

**ADJUSTMENT IN ADOLESCENTS WITH
CLEFT LIP AND PALATE: A
PRELIMINARY INVESTIGATION INTO
EXPERIENCES OF SHAME AND
BULLYING**

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by

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Adjustment in adolescents with cleft lip and palate: A preliminary investigation into experiences of shame and bullying.

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Abstract

For some young people, the experience of having a facial disfigurement such as a cleft lip and palate can result in negative social interactions, often originating from the stereotyping reaction of others. Using the social rank theory of shame, the effects of bullying and teasing were investigated in a patient group of 16, 12-18 year olds with cleft lip or cleft lip and palate. The patient group were compared with a group of 16 of their peers with regards to their experiences of bullying and teasing, shame-proneness and the focus of their shame. The interactional effects of shame and bullying were also investigated in order to test a shaming-loop model of negative social interaction. The investigation necessitated two separate studies. The first study involved 215 adolescents from a secondary school and was required for the development of a focus of shame scale and the gathering of data for establishing its psychometric properties. It also enabled data to be collected regarding the experiences of shame and bullying in adolescents without cleft lip and palate, in order that a random sample of 16 school adolescents matched with the patient sample on age and gender, may act as a comparison group. Participants completed self-report questionnaires concerning shame-proneness and focus of shame, and a semi-structured interview regarding their experiences of bullying. The second study involved the administration of the same measures to the patient sample. Results showed high levels of bullying for both groups although there was no overall difference between the groups. Differences were seen in focus of shame scores, with the patient group having higher scores on shame related to facial appearance than their comparisons. No overall differences were seen on scores of shame-proneness. The implications of the findings are discussed and limitations of the study acknowledged.

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1. INTRODUCTION

1.1 Overview

Cleft Lip and palate is the commonest of the congenital causes of facial disfigurement. In the United Kingdom it affects about 750 children a year, about 0.1% of live births (OPCS 1993). Although the surgical treatment for this condition can result in great improvements in the appearance of affected children, many will still look different and will therefore be the objects of attention and curiosity. (In this report, unless specifically stated the term cleft lip and palate refers to all the conditions of cleft lip, cleft palate or cleft lip and palate as a whole)

Unlike with some disabilities, which may elicit sympathy and compassion, the reaction to facial disfigurement is often one of avoidance and disdain (Bradbury, 1993; 1996; Macgregor, 1990). Although adults may try to hide this discomfort, children will often openly display their disapproval and limited tolerance of anyone who looks different (Shaw, 1988, Gerrard, 1991), and this can often take the form of bullying or teasing. This type of social rejection may have profound effects on youngsters resulting in low self-esteem, anxiety and depression (Bradbury 1993; Bradbury, Hewison and Timmons, 1992; Kapp, 1979; Pillemer and Cook, 1989; Strauss and Broder, 1990). Surprisingly the literature relating to facial disfigurement, bullying, and teasing is sparse, although it is often referred to anecdotally (e.g. Lansdown et al, 1997). Nevertheless, in studies where bullying and teasing have been examined with this population, it is found to be a significant problem (Gerrard 1991; Harris, 1981; Noar 1991).

Bullying can be defined as the systematic abuse of power (Smith and Sharp 1994) and can involve direct physical or verbal abuse as well as indirect abuse such as pushing out of friendships, spreading rumours, or getting others to “gang-up” against a person. There has been increasing public and media interest in bullying over recent years, particularly because of the devastating consequences for some individuals. Research suggests there are potentially serious consequences, for both bullies and victims if it is not tackled (Olweus 1991; Rutter 1989).

Some research suggests that children who are bullied may lack assertiveness skills and generally be more vulnerable to bullying because of a shy or weak temperament (Olweus 1994). Being different in some way such as ethnic group, or physical appearance can also increase vulnerability to bullying (Smith and Sharp 1994). The temperamental factors stated to be responsible for the increased risks for some individuals to being the victim of bullying, are also noted by some as being the consequences of bullying e.g. Gerrard (1991) noted that a vicious cycle of teasing can be established where the responses of the teased child, such as withdrawal, distress and lowered self esteem can fuel further teasing.

It is the experiences of being the victims of bullying for youngsters with cleft lip or cleft lip and palate, which will be examined in the present research, in addition to the psychological and behavioural consequences for these individuals. In particular the affect of shame is examined, as it has been described as central to the emotional response to stigma (Goffman 1968), and the possible links which may exist between the experiences of shame and teasing and bullying for these youngsters. Adolescence is the primary focus for this research, as it's association with peer relations and body image take on particular significance for this age group (Pombeni, Kirchler and Palmanari, 1990; Cash and Pruzinsky 1990).

The review of the relevant literature which follows, is organised into seven major sections. In the first, information about cleft lip and palate is introduced which includes the types of cleft, their physical effects, and standard treatment for this condition. In the next section, some of the literature on attractiveness is reported, and the implications from this for individuals with a facial disfigurement are discussed. This is expanded upon further in the next section when the literature regarding attitudes towards peers with a facial disfigurement is reviewed and an attempt to account for this from the social cognition literature is presented. Following this, the literature on the psychological effects of cleft lip and palate and facial disfigurement is reviewed and discussed. In the next section the bullying literature is discussed with emphasis on, albeit the scarce literature regarding facial disfigurement and bullying. The shame literature is then reviewed and the major theories of shame are presented, in particular a social rank theory and its possible relevance to bullying is discussed. In an attempt to highlight some of the difficulties that youngsters with cleft lip and palate experience, some conclusions are presented from a tape recorded interview with a 24 year old man with cleft lip and palate. This interview took place as a forerunner to the present study, and the retrospective account of this mans experiences at school encompass the main themes of the present study. To conclude, the main themes of the present study will be summarised.

1.2 Cleft lip and palate: Facts

Cleft means a separation, or split of parts. During the early part of pregnancy separate areas of the head and face develop individually in the foetus, and then join together. If certain parts do not join properly, the result is a cleft lip and/or palate. A cleft lip

and/or palate can be either unilateral or bilateral. A unilateral cleft involves a single cleft of the lip and the hard and soft palates are divided. A bilateral cleft involves the division of the upper lip on both sides of the nose, and the palate is not joined in the middle.

The cause of cleft lip and palate is not well understood, although in some cases it may be genetic. Boys are affected by clefts about twice as frequently as girls (Hanson and Murray 1990). The condition can also occur with other malformations, as part of a syndrome.

A cleft lip may occur alone or in addition to a cleft palate. A cleft palate may also occur on its own, more commonly in girls. Unilateral clefts are more common and are considered less severe than bilateral clefts, as they involve less cranio-facial structure and the post-operative results tend to leave less residual disfigurement. Even the highest standard of surgery will inevitably leave scars, furthermore the child may be left with a slightly misshapen nose.

Both conditions can be corrected surgically. For cleft lips, a primary lip repair is carried out at around three months of age. Surgery to correct a cleft palate is usually conducted at around six to ten months, with follow up surgery usually carried out when the child is around eight or nine years old, when sufficient bone is available for grafting.

A child with a cleft lip and palate will often require orthodontic treatment, particularly at secondary school age, as their teeth may be crooked or missing. Speech therapy is often necessary, as a cleft palate can leave the child with hypernasal speech, which may be difficult to understand. Hearing can also be affected because the muscles of the palate are joined to the inside of the ear and often do not work efficiently, which can cause 'glue ear' and repeated ear infections. This may also

affect their speech due to volume control difficulties and further surgery may be required to insert grommets which correct the ‘glue ear’.

1.2.1 Conclusion

A number of specialists are involved in the treatment of cleft lip and palate which include; a plastic surgeon, speech and language therapist, orthodontist, oral surgeon, ear nose and throat surgeon, paediatrician, audiologist, and in some cases a child psychologist. Treatment for this condition can be ongoing for many years, up to later childhood or adolescence, as further surgery may often be carried out to improve function or cosmetic appearance. This lengthy treatment process will frequently involve:

- Many hospital admissions:
- Separation from home and family, often at critical stages
- Experience of pain and prolonged recovery from surgery
- Parents having to cope with a distressed child
- Regular absences from school to attend hospital and dental appointments

1.3 Attractiveness

Much of the literature regarding emotional dysfunction in children with cleft lip and palate draws upon the literature of facial appearance (Rumsey and Bull 1986, Canady 1995 and Tobiason and Hiebert 1993). The notion of ‘reflected appraisals’ (Shrauger and Schoeneman 1979) is the theoretical viewpoint taken. This suggests that children with cleft lip and palate are at a developmental disadvantage emotionally because they incorporate a negative societal view of facial deformity into the self-concept. As facial anomalies are generally assumed to have a negative impact on attractiveness, some researchers suggest that the negative reactions of others play a role in the

development of emotional distress noted in children with cleft lip and palate (Tobiason, 1984). This ‘reflected appraisals’ view is supported by the vast literature on physical attractiveness, which suggests there are many social benefits for the physically attractive, and severe negative social consequences for those considered to be physically unattractive. (Studies of physical attractiveness usually use head and shoulder photographs as their stimuli, and can therefore, be reasonably interpreted as studies of facial attractiveness). Studies have generally found support for the existence of ‘beautiful is good’ stereotyping, whereby attractive males and females are viewed as more intelligent, successful, happy, warm, interesting and sociable than less attractive counterparts (Cash and Pruzinsky 1990). Regardless of the gender of the perceiver the strongest component of this beauty is good stereotype, concerns social confidence (socially skilled, outgoing, popular and likeable), and adjustment (happy, confident and well adjusted) (Cash and Pruzinsky 1990). Even from an early age, facial attractiveness has a profound impact on social perception, with pre-schoolers rating attractive youngsters as friendlier, cleverer and less likely to engage in antisocial behaviour than their unattractive counterparts (Bull and Rumsey 1988, Dion 1973; 1977; 1986; Hildebrant, 1982; Massimo, 1978).

Evidence for the emphasis placed on physical appearance in current society can also be found from many anecdotal sources. The success of cosmetic firms, and the fashion and diet industry, as well as the images which are portrayed through the advertising, media and film worlds, all attest to the crucial importance of ‘looking good’.

Despite the evidence supporting ‘beauty is good’ stereotyping some problems with it are apparent. There is some research which suggests that the consequences of physical attractiveness are not always positive, for example Dermer and Thiel (1975)

found that ratings of socially undesirable attributions such as vanity, egotism and snobbishness increased with the physical attractiveness of persons depicted in photographs. Additionally the methodology used in some studies may not always be adequate often small black and white head and shoulder photographs, not conducive to naturalness are used. The complex structural and dynamic characteristics of living faces can not always be disclosed by such methodology, and a distorted impression may be gained because face-specific information, such as expression, may be lost in experimental methodologies, yet may be of major importance in natural settings. Barnes and Rosenthal (1985) in their study of impression formation found that when actual people were used instead of photographs the effects of attractiveness were diluted by other information such as self-presentation, clothes, competence and outward signs of personality. The notion of ‘beauty is skin deep’ may well be of significance to the physical attractiveness debate in that physical appearance could be mainly important in initial meetings.

What process gives physically attractive people the potential advantage in initial encounters? Adams (1977) to conceptualise the relationship between physical appearance and social interaction proposed a four-stage model;

- The first stage involves stereotyping which develops through our experience of social interaction and cultural influences. ‘What people are like’ stereotypes, or schemata, act as channels or filters of information guiding individuals to pay attention to information that fits the schema and ignoring that which doesn’t. Cues derived from physical appearance are crucial for this process in initial encounters.
- The second stage is that of social exchange, where based on our differing stereotypes we behave differently towards the attractive than the less attractive. It

is these stereotyped patterns of behaviour that are frequently thought to underlie teasing and nicknames.

- The third stage is the development of an internalised self-concept on the part of the person who is on the receiving end of the stereotype in the initial encounter. This will differ depending on attractiveness.
- The fourth stage is the operation of a self-fulfilling prophecy, whereby as a result in part of positive social behaviour from others and positive feelings of self worth, attractive people behave differently from unattractive people. Pressure is on people to play out their expected role, and the strain this may put upon the unattractive may lead to social withdrawal, constriction of interaction and lowering of self-esteem. Events that occur may be unrelated to the person's appearance, but may still be interpreted as such.

There are problems with this conceptualisation, as it implies the process of interaction is uniform and universal, and ignores factors such as the strength and certainty of the perceiver's stereotype (Deaux and Major 1987). However, it provides a useful framework to study the process of social interaction and physical appearance for initial encounters.

As well as the problems identified with the 'beauty is good' stereotyping there are some difficulties with the 'reflected appraisals' view which are identified by Bennet and Stanton (1993). It is suggested that the social experiences of those with facial anomalies are profoundly different to those who are unattractive individuals. Society generally responds with ambivalence to the former (e.g. there are strong cultural traditions of help and sympathy for the handicapped which coexist with avoidance and discomfort), however generalised negativity is thought to accompany unattractiveness. They caution against equating perceptions of physical

unattractiveness with those of physical deformity, and qualify this with the observation that although there is a Cleft–Palate Craniofacial Association, there is no such organisation for ‘plain’ individuals.

1.3.1 Conclusion

The research on attractiveness is problematic, as it generally requires more ecologically valid methodology where appearance cues can be presented within the context of dynamic information about personality and behaviour, without too much trade-off of stimulus control.

The application of attractiveness research to facial disfigurement is also problematic until more is known about whether disfigurement stereotypes differ from attractiveness – unattractiveness stereotypes.

Nevertheless, there is evidence to support the importance ascribed to physical appearance from a variety of sources, including the research literature and through the media. Assumptions relating to personality intelligence and success are initially made on the basis of appearance, influenced by powerful stereotyping processes. These research findings may lead us to tentatively conclude that those who are perceived as unattractive (which may include those with a facial disfigurement) are at a social disadvantage, particularly in their initial encounters with people. Even if attractiveness only has an influence in initial encounters, it could be expected to have some enduring impact as many of a person’s social contacts occur no more than a few times (e.g. in job interviews) and the attractiveness stereotype may give direction to the course of interaction by influencing early interactive behaviour according to Adams(1977).

1.4 Attitudes towards individuals with a facial disfigurement

Although it is argued that reactions to unattractiveness differ from those to disfigurement, it seems clear that reactions to facial anomalies do provoke negative reactions, particularly amongst the peer group of young people (Bradbury, 1993; 1996; Macgregor, 1990). Research suggests that in impression formation a disfigured appearance is such a salient cue that it takes precedence over all other personal and social traits (Centres and Centres, 1963; Richardson 1970; Siperstein and Gottlieb, 1977).

A facial deformity may be particularly stigmatising because of the unique importance of the various functions of the face in providing both verbal and non-verbal information through expression. Goffman (1963) speculated that the closer a disfigurement is to the centre of facial communication (e.g. nose and mouth) the more potent it seems to be in eliciting unfavourable responses. Lansdown and Polak (1975) investigated children's preferences for disfigurements in various parts of the face. Children aged from nine to eleven years old were asked to rank in order of preference a number of line drawings of the same child's face appearing with a range of different disfigurements, (e.g. non-disfigured, with bat ears, a squint, protruding teeth, a cleft lip or a misshapen nose). They found that boys and girls consistently selected the drawings of a child with protruding teeth or a cleft lip as their least preferred choices, supporting the idea that a disfigurement to the mouth is particularly significant in determining social evaluations. However, the results of this study should be evaluated cautiously as the use of line drawings produces rather unrealistic facial stimuli. Tobiason (1987) found similar results with children from a wider age range (eight to sixteen) when photographic slides were presented to them, depicting individuals with unilateral or bilateral cleft lip and palate. The photos were also retouched to remove

scarring and nasal deformity and raters were asked to respond to questions about friendliness, popularity, intelligence, attractiveness and how likely they would be to choose them as a friend. Overall, the photos showing the individuals with the cleft prior to being retouched, were rated more negatively.

Criticism levelled at studies of attractiveness and perception of facial disfigurement is often directed towards the methodology (e.g. Canady 1995). The use by many studies of photographs or line drawings are often not realistic enough. Although recent studies have used computer graphics to produce more realistic facial stimuli they still ignore the effect that other factors play in impression formation, such as vocal qualities, social skills, clothes and gesturing.

Some research demonstrates that it is during the pre-school years when children first display negative reactions to those who are in some way physically different e.g. the opposite sex (Martin and Halverson, 1981). However, attitudes towards disabled children have been found to improve over the childhood years, (Richardson 1970). Research aimed at discovering the extent to which children develop a generalised aversion to anyone who is physically different, and to what extent they form attitudes specific to particular attributes, was conducted by Sigelman, Miller and Whitworth (1986). They looked at children aged from four to eight, and their reactions to potentially stigmatising physical attributes. Drawings of children portrayed as normal, black, of the opposite sex, wearing glasses, wheelchair bound, facially disfigured and obese were shown to them, and they were asked to express preferences through free and forced choice tasks. Findings from the study showed that children of all ages preferred the child most like themselves e.g. same sex, same race and able bodied. The younger children made few distinctions between the other target drawings. Older children expressed greater distinctions in their

preference, and although they also preferred those target drawings of children most like themselves, the first grade children evaluated the obese child more negatively, whilst the elementary school children expressed more negative reactions to the facially disfigured child, than to other target children with stigmatising attributes. The authors concluded that stigmatisation in childhood seems to be primarily a matter of discrimination between the 'normal' and any deviation from this. This progresses as children develop and as well as a preference for the 'like me' there is an increasing differentiation among 'not like me' children. Although the study was conducted on a large sample ($n = 119$) of children, and attempts were made to control for gender of participants and its interaction with gender of the researcher, there were some methodological issues drawn to reader's attention by the authors. These included a possible unrepresentative sample, as participants were drawn from a university school attended by faculty staff's children, making it a predominately white middle class sample, who had relatively little exposure to diversity. As with other similar studies the use of drawings limits generalisation of the findings.

Assessment of facial appearance is an important aspect in craniofacial clinical practice, as the professionals working within such areas make important decisions regarding treatment based upon their assessment of facial characteristics. However, it is possible that their objective ratings of a person's facial appearance will be judged on different criteria than the subjective rating of their own appearance made by the individual in their care. One study (Eliason et al 1991), examining the influence of familiarity and gender of raters on judgements of facial appearance for individuals with cleft lip and palate, compared the responses of 40 professional adults familiar with cleft lip and palate with 40 adults unfamiliar with the disorder. They found that those professionals who are familiar with the condition and involved in treating those

with cleft lip and palate responded more negatively to the cleft appearance than those unfamiliar with the disorder. They suggest that those working on craniofacial teams may examine facial appearance more critically than others, because they react to improvements which could be accomplished by additional surgery, and instead of responding to the total face may focus on isolated features of the face.

Facial disfigurement may be particularly salient in the categorisation process as facial configuration has been shown to have a role in determining social perception (Berry and McArthur 1986). Existing literature on child and adult face recognition has shown that distinctiveness can affect the way information from facial stimuli is organised and encoded by perceivers (face processing). Typically, faces judged to be physiognomically distinct have a recognition advantage over those that are more typical in appearance, possibly because they are so different from the norm (Bruce et al, 1994, Ellis 1990, Ellis et al, 1988). As many cranio-facial conditions extend beyond single feature deformities, (for example a cleft lip is often accompanied by a characteristic flattening of the nose), this may mean they are distinctive and therefore easier for children to categorise or group as different from themselves or others. This grouping process is particularly important from a social cognitive perspective, as the starting point for any stereotypical attitude is thought to be the act of categorisation (Fiske and Taylor, 1991). The proposal is that differently perceived groups become associated with specific traits or behavioural characteristics, and that instances that are highly prototypical or characteristic of the group are more likely to trigger future stereotypic effects in attention, memory and behaviour (Fiske and Taylor, 1991).

The origins of the prejudices that tend to disadvantage those perceived as visibly different are unknown. Speculation includes theories about instinctive rejection, which focus on the idea that a legacy of behaviour originating from natural

selection has been handed down to modern man. From this perspective facial deformity may be considered to be a visible indication of more profound physical or mental disorder which gives rise to instinctual aversion. Others (e.g. Wright 1960) suggest that fear results when a person's unconscious body image is threatened by the appearance of a person with a deformity.

1.4.1 Conclusion

Research on social and psychological responses to disfiguring conditions has often resulted in findings consistent with those on attractiveness. Despite the scarcity of research into other children's attitudes towards their disfigured peers, and the difficulties arising from the methodology of some existing studies, it is clear that negative stereotyping of those with a facial disfigurement does take place. Even those involved in the treatment of facial disfigurement respond negatively to facial deformities although perhaps for different reasons to those of the general public. Nevertheless, these amongst other factors are likely to have a negative impact on those who experience such attitudes.

1.5 The psychological impact of cleft lip and palate and facial disfigurement

Studies evaluating the effects of having a facial disfigurement on the individual have been conducted with a wide range of age groups, from infants to adults.

Responses of parents to the birth of a child with a cleft differ, as does their ability to adapt and adjust to the baby (Bradbury and Hewison 1994). Ability to cope with the period following the birth can be influenced by factors such as the extent of the cleft and familiarity with the condition (Riski, 1991). Early responses may appear similar to grief reactions, often including denial, anger and tearful distress (Riski

1991). Their responses may lead to rejection of the child or to over-protection and separation problems (Bradbury and Hewison 1994). A high incidence of reactive depression has been found in mothers of babies with a deformity (Field and Vegha-Lahr, 1984). However, despite these initial reactions, it seems that most adjustment problems are soon resolved, with the accompanying reduction in parents feelings of grief and distress (Clifford and Crocker, 1971).

Some evidence suggests that attachment and interaction may be more difficult with babies who have cleft lip and/or palate. For example, there may be a dampening of facial expression making the baby “difficult to read” (Field and Vegha-Lahr, 1984), and resulting in the mother being less responsive to signals from such babies (Chapman and Hardin, 1991). Difficulties are also sometimes experienced with some of the ‘normal’ aspects of having a baby, such as social exposure of the child, worries about feeding, taking photographs, etc (Bradbury 1996). Evidence shows that some parents tend to withhold attachment until the cleft lip is repaired (Bradbury and Hewison, 1994). Parental acceptance and adjustment are important factors in determining a child’s psychological strength, which can affect the child’s psychological and social development (Werner and Smith, 1982; Rutter and Rutter, 1992). Early insecure patterns of attachment as evidenced by inconsistent responding of mother to child have been shown to cause problems for the child in later relationships (Bradbury and Hewison 1994). The problems of acceptance and attachment experienced by some parents could therefore have a serious adverse effect on their child’s long term well being. In some cases, the issues for the parents of children with a cleft lip and palate may remain unresolved as the child grows up. For example it has been found that parents of girls with a cleft often express more concern about their daughter’s facial appearance than the daughter (Strauss, Broder and Helms

1988). This may in turn influence the child's ability to cope with and adapt to her disfigurement.

As a child develops, and before the age of five, they learn to discriminate facial expressions and to recognise their own face. They also experience increased exposure to others, making this a potentially difficult time for children and their parents (Bull and Rumsey, 1988). Research has shown that children with cleft lip and palate also experience parental overprotection (Tobiason and Hiebert 1993). This may be an understandable response whereby parents seek to protect their child from adverse social pressures, but it may result in an increased tendency for the child to become dependent on others, and may affect their confidence in their ability to make decisions (Broder, Smith and Strauss 1994).

Between the ages of five and ten, children develop increased self-consciousness and a sense of difference. The development of children with a cleft lip and palate may be affected by the treatment they receive from others. Children with a facial disfigurement may be less likely to receive positive communication, which may cause them to become less responsive, and less likely to learn about themselves from others (Adams, 1977).

Children with cleft lip and palate have also been found to encounter reduced teacher expectations (Richman and Harper, 1978). These experiences may have profound implications for their academic development and psychological adjustment. It has been found that children with cleft lip express greater dissatisfaction with their appearance than those without a cleft lip or with cleft palate only. They have also been found to have lower educational aspirations compared with their peers (Peter and Chinskey, 1975). Some research has shown children with cleft lip and palate to exhibit particular psychological and behavioural patterns, including poor self-concept

and low self-esteem; a lack of skills necessary for reciprocal play; a lack of belief in the ability to be happy; lower educational achievement; and an increased risk of behaviour problems (Kapp, 1979; Richman and Harper, 1978; Bull and Rumsey, 1988).

The period of adolescence has been stated as being a difficult time generally, where much change takes place for the individual. Although the ‘storm and stress’ myth (Blos 1970) is disputed in empirical research findings, it is clear that factors such as a changing body image and the need to establish a separate identity from the family identity, can create adjustment problems for some individuals. The developmental tasks of adolescence (Erikson, 1963), are summarised by Kapp-Simon (1995) as the evolution of personal identity and the achievement of independence. The physical and emotional changes which accompany puberty may create issues of identity. Self-consciousness regarding one’s body and appearance emerges, and comparisons with the peer group take place partly to affirm normality. The peer group take over from the family in providing benchmarks used to measure one’s personal values and redefine them in the context of that group. Social acceptance becomes all the more important as the adolescent redefines his/her relationships with parents and other adults, and establishes an identity apart from the family. It is then not surprising that adolescents with cleft lip and palate can experience difficulties at this time, as they have to cope with integrating their facial differences into an already changing body image, developing relationships despite possible dissatisfaction with facial appearance, and dealing with surgery which may alter their facial appearance (Kapp-Simon, 1995).

Studies with adolescents who have cleft lip and palate suggest that when difficulties do occur they are in the social domain. Tobiason et al (1992) reported that

fifty-seven percent of the youngsters he studied, between the ages of twelve and sixteen, were rated as less socially competent than their peers. Harper and Richman (1978) found their sample of adolescents with cleft lip and palate displayed self-concern and self-doubt regarding interpersonal relationships. Anxieties may arise for adolescents with cleft lip and palate concerning their first experience of kissing, which may influence the area of relationships. For example, adolescents consistently report having problems as a result of their cleft in the area of relationships, particularly in their confidence and ability to attract boyfriends and girlfriends (Noar 1991). Research has found that the self-concept of girls with cleft lip and palate becomes increasingly negative as they move from childhood to adolescence, while adolescent boys have a more positive self-concept compared with younger boys (Leonard et al. 1991). This may be linked to the findings from the literature on body image, which suggests that female adolescents have the strongest appearance orientations and the most negative appearance evaluations. Positive feelings about these aspects are associated with favourable psychological adjustment, and negative evaluations with lower levels of psychological adjustment (Cash and Pruzinsky 1990). For example a negative body image has been found to be associated with eating disturbances, social anxiety and self-consciousness, depression, sexual difficulties and poor self-esteem (Thompson, 1990)

The social difficulties that some individuals with cleft lip and palate experience may continue into adulthood. Research was conducted in Norway involving a large sample of adults aged from twenty to thirty five years old, with repaired cleft lip and palate (Ramstad, Ottem and Shaw 1995). Some of their findings were that subjects were less often employed in sales jobs and more often in clerical jobs (compared with their control group) and had less stable jobs. Fewer people with

cleft lip and palate married and they married at an older age than those without a cleft. It was found that the cleft lip and palate group reported higher levels of depression and anxiety, and these problems were strongly associated with concerns about appearance, dentition, speech and a desire for further treatment.

The severity of a disfiguring condition might be expected to be an important factor mediating the adjustment of individuals. It has been found that those with a more severe disfigurement can accurately predict an unfavorable reaction from those they meet, however for those with a milder disfigurement the reaction of others is not so certain (Lansdown et al 1991). The authors suggest that this can lead to greater difficulties for those with a mild disfigurement as they worry about whether or not their disfigurement has been noticed, whereas those with a more severe disfigurement can employ coping strategies at the outset to combat negative responses from others.

Despite the research cited above, the psychological consequences for individuals with cleft lip or cleft lip and palate remain unclear. Some research gives empirical support to the notion that these individuals have few adjustment problems. For example, Broder, Smith and Strauss (1992) found in their study of school-aged children and their parents, that fifty-four percent of the children with cleft lip or cleft lip and palate were pleased with their appearance. A study comparing a cleft palate sample with obese and normal adolescent samples found the cleft sample expressed a greater degree of self-confidence and self-esteem (Brantley and Clifford, 1979). Richman (1983) stated that there were no significant increases in severe personality or adjustment problems in adolescents with cleft lip and palate compared with their peers. Other authors agree that as a group individuals with a cleft lip and palate are well adjusted socially although problems do occur on an individual basis. Some authors feel that members of some stigmatised groups may use their stigmatised status

for self-esteem enhancement. It is suggested that any negative feedback they receive is attributed to their stigma, thereby protecting their self-esteem (Crocker and Major, 1989). This may therefore apply to individuals with a facial disfigurement, and may be one of the factors involved in some of the research findings of a positive outcome.

1.5.1 Conclusion

Clearly there are many and varied factors affecting the outcome for individuals with cleft lip and palate. Factors such as severity of the cleft, social support and personal qualities are all relevant as mediating factors in the individual's ability to cope. The research demonstrates that there are inconsistencies in psychological adjustment for this group. Nevertheless, there does seem to be a clearer picture with regard to social adjustment. How individuals with a cleft lip and palate relate to their peers, and how their peers relate to them are the most frequently cited problem areas from inspection of the literature. It is the nature of particular negative social interactions which is given further attention in the following section.

1.6 Teasing and bullying

Bullying and teasing are terms used in this section to refer to the experience of peer victimisation. This is the experience, among children, of being the target of aggressive behaviour by another child or children. Peer victimisation can take several forms among children, but researchers disagree about how these forms are to be distinguished. A full discussion of this is beyond the scope of the present study, but generally studies distinguish between physical victimisation, verbal victimisation and indirect victimisation (e.g. spreading rumours or 'sending to coventry') (e.g. Osterman, et al. 1994). It also includes some form of aggression in which the victim is

targeted repeatedly or over a prolonged period, and in which the aggressor is in some sense more powerful, or stronger, than the victim (Olweus 1994).

It is clear that teasing and bullying is a reasonably common occurrence among children. Sharp and Smith (1991) reported that twenty-seven percent of primary school children and 10% of those of secondary school age have experienced bullying in some form. Their study also reported that verbal teasing was more common in girls, whilst physical bullying was more common in boys. Other studies have found bullying and teasing to be more frequently reported at secondary school than at primary, for example Branwaite (1994). It could be argued that bullying and teasing of any kind may be more hurtful in adolescence, because of the vulnerability of the individual's self-esteem and identity, and because of the need for acceptance by the peer group.

Of particular interest are the studies which appear to show that bullying and teasing are often encountered by children who, like children with cleft lip and palate, are different in some way. For example it has been demonstrated that children with learning difficulties (Nabuzoka and Smith, 1993) and cancer (Charlton et al. 1986) are likely to experience bullying, especially in mainstream schools.

Studies investigating the experiences of teasing and bullying, for children of any age, with cleft lip and palate, are scarce. Noar (1991) used questionnaire methods to look at the concerns of young people aged sixteen to twenty five years with cleft lip and palate. Teasing was one of the concerns raised, with seventy-five percent of his sample reporting that they had been teased because of their cleft. Qualitative methodology was used by Rose and Loewenthal (1998) in their study to investigate the need for counselling/psychotherapy services for people with cleft lips. Their nine participants aged from 18 to 71 years old, had all been subjected to varying degrees of

teasing about their looks, and although they found that the teasing lessened as they got older, the impact of earlier taunts remained with them for a long time. The adolescent years were identified by the group as being the most difficult. Gerrard (1991) investigated the effects of a treatment aimed at helping children attending a cranio-facial clinic, including children with a cleft lip and palate, to cope with teasing. He estimated that teasing was a problem for approximately forty percent of the youngsters attending the clinic. Additional to these studies are the many anecdotal reports of teasing that individuals with cleft lip and palate and other facial disfigurements express. However, there is no existing research which indicates whether the teasing experienced by this group occurs more frequently than for 'normal' samples of school aged children. Certainly, appearance-related teasing does seem to be a relatively common experience for many school children. For example, a survey of nicknames and harassment among school children revealed that sixty-six percent of the 531 school children in the sample were teased about one or more characteristics. This included height and weight as the most common targets for teasing, with teeth and nose being the fourth and sixth most common targets respectively (Shaw, Meek and Jones 1980).

Although bullying and teasing are relatively common experiences for school children, their effects should not be under-estimated. Sharp and Thompson (1992) found in a sample of 723 secondary pupils that forty percent had been bullied during that academic year; twenty percent said they would truant to avoid being bullied; twenty-nine percent found it difficult to concentrate on their school work; twenty-two percent felt physically ill and twenty percent had experienced sleep difficulties as a result of bullying. Olweus (1993) showed that boys who had been victims at school

between the ages of thirteen and sixteen years, when followed up at the age of twenty-three, were more likely to have depressive symptoms and poor self-esteem.

Recurrent teasing and criticism of appearance may foster the development of a negative body-image development. Cash, Winstead and Janda (1986) found that women and men who reported that childhood peers teased or rejected them because of their appearance were more body-dissatisfied as adults than non-teased controls. Cash (1995) also observed that teasing severity was significantly correlated with a more negative body image. More serious affects of appearance-related teasing have been demonstrated by the rare cases reported in the press of youngsters taking their own lives, allegedly because of these experiences.

Some authors have looked at the characteristics of the typical victim of bullying. Olweus (1994) summarises the findings of some of this work, stating that the “typical victims are more anxious and insecure than other students in general. Further, they are often cautious, sensitive and quiet. When attacked by other students they commonly react by crying (at least in the lower grades) and withdrawal. Also, victims suffer from low self-esteem, they have a negative view of themselves and their situation; they often look upon themselves as failures and feel stupid, ashamed and unattractive.” Olweus labels these children as passive/submissive victims stating that it is their behaviour and attitude which signals to others that they are insecure and will not retaliate if attacked or insulted. Sharp (1996) investigated this further when she looked at the relationship between self-esteem, response style and the stressfulness of being bullied. Although she found that both students with high and low self-esteem had been bullied, those with low self-esteem had been bullied more extensively and experienced greater stress as a result of this. These characteristics of typical victims of bullying may have particular relevance for individuals with a cleft

lip and palate, as if they already suffer from low self-esteem, this may make them more obvious targets for bullying. Gerrard (1991) makes a similar claim when he discusses the dynamics of teasing for children attending a cranio-facial clinic. He speculates that a child may feel vulnerable even before being teased, because of the incorporation of the parent's perception of them at an early age. This may then lead to peer group teasing of a vulnerable child. If as a result of this teasing the child becomes distressed and withdrawn, this response may fuel further teasing by the peer group, and a vicious cycle of teasing is then established.

1.6.1 Conclusion

Bullying and teasing is a significant problem in schools which can have long-term consequences for the victims. Appearance related teasing is a major source of teasing and those with a visible difference may be more vulnerable to this type of victimisation. Passive/submissive behaviours have been noted in those who are bullied or teased by some researchers. If these passive/submissive behaviour patterns are the consequences of being bullied, or the factors involved in initially attracting the aggressors, what processes underlie their development? It is the theories of shame, and in particular social rank theory which may have relevance to this question. These theories also have implications for facial disfigurement, and with these two areas in mind, the literature relating to shame will be discussed in the following section.

1.7 The role of shame for individuals with cleft lip and palate

Shame experiences for people with a facial disfigurement have not previously been examined. However, their relevance is shown by the many personal reports by this population of encounters with non-disfigured individuals, where shame is revealed as a predominant feeling. The English word "shame" originates from the Indo-European

“skam” meaning to hide, and this is exactly what many individuals with a facial disfigurement try to do. They may do this by not going outdoors unless absolutely necessary, or they may try to disguise their disfigurement with make-up or cover it with hair (see Lansdown et al 1997 for personal accounts). The primary motive for this behaviour is usually to avoid the stares of others. In studies carried out by Frances Macgregor, it was found that the major difficulties experienced by those with facial disfigurements were centred around other’s reactions to them, “while distressed each day by the reflection in their own mirrors, as much if not more hurtful and damaging to their self-image and self-esteem is seeing their own flawed faces reflected in the reactive behaviour of the non-disfigured” (Macgregor 1990). Shame is often defined as acute arousal or fear of being exposed, scrutinised and judged negatively by others (Lewis 1971, 1987; Gilbert and Trower 1990), and it is the self-other evaluative domain which seems central to the experience of shame, and also to the experience of individuals with a facial disfigurement. Generally, shame seems to focus on either the social world (beliefs about how others see the self), the internal world (how one sees oneself), or both (how one sees oneself as a consequence of how one thinks others see the self). The beliefs that accompany shame state that one cannot create positive images in the eyes of others, one will not be chosen, one will be found lacking in some way such as talent or appearance, and one will be ignored or rejected, or even the object of scorn and ridicule to others (Gilbert and Andrews 1998). One of the more popular ideas about emotional dysfunction in children with a cleft lip and palate is also that which originally gave rise to ideas about shame processing; the “looking glass self” put forward by Charles Cooley at the turn of the century (Cooley 1902 cited in Bradford Brown and Lohr 1987). This refers to the way we judge ourselves according to the way we feel we are judged by others.

The emotion of shame is receiving increasing amounts of attention, with a variety of theoretical models used to explain its development and relation to psychological adjustment. Some of these theories will be briefly reviewed.

Some psychodynamic theories attempt to explain how shame might develop. For example current Freudian psychoanalytic theories within the Freudian school suggest that shame arises out of dysfunctional child-parent interactions. As a result of the parent being experienced as a negative stimulus who does not reflect their sense of joy, the child's sense of self is damaged and shame is experienced (Schorer 1991). Similarly in object relations theorists argue that shame develops when self-other boundaries are threatened, and damaging self and object representations are interposed onto the self (Spero 1984). A further psychodynamic model of shame has been developed from self-psychology, (Kohut 1977). It is suggested in this approach that there is a nuclear self that is the central integrating structure of the personality. "Self-selfobject" relations determine how the individual experiences themselves in relation to the outside world, and they involve interactions with social others whom the person identifies with and values. It is suggested that shame is experienced when the person perceives that "self-selfobject" relations are critical of the self, and are capable of damaging the self. Consequently, the person attempts to withdraw or hide from the influence of others (Stern 1985).

Another group of theories propose that shame arises from disturbed power relationships derived from negative self-other comparisons (Lewis 1971, 1987). Similarly Gilbert (1992) suggests that shame differs from guilt on dimensions of helplessness, inferiority and being overpowered by others, and puts forward a ranking theory, which originates from evolutionary notions of status hierarchy (Gilbert 1989; 1992). In ranking theory, shame is seen as developing out of rank and status

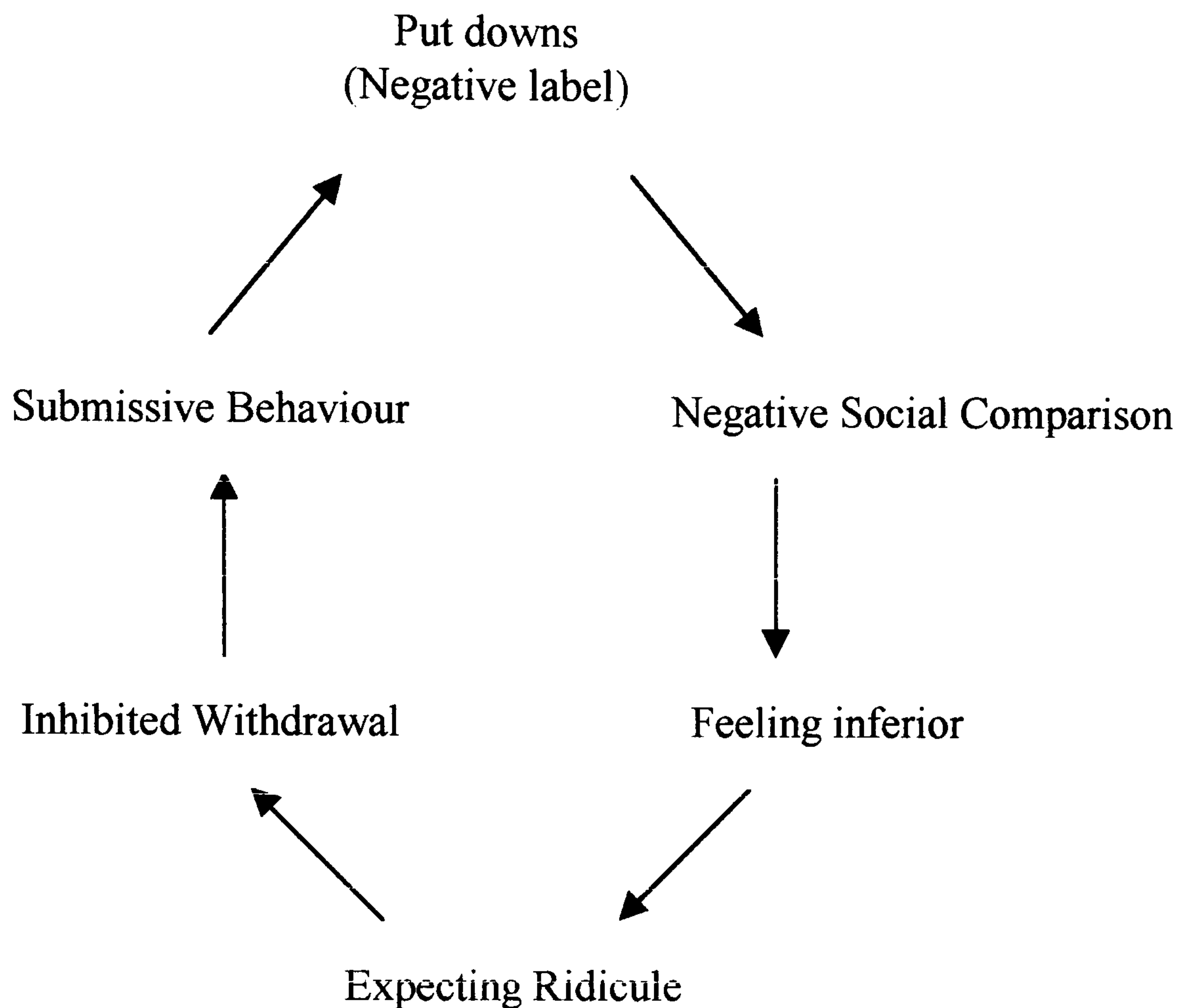
judgements which place the individual in an inferior and/or powerless position in comparison to another. Humans have two main pathways in social ranking. The first is based on threat and dominance, which is also seen in animals. However, unlike animals the second pathway is based on social attractiveness. This latter pathway is seen to be the most important in developing a sense of shame.

Ranking theory suggests that assessments of one's relative rank are based on social comparison judgements. Constructs used in these judgements include inferior/superior assessments and similar/different assessments. It is hypothesised that if the self is seen as inferior or different in a negative sense then a shaming response may occur.

Another hypothesis of ranking theory is that submissive judgements and behaviours may also be a common response to a shaming incident. Behaviours identified as submissive from research include: allowing others to criticise without defending oneself, offering frequent apologies to others, refraining from initiating conversations and giving in to others demands (Buss and Craik 1986). These behaviours are mediated via gaze, body posture, proximity behaviours, voice tone, volume and clarity, so may typically include slouched posture, avoidance of eye contact and mumbling (Gilbert 1992). These behaviours may also be responsible for triggering future shaming incidents through the process of a shaming loop (Gilbert and Lang 1994). This process is illustrated in Figure 1.

Figure 1

The Shaming Loop (from Gilbert and Lang 1994)



This shaming loop model suggests that once an individual experiences shame, a pattern of negative social comparisons develop, which lead to feelings of inferiority and expectation of further ridicule. This results in the individual becoming inhibited and withdrawn, and developing submissive behaviour. The persons who are shaming soon pick up on this, and because they know the individual is unlikely to defend him or herself the process is set in motion again with further put downs.

The shaming loop has obvious implications for bullying and teasing. As discussed above previous studies have looked at the behaviours of victims of bullying and identified in some a passive/submissive behaviour style. If social rank theory is applied to bullying situations, it suggests that bullying is a way of asserting social rank and victimisation is the experience of being down-ranked. Verbal aggression (or put downs), such as name calling or teasing, may be seen as reinforcing low

dominance rank to the extent that the victim is unable to retaliate and end the teasing. Victims may be told they are weak, stupid, fat ugly, boring or slow (Gilbert and Lang 1994). Each of these can be seen as a put down which is used to show them that they are less important, powerful, or well regarded than their aggressor. The submissive behaviours that result are, according to social rank theory, involuntary subordination strategies, an evolved automatic behavioural response given by a weaker animal in a dominance struggle when it submits to the stronger.

What is not clear from the research on behavioural responses to bullying and teasing, is whether these submissive behaviours exist prior to the individual being bullied, thus making the individual an easy target for bullies. This is suggested in the study of teasing amongst children with cranio-facial disfigurements by Gerrard (1991), but has not been demonstrated empirically. Certainly a number of studies have suggested that an inhibited behaviour style is common in youngsters with cleft lip and palate or cranio-facial disfigurements. For example Richman et al (1985) noted an association with facial dissatisfaction and behavioural inhibition in this population. McGuire (1992, cited in Kapp-Simon 1995) collected observational data on young adolescents with facial disfigurements in school settings and found that they made fewer approaches to their peers, and were approached less often by their peers. Their behaviour when they did approach others included infrequent eye contact, slouched posture, tentativeness and monotonous tone of voice, often resulting in them being ignored. These reported behaviours could well be manifestations of the involuntary subordination strategies described by social rank theorists, but as bullying and teasing were not investigated in the studies above it remains unclear whether they predate bullying or are a consequence of it.

Shame proneness or vulnerability refers to those factors which are already in place before shame is aroused and relates to the readiness to experience certain types of emotion and engage in certain types of behaviour in certain situations, as well as the severity of the negative affects and behaviours triggered in certain situations (Gilbert and Andrews 1998). Factors such as trauma, early negative self and other schemas, low self esteem and genetic factors, are all hypothesised as increasing an individual's vulnerability to the experience of shame (Gilbert and Andrews 1998).

The early experiences of individuals with cleft lip and palate, such as the reactions and ability to cope by parents as well as their peers reactions to them may mean that their self-concept is that of being different to others in a negative context. These experiences may result in individuals with cleft lip and palate being likely to be more shame prone than their non-disfigured peers.

Gilbert (1989, 1992) and Kaufman (1989) suggest that shame can be generalised or specific. When specific it can be focussed on one or more of the following six areas:

- *Body shame* – this applies to evaluations and judgement about one's body and physical appearance. Various attributes such as size and shape, texture and bodily functions can be a source of shame.
- *Body in action* – One may feel comfortable with one's body until it is seen in action. For example being awkward at ball games or dancing can lead to avoidance of these activities.
- *Achievements* – Failures of all kinds, and not reaching certain standards or achievements can be a source of shame. As many theorists have pointed out, some children grow up in an atmosphere where they only feel accepted and loveable if they demonstrate the ability to achieve certain standards and goals.

- *Relational shame* – This refers to shame that is not only personal, but brought on by one's family and/or associates. It relates to the disgrace and dishonour that can be seen to befall others from the actions of a person.
- *Group shame* – Shame can relate to a social identity and as such personal shame or humiliation can be felt for any demotion or disgrace that falls on one's group from which one takes an identity.
- *Feelings* – Children can learn early on which feelings are acceptable and which are not. Any internal feeling state can become a source of shame, such as anger, envy, expressing pain, crying and expressing affection. This is often experienced as 'I should not feel this way' or 'I am a bad person for having these feelings'

Although these six areas of shame focus are hypothetical at present, it is possible that some factors may make individuals more prone to experience shame in a particular domain. Factors such as developmental stage, gender, race, physical illness, congenital conditions, etc may all interact with the focus of an individual's shame. However, this area has yet to be explored.

1.7.1 Conclusion

There are still many issues to be resolved in the study of shame. Nevertheless its importance is well established. It has been seen to play a role in many forms of psychopathology, from violence to depression and anxiety, through to the loneliness of shyness (Gilbert and Andrews 1998). Theories of shame may offer useful insights into the social interaction difficulties which some individuals with a visible difference, such as cleft lip and palate, experience.

1.8 John

To demonstrate some of the difficulties experienced by some individuals with cleft lip and palate, a brief summary of a tape recorded interview with someone with this condition is presented. This interview took place prior to data collection, and was one of the factors involved in identifying a focus to this study and as such should illustrate some of the themes of the research.

John (not his real name) is a 24 year old man who was born with a unilateral cleft lip and palate. He underwent treatment for this and was discharged from the cleft lip and palate team in late adolescence. He is presently living with his mother and younger brother, and is attending college to complete an access to nursing course.

John stated that he had experienced name-calling which started at secondary school; it was a frequent occurrence which was initiated by a group of boys in his class. As a result he felt he was unable to concentrate on his school work, and achieved disappointing exam results. He told members of the teaching staff about the name-calling, but felt that their suggestions, such as ‘stand up to them’ or ‘it will pass over’ were not very helpful. Some teaching staff showed a certain amount of ignorance and insensitivity about his condition, which was demonstrated to John when another boy with a cleft lip and palate joined the school, and was assumed by some teachers to be related to him.

He described himself at this time as completely lacking in confidence, which he said resulted in him going about with his “head on the floor, unable to look up”. He stated that he felt those that teased him saw his weakness as being a lack of confidence and used that knowledge to tease him further.

His descriptions of the difficulties he faced when undergoing surgery are typical of many accounts of the problems faced by individuals undergoing surgery

which changes their appearance (e.g. Lansdown et al 1997). He spoke of a desperate need to see the results of the operation almost immediately when his face was still red and swollen, and the bitter disappointment he experienced when the results were not exactly what he expected.

Another problem which John described was his anxiety regarding intimate relationships. At 24 he had not yet been involved in an intimate relationship and was clearly concerned about this. He stated that at the time his peers were starting to have relationships he was too concerned with the problems he was experiencing with teasing and with his schoolwork to do likewise. He now felt that his confidence to initiate any form of intimate relationship had been affected by these earlier experiences. John's lack of confidence in this area is not an uncommon experience for young people with cleft lip and palate. Noar (1991) found in his sample of 16-25 year olds with cleft lip and palate that half of them reported that their confidence and their ability to attract boy or girlfriends had been affected.

John seemed to cope with these experiences by taking rather a philosophical view, stating for example that "you've got to get on with life" and "it could be worse". He stated that seeing other children who were in wheelchairs or had leukaemia, when he attended the hospital for treatment made him feel that things could be a lot worse for him.

John's descriptions of his behaviours at school such as having his 'head on the floor unable to look up' bear resemblance to signals of subordination discussed in the shame literature. Additionally his recognition of the fact that his lack of confidence was instrumental in experiencing further bullying lends support to the shame feedback loop described above. It could be hypothesised from the cognitive theories of shame that those experiences of teasing had resulted in John experiencing himself as inferior

and different in the perceptions of other people, and could explain his reluctance to seek intimate relationships perhaps fearing rejection if he tried to initiate such relationships.

1.9 Summary

Surgical treatment for cleft lip and palate, although good, does not always result in a ‘perfect’ face. The lip and nose may be slightly misshapen and there are often slight scars visible. In addition a hypernasal voice may contribute to the fact that children affected by this condition may appear and sound slightly different to many of their peers.

Studies of attractiveness have been cited by some authors to explain some of the difficulties that these youngsters experience. They suggest that the cleft lip and palate has a negative impact on attractiveness, and the problems that these individuals encounter are similar to those individuals who are unattractive, as explained by the ‘beauty is good’ stereotyping found in studies of attractiveness. However problems are found with this explanation by some who hold that a facial disfigurement has a different impact on others than does unattractiveness, with the public being on the whole sympathetic to the former group.

Those few studies that have looked at other’s perceptions of individuals with a facial disfigurement do however produce similar results to those comparing responses to attractive and unattractive individuals. They are often seen as less intelligent, friendly and popular and the least preferred choice of friend than the comparisons utilised for the studies. The social cognition literature explains this by using theories of stereotyping and categorisation, whereby children will discriminate between those most like them and most not like them. The facial features produced by having cleft

lip and palate may make the categorising process easier for children by producing distinctive differences.

Studies throughout the age range conducted with individuals with cleft lip and palate produce ambiguous results particularly when self-concept and self-esteem are examined. Less ambiguous however are those which look at the social interaction experiences of these individuals. Here it is often found that children with cleft lip and palate lack confidence, skills and abilities in this domain. Anecdotal reports suggest that they are often on the receiving end of negative social interactions and in the few studies where bullying or teasing have been a line of enquiry this is shown to be a considerable problem.

It could be predicted from a social cognitive perspective that any child with a stigmatising difference may be more likely to be teased, particularly where the difference is one of those which have negative stereotypical beliefs associated with them. Although this has been investigated with a few conditions, it has never been firmly established empirically with a sample of children with cleft lip and palate.

Important research on bullying and teasing has identified characteristics typical of victims. It is suggested here that the literature on shame has considerable potential in explaining the process by which the victims responses develop as well as the continuous bullying and teasing that one individual may experience. Theories of shame, particularly social rank theories, may also offer some theoretical underpinnings to the development of some of the psychosocial problems experienced by those with cleft lip and palate. It may be predicted that some of these individuals will develop negative self-other comparisons, construing themselves as different and/or inferior to their peers, possibly as a result of early attachment experiences and early social interaction experiences. This would make them likely to be more shame

prone, and this may take on special significance during adolescence when peer-related comparison appears to be most salient. Furthermore, if these individuals are more shame-prone and their facial differences make them more likely to be teased and bullied, then the resulting involuntary subordination responses may be more easily evoked.

A starting point for further investigation of these issues would be to establish if bullying and teasing is more of a problem for children with cleft lip and palate. Next, it would be important to know if these children were likely to be more shame-prone and if so, if there were an association between shame-proneness and being a victim of bullying. As shame may be particularly relevant to adolescence in general, it would be important to establish whether, in studying this age group, those with cleft-lip and palate had a focus of shame specifically related to their difference.

1.10 Hypotheses of the present study

1. Adolescents with cleft lip and palate will be more likely to experience bullying and/or teasing than their peer group.
2. High shame-proneness will be more likely in adolescents with cleft lip or cleft lip and palate than in their peer group.
3. The focus of shame for adolescents with cleft lip or cleft lip and palate will differ from the focus of shame in their peer group.
4. Adolescents who are victims of bullying and teasing will be more likely to be shame-prone.

2. METHODOLOGY

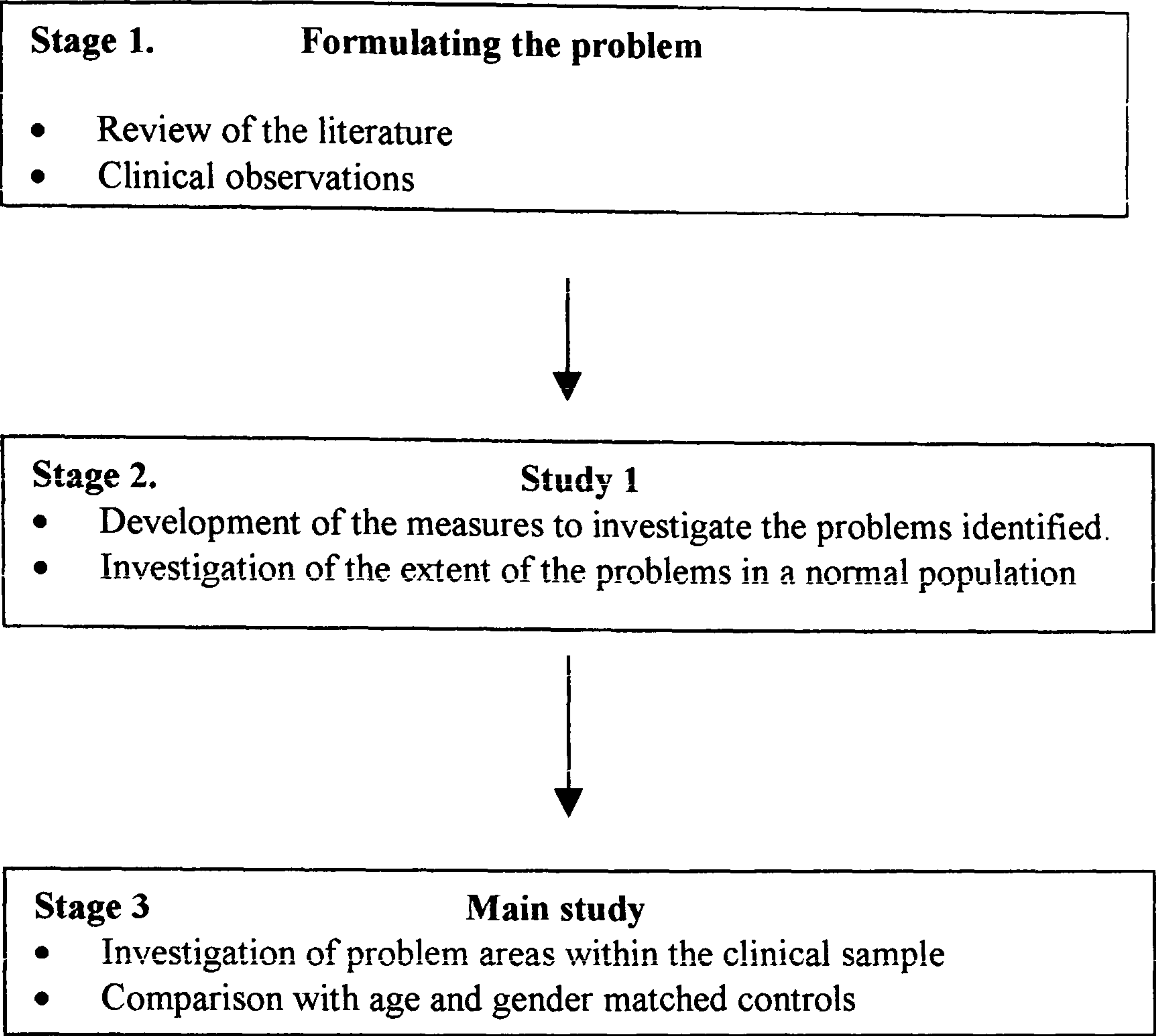
2.1 Overview

From the review of the literature, a clinical problem was identified as being worthy of investigation. The experiences of being victims of bullying and the possible interactional effects of shame-proneness and a specific focus of shame were raised as important factors to investigate in a sample of adolescents with cleft lip or cleft lip and palate. However, before the research hypotheses could be tested, acceptable measures were needed. As there are no existing measures with which to identify a focus of shame, a separate study was thought to be necessary in order to develop such a scale. Additionally it was important to establish the extent to which the factors under investigation with the sample of adolescents with cleft lip or cleft lip and palate were present within a normal population of adolescents. It may be that the problems under investigation are no more significant for the adolescents with cleft lip or cleft lip and palate than for their peers.

The stages of the research are illustrated in Figure 2.

Figure 2

Stages of the present research



2.2 Aims of the present study

This study has four main aims:

1. To develop a valid and reliable measure which will examine the focus of shame for adolescents, in order to explore the focus of shame for adolescents with cleft lip or cleft lip and palate.
2. To establish data related to shame-proneness, bullying and teasing and focus of shame for adolescents without cleft lip or cleft lip and palate, in order to provide a comparison for data from a cleft lip or cleft lip and palate group.

3. To determine the extent of bullying and teasing which is experienced by adolescents with cleft lip or cleft lip and palate.
4. To examine shame-proneness experienced by adolescents, and its relationship to bullying and teasing.

To achieve the aims of the present study two separate studies were conducted. The first study involved the development of a focus of shame scale as there are no existing scales which examine this. It also involved the use of existing scales for a) establishing the validity of the focus of shame measure, and b) obtaining data from a sample of adolescents without cleft lip or cleft lip and palate, in order to be able to compare with data from these scales obtained in a second study with adolescents with cleft lip or cleft lip and palate.

The second study involved the administration of the same scales used in study one to a sample of adolescents with cleft lip and palate, on a later occasion.

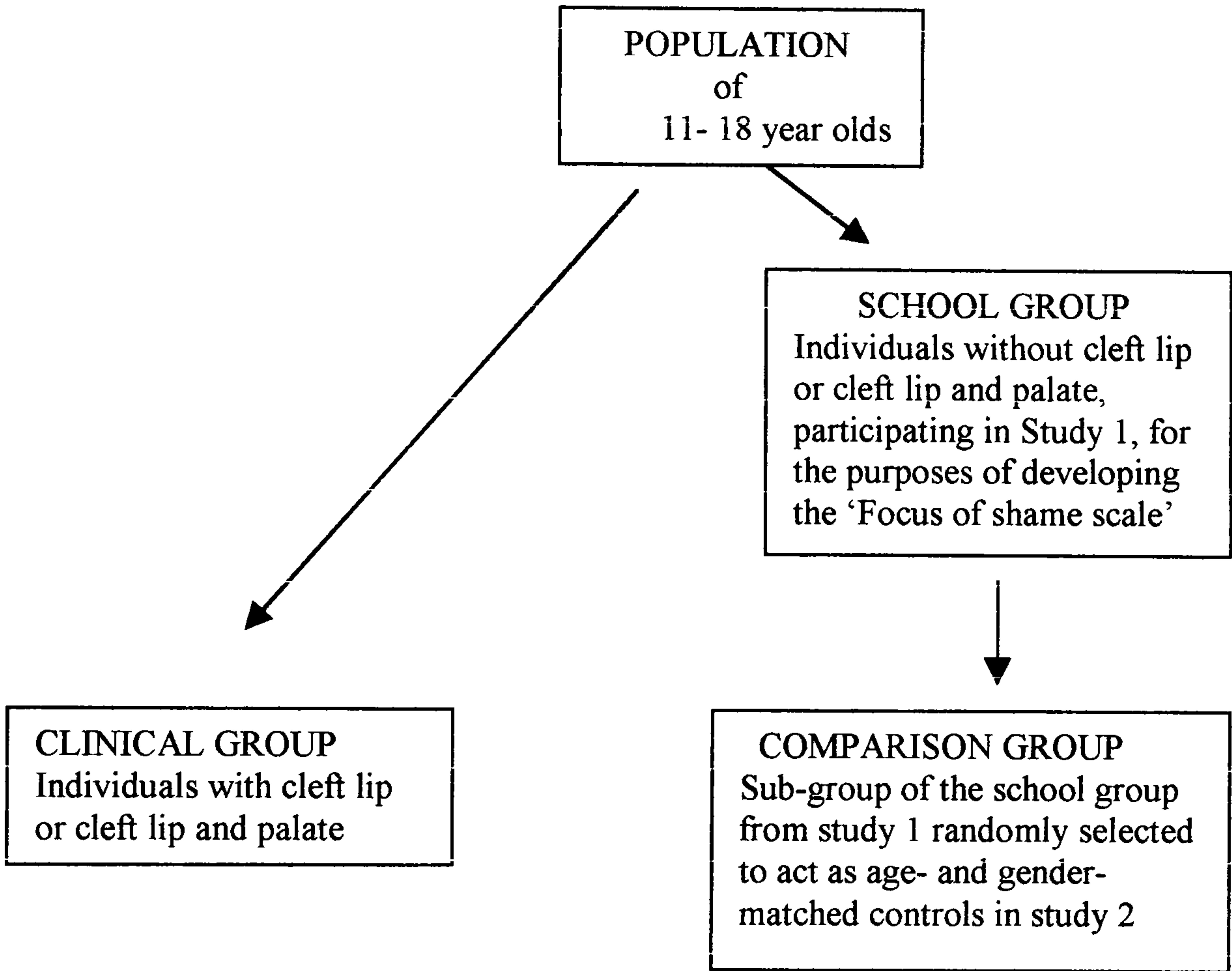
2.3 Design

A questionnaire-based research design was used for both studies which involved the presentation of two sets of questionnaires and one semi-structured interview on one occasion to participants.

The design of the study was structured to facilitate both between-group and within-group comparisons and is illustrated in figure 2.1. Two separate groups were included, the group with cleft lip, or cleft lip and palate, labeled the ‘clinical group’ and the group without cleft lip, or cleft lip and palate labeled the ‘school group’; this was the group used to validate the focus of shame scale. Subsequently a set of potential age- and gender-matched controls were identified for each member of the clinical group from among the school group. This process involved selecting every

participant in the school group who matched an individual in the clinical group for age and gender; taking the numbers assigned to each of these potential matches in the data entry process; placing those numbers in a receptacle; and randomly taking one out which then became the match for the clinical group individual. This process was repeated on 16 occasions until there were matches for each member of the clinical group. The age- and gender-matched controls were labeled the ‘comparison group’.

Figure 2.1 Study design



The primary design of the study was a between-groups analysis (clinical and comparison groups) of the dependent measures of shame-proneness, focus of shame and being the victim of bullying. Within the clinical group a further within-group analysis was undertaken with degree of shame-proneness serving as the independent variable and experiences of bullying and focus of shame relating to facial appearance as the dependent variables. This was repeated with the comparison group.

3.STUDY ONE

3.1 Study One - Materials

The materials used in this study comprised two questionnaires and a semi-structured interview. They are presented below in the order of use, and their construction and psychometric properties are discussed where relevant. Copies of all scales used in this study may be found in the appendix.

1. The Adolescent Focus of Shame Scale (AFOS). This scale is a 27 item questionnaire developed during this study, for use in the second study of adolescents with cleft lip or cleft lip and palate. It is intended to identify possible interpersonal areas towards which adolescents may feel shame. Items are based on theoretical work which suggests that shame may be focussed on six specific areas (see section 1.7 above). Items were initially generated by the author in collaboration with a clinician with research experience in the area of shame. Initially three items were chosen to represent each of the six possible foci of shame. After discussion it was decided to only use two items per foci of shame but to elaborate upon the items related to appearance as these were particularly salient to the research questions and the two general questions about appearance related shame may have missed many potential areas of appearance which youngsters may feel shame towards. Prior to its use with the sample in this study the AFOS was completed by a 12 year old girl (a daughter of the authors friend) to ensure the language used in the scale would be comprehensible for the intended sample. The AFOS asks participants to rate on a five point scale (never, seldom, sometimes, often, almost always) the frequency with which they feel ashamed of aspects related to themselves. Higher scores indicate higher shame about the particular item and vice-versa. To attempt to ensure participants know the

meaning of the term 'ashamed' a brief definition of this is given at the top of the questionnaire; this included cognitive, emotional and behavioural responses associated with feeling ashamed.

2. The Adolescent Shame-Proneness Scale (ASPS). This scale was developed by Lang (1994) to assess peer-related adolescent shame experiences. In this scale ten specific peer-shaming scenarios relevant to an adolescent age-group are presented, and participants are asked to assess the imagined degree of upset that would be caused by experiencing them. This is then rated on a five point scale (not upset, a little upset, quite upset, really upset, very upset). As with the AFOS scale higher scores indicate higher shame-proneness and vice-versa. The ASPS was constructed using a large ($n = 436$) school sample of adolescents aged from 12 – 19. It has good internal consistency, with a Cronbach α coefficient of 0.88. There is no test – retest data available for this scale.
3. Bullying interview. This was a modified version of the interview used by Whitney and Smith (1993) as part of a large ($n = 6,758$) study of bullying within schools in the Sheffield LEA. Permission to use and modify this interview was obtained from one of the authors of the above study (Irene Whitney). This was given in questionnaire format as the sample used in this study was too large ($n = 225$) for one researcher to conduct separate interviews, given the time constraints. There are 11 items associated with bullying, of which three ask for qualitative information to be given if relevant, while the rest of the questionnaire offers single or multiple-choice questions, which pupils answer by circling one or more of the relevant responses. As with the Whitney and Smith study, a brief definition of bullying was given at the top of the questionnaire, based upon that used by Olweus (1991). The interview is concerned with current experiences of bullying.

Additionally, participants were given a sheet at the front of the questionnaires to read. This contained information about completing the questionnaires, and also asked for some supplementary information about the questionnaires, such as how long they took to complete, and what they thought of them, to be written at the end of the sheet.

3.2 Study One - Participants

This study involved 225 pupils of a suburban secondary school (Wilsthorpe School, Long Eaton, Nottingham). The school was a large mainstream comprehensive school for male and female pupils aged 11 to 18 years. The sample population consisted of 106 males and 119 females. The mean age of the sample was 12.7 years, with a standard deviation of 0.9 years. Pupils' ages ranged from 11 years to 14 years.

3.3 Study One - Procedure

The school was approached initially by telephone, and then by letter, to request their permission to carry out some questionnaire-based research with their pupils. Permission was obtained from the Head Teacher following consultation with the governors and school staff. An explanation of the purpose of this research was given in both written and verbal form. A meeting took place with a member of the teaching staff to identify the classes to which it would be possible to administer the questionnaires, based on practical issues such as lesson timings and location within the school. It was decided that certain years should be excluded because the timing of the research coincided with exams.

Two weeks prior to the questionnaires being completed, letters were sent via the school to parents explaining the purpose of the research, and asking for their consent to allow their child to participate should they be willing.

The questionnaires were administered at the school in June 1998. They were given out to pupils from nine classes (four in year 7, two in year 8, and three in year 9) during a morning of science lessons. The researcher attended the nine classes to give out the questionnaires, administer a standard set of instructions for them from the front sheet, and answer any questions pupils had prior to filling them in. Additionally they were informed that they were not obliged to complete the questionnaires as it was not part of their school work, and that they did not need to put their names on them, although they did need to include their age, class and gender on the questionnaires. The definitions at the top of the AFOS scale and bullying interview were read aloud to pupils before they began completing the questionnaires.

The pupils were asked to complete the questionnaires without conferring or copying, and were told that there were no right or wrong answers. The researcher attended each class on at least one occasion whilst pupils completed the questionnaires, in case any individuals needed help to complete them. There was no time limit for completion of the questionnaires. Feedback sheets from pupils indicated that the questionnaires took approximately 20 minutes to complete. After their completion, the researcher collected the questionnaires from the pupils for analysis. (It should be noted that pupils were advised on the bullying questionnaire to talk to a teacher, school nurse or a parent/guardian if they were experiencing bullying)

3.4 Results – Study One

Data analysis was conducted using the SPSS for windows package. Item analysis of the AFOS scale was guided by written advice on the construction of scales from the Trent Institute for Health Services Research (Dewey 1997) and consisted of distributional check of scores, inter-item correlations, and Cronbach's alpha for internal consistency. The concurrent validity of the AFOS scale with the ASPS was

assessed by using Pearson’s Product Moment Correlation Coefficient (Pearson’s *r*). A two-tailed level of significance was chosen as the direction of any relationship was not predicted.

3.4.1 Study One – sample characteristics and summary statistics

Relevant demographic information for the school group was elicited in response to questions included in the questionnaires. This is summarised in Table 1a. It was noted that 10 of the original 225 participants (6 males and 4 females) exercised their choice not to complete the questionnaires.

Table 1a School group demographic data

	School group N215
Age (years)	Mean 12.7 Range 11-14
Gender	Female 115 Male 100 Total 215

Means, standard deviations and range of scores were completed for the variables of the AFOS scale and the ASPS total scores. These are presented in Table 1b.

Table 1b. Means, standard deviations and range of scores for the AFOS and ASPS in the school sample.

	N	Range	Mean	Std. dev.
AFOS (max. poss. score= 108)	215	0 - 84	24.3	16.9
ASPS (max. poss. score = 50)	215	10 - 48	24.1	8.5

These values were also completed for age and gender sub-groups (11 and 12 year olds versus 13 and 14 year olds, and males versus females). These results are presented in Tables 1c and 1d. It was noted that the mean scores for females were higher than those for males on both the AFOS scale and the ASPS. These differences were significant ($U = 2556, p < 0.01$ and $U = 2264, p < 0.01$ respectively).

The mean scores for the ASPS are similar to those found in the Lang (1994) study where the same gender differences were also demonstrated. In the Lang study the means and standard deviations for males ($N = 89$) and females ($N = 80$) in year 8 were 25.1 (s.d. 8.99) and 28.0 (s.d. 7.24) respectively.

Table 1c. Means, standard deviations and range of scores for the AFOS scale and ASPS, for 11 and 12 year olds versus 13 and 14 year olds in the school sample.

	N	Range	Mean	Std. dev
AFOS 11 & 12 year olds. ASPS	110	0 -56	24.8	16.6
	110	10 - 48	25.8	8.9
AFOS 13 & 14 year olds. ASPS	105	1 - 84	23.6	17.3
	105	10 - 46	22.2	7.8

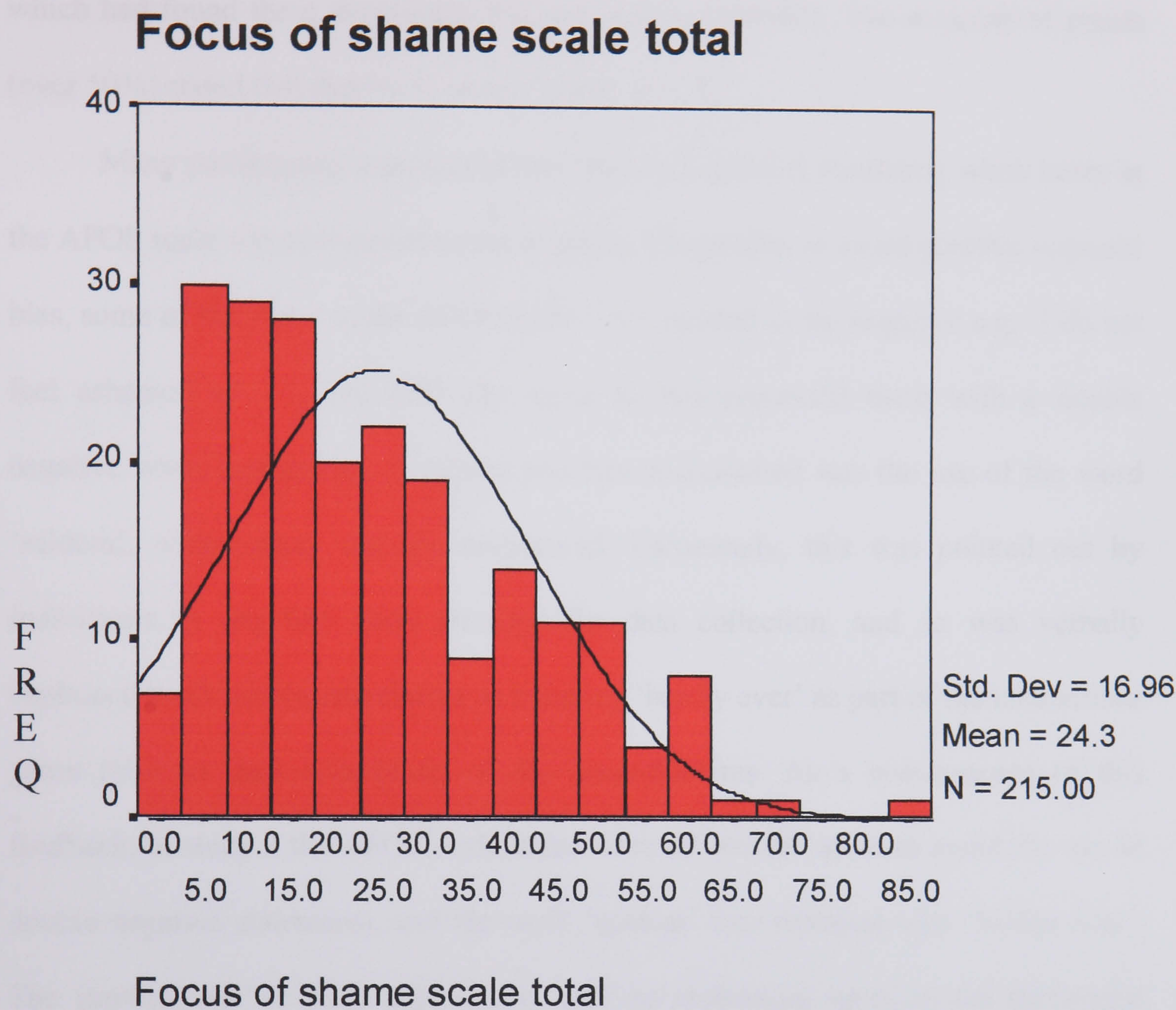
Table 1d. Means, standard deviations and range of scores for the AFOS scale and ASPS for males versus females in the school sample.

	N	Range	Mean	Std. dev.
Males	AFOS	100	0 - 84	16.4
	ASPS	100	10 – 48	19.6
Females	AFOS	115	3 – 63	31.1
	ASPS	115	12 - 46	28

3.4.2 Item analysis of the AFOS scale

The structure of the AFOS scale was explored by looking at the distribution of total scores (see figure 3) and examining inter-item correlations for patterns of low or negative correlation. The distribution of total scores and all individual items of the scale were highly skewed towards the lower end of the scale and all inter-item correlations were positive. Internal consistency was assessed using Cronbach’s α and this gave a coefficient of $\alpha = 0.89$ indicating good reliability.

**Figure 3. Frequency distribution of total AFOS scale scores
(max. possible score = 108)**



To assess concurrent validity of the AFOS scale with the ASPS, Pearsons Product Moment Correlation Coefficient (Pearson’s *r*) was calculated following a visual inspection of the scattergram which established that this calculation was appropriate. This showed a significant association between these measures, ($r = 0.53$, $p < 0.01$ two-tailed). Additionally face validity was assessed as satisfactory by an independent clinician with research experience in the area of shame (Goss et al 1994).

3.4.3 Supplementary information obtained from feedback sheets

There were numerous comments about the questionnaires as a whole ranging from those, which were positive and had found them easy and interesting to fill in, to those which had found them depressing and personal to complete. The majority of pupils (over 50%) stated that they were either ‘good’ or ‘OK’.

Many participants commented that they had found it confusing when items in the AFOS scale were presented in the negative, (originally, to avoid positive response bias, some of the items in the AFOS scale were worded in the negative e.g. ‘I do not feel ashamed of...’). The difficulty arose as this presented them with a double negative when responding. A further problem encountered was the use of the word ‘seldom’, which many did not understand. Fortunately, this was pointed out by individuals in the first class attended for data collection, and so was verbally explained to all subsequent classes as meaning ‘hardly ever’ as part of the instructions given prior to their completion of the questionnaires. As a consequence of this feedback, in study 2 the AFOS scale items were all worded so as to avoid the use of double negative statements, and the word ‘seldom’ was replaced with ‘hardly ever’. The implications of these adjustments will be elaborated upon in the discussion section.

The average length of time taken to complete the questionnaires was 16 minutes.

3.4.4 Summary of results from Study One

3.4.4.1 The AFOS scale

Psychometric analysis of the AFOS scale indicated that the scale has good reliability which suggests that the scale is measuring a trait-like concept. However as there was no test-retest reliability analysis, the stability of the construct over time is unknown.

The scores for all of the items in the AFOS were positively skewed, i.e. low shame about the items. This indicates the trait is not normally distributed and that most adolescents felt little or no shame about the areas assessed by the items. Inter-item correlations within the AFOS scale were all positive, but none were too high to suggest that they were asking the same question in a different way. The lack of negative correlations indicates that all of the items were related to the same construct. Empirical validity was assessed by correlation of the AFOS scale with the ASPS to give concurrent validity. The correlation was significant suggesting that both scales are measuring similar constructs, but not so high as to suggest that they are measuring identical constructs.

The low non-completion rate for the questionnaires (10 out of 225) indicates that most participants found them acceptable.

3.4.4.2 Demographic influences in the sample

Females were found to have significantly higher levels of shame as measured by both scales, than males.

With regard to age, the younger group aged 11-12 years expressed slightly higher levels of shame as measured by both scales, than the older group aged 13-14 years. However, this difference did not appear large enough to implicate the use of a statistical test of difference.

4.STUDY TWO

4.1 Study Two- Materials

The materials used were those also used in study one (see above). However, as previously stated some minor alterations were made to the AFOS scale, because of feedback obtained from the participants in study one.

Additionally the bullying interview was given in interview format, as it was felt that this would enrich the information obtained about bullying from the cleft lip or cleft lip and palate sample.

4.2 Study Two – Participants

This study involved the participation of 16 individuals who had attended The Birmingham Children's Hospital for treatment of cleft lip or cleft lip and palate. Those with cleft palate only were excluded, as this does not necessarily affect facial appearance. Also individuals with accompanying syndromes or learning disabilities were excluded as these additional factors may confound experiences of bullying and shame.

Participants included 8 males and 8 females with a mean age of 13.9, and a standard deviation of 1.7. Their ages ranged from 12 to 17 years of age, a wider age range than in the school sample. Twelve of the participants had unilateral cleft lip and palate and four had cleft lip only.

4.3 Study Two – Procedure

Initially the Cleft Lip and Palate Team at the Birmingham Children's Hospital were approached and the research protocol was discussed with them. Following their approval and support for the study, permission was sought to carry out the research from the South Birmingham Local Research Ethics Committee and the Birmingham Children's Hospital Research Ethics Sub-Committee. Ethical permission took

approximately seven months to obtain delaying the start of the research considerably. This was partly due to external factors such as the major upheaval taking place at the Children's Hospital because of their move to a new site. When this had been granted, information was obtained from a database kept by the Cleft Lip and Palate Team. This gave the hospital numbers of all those individuals aged between 12 years and 18 years who had received treatment for cleft lip or cleft lip and palate at the hospital. This identified 41 individuals. The medical notes of these individuals were obtained and screened in order to exclude those individuals who had other medical difficulties which may confound the results of the study. Addresses of the individuals to be included in the study were obtained from the medical notes. It was ascertained from inspection of the notes that some individuals had left the area. The final sample for inclusion in the study was 31 individuals.

The 31 identified subjects included 20 males and 11 females. The following information, which can be found in the appendices, was sent by post to these individuals and the parents of those under 16 years old:

- A letter of introduction from the Consultant Paediatric Surgeon with the Cleft Lip and Palate Team.
- An information sheet giving the parents of those children under 16 years of age detailed briefing information regarding the study and assuring participant confidentiality and anonymity.
- A separate information sheet for adolescents both 16 years and older, and under 16 years.
- A letter and consent form for parents and adolescents under 16 years of age, or a letter and consent form for adolescents over 16 years of age.
- A stamped addressed envelope for the return of completed consent forms

If adolescents or their parents did not wish to participate in the study they were asked to either return their consent forms indicating this, or not return the forms at all. It was clearly stated in the information sheets that participants could withdraw their consent at any time should they change their mind about taking part in the study.

Sixteen out of the 31 individuals contacted gave their consent to take part in the study and these individuals were contacted by telephone to make arrangements to meet with them to complete the questionnaires. Most chose to be seen at their homes. The researcher met with them on one occasion to complete the questionnaires. Complete confidentiality was again emphasised. Participants were offered the option of meeting with a Clinical Psychologist on another occasion should the research highlight any areas of difficulty for them. Although none took this up, two participants and their families contacted the researcher following their participation in the research to request advice about accessing their local Clinical Psychology service.

4.4 Results – Study Two

The results are divided into 3 sub-sections. The first contains sample characteristics and summary statistics. The second subsection includes between-group comparisons (for the clinical and comparison groups) in the areas of shame proneness, focus of shame, and experiences of bullying, in order to test the hypotheses stated above. The third subsection contains the within-group comparisons to test the hypothesis concerning the relationship between shame-proneness and being bullied.

Data analysis was conducted using the SPSS for windows package. Non-parametric statistics were judged to be most appropriate for the group comparisons, as the data did not meet the requirements for parametric analysis; for example, visual inspection of the AFOS scale histogram indicated that it was not normally distributed.

As the age and gender matches for the clinical group were not perfectly matched for age (since there were no individuals above 14 years in the school group), the ages of the clinical and comparison groups were compared using a Mann Whitney (U) test to ensure there was no overall significant difference between the two groups. Further between-group analysis involved using the Mann-Whitney (U) test for independent samples at one-tailed significance levels to examine between-group differences in shame-proneness. The same analysis was conducted for focus of shame using two-tailed significance levels as the direction of difference was not predicted. Additionally the scores of each individual in the clinical group on the AFOS scale and the ASPS were converted to standard (z) scores based on the means and standard deviations for these scales found in the school group in order to explore the distribution of scores in the clinical group in relation to that found in the school sample. Two Chi-square (χ^2) tests were used to investigate experiences of bullying between groups. The Chi-square test was also used to look at between-group differences for a focus of shame related to facial appearance.

Within-group analysis of data from the clinical group and from the comparison group involved using Pearson's r to determine the relationship between frequency of bullying and level of shame-proneness at a one-tailed level of significance.

4.4.1 Study Two – sample characteristics and summary statistics.

As in study one, relevant demographic information for the clinical group was elicited in response to questions included in the questionnaires. This information is summarised in Table 2a, along with the same information obtained from the

individuals in the school group randomly selected to act as age and gender controls to the clinical group, and referred to as the comparison group.

Table 2a. Clinical and comparison group demographic data

	Clinical group N16		Comparison group N16	
Age (years)	Mean	13.9	Mean	13.3
	Median	13.5	Median	13.5
	Range	12- 17	Range	11 - 14
Gender	Female	8	Female	8
	Male	8	Male	8
	Total	16	Total	16

No significant differences were found between the clinical and comparison groups with regards to age (U = 108, p = 0.434 NS)

Means, standard deviations and range of scores were calculated for the AFOS scale and the ASPS for the clinical and comparison groups as a whole, and for males and females in each group. These are presented in Tables 2b, 2c and 2d respectively.

Table 2b. Means (medians), standard deviations and range of scores for the AFOS scale and the ASPS in the clinical and comparison groups.

	N	Mean (Median)	Range	Std. dev.
AFOS (Max. poss. score = 108) Clinical group	16	23.3 (20)	5 – 55	14.6
	16	24.5	12 – 47	8.7
AFOS (Max. poss. score = 108) Comparison group	16	22.5 (17)	3 – 53	14.7
	16	22.4	14 – 32	5.9
ASPS (Max. poss. score = 50)				

The means for both groups were similar for both of the scales, with the clinical group mean scores only slightly higher than those of the comparison group. Additionally as the standard deviation scores for the AFOS scale were so large it was thought to be important to include median scores. These are shown in brackets below the mean values in Table 2b. This was to check that there were no large differences between the mean and median scores for the scale and ensure the mean score reflected the actual central tendency for this scale.

When compared by gender the clinical groups mean scores are only higher on the ASPS scores and the male AFOS scale scores. As in study one gender differences were demonstrated, with females scoring higher than males for both scales. However, these differences within the clinical group were not significant (for the AFOS scale $U = 21, p = 0.247$ N.S. and for the ASPS $U = 20, p = 0.206$ N.S.)

Table 2c. Means, standard deviations and range of scores for the AFOS scale and the ASPS for males and females in the clinical group.

	N	Mean	Range	Std. dev.
AFOS MALE ASPS	8	20.6	5 - 49	16.2
	8	21.4	12 - 33	6.9
AFOS FEMALE ASPS	8	26.1	13 - 55	13.3
	8	27.8	19 - 47	9.6

Table 2d. Means, standard deviations and range of scores for the AFOS scale and the ASPS for males and females in the comparison group.

	N	Mean	Range	Std. dev.
AFOS MALE ASPS	8	15.5	4 - 32	7.9
	8	19.3	15 - 26	4
AFOS FEMALE ASPS	8	29.5	3 - 53	17
	8	25.5	14 - 32	6

In addition to comparing clinical group scores with comparison group scores, the clinical group scores were considered in relation to those of the overall school group, in order to explore how they related to the distribution of scores in that sample. z scores were computed enabling the scores of the clinical group to be expressed in terms of their deviation from the mean of the school sample. Although it is recognised that this sort of analysis may not be methodologically correct where data is not normally distributed such as with the AFOS. For exploratory purposes there seemed to be a good reason for doing this analysis and the variance for the school and clinical samples AFOS scores were similar. The results are shown in figures 4 and 4.1

Figure 4.

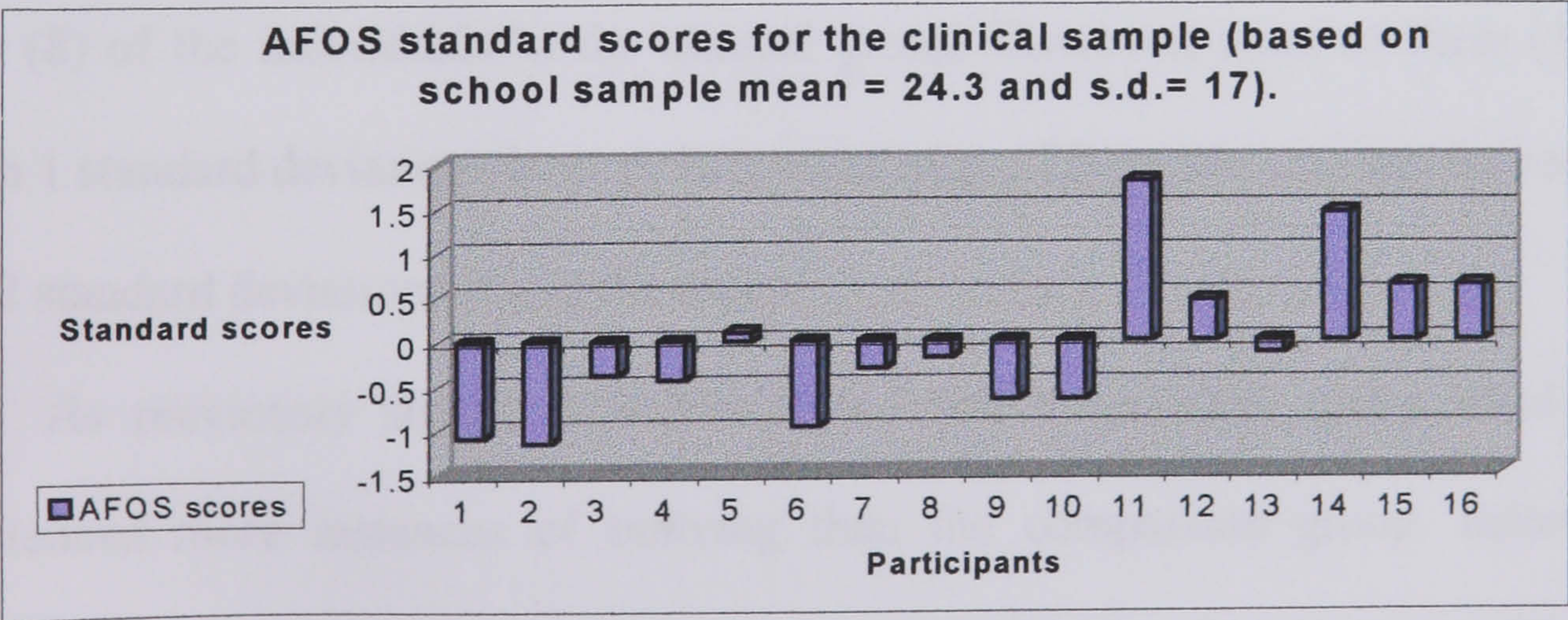
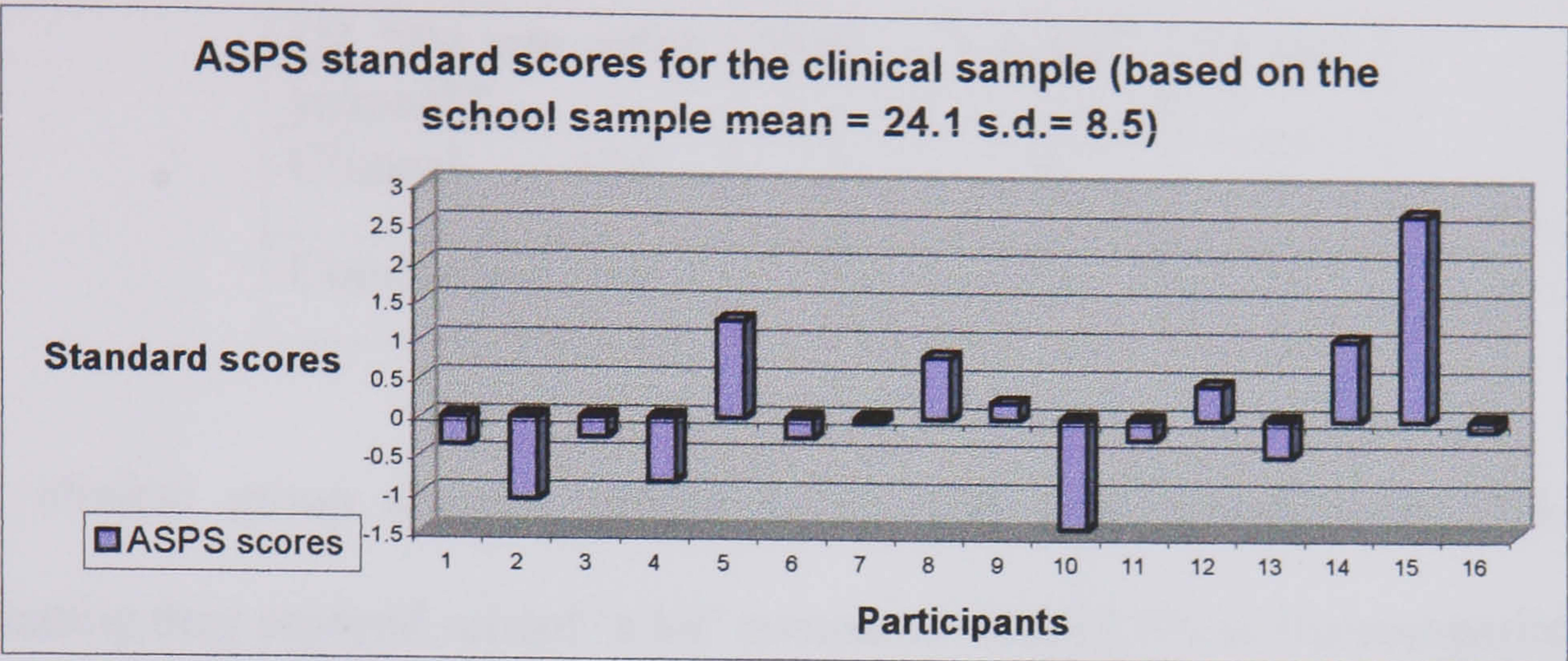


Figure 4.1



Interestingly for the AFOS scale the majority of scores (9) fell below the school sample mean. However, some of the scores above the mean were quite substantially so. Given that the distribution of the scale was positively skewed and the standard deviation was large, these indicate a few extreme scores.

The ASPS standard scores were similarly below the school sample mean for many (8) of the individuals in the clinical group. However, most of them (10) fell within 1 standard deviation above or below the mean. There was one extreme score of over 2 standard deviations above the mean.

As previously stated, it was expected that the clinical group would have experienced more instances of bullying than the comparison group. Information obtained from some questions in the bullying interview is summarized in tables 2e – 2i below, for both the clinical and comparison groups. Not all of the information

obtained from the interview was used in the analysis; only information of relevance to the research hypotheses is presented.

Table 2e. Clinical and comparison groups satisfaction with school.

<i>Q1 “Do you enjoy school?”</i>	“No”	“ A bit”	“A lot”
Clinical N16	1	9	6
Comparison N16	2	12	2

The clinical group showed greater satisfaction with school with 35% of them indicating they enjoyed school ‘a lot’ compared with 12.5% of the comparison group.

Table 2f. Clinical and comparison groups satisfaction with numbers of friends.

<i>Q2b. “Would you like more friends?”</i>	“Yes”	“No”
Clinical N16	6	10
Comparison N16	7	9

Both groups were similar in their satisfaction with the number of friends they had, with over 50% in each group indicating that they would not like more friends compared with 37.5% of the clinical group and 43% of the comparison group indicating that they would like more friends.

Table 2g. Clinical and comparison groups rates of bullying

<i>Q3 “Quite a lot of young people seem to be bullied in school. Is there anyone at school who bullies you?”</i>	“Yes ”	“No ”
Clinical N16	8	8
Comparison N16	5	11

Fifty percent of the clinical group indicated that they had experienced bullying compared with 31.2% of the comparison group.

Table 2h. Emotional consequences of bullying for clinical and comparison groups.

<i>Q6. “How does the bullying make you feel?”</i>	Not applicable	Not answered	Describes 1 emotion	Describes 2/3 emotions	Describes extreme emotion
Clinical N16	8	0	5	2	1
Comparison N16	11	2	0	3	0

All of those bullied within the clinical group indicated degrees of distress varying from mild to extreme, compared with 3 of the 5 individuals in the comparison group who were bullied, who indicated moderate distress. The question was not answered by the remaining 2 individuals.

Table 2i. Frequency of bullying for clinical and comparison groups.

<i>Q7. “How often are you bullied?”</i>	Not applicable	Once or twice a term	Every 2 weeks	Once a week	Two or three times a week	Everyday
Clinical N16	8	2	0	1	1	4
Comparison N16	11	2	1	1	1	0

Of those bullied in the clinical group 75% were bullied once a week or more compared with 40% of those in the comparison group.

4.4.2 Between group analyses

Additional to the summary statistics from the measures of shame proneness, focus of shame and bullying, analysis of the differences between the two groups on these measures was conducted.

Bullying

Based on the premise that individuals with a cleft lip and palate may be more likely than their peers to be the victims of bullying and teasing, two chi-square analyses were conducted on the data from the bullying interview, in order to test Hypothesis One. Firstly bullying was examined by the numbers of individuals endorsing “yes” or “no” for item 3 on the bullying interview from each group. Secondly frequency of bullying for each group was determined by categorising those not bullied or bullied once or twice a term (as determined from item 7 of the bullying interview), as ‘never or rarely bullied’, and those bullied once every two weeks or more according to the above item, as ‘frequently bullied’. The differences in these two categories were then examined for the clinical and comparison groups. For the data relating to whether individuals were bullied or not, the analysis revealed that there was no significant difference between the groups for experiencing bullying, ($\chi^2 = 1.17$, $p = 0.236$ N.S.). Similarly for the data relating to frequency of bullying, there was no significance between the two groups ($\chi^2 = 1.39$, $p = 0.217$ N.S.) thus Hypothesis 1 was not confirmed.

Shame – proneness

Hypothesis two states that adolescents with cleft lip and palate will be more shame – prone than their peers, based on the premise that early experiences may make this more likely. However, there was no significant difference between the groups on the

measure of shame-proneness ($U = 113$, $p = 0.571$ N.S.) and thus Hypothesis 2 was not supported.

Focus of shame

Hypothesis 3 was tested in two ways. Firstly a Mann-Whitney (U) analysis was performed on the total AFOS scale scores for the two groups. This revealed no significant differences between the groups ($U = 115$, $p = 0.624$ N.S.). Secondly, a Chi-square analysis was performed to explore whether patterns of responding to items in the AFOS scale associated with facial appearance differed in the two groups. This was done by summing the scores of the items on the AFOS scale related to facial appearance; item 4, item 14, item 17, item19, and item 27, and establishing the mean value for these variables in the school group ($N = 215$). The contingency table (table 2h) contains the frequencies of those scoring above the mean ($X = 3.7$) for the above variables in each group. The analysis revealed that significantly more individuals in the clinical group had scores above the mean for items on the AFOS scale relating to facial appearance, than in the comparison group ($\chi^2 = 8$, $p = 0.005$). This supports hypothesis 3 to some extent, as although there were no differences between the two groups for total AFOS scale scores, differences were seen in the patterns of responding to items associated with facial appearance.

Table 2j. Contingency table for facial item endorsement within AFOS scale in the clinical and comparison groups.

	High facial endorsement	Low facial endorsement
Clinical group	12	4
Comparison group	4	12

4.4.3 Within group analyses

Shame – proneness and bullying

Relationships between shame-proneness and experiencing bullying were investigated to address Hypothesis 4. Pearson’s product moment correlation coefficient (Pearson’s *r*) was calculated to establish the strength of any relationships between scores on the ASPS and frequency of bullying as established by question 7 of the bullying interview. Tests were conducted for the clinical and comparison groups separately and then together. Visual inspection of scattergrams revealed that calculation of correlation coefficients was appropriate. Tests of significance were one-tailed as it was predicted that high shame – proneness scores would be likely to be associated with experiencing bullying. These results are presented in Table 3.

Table 3. Relationship between shame-proneness and frequency of bullying.

Group	Clinical group	Comparison group	Clinical group + Comparison group
N	16	16	32
<i>r</i>	0.45	0.55	0.49
p<	0.05	0.05	0.01

The analysis revealed significant associations between shame-proneness and frequency of bullying for all three groups. This supports Hypothesis 3 that adolescents who are bullied are more likely to be shame-prone.

4.4.4 Summary of results from Study Two

4.4.4.1 Between group findings

Although the mean scores of the clinical group for both the measures of shame were higher than those for the comparison group, these differences were not of statistical significance. The gender differences apparent in the school sample for the shame measures, although present for the clinical group, were not of statistical significance.

The clinical and comparison groups were discriminated by their endorsement of items in the AFOS scale relating to facial appearance. Compared to the other group the clinical group expressed higher levels of shame related to facial appearance.

Although a larger percentage of participants in the clinical group had experienced bullying than in the comparison group, and the bullying also occurred more frequently for them, this difference did not reach statistical significance.

4.4.4.2 Within group findings

Within both clinical and comparison groups there was a statistically significant association between frequency of bullying and shame-proneness.

4.5 Illustration of the data with case examples

To illustrate the findings within the clinical sample and attempt to draw together the data gathered, two case examples are outlined below.

Case 1.

A twelve year old female with a unilateral cleft lip and palate. This girl scored 35 on the AFOS scale, higher than the mean score for females in her group and the comparison group. Her score for items on the focus of shame scale relating to facial appearance was 12. Her ASPS score was extremely high at 47. She described liking

school a bit, and having two friends. She stated she would like more friends. She described bullying as occurring on a daily basis and involving name calling about her appearance e.g. “squashed nose” and mimicking of her voice which was slightly nasal. She was also hit, threatened, had rumours spread about her, her belongings taken off her and was isolated by her classmates. This involved all but one person in her class. She had told her teachers and parents about the experiences which clearly were very distressing. She described feeling “very very upset” about these experiences which had even happened outside of school. Her mother had been to the school to discuss the problems with the school staff. This was one of the individuals who requested advice on accessing services to help her cope with the bullying experiences.

Case 2.

A twelve year old female with a unilateral cleft lip and palate. Her score for the AFOS was 19, lower than the mean scores for females in either the clinical or comparison groups, and her score for items on the AFOS scale relating to facial appearance was 4. She scored 19 on the ASPS scale, again below the mean for her group and the comparison group’s mean ASPS score. She described enjoying school a bit but only having one friend and felt she would like more friends. She had not experienced bullying or teasing at school at all nor had she had any such problems outside school.

5. DISCUSSION

5.1 Introduction

The following section will contain a brief resume of the study. This will be followed by the results, which will be interpreted within the context of the main aims and hypotheses posed, and the implications for the existing literature. The limitations and strengths of the study and its clinical implications will then be considered.

5.2 Summary of the study

Previous research concerning the psychological adjustment of individuals with cleft lip and palate has yielded inconclusive findings. Nevertheless there is some research and clinical evidence to show that a proportion of individuals with this condition suffer distress. Despite the growing bullying literature there is no previous research to demonstrate the experiences of bullying for this group, and this seems to be a major oversight given that much of the distress noted is in the social domain.

The present study attempted to quantify the experiences of bullying for adolescents with cleft lip and palate and provide an explanatory model linked to a theory of shame, regarding the process of victimisation. This was achieved by interviewing 16 adolescents with cleft lip or cleft lip and palate about their bullying experiences.

Additionally, self-report data concerning their feelings of shame-proneness was obtained via a measure developed in a previous study of shame in adolescence. It was thought to be important given the relevance of shame to this age group, to determine if the presence of shame feelings was linked to the individual's cleft lip or cleft lip and palate. In order to do this a scale to assess the focus of shame was

needed, and as none existed a separate study was required to develop such a scale and provide data about its psychometric properties and normative scores for adolescents. Consequently, prior to the main study, a study took place with 215 secondary school pupils who completed a focus of shame scale developed from the theoretical works of Gilbert (1989, 1992) and Kaufman (1989). The measures to be used in the later study with the cleft lip and palate adolescents were administered to the school participants in order to provide comparison data in addition to data for the purposes of assessing the concurrent validity of the focus of shame scale.

5.3 The development of the Adolescent Focus of Shame Scale

The initial aim of the present study was to develop and evaluate an adolescent measure of shame. There is one existing measure of shame-proneness for this age group, but no measure of shame focus exists for adolescents or adults. The major challenge therefore was to design a questionnaire that would tap this construct appropriately and be meaningful and comprehensible for the participants at whom it was aimed i.e. 12-18 year olds. The effectiveness of this process was evaluated in two ways. The first was to conduct psychometric analysis on the measure and evaluate its validity and reliability. The second was to use personal impressions gained from the participants in the written feedback.

As previously stated the psychometric analyses of reliability were satisfactory with good Cronbach's Alpha and positive inter-item correlations. Although the scale was positively skewed, there were a few extreme scores. This is likely to make the scale particularly sensitive to shame experienced by a clinical group, such as the sample in study 2. The concurrent validity of the AFOS scale with the ASPS was also good. Additionally the face validity of the AFOS scale was evaluated as satisfactory

(e.g. it appears to assess areas that individuals may feel ashamed about). This was evaluated by an independent assessor with considerable experience in research and clinical work, with shame-prone individuals (e.g. Goss et al 1994).

The personal impressions gained from the participants were varied. Over fifty percent made positive statements about the questionnaire in their written feedback such as “we should get more questionnaires like this” “it’s good to be asked about our point of view” and “it’s good to share feelings”. Naturally there were also negative comments such as the questionnaire was “boring” or “there should be questions about boyfriends”, nevertheless the majority of participants indicated that they found the scale acceptable. This was also indicated by the low non-completion rate for the questionnaires, however this could also be attributed to the general expectation of compliance which exists in most schools.

There were a few participants who needed some help to complete the questionnaires and the author or teacher helped these individuals. The difficulties which a few participants had with the use of the word ‘seldom’ and the negatively worded items enabled changes to be made to the AFOS scale for study 2. This may mean that the results from the two groups in study 2 are not directly comparable. However, as both of these difficulties were elicited at the start of the data collection process in study 1 it enabled the author to incorporate further explanation of these points into the general instructions given to the participants. The lack of negative inter-item correlations indicates that the negatively worded questions did not affect the overall results.

A final point relates to the findings for both the AFOS scale and the ASPS. The gender differences seen reflect similar differences noted by Lang (1994) for the ASPS, with females scoring higher than males. As both of these measures are

affective measures this finding is consistent with research that suggests that female adolescents and adults are more likely to self-report negative emotions than males (Peterson et al 1991).

5.4 The experience of bullying for adolescents with cleft lip and palate. (Hypothesis 1)

Based on the premise that cleft lip and palate is a stigmatising condition which may give rise to negative stereotypes and thus increase vulnerability to being the victim of bullying, it was hypothesised that adolescents with cleft lip and palate would be more likely to experience bullying. No statistically significant differences were found between the clinical and comparison groups on the bullying measure for either experiencing bullying or frequency of bullying. Some evidence of difference between the two groups emerged from the percentages of those reporting bullying and frequency of bullying, with these being higher for the clinical group. However these findings do not represent a statistical difference.

The lack of significance found between the two groups is surprising given that the percentage of those bullied in the clinical group was quite high. There are a number of possible explanations for this finding. Firstly, it may be due to a type two error brought about by sampling or design errors. The sample size of the clinical group was small and combined with the use of non-parametric statistics this may have made any effect difficult to discern (see appendix 12 for calculation of power of the sample sizes to detect relevant differences). The numbers of individuals reporting bullying in the school group and hence the comparison group was high. Research suggests that rates of bullying in secondary schools is around ten percent (Whitney and Smith 1993), although this figure varies from study to study. The rate of thirty-

one percent found in the comparison group may have been artificially high due to the differences in the administration of the bullying interview. Given in questionnaire format it may have led to misunderstandings, for example although the questionnaire is worded in the present tense, some participants may have understood it to be asking about any experiences of bullying that had occurred, even if they were no longer occurring.

The interview format of the bullying measure used for the clinical group certainly offered more illuminating information about the qualitative experiences of those who were bullied. The twelve year old female participant in 'case 1' (page 63) described having only one 'good' friend at school, and the rest of her class mates teased her about the way she looked and talked. Her mother had attempted to help her to make friends when she first started at the school by inviting all of her class to their house for a party. However, the night before the party her friend telephoned to say the rest of the class would not be coming, and if she came she did not want it to be known to the rest of the class. For this girl it seemed that the relational aspects of bullying i.e. being left out of friendships, was the most difficult for her to cope with. This type of bullying has been found to result in more distress than physical bullying in some studies (e.g. Crick and Grotpeter 1996), and is also a form of bullying used more commonly by girls than boys (Crick and Grotpeter 1995, Olweus 1994).

The notion that conditions giving rise to negative stereotyping do not increase vulnerability to bullying is another possible explanation for these findings. It is also possible that psychosocial factors not included in the present study were operating to shield the cleft lip and palate adolescents from bullying, such as protective peer relationships. The case examples used to illustrate the results demonstrated differences between two individuals of the same age and gender and with the same

condition. The bullying experiences of both girls were completely different with case 1 experiencing extreme bullying and case 2 experiencing none. Although both girls described having few friends, the girl in case 2 described her friend as a best friend with whom she spent most of her time at school with, and who shared similar interests. The girl from case 1 described having two friends, one of whom she said was a good friend. However, possibly this friend was not such a good friend e.g. when it came to coming to the party the girl from case 1 was having she did not want the rest of the class to know if she came. It could be speculated that the quality of the friendship that the girl from case 2 had with her friend was operating as a protective factor against bullying, but the girl from case 1 was not so fortunate. The bullying findings from this study may justify further study into this area, using a larger sample size and different age groups, to determine if the high rate seen in this study is duplicated among other groups, and to take into account quality of friendships.

5.5 Shame-proneness in adolescents with cleft lip and palate (Hypothesis 2)

Using the notion of shame as consisting of judgements about ourselves and how we are judged by others (Gilbert 1992) as different and inferior, it was hypothesised that early stigmatising reactions to individuals with cleft lip and palate, may leave them more vulnerable to shame-proneness. Specifically, it was expected that the clinical group would demonstrate higher scores on the shame-proneness measure than their comparison group. No statistically significant difference was found on this measure.

One finding that did emerge from the shame-proneness results within the clinical group was the lack of significant difference between male and female scores, unlike in the school group where males scored significantly lower than females. This finding is difficult to account for as few researchers have investigated the effect of

gender differences on the adjustment of those with a facial disfigurement. It could be speculated that females would be more likely to suffer the negative effects of disfigurement given the high value placed on the attractiveness of women in our society. However, a finding from Lang's study (1994) was that shame was related to peer group interaction particularly for mid-adolescent (14-15 year olds) males, suggesting that males of this age may be particularly sensitive to peer-induced shaming experiences. This may account for the finding in the present study if the males in the clinical sample had experienced significant negative peer relationships. Another possibility is that the finding is an artifact of having a small N.

The lack of difference between the clinical and comparison group on scores of shame-proneness may be due to the relevance of shame to adolescents generally. This period of development is marked by increased consciousness of others opinions and reactions, and powerful fantasies of others motives and reasoning (Elkind and Bowen 1979), indicating that vulnerability to criticism from others is at its height. It may be that the effects of adolescence are more powerful than the effects of cleft lip and palate on shame-proneness. If this is the case then a study of shame-proneness in adulthood may be more likely to illustrate potential differences in the experiences of cleft lip and palate individuals versus those without it.

5.6 The focus of shame for adolescents with cleft lip and palate (Hypothesis 3)

The shame literature speculates that shame may be focussed on a number of different areas including areas of the body. It was hypothesised that a particular focus would be more likely in the cleft lip and palate group and this would be associated with their cleft. Although scores on the focus of shame measure were similar for both the clinical and comparison group, those items within the measure relating to facial

appearance received more endorsement from the clinical group. This suggests that those adolescents with cleft lip and palate are at risk of experiencing shame feelings about their facial appearance because of their cleft. This finding may be related to findings from a large study (N= 495) of children with cleft lip and palate where although there was increasing satisfaction with speech in the older age group (14-18 years) satisfaction with appearance did not improve with age (Broder et al 1992). This could in part be due to the stage of treatment that the adolescents have reached. Treatment for speech problems is usually concluded before secondary school is commenced, but further orthodontic treatment and sometimes facial surgery is not uncommon during early and mid-adolescence. Another explanation for this finding is that of teasing or bullying about facial characteristics. Although this was not specifically investigated, all of those who had been bullied in the clinical sample described these incidents as being related to their cleft. Nevertheless difficulties arise inferring causality, as unless the exact content of the bullying incident is known it may be that a self-fulfilling prophecy is operating as suggested by Adams (1977) in his model of the relationship between social interaction and physical appearance.

As the shame-proneness scores were no different between the two groups, it would not necessarily be expected that the total scores of the AFOS scale would differ, if the total AFOS score is representative of a global shame score. However factor analysis of the AFOS scale, particularly if the six speculated areas of shame foci were identified, may have provided more insightful differences or similarities between the two groups. For example it may have been found that adolescent girls in both groups were more concerned about bodily shame i.e. their size and shape. Whereas it could be speculated that the clinical group would be more likely to

experience relational shame i.e. shame because of one's family, because of earlier experiences of over-protection.

Given the findings of higher frequencies of facial shame in the clinical group the shame-proneness findings are surprising. Some shame literature suggests (e.g. Tangney 1996) that shame relates to blaming the self (characterological self-blame) and guilt to blaming one's behaviour (behavioural self-blame) the former being associated with more negative consequences (Tangney 1992). It would follow that those with a facial disfigurement who blame their difficulties on their appearance would be likely to be more ashamed of themselves than those who blame their behaviour. However, it may be that these findings support the alternative suggestion that attribution of negative feedback to stigma can protect self-esteem (Crocker and Major 1989).

A difficulty that will be discussed in more detail below arises from the use of the shame-proneness scale. In brief, this scale is an event-focussed scale where situations are described which present as potential shame response triggers. The problem arises as some shame theorists see shame as a global and stable trait, which is central to the experiences of self, rather than a response evoked only in specific situations. Therefore, it may be that there were differences between the groups which were not revealed by the particular shame scale used, and repeating the study using a shame scale focussing on more global beliefs about the self and others may circumvent this difficulty. However there are no adolescent versions of scales such as the Internalized Shame Scale (Cook 1988) which was developed for use with adults. This issue will be returned to in a later section of this discussion.

One final point to note is that the small sample size made it difficult to take into account the effects of gender in the clinical sample. The findings of differences

between the two groups for the facial appearance items may have been affected by gender. This may be an important issue for further research with the AFOS scale, especially since some research investigating children's attitudes to facial disfigurement has shown that female faces are more often the focus of stereotyping than male faces (e.g. Rumsey et al 1986).

5.7 Shame-proneness and bullying (Hypothesis 4)

This hypothesis arose from the ranking theory of shame whereby submissive and inhibited behaviours are thought to be common responses of shaming incidents originating from biologically evolved mechanisms. The basis for the hypothesis is the shaming loop described above (Gilbert and Lang 1994) whereby shaming incidents such as bullying lead to negative social comparisons, feelings of inferiority and behavioural inhibition which in turn signal to those who are bullying that the person will not retaliate and thus makes them an easy target for further bullying.

An association was found between bullying frequency and shame-proneness, indicating that the more often individuals were bullied, the more likely they were to be shame-prone or vice-versa. Although it was not hypothesised that the association between these two factors would be stronger for the clinical group, this could have been predicted had the first two hypotheses proved correct; however, this was not the case.

Previous shame research with adults has found that shame is associated with submissive behaviour and inferiority experiences (Gilbert et al 1994). In Lang's study (1994) the shame-proneness scale was correlated with high submissiveness and less favourable social comparison scores in adolescents. Together with the findings from the present study there would seem to be some empirical support for the shame-

feedback loop (Gilbert and Lang 1994). This would suggest that some inhibited behaviours which have been observed in children who are bullied (Olweus 1994) arise from the behavioural consequences of shame and are partly responsible for the continuation of bullying through a feedback loop. However, what is not known is whether bullied individuals are targeted by bullies because they display these submissive behaviours or whether the behaviours arise purely as a consequence of bullying. Longitudinal studies of schoolchildren may offer the best methodology to investigate this question. They may also offer the best methodology to test the hypothesis relating to the final part of the shame feedback loop, i.e. that shame-based behaviours result in a continuation of bullying and teasing for the individual concerned.

One factor which was not controlled for but which may be important for further bullying research is the impact of different types of bullying. Although all types of bullying cause distress for their victims, the processes operating may, for example, be different for physical than for non-physical bullying. It is conceivable that a person who is picked on physically at school may not develop inferior/different self-evaluations, but perhaps less conceivable that someone who is called names or marginalised from peer groups would do so. In practice, this may be difficult to operationalise in a research project because if the clinical group are representative of those who are usually bullied, most bullying seems to involve victims being subject to a combination of physical, verbal and relational bullying.

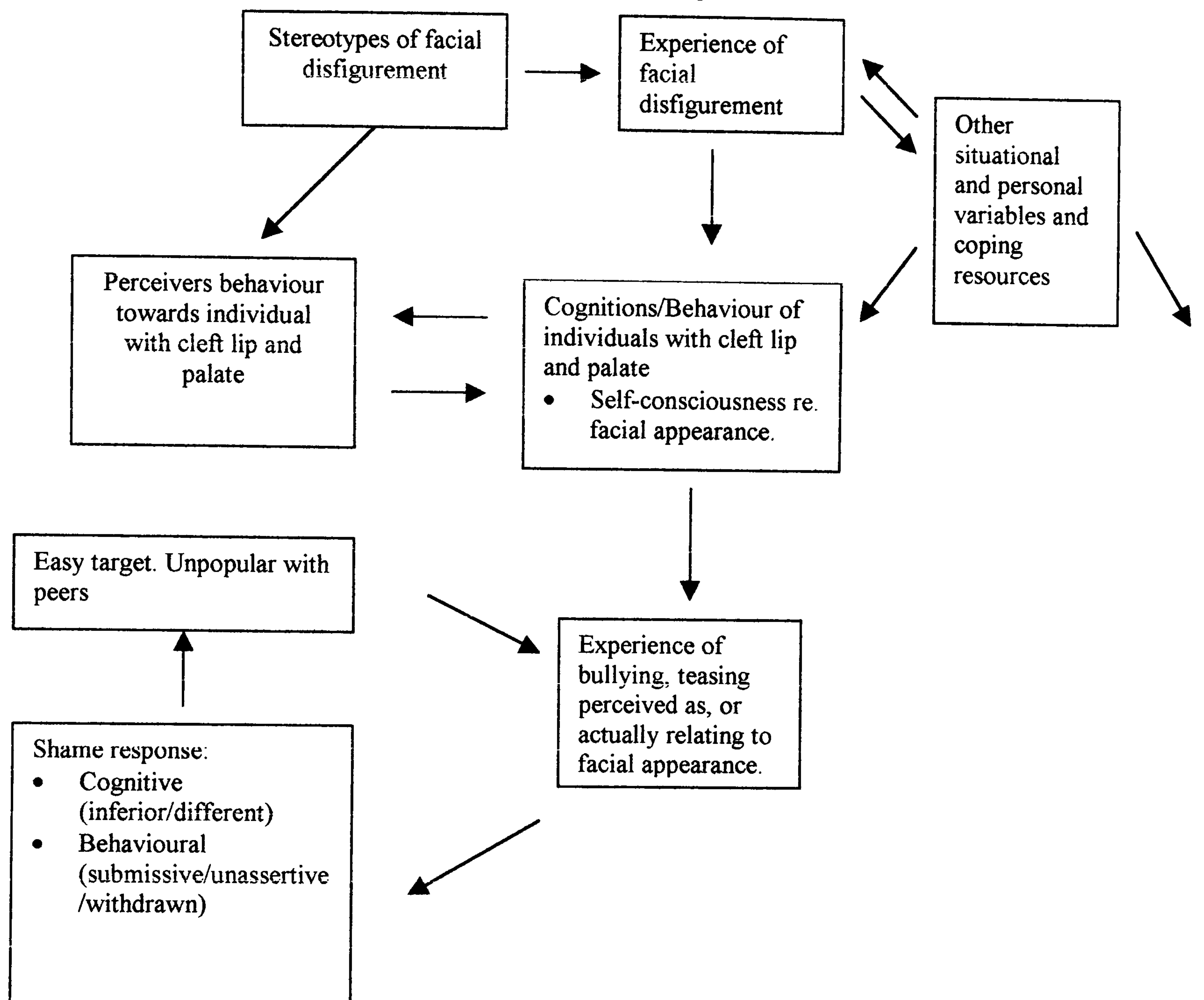
This finding also poses additional questions of particular relevance to the clinical group. What is the relevance of the severity of the cleft type to bullying and focus of shame related to facial appearance? For example, are those with a more severe cleft, such as cleft lip and palate as opposed to cleft lip only, more likely to be

self-conscious about their facial appearance, and does this predict higher shame-proneness and hence bullying experiences? The work of Lansdown and colleagues (Lansdown et al 1990) would imply that the severity makes a difference to the level of distress experienced, with those who have milder abnormalities experiencing more anxiety because of difficulties predicting the responses of others. However, severity of facial disfigurement may effect bullying and shame-proneness in a more predictable way.

5.8 Conclusion from findings

The above discussion of the findings of the present study lead to the proposal of a speculative model of the maintenance of bullying/teasing for individuals with cleft lip and palate (Fig 5). It incorporates both Adams(1977) proposed model of the relationship between physical appearance and social interaction and the shame-feedback loop proposed by Gilbert and Lang (1994). It is recognised that there will be other mediating factors which would impact on the model such as situational factors and the internal and external resources of the individual.

Figure 5: Proposed model of the maintenance of bullying and teasing for individuals with cleft lip and palate.



It is proposed that it is the negative stereotyping reactions of others towards those with a facial disfigurement, which lead to expectations of further negative interactions. Depending on an individuals personal, situational and coping resources, shame related to facial appearance may develop, as demonstrated by the higher scores for the clinical group for those items in the AFOS scale relating to facial appearance. Shame related to facial appearance may cause the individual to be vigilant for teasing

and bullying behaviours from others, attributing these as relating to their appearance (which may be the case). If shame responses occur the person is vulnerable to further teasing and bullying as evidenced by the correlations between bullying and shame-proneness.

5.9 Study limitations

There are a number of limitations to the present study that could have affected the results, these include the sample, the measures and the methodology used. These are discussed below.

5.9.1 Study sample

The participants in the clinical group may not be representative of young people aged 12 – 18 years with cleft lip and palate. The response rate of those agreeing to participate in the study from this group was approximately 50 percent of those contacted. Those who responded may have done so because of difficulties they were experiencing and the need to discuss them. In some cases, parents may have encouraged them to participate in order to get help for their problems. Alternatively those who were experiencing difficulties at school or at home may have been less likely to volunteer to participate because of an unwillingness to discuss personal problems with a person unfamiliar to them.

There were variations within the group regarding the type of cleft that they had, and as indicated earlier severity of disfigurement is thought to have an effect on some adjustment variables. Additionally the affect of vocal characteristics was not taken into consideration and as a cleft palate can effect vocal quality, this may be important. During data collection, a few participants stated that they had been teased about the way their voice sounded with some school peers mimicking them in an

unpleasant way. It was hoped to involve professionals from the Cleft Lip and Palate Team in the study for the purposes of rating severity of cleft and vocal qualities (the plastic surgeon and the speech and language therapist respectively). However, practical difficulties and their other time commitments prevented this. Nevertheless, to take account of these additional variables in the analysis would have required more participants in order to achieve adequate statistical power. The results of the study may have been clearer had it focussed on a distinct group within the population e.g. those individuals with unilateral cleft lip and palate only. However this would have greatly reduced the number of participants due to the incidence of the condition. In previous studies with this population the sample sizes were generally small, the exception being the study by Broder et al (1992) which had a sample size of 495 children and adolescents; however, their data was collected over a 10 year period.

The developmental differences within the samples in study 2 may have been a further compounding variable. To maximise the potential sample size for the clinical group the age limits were from 12 – 18 years, and the age range of those participating was 12 – 17 years. Again, a small sample size meant the affects of the different developmental levels within each group could not be accounted for in the analysis. This also applies to within group gender differences.

The comparison group can be criticised as being too different from the clinical group on some demographic variables to provide a fair comparison. The comparison group were probably more homogeneous as they all attended the same school, and were therefore likely to be from similar social backgrounds. The comparison group's geographical origins may not be an ideal comparison for Birmingham children. Nevertheless, the Birmingham Children's Hospital Cleft Lip and Palate Team are a regional team taking referrals from around the West Midlands. This is likely to mean

that the clinical group's social backgrounds are heterogeneous making the matching task more difficult. Although attempts were made to attain a school sample from within Birmingham this was not possible as the schools approached did not grant permission. Therefore, the school sample used was a sample of convenience as it was in the catchment area of the Clinical Psychology department where the author was on placement at that particular stage of the study. In addition, ethnicity was also not included for analysis although only one of the clinical group participants was from an ethnic minority group. A more stringently matched comparison group may have been obtained by asking the clinical group participants to recruit a relative or friend for this purpose. This may however have placed an additional burden on the participants making them less likely to volunteer for the study and might produce other artifacts e.g. one victimised child might be friendly with another.

5.9.2 Study measures

The development of the AFOS scale was influenced by the time constraints of the present study and as such the generation and selection of items for the scale did not follow a traditional course. Ideally, many more items should have been included to reflect the different content areas. The questionnaire should then have been piloted on a small number of adolescents around the ages of the participants in study one and study two. Following this items should have been selected or deselected according to certain criteria. For example items with a poor facility index should not be included, as these represent items always answered in the same way. This is calculated by summing the score for the item for each respondent and then dividing this by the total number of respondents. Items which are equal to or approaching either of the extreme scores for the item should not be included. It is also recommended that items which have very skewed distributions should be excluded from scales (Dewey 1997),

however using this criteria all of the items in the scale would have been excluded as they were all positively skewed.

Difficulties arise from the use of the Adolescent Shame Proneness Scale, as with most shame scales because of the problems of operationalising Shame in Questionnaire measures. The expression of shame may share similarities with other emotions and there may be many different expressions characterising one emotion. The ASPS like other shame scales attempts to assess the extent to which an individual may be inclined to feel shame as a reaction to particular events. However, the problem of ecological validity arises as with all scales using hypothetical scenarios, in that participant's responses may not reflect what they do or feel in real-life situations (Brewin and Andrews 1992). There is also the question of whether a propensity to experience shame about a specific aspect of oneself is independent of a propensity to feel shame as a result of personal behaviour, as the work of Andrews and Hunter (1997) suggests. This is also indicated in the present study by the clinical group's high endorsement of facial shame items in the context of equivalent scores to the comparison group on the ASPS.

Without test-retest reliability it is unclear whether the shame-proneness scale is measuring an enduring characteristic, as it may be that like some global negative self-referent questionnaires the scale is mood-dependent (Brewin 1985).

Additional measures other than self-report scales would have provided informative data, for example teacher and parent ratings regarding responses to potentially shaming events and teacher's ratings of bullying, but the practicalities involved in obtaining such ratings outweighed the benefits for this particular study.

5.9.3 Study Procedure

Ideally, there would have been a number of additional steps involved in study 1 and its progression to study 2. These would have included a small pilot study of the AFOS scale, assessment of test-retest reliability for the AFOS scale and the ASPS, and factor analysis of the AFOS scale to see if the factors which emerged reflected the theoretical work upon which they were based. Additionally a separate control group would have been recruited which matched the clinical group more closely. However, as the study was dictated to a large degree by time and resources these intervening steps were not possible.

To make both groups in study 2 more comparable the bullying interview could have been given in questionnaire format to both groups. As previously stated it was thought to be important to gain qualitative information about the bullying experienced by the clinical group to achieve a better understanding of those experiences and their relevance to their condition, but this was achieved at the expense of being able to make direct comparisons with the qualitative experiences of the comparison group. Had more time been available the bullying data collected could have been analysed in detail.

The shame measures were administered differently for the groups in study 2, in so far as the participants in the clinical group were in a one to one situation with the researcher, whereas the comparison group could remain anonymous as the measures were administered to the group. There is some evidence that face to face interviews with already shame-prone individuals can decrease the likelihood that shame will be divulged as they may feel uneasy answering questions about shame (Dixon et al 1996). Therefore, the comparison group may have felt more able to divulge shame as

their anonymity was preserved thus affecting the comparison of the measures between the two groups.

In both studies, the measures were presented in the same order and it is possible that an ordering effect will have influenced the results.

Another confounding factor may have occurred if the participants in study 1 discussed their responses with others resulting in them changing their subsequent answers. Although they were requested not to do so it was impossible to monitor this.

5.10 Strengths of the study

Despite the methodological limitations outlined above, the study has significant strengths. These include the following:

- With some further development, the AFOS scale may be a better way of measuring shame than the ASPS, particularly that experienced by a patient sample. The reasons for this are that it is not situational; it does not rest on the assumption that high-shame adolescents will have generalised shame but questions specific areas where individuals may feel shame and it may be less vulnerable to mood state effects. The low mean and high standard deviation may make it more likely to tap high shame particularly amongst adolescents for whom it is a salient issue anyway. Although the scale is highly biased towards bodily shame, the body provides a common real-life focus and is a central concern in shame (Gilbert 1989). This may make it particularly useful for any group of adolescents with body image concerns.
- It is possible that for shame-prone individuals the focus may change at different developmental stages. However, this requires further investigation and the AFOS

may be a useful tool for this purpose and for other research into adolescent shame, a hitherto neglected area.

- The study represents a methodical approach to applied research. The author met with patients with cleft lip and palate and their parents, members of a self-help group for the condition, the Cleft Lip and Palate Team and attended an out-patients clinic prior to consulting the relevant literature. This progressed to the identification of research questions and then to the development of the measures felt to be required to answer the questions raised. The final stage was the investigation of the research questions using the measures developed. This approach enabled the research questions asked to have real-life relevance for the group they concerned.
- Much of the previous research into difficulties faced by individuals with cleft lip and palate is without a theoretical underpinning. This study represents an attempt to bring the research in this area into mainstream psychology by applying and testing a theoretical model in an effort to make sense of the difficulties experienced by these individuals.

5.11 Clinical implications

The bullying findings from the study have some clinical implications for adolescents generally. If applied to preventative work with victims of bullying it is suggested that this would need to include ways of helping individuals who are shame-prone to gain higher ranking status. For example, if they are helped to build upon their particular strengths such as those that are physical or intellectual, they may be able to gain experiences of being similar and equal to their peer group which would perhaps

protect them from developing feelings of shame and demonstrating associated behaviours which may make them vulnerable to bullying.

Further implications for bullying from the study include that it may be more prevalent than some previous research has suggested, and would imply that there is a need for educators to be aware of the potentially high rates of bullying in their schools.

For adolescents who have cleft lip and palate, the findings from the present study suggest that some may be vulnerable to experiencing shame related to facial appearance. For these individuals it would be important to help them to develop alternative ways of attributing the behaviours of others where appropriate. The reasoning for this is that if these adolescents are misattributing negative behaviours of others as being due to their appearance this may make them vulnerable to experiencing characterological shame, it would also be likely to have a transactional effect on the behaviour of others. Although some of the literature suggests that this style of attribution protects self-esteem, the accompanying emotional response may lead to difficulties in the long term as it is thought that repeated patterns of emotional response whether caused by situational or endogenous processes can become dysfunctional over time (Oatley and Jenkins 1992). The use of cognitive methods such as Socratic questioning may help these individuals to make appropriate attributions of other's behaviours which may help their social interaction in the long term. Of course, there may be occurrences when the behaviour of others is perceived correctly as due to their facial appearance and in these cases appropriate coping strategies may need to be taught.

It will be important for all those working with these individuals to be aware of the possibility that they may develop shame feelings related to their appearance. The

modeling of acceptance of the young person would be an important way for their expectations of stereotyping behaviour to be indirectly challenged.

Additionally it would be important for clinical teams working with any group of individuals such as cleft lip and palate youngsters who may be 'at risk' from bullying because of their facial difference to ensure appropriate support is available for them in schools, particularly during the adolescent years when their vulnerability may be increased. The Cleft Lip and Palate Association recognises this is an area of concern for parents of children with this condition and provide literature specifically on the topic of teasing and bullying (CLAPA, personal communication).

The findings from the shame-proneness questionnaire give reason for optimism for this group of adolescents. They would suggest that for the majority of adolescents with cleft lip and palate their social difficulties are overcome and do not result in negative self-perceptions. There are a few who have difficulties nevertheless, and early identification of these may be important to prevent ongoing problems with social interaction.

Perhaps the most important time for clinicians to target their interventions is directly after the birth of a child with cleft lip and palate. If parents are able to feel able to cope with the difficulties that lie ahead of them and are given sensitively delivered and accurate information about the condition, its treatment and likely outcome this may initially help with attachment processes and benefit later emotional development. Although this is not inferred as a direct result of the findings from the present study it could be an indirect conclusion given that shame-proneness is thought to be associated with early experiences in some cases (Gilbert and Andrews 1998).

The literature has little to say about interventions with those with cleft lip and palate, partly because there is no theoretical basis upon which interventions can be

based. Some studies suggest that these individuals lack social skills and social skills training is identified as a possible way of enabling the individual to be more socially accepted (Landsdown et al 1997, Kapp-Simon 1995). However, if shame is taken into consideration it may be that the identified 'poor social skills' are actually the behavioural consequences of shame, and interventions should be directed at the source of the persons distress and not the consequences. It is likely that questionnaires are a useful way to identify distressed individuals with cleft lip and palate, particularly in an adolescent population who may find it difficult to vocalize their distress. Their use as part of standard practice in clinical teams such as the Cleft Lip and Palate Team should be considered.

As the findings suggest that individuals are vulnerable to developing feelings of shame related to their facial appearance and this may be related to their experiences of stereotyping reactions, scope exists for further preventative work at a more political/community/population level. By raising awareness of stigmatising and stereotyping reactions and their effects in an effort to reduce them this affirms that shame experienced by some individuals is not assumed to be a type of individual pathology but a natural response to factors in their environment.

The findings of the present study may have limited clinical implications until more is known about the affect of shame and its links with psychopathology. Although there are strong correlations between some measures of psychopathology and shame such as somatization, obsessive compulsivity, anxiety and depression (Gilbert and Andrews, 1998), it is possible that they are measuring the same thing. The high reliance on some shame scales on negative and global self-referent items may result in both types of measure merely reflecting diffuse negative affectivity. In addition most of the work linking shame to psychopathology is with adult samples

and little is known about the effects for adolescents. A speculative suggestion is that shame is important because it precedes the onset of symptoms and thereby confers a vulnerability to particular disorders. This would support the value of preventative work and early intervention.

5.12 Conclusion

The present study gives rise to the conclusion that the experience of having a cleft lip and palate is likely to result in bullying for some adolescents. However, this may be no more likely than for adolescents without cleft lip and palate in adolescent populations where rates of bullying are high. A tendency to shame-proneness is associated with bullying and this is explained here by the social rank theory of shame. This may have important implications for interventions with those who are bullied.

The importance of shame, particularly shame with a focus on facial appearance is highlighted as a concern for those with cleft lip and palate. It is suggested this arises from stereotyping reactions by others and it is thought to be important to target interventions to either prevent this focus of shame developing or to cope with it should it arise. As stereotypes are ingrained within our social fabric, changing these beliefs is likely to be a slow and arduous process; therefore the burden of coping seems to rest with those on the receiving end of such stereotypes.

The Adolescent Focus of Shame scale is a valid and reliable measure which may have considerable advantages over some other shame measures. Its usefulness for future research with populations such as the clinical group in this study is anticipated particularly if it is developed further. That we may feel ashamed of what we are as well as what we do is an important part of Goffman's work on stigma. There are very few individuals who are exempt from stigmatisation and the natural

human tendency to break the world into ‘them’ and ‘us’ means that individuals must deal with their ‘differentness’ as far as possible. However, those who are unsuccessful at doing so may have a tendency to experience shame which may mediate social interaction problems and emotional problems in the long term. Further research is needed into the consequences of shame however, particularly in adolescents.

The findings here support the need for Clinical Psychology interventions and offer scope for help with this group of individuals.

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Appendix 1

Adolescent FOS scale

AGE _____ MALE/FEMALE _____

The statements below are about feeling ashamed. It is important that you know what feeling ashamed means, so that you can answer the questions carefully. Feeling ashamed is different to feeling guilty or embarrassed. It is when a person feels that they are either weaker, smaller or not as good as other people in some way. They also think that other people see them like this too. When a person feels like this it may make them blush, cry, feel angry or want to hide themselves away.

DIRECTIONS: Below is a list of statements about feeling ashamed, that some people may have from time to time.

Please read each statement carefully and then circle the number to the right of the item that shows how often you find yourself feeling what is described in the statement.

Please do not miss any items out.

SCALE				
0	1	2	3	4
NEVER	HARDLY EVER	SOMETIMES	OFTEN	ALMOST ALWAYS

- | | | | | | |
|---|---|---|---|---|---|
| 1. I feel ashamed of my body | 0 | 1 | 2 | 3 | 4 |
| 2. I feel ashamed when I am with kids in my class. | 0 | 1 | 2 | 3 | 4 |
| 3. I feel ashamed when I play sport. | 0 | 1 | 2 | 3 | 4 |
| 4. I feel ashamed of my facial appearance | 0 | 1 | 2 | 3 | 4 |
| 5. I feel ashamed if I do things badly | 0 | 1 | 2 | 3 | 4 |
| 6. I feel ashamed if I get low marks for my school work | 0 | 1 | 2 | 3 | 4 |
| 7. I feel ashamed of how I run/walk | 0 | 1 | 2 | 3 | 4 |
| 8. I feel ashamed if I show some of my feelings. | 0 | 1 | 2 | 3 | 4 |

- | | |
|--|-----------|
| 9. I feel ashamed of my friends. | 0 1 2 3 4 |
| 10. I feel ashamed when I am with my best friend | 0 1 2 3 4 |
| 11. I feel ashamed of my family. | 0 1 2 3 4 |
| 12. I feel ashamed if I show any feelings | 0 1 2 3 4 |

In this section, we are interested in your feelings about the way that you look.

- | | |
|---|-----------|
| 13. I feel ashamed of the size of my body. | 0 1 2 3 4 |
| 14. I feel ashamed of my eyes. | 0 1 2 3 4 |
| 15. I feel ashamed of my legs. | 0 1 2 3 4 |
| 16. I feel ashamed of my skin. | 0 1 2 3 4 |
| 17. I feel ashamed of my nose. | 0 1 2 3 4 |
| 18. I feel ashamed of the shape of my body. | 0 1 2 3 4 |
| 19. I feel ashamed of my teeth | 0 1 2 3 4 |
| 20. I feel ashamed of my arms | 0 1 2 3 4 |
| 21. I feel ashamed of my stomach | 0 1 2 3 4 |
| 22. I feel ashamed of my hands | 0 1 2 3 4 |
| 23. I feel ashamed of my ears | 0 1 2 3 4 |
| 24. I feel ashamed of my feet | 0 1 2 3 4 |
| 25. I feel ashamed of my chest. | 0 1 2 3 4 |
| 26. I feel ashamed of my voice | 0 1 2 3 4 |
| 27. I feel ashamed of my lips | 0 1 2 3 4 |

Thank you for completing this questionnaire. Your answers are confidential, that means no one will know what you have put unless you tell them.

Appendix 2

Adolescent Shame-Proneness Scale (ASPS)

We would like you to imagine how you might feel if some of the things below happened to you. To help you fill in this form consider this example. Imagine you had planned to go to the pictures with someone but they were unable to go.

Eg. I wanted to go to the pictures with a friend but they could not go.

1	2	3	4	5
Not upset		Quite upset		Very upset

If you couldn't go to the pictures how upset might you feel?

- If you would not feel that upset, circle 1.
- If you would feel a little upset, circle 2.
- If you would feel quite upset but felt you could get over it, circle 3.
- If you would feel really upset, circle 4.
- If you would feel so upset that you feel it would be difficult to get over, circle 5.

1. Imagine that someone in your class makes a critical comment about how you look.

1	2	3	4	5
Not upset		Quite upset		Very upset

2. I put my hand up in class and others laugh and think my answer is silly.

1	2	3	4	5
Not upset		Quite upset		Very upset

3. I ask someone I like to go out with me but they laugh and say no.

1	2	3	4	5
Not upset		Quite upset		Very upset

4. I try to score a goal in football or hockey and I miss badly and everybody shouts at me.

1	2	3	4	5
Not upset		Quite upset		Very upset

5. I do badly in a test and the results are read out in class.

1	2	3	4	5
Not upset		Quite upset		Very upset

6. When it comes to picking a team I am the last to be picked.

1	2	3	4	5
Not upset		Quite upset		Very upset

7. Everybody in my class is asked about how they feel on something, but when my turn comes nobody listens to what I have to say.

1	2	3	4	5
Not upset		Quite upset		Very upset

8. I am acting in a school play and I make a mistake and my friends laugh at me.

1	2	3	4	5
Not upset		Quite upset		Very upset

9. When I am doing work with others in the class, some of them say I'm thick and stupid.

1	2	3	4	5
Not upset		Quite upset		Very upset

10. I find that I have been left out from a party that all my friends are going to.

1	2	3	4	5
Not upset		Quite upset		Very upset

Appendix 3

Bullying Interview

I am going to ask you a few questions about how you feel about school, and whether anyone has bullied you at school.

Some people describe bullying as being when a young person is picked on, or has unpleasant things said about them by another young person, or group of young people. It is also bullying when young people hit you, kick you, threaten you, lock you inside a room, send you unpleasant notes, or if they deliberately ignore you, or tease you in an unpleasant way. These things can make you very unhappy, especially if they happen a lot, and you are unable to stop them. However, it is not bullying if you just have the odd argument, which does not happen a lot.

1.Do you enjoy school?

No / a bit / a lot

2a. How many good friends do you have at school?

None / one / two or three / Many

2b. Would you like more friends?

Yes/No

3. Quite a lot of young people seem to be bullied in school. Is there anyone at school who bullies you?

Yes / No

4. How do they bully you?

Do they call you unpleasant names about your colour? *Yes/ No*

Do they call you unpleasant names about the way you look? *Yes / No*

Do they call you unpleasant names in other ways? *Yes / No*

Do they hit you? *Yes / No*

Do they threaten to do things to you? *Yes No*

Do they stop talking to you? *Yes No*

Do they spread unpleasant rumours about you? *Yes no*

Do they take your belongings away from you? *Yes No*

Do they bully you in any other way?

Yes No

If **YES** what do they do to you?

5. Have you been bullied by more than one person at school?

Yes 2 / 3 / more than 3

No

6. If you have answered YES to any of the questions above about bullying, how does the bullying make you feel?

7. How often are you bullied?

Only once or twice a term

About once every two weeks

About once a week

About two or three times a week

Everyday, or nearly everyday.

8. Have you told any member of the school staff about being bullied?

Yes / No

9. Have you told anyone at home about being bullied?

Yes / No

10. Have you been bullied by anyone else outside school

Yes / No

Please tell us about this if you want to.

Thank you for taking the time to go through these questions. Your answers will not be told to anyone else, but you can tell others about them if you wish.

It is important to talk to someone if you are being bullied. If you feel you need to talk to someone about this you could:

- Talk to your parents
- Talk to your teacher
- Talk to the school nurse

Appendix 4 The instruction and feedback sheet (school sample only)

Introduction to the questionnaires

Thank you for agreeing to complete these questionnaires for my research.

There are 3 questionnaires in total. For 2 of them you are asked to circle the number that matches your answer, (the instructions are at the top of the questionnaires).

The bullying interview asks questions and you are asked to circle your answer from a choice. Please only circle one answer for each question. For question 6 and parts of question 4 and 10, there is a space for you to write your answer in your own words if you want to.

Please read the questions carefully and answer all of the questions on all of the questionnaires. There are no right or wrong answers and it is not a test, so try to be as honest as possible.

At the top of the first questionnaire could you remember to fill in the parts that ask for your age, whether you are male or female, and what class you are in, you do not need to put your name though.

When you have finished the questionnaires, I would like you to tell me at the bottom of this sheet firstly how long it took to complete them, and secondly if you would recommend filling the first questionnaire (The Adolescent FOS scale), to a friend, (e.g. was it o.k. to fill in, or was it boring or difficult).

- 1) The questionnaires took ----- minutes to fill in.
- 2) Would you recommend the AFOS to a friend? Yes/No

Any other comments?

Appendix 5 Letter to parents of the school sample

To Parents and guardians
of Years 7,8 and 9 pupils
at Wilsthorpe School.

8/6/98

Dear parents/guardians

Following permission from the Head Teacher, Mrs Harrison, I am writing to ask your consent to allow your child to take part in a small study. This study is being conducted under the supervision of a Clinical Psychologist working for Southern Derbyshire Mental Health Trust. The study will take place during a school science lesson, and will involve the anonymous completion of a number of questionnaires by all the class. These questionnaires should take about 20 minutes to complete. We are interested in adolescent's feelings about their body image and on how this relates to their general psychological well being.

If you are happy about your child taking part in the study, then he/she will automatically be given the questionnaires to complete during a school science lesson. However if you are unhappy about the study, then you should complete the form on the next page and return it to school.

Thank you for giving this your consideration.

Yours sincerely

Jayne Eaton
Clinical Psychologist in Training

Supervised by
Ken Goss
Clinical Psychologist

You should only complete this slip if you are unhappy about taking part in the study.

I do not want my son/daughter to take part in the study about adolescent’s body image.

_____ (Signed) _____ (Name of child in block capitals)

Appendix 6 Letter of introduction for the clinical sample

Dear Parent/Guardian/Adolescent

The Clinical Psychology department often carries out research in collaboration with other departments within the Birmingham Children's Hospital. The Cleft Lip and Palate Team are keen to obtain input to our service from the department of Clinical Psychology, so that we are able to provide a fuller service to our patients. However, in order to do this we first need to find out what sorts of psychological difficulties may exist for some of our patients.

A research project to look at difficulties that adolescents with a cleft lip and palate may have encountered is being conducted by a Clinical Psychologist in training, from the Clinical Psychology department. She is interested in talking to adolescents with cleft lip, or cleft lip and palate about some of their experiences at school or at home, whether they have experienced problems or not.

Our service feels it is a good idea for research of this nature to be conducted, and give it our support. The researcher, Jayne Eaton, will be writing to you with more information about the project. We hope you will feel able to get involved, and do not mind being contacted about this. Obviously, it is entirely up to you if you decide to take part or not. If you decide not to take part, this decision will not affect your treatment with our service.

Yours Sincerely

Mr P. Gornall
Consultant Paediatric Surgeon

Appendix 7

LETTER AND CONSENT FORM TO ADOLESCENTS AGED 16 & OVER

‘Adjustment in Adolescents with Cleft Lip and Palate’

Dear (Name)

We are carrying out a research study to investigate the difficulties that some adolescents with cleft lip or cleft lip and palate experience, which may lead in some cases to emotional distress. The research will involve youngsters between the ages of 12 and 18. Participants will be asked to complete 3 questionnaires with the researcher, and answer questions relating to experiences at school. This should take approximately 60 minutes and would be carried out on one occasion, either at your home, or, if preferred, at the Birmingham Children’s Hospital.

It is not intended that participating in the research should cause you any distress. However, should any concerns arise as a result of participation, a Clinical Psychologist at the Children’s Hospital will be available to offer an advisory service for you and members of your family - if you wish, who would like to meet and talk through any worries.

Before taking part in the study, you will be asked if you still wish to participate in the study. It is stressed that you are free to withdraw from the study at any time and that your responses to questionnaires etc will be coded to ensure confidentiality.

Mr Gornall, Ms Slator and Mr Pinson and the rest of the Cleft Lip and Palate Team are in full agreement with the study and they support it.

If you have any concerns about any aspects of this study or wish to discuss it further then you can contact me via the number at the top of this letter.

If you are happy to participate in this study, I would be grateful if you would sign and return the tear off slip at the end of this letter as soon as possible and return it in the stamped addressed envelope provided. Of course, you may change your mind about participating in the study after the interview has taken place. If this happens, then you can contact the researcher to inform them, and any information already collected will be destroyed.

Yours sincerely

Jayne Eaton
Clinical Psychologist in Training

Julie Reed
Consultant Clinical Psychologist

‘ADJUSTMENT IN ADOLESCENTS WITH CLEFT LIP AND PALATE’

Name

Please tick one box

<u>For young people</u>	‘I am happy to take part in the above study’	<input type="checkbox"/>
	‘I do not want to take part in the above study’	<input type="checkbox"/>

Appendix 3

LETTER AND CONSENT FORM TO PARENTS/GUARDIANS OF YOUNGSTERS UNDER 16

‘Adjustment in Adolescents with Cleft Lip and Palate’

Dear (Name)

We are carrying out a research study to investigate the difficulties that some adolescents with cleft lip or cleft lip and palate experience, which may lead in some cases to emotional distress. The research will involve youngsters between the ages of 12 and 18. It will involve completing 3 questionnaires with the researcher, and answering questions relating to experiences at school. This should take approximately 60 minutes and would be carried out on one occasion, either at the youngster’s home, or, if preferred, at the Birmingham Children’s Hospital.

It is not intended that participating in the research should cause any distress to the youngsters concerned. However, should any concerns arise as a result of participation, a Clinical Psychologist at the Children’s Hospital will be available to offer an advisory service for any youngster and his/her family who would like to meet and talk through any worries.

Before taking part in the study, each youngster will be asked if they still wish to participate in the study. It is stressed that he/she is free to withdraw from the study at any time and that his/her responses to questionnaires etc will be coded to ensure confidentiality.

Mr Gornall, Ms Slator and Mr Pinson and the rest of the Cleft Lip and Palate Team are in full agreement with the study and they support it.

If you have any concerns about any aspects of this study or wish to discuss it further then you can contact me via the number at the top of this letter.

If you/your child are happy to participate in this study, I would be grateful if you would sign and return the tear off slip at the end of this letter as soon as possible and return it in the stamped addressed envelope provided. Of course, you may change your mind about participating in the study after the interview has taken place. If this happens, then you can contact the researcher to inform them, and any information already collected will be destroyed.

Yours sincerely

Jayne Eaton
Clinical Psychologist in Training

Julie Reed
Consultant Clinical Psychologist

‘ADJUSTMENT IN ADOLESCENTS WITH CLEFT LIP AND PALATE’

Name of child

Please tick one box

<u>For parents</u>	‘I am happy for my child to take part in the above study’	<input type="checkbox"/>
	‘I do not want my child to take part in the above study’	<input type="checkbox"/>

<u>For young people</u>	‘I am happy to take part in the above study’	<input type="checkbox"/>
	‘I do not want to take part in the above study’	<input type="checkbox"/>

Appendix 9 INFORMATION SHEET (16's and over)

‘Adjustment in adolescents with cleft lip and palate’

1. What is the study about?

We want to find out more about the emotional effects that may occur as a result of having a cleft lip and palate. It is hoped to discover what the experiences are that youngsters with cleft lip and palate have, which may in some cases lead to emotional difficulties and distress.

2. What will I have to do?

First we will explain what the study is about, and answer any questions you may have about it. Then we will ask you for your written consent to participate in the study. The study can be opted out of at any time. You will then be asked to complete 3 questionnaires with the researcher and answer a few questions about experiences at school and friendships. This would take about 1 hour.

3. What are the benefits?

The study aims to increase our understanding of the underlying causes of emotional distress, which affects some individuals with cleft lip and palate. It is hoped that this would help Clinical Psychologists and members of the Cleft lip and palate team who are working with these youngsters to provide additional support at a time when it is needed.

4. What are the risks?

There is a small risk that if individuals have had unpleasant experiences, related to having a cleft lip and palate, for example, being teased at school, they could find it upsetting to talk about them. The researcher is a Clinical Psychologist in Training in her final year, and has had seven years postgraduate clinical experience. She will try to deal with all individuals as sensitively as possible. However should it be felt that more support is required, a Clinical Psychologist at The Birmingham Childrens Hospital will be happy to offer an advisory service to those youngsters and their families who wished to discuss any related concerns.

5. What if I do not want to take part?

If any young person does not want to participate in the research, they can either record their wishes by ticking the appropriate boxes on the enclosed tear off slip that accompanies the letters. Alternatively do not return the tear off slip. Individuals will be asked again if they are happy to take part in the study before the researcher administers the questionnaires, and if they say ‘no’ there will be no attempt on behalf of the researcher to persuade them to change their mind.

6. What happens to the information?

Your answers will be written down against a confidential number. This information will be stored on a computer disk and analysed with the answers given by other individuals taking part in the study.

7. Who else is taking part?

Adolescents aged 12-18 who have been treated by the Cleft lip and palate team at Birmingham Childrens Hospital. Also adolescents without cleft lip and palate attending local schools will be completing the questionnaires used in this study.

8. What happens at the end of the study?

All the answers will be analysed and the results of the study will be summarised. This will be sent to all individuals who took part in the study, and for those under 16 their parents/guardians, in a feedback sheet. We will discuss the overall results with the Cleft Lip and Palate Team.

9. What if I have anymore questions?

You can contact the researcher, Ms Jayne Eaton, or you can contact Julie Reed, Consultant Clinical Psychologist, at the Department of Clinical Psychology, Birmingham Childrens Hospital, by letter or telephone (tel: 450 6379).

10. What happens now if I decide to take part?

Please tick the 'I am happy to take part in the above study' box (in the enclosed letter). Return the tear off slip in the envelope provided, and you will be contacted as soon as possible.

11. What happens if I change my mind during the study?

You can change your mind at any stage. Contact either of the individuals named in 9. above and any information already collected will be destroyed.

12. Contact name and number?

As 9. Alternative address for Jayne Eaton: Clinical Psychologist in Training, Leicester University, Centre for Applied Psychology (Clinical section), Leicester University, Leicester.

INFORMATION SHEET FOR ADOLESCENTS AGED 12 - 15

‘Adjustment in adolescents with cleft lip and palate’

1. What is the study about

We want to find out more about the emotional effects that may occur as a result of having a cleft lip and palate. It is hoped to discover what the experiences are that youngsters with cleft lip and palate have, which may in some cases lead to emotional difficulties and distress.

2. What will I have to do?

First we will explain what the study is about, and answer any questions you may have about it. Then we will ask for your written consent to participate in the study. You can come out of the study at any time. You will then be asked to complete 3 questionnaires with the researcher and answer a few questions about experiences at school and friendships. This would take about 1 hour.

3. What are the benefits?

We hope to understand better some of the reasons why some youngsters with cleft lip and palate experience distress. It is hoped that this would help Clinical Psychologists and members of the Cleft Lip and Palate Team who are working with these youngsters to provide additional support at a time when it is needed.

4. What are the risks?

There is a small risk that if you have had unpleasant experiences, related to having a cleft lip and palate, for example, being teased at school, you could find it upsetting to talk about them. The researcher is a Clinical Psychologist in Training in her final year who has had several years of experience of working with children. She will try to deal with you as sensitively as possible. However, should you feel that you would like more support, a Clinical Psychologist at The Birmingham Children's Hospital will be happy to offer an advisory service to you and your family if you wish to discuss your concerns.

5. What if I do not want to take part?

If you do not want to take part in the research, you can either record your wishes by ticking the appropriate boxes on the enclosed tear off slip that accompanies your letter. Alternatively, do not return the tear off slip. You will be asked again if you are happy to take part in the study before the researcher administers the

questionnaires and if you say 'no' there will be no attempt on behalf of the researcher to persuade you to change your mind.

6. What happens to the information?

Your answers will be written down against a confidential number. This information will be stored on a computer disk and analysed with the answers given by other individuals taking part in the study.

7. Who else is taking part?

Adolescents aged 12-18 who have been treated by the Cleft Lip and Palate Team at Birmingham Children's Hospital. Also, adolescents without cleft lip and palate attending local schools will be completing questionnaires used in this study.

8. What happens at the end of the study?

All the answers will be analysed and the results of the study will be summarised. This will be sent to those who took part in the study, and for those under 16 their parents/guardians, in a feedback sheet. We will discuss the overall results with the Cleft Lip and Palate Team.

9. What if I have any more questions?

You can contact the researcher, Ms Jayne Eaton, or you can contact Julie Reed, Consultant Clinical Psychologist, at the Department of Clinical Psychology, Birmingham Children's Hospital, by letter or telephone (tel: 0121 333 8047).

10. What happens now if I decide to take part?

Please tick the 'I am happy to take part in the above study' box (in the enclosed letter). Return the tear off slip in the envelope provided, and you will be contacted as soon as possible.

11. What happens if I change my mind during the study?

You can change your mind at any stage. Contact either of the individuals named in 9. above and any information already collected will be destroyed.

12. Contact name and number?

As 9. Alternative address for Jayne Eaton: Clinical Psychologist in Training, Leicester University, Centre for Applied Psychology (Clinical section), Leicester University, Leicester.

INFORMATION SHEET FOR PARENTS OF YOUNGSTERS UNDER 16

‘Adjustment in adolescents with cleft lip and palate’

1. What is the study about

We want to find out more about the emotional effects that may occur as a result of having a cleft lip and palate. It is hoped to discover what the experiences are that youngsters with cleft lip and palate have, which may in some cases lead to emotional difficulties and distress.

2. What will my child have to do?

First we will ask for written consent from the child’s parents/guardians to allow them to participate in the study. If this were agreed upon we would ask the child for their written consent following any further explanation or clarification that may be required. The study can be opted out of at any time. The child will then be asked to complete 3 questionnaires with the researcher and answer a few questions about experiences at school and friendships. This would take about 1 hour.

3. What are the benefits?

The study aims to increase our understanding of the underlying causes of emotional distress, which affects some individuals with cleft lip and palate. It is hoped that this would help Clinical Psychologists and members of the Cleft Lip and Palate Team who are working with these youngsters to provide additional support at a time when it is needed.

4. What are the risks?

There is a small risk that if individuals have had unpleasant experiences, related to having a cleft lip and palate, for example, being teased at school they could find it upsetting to talk about them. The researcher is a Clinical Psychologist in Training in her final year and has had seven years postgraduate clinical experience. She will try to deal with all individuals as sensitively as possible. However, should it be felt that more support is required, a Clinical Psychologist at The Birmingham Children’s Hospital will be happy to offer an advisory service to those youngsters and their families who wished to discuss any related concerns.

5. What if I do not want my child to take part?

If either parent or child do not want to participate in the research/ or have their child participate in the research, they can either record their wishes by ticking the appropriate boxes on the enclosed tear off slip that accompanies the letters.

Alternatively do not return the tear off slip. The child will be asked again if they are happy to take part in the study before the researcher administers the questionnaires. and if they say 'no' there will be no attempt on behalf of the researcher to persuade them to change their mind.

6. What happens to the information?

Your child's answers will be written down against a confidential number. This information will be stored on a computer disk and analysed with the answers given by other individuals taking part in the study.

7. Who else is taking part?

Adolescents aged 12-18 who have been treated by the Cleft Lip and Palate Team at Birmingham Children's Hospital. Also, adolescents without cleft lip and palate attending local schools will be completing questionnaires used in this study.

8. What happens at the end of the study?

All the answers will be analysed and the results of the study will be summarised. This will be sent to all individuals who took part in the study and their parents/guardians in a feedback sheet. We will discuss the overall results with the Cleft Lip and Palate Team.

9. What if I have any more questions?

You can contact the researcher, Mrs Jayne Eaton, or you can contact Julie Reed, Consultant Clinical Psychologist, at the Department of Clinical Psychology, Birmingham Children's Hospital, by letter or telephone (tel: 0121 333 8047).

10. What happens now if I decide to take part?

Please tick the 'I am happy for my child to take part in the above study' box (in the enclosed letter). Return the tear off slip in the envelope provided, and you will be contacted as soon as possible.

11. What happens if I change my mind during the study?

You/your child can change your mind at any stage. Contact either of the individuals named in 11. above and any information already collected will be destroyed.

12. Contact name and number?

As 9. Alternative address for Jayne Eaton: Clinical Psychologist in Training, Leicester University, Centre for Applied Psychology (Clinical section), Leicester University, Leicester.

Appendix 12

Power calculation for the assessment of the power of the study's sample sizes.

Power is defined as the probability of correctly rejecting a false null hypothesis, a more powerful experiment is one that has a greater probability of rejecting a false null hypothesis than does a less powerful experiment (Howell 1985).

Power is a function of several variables of which sample size is an important one. To calculate power it is necessary initially to estimate the effect size (γ). The effect size is the difference between two population means divided by the standard deviation of either population. This can be done by looking at data from past research and estimating the values that might be expected for the means and standard deviations for the null hypothesis and the research hypothesis. It can also be estimated by personal assessment, whereby the researcher states the difference in scores that they are interested in detecting. However, for the present study it was decided to employ the use of special conventions. These are a set of conventions proposed by Cohen (1977, cited in Howell 1985), for use when there are difficulties estimating the required parameters. This was thought to be justified because of the lack of prior research in the areas of adolescent shame, and facial disfigurement and bullying, which made it difficult to estimate an effect size from prior research. Personal assessment of expected differences was also difficult given that one of the scales (the AFOS) was developed as part of the present study.

Cohen has defined three values of γ , which vary as a function of the size of effect that is required, i.e. small, medium or large. The value for a large effect was chosen for the following calculation, so that the power value reflected a

value with a greater chance of detecting a difference between the research hypothesis and the null hypothesis.

The following power calculation for equal sample sizes was employed:

$$\delta = \gamma \sqrt{\frac{N}{2}}$$

N equals the number of cases in any one sample thus:

$$\delta = 0.80 \sqrt{\frac{16}{2}} = 2.26$$

This gives a value of 0.63 for a two-tailed test with a significance level of 0.05 (Howell 1985).

From the above calculation the power of the sample size of the study to detect a large effect between the clinical group and the comparison group is 63%, which also means that there is a 37% chance of accepting the null hypothesis and making a Type II error.