerns during the active treatment pathway. Such coping behaviour was adopted by individuals to pass without drawing attention to their visible difference. Concealment was identified as a strategy adopted by individuals for 'passing' their visible difference or stigma and blending in with the dominant non-stigmatised group (Herek, 1996, Goffman, 1963b). Passing was for the first time defined as "the management of undisclosed discrediting information about self" (Goffman, 1963b, p. 42). Therefore, the findings of this study suggests that individuals with facial visible difference, considering orthognathic treatment, use concealment for passing. This aspect of coping with the facial visible difference related to orthognathic treatment has not been theorised before.

The coping behaviours adopted to conceal this visible difference pre-treatment and during active treatment pathway identified in this study were; keeping a hand on mouth while smiling/laughing and eating, avoiding smiling/laughing, males wearing a baseball cap, female use of makeup and hairs styling. These findings were similar to one earlier study, which identified the habits adopted by individuals before having orthognathic surgery (Sadat-Marashi et al., 2015). Interestingly, concealment or adaptation behaviours of this nature was also found to be common in those who seek orthodontic treatment (Patel et al., 2016) However, this study had not conceptualised these adaptations as a coping behaviour. The current study, for the first time, conceptualised concealment as a coping behaviour adopted by individuals in normal facing which aided in ‘passing’ within society.

It was found in this study that ‘passing’ was also aided by making functional adaptations in the person’s day to day activities. The functional adaptations identified were; cutting food instead of biting into them, chewing with back teeth, avoiding eating certain food in public, dietary adjustments during recovery from surgery and using palliative measures to deal with TMJ disorders. This was the first study, which identified these measures as a coping behaviour adopted by patients who undergo orthognathic treatment. While most of these functional adaptations are approaching coping behaviours that are associated with good adjustments (Baker et al 2009, Holahan and Moss1987), the concealment used to cope with visible difference were avoidance coping to minimise the impact of the visible difference (Ogden 2007, Penley et al., 2002). Nevertheless, both approach and avoidance coping behaviours were adopted by individuals to deal with visible difference and orthognathic treatment.

b) Social support and information seeking behaviour as a coping resource

Studies in the past have consistently identified the positive influence of social support on orthognathic treatment (Alnko 2014, Carvalho 2012, Cadogan and Bennum 2011, Cunningham 2000b, Holman 1995). This study, in line with the findings of Cadogan and Bennum (2011), identified that social support received by patients who undergo orthognathic surgery had a positive influence on how they coped. However, the current study also identified the positive influence of social support in coping with the facial visible difference of the individuals during the pre-treatment phase and the change in facial appearance following orthognathic treatment.

Recently, Bhamrah and colleagues (2015) studied online discussion forms and identified that patients sought additional information, support and reassurance from peers undergoing similar treatment from the online resources. Similarly, the current study also found the information seeking behaviour of patients who undergo orthognathic treatment in pursuit of the support and reassurance they needed from other patients in similar types of treatment pathways. Additionally, information obtained by individuals about their worries and concerns through the normal facing status passage was identified as a positive coping behaviour in the current study. Therefore, information seeking behaviour was identified to be a problem-solving skill of the individual that helped them cope with normal facing. Although the need for information in improving treatment experience of patients who undergo orthognathic surgery has been identified in various studies in the past (Pachêco-Pereira et al., 2016, Flett et al., 2014, Stirling et al., 2010, Cunningham et al., 1996), this was the first study to have identified information seeking behaviour as a means of coping for individuals in the normal facing status passage.

c) Role of other coping resources

Among the various coping resources that are identified in the coping literature (See section 2.5.1), not many of these resources were identified in the study. For example, self-esteem has been identified as a coping resource to manage stressful situations (Taylor and Stanton, 2007, Dumont and Provost, 1999, Thotis, 1995). However, it was found that most patients in the active treatment pathway experienced lowered self-esteem and it was not regarded as a helpful coping resource. Similarly, resilience was also another coping resource identified in past studies (e.g. Tugade and Fredrickson, 2004, Dumont and Provost, 1999). Although there was evidence of improved resilience among patients who went through normal facing, patients did not openly discuss resilience in this study. Therefore it could be that resilience was a latent coping resource among individuals who went through the normal facing status passage. There was no evidence of influence of any other coping resources such as optimism in this study.

5.3. Limitations

Like any other research project, this research has certain methodological limitations that influence the interpretation of the results. These limitations include general limitations of GT and also limitations that are specific to this study.

5.3.1. Limitations specific to this study

a) Sampling

In GT, findings from the initial purposive sampling; guides further sampling, data collection and analysis (Sbaraini et al., 2011). Initial sampling in this study was from a single site – Sheffield Teaching Hospital Trust. Participants were identified and included in the study from among who were treated under the NHS healthcare system by the same Oral and Maxillofacial surgeon, although they would have been seen by a different orthodontist. Nevertheless, all the participants experienced similar quality of surgical care and treatment methods. For example, all bi-maxillary surgical patients were provided with a wafer and intermaxillary fixation for a week following surgery. However, it is known that other surgeons use elastic band fixation instead of surgical wafer during the first week after surgery or no inter-maxillary fixation (Ross, 2011). Such differences in surgical care are found to influence the recovery and treatment outcome of the patients. Including patients who underwent treatment by a different surgical team, would have provided better variability and hence more comprehensive findings in the substantive area. However, the use of theoretical sampling from the online data compensated for this lack of variability to a certain extent.

In the theoretical sampling process, the data that were obtained from online blogs was largely from American blogs, and very few were from the UK. The nature of orthognathic treatment care in America is very different from that of UK patients within the NHS. The major and most obvious difference is in funding for the treatment. American patients found this as a large concern and discussed this online, while the UK based patients were not concerned about this issue. While this variation implied a better generalisability of the normal facing theory, it also limited the specificity of the theory for patients receiving treatment under different funding systems.

Participants recruited for face to face interview were from a wide variation of age groups. However, the gender distribution was skewed towards females. Given the small proportion of male patients (18%), gender differences could not be explored. Further, the data obtained online were often anonymised and little demographic information was available, especially regarding gender and sometimes age, which made it difficult to explore the differences in experience. Therefore, the results of this study should be used with caution with regard to male orthognathic patients' experiences.

b) Study design

This being a PhD study, unlike other GT studies, there was a need for a protocol (Gibson and Hartman, 2013). The protocol was required to obtain NHS ethics approval, and this required a set of inclusion and exclusion criteria. Unlike classical GT that emphasises openness and all is data, the adherence to the exclusion criteria was a limitation for the current study. For example, CLP patients were excluded because of a congenital birth defect which is known to cause extensive functional and appearance concerns which are not common to other patients undergoing orthognathic treatment. Similarly, patients who undergo orthognathic treatment for obstructive sleep apnoea were also excluded from the study because the reason for surgery was not due to a visible difference. Therefore, the outcome of the treatment for these patients would be different from those of other orthognathic patients.

The protocol also excluded non-English speaking patients to enable the ease of data collection and analysis. However, a large number of patients who underwent orthognathic surgery were not included in the study and thus findings cannot be applied to this patient subset.

The study was designed to recruit patients who attended hospital appointments either for initial consultation appointments, post-operative assessment appointments or long term follow-up appointments. Hence, most of the patients recruited in the study were in the active treatment phase with the exception of the one to two years post-surgery follow-up patients. Correspondingly, the data obtained were also largely centred on the active treatment pathway and lesser on the normal facing, which extended before entering the active treatment pathway. However, data was obtained regarding this phase from the recollection of the patients in the active treatment pathway; possibility of recall bias should be noted.

Another limitation of the current study design was the lack of data from people who refused orthognathic treatment. Although patients were recruited while in the decision-making phase, there was no participant who refused surgery. There was only one undecided participant in the face to face interviews and limited data were obtained online regarding patients who refused surgery. Therefore, the results of this study need to be treated with caution in the normal facing status passage of people who refuse orthognathic treatment.

Finally, the study design was a cross-sectional study with all of its associated limitations. A longitudinal study, following patients before, during and after orthognathic treatment, would allow exploration and comparison of the perceptions and experiences of patients through the entire orthognathic journey.

c) Analysis

The analysis of data in this study was largely based on conceptualisation as in any grounded theory study. The author, being a novice grounded theory researcher, would like to acknowledge the use of received and loaded concepts in the analysis of data in this study. The problems associated with the use of such concepts could be rectified and the study would benefit from further conceptualisation and theoretical development.

5.3.2. Limitations of using GT in this study

a) Presentation of results

GT is a methodology widely used in qualitative research (Gibson and Hartman, 2013). However, GT methodology is relatively new to the discipline of dentistry. The presentation of the study design and results is a challenge within a new discipline. The highly qualitative nature of the GT results makes it a very difficult task to present it in a manner that is readily useable for practitioners.

b) Exploring ‘normality’

The core findings of this study revolve around ‘normality’. There is a vast literature in disability studies that discuss ‘normality’. However, in the current study, the literature on normality has not been explored in depth simply because it is found to be beyond the scope of this study. However, there is possibility to explore this further and explore its implications for the current theory.

c) Limited generalisability

Normal facing is a substantive theory based on a formal theory called status passage. While status passage has a general applicability, normal facing holds true only within the substantive area. Limited generalisability of GT was pointed out as a limitation of the research method (Hussein et al., 2014). Therefore, generalised application of normal facing theory on other substantive areas must be exercised with caution.

Despite these limitations, this study adds substantial knowledge to the literature on orthognathic treatment. This study remains the first study to develop a theory on what happens to patients who undergo orthognathic treatment.

Chapter Six: Conclusions and Recommendations

6.1. Conclusions

This GT study intended to develop a theory for what happens to patients who undergo the orthognathic journey. Data were collected regarding patients experiences before, during and following orthognathic treatment from patients seen at the Sheffield Teaching Hospitals NHS Trust through face-to-face interviews. Further theoretical sampling and data collection was done from online blogs and forums about orthognathic treatment. The data were analysed using GT methodology to develop a theory, which detailed patient experiences and changes that they perceived through the treatment journey.

This study has contributed to current knowledge by identifying normal facing as a status passage that occurred to patients who enter the active treatment pathway of orthognathic treatment. This is the first study to have explored the entire experience of orthognathic patients beginning from initial awareness of facial visible difference to the acceptance of changed facial appearance into their self-perception.

- 1) Patients opting for orthognathic treatment undergo a scheduled status passage called ‘normal facing’.
- 2) The actual period in which a patient receives orthognathic treatment at the hospital is called the active treatment pathway, and is conceptualised here as a status passage. This status passage is embedded within the larger status passage of normal facing.
- 3) The status passage of normal facing can be completed without entering the active treatment pathway. This occurs in patients who refuse to have orthognathic treatment and proceed with the status passage which finally leads to acceptance of normality.
- 4) Initiation into the status passage of normal facing occurs prior to actual entry into active treatment pathway. Initiation occurs in the form of patients’ awareness of their facial visible difference. This awareness may come from many sources including bullying, teasing and name-calling, photograph images, or and due to knowledge given to them from dental professionals.

- 5) Decision making in orthognathic treatment is a very crucial phase in the status passage. Information provided to the patients played a huge role in determining the patients' experience of orthognathic treatment.
- 6) Patients showed keen interest in obtaining first-hand information from other people from the same age group who had had similar surgery. Younger patients were found to seek more information from online resources.
- 7) Social support was found to be hugely beneficial for patients during decision making, recovery and in accepting the change on completion of the status passage.
- 8) Completion of status passage was marked by the patient's acceptance of their new face into their self- perception.
- 9) The shape of the passage is influenced by various clinical, demographic and psychosocial factors, which consequently influenced the patient's self- perception.
- 10) The time of completion of this status passage varies from individual to individual but is determined by patients' acceptance of the change.
- 11) It is not the perfection of the clinical outcome that determines patient satisfaction and completion of the status passage, but rather the acceptance of the 'new face' into the individual's self-perception that marks the success of orthognathic treatment.
- 12) The real motivation for patients to have orthognathic treatment was to become 'normal' within the social structure and satisfaction came from their self- perception of being normal.
- 13) Patients did not desire perfection but normality.

6.2. Recommendations

The recommendations based on the findings are as follows:

6.2.1. Recommendations for clinical practice

- a) Case selection should be carried out not only based on clinical information and functional impacts, but also consideration of the psychosocial expectations of the person.

- b) Considering the significant role played by general dentists in induction of normal facing, all dentists should be adequately trained to appropriately deliver information regarding orthognathic treatment.
- c) Information aids in the form of access to a network of patients who have undergone orthognathic surgery and/or online or face-to-face support groups should be considered in clinical practice.
- d) Provision for long term follow up for patients who have been discharged from the active phase of orthognathic treatment, including where necessary psychological input, should be considered.

6.2.2. Recommendations for research

- a) GT does not verify or justify the theory developed. Therefore, the normal facing theory can be used in a future study designed for a prior testing of its hypotheses.
- b) All the data presented here were collected during the active treatment pathway. There is a lack of knowledge regarding the status passage of people who refuse orthognathic treatment and proceed with normal facing. Future studies could be designed to explore the experiences of people who refuse orthognathic treatment to further understand and develop the current theory.
- c) Normality is a vast literature within disability studies. The current study identified the importance of being ‘normal’ among patients who undergo orthognathic treatment. However, it does not explore the relationship between normal facing and normality. Future studies could, potentially, explore this relationship in order to develop the current theory further.

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APPENDICES

Appendix A: Patient Information Sheet

Appendix B: Cover letter

Appendix C: Participant consent form

Appendix D: Interview guide

Appendix E: NHS Ethics Approval letter

Appendix A: Patient Information Sheet



What factors influence quality of life and resilience following orthognathic surgery?

INFORMATION SHEET

Hello, I am Ninu Paul, a PhD student at the University of Sheffield Dental School. You are being invited to take part in this research project. This information sheet will tell you about why this research is done and what it involves. It is important that you read this sheet carefully before you decide if you are happy to take part in this research. You can ask me for any more information or if anything is not clear. Thank you for taking time to read this information sheet.

What is the purpose of this research?

The purpose of the study is to find out more about how jaw conditions and treatment of them affects people. I want to know more about how your condition affects you, your expectations of surgery, the support you received from others and how you cope in life generally. From this research we hope to better understand the influence of patient's resilience on orthognathic treatment.

Why have I been invited to take part?

You have been chosen because you are registered at the Charles Clifford Dental Hospital or Barnsley Hospital NHS foundation Trust and you are about to have jaw surgery. I will be asking around 120 adults like you registered at the clinic to join in this study – you are not the only one!

Do I have to take part?

It is totally up to you to decide! I will describe the study for you and after you have read this information sheet, if you decide to take part we will then ask you to sign a consent form. You are free to withdraw from the study at any point without having to give any reason. This decision will not affect your surgery/ treatment in any form.

What will happen to me if I take part?

If you decide to take part, you will be asked to answer a series of questions in the booklets you have received, and will be asked to return it to me on the clinic or during the next appointment. The questions will take you about 20-40 minutes to complete. If you agree, you will be given a similar questionnaire booklet when you come in to get your braces off after the surgery and orthodontic treatment. If we fail to meet during this appointment then we will send out a copy of the questionnaire by post to you and may contact you by phone. Some of you who wish to share your experience of the surgery and indicate so on the baseline questionnaire will be invited for a short 45-60 minutes interview with me following the surgery. The research team will also look at your clinical notes to collect information about your condition and treatment.

What are the possible benefits of taking part?

The study will not change the care or treatment that you receive at the hospital. We can't promise that the study will help you directly but the study will help us understand how young adults cope with jaw conditions and their treatment. This information will be used to help provide better ways of supporting patients in the future.

What are the possible disadvantages and risks of taking part?

There are no risks to you from taking part in the study. You don't have to talk about anything you don't want to. Your name will not be in any report I write about the study, so you need not worry that other people will know what you have said to me. Everything you tell me during the interview or in the questionnaires will be entirely confidential.

What happens when the research project ends?

When the study has finished I will look at all of the questionnaires and the information from the interviews taken. I will then write some reports on the findings and send you a copy via email if you like me to! You will just continue your regular care with the hospital as normal.

What if there is a problem or something goes wrong?

We cannot see anything going wrong during this project. But if you feel unhappy about anything to do with the project, I will be very happy to talk to you about your concerns at any time. You are also free to stop being in the study at any time.

Will my taking part in the study be kept confidential?

All information that is collected about you during the course of the research will be kept private. You will not be asked to write your name on your questionnaires and the only people who will see the information will be me and others in the research team. The information obtained from the interview will also be treated with similar confidentiality. Nothing that identifies you will be kept on a computer. All the forms from the research will be kept in a locked cabinet at the University of Sheffield. The reports from this research will not mention any of the young adults who took part. The questionnaires will be stored safely and kept for three years before being destroyed.

Who is organizing and funding the research?

The research is organised by me Ninu Paul, who is currently a PhD student at the School of Clinical Dentistry at the University of Sheffield. I am supported by a team of supervisors, Dr Sarah Baker a Chartered Health Psychologist from the Department of Oral Health and Development at the University of Sheffield and Dr Keith Smith a Consultant in Oral and Maxillofacial surgery who will be overseeing this research at Charles Clifford Dental Hospital. Dr Nicola Parkin a Consultant in Orthodontics will be overseeing this research at the Barnsley Hospital. The project is funded by the University of Sheffield.

Who has reviewed the study?

Before any research in the NHS goes ahead it is checked by an independent group of people called a Research Ethics Committee. They make sure that the research is OK to do and it protects your interests. This project has been checked and given favourable opinion by the London Stanmore REC.

Contact details

If you have any further questions or want to find out more, please contact me by telephone on 07768980789 or email: nrpaul1@sheffield.ac.uk. Alternatively you could contact:

Dr Keith Smith- Phone: 01142717862, email:

k.g.smith@sheffield.ac.uk

Dr Nicola

Parkin- Phone: 01226432688, email: nparkin@nhs.net

If you wish to make a formal complaint about the study you can do this by contacting the Patient Advice and Liaison Service at the hospital on: Tel: (0114) 271 2450

Thank you for taking time to read this information sheet. Please feel free to ask any questions if you need to.

Appendix B: Cover Letter



Unit of Dental Public Health

Ninu Paul

School of Clinical dentistry
19, Claremont Crescent, Sheffield
S10 2TA

<<Date>>

<< Name >>

<< Address>>

<<Postcode>>

**Re: Quality of Life and Resilience following orthognathic surgery – STH18255,
Investigator- Ninu Paul**

Dear <<Name>>,

I am a PhD student at the University of Sheffield Dental School. As part of my research I am looking into the experience of patients referred for orthognathic treatment particularly focusing on quality of life and psychological resilience of patients. You are being invited to take part in this research project because you have <<been referred to Charles Clifford dental hospital for an option to have orthognathic surgery>>/ << had orthognathic surgery at the Royal Hallamshire hospital >>. The enclosed information sheet will tell you more about why this research is done and what it involves.

It is important that you read the information sheet carefully before you decide if you are happy to take part in this research. You can ask me for any more information or if anything is not clear when you come for your next scheduled clinical appointment at the dental hospital.

After having read the information sheet, if you are happy to take part in the 45-60 minutes interview for this research, you will be approached for consent on the day of your clinical appointment. The interview will be conducted in the dental school following your clinical appointment, if it suits your convenience.

Should you have any further queries you can contact me contact me by telephone on 07768980789 or email: nrpaul1@sheffield.ac.uk. Alternatively you could contact: Dr Keith Smith- Phone: 01142717862, email: k.g.smith@sheffield.ac.uk

Your participation in this research will be greatly appreciated.

Thank you.

Yours sincerely,

Ninu Paul

Appendix C: Patient consent form



Study Number: STH18225

Participant Identification Number:

CONSENT FORM- Interview Study

Project title: What factors influence quality of life and resilience following orthognathic surgery?

Name of the researcher: Ninu Paul

- 1. I confirm that I have read and understand the information sheet dated 29/10/2014 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. 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.
- 3. I understand that anonymity and confidentiality will be preserved at all times. Any information will be used for research purpose only; including research publications and reports.
- 4. I confirm that I understand the interview may take up to 1 hour and I am willing to take part in the interview part of the above mentioned study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Appendix D: Interview guide

Topic guide

Welcome and establishment of ground rules

Participants will be thanked for agreeing to take part in the study and sparing time for the interview. They will be reassured there are no right or wrong answers. It will be explained that the use of a tape recorder by the researcher is to help them remember what is said without them having to take notes. Participants will be assured that the researcher will treat the information given as confidential.

Warm-up questions: Each participant will be asked to introduce themselves with their chosen name and say a little about themselves.

Background: Participants will be asked:

- To describe how they came to be undergoing orthognathic/ orthodontic treatment
- What concerns they had about their teeth/ face before treatment started

Q: Can you tell me about your story of having come to have orthognathic treatment and the treatment you received so far?

Resilience: Participants will be asked:

- To describe any difficulties (if any) they had before starting the treatment both functionally and psychologically
- How do they generally cope with difficult situations?

Q: Can you tell me if you have had any difficulties both functionally such as chewing, biting or speech and psychologically before you started treatment?

Q: Can you tell me, may be with any example you can think of, how do you cope with difficult situations generally?

Expectations and Motivations: Participants will be asked:

- To talk about their initial expectations from the treatment and their thoughts about the actual outcome
- If there was anything that motivated them for the surgery

Q: What is it that made you think of having this surgery?

Q: Could you tell me about what you expected from the treatment?

Q. What are your thoughts about the outcome of the treatment now?

Decision Making and Information: Participants will be asked:

- To discuss the decision making process in detail about who was involved and how easy or hard was it
- If they thought more information or support was needed from the service team to make the decision
- If there was any influence of the previous experiences in life on their decision for surgery
- To discuss about how they feel about the decision they made now

Q: Can you tell me who was or were involved in deciding about you having the surgery and how hard or easy what it to decide?

Q: Do you think there is anything else the service team could have done to make it easier for you, say in the form of support or information?

Q: Do you think any of your previous experiences in life, say at school, home, work place etc. had an influence on your decision making for the surgery?

Q: Was this the right decision for you?

Q: How do you feel?

Closing

Participants will be asked if they would like to add any further information and thanked for the discussion.

Participants will be de-briefed on the next steps of the research process.

Appendix E: NHS Ethics Approval

13 August 2014

Miss Ninu Paul
PhD student
University of Sheffield
Department of Oral Health and Development
School of clinical dentistry
Claremont Crescent,
S10 2TA

Dear Miss Paul

Study title: What factors influence quality of life and
resilience following orthognathic surgery?
REC reference: 14/LO/1488
Protocol number: STH18225
IRAS project ID: 158412

The Proportionate Review Sub-committee of the NRES Committee London -
Stanmore reviewed the above application on 11 August 2014.

We plan to publish your research summary wording for the above study on the
NRES website, together with your contact details, unless you expressly
withhold permission to do so. Publication will be no earlier than three months
from the date of this favourable opinion letter. Should you wish to provide a
substitute contact point, require further information, or wish to make a request
to postpone publication, please contact the REC Manager, Julie Kidd,
nrescommittee.london-stanmore@nhs.net .

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

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

1. The applicant suggests that participants may need help during the interview as they may become upset. The Committee suggest that the applicant have this help in place ie. A psychologist/councillor to whom she may refer them to.
2. The PIS should have the name of London-Stanmore REC rather than Yorkshire and Humber Ethics Committee
3. The two consent forms should have headings to clarify which is for the questionnaires and which is for the interviews.
4. The Committee recommend that the applicant use a pay as you go phone dedicated to this study rather than a personal phone number.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

Ethical review of research sites

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

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance]	version-1	16 July 2014
Interview schedules or topic guides for participants [Topic guide]	version 1	28 July 2014
IRAS Checklist XML [Checklist_31072014]		31 July 2014
Non-validated questionnaire [Non- validated questionnaire]	version-1	28 July 2014
Other [Consent form for Interviews]	version-1	26 July 2014
Other [Reviewer's checklist 2]	version-1	28 July 2014
Other [Reviewer's checklist 1]	version-1	24 July 2014
Other [Supervisor 2 CV]	version 1	28 July 2014
Participant consent form [Consent form for Questionnaires]	version-1	26 July 2014
Participant information sheet (PIS) [Patient information sheet]	version-1	26 July 2014
REC Application Form [REC_Form_31072014]		31 July 2014
Research protocol or project proposal [Research Protocol]	version-1	28 July 2014
Summary CV for Chief Investigator (CI) [CV summary CI]	version 1	28 July 2014
Summary CV for supervisor (student research) [Supervisor 1 CV]	version 1	25 July 2014
Validated questionnaire [Validated questionnaire]	version-1	28 July 2014

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

14/LO/1488

Please quote this number on all correspondence

Yours sincerely



Mrs Rosemary Hill Chair

Email: nrescommittee.london-stanmore@nhs.net

Enclosures: List of names and professions of members who took part in the review

“After ethical review – guidance for researchers” [\[SL-AR2\]](#)

Copy to: Ms Samantha Heaton, Sheffield Teaching Hospital NHS Foundation Trust

NRES Committee London - Stanmore

**Attendance at PRS Sub-Committee of the REC meeting on
11 August 2014**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Rosemary Hill	Statistician	Yes	
Mrs Elayne Nasr	Retired	Yes	
Mrs Marina Wells	Midwife/Matron	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Amy Spruce	REC Assistant



Health Research Authority

NRES Committee London - Stanmore

Ground Floor
NRES/HRA
80 London Road
London
SE1 6LH

Tel: 0207 972 2559
Fax: 0207 972 2592

04 December 2014

Miss Ninu Paul
PhD student
University of Sheffield
Department of Oral Health and Development
School of clinical dentistry
Claremont Crescent,
S10 2TA

<i>Document</i>	<i>Version</i>	<i>Date</i>
Non-validated questionnaire [Informed consent questionnaire study (tracked)]	3	29 October 2014
Notice of Substantial Amendment (non-CTIMP)		24 November 2014
Other [Participant Letter - 1]	1	29 October 2014

Other [Participant Letter -2]	1	29 October 2014
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Dear Miss Paul

Study title: What factors influence quality of life and resilience following orthognathic surgery?
REC reference: 14/LO/1488
Protocol number: STH18225
Amendment number: Am02: Additional questionnaires/Site
Amendment date: 24 November 2014
IRAS project ID: 158412

The above amendment was reviewed at the meeting of the Sub-Committee held on 04 December 2014.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Participant consent form [Informed consent form interview (tracked)]	3	29 October 2014
Participant information sheet (PIS) [Tracked]	3	29 October 2014
Research protocol or project proposal [(STH18225) Tracked]	2	29 October 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

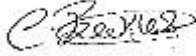
Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/LO/1488: Please quote this number on all correspondence

Yours
sincerely pp



Mrs Rosemary Hill Chair

E-mail: nrescommittee.london-stanmore@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Samantha Heaton, Sheffield Teaching Hospital NHS Foundation Trust

NRES Committee London - Stanmore

**Attendance at Sub-Committee of the REC meeting on 05
December 2014**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Marion Cumbers	Retired	Yes	
Mrs Rosemary Hill	Statistician	Yes	



Health Research Authority

London - Stanmore Research Ethics Committee

Ground Floor
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80 London Road
London
SE1 6LH

Tel: 020 79722571

22 September 2015

Miss Ninu Paul,
PhD student,
University of Sheffield,
Department of Oral Health and Development,
School of clinical dentistry,
Claremont Crescent,
S10 2TA

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview schedules or topic guides for participants [Topic Guides for Participants, Clean]	2	21 September 2015
Interview schedules or topic guides for participants [Topic Guides for Participants, Tracked]	2	21 September 2015
Letters of invitation to participant [Clean]	2	21 September 2015
Letters of invitation to participant [Tracked]	2	21 September 2015

Notice of Substantial Amendment (non-CTIMP)	Amendment number: 2	19 August 2015
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Dear Miss Paul,

Study title: What factors influence quality of life and resilience following orthognathic surgery?
REC reference: 14/LO/1488
Protocol number: STH18225
Amendment number: Amendment number: 2 10/08/2015
Amendment date: 19 August 2015
IRAS project ID: 158412

The above amendment was reviewed 09 September 2015 in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

	10/08/2015	
Other [Changes in IRAS]	1	10 August 2015
Participant consent form [3 New Interviews, Clean]	2	21 September 2015
Participant consent form [3 New Interviews, Tracked]	2	21 September 2015
Participant information sheet (PIS) [New]	1	10 August 2015
Research protocol or project proposal [Research Protocol, Clean]	3	10 August 2015
Research protocol or project proposal [Research Protocol, Tracked]	3	10 August 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/LO/1488: Please quote this number on all correspondence
--

Yours sincerely
PP



Mrs Rosemary Hill Chair

E-mail: nrescommittee.london-stanmore@nhs.net

Enclosures: List of names and professions of members who took part in the review

*Copy to: Ms Samantha Heaton, Sheffield Teaching Hospital NHS Foundation Trust
 Ms Samantha Heaton, Sheffield Teaching Hospital NHS Foundation Trust*

London - Stanmore Research Ethics Committee

Attendance at Sub-Committee of the REC meeting in Correspondence

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Rosemary Hill	Statistician	Yes	
Mrs Susan Ruben	Pharmacist / Pharmacy Manager	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Sivatharshini Sivakumaran	REC Assistant