Social Rejection in Adolescents With a Visible Facial

Disfigurement: A Qualitative Study

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UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name: Suzy Beak

Date: 19th June 2015

Overview

Much of the research focusing on the difficulties experienced by young people with a visible facial disfigurement (VFD) has focused on the view from the outside (social/cultural views towards disfigurement) and the view from the inside (the psychological impact of living with a VFD).

Part 1 presents a review of the literature on the attitudes of non-disfigured children towards individuals with a VFD. Sixteen studies were included in this review following a systematic search of the literature. Overall, results indicated that non-disfigured children demonstrate a negative bias towards individuals with a VFD.

Part 2 presents a qualitative study which explored the lived experiences of young people with a VFD, specifically focusing on their peer relationships and experiences of social rejection relating to their appearance. Semi-structured interviews were completed with 10 adolescents (aged 11-14 years) with a range of congenital VFDs and analysed using thematic analysis. All young people described experiencing negative and unwanted attention from others. Many identified positively with their disfigured appearance and saw it as a part of who they were. In spite of this, the majority of young people did not wish to have a VFD for the rest of their lives.

Part 3 presents a critical appraisal of the qualitative study. It explores the possible barriers to engaging young people in research and considers the unique

contributions made by this study in considering the focus on psychopathology in

the existing literature on young people with VFDs and in understanding the

heterogeneity reported by this population.

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Part 1: Literature Review

Acknowledgements

The writing of this thesis would not have been possible without the tireless support from my research supervisors (Kristina Soon and Dr Stephen Butler) and the love and encouragement from my friends and family. A special thank you goes to Rob whose unconditional care and patience has kept me going.

Finally, I would like to dedicate this to my loving Grandma who was my greatest supporter.

7th December 1926 – 13th April 2015

Part 1: Literature Review

Children's Attitudes Towards Individuals With a Visible Facial Disfigurement: A Review of the Literature

Abstract

Aims. This paper provides a review of the literature of the attitudes of non-disfigured children towards individuals with a visible facial disfigurement (VFD).

Method. An electronic search of three databases elicited 905 papers published between 1970 and October 2014. Sixteen papers were included which investigated the attitudes of non-disfigured children aged between 2 and 18 years on cognitive, affective and behavioural measures.

Results and Conclusions. Overall, results indicated that non-disfigured children demonstrate a negative bias towards individuals with a VFD. The impact of the demographic characteristics of the rater (e.g., age and gender) on attitudes were inconsistent. These findings are considered in light of methodological limitations including poor ecological validity and an absence of indirect measures of behaviour. Areas for further research are also outlined.

Introduction

Visible Facial Disfigurements

It is estimated that one in 111 people in the UK have a visible facial disfigurement (VFD) (Office of Population Censuses and Surveys, 1988; Partridge & Julian, 2008). Causes of VFDs are diverse and can be the result of congenital conditions (e.g., cleft-lip, birthmarks) or acquired through trauma, disease or medical intervention (Rumsey & Harcourt, 2005).

Much of the research focusing on the nature of difficulties experienced by this population has taken two different, yet related, perspectives; the view from the outside (social and cultural views towards appearance and disfigurement) and the view from the inside (the psychological impact of living with a disfigured appearance) (Cash, 1990; Thompson & Kent, 2001).

View from the outside

It is assumed that young people with a VFD are more vulnerable to experiencing social rejection as a result of their disfigured appearance (Broder, Smith, & Strauss, 2001; Carroll & Shute, 2005; Feragen & Borge, 2010; Hunt, Burden, Hepper, Stevenson, & Johnston, 2007). Individuals with VFDs describe receiving unwanted attention in the form of staring (Dures, Morris, Gleeson, & Rumsey, 2012; Strauss et al., 2007), teasing (Gerrard, 1991; Magin, Adams, Heading, Pond, & Smith, 2006; Masnari et al., 2012; Rumsey & Harcourt, 2007; Strauss et al., 2007; Turner, Thomas, Dowell, Rumsey, & Sandy, 1997) and intrusive and unsolicited questions (Lawrence, Rosenberg, Mason, & Fauerbach, 2011; Locker, Jakovic, & Tompson, 2005; Rumsey, 2002). However whilst it has

been widely assumed, by researchers and clinicians alike, that young people with VFDs are more likely to experience negative social experiences, this has not been empirically tested (Caroll & Shute, 2005), and it is not clear whether prevalence rates differ from the non-clinical population where reports of appearance-related teasing are also high (Eisenberg, Neumark-Sztainer, Haines, & Wall, 2006; Kowalski, 2000; Lovegrove & Rumsey, 2005).

View from the inside

Despite assumptions that individuals with a disfigured appearance are viewed negatively by the non-disfigured population, the impact of this presumed social rejection on young people with a VFD is unclear. Some studies have found poorer adjustment in young people with VFDs compared to their peers (Frances, 2004; Horn & Tidman, 2002; Hunt et al., 2007; Newell & Marks, 2000; Papadopoulos, Walker, Aitken, & Bor, 2000; Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004; Thompson & Kent, 2001; van Scheppingen, Lettinga, Duipmans, Maathuis, & Jonkman, 2008; Williams, Gannon, & Soon, 2011), whilst other studies have found equivalent or better rates of adjustment in the disfigured population (Bilboul, Pope, & Snyder, 2006; Cochrane & Slade, 1999; Egan, Harcourt, & Rumsey, 2011; Feragen, Kvalem, Rumsey, & Borge, 2010; Walters, 1997).

Attitudes

Although no consensus has been reached on a universal definition of attitudes (Olson & Zanna, 1993; Rao, 2004), many theorists have adopted a tripartite view and distinguished between affective (a measure of how

participants feel towards the object), behavioural (behaviours directed at the object or an intention to behave in a particular manner) and cognitive (the beliefs, thoughts and attributes associated with the object) correlates of attitudes (Eagly & Chaiken, 1993; Nowicki & Sanderson, 2010; Olson & Zanna, 1993).

Measures of attitudes

Measures of attitude have been categorised into direct, where the respondent is aware of what is being measured, and indirect, where the respondent is unaware of what is being measured (Antonak & Livneh, 2000). Direct measures include semantic differential scales and preferential ranking tasks where the respondent is made aware of what is being measured explicitly through the task itself. These measures have been criticised due to threats to validity including experimenter demand effect, where the participant provides a response that they believe is in line with the hypotheses of the study, or social desirability bias, where the participant provides a socially desirable answer. Additionally, the nature of direct measures means that a response is demanded from the participant, which is subsequently assumed by the researcher to be meaningful. However, the very nature of the task means that participants are forced to give a response, or indeed form an attitude, where one may not have previously existed.

Indirect measures are defined as those where the respondent is either unaware of what is being measured (e.g., Implicit Attitudes Test; Greenwald, McGhee, & Schwartz, 1998), unaware that they are being observed, or are inactive participants (e.g., a measure of physiological response).

Children's Attitudes Towards Individuals With a VFD

Much of the research interest in this population is based on the assumption that individuals with a disfigured appearance are more likely to experience negative social experiences, placing them at an increased risk of psychological maladjustment. However both the assumption that children with a VFD will experience more social rejection, and the underlying belief that public attitudes towards individuals with VFDs are negative, have not been empirically tested. The last published review of visible differences suggested that non-disabled children show a low preference for children with a VFD, however despite this, report both positive and negative attitudes (Harper, 1995). A review of the available, and more recent, evidence is necessary in order to better understand the attitudes of non-disfigured children towards VFDs and to determine the credibility of the assumptions that have historically guided research within this population. This will also help support those young people with a VFD who experience psychological difficulties and help inform interventions designed to reduce appearance-related teasing and stigma in schools, if indeed it is present (Frances, 2004; Stock, Whale, Jenkinson, Rumsey, & Fox, 2013).

Aims of This Review

The current review sets out to answer the following two key questions:

1. How are VFDs viewed by non-disfigured children?

2. What factors influence attitudes towards individuals with a VFD?

Method

Criteria for Considering Studies for Review

Guidelines published by the Cochrane Collection (Higgins & Green, 2011) and Centre for Research Dissemination (CRD, 2009) were used to provide a framework for this systematic review. The criteria for selecting studies for review are outlined in the full research protocol (Appendix A) according to type of study, participants and outcome measures.

Inclusion criteria

The inclusion criteria stated that journal articles judged as suitable for review must:

- Describe a study that focuses on the appearance-related attitudes of children/adolescents towards individuals with a VFD including those defined as congenital, acquired or counterfeit

- Use a sample of children and adolescents under the age of 18 without a VFD or physical/intellectual disability

- Be published in English and between January 1970 and October 2014

- Be an empirically based study including quantitative and/or qualitative methodology.

Exclusion criteria

Papers were excluded from the review if they:

- Focused on the attitudes of children/adolescents with a VFD towards their own appearance (self-perception) or the appearance of others

- Did not consider appearance-related attitudes (e.g., psychological adjustment, medical treatment)

- Focused on a disfigurement away from the face (e.g., physical disabilities or dental abnormalities)

- Focused on attitudes towards disfigurement as a result of surgery

- Explored the attitudes of anyone over the age of 18

- Explored changes in attitudes following an intervention

- Were published in a non-English language

- Were non-published articles including dissertations and theses

- Were published outside of the dates specified

- Were in the format of a review paper or single case design.

Search Methods for Identification of Studies

Electronic searches

The electronic databases of PsycINFO, Medline and CINAHL Plus were searched for the period of January 1970 to October 2014. The three key domains addressed by the research question were identified (children, attitudes and facial disfigurement) and provided a structure for the search. The search terms used for each database are listed in Appendix B.

Searching other resources

The references of publications which fulfilled the inclusion criteria were scanned to identify any additional papers relevant to this review which were not identified by the original electronic search.

Data Collection and Analysis

The titles and abstracts of papers were screened according to the inclusion and exclusion criteria to determine suitability. A flow diagram was completed simultaneously to record attrition and reasons for exclusion. Data was extracted from each paper which met the inclusion criteria using a data extraction form (Appendix C) which was adapted from the guidelines which informed this review (Higgins & Green, 2011; CRD, 2009).

Results

A total of 905 publications were retrieved following a systematic search of three electronic databases. Following review of the titles, 844 papers were removed and a further 39 following review of the abstracts. The full text articles were sourced for the remaining 22 papers, of which 14 met the inclusion criteria. A hand search of the reference lists of these papers was completed and resulted in the inclusion of two additional papers. A total of 16 papers were included in the final review. Figure 1 summarises the process of attrition of search results in a flow diagram. Table 2 summarises the characteristics of studies included in this review.

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│ Title and abstracts retrieved following electronic search │
│                    N = 925                       │
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│ Papers remaining after duplicates were removed   │
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                 │        Papers excluded N = 844           │
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                 │ Medical treatment/management N = 382     │
                 │   Unrelated to topic N = 244             │
                 │   Other medical conditions N = 92        │
                 │   Psychological adjustment N = 73        │
                 │      Mental health N = 51                │
                 │       Non-human N = 2                    │
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                 │         Papers excluded N = 39           │
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                 │     Adult population N = 15              │
                 │     Unrelated to topic N = 9             │
                 │      Self-perception N = 8               │
                 │   Psychological adjustment N = 7         │
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│  Full text retrieved and assessed for eligibility │
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                 │          Papers excluded N = 8           │
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                 │        Missing data N = 3                │
                 │        Intervention N = 2                │
                 │       Adult population N = 1             │
                 │        Review paper N = 1                │
                 │ Attitudes towards dental abnormality/post-surgery │
                 │                  N = 1                   │
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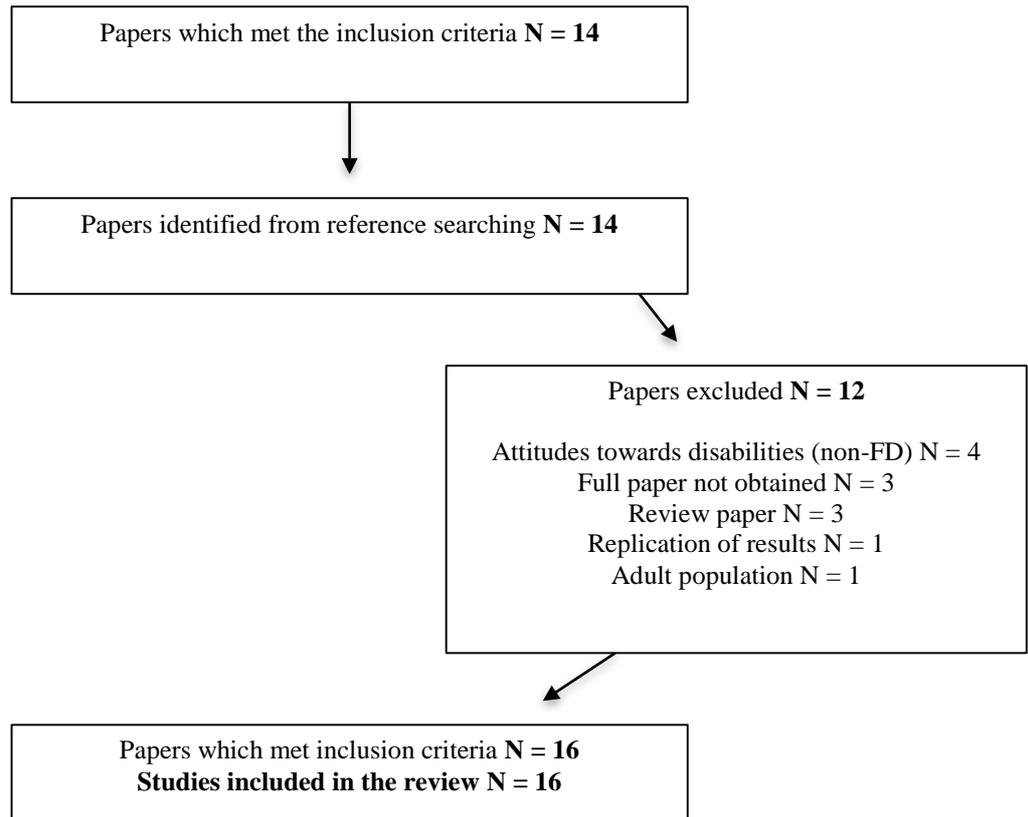
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│     Papers which met the inclusion criteria **N = 14**      │
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│   Papers identified from reference searching **N = 14**     │
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                    │       Papers excluded **N = 12**         │
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                    │ Attitudes towards disabilities (non-FD) N = 4 │
                    │     Full paper not obtained N = 3        │
                    │         Review paper N = 3               │
                    │     Replication of results N = 1         │
                    │       Adult population N = 1             │
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│    Papers which met inclusion criteria **N = 16**           │
│       **Studies included in the review N = 16**             │
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Figure 1. Flow chart of attrition following systematic search.

Table 1

Characteristics of Studies Included in This Review

Study	N	Age (category[1], *range in years*)	Country	Stimuli[2]	Type of FD	Comparators	Outcome measure	Outcome measure categorisation[3]	Confounding Variables	Results
Crystal, Watanabe, & San Chen (2000)	431	L and A *10-17*	USA and Japan	D	Scar	No VFD	Open ended question about participant's willingness to interact with child with a VFD	A	Age Nationality	Japanese students were more accepting of a child with a VFD Younger children were more accepting and showed greater empathy towards a child with a VFD
Darrow & Johnson (1994)	699	N	USA	N	Scar	Heart condition Physical deformity Deafness Blindness Amputation Cancer Paralysis AIDS Epilepsy	DFS[4]	C	Age Gender	Participants were more accepting of children with a visible scar compared to children with other physical conditions. Females were significantly more accepting of children with a visible scar compared to males.

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[1] Participant's mean age was categorised according to Piaget's cognitive stages; M = middle childhood (ages 4-7), L = late childhood (ages 8-11), A = adolescence (ages 12-18) and N where mean age was not given.

[2] Stimuli categorised as D = Line drawing, P= photograph, V= video, and N = none used

[3] Outcome measures categorised as A = affective, B = behavioural and C = cognitive

[4] Disability Factor Scale (Siller, Ferguson, Vann, & Holland, 1967)

Study	N		Location		VFD	Comparison	Measure		Moderators	Findings
Demellweek, Humphris, & Hare (1997)	96	L *8-11*	UK	V	Port-wine stain	No VFD	(1) Willingness to interact designed by authors and adapted from CATCH[5] and the IDP[6] (2) Attribution of positive characteristics adapted from Lansdown et al. (1991) (3) Beliefs concerning social interaction	(1) B (2) & (3) C	Age Gender	The presence of a VFD did not impact participant's ratings of attractiveness or willingness to interact. Participants were significantly more likely to believe that a child with a VFD would be teased or stared at.
Harper (1997)	96	N *10-12*	Nepal	D	Cleft-lip	Healthy child Crutch Amputated foot Amputated hand Obese child	Preferential ranking task (preference, willingness to interact)	A, B	Familiarity Gender	Participants viewed a child with a VFD more negatively compared to a healthy child and children with other physical disabilities. Female participants rated children with a VFD as their least preferred child.
Harper & Peterson (2001)	68	L *8-12*	Philippines	D	Cleft-lip	Healthy child Crutch Wheelchair Amputated hand Obese child	Willingness to interact using preferential ranking task	B	Familiarity	Participants were less willing to interact with a child with a VFD compared to children with other disabilities and a healthy child.
Johnson & Darrow (2003)	229	N	USA and Italy	N	Scar	Heart condition Physical deformity Deafness Blindness Amputation Cancer Paralysis AIDS Epilepsy	DFS	C	Gender Nationality	Participants were more accepting of children with a visible scar compared to children with other physical conditions.
Koroni et al., (2009)	1861	L *10-11*	Greece	D	Scar	Healthy child Crutch Wheelchair Amputated hand Obese child	Preferential ranking task	A	Gender	Participants showed a preference for the healthy child over a child with a VFD and other disabilities. Girls ranked the VFD figure significantly lower than boys.

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[5] Chedoke-McMaster Attitudes Towards Children with Handicaps scale (Rosenbaum, Armstrong, & King, 1986)
[6] Interactions with Disabled Persons scale (Gething, 1991)

Masnari, Schiestl, Weibel, Wuttke, & Landolt (2013)	344	A *8-17*	Switzerland	P	Burn scars, infantile haemangioma, port wine stain, congenital melanocytic nevi	No VFD	(1) Semantic differential scale adapted from previous studies (Edwards et al., 2011; Schneiderman & Harding, 1984) (2) Willingness to interact questionnaire, based on previous studies (Demellweek et al., 1997; Nabors et al., 2004) (3) Hostile behaviour subscale of PSQ[7]	(1) C (2) B	Age Experience of hostile behaviour Familiarity Gender	Participants rated children with a VFD as less likeable, attractive and happy and were less willing to interact or befriend the child.
Nabors & Keyes (1997)	99	M *2 - 6*	USA	D	Scar	Healthy child Wheelchair Leg brace	Preferential ranking task	B	-	Participants showed a preference towards the healthy child across contexts. Children ranked child with VFD higher in playground play preference compared to child with a physical disability.
Nabors, Lehmkuhl, & Warm (2004)	228	M *5-9*	USA	D	Scar	No VFD	Acceptance rating scale using a 4-point Likert scale	A	Age Ethnicity Familiarity Gender Scripts	Participants were significantly more accepting of children without a facial scar. Providing positive information about a child with a VFD improves acceptance ratings
Reed et al., (1999)	92	L *7-10*	UK	P	Cleft-lip and misshapen nose	No VFD	(1) Social distance scale designed by authors (2) Social behaviour questionnaire designed by authors	(1) & (2) B		Participants showed no differences in their willingness to interact with a child with or without a VFD.
Richardson (1970)	1,043	N *5-18*	USA	D	Cleft-lip	Healthy child Crutch Wheelchair Amputated hand Obese child	Preferential ranking task	A	Age	Participants viewed a child with a VFD more negatively compared to children with other physical disabilities and a healthy child.
Schneiderman & Harding (1984)	78	N *7-10*	USA	P	Cleft-lip (bilateral and unilateral)	No VFD	Rating scale using 15 bipolar adjectives	C	Age Gender	Participants viewed children with a cleft-lip more negatively than a child without a VFD.

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[7] Perceived Stigmatization Questionnaire (Lawrence, Rosenberg, Rimmer, Thombs, & Fauerbach, 2010)

Sigelman, Miller, & Whitworth (1986)	119	M *4-8*	USA	D	Deformed cheek	Healthy/white child Wheelchair Obese child Black child Opposite sex Glasses	(1) Open ended question ("*Tell me what you think this kid is like*") (2) Trait description task adapted from Lerner and Schroeder (1975) (3) Preferential ranking task	(1) C (2) & (3) A	Age Gender	Participants were more likely to negative evaluate a child with a VFD (46.2%) compared to a child with a physical disability (12%). Participants rated the child with a VFD amongst their least preferred in the free and forced choice tasks. Younger children showed a greater preference towards the child with a VFD in the forced choice task.
Tobiasen (1987)	307	N *8-16*	USA	P	Cleft-lip	No VFD	Trait description task using 9-point Likert scale	C	Age Gender (of participant and stimulus)	Participants attributed significantly less positive personality and behavioural traits to children with a VFD.
Veeneman, Rohan, & Nabors (2014)	273	A *10-14*	USA	D	Scar	No VFD	(1) Acceptance (2) Willingness to interact (3) Willingness to help	(1) A (2) & (3) B	Gender	Participants were accepting of children with a VFD and reported a greater willingness to help a child with a VFD compared to a child without a VFD.

Description of Studies

The papers included in this review were published between 1970 and 2014. Publications in the last 10 years have been sparse, with only three papers published in the last decade (Koroni, Garagouni-Areou, Roussi-Vergou, Zafiropoulou, & Piperakis, 2009; Masnari, Schiestl, Weibel, Wuttke, & Landolt, 2013; Veeneman, Rohan, & Nabors, 2014). No papers have been published in the UK since 1999 (Reed et al., 1999).

Description of sample

Country of origin

Ten studies recruited participants from the USA (Crystal, Watanabe, & Chen, 2000; Darrow & Johnson, 1994; Johnson & Darrow, 2003; Nabors & Keyes, 1997; Nabors, Lehmkuhl, & Warm, 2004; Richardson, 1970; Schneiderman & Harding, 1984; Sigelman, Miller, & Whitworth, 1986; Tobiasen, 1987; Veeneman et al., 2014). Two of these compared the attitudes of American children with children from Italy (Johnson & Darrow, 2003) and Japan (Crystal et al., 2000). Harper and his colleagues recruited participants from Nepal (Harper, 1997) and the Philippines (Harper & Peterson, 2001). Two studies were from the UK (Demellweek, Humphris, & Hare, 1997; Reed et al., 1999) and the remaining two were from Greece (Kornoni et al., 2009) and Switzerland (Masnari et al., 2013). Given that the vast majority of studies were completed on populations outside of the UK the extent to which the results can be used to increase our understanding of children's attitudes towards VFDs in the UK is limited.

Sample size

The sample sizes used in these studies ranged from 68 (Harper &
Peterson, 2001) to 1861 (Koroni et al., 2009), with the average sample consisting
of 379 participants. Only one study (Reed et al., 1999) made reference to power
and reported that a further 53 participants (to the existing sample of 92) were
required to achieve adequate statistical power. Where specified, sample response
rates were high (100% Demellweek et al., 1997; 87% Harper & Peterson, 2001;
68.11% Masnari et al., 2013).

Age

The age of participants ranged from 2 to 18 years. Richardson (1970)
used the widest age range including children between the ages of 5 and 18.
Narrow samples, defined as an age range of less than 3 years, were used in four
studies (Demellweek et al., 1997; Harper, 1997; Kornoni et al., 2009;
Schneiderman & Harding, 1986). Two studies did not provide specific
information on the age of participants who were described as junior (Johnson &
Darrow, 2003) and senior high school students (Darrow & Johnson, 1994). Data
on mean age was provided in nine studies. Three focused on attitudes towards
VFDs in middle childhood (Nabors et al., 2004; Nabors & Keyes, 1997;
Sigelman et al., 1986), four in late childhood (Demellweek et al., 1997; Harper &
Peterson, 2001; Koroni et al., 2009; Reed et al., 1999) and two in adolescence
(Masnari et al., 2013; Veeneman et al., 2014).

Ethnicity

Reference to the ethnicity of participants was made in seven studies. Four studies conducted in the USA and UK provided exact details of participant ethnicity and were notably less representative of non-Caucasian ethnic minorities. The percentage of participants from ethnic minorities in each sample was 0% (Reed et al., 1999), 16% (Veeneman et al., 2014), 17% (Nabors & Keyes, 1997) and 33% (Nabors et al., 2004). The remaining three studies failed to provide data on the ethnicity of the sample, and descriptions were, at best, vague e.g., "*predominately white*" (Demellweek et al., 1997; Sigelman et al., 1986; Tobiasen, 1987).

Socio-economic status (SES)

None of the 16 studies included in this review provided data on the SES of participants. Again any reference made was vague and descriptive e.g., "*school situated in an economically deprived area*" (Demellweek et al., 1997). Based on the author's interpretation of the descriptions given, samples from two studies were categorised as low SES (Demellweek et al., 1997; Reed et al., 1999), three as high SES (Richardson, 1970; Sigelman et al., 1986; Tobiasen, 1987) and two from mixed SES backgrounds (Crystal et al., 2000; Koroni et al., 2009).

Recruitment

All participants were recruited from schools. The number of schools used to recruit participants ranged from one (Demellweek et al., 1997; Harper & Peterson, 2001; Sigelman et al., 1986) to 45 (Koroni et al., 2009). Ten studies

recruited children from public schools (Crystal et al., 2000; Demellweek et al., 1997; Harper & Peterson, 2001; Koroni et al., 2009; Masnari et al., 2013; Nabors & Keyes, 1997; Reed et al., 1999; Richardson, 1970; Schneiderman & Harding, 1984; Tobiasen, 1987), one from a private school (Sigelman et al., 1986) and the remaining four from a combination of the two (Harper, 1997; Johnson & Darrow, 2003; Nabors et al., 2004; Veeneman et al., 2014). It was anticipated that studies which recruited participants from both public and private schools would have more diverse samples and therefore the results of these studies were expected to have greater generalisability. For example, Harper (1997) recruited participants from six schools across both city and rural areas of Nepal.

Description of stimulus

Line drawings and photographs were the most common way of presenting the stimulus image and were used in 12 of the 16 studies. Only one study used a live stimulus and presented the child with a VFD in a short video clip (Demellweek et al., 1997). Two studies did not use any visual stimuli and instead participants were provided with a written description of the illness or condition (Darrow & Johnson, 1994; Johnson & Darrow, 2003).

Description of study designs

Three studies used between-subject designs (Nabors et al., 2004; Reed et al., 1999; Veeneman et al., 2014), where participants were randomly allocated to independent groups. Unfortunately information on the process of random allocation or homogeneity between groups was not provided and therefore the risk of bias is unclear. Two studies stated that their samples were randomly

selected however, again, explicit details were not provided (Crystal et al., 2000; Sigelman et al., 1986). Overall the studies in this review provided poor and inadequate detail of the recruitment process and therefore assessment of the risk of bias in sampling is limited.

Description of methods of measurement

Evaluative measures have been categorised according to the classification scheme used in Nowicki and Sanderson's (2010) meta-analysis of children's attitudes towards disabilities. Measures are coded as either affective 'A' (a measure of how participants feel towards the object), behavioural 'B' (behaviours directed at the object or an intention to behave in a particular manner) or cognitive 'C' (the beliefs, thoughts and attributes associated with the object). Studies involving more than one measure were assigned multiple categories.

Likert scales are one of the most common tools to measure outcomes in the paediatric population (Chambers & Johnston, 2002) and were used in nine studies (Darrow & Johnson, 1994; Demellweek et al., 1997; Johnson & Darrow, 2003; Masnari et al., 2013; Nabors et al., 2004; Reed et al., 1999; Schneiderman & Harding, 1986; Tobiasen, 1987; Veeneman et al., 2014). Despite their relative ease to complete (Laaerhoven, van der Zaag-Looren, & Derkx, 2004), the use of Likert scales in studies involving young children has been criticised. Young children's dichotomous thinking styles influence their tendency to endorse either extreme end of the scale (Chambers & Craig, 1998; Chambers & Johnston, 2002; Gelman & Baillargeon, 1983). Children are also more likely to have difficulties

responding to Likert scales which use a number format (Mellor & Moore, 2013), as was the case in the majority of studies used here.

The lack of any direct measures of behaviour reduces the quality of evidence provided by these studies. As such the evidence is at risk of bias as it relies solely on the self-reported attitudes of children (Dovidio, Kawakama, Johnson, Johnson, & Howard, 1997; Hewstone, Rubin, & Willis, 2002). None of the studies included here have measured the implicit attitudes of children, those which are not consciously available (Granfield, Thompson, & Turpin, 2005), as has been done in the adult literature through direct observation or confederate based tasks. Without this evidence it is difficult to infer the extent to which the self-reported attitudes of children translate into real life behaviour. This is particularly significant in light of recent criticism of the theory of planned behaviour (Ajzen, 1985) which suggests that the majority of the variability in observed behaviour is not accounted for by the factors considered by this model (attitudes, subjective norms, perceived behavioural control and behavioural intention) (Sniehotta, Presseau, & Araujo-Soares, 2014).

How are VFDs Viewed by Non-Disfigured Children?

The majority of studies included in this review support the notion that non-disfigured children display negative attitudes towards individuals with a VFD. Ten studies reported that children showed a negative bias towards individuals with a VFD (Harper, 1997; Harper & Peterson, 2001; Koroni et al., 2009; Masnari et al., 2013; Nabors & Keyes, 1997; Nabors et al., 2004; Richardson, 1970; Schneiderman & Harding, 1984; Sigelman et al., 1986; Tobiasen, 1987). Conflicting findings were reported in four studies which

indicated that the attitudes of non-disfigured children towards VFDs were positive or neutral (Darrow & Johnson, 1994; Johnson & Darrow, 2003; Reed et al., 1999; Veeneman et al., 2014). The remaining two studies reported mixed findings (Crystal et al., 2000; Demellweek et al., 1997).

Negative attitudes

All 10 studies reporting negative attitudes used forced-choice tasks where participants were asked to indicate a preference for one or more stimulus image. Non-disfigured children were less accepting of individuals with a VFD (Nabors et al., 2004), rated them as less popular, attractive and happy, and were significantly less willing to interact with them compared to a child without a VFD (Masnari et al., 2013; Schneiderman & Harding, 1984; Sigelman et al., 1986; Tobiasen, 1987). Participants also believed that children with a VFD were more likely to be stared at and experience teasing compared to their non-disfigured peers (Demellweek et al., 1997). In preferential ranking tasks, children consistently ranked the healthy child as their most preferred playmate (Harper & Peterson, 2001; Harper, 1997; Koroni et al., 2009; Nabors & Keyes, 1997; Richardson, 1970). Evidence of a negative bias was also shown in one study which incorporated a forced-choice, free-choice and open-ended task (Sigelman et al., 1986). Results suggested that non-disfigured children were more likely to negatively evaluate a child with a VFD (46.2%) compared to a child with a physical disability (12%).

In seven studies participants were presented with a line drawing depicting the stimulus child (Harper, 1997; Harper & Peterson, 2001; Koroni et al., 2009; Nabors & Keyes, 1997; Nabors et al., 2004; Richardson, 1970; Sigelman et al.,

1986). Whilst the use of line drawings has allowed researchers to control for physical characteristics which may confound results (e.g., attractiveness, hair colour, race), their simplicity and lack of ecological validity limits the extent to which results can be generalised. This was highlighted by one study where 42% of children failed the manipulation check which assessed the child's understanding of the disability depicted in the line drawing (Nabors & Keyes, 1997).

The limitations associated with line drawings were overcome in four studies which used photographs (Masnari et al., 2013; Schneiderman & Harding, 1984; Tobiasen, 1987) or videos (Demellweek et al., 1997) to depict an individual with a VFD. Photographs were verified by professionals in two studies which increased the ecological validity further (Masnari et al., 2013; Tobiasen, 1987). The use of multiple stimulus images depicting a range of ages (boy, girl and baby) and VFDs in one study also allowed for greater generalisation of results thus increasing the validity further (Masnari et al., 2013).

Only one study presented an interactive 3D stimulus of a child with a VFD (Demellweek et al., 1997). In this study, a counterfeit port wine stain was created using make up and the stimulus child was shown in a short video clip smiling and giving their name. The ecological validity of this study is therefore considered to be higher in contrast to studies which have used a non-interactive 2D stimulus.

Results will be privileged when drawing conclusions in studies where real life images have been used and validation checks were completed as these are judged the most reliable and valid (Demellweek et al., 1997; Masnari et al.,

2013; Schneiderman & Harding, 1984; Tobiasen, 1987). The results of these studies indicate that non-disfigured children show a preference for children without a VFD and are less accepting and willing to interact with a disfigured child as a result.

Positive attitudes

In four studies using forced-choice tasks participants were more accepting (Darrow & Johnson, 1994; Johnson & Darrow, 2003) and reported a greater willingness to interact with children with a VFD (Reed et al., 1999; Veeneman et al., 2014). Results also suggested that the presence of a VFD did not result in significantly lower ratings of attractiveness (Demellweek et al., 1997).

The results from three of these studies are downgraded due to clear risks to validity caused by the type of stimulus used. As above, studies which use line drawings and fail to include validation checks are excluded (Veeneman et al., 2014). Two studies did not use any visual stimuli and instead participants were provided with a written description of the illness or condition (Darrow & Johnson, 1994; Johnson & Darrow, 2003). The validity of these results is therefore judged to be poor given probable variation in the participants' conceptualisation of a VFD (e.g., in terms of the degree of severity and permanency) and consequently there is no real sense of what participants are rating here.

One study (Reed et al., 1999) used measures that have also been heavily criticised for poor ecological and predictive validity. The social distance scale and social behaviour questionnaire developed by Reed and colleagues has been

criticised for its use with young children of poor SES. The social distance scale required children to place figures representing themselves, their best friend and a child with a VFD on a 2D pictorial plan of a playground and classroom. Its use in younger children has been criticised given the perquisite knowledge of scaling transformations and the ability to conceptualise a bird's eye view (Hayduck, 1978). Moreover no validation measure was used to ensure the task was fully understood by participants.

Results from the social behaviour questionnaire may also be confounded by participant's enthusiasm to engage in activities presented by the measure (e.g., attending a party) which may take precedence over their underlying attitudes towards the stimulus child, particularly given the SES of the children used in this study. Similar contexts were used by Veeneman et al. (2014) who asked children to rate their willingness to go to a party or the cinema with the stimulus child. Whilst the SES of participants was not stated in this study, it is possible that results are confounded as above.

Given the lack of reliability and validity of the measures designed and used by Reed and colleagues, the quality of the results is viewed as poor. Further both Reed et al. (1999) and Veeneman et al. (2014) used between-subject designs and failed to provide data on the demographic characteristics of the two groups. The ability to interpret these results is therefore limited given possible heterogeneity between groups.

Conclusion

Despite inconsistencies in findings and possible error variance due to methodological problems, the weight of the evidence indicates that non-

disfigured children display a negative bias towards individuals with a VFD and consistently show a preference for healthy non-disfigured children. This finding is in line with the assumption that living with a disfigured appearance will have a negative impact on the individual's social experiences. Although some studies reported that non-disfigured children have positive or neutral attitudes towards individuals with a VFD, these studies are methodologically weaker and therefore fail to pose a strong challenge to an assumption of negative bias.

What Factors Influence Attitudes Towards Individuals With a VFD?

Age

The influence of the participant's age was considered in eleven studies. Six studies reported that age was a significant predictor (Crystal et al., 2000; Masnari et al., 2013; Nabors & Keyes, 1997; Schneiderman & Harding, 1984; Sigelman et al., 1986; Richardson, 1970).

Two studies reported that older children (aged 17 and 10 respectively) were more accepting of individuals with a VFD (Masnari et al., 2013; Schneiderman & Harding, 1984) compared to younger children (aged 8 and 7 respectively). Although significant differences were observed between participants in grade two and four on five variables (interesting/boring, strong/weak, funny/boring, brave/frightened, smart/stupid), no differences were reported between participants in grades three and four on any of the 15 variables (Schneiderman & Harding, 1984). Additionally age alone failed to account for a large percentage of the variance in the findings (<10%, Masnari et al., 2013). Unfortunately it is difficult to draw strong conclusions from the available evidence given the variability in the samples used, including country of origin

(Switzerland vs. USA) and time of publication (a difference of 29 years), and inconsistencies in the data.

Conflicting findings were reported in four studies which found that younger children were more accepting of individuals with a VFD (Crystal et al., 2000; Nabors & Keyes, 1997; Richardson, 1970; Sigelman et al., 1986). In contradiction to Masnari et al. (2013), Crystal et al. (2000) reported that children aged 10 were more accepting of individuals with a VFD compared to older children aged 16. These studies did however differ in their methodology (quantitative vs. qualitative), which may in part explain these contradictions.

A similar ranking task was used in three studies which reported that younger children (aged 6 and below) were more accepting of individuals with a VFD (Nabors & Keyes, 1997; Sigelman et al., 1986; Richardson, 1970). However results were not consistent across ages or tasks (Sigelman et al., 1986). No significant differences were reported amongst the younger children in the sample (between children aged 4 and 5 or 5 and 6) or in the remaining two tasks (open-ended or free-choice evaluation). All three studies used line drawings and failed to incorporate validation checks to ensure that the task was fully understood. The reliability and validity of these results is therefore lessened.

The trend for older children to display more discriminative attitudes towards children with a VFD is supported by an increase in preoccupation with appearance (both one's own and others) in adolescence (Brown & Witherspoon, 2002; Holmbeck, 2002; Prokhorov, Perry, Kelder, & Klepp, 1993). Whilst this hypothesis supports the trend for younger children to express more positive attitudes (Crystal et al., 2000; Richardson, 1970), it fails to account for findings

which report prejudice attitudes towards VFD in pre-pubertal children (Masnari et al., 2013; Schneiderman & Harding, 1984).

Evidence on the impact of age on attitudes towards VFD is weak. Findings between studies and tasks within a single study have been inconsistent. Although these preliminary findings suggest an effect of age on attitudes, which fits with the existing literature, the direction of this trend is not clear.

Gender

The impact of the participant's gender on attitudes towards VFDs was considered in 14 studies with nine studies reporting significant findings (Darrow & Johnson, 1994; Harper, 1997; Koroni et al., 2009; Nabors & Keyes, 1997; Nabors et al., 2004; Richardson, 1970; Schneiderman & Harding, 1984; Tobiasen, 1987; Veeneman et al., 2014). A significant main effect of gender was reported by Tobiasen (1987), however findings were not explored in detail as the author felt they were not relevant to the aims of the study. All studies reporting significant findings used samples with a comparable number of males and females (% of males in the sample ranged from 42.5 to 52.2). No gender effects were found in the remaining five studies (Demellweek et al., 1997; Johnson & Darrow, 2003; Masnari et al., 2013; Reed et al., 1999; Sigelman et al., 1986).

Four studies reported that girls were more accepting of individuals with a VFD (Darrow & Johnson, 1994; Nabors et al., 2004; Schneiderman & Harding, 1984; Veeneman et al., 2014). One study also reported that girls were more accepting overall regardless of the presence of a VFD (Veeneman et al., 2014). Effect sizes were however small (Cohen, 1988) e.g., 0.24 (Nabors et al., 2004), and findings were not consistently replicated across variables e.g., a significant

effect of gender was only found on one (like/hate) of the 15 variables used (Schneiderman & Harding, 1984).

The notion that females are more accepting of difference is replicated outside of the literature on VFDs. Research suggests that girls are more accepting of children who are overweight (Bell & Morgan, 2000), physically unwell (Rosenbaum, Armstrong & King, 1988) and/or have a physical or intellectual disability (Nowicki & Sandieson, 2002). These findings have been understood in line with traditional female stereotypes in which women are viewed as more sensitive, nurturing, caring (Zahn-Waxler & Smith, 1992) and empathetic (Mestre, Samper, Frias, & Tur, 2009) than their male counterparts.

Three studies (Harper, 1997; Koroni et al., 2009; Richardson, 1970) compared attitudes towards children with a range of physical disabilities. These studies have consistently found that boys show a preference for cosmetic differences (e.g., a child with a VFD) over functional impairments (e.g., a child in a wheelchair or a child with a crutch). These findings are supported by a sociocultural perspective where girls are believed to place greater value on appearance and therefore display discriminative attitudes towards those who don't conform to social norms (Borzekowski, Robinson, & Killen, 2000; Jackson, 1992). Interestingly this concept, which is assumed to be prominent within Westernised cultures, has also been replicated in studies published in the developing world (Harper, 1997). Contradictory findings were reported in two studies using similar preferential ranking tasks (Harper & Peterson, 2001; Nabors & Keyes, 1997).

One study also reported that attitudes were highly moderated by the gender of the interviewer. Sigelman et al. (1986) reported that girls expressed

more discriminative attitudes when interviewed by a male researcher compared to boys. No gender differences were found when participants were interviewed by a female researcher. These findings may imply that girls are more influenced by social desirability bias when interviewed by a same-sex researcher. If founded, the risk of bias in later studies (Harper & Peterson, 2001; Nabors et al., 2004; Nabors & Keyes, 1997), which fail to consider the impact of the gender of the interviewer, is high.

Three studies reported a same-sex bias where participants displayed a preference for a child of the same sex regardless of the presence of a VFD (Demellweek et al., 1997; Reed et al., 1999; Schneiderman & Harding, 1984). These results may suggest that children's attitudes are influenced more so by the gender of the stimulus child than their appearance. Studies which fail to consider the impact of same-sex bias are consequently at risk of bias.

Nationality and ethnicity

Two studies compared attitudes towards children with a VFD in participants from different nationalities with mixed findings (Crystal et al., 2000; Johnson & Darrow, 2003). No significant differences were found between the attitudes of children from the USA and Italy who both rated children with a visible scar positively (Johnston & Darrow, 2003). However it is not clear how culturally similar or different these groups were and what impact this might have on their attitudes towards appearance.

Significant differences were reported between children from America and Japan (Crystal et al., 2000). Findings suggested that children from America held

more discriminative attitudes towards children with a VFD and were less accepting of them.

One study reported findings based on the ethnicity of participants recruited from elementary schools in America. Nabors et al. (2004) found no significant differences between the attitudes of children who were described as Caucasian, African American, Asian, Hispanic or Indian.

Overall few studies included participants from ethnic minority backgrounds. Given that attitudes are influenced by social context, there continues to be little information about the relative influence of national, cultural or ethnic grouping on attitudes towards VFD.

SES

Participants from low SES backgrounds expressed positive attitudes towards children with a VFD. These children were more willing to engage with a child with a VFD (Reed et al., 1999) and did not rate them as any less attractive (Demellweek et al., 1997). In line with this, children from high SES backgrounds were more likely to display negative and discriminative attitudes towards children with a VFD, rating them as their least preferred child (Richardson, 1970; Tobiasen, 1987) and voicing more negative evaluations about the child (Sigelman et al., 1986).

Familiarity

Familiarity was considered in four studies (Harper & Peterson, 2001; Masnari et al., 2013; Nabors et al., 2004; Reed et al., 1999). Three studies found no effects of familiarity (Harper & Peterson, 2001; Nabors et al., 2004; Reed et

al., 1999). This is supported by findings in the existing literature (Langlois et al., 2000) where children's ratings of attractiveness were not influenced by familiarity (which ranged from brief to extensive interaction e.g., parent-child relationships).

Only one study reported a significant effect of familiarity with children who reported knowing someone with a VFD (85% of the sample) expressing more favourable attitudes and a greater willingness to interact with the stimulus child (Masnari et al., 2013). These mixed findings may be explained by ambiguity in measures of familiarity which ranged from previous sightings (Nabors et al., 2004; Reed et al., 1999) to knowing someone with a VFD (Masnari et al., 2013).

Type of VFD

Two studies explored the effects of severity and permanency of a VFD on children's attitudes. Findings suggested that children with a severe VFD (bilateral cleft-lip) were viewed more negatively than children with a less severe VFD (unilateral cleft-lip) on seven of 15 adjective subscales; clean/dirty, friendly/mean, funny/boring, strong/weak, brave/frightened, fast/slow and happy/sad (Schneiderman & Harding, 1984). These findings were not consistent and no significant differences were reported on the remaining eight subscales, which included beautiful/ugly, good/bad and like/hate. Unlike severity, the permanency of the VFD did not influence children's attitudes (Nabors et al., 2004).

Other

Two studies also considered the influence of positive scripts and previous experiences of hostile behaviour. Nabors et al. (2004) reported that attitudes improved when positive information about the child's skills and abilities were provided. The effect size was, however, modest (Cohen, 1988). Previous experience of hostile behaviour was found to be a significant factor influencing attitudes. Participants who reported experiencing hostile behaviour in the past were less willing to interact with, or befriend a child with a VFD (Masnari et al., 2013).

The setting in which tasks were completed may also impact results. Seven studies were completed in a classroom setting or with a parent present (Crystal et al., 2000; Demellweek et al., 1997; Harper & Peterson, 2001; Koroni et al., 2009; Masnari et al., 2013; Schneiderman & Harding, 1984; Tobiasen, 1987). The presence of others may have impacted the participant's ability to provide an honest and un-biased response. For example Schneiderman and Harding (1984) stated that children were heard laughing and name calling in response to a stimulus image showed in a classroom setting.

Conclusion

Eleven confounding variables were considered in this review. The findings were largely inconsistent and therefore, although variables such as age, gender and social context appear to influence children's attitudes towards VFDs, the direction of these trends is unclear. Further research is required to explore these variables further.

Discussion

Summary of Main Results and Review of the Quality of Evidence

Despite reviewing the literature from the past 44 years, only 16 studies fitted the criteria for this review, and of these only three papers were published in the last 10 years. Many of these studies are therefore quite dated, and unfortunately some of the more recent studies have failed to address the limitations raised by previous research in the field. For example, the most recent study was criticised for its use of line drawings and failure to incorporate validation checks (Venneman et al., 2014).

Overall, the available evidence indicates that non-disfigured children demonstrate a negative bias towards individuals with a VFD. This finding was found on the balance of study quality where studies judged as reliable and valid were privileged. Although there was some evidence that non-disfigured children display positive or neutral attitudes towards children with a VFD, these studies were methodologically weaker and therefore fail to pose a strong challenge to an assumption of negative bias. However given the infancy and overall quality of the research in this area, further methodologically sound studies are required in order to test the rigour of this assumption.

Implications for Research

Participants

Participants were predominately from white middle class backgrounds in the USA. Few studies compared attitudes between participants of different nationalities or explored attitudes between participants of different ethic or

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cultural sub-groups. As a result this review is limited in its ability to consider the effects of social influences (including nationality, ethnicity, culture and SES) on children's attitudes towards VFDs. Further research should recruit children from a range of ethnic and economic backgrounds to allow social influences to be considered as confounding variables and results to be generalised.

Stimuli

Nine studies used line drawings to depict the stimulus child. The use of line drawings has been heavily criticised due to their lack of ecological validity. Further research should use photographs or videos to increase validity.

The majority of studies in this review explored attitudes towards a facial scar, cleft-lip and/or port-wine stain. None of the studies included in this review explored the attitudes of non-disfigured children towards rare and/or severe forms of VFD e.g., epidermolysis bullosa. This should be considered in future research to further our understanding of the impact of familiarity and severity of VFDs on children's attitudes.

Measures

Unlike the adult literature, none of the studies included in this review used indirect measures of attitude e.g., behavioural observation or confederate based tasks. Indirect measures should be used in further research to overcome social desirability bias and increase ecological validity.

Cognitive measures of attitude, particularly semantic differential scales, used appearance-related items (e.g., beautiful/ugly) to measure attitudes towards VFDs (Masnari et al., 2013; Scheneiderman & Harding, 1984). The absence of

non-appearance related items may be indicative of researcher bias, particularly in studies which assume that disfigured children are more likely to experience negative social interactions due to their appearance. In order to gain a more holistic understanding of children's attitudes towards individuals with a VFD, future studies should incorporate non-appearance related items, e.g., humble/arrogant, into their measures.

Two studies explored children's willingness to interact with a child with a VFD according to context e.g., going to a party (Veeneman et al., 2014; Reed et al., 1999). Further studies should explore children's willingness to interact with a facially disfigured child in everyday contexts (e.g., sitting next to child on a bus or working with them in class) given research which suggests that attitudes are influenced by social context (Harper, Wacker, & Cobb, 1986).

Study design

The majority of studies included in this review used quantitative measures which required participants to indicate a preference for one or more stimulus images. The use of forced-choice tasks may therefore have forced participants to form an opinion where one may not have previously existed. For example, Lerner and Schroeder (1975) found no signs of racial prejudice when children were asked open-ended questions, moderate levels in a free-choice evaluation task, and high levels of prejudice on a task which required participants to indicate a preference for a black or white child. The validity of findings based on such measures is therefore limited.

Quantitative measures are likely to fail to fully capture the complexity of children's attitudes towards VFDs. Emerging qualitative evidence suggests that

children (with and without disfigurements) experience a range of conflicting emotions towards individuals with a VFD e.g., sympathy, shock and fear (Stock et al., 2013). These complex emotions are unlikely to be fully captured by quantitative measures designed to assess preference or willingness to interact. Future research should therefore adopt qualitative designs to explore this concept in more depth.

Age was considered as a confounding variable in nine studies which used within-subject designs. Further research should consider collecting longitudinal data to monitor changes in attitudes from early childhood to late adolescence to capture any developmental trends.

Further research should also consider the influence of other confounding variables given the lack of variance explained by those considered in this review (Masnari et al., 2013). For example, future studies could consider the meaning that participants assign to the image of a VFD. As highlighted by the use of the DFS (Darrow & Johnson, 1994; Johnson & Darrow, 2003) there may be variation in children's conceptualisation of the stimulus presented to them. For example children may rate a facial scar, which is viewed as temporary and the result of a childhood accident, more favourably than a port-wine stain which is viewed as permanent and contagious. The importance of considering causality has been highlighted in the adult literature which reported that university students demonstrate similar displays of disgust emotions and behavioural avoidance towards individuals with a port-wine stain and individuals with influenza (Ryan, Oaten, Stevenson, & Case, 2012).

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Part 2: Empirical Paper

Social Rejection in Adolescents With a Visible Facial
Disfigurement: A Qualitative Study

Abstract

Aims. This study aimed to use qualitative methodology to understand the lived experiences of young people with a visible facial disfigurement (VFD), specifically focusing on their peer relationships and experiences of social rejection relating to their appearance.

Method. Semi-structured interviews were completed with 10 adolescents with a congenital VFD. Responses were transcribed and analysed using inductive thematic analysis to identify key themes.

Results. All participants described experiencing negative and unwanted attention from others in response to the way they looked (viewed by others as different) e.g., name-calling, teasing, staring and intrusive questioning. Young people described feeling upset and angry in response to being treated differently by others, and reported a lack of self-confidence as a result of the persistent negative feedback they received. Many tried their best to ignore the negative reactions of others and focus on the things they enjoyed doing. Despite the challenges of living with a VFD, many young people valued being different and saw their VFD as a part of who they were. Several young people reported receiving positive messages from their parents as they were growing up which celebrated their unique appearance and helped shape their perspective on looking different. In spite of this, the majority of young people did not wish to have a VFD for the rest of their lives and worried about the impact their appearance would have in

the wider context of their lives (e.g., work and intimate relationships) as they got older.

Conclusions. Young people's accounts of their experiences of living with a VFD have provided a unique insight into the complexity and subtleties of difficult social experiences in this population, which have yet to be acknowledged in previous studies. Young people were actively engaged in making sense of their experiences which enabled them to maintain a positive sense of self despite the challenges they faced as a result of looking different. However this was not always possible and there was a degree of fragility in young people's acceptance of their VFD, particularly at times of transition. These findings suggest the need for future research in line with a developmental multi-factorial model to further understand the relationship between VFDs, social rejection and psychological adjustment.

Introduction

The face plays an important role in our identity, social interaction and communication (Macgregor, 1979). Its visibility and central position mean that it is one of the most noticeable physical attributes of the human body and as a result, is hard to conceal. Approximately one in 500 children in the UK have a visible facial disfigurement (VFD) (Office of Population Censuses and Surveys, 1993). Causes are diverse and include congenital conditions (e.g., cleft-lip, birthmarks) or those acquired as a result of trauma (e.g., burns, scars), disease (e.g., eczema, cancer) or medical intervention (e.g., surgery, radiotherapy) (Rumsey & Harcourt, 2005).

Existing literature has highlighted the heterogeneity of this population both in terms of variability between VFDs (type, severity, permanence and treatment; Kish & Lansdown, 2002) and the individual's adjustment or experience of living with a disfigured appearance. Research has historically adopted a problem-focused stance and focused on psychopathology and the challenges that the researchers assume are experienced by this population. However, recent research has begun to explore the experiences of young people who adjust positively to living with a VFD (Egan, Harcourt, & Rumsey, 2011; Eiserman, 2001). What is now known, based on existing literature, is that whilst some young people with VFDs report high levels of psychological distress and poor quality of life (Horn & Tidman, 2002; Kent & Thompson, 2002; Millard & Richman, 2001; Papadopoulos, Walker, Aitken, & Bor, 2000; Rumsey, Clarke, & Musa, 2002; Titman, 2001), some young people adjust relatively well

(Bilboul, Pope, & Snyder, 2006; Cochrane & Slade, 1999; Egan et al., 2011; Feragen, Kvalem, Rumsey, & Borge, 2010; Walters, 1997).

Social Relationships

There is a large body of socio-anthropological, theoretical and empirical literature that supports the notion that young people with VFDs will experience more negative social interactions due to the role that appearance plays in social relationships (e.g., Langlois et al., 2000). In contrast, there is disagreement in the more recent literature on the quality of peer relationships and experiences of social rejection in this population. There is some evidence to suggest that young people with a VFD are more likely to experience social rejection (Broder, Smith, & Strauss, 2001; Carroll & Shute, 2005; Feragen & Borge, 2010; Hunt, Burden, Hepper, Stevenson, & Johnston, 2007; Turner et al., 1997) and describe receiving unwanted attention in the form of staring (Dures, Morris, Gleeson, & Rumsey, 2012), teasing (Gerrard, 1991; Magin, Adams, Heading, Pond, & Smith, 2006; Masnari et al., 2012; Rumsey & Harcourt, 2007; Strauss et al., 2007; Turner, Thomas, Dowell, Rumsey, & Sandy, 1997), and intrusive and unsolicited questions (Lawrence, Rosenberg, Mason, & Fauerbach, 2011; Locker, Jakovic, & Tompson, 2005; Rumsey, 2002a). This increased likelihood is, in part, attributed to evidence of discriminative attitudes displayed by non-disfigured children towards individuals with a VFD. Results from several studies have suggested that children are less accepting (Harper, 1997; Masnari, Schiestl, Weibel, Wuttke, & Landolt, 2013; Nabors, Lehmkuhl, & Warm, 2004; Schneiderman & Harding, 1984; Tobiasen, 1987) and are less willing to interact

with children with a VFD compared to children without a disfigurement (Harper & Peterson, 2001).

Evidence suggests that children in the general population who have poor quality friendships and/or experience social rejection report low self-esteem, and high rates of psychological distress in adulthood (Bagwell, Newcomb, & Bukowski, 1998; Feragen & Borge, 2010; Hunt, Burden, Hepper, Stevenson, & Johnston, 2006; Rubin, Bukowski, & Parker, 1998; Storch, Masia-Warner, & Brassard, 2003; Storch et al., 2004). As in the general population, a relationship has been proposed between experiences of social rejection and psychological adjustment in children with a VFD (Berndt, Hawkins, & Jiao, 1999; Hawker & Boulton, 2000; Liossi, 2003; Newell, 1999; O'Dea, 2006; Rubin et al., 2004).

However whilst it is assumed, by researchers and clinicians alike, that young people with a VFD are more likely to experience social rejection, this has not been empirically proven (Caroll & Shute, 2005; Eaton, 1999). Contrary to reports of a negative bias towards children with VFDs (Masnari et al., 2013; Nabors et al., 2004), there is some evidence that young people with a VFD are viewed positively by non-disfigured children (Darrow & Johnson, 1994; Demellweek, Humphris, & Hare, 1997; Johnson & Darrow, 2003; Reed et al., 1999; Veeneman, Rohan, & Nabors, 2014).

The Importance of Understanding the Link Between Social Relationships and Psychological Adjustment in Young People With VFDs

Much of the research interest in psychological difficulties in this population is based on the assumption that having a disfigured appearance will have a negative impact on the individuals' social experiences, which may negatively influence their psychological adjustment. However, the existing

literature on the experiences of social rejection in young people with a VFD mirrors that of psychological adjustment more generally speaking in young people and reveals a heterogeneous population. What is indicated is that not all young people with a VFD experience social rejection and not all of those who experience social rejection find it upsetting (Rumsey & Harcourt, 2007).

Previous research on psychological adjustment and social relationships in this population has often relied on proxy reports (e.g., parents and teachers; Broader et al., 2001; Hunt et al., 2007; Lawrence et al., 2011; Turner et al., 1997) and simplistic measures of teasing/bullying (e.g., Feragen & Borge, 2010), however few have explored the negative social experiences, and possible experiences of social rejection, from the perspective of the young people themselves.

Current Study

Given evidence of the importance of peer relationships in the general population (Bagwell et al., 1999) and limitations in the existing literature on psychological adjustment and experiences of social rejection in individuals with VFDs (Feragen et al., 2009), this study aims to better understand the lived experiences of young people with a VFD, specifically focusing on peer relationships and experiences of social rejection relating to their appearance. It is hoped that by understanding how young people with a VFD make sense of living with a VFD and possible socially rejecting experiences, it will help us to understand why some young people cope better than others (Crick & Dodge, 1994; Thompson & Kent, 2001). This study will use an adolescent sample of young people aged between 11 and 14, given the importance of physical

appearance (Brown & Witherspoon, 2002; Elkind, 1967; Prokhorov, Perry, Kelder, & Klepp, 1993; Strauss et al., 2007; Turner et al., 1997), and peer relationships (Bagwell et al., 1998; Liossi, 2003) to adjustment in this age group, with a range of congenital VFDs. This study will use a qualitative design in an attempt to capture the range and complexity of issues raised by this population (Cramer, 2000; Yardley, 1997). It is hoped that this approach will also allow the whole child to be captured (including their strengths and difficulties) (Eiserman, 2001), and potentially allow for the identification of factors associated both with difficulties and those that promote the health and well-being of the child (Antonovsky, 1987; Eiserman, 2001).

The current study aims to explore the following research questions:

1. What are young people's experiences of living with a VFD?

2. How do young people with a VFD get on with their peers?

3. How do young people with a VFD make sense of their socially rejecting experiences?

Method

Design

This study adopted a qualitative design in order to explore the lived experiences of young people with a VFD, specifically focusing on their social relationships and possible experiences of, and responses to social rejection relating to their appearance. Data was analysed using inductive thematic analysis (Braun & Clarke, 2006) in order to reflect the reality of young people's experiences of living with a VFD, and to capture the variation in experiences

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across the dataset. This method of analysis was selected over other phenomenological approaches e.g., interpretative phenomenological analysis (IPA), given that few qualitative studies have attempted to understand the social experiences of young people with a VFD and therefore the sophisticated level of interpretation associated with alternative approaches, such as IPA, were deemed unhelpful within such an under-researched area. In addition, given the lack of previous research in this area, a larger sample size was desired which does not lend itself well to IPA.

Recruitment

Participants were recruited from the dermatology outpatient department of a London based hospital using a staged recruitment process. This method of recruitment was recommended by the ethics committee in order to ensure that all young people who expressed an interest in the study were allowed to take part.

Participants who appeared to meet the inclusion criteria based on the information available from the Patient Information Management System (PIMS) were randomly assigned a number. Inclusion criteria were: to be aged between 11 and 14 years; attend secondary school; be fluent in spoken English and have a congenital VFD. Individuals were excluded from the study if they had comorbid conditions, complex syndromes or disabilities (e.g., learning disabilities, Fragile X, chronic pain), were acutely unwell or were unable to understand or communicate in conversational English. This study aimed to recruit between six and 14 participants based on guidelines which suggest that this is an appropriate sample size for small-scale qualitative studies (Braun & Clarke, 2013; Guest, Bunce, & Johnson, 2006).

Procedure

Letters and information sheets (See Appendix D, E and F) were initially sent to the first 14 participants inviting them to take part in the study. Further stages of recruitment were carried out in a stepwise manner until the desired sample size was reached.

Parents were contacted one week after receiving the invitation letter to determine their child's suitability for the study and gain verbal consent where applicable. Eligible participants were invited to attend a pre-interview meeting (approximately 20 minutes) and a formal interview (approximately 40 minutes). The pre-interview meeting was designed to allow the researcher to get to know the young person and build rapport. If participants were unable to attend a pre-interview meeting they were offered an extended formal interview of approximately 60 minutes. Interviews were carried out in a quiet consultation room within the hospital or in the family home, based on the participant's wishes. Participants were interviewed on their own. If requested by the young person, parents were invited to be present during the interview. Written consent (Appendix G) and assent (Appendix H) from the young person was gained immediately before the formal interview.

Ethics

Ethical approval was obtained by the relevant NHS Research Ethics Service Committee on 20th November 2014 (See Appendix I).

Participants

In total, letters were sent to 91 parents of young people inviting them to take part in the study. Twenty-three young people were excluded following telephone contact, as they did not meet the inclusion/exclusion criteria for the study. Young people were excluded due to a comorbid diagnosis e.g., learning disabilities or autism (n=3), not speaking fluent English (n=1) or having a disfigurement away from the face (n=19).

Twenty-eight families did not wish to take part in the study. Many parents expressed their concern about the sensitive nature of the interview (e.g., exploring experiences of being teased or picked on) and worried that the study would draw attention to their child's VFD, and in doing so cause them distress. A number of families were unable to take part as they did not have any upcoming appointments within the timescale of the study, or were already involved in ongoing research projects in connection with the hospital. Fourteen families did not respond to the letter or follow-up telephone call and therefore were unable to take part in the study.

Twenty-six (28.6%) families agreed to take part in the study. Nine (34.6%) families cancelled or did not attend the interview due to ill health, delays caused by travel or preceding appointments, and extenuating circumstances (e.g., family bereavement). Interviews were completed with a total of 17 young people. Data from five participants was not included in the final data set, as the young person's disfigurement was either not visible or away from the face. Unfortunately the information obtained by the researcher during the follow-up telephone call was not adequate enough to exclude these five children prior to the interview. A further two participants were also not included in the final data set

on the grounds that they provided very limited responses (e.g., "*I don't know*", "*not sure*").

The final sample consisted of 10 young people with a mean age of 13 years and 2 months. Participant characteristics are displayed in Table 1. Only one participant chose to attend a pre-interview meeting and complete the interview at home (P3). The youngest two participants included in the sample requested that one of their parents remain present with them during the interview (P4 and P9). Their presence was felt to be complementary as both parents were able to scaffold their child's narrative and in doing so increase the richness and completeness of data, which may not have been possible had the young person been interviewed alone (Irwin & Johnson, 2005).

Table 1

Characteristics of Participants

Participant number	Gender	Age (years.months)	Type of VFD	Location of interview	Parent present
1	Female	12.3	Port-wine stain	Hospital	No
2	Female	13.3	Birthmark	Hospital	No
3	Male	13.11	Eczema	Home	No
4	Male	11.9	Eczema	Hospital	Yes
5	Male	12.5	Eczema	Hospital	No
6	Female	13.0	Port-wine stain	Hospital	No
7	Female	14.3	Birthmark	Hospital	No
8	Female	14.9	Lymphangioma	Hospital	No
9	Male	12.5	Eczema	Hospital	Yes
10	Male	13.9	Warts	Hospital	No

Measures

Each participant was interviewed using a semi-structured interview schedule, which was developed based on research guidelines (Braun & Clarke, 2013; Willig, 2008), existing literature, and in consultation with a clinical psychologist within the dermatological department. The interview schedule was adapted following a pilot study involving three young people with a VFD aged between 9 and 12 years. The decision to use a younger participant, outside of the age range of this study, was intended to ensure that the interview questions were developmentally appropriate for children aged 11 to 14 years with a range of cognitive abilities.

The interview was designed using a funnelling approach to allow the interviewer to develop rapport with the young person before asking questions of increasing sensitivity and complexity (See Appendix J). Participants were initially asked about their experiences of living with a disfigured appearance and the impact it had on their day-to-day lives. Participants were then asked about the value they placed on appearance and their current relationships with their peers in and out of school. Towards the latter half of the interview, participants were asked about any difficult social experiences (e.g., where they had felt teased or left out) and how they had managed these experiences. At the end of the interview, participants were asked about their experience of being interviewed and anything that they had found difficult. The majority of the young people reported that they had found the overall experience positive and did not report or display any distress. One participant became upset during the interview and sought reassurance from his father (P4).

The interview schedule was used to guide the structure of the interview, however the interviewer remained flexible and responded to the natural flow of conversation in order to build rapport and ensure the dialogue reflected the participant's own narrative.

All interviews were audio recorded. Interviews were transcribed verbatim and identifying material was removed. All data was securely stored according to the Data Protection Act (1998).

Analysis

Data was analysed using the six phases of analysis outlined by Braun and Clarke (2006). This entailed (1) familiarisation of the data through the process of transcribing and repeated reading, (2) development of initial codes, (3) organising and grouping of initial codes to generate themes, (4) reviewing and refinement of common themes across the full data set, (5) defining themes and subthemes and, (6) the selection of quotations to illustrate themes to create an overall narrative. The process of analysis was supported by the use of NVivo qualitative data analysis software (QSR International).

In vivo coding (e.g., the use of the participant's own language) was used during phases two and five. This prevented over interpretation by the researcher and ensured that the themes were reflective of participant's own experiences and the explicit meaning they assigned to these experiences (see Appendix K). Low frequency codes (e.g., those only present in one or two transcripts) were not included in the generation of themes (phase three).

As recommended by guidelines for good practice in qualitative research, two formalised validation checks were completed (Barker & Pistrang, 2005;

Elliott, Fisher, & Rennie, 1999; Mays & Pope, 2000). An audit trial was

completed by one of the research supervisors, who has extensive experience

completing qualitative research and in working clinically with adolescents, at

three separate junctures following phases two, four and five. This audit resulted

in slight revisions to the structure and labelling of themes at phase five. Member

checks were also completed by sharing a summary of emerging themes with

participants (See Appendix O). This was intended to "*give voice*" to young

people's experiences and ensure that the themes were representative of

participant's own experiences of social rejection, and their understanding of

these experiences (Braun & Clarke, 2013, p. 282). Unfortunately none of the

participants provided feedback within the timescale of the study.

Researcher's perspective

Research is understood as a subjective process where the researcher's

own assumptions, experiences, and values are assumed to influence collection

and interpretation of the data. Good practice guidelines recommend that

researchers specify their personal assumptions and theoretical orientation in

advance of data collection, in addition to those that emerge as the research

progresses (Braun & Clarke, 2013; Mays & Pope, 2000).

My interest in this area of research stemmed from my experience of

working with children and young people in a clinical health setting. This work

was largely guided by child-focused principles, and influenced by narrative ideas

e.g., supporting the development of an alternative narrative in the context of a

problem-saturated, dominant narrative. This theoretical stance influenced my

approach to conducting interviews and whilst I was interested in hearing about

the potential difficulties that young people with VFDs experience, I was also interested in exploring the strengths and experiences of positive adjustment in this population.

Prior to completing this research project I had not had any personal or clinical contact with children or young people with a disfigured appearance. As a somewhat self-conscious, white, non-disfigured woman, the impact of my own appearance on data collection and analysis was discussed and reflected upon regularly in supervision. At the outset of the study, I assumed that young people with a VFD would report emotional distress as a result of negative social experiences e.g., social rejection from their peers. This may reflect both my awareness that teasing/bullying is common in children without VFDs, and the value I myself place on appearance.

During the pilot study, I was struck by the accounts of positive adjustment in disfigured young people and the resilience that they displayed despite the unwanted attention they received from others. This enabled me to reflect on my preconceptions and review the interview schedule to ensure that participants were given the opportunity to express a range of ideas

Results

Thematic analysis generated 12 themes, which were grouped into four superordinate themes (Table 2). Each theme is presented in turn with supporting quotations to ensure that the themes are grounded in the data (Elliott et al., 1999). Participant numbers are given following each quotation to denote the speaker and orientate the reader (see Table 1). All 12 themes were located across the dataset and therefore the amount of analysis provided for each theme is not representative of its prevalence across the dataset.

Overview and Context

All 10 participants had a congenital VFD and were reviewed quarterly or annually within the hospital's dermatology department. Several of the participants were currently seeking treatment to reduce or remove their VFD. Treatments included medication, infusions and laser treatment.

All of the young people described experiencing negative social interactions with strangers or their peer group, however the degree of severity varied amongst participants. None of the participants had sought psychological help to manage their difficulties.

Themes

Four superordinate themes were generated following analysis of the data. The first theme focused on the view from the outside (the views and attitudes of the observer). The final three themes focused on the view from the inside and

reflected the participants' own thoughts and attributions associated with living

with a VFD and their experiences of social rejection.

Table 2

Summary of Themes

Superordinate themes	Subordinate themes
1. Different in a bad way	1.1: Viewed by others as different
	1.2: "*Life is 10 times harder*"
	1.3: "*I am sick and tired of it*"
	1.4: It is harder when you are younger
2. This is me	2.1: Being different is good
	2.2: I should be treated normally
3. Growing acceptance	3.1: "*Learn to suck it up*"
	3.2: My parents told me that …
	3.3: "*I don't care what people think*"
	3.4: "*Don't judge a book by its cover*"
4. Worries about the future	4.1: "*I don't want it when I grow up*"
	4.2: I will always be seen as different

1. Different in a bad way

Theme 1.1. Viewed by others as different

A common theme shared by all participants was the experience of being

viewed negatively by others as a result of their disfigured appearance.

Participants reported being stared at, teased and called names. Name-calling was

common amongst participants, particularly at school e.g., "*mole face*" (P2),

"*lizard*" (P3) and "*granny skin*" (P4).

Several participants also described feeling left out and isolated by their peers, both in and out of school, as a result of their appearance. One participant reported that his classmates were reluctant to pair up with him in class and would ask to be put with someone else.

> *If I was paired up with someone they would always be like oh why am I with him, can't I be with them.* (P10)

> *I don't get invited to people's birthday parties and that. I like, I invite them but they don't invite me.* (P4)

One participant described feeling "*unwanted*" by his peer group. He described having to move schools twice due to persistent teasing.

> *Everything I touched became something that had the (name) touch and it was really upsetting. That's why I left … The entire year started doing it…. The entire 240 people.* (P3)

As well as being stared at and teased by others, a number of young people reported being asked intrusive and repeated questions about the way they look. Several participants described this as a difficult experience and considered it a form of teasing. One young person described being asked questions daily by her peers.

> *Yeah, cos, even though I'd tell them, they would come back the next day just so I could tell them again and they would laugh.* (P1)

Several participants distinguished between being asked questions "*in a horrible way*" (P10) and out of curiosity. Although many acknowledged that some questions, albeit intrusive, were out of genuine curiosity they felt that this occurred less often than questions that were intended to be hurtful. Many young people also spoke about how questions seemingly asked out of curiosity could still be upsetting regardless of the observer's intention.

> *There is (sic) a few people who ask because they genuinely want to know but the majority of people ask because they want to make you feel bad about yourself.* (P10)

Participants made sense of the negative preconceptions of others in terms of the observers' narrow-minded beliefs that difference was bad or their appearance was displeasing.

> *I don't know, maybe its cos the way they were like brought up. Their surroundings. Like they were secluded to certain types of people, they didn't see people like me.* (P8)

Theme 1.2. "Life is 10 times harder" (P10)

The majority of participants described feeling upset and sad by the negative reactions of others. Many participants described ruminating on negative comments, despite trying their best to ignore them.

> *When I am feeling upset, it's just like the words they say keep going around in my head. Stuff like you are ugly, you are ugly, keeps going round in my head.* (P8)

Although these experiences were often very distressing for participants, a number of young people spoke about putting on a brave face in front of their friends and family. All participants did their best not to get upset in front of those calling them names as they felt this only encouraged them and placed them in a position of power.

> *I become really upset but I don't show them, I don't show them that I am crying or I am upset cos it makes them … feel like they have the power to say more things to me, the power to get to me. So I just go home and do all that stuff by myself. I don't tell anyone about it.* (P8)

> *I usually went up to my room and said I was fine and just felt bad. And then the next day like put on like a face like a mask of how I am fine but not really.* (P10)

Many young people spoke about the impact of having a VFD on their self-esteem. Several young people described lacking confidence as a result of their disfigured appearance and reported feeling self-conscious, particularly when stared at by others. Many spoke about their wish to change their appearance and look "*normal*" (P4).

> *I just feel really really shy, I just automatically feel really really horrible because I don't like the fact that everyone is looking at me and I would rather them just like do what they were doing before they saw me.* (P2)

A number of young people spoke about the difficulty of living with a VFD as an adolescent. They described having to cope with the worries and difficulties of living with a VFD on top of the physical and emotional changes associated with adolescence.

And people say oh my life is so hard but when you have a skin condition your life becomes 10 times harder because you have to worry about these things, and then also have to worry about your skin and how people look at you even more. (P10)

Theme 1.3. "I am sick and tired of it" (P1)

As well as feeling upset by negative comments from others, feelings of anger and frustration were common amongst participants.

And I am just getting to the point where I am sick and tired of it and so I'll just get rid of it so I don't keep getting all this grief from everyone. (P1)

Participants were particularly frustrated when they received unwanted attention from strangers. The majority of young people felt that strangers had no right to question them on the basis of their appearance; especially given they had no control over the way they looked.

I felt a bit angry that they were sort of questioning me like I was some sort of alien or something. (P9)

Theme 1.4. It is harder when you are younger

The majority of young people appeared to face their biggest challenges within their peer group during primary school. Many were able to reflect on their past experiences and described worrying about their appearance as well as their difficulties managing the negative reactions of others in primary school.

Like in primary school I used to get that a lot, like people would say I am disabled. In high school I have never really gotten that. (P8)

Some had begun to make sense of these experiences and attributed the negative reactions of primary school children to their lack of understanding and intolerance of difference. A number of participants felt they stood out from their peers in their small year group, making them more vulnerable to teasing. Many felt that things became easier in secondary school as the larger year groups meant that there was usually someone they could talk to.

> *They are aware that some people are different whereas the little ones they are not really that aware.* (P5)

> *Cos they don't understand. And I think adults know more about it. And they have probably learnt about it.* (P6)

2. This is me

Many young people identified with a disfigured appearance and saw their VFD as a part of who they were. Several participants spoke about how looking different had shaped their personalities and made them who they were today.

> *I think the way you look is who you are ... I am me. I can't change that.* (P1)

Theme 2.1. Being different is good

The majority of young people conceptualised their differences positively as it set them apart from their peers. A number of participants spoke about their wish not to look the same as everyone else and referred to individuals without a VFD as "*robots*" (P10). Several young people described feeling special and "*unique*" as a result of their VFD (P1 and P2).

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I feel special because I am different. (P2)

But I don't see it in a bad way. I see it in like a good way because it means you are different, and that you are not normal which is good! (P7)

Theme 2.2. I should be treated normally

Although the majority of young people valued being different, they did not feel that others should treat them any differently as a result of their appearance. Participants made direct comparisons to their peers, in terms of the things they could and couldn't do, and described their VFD as having minimal impact on their day-to-day lives or functioning.

I don't deserve to be treated differently just because I have a birthmark. They should treat me like a normal person … I live a normal life. I eat, drink, go to sleep, everything. It doesn't affect my everyday life. I am who I am and I live like a normal person. (P1)

You might just look different but have a completely normal life. You go to school, come home, have dinner, go (sic) bed. (P8)

Participants also made downward social comparisons and expressed empathy towards those with disabilities or chronic illnesses whom participants saw as worse off than themselves. This allowed participants to gain some perspective of the impact of living with a VFD and in doing so help maintain their self-esteem.

Not having an arm or a leg cos that would be hard. (P5)

3. Growing acceptance

Theme 3.1. "Learn to suck it up" (P8)

Several participants described a change of perspective as they reached adolescence. They reported worrying less about their appearance and learning to cope better with the social challenges that they faced as a result of living with a VFD. Participants acknowledged the time they had spent worrying about their appearance at primary school and their decision to use this time and energy doing the things they enjoyed instead.

> *But I've kind of got to a point where I don't have the energy, I'm not bothered. Like when I was younger I would spend all my energy on getting worked up, and getting upset but I'm just like I have better things to do.* (P8)

> *When I was younger I worried about it more but now I have got older I have started to just think not (sic) about what I looked like as much.* (P9)

With age, participants described being more accepting of their VFD. Many reported that they had learnt to live with their disfigured appearance and ignore the attitudes of others. Several participants identified their VFD as a part of them but not something that defined them.

> *This is what you have. Now deal with it. You wont get anything done crying in your room.* (P10)

> *You can't just cry about it all the time. You are going to get upset about it of course but you have to learn to suck it up and be like this is who I am. If you don't like me, tough. Go away.* (P8).

A number of participants spoke about how their experiences of being viewed negatively by others had made them a stronger person and shaped their personalities.

> *That moment of feeling really down, it's not nice. It's a really terrible feeling but it passes really quickly. And once that moment passes, you think ok that has made me a bit stronger. That has made me face stuff. I haven't faced that before so if something like that happens again I know not to get this upset about it.* (P8)

Theme 3.2. My parents told me that…

Many young people spoke about the active role their parents had played in their growing acceptance of their appearance. They described the positive messages they had received from their parents as they were growing up and the role these had played in helping to shape their perspective on looking different.

> *Well my Mum says that you are lucky if you have anything special with you.* (P1)

> *With my Mum and Dad saying that I don't need to be ashamed of it. It made me feel better about myself.* (P2)

> *I have always been told by my parents that you play with the cards you are dealt.* (P10)

> *But they have always told me from the beginning that just because you may look different and you may, you may experience different things, the way people treat you, you need to know that everyone gets to one place the same way. You work hard.* (P8)

Theme 3.3. I don't care what people think

A central theme for all participants was the importance of standing up for themselves. Many young people felt that they would be vulnerable to further teasing and exclusion from their peers if they were unable to assert themselves.

> *I want to be people's friends but then if they push me around, if they treat me like I am nothing then I am not going to be their friend. ... I don't take crap.* (P8)

> *And if someone is being not nice to (sic) you then you have a right to stick up for yourself.* (P7)

Several participants voiced their frustration that they were often judged by strangers based on the way they looked. Many were dismissive of comments from strangers and believed that their appearance should not be important to others.

> *And whether they like it or not is their business. I don't really care if you like it or not. Its not you, you don't have to live with it so I don't care.* (P1)

> *So at the end of the day you just need to realise that it is not their opinions that matter, it's yours, and the ones that you love that matter. But if it is just like random people on the streets, or like guys in your school, girls in your school that you don't like just be like I don't know you, you don't know my story, go away.* (P8)

Theme 3.4. "Don't judge a book by its cover" (P7)

As participants got older, and worried less about the way they looked, they appeared to value personal and relational traits over physical attributes of

themselves and others. All participants held the firm belief that appearance was not important and spoke about the importance of personality and "*what is on the inside*" (P7 and P8). Many young people reported that their friends shared their views on appearance but acknowledged that some people in their year group were more conscious of the way they looked.

> *It is more about the kind of person you are than the way you look.*
> (P3)

> *Well you shouldn't judge people on their looks you … shouldn't judge them at all. You should just think about their personality and don't take their looks into account.* (P6)

> *If the person is a nice person, if the person is not horrible then yeah looks do not matter at all.* (P10)

4. Worries about the future

Theme 4.1. "I don't want it when I grow up" (P4).

Although participants appeared to value being different and identified positively with their disfigured appearance, many spoke about their wish not to have a VFD for the rest of their lives. These conflicting ideas emerged throughout the transcripts and suggested that whilst the perspectives of young people appear to shift during adolescence, many continue to struggle to fully accept their appearance.

> *And like, I do like it but it's just where I am getting to the older age I'm like I don't really want it anymore.* (P1)

Sometimes I do wish that I am the same as other people but then most of the time I feel happy because I like being different cos it is nice to be unique in your own way. (P2)

And I don't think anyone would really want it for the rest of their life because they would want to be like other people. (P7)

Several young people also shared their concerns about the impact that their disfigured appearance would have on key areas of their lives as they got older e.g., work, intimate relationships and having a family. Many participants worried that they would have difficulty finding a partner and that others would be *"put off"* by their appearance (P7). Few participants had communicated these worries to friends or family.

So I think on a level when I get older I am more worried about family and stuff. I have never actually told my parents that, like cos … they will be like you have ages until then but it does cross my mind like once a fortnight. (P8)

A number of young people also spoke about the impact that their appearance may have on their future careers. One participant spoke about her wish to become an actress but wondered whether this would be possible because of the way she looked.

Actually I wanted to be an actress at some point and then I realised that in most movies the main characters are white and they don't have birthmarks so I got really self-conscious about that. (P2)

However not all participants shared these concerns and several believed that their future careers depended on their hard work as opposed to the way they looked.

> *Work wise it doesn't worry me very much. Like career wise it doesn't really matter how you look. As long as you have the grades and the qualifications to get where you want to go.* (P8)

Theme 4.2. I will always be seen as different

Several participants expressed their concerns that their appearance may make them vulnerable to teasing or discrimination when they were older.

> *I am mostly worried that it would attract people to have a go at me.* (P3)

One participant felt that his difficult experiences at school would be replicated as he got older and believed that adults would be no more accepting of him than his current peer group.

> *It might not be in the schoolyard but people do still think the same things even at adult age … If there is a horrible person when he was a kid, he is usually going to be a horrible person when he is an adult.* (P10)

Discussion

This study used a qualitative design to explore the lived experiences of young people with a VFD, aged between 11 and 14 years, specifically focusing on their peer relationships and experiences of social rejection relating to their appearance. Much of the research within this population has been deficit-led and focused on the psychological difficulties experienced as a result of living with a VFD. The existing research has largely been underpinned by the assumption that young people with a VFD are more likely to experience social rejection as a result of their disfigured appearance, and are therefore at greater risk of psychological maladjustment as a result. However, despite underpinning research in this field for a number of decades, there is little empirical evidence to support this assumption (Carroll & Shute, 2005) and few studies have attempted to understand the social experiences of this population from the perspective of the young people themselves.

Summary of Main Themes

Awareness of being different

All participants described experiencing negative and unwanted attention from others in response to the way they looked (viewed by others as different). Name–calling and teasing (explicit social rejection) were commonly experienced in varying degrees of intensity and frequency. Implicit and insensate teasing was also widely reported amongst young people with a VFD. Participants described being stared at and repeatedly asked intrusive questions about the way they looked. Several young people reported being left out and

feeling unwanted by their peers, for example not being invited to social events outside of school and the reluctance of their peers to work with them in class. Both forms of social rejection were equally distressing for young people with a VFD. Participants described feeling upset and angry in response to being treated differently by others, and reported a lack of self-confidence as a result of the persistent negative feedback they received.

Positive sense of self

Young people were able to articulate the complexities of living with a VFD in their accounts of socially rejecting experiences. The negative reactions they received from others acted as a stark reminder of their disfigured appearance. In spite of this, or perhaps because of it, many young people worked hard to maintain their self-esteem and develop a positive sense of self (Bilboul et al., 2006; Cochrane & Slade, 1999; Egan et al., 2011; Feragen et al., 2010; Walters, 1997). The majority of participants valued being different and felt that their "*unique*" and "*special*" appearance set them apart from their peers (Eiserman, 2001; Wallace et al., 2007). Many tried their best to ignore the negative reactions of others and focus on the things they enjoyed doing e.g., dance, football and computing (Stavropoulos, Hallberg, Mohlin, & Hagberg, 2011; Thambyrajah, Herold, Altman, & Llewellyn, 2010). The ability to maintain a positive sense of self was influenced by the messages young people had received from their parents as they were growing up. Many participants spoke about receiving messages of support and encouragement from their parents, which celebrated their unique appearance and placed little value on the way people look.

The young people in this study expressed a level of sophistication in their accounts beyond what might be expected given their chronological age. Far from being passive recipients to the negative reactions of others, young people were actively engaged in making sense of their experiences and the world around them. Many young people appeared to have begun to positively identify with their VFD and placed little value on appearance or the opinions of others. The majority of participants described their VFD as a part of who they were and felt that looking different had shaped their personalities and made them who they were today. As a result, young people appeared to cope better with looking different and were, for the most part, less influenced by the opinions of others (Erikson, 1972, 1974; Marcia, 1980).

Fragile sense of self

However, it was not always easy for young people to maintain a positive sense of self when faced with regular, and often cruel, reminders of their visible difference. Many expressed a clear and unwavering sense of self as devalued and rejected, a belief system which is known to be associated with poor psychological well-being in adulthood (Baumeister, Campbell, Kruger, & Vohs, 2003; Orth, Robins, Trzesniewski, Maes, & Schmitt, 2009; Trzesniewski et al., 2006). The fragility of participants' self-esteem, and acceptance of their disfigurement was evident in young people's accounts, particularly as they thought about their VFD in the context of their whole lives (Thompson, Kent, & Smith, 2002). Although many dismissed the importance of appearance in early adolescence (contrary to existing literature; Brown & Witherspoon, 2002; Elkind, 1967; Prokhorov et al., 1993), many believed that appearance was highly

valued when forming intimate relationships and feared that others would be "*put off*" (P7) by their VFD (Hamlet & Harcourt, 2015; Rumsey & Harcourt, 2004). This disputes recent findings where disfigured adolescents reported their belief that non-physical attributes, such as personality, were more important in developing romantic relationships than their appearance (Griffiths, Williamson, & Rumsey, 2012).

These findings highlight the dynamic process of adjusting to disfigurement and suggest that maladaptive pressures, e.g., times of transition, require individuals to use increased psychological effort to maintain a positive sense of self, which evidently is not always possible (Thompson et al., 2002).

A move towards a developmental multi-factorial model of psychological adjustment and social rejection in disfigured young people

The findings of this study have demonstrated the complexity in the way in which negative social experiences might influence psychological adjustment and have highlighted several variables which may need to be considered in order to better understand the experiences of social rejection in this population.

Heterogeneity in experiences of, and responses to, social rejection

Although all participants described experiencing unwanted negative attention from others, there was clear heterogeneity in both the frequency and severity of socially rejecting experiences. For example, whilst some young people reported minimal and occasional teasing or name-calling, some young people described feeling left out and isolated by their peers on a daily basis. One participant described a particularly difficult experience where he was forced to

move schools twice due to persistent teasing.

Young people expressed a range of internal responses to socially rejecting experiences, which appeared to influence the way in which the young person coped with being viewed as different. Young people described feeling sad and upset in response to some of the negative comments or attention they received. A number of young people described questioning the significance of their disfigurement when feeling sad ("*Why was this given to me? Why do I have this disease?* P10). Several young people felt a knock to their confidence and reported that they would try to hide their feelings from others. Almost all of the young people described feeling angry when they were judged negatively by others, particularly by those who didn't know them well. These feelings of frustration often resulted in young people standing up for themselves and confronting the person who had, for example, called them names.

Attribution style

The adolescents in this study were actively engaged in making sense of their experiences in such a way to preserve their positive sense of self, despite the negative reactions of others (Tesser, 1998). As participants got older they reported worrying less about their appearance and began to think more profoundly about themselves and those around them. Young people described evaluating the self and others beyond the way people look, and on the basis of "*what is on the inside*" (Egan et al., 2011; Thompson & Broom, 2009; Thompson & Kent, 2001; Wallace, Harcourt, Rumsey, & Foot, 2007). By devaluing the importance placed on appearance, the disfigured adolescents were able to preserve their positive sense of self. This became fragile at times when

appearance was more highly valued, e.g., when thinking about intimate

relationships, due to the inadequacy of the related self-concept, given their

disfigured appearance (Moss & Carr, 2004; Thompson & Broom, 2009).

The way in which participants made sense of the negative reactions of

others, and the value they placed on them also enabled young people to maintain

a positive sense of self. The adolescents in this study expressed their frustration

at the unwanted attention they received both from their peer group and people

they didn't know. Participants were dismissive of the comments they received

and placed little value on the opinions of others (I don't care what people think)

(Festinger, 1957; Snyder & Pope, 2003).

Young people also attributed their negative experiences externally to the

unfavourable characteristics of the observer e.g., "*immature*" (P1 and P8),

uneducated and "*narrow-minded*" (P8) (Thompson & Broom, 2009; Thompson

et al., 2002), as opposed to internally to aspects of the self e.g., their disfigured

appearance. These finding suggest that the way in which young people make

sense of their negative experiences, in other words their individual attribution

styles (Anderson, 1983; Kent, 1999), may be crucial in determining their path

towards adjustment or maladjustment (Thompson & Kent, 2001).

Coping styles

The accounts provided by young people suggested heterogeneity, not

only in their experiences, but also in the way young people with a VFD cope

with being viewed as different. Many young people described hiding their

feelings from others, particularly those who had acted negatively towards them

('the bully'). Several young people spoke about trying their best to forget the

hurtful things that were said to them but reported struggling to do so. These avoidant coping strategies, e.g., rumination, have been associated with psychological difficulties and maladjustment (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2002). However, some young people adopted more proactive strategies such as talking to a teacher, relaxation and standing up for themselves, which have been associated with positive psychological outcomes (Thompson & Kent, 2001).

Many young people spoke about the positive messages they had received from their parents as they were growing up, and how these had supported them in coming to terms with their VFD and learning to cope with the negative reactions of others (Sartor & Youniss, 2002). The protective role of parents has been widely reported in previous literature on adjustment, and supports the finding that acceptance from family members and social support is associated with positive adjustment in children and young people (Dennis, Rostill, Reed, & Gill, 2006; Egan et al., 2011; Masnari et al., 2012; Rumsey & Harcourt, 2007; Thompson & Broom, 2009; Thompson & Kent, 2001).

Internal conflict relating to the disfigurement

Conflicting ideas emerged throughout young people's accounts of their experiences of living with a VFD. On the one hand, young people with a VFD valued being different and saw it as a part of who they were. Many felt that their disfigured appearance made them special and unique, and helped them to stand out positively from their peers. However on the other hand, given the challenges associated with looking different, many young people expressed a wish not to have a VFD for the rest of their lives and to be treated normally by their peers.

This left many in an unresolvable dilemma of wanting to be like their peers ('normal') but also identifying positively with looking different (Rumsey & Harcourt, 2007).

Conclusion

The accounts provided by young people in this study have allowed a richer understanding of the subtleties and complexity of adverse social experiences in young people with VFDs. Young people were able to articulate the challenges of living with a disfigured appearance and their struggle to maintain a positive sense of self in spite of these difficulties. Young people described their distress at being excluded by their peers and being asked repeated, and intrusive questions about the way they looked (Feragen et al., 2009; Parker, 2013; Shute et al., 2002). Although many acknowledged that, to an extent, these questions were driven by the curiosity of the observer (Stock et al., 2013), the majority of young people identified them as a form of teasing (Feragen et al., 2009).

The qualitative accounts provided by facially disfigured adolescents appear to suggest that this sub-group experience emotional distress in response to social rejection, expressed partly in subtle forms of teasing which may be unique to the disfigured population. These subtleties, and the heterogeneity of experiences identified across young people's accounts, suggest that there are likely to be individual differences in how teasing is defined (e.g., context, content and frequency) within this population, and across children and adolescents as a whole. This may in part explain why these findings have not been clearly identified by previous studies, which have relied on quantitative

methods of explicit teasing (Feragen & Borge, 2010; Shute, Owens, & Shee, 2002).

Limitations

Several limitations of this study should be considered. Firstly, this study reports findings based on semi-structured interviews with 10 adolescents with a range of VFDs. Given the known heterogeneity of this population both in terms of the type/severity of the disfigurement (Kish & Lansdown, 2002) and in individual psychological adjustment, the extent to which these results can be generalised to all adolescents with a VFD is limited. However within the field of disfigurement research, the sample used in this study is considered to be both homogeneous and a neglected sub-group of the population, given that previous work has largely focused on children and young people with cleft-lip and palate (e.g., Feragen & Borge, 2010) The sample size is also considered adequate for a small-scale study (Braun & Clarke, 2013; Guest et al., 2006), and achieves its main goal of providing a "*new and rich*" understanding of social rejection in this population (Sandelowski, 1995, p.183).

Only 48.1% of eligible participants expressed a wish to participate in this study. A number of parents who did not wish for their child to take part expressed their concerns that their child's involvement would draw attention to their VFD and in doing so cause them distress (Bradbury, 1997; Edwards & Titman, 2011). In contrast to the assumption that it would be distressing for young people to talk about their VFD, many young people spoke positively about the interview process and the opportunity to talk about their experiences of living with a VFD. Nonetheless, given that a number of parents who chose not to

participate in the study at least partly because they believed that having their child talk about experiences of social rejection may upset them, it is possible that this sub-group of young people who were not interviewed had experienced greater difficulties with their peers compared to those young people who were interviewed. The results of this study may therefore be positively skewed. However, given the finding that all young people who were interviewed reported experiencing negative and unwanted attention from others, it is likely that the degree of bias in the sample is limited.

Future Research

The use of qualitative interviews in this study has provided a unique opportunity to explore the lived experiences of young people with a VFD specifically focusing on their peer relationships and experiences of social rejection relating to their appearance. The accounts provided by young people have highlighted the heterogeneity of this population and allowed us to begin to understand why some young people with a VFD cope better than others. These preliminary findings have allowed researchers to consider how adolescents with a VFD make sense of difficult social experiences, and in doing so has moved away from a deficit-led model which assumes negative experiences as a result of disfigured appearance (Dahlquist, 2003). The heterogeneity of the disfigured population, as demonstrated in this study, suggests the need to approach research from a salutogenic perspective (Antonovsky, 1987) and consider a developmental multi-factorial model of adjustment, including variables which may promote adjustment and well-being (Eiserman, 2001; Feragen et al., 2009; Strauss, 2001).

Future research is warranted to develop this model further and explore the variables which are likely to influence the relationship between a disfigured appearance, difficult social experiences and psychological adjustment e.g., attribution styles, coping styles, the role of identity and social support. A developmental perspective should also be taken to understand the experiences of young people living with a VFD and specifically their responses to social adversity and rejection. This is needed across childhood, adolescence and in young adults. This study recruited young people aged between 11 and 14 in order to capture difficulties typically associated with the transition to secondary school. Future research should consider the impact of later transitions on the adolescent's psychological adjustment, e.g., leaving school, attending university etc., given findings which suggest that young people worry about the impact that their VFD will have on their lives as they get older.

Clinical Implications

Given findings which suggest that the way in which the individual makes sense of their experiences (e.g., attribution style) is likely to affect psychological adjustment, there are clinical implications for working both directly and indirectly in order to promote well-being in young people with a VFD.

Clinicians working with young people with VFDs should be mindful of the range of experiences that this population face, and reflect on the possible negative assumptions which may misguide their work. Furthermore, whilst clinicians should not assume that all young people with a VFD experience social rejection, given that the majority of participants reported experiencing frequent negative implicit and explicit social experiences, clinicians should aim to

regularly inquire about the nature of social experiences in young people with VFDs and, if relevant support those who report negative experiences by aiding them to develop constructive, problem-focused coping strategies (Folkman & Moskowitz, 2000; Lazarus & Folkman, 1984).

Clinicians should also adopt a solution-focused perspective by focusing on the young person's strengths and resilience as opposed to defining these young people by a single characteristic (their VFD). This may include getting to know the young person aside from their disfigurement and exploring their hobbies, interests ands likes. It may also be helpful for clinicians to consider the individual's coping styles, attributions and subjective meaning assigned to their VFD rather than assuming distress as a result of negative social experiences.

Given findings which suggest that the value of appearance may impact adolescent's ability to cope with difficult social experiences, clinicians should encourage young people to reflect on the value they place on appearance in relation to non-appearance related attributes such as personality, social skills, hobbies and work (Griffiths et al., 2012). In doing so, clinicians may be able to explore the child's strengths in these areas, and consider increasing their perceived importance. One participant described her experiences at Changing Faces and how this approach had helped her to feel more confident in herself; "*they made me focus on the good things rather than the bad things*" (P8).

Clinicians should also be aware of the worries young people have about the impact of their disfigured appearance as they get older. Contrary to previous literature, these young people described placing little value on their appearance during adolescence. However young people voiced their worries about the impact of their VFD as they got older and started to form intimate relationships.

Therefore clinicians working with disfigured individuals across both child and adult services should be mindful of this when supporting young people with a VFD in their late adolescence/20s.

In addition, given the positive influence of parental support on adjustment, clinicians should consider involving the wider family in their individual work with adolescents, as well as working directly with parents of disfigured children from a young age in order to support their own adjustment and acceptance of their child's appearance. It is hoped that this will in turn promote the child's well-being (Blakeney et al., 2005; Dennis et al., 2006; Rumsey & Harcourt, 2007).

The finding that all participants experienced unwanted negative attention from others highlights the need for psycho-education to reduce prejudice and to promote positive attitudes and behaviours towards individuals with VFDs (Changing Faces, 2009). Psycho-educational campaigns are required across multiple settings given that young people report receiving unwanted negative attention and implicit/explicit teasing from their same-age peers, younger/older children and adults. Such campaigns may involve increasing awareness of VFDs, challenging negative assumptions held by the non-disfigured population (e.g., that VFDs are contagious; Ryan, Oaten, Stevenson, & Case, 2012; Stock et al., 2013) and supporting individuals without a VFD to understand the negative impact that all forms of teasing (including implicit) can have on disfigured individuals.

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Part 3: Critical Appraisal

Introduction

This paper offers some critical considerations of the study outlined in Part 2 of this thesis which explored young people's experiences of living with a VFD, specifically focusing on their peer relationships and experiences of social rejection. This study aimed to develop a richer understanding of their complex experiences, from the voices of the young people themselves. This was intended to enhance the existing literature in this field, which has been limited by its reliance on quantitative methods, proxy and forced-choice reports, and the researcher's assumption of psychopathology and negative social experiences.

First, this paper considers a number of possible barriers to engaging young people with VFDs that present a challenge to all researchers working with children and adolescents. Second, I consider the unique contributions made by this study in considering the focus on psychopathology in the existing literature on young people with VFDs. Finally, I consider the psychological heterogeneity reported in this population and the contribution that the current study makes to understanding this better.

Hearing the Voices of Young People in Research

Involving Young People in Qualitative Research

Recently, the value of directly involving children and young people in research in order to better understand their experiences has been recognised. This has been influenced by government initiatives (Shaw, Brady, & Davey, 2011), evidence of heterogeneity in young people's experiences, and research which has

highlighted the benefits of collaborative ways of working (Street & Herts, 2005).

Qualitative research in the field of disfigurement has been largely neglected, and

few studies have tried to understand the lived experiences of young people with a

VFD from their own perspective. Whilst early quantitative studies have

attempted to understand how VFDs affect young people psychologically, they

have been criticised for their reliance on proxy reports and their potential to

reduce complex phenomena to a simple cause and effect relationship. Whilst the

use of standardised measures and proxy reports has enabled us to begin to

understand the difficulties experienced by this population, in comparison to their

peers, it is less able to provide us with a true understanding of young people's

experiences, and how they make sense of these experiences, from their own

perspective (e.g., Broder, Smith, & Strauss, 2001; Hunt, Burden, Hepper,

Stevenson, & Johnston, 2007; Lawrence, Rosenberg, Mason, & Fauerbach, 2011;

Turner, Thomas, Dowell, Rumsey, & Sandy, 1997).

     The current study aimed to use a qualitative design to allow the voices of

young people with VFDs to be heard and to attempt to capture the range and

diversity of their experiences, both positive and negative, of living with a VFD.

In attempting to learn about young people's experiences from their own

accounts, it was thought that this design may allow us to have a better, more

comprehensive and potentially new understanding of their experiences, which

may not have been possible to capture through the use of pre-determined

measures adopted in previous studies.

     Although some have highlighted the challenges of interviewing young

people (Coupey, 1997), this study yielded a rich data set and captured the subtle

and unique challenges experienced by this population. Several factors may have

facilitated this including the choice of language, interview structure and content, and the use of my clinical skills.

Consistent with postmodern research and the views expressed by young people accessing mental health services (Street & Herts, 2005), the use of non-jargonistic language was considered when designing this study. The language used to disseminate the findings of this thesis amongst researchers and clinicians (e.g., VFD, disfigurement) was not considered developmentally appropriate for the young people in this study. Therefore alternative language was used during correspondence with the young people and data collection. For example, the invitation letter referred to '*young people who look different'* and the language used by participants to refer to their VFD was mirrored by the interviewer. On the whole, young people tended to use the medical term for their condition, e.g., eczema, or referenced the location of their disfigurement, e.g., "*chin*" (P8).

The interview schedule was designed in consultation with a clinical psychologist within the direct care team and piloted on three young people (aged between 9 and 12 years) to ensure that the interview was developmentally appropriate for the intended sample. First, the interview schedule was semi-structured, which provided a degree of flexibility and allowed me to respond to the natural flow of conversation. This enabled me to clarify my understanding if the young person's responses were vague or difficult to understand, encourage participant's to provide more detail where necessary and validate their efforts. This helped to facilitate rapport-building and ensure that the voice of the young person was heard. Second, the interview started with the easiest and least intrusive questions (e.g., school/hobbies) before moving on to more difficult and sensitive questions (e.g., experiences of social rejection) (Britten, 1999). In doing

so, the interview structure attempted to minimise the difficulties that may arise when asking a young person to discuss sensitive topics with an unfamiliar adult and again was intended to allow me to build rapport with the young person. The interview schedule adopted a person-centered approach and aimed to explore the difficulties unique to each young person with a VFD, as well as focusing on the young person's own strengths and positive experiences of coping (Harniss, Epstein, Ryser, & Pearson, 1999; Tedeschi & Kilmer, 2005). It was hoped that this approach would facilitate engagement and empower the young person. It also served to acknowledge the tendency for past research to focus on pathology and forced-choice methods.

The aim to capture the lived experiences of young people with VFDs is likely to have been facilitated by my ability to draw on my skills as a clinician. These skills enabled me to engage young people and facilitate their ability to communicate a range of experiences, including those which they may have found distressing. I was able to clarify my understanding in order to ensure that the themes, which emerged from participant's accounts, were a true reflection of the reality of their experiences and the way in which they made sense of them. My clinical experience of working with children and young people also enabled me to scaffold my questions, to support young people to express complex and difficult emotions/experiences, and allow me to respond to these in a developmentally appropriate manner.

Although my clinical skills were largely seen as complementary in allowing the voices of young people to be heard, some researchers have highlighted the conflict that dual roles can pose and have encouraged researchers to reflect on their role as a researcher in comparison to their previous roles as a

clinician (Orb, Eisenhaur, & Wynaden, 2001). Guidelines on conducting

qualitative research recommend that researchers reflect on the process and

content of interviews early on by listening to audio recordings (Britten, 1999).

The recordings from the pilot interviews highlighted my tendency to adopt a

therapeutic stance and quickly provide empathy and reassurance to participants

when they shared difficult feelings/experiences (e.g., "*it sounds like that was

really difficult for you*"). It is likely that the use of my clinical skills in this way

may have in effect 'put words' in their mouths and prevented participants from

expressing their full range of feelings and experiences in their own narrative. The

potential adverse impact of my dual role as a clinician was reflected upon in

supervision. This allowed me to acknowledge the potential conflicts of my dual

role as a clinician and researcher, and alter my approach to responding to young

people's difficult feelings/experiences to facilitate further exploration whilst

remaining empathetic (e.g., "*can you tell me a bit more about that*?").

Parents as Potential Barriers to Young People's Involvement in Research

This study aimed to explore the lived experiences of young people with a

VFD from their own accounts. Given the age of participants, letters were initially

sent to parents inviting their child to participate in the study. These letters were

followed up a week later with a telephone call. Although letters were sent to the

parents of 91 children, only 26 expressed a wish to take part. Possible reasons for

poor uptake are discussed.

Twenty-eight parents expressed a wish not to take part in this study.

Parents who declined to participate were asked their reasons for non-

participation during the follow-up telephone call. Many of the parents I spoke to,

who were reluctant to allow their child to participate, reported that their child was currently doing well and had not mentioned their VFD for some time. As a result, many of the parents worried that talking about their VFD would bring any underlying issues to the surface and cause their child long-term distress. Whilst these parents were clearly motivated to act in the best interests of their child and to protect them from distress, it is possible that, in doing so, they were denying their child the opportunity to share their unique experiences, thereby potentially influencing the data and the subsequent analysis (Harden, Scott, Backett-Milburn, & Jackson, 2000; Hill, Laybourn, & Borland, 1996).

The assumption underlying this study was the importance of hearing from young peoples' perspective in order to try to better understand, and essentially support, young people with a VFD. This is consistent with the professional assumption in clinical psychology that talking about difficulties generally does more good than it does harm. Whilst I was approaching recruitment from this perspective, it is possible that many of the parents who did not wish for their child to take part adopted a different perspective, which was driven by their understandable desire to protect their child from any unnecessary distress.

The dilemma, which many parents appeared to face, about whether it was helpful for their child to talk about their VFD, was evidenced in one of the pilot interviews. During this interview, the parent (mother) commented that the family tried not to talk about her son's VFD at home in an attempt to reduce the impact it had on his life. However, this young boy spoke positively of the opportunity to talk about his experiences of living with a VFD during the interview. This may demonstrate the conflict between this parent's desire to protect her child and the child's wish to talk about his VFD.

Actually really interesting, cos I get (sic) to explain more about my eczema and my life cos I don't get that much time to tell people.

The majority of young people who took part in this study appeared enthusiastic about the research and spoke positively of the interview process. One participant (P2) commented that the interview had not been as scary as she had initially thought. Several participants clearly showed their enthusiasm for taking part, both through their body language and the openness with which they shared their experiences of looking different. It is possible that some parents contacted about the study placed less value on the importance of the study than their child may have done and may have held greater concerns about potential distress as a result of participation. Those young people whose parents declined participation may have welcomed the opportunity to share their experiences of looking different.

It appears that many parents had a number of anxieties about allowing their child to participate in this study. For many parents it seemed that they were concerned that talking about difficult and sensitive experiences may cause their child distress. In many cases the parents had not discussed the study with their child and therefore it is not known whether these young people would have been willing to participate. The decision to allow their child to participate (to talk or not to talk) may reflect the parent's dilemma of balancing the need to protect their child from distress and recognising their need for autonomy (Carter & McGoldrick, 1989; Claveirole, 2004).

My perspective as a researcher, and my experience that talking about difficulties generally does more good than harm, may have differed from the perspective of the parent. Although I could understand the parent's wish to protect their child, the impact that this had on recruitment left me feeling somewhat frustrated, particularly as the pilot interviews appeared consistent with my understanding that some young people can benefit from talking about their difficult experiences.

It may have been helpful to have approached the recruitment process differently given parent's hesitation about whether to consent to their child taking part. In this study, parents of potential participants were sent a letter inviting their child to take part. This was followed up a week later by a telephone call. Given the potential anxieties and reluctance of some parents to allow their child to take part, it may have been helpful to approach parents and young people directly during their routine consultations at the hospital. This may have provided the opportunity to explore some of the parent's/child's anxieties and explain the rationale of the study and its underlying assumptions that talking about difficulties can be helpful. In addition, given that I had had no prior contact with parents or young people, it may have been helpful to involve a member of the direct care team in this process, which may have aided recruitment.

Relational Issues as a Possible Barrier to Engagement

Although this study was designed to support young people to express the full range of their experiences, it is possible that this was limited by a number of relational issues, which may have acted as a barrier to engagement e.g., the

impact of my role as a professional, the location of the interview and difficulties building rapport with participants.

Firstly, my position as a healthcare professional and an adult may have impacted my ability to engage the young people in this study. Given the novelty of this experience, it is likely that some young people found the interview anxiety-provoking, which may have prevented them from fully opening up about their experiences. However, the degree to which my role as a professional/adult impacted on engagement may have been reduced by my ability to draw on my clinical skills and my position within the hospital. In my role as a trainee and researcher, it is likely that I came across in a less formal manner to participants, in comparison to the doctors and nurses working clinically in the hospital. Participants were informed that the information they gave would be kept confidential and not shared with the doctors in the hospital, and that their participation in the study would not impact the medical care they received. In stating this, both verbally and in the information sheets, it is likely that this also helped to distinguish myself from the other health professionals in the hospital. As a result, I may have appeared less threatening, which is likely to have facilitated my engagement with participants and enhanced their ability to talk about difficult experiences.

The majority of young people were interviewed in a medical context, which is likely to have impacted engagement. Evidence suggests that the richness of data is improved when young people are interviewed *"on their own turf"* (Gill, Stewart, Treasure, & Chadwick, 2008; Warr, 2004, p.580). Although participants were offered the opportunity to choose the location of the interview (home or hospital), only one participant was seen at home. This outcome was in

part explained by logistical difficulties, which prevented my ability to offer a home appointment. As the hospital was a specialist in its field, many families travelled from all over the country to attend their appointments. A number of families lived far away and therefore a home visit was felt to be unrealistic within the constraints of the study. For example, one family lived in Scotland and therefore an appointment was only offered at the hospital, which unfortunately the family was unable to attend. In order to try to limit the barrier to engagement which this may have posed, the consultation rooms used to complete the interviews at the hospital were made as child-friendly as possible.

Finally, it is possible that the difficulties arranging multiple meetings with the participants in this study may have acted as a barrier to engagement. All participants were offered a pre-interview meeting (approx. 20 minutes), which was intended to provide an opportunity for the researcher to begin to build rapport with the young person in order to facilitate the collection of a richer dataset (Gill et al., 2008). However, in reality this was not always possible and only one family opted-in to attend a pre-interview meeting. What was not known prior to the study was that many of these young people only visited the hospital every two, six or 12 months. Therefore for participants travelling from outside of London, it was not possible for families to attend a pre-interview meeting and the interview alongside their pre-existing medical appointments, within the timescale of the study. Parents were reluctant to visit the hospital more than once and, therefore, families were offered the chance to attend a one-off interview where additional time was made prior to the interview to build rapport. However, although I intended to set aside time at the beginning of the formal interview to get to know the young person and build rapport, it was not always possible to do

this adequately as participants often had to rush to another appointment, or return home.

It is likely that the richness of the data could have been improved if all participants had the opportunity to meet with me prior to the formal interview. This procedure has been recommended by other qualitative researchers who suggest that a one-off meeting does not allow young people the time or space to express the full range of their ideas (Baumann, 1997; Bricher, 1999; Holman, 1987). My intention to allow participants to choose the location of the interview and offer a pre-interview meeting are both examples of the discord between what I had hoped to do in order to improve the richness of the data and the practicalities of carrying out research in the real world (MacDonald & Greggans, 2008).

Focus on Psychopathology

Researchers and clinical psychologists are often interested in what is wrong with individuals (Lyons, 1991; Tedeschi & Kilmer, 2005) and have been criticised for their continuous "*hunt for indicators of maladjustment*" (Dahlquist, 2003, p. 45). Historically, research in child mental health has focused on pathology and much of the existing literature exploring psychological adjustment in individuals with a VFD has focused on the challenges that the researchers assume are experienced by this population. Much of this research has been based on the assumption that having a disfigured appearance will have a negative impact on the individuals' social experiences, which may negatively influence their psychological adjustment (Thompson & Russo, 2012). This assumption has

been influenced by the vast literature on appearance which suggests that attractive individuals are treated more favourably and believed to possess more socially desirable characteristics than individuals labelled unattractive (Conant & Budoff, 1983; Dion, Berscheid, & Walster, 1972; Langlois et al., 2000; Lansdown, Rumsey, Bradbury, Carr, & Partridge, 1997; Nabors, Lehmkuhl, & Warm, 2010; Sigelman, Miller, & Whitworth, 1986). Researchers have argued that beauty is no longer in the eye of the beholder and in fact common appearance-related judgments are shared across the world.

The negative bias within research on facial disfigurements has been largely accepted by the research community. Researchers have, until more recently, continued to study the difficulties experienced by this population and in doing so have tended to define these young people by an important, but nonetheless singular characteristic, their VFD, as opposed to seeing beyond their appearance and viewing them as a whole person. This may reflect the value society places on appearance, and researchers own views that "*what is beautiful is good*" (Dion et al., 1972, p.285).

Explaining Psychological Heterogeneity in Young People with VFDs

Past research in this field appears to have viewed young people with VFDs as a homogenous group and have assumed that individuals with a VFD will face similar difficulties as a result of their disfigured appearance. In doing so, researchers are at risk of ignoring the possible complex and multi-factorial variables, which may impact adjustment (e.g., the influence of individual, family

and social factors; Thompson & Kent, 2001), and assume a simple and direct relationship between disfigurement and negative adjustment.

Evidence of heterogeneity in individual's adjustment and experiences of living with a VFD (Rumsey & Harcourt, 2007) has prompted researchers to acknowledge that this population reports a range of positive and negative experiences. What is now known is that whilst some young people with VFDs experience psychological distress (Horn & Tidman, 2002; Kent & Thompson, 2002; Millard & Richman, 2001; Papadopoulos, Walker, Aitken, & Bor, 2000; Rumsey, Clarke, & Musa, 2002; Titman, 2001), some young people adjust relatively well (Bilboul, Pope, & Snyder, 2006; Cochrane & Slade, 1999; Egan, Harcourt, & Rumsey, 2011; Feragen, Kvalem, Rumsey, & Borge, 2010; Lansdown et al., 1997).

The focus on heterogeneity and the call to consider resilience, coping and positive adaption has emerged over the past decade in line with the developmental psychopathology framework (e.g., Cicchetti & Cohen, 2006) that incorporates multiple and interacting variables to explain multifinality in developmental pathways. e.g., childhood sexual abuse and trauma (Cicchetti, 2013; Toth & Cicchetti, 2013). This study used a qualitative approach in order to attempt to hear and understand the experiences of young people with a VFD from their own accounts. Its design was influenced by these emerging ideas and a desire to explore the complexities and range of experiences reported by this population. The findings of this study are considered in the context of the existing literature, and implications for future work are discussed.

The use of this methodology allowed young people to speak about the complexities of living with a VFD and to share a range of experiences. Many

young people described the difficulties of living with a VFD as a result of the negative reactions and attention they received from others e.g., name-calling, teasing, intrusive questions and being left out by their peers. This finding is consistent with the literature reviewed in Part 1 of this thesis which suggests that non-disfigured children demonstrate a negative bias towards individuals with a VFD (Harper, 1997; Harper & Peterson, 2001; Masnari, Schiestl, Weibel, Wuttke, & Landolt, 2013; Nabors et al., 2004; Schneiderman & Harding, 1984; Sigelman et al., 1986; Tobiasen, 1987) and suggests that the view from the outside (evidence that non-disfigured children show a negative bias towards individuals with VFDs) is consistent with the view from the inside (that young people with a VFD report social rejection by their peers).

However, although young people with VFDs found these negative social experiences distressing, most of the participants reported working hard to develop and maintain their positive sense of self. Young people described utilising a range of cognitive, behavioural, emotional and relational coping strategies in order to modulate the impact of these negative social experiences on their sense of self. For example, many of the participants appeared to identify positively with their VFD and saw it as a valued part of who they were. Despite this, several young people worried about the impact that their VFD would have as they got older and expressed a wish not to have a VFD for the rest of their lives.

These findings highlight the subtleties and complexities of young people's experiences of social rejection, and the difficulties they faced in maintaining a positive sense of self in light of these experiences. Although many young people appeared to value being different, there was a degree of fragility in

their ability to fully accept their appearance evidenced in their wish not to have a VFD for the rest of their lives. It appeared therefore that greater psychological effort was required at certain times to balance the views they had about themselves (the view from the inside) and the messages they received from others (the view from the outside).

These findings are consistent with the concept of a multi-factorial explanatory model and suggest that individual coping styles may account for the psychological and social heterogeneity that young people with VFDs report. Researchers in the field of disfigurement have begun to explore variables which may modulate the relationship between VFDs and adjustment in adults with a VFD (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2013). However this is only starting to be explored in young people with a VFD (e.g., Feragen et al., 2010). Future research should aim to consider complex and multi-factorial causal pathways in young people with a range of VFDs, given the likelihood that they will help inform our understanding and ability to support young people with VFDs.

Conclusion

This study aimed to hear the voices of young people and to understand the experiences of living with a VFD from the young people themselves. The study was designed to support young people to express the full range of their experiences, and the feelings that these experiences evoked. A number of barriers to capturing the voices of young people were experienced in the course of conducting this study, including difficulties facilitating engagement and parents'

anxieties about whether to allow their child to talk or not to talk. Despite these difficulties, this study has made a unique contribution to the existing literature and has highlighted the subtleties and complexity of young peoples experiences and the difficult balance struck between managing the views young people have about themselves (largely positive) with the views of others (largely negative). The ability to maintain a positive sense of self appeared to be influenced by the use of a range of cognitive, behavioural, emotional and relational coping strategies. These findings support the use of multi-factorial models to understand psychological functioning in this population, which has only recently begun to emerge in the adult population. Further research should consider the variables which may modulate the impact of adverse social experiences on adjustment in young people with a VFD.

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Appendices

Appendix A

Full Research Protocol

Full Research Protocol

Types of Studies

Empirical papers which explore the attitudes of non-disfigured children towards individuals with a VFD using quantitative and/or qualitative methodology will be included in this review. Unpublished papers, single case designs and review papers will be excluded. Studies that consider attitude change following an intervention will also be excluded.

Types of Participants

The target population of this review will be children and adolescents between the ages of 2 and 18 years without a VFD, physical disability or intellectual disability. The attitudes of disfigured children towards their own (self-perception) and others appearance has been extensively researched and therefore will not be considered as part of this review. It is anticipated that participants will largely be recruited from non-clinical populations e.g., schools.

Types of Stimulus

Attitudes towards children and adolescents, aged between 0 to 18 years, with a VFD will be measured. For the purposes of this review a VFD will include conditions classified as congenital (e.g., port-wine stain), acquired (e.g., facial scar), or counterfeit (e.g., replicas which are likely to be created by the researchers using make up or face paint).

Attitudes towards individuals with a physical disability, oral or dental facial disfigurement (e.g., misshapen jaw) or who have a disfigured appearance

as the result of surgery will not be included in this review. Individuals with a non-visible disfigurement, or a disfigurement away from the face will also be excluded.

It is anticipated that the child depicted in the stimulus image will be presented to the target population using drawings, photographs, or in person.

Types of Outcomes Measures

Data will be self-reported by the participant using both quantitative and qualitative methodology. The focus of this review is on studies which explore the attitudes of non-disfigured children towards VFD therefore outcome measures will likely include direct or indirect measures of attitude which will be categorised as either affective, behavioural or cognitive.

Search Methods for Identification of Studies

Electronic searches

The electronic databases of PsycINFO, Medline and CINAHL Plus will be searched for the period of January 1970 to October 2014. Search items will be used from the three key domains which represent the research question.

Searching other resources

The references of publications which fulfill the inclusion criteria will be scanned to identify any additional papers relevant to this review which were not identified by the original electronic search.

Language

Papers written in non-English language will not be sourced.

Data Collection and Analysis

Selection of studies

The selection of studies will involve five stages which will be completed by the author. The five stages include:

Stage 1: Duplicates will be removed using the function available on EndNote.

Stage 2: A preliminary screen of the titles will be undertaken according to the inclusion criteria of this review. Irrelevant subject headings will be listed under reasons for exclusion.

Stage 3: The abstracts of the remaining papers will be screened.

Stage 4: The full text articles of papers will be sourced and reviewed where further information is required to determine suitability for the review.

Stage 5: The reference lists of papers included in the review following stage four will be scanned and the abstracts and/or full text articles will be reviewed to determine suitability.

A flow diagram of attrition will be completed simultaneously to this process and reasons for exclusion noted at each stage.

Data Extraction and Management

Data will be extracted from each paper which meet the inclusion criteria using the data extraction form (Appendix C) which has been adapted from guidelines which informed this review (Higgins & Green, 2011; CRD, 2009).

Quality Assessment

The data extraction form will include questions designed to assess the methodological quality of each paper. These questions will be adapted from relevant guidelines (Higgins & Green, 2011; CRD, 2009) based on the type of studies included in this review. The quality of papers will be assessed according to sample size, the reliability and validity of outcome measures and risk of bias (selection bias, incomplete outcome data and selective outcome reporting). Studies of higher quality and low risk of bias will be given more weight when drawing conclusions.

Data Synthesis

Following data extraction, information on participants, outcome measures and results will be synthesised into a characteristics of studies table (Table 2). At this stage data will be categorised for ease of interpretation. The age of participants will be categorised according to Piaget's cognitive stages using the mean age where available; middle childhood from ages 4-7 (corresponding to the pre-operational stage), late childhood from ages 8-11 (concrete operational) and adolescence from ages 12-18 (formal operational).

It is anticipated that there will not be a sufficient number of comparable studies to complete a meta-analysis. It is expected that a narrative synthesis will be used to explore the relationship between studies and provide an assessment of the quality of the data.

Appendix B

Table of Search Strategy and Results

Table 1

Search Strategy and Results

	PsycINFO	Ovid Medline	CINAHL Plus
Search 1 "Children"	#1: Child.ab, ti. #2: Children.ab, ti. #3: Pupil*.ab, ti. #4: Adolescent*.ab, ti. #5: Student*.ab, ti.	#1: Child.ab, ti. #2: Children.ab, ti. #3: Pupil*.ab, ti. #4: Adolescent*.ab, ti. #5: Student*.ab, ti.	#1: Child.ab. #2: Children.ab. #3: Pupil*.ab. #4: Adolescent*.ab. #5: Student*.ab.
	#6: Combine #1 OR #2 OR #3 OR #4 OR #5	#6: Combine #1 OR #2 OR #3 OR #4 OR #5	#6: Combine #1 OR #2 OR #3 OR #4 OR #5
Search 2 "Attitudes"	#7: Stereotyped attitude exp #8: Attitude*.ab,ti. #9: Response*.ab,ti. #10: Rating*.ab,ti. #11: Perception*.ab, ti.	#7: Attitude*.ab,ti. #8: Response*.ab,ti. #9: Rating*.ab,ti. #10: Perception*.ab, ti.	#7: Attitude*.ab. #8: Response*.ab. #9: Rating*.ab. #10: Perception*.ab.
	#12: Combine #7 OR #8 OR #9 OR #10 OR #11	#11: Combine #7 OR #8 OR #9 OR #10	#11: Combine #7 OR #8 OR #9 OR #10
Search 3 "Facial Disfigurement"	#13: Physical disfigurement exp #14: Facial* disfigure*.ab, ti. #15: Facial* differen*.ab.ti. #16: Facial* deform*.ab, ti. #17: Visib* disfigure*.ab, ti. #18: Visib* differen*.ab, ti. #19: disfigure* appearance.ab, ti.	#12: Facial* disfigure*.ab, ti. #13: Facial* differen*.ab.ti. #14: Facial* deform*.ab, ti. #15: Visib* disfigure*.ab, ti. #16: Visib* differen*.ab, ti. #17: disfigure* appearance.ab, ti. #18: disfigure* condition.ab, ti.	#12: Facial* disfigure*.ab. #13: Facial* differen*.ab. #14: Facial* deform*.ab. #15: Visib* disfigure*.ab. #16: Visib* differen*.ab. #17: disfigure* appearance.ab. #18: disfigure* condition.ab.

	#20: disfigure* condition.ab, ti.	#19: dermatology* condition.ab, ti.	#19: dermatology* condition.ab.
	#21: dermatology* condition.ab, ti.	#20: scar.ab, ti.	#20: scar.ab.
	#22: scar.ab, ti.	#21: scars.ab, ti.	#21: scars.ab.
	#23: scars.ab, ti.	#22: burn.ab, ti.	#22: burn.ab.
	#24: burn.ab, ti.	#23: burns.ab, ti.	#23: burns.ab.
	#25: burns.ab, ti.	#24: cleft.ab, ti.	#24: cleft.ab.
	#26: cleft.ab, ti.	#25: birthmark.ab, ti.	#25: birthmark.ab.
	#27: birthmark.ab, ti.	#26: port wine stain.ab, ti.	#26: port wine stain.ab.
	#28: port wine stain.ab, ti.		
Combine Searches	#29: Combine #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28	#27: Combine #12 OR #13 OR #14 OR #15 OR #16 OR #17OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26	#27: Combine #12 OR #13 OR #14 OR #15 OR #16 OR #17OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26
Combine Searches	#6 AND #12 AND #29	#6 AND #11 AND #27	#6 AND #11 AND #27
Results	196	811	208

Appendix C

Data Extraction Form

Data Extraction Form

Authors:

Date:

Title:

Journal:

Part 1: Eligibility

Type of study

Quantitative YES / NO
If yes provide details of study design (e.g. descriptive, comparative or other)

Qualitative YES/NO
If yes provide details of method used (interviews, focus group) and method of analysis

Participants

Are the participants used in this study non-disfigured?

YES   UNCLEAR   NO

Are all participants under the age of 18?

YES   UNCLEAR   NO

Does the study measure the attitudes of participants towards a VFD?

YES   UNCLEAR   NO

If you have answered NO to any of the questions please STOP HERE. If you have answered YES for all questions, please proceed to Part 2.

Part 2: Information About the Study

Characteristics of the study

Country

Where were participants sourced (e.g., school, clinic)?

Was the study funded and if so how?

Characteristics of the participants

Inclusion criteria (please describe)

Exclusion criteria (please describe)

Number of potential participants (i.e. those approached for inclusion)

Number who did participate, including reasons for exclusion

Demographic characteristics

Age range (mean, S.D.) of participants

If mean stated categorise according to Piaget scales.

Gender – number/% of males and females

Ethnicity of participants

Socioeconomic status of participants

Stimuli

Source e.g., photograph, line drawings, confederate

Type of disfigurement depicted by stimulus

Congenital or acquired?

Areas affected

Demographics of stimuli

Age

Gender

Comorbidities

Characteristics of stimuli comparison group (other disfigured, non-disfigured /physical disabilities/illness)

Outcome measures

What were the outcome(s) being studied?

What outcome measures were used?

Categorise as affective/behavioural/cognitive.

Were these measures standardised?

How was the outcome data obtained? (Face-to-face, telephone interview, postal, other)

Gender of interviewer

Place of outcome assessment (clinic, school, home)

Results of outcome data

Are significant differences reported?

Part 3: Study Quality

Were the aims/hypotheses stated prior to the start of the study? YES/NO

Were all aspects of the study conducted prospectively?

How were the patients selected?

What was the sample size?

Was the stimuli used verified by professionals? Were they considered ecologically valid?

Were measures used for outcome assessment reliable? YES/NO/NOT ADDRESSED
Details

Were measures used for outcome assessment valid? YES/NO/NOT ADDRESSED
Details

Were validation checks included within the measure?

Where was the study carried out (individually/classroom setting)?

Were confounding factors considered? If so, which?

Was the method of analysis (qualitative and quantitative) adequately described and appropriate to answer the research questions?

For qualitative studies only, were the researchers blind?

Were sources of bias considered? Rate as low, high or unclear.

    Selection bias
    Reporting bias
    Incomplete outcome data

Limitations identified by the study

Any further comments about this study?

Appendix D

Participant Invitation Letter

"Date"

"Name and address of recipient"

To the Parents/ Guardians of (Name of participant),

Re: Research Project for Young People who look Different

A project, run by ███████████████████████ and University College London Institute of Child Health (UCL-ICH), has been set up to help us to understand what helps children to cope when their appearance is different as a result of a dermatological condition.

You may already be aware of earlier phases of this study, which looked at how young people with a dermatological disfigurement felt about the way they looked and the role of others in supporting these young people. In this study we hope to look more closely at how young people with a dermatological disfigurement interact with their peers and how they manage difficult social situations. For this study, we would like to find out the opinions and experiences of as many young people as possible, between the ages of 11 and 14 years. As such, we would like very much for you and your son or daughter to take part.

We all know that looking different can be very challenging for anyone at any age. Surprisingly, there has been very little scientific research in this area so far. By finding out this kind of information, from as many young people as possible, we hope to be able to develop our psychology service here at ████ to meet the needs of our patients who look different, and their families, in a more effective and sensitive way. We also hope to be able to share this information with people working with similar children all around the world so that they can develop their services too.

We have enclosed two information sheets with this letter (one for parents and one for the young person), which explain the details of this study. These explain what we would want you and your child to do if you agreed to take part. Please read this information carefully. One of the researchers will be in touch with you over the next few days to answer any questions you may have about the project in order to help you decide if you would like your son or daughter to participate. In the meantime, you are welcome to contact us on the telephone numbers below if you have any queries about the project.

Yours sincerely

Kristina Soon
Clinical Psychologist for Dermatology
Chief Investigator

████████████████████
London

Suzy Beak
Trainee Clinical Psychologist
Researcher
University College London
(Ph: 020 7679 1897)

Appendix E

Information Sheet for Parents

Information Sheet for Parents

An exploration of peer relationships and difficult social experiences in young people who look different.

What is this about?

████████████████████████ is in the process of studying several factors that might help us to understand how young people cope with looking different. In earlier phases of this project we looked at how young people with disfiguring medical conditions felt about their own appearance and their experience of how other people react to them. In this phase of the project we are focusing on the relationships that these young people have with other children their age and how they cope in difficult situations, for example where they are stared at by other children.

Why are we doing this?

Previous research shows that looking different can be difficult for young people to deal with, with many children and adults reporting problems, particularly, in social relationships. However, many young people cope very well and have excellent social relationships, despite looking different. We hope that if we can identify the factors that help young people to cope well, we can use this information to support the young people who are coping less well.

How will we do this?

We are asking young people aged between 11 and 14 who have a dermatological condition that makes them look different to meet with us and answer a series of questions about their relationships with other children their age and how they cope in situations which may be difficult. If you agree for your child to take part in this study, we will meet with you and your child in order to get to know you both a bit better before arranging a time to complete the formal interview with your child. This initial meeting should only take about 10-20 minutes and can be arranged to coincide with your child's next outpatient appointment. The formal interview stage is likely to take between 30-40 minutes and can be done in the hospital or, if you prefer, in your home.

Are there any risks involved?

As this is a non-invasive task, there are very few potential dangers or risks to your child. However, because some of the questions we will ask your child may seem quite personal or sensitive, such as questions about how your child gets on with other children, there is a possibility that some of the children may feel upset or sad by answering certain questions. If this happens, the researcher, who is a trained psychologist, will be able to provide support to your child. The researcher will inform your child at the start of the interview that they are able to take a break or stop the interview at any time if they wish. If more support is necessary

you and/or your child will be able to meet with the clinical psychologist attached to the Dermatology Team at ▮▮▮ for further assessment or support.

What about the results of the interviews?
In order to remember all the information your child tells us we will audio record the interview. The recorded interview will be transcribed into written form and the recording will be destroyed at the end of the study. Because we believe that this information is of a sensitive nature and should remain private, the name of your child will not be attached to any of the information that we collect. Only the researchers will ever listen to the recording. Therefore, it will be impossible to provide individual results to you and/or your child and the results with remain confidential. Confidentiality will only be breached if a disclosure is made that indicates significant risk of harm to the individual or to someone else by the individual. However, this is a very rare occurrence.

The overall results of the study will be shared with all participants at the end of the project when the results have been analysed. The overall results will also be published in a scientific journal so that other professionals and organisations can benefit from the new information. Again, no information that is shared will reveal the identity of the individuals who participated in the study.

Who will have access to the completed interviews?
The interviews are "owned" by the ▮▮▮ Psychosocial and Family Service and only people belonging to this team, who have been directly involved with this project, will be able to look at the information if they want to. Because names will not be attached to the recordings, no-one will know which participant said what.

The recordings of the interviews and any data entered onto the computer system will be stored safely according to the Data Protection Act (1998). The recordings will be destroyed at the end of the study. If you have any questions about data protection, please contact the Data Protection officer via the switchboard on ▮▮ ▮▮▮▮▮▮▮▮▮

Does my son or daughter have to take part in this project?
No. If you decide that you do not wish for your child to take part in this project, this is entirely your right and will not in any way affect your child's present or future treatment.

What are the arrangements for compensation?
This research project has been approved by an independent Research Ethics Committee that believes that it is of minimal risk to your child. However, all research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in this project.

No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This will require you to prove a fault on the part of the hospital.

Your child will be offered a £15 WHSmith store voucher as compensation for their time given up to take part in this study. This will be sent to your child following the formal interview.

Who do I speak to if I have further questions or worries?
Please contact Kristina Soon who is leading this project. You can contact her either through the ███ switchboard on ██████████ or by contacting the Department of Psychosocial and Family Services on ██████████

If you have any complaints about the way in which the project is being or has been conducted, in the first instance please discuss them with Kristina. If the problems are not resolved, or you wish to comment in any other way, please contact the Patient Advice and Liaison Office (PALS) at ████████████ ██████, which provides free confidential service to help patients, parents and carers with any information, concerns, or problems that they have about their NHS care/service. You can contact PALS on ████████████ ████████

What happens now?
In about a week, one of the research team will contact you by telephone to answer any questions you may have about the project and to ask you if you would like your child to take part. If you agree to participate, the researcher will explain what will happen next. You are free to change your mind, at any stage, about whether you want your child to participate or not.

Appendix F

Information Sheet for Young Person

<u>Information Sheet for Patients (11-14 years)</u>

An exploration of peer relationships and difficult social experiences in young people who look different.

What is this about?

We are trying to find out from young people what it is like to have a medical condition that makes you look different. We know that it can sometimes be quite difficult and some children who look different can find it hard to cope when other people stare at them. We've already been collecting some information about the ways in which young people cope with looking different and now we want to try to understand more about how young people who look different get on with other children their age.

What will you have to do?

If you and your parents agree to take part in this study we will arrange to meet you the next time you come to the hospital to introduce ourselves and get to know you a bit better. After this, we will arrange to meet you for a slightly longer time to ask you some questions about how you get on with other children your age and how you cope if other people stare at you. This should take about 30-40 minutes and can be done at the hospital or in your home if that's easier for you. We will record the interview so that we can remember everything you say.

Why are we asking you?

We are asking as many young people as possible between 11 and 14 years of age who have a medical condition that makes them look different and who come to ████████████████ Hospital for check ups and treatments.

Do you have to take part?

No. It is up to you and your parents to decide. If you decide you don't want to, that's absolutely fine. The doctors and nurses will look after you just the same as ever.

What about the results of the interview?

Your name will not be written onto the recording of your interview and therefore, no one will know what you said. Once we take the information that we need from the recording of your interview, we will delete it so that no one else can see it. All of your answers will be recorded onto our computer but your name will not be stored with your answers. No one will ever be able to find out what you said.

Who will know about the results of the project?

When the project is finished, we will put all the answers together and try to work out how young people feel about looking different. This information will be sent

to you and your parents. The results will also be shared with other doctors and nurses because it might help them to be more aware about the feelings of young people who look different and how to support these young people best. Most importantly, we hope that the information you and the other young people give us will help ▮▮▮▮▮▮▮▮▮▮ provide a better service to all young people with medical conditions that make them look different.

Who can you speak to if you have any questions?
You can speak to your parents. They have been given information about this project. You can also speak to any of the doctors or nurses in Dermatology. One of the people involved in running this project is Kristina Soon, the clinical psychologist who works in Dermatology. You and your parents can always speak to her if you have any more questions.

Your parents have also been given some other contact details of people to speak to if they have any complaints or worries.

What happens now?
In about a week, one of the researchers will contact your parents by phone to answer any questions you may have about the project and to ask if you would like to be involved. If you agree to participate, the researcher will explain what will happen next. You are free to change your mind, at any stage, about whether you want to take part or not.

Appendix G

Consent Form for Parent

Consent Form for PARENTS/GUARDIANS whose child is participating in research studies

Title: An exploration of peer relationships and difficult social experiences in young people who look different.

Please initial each box.

1. I confirm that I have read and understood the information sheet dated 26.09.14. Your child will also be given an information sheet. I confirm that I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐

2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason and without their medical care or legal rights being affected. ☐

3. I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by responsible individuals from regulatory authorities or the NHS trust, where it is relevant to their taking part in this research. I give permission for these individuals to have access to my child's records. ☐

4. I understand that the interview with my child will be audio recorded. I give my permission for all interviews with my child to be audio recorded. ☐

5. I understand that the recording of the interview will be transcribed into written form. I give permission for anonymised quotations to be used in the write up of this study. ☐

6. I agree for my child to take part in the study. ☐

_____   _____

Name of Parent/Guardian   *Name of Child*

_____   _____

Signature of Parent/Guardian   *Date*

_____

Name of Person Taking Consent

_____   _____

Signature of Person Taking Consent   *Date*

Appendix H

Assent Form for Young Person

Assent Form for YOUNG PEOPLE (11-14 years) Participating in Research Studies

Title: An exploration of peer relationships and difficult social experiences in young people who look different.

NOTES FOR YOUNG PEOPLE

1.   You have been asked to take part in a research project. The person organising the research must explain the project to you before you agree to take part.

2.   Please ask the researcher any questions you like about this project, before you decide whether to join in.

3.   If you decide, now or at any other time, that you do not wish to be involved in the research project, just tell us and we will stop the research. Your treatment will carry on as it would normally.

4.   You will be given an information sheet which describes the research. This information is for you to keep and to read at any time. *Please read it carefully.*

ASSENT

I _____ agree that the Research Project named above has been explained to me to my satisfaction, and I agree to take part in this study.

I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

SIGNED   **PRINTED**   **DATE**

--------------------------------   ------------------------------------   ---------------------------
----

SIGNED (Researcher)   **PRINTED**   **DATE**

--------------------------------   ------------------------------------   ---------------------------
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Appendix I

Ethical Approval Letter

20 November 2014

[BLACK REDACTED BLOCK]

Dear Ms Soon

Study title:	**Social rejection in adolescents with a dermatological disfigurement: A qualitative study (An exploration of peer relationships and difficult social experiences in young people who look different)**
REC reference:	14/LO/1497
IRAS project ID:	158019

Thank you for your letter of 17 October 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, [REDACTED]

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper		30 July 2014
Covering letter on headed paper		10 November 2014
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [UCL Insurance Confirmation Letter]	Arthur J Gallagher	14 July 2014
Interview schedules or topic guides for participants	3	15 October 2014
Letters of invitation to participant [Parent invitation letter]	2	28 July 2014
Other [CRAC Approval Letter]		30 July 2014
Participant consent form [Patient Assent Form]	2	28 July 2014
Participant consent form [Parent/Guardian]	4	02 November 2014
Participant information sheet (PIS) [Information sheet for patients]	2	28 July 2014
REC Application Form		01 August 2014
Referee's report or other scientific critique report [Scientific Critque of Proposal]	Will Mandy	24 October 2013
Research protocol or project proposal	3	15 October 2014
Response to Request for Further Information		17 October 2014
Response to Request for Further Information		10 November 2014
Summary CV for Chief Investigator (CI) [CV Kristina Soon]	Kristina Soon	28 July 2014
Summary CV for student [CV Suzy Beak]	Suzy Beak	28 July 2014
Summary CV for supervisor (student research) [CV Dr Stephen Butler]	Stephen Butler	28 July 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Data Collection Protocol]	2	28 July 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form
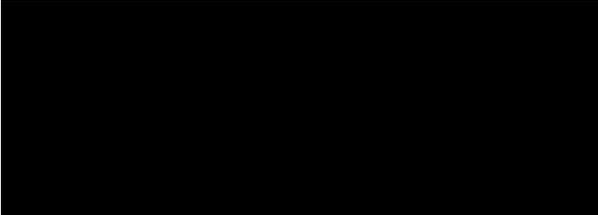
available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

14/LO/1497	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.
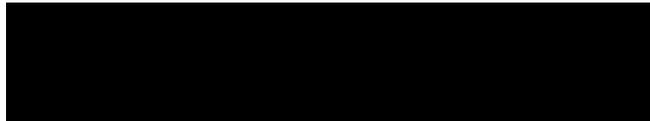
Yours sincerely

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

             "After ethical review – guidance for researchers"

Copy to:

Miss Suzy Beak - University College London

Dr Stephen Butler - University College London

Appendix J

Interview Schedule

Interview schedule

Living with condition

Can you tell me a bit about your condition*[8]?

Can you describe, in your own words, what it is like to live with your condition?

How much does it affect the things you do each day? (Prompt: In what areas do you notice that is seems to affect you the most/the least?)

How much does it affect your relationships with others? (Prompt: family, teachers, peers).

Appearance

Can you tell me a bit about your thoughts on how important the way people look is to you?

Can you tell me your view on how important you find the appearance of others and your own?

How important do you feel it is to others? How can you tell?

Peer relationships

Can you tell me a bit about what it was like when you started at secondary school? (Prompt: what was it like meeting new people?)

Can you tell me a bit about how you get along with other people your age?

Can you tell me a bit about how you think other people view your condition? (Prompt: peers, teachers, family)?

Experiences of social rejection

Can you tell me a bit about a time where things haven't gone so well with other people your age? (Prompt: at school or outside of school?)

Can you tell me about any situations where you have felt unfairly treated by others? (Prompt: left out, teased or bullied).

What are your thoughts on why you were treated in this way?

---

[8] * Use the child's language to refer to condition throughout

Can you tell me a bit about how this situation made you feel and what went through your mind at the time?

How did you react?

Responses to social rejection

Can you tell me a bit about what helps you get through these difficult situations?

Have these situations changed the way you act around other people at all?

Close

If you could give one bit of advice to someone who is the same age as you with your condition who is finding things difficult at school what would it be?

Appendix K

Worked Example of Analysis

P8   Well, just, I would say like focus on, I know they have probably heard this from a million other people but coming from a girl with experience of this, experienced bullying and experienced the worst, just focus on what you want to do and don't worry about others, well your friends, but don't worry about what other negative things people have to say. Like they are just saying it because they have stuff wrong with their lives and they want to bring you down. But technically, and they think you have a hard life because of the way you look but you might just look different but have a completely normal life. You go to school, come home, have dinner, go bed. So just think in your mind, they think that I have a whole, a really bad life, and just prove them wrong. Be like ok and then if you just don't react then they are not going to get the satisfaction of keep saying that and they will stop, hopefully they will stop. And if they don't keep saying what makes you think I want to hear your comments. Do you actually think that I want to believe you? Cos they are just saying it to wind you up, they are not saying it because they are curious, they are just saying it to wind you up straight. So at the end of the day you just need to realize that it is not their opinions that matter, it's yours, and the ones that you love that matter. But if it is just like random people on the streets, or like guys in your school, girls in your school that you don't like just be like I don't know you, you don't know my story, go away. Like there is not, that is literally the only thing, and focus on what you like your hobbies, find hobbies, and its fine.

I   Ok, great. That is really helpful. Have there been any times where you haven't coped so well?

Handwritten margin notes (left): Experienced worst bullying / Focus on what want to do / normal / don't react ignore them / not acting in a curious way / Other peoples opinions don't matter / Focus on hobbies

Handwritten margin notes (right): Ignore negative comments / don't care what people think / Bully makes you feel bad about self / Assume you have bad & hard life / Don't cry in front of them

I shut down

go home and cry

don't tell anyone

P8   Um, when I haven't coped so well. Well sometimes I get, sometimes if people say something really not nice to me I kind of shut down and don't say anything. And they are like yeah she didn't say anything, she kept quiet. And in my head I'm like don't say anything, can I just go, I just walk. And sometimes I go home and I cry and I become really upset but I don't show them, I don't show them that I am crying or I am upset cos it makes them, it makes them feel like they have the power to say more things to her, the power to get to her so I just go home and do all that stuff by myself. I don't tell anyone about it.

got upset

hide feelings

I   What is going through your mind when you are at home upset?

why me?

feel really down

P   I am just like, in my mind I am like why do they say that, why do they pick on me like. But that passes, it passes quickly. That moment of feeling really down, its not nice, it's a really terrible feeling but it passes really quickly and once that moment passes, you think ok that has made me a bit stronger, that has made me face stuff, I haven't faced that before so if something like that happens again I know not to get this upset about it.

it made me stronger I am

learn to suck it up

I   Hmm.

Rare that I get upset

P8   And to be honest it is rare now that I get upset about people making comments about my chin. Unless I am having a really bad day and they are getting on my last nerve or like I don't know, something is really really bad what they said or

less upset now I am a teenager

Appendix L

Table of Themes From Initial Analysis of all Transcripts

Table 2

Themes Emerging From Initial Analysis of all Transcripts

Theme cluster	Themes
Experiences of being treated differently	Staring
	Name calling
	Repeated questions
	Curious questions
	If they said it nicely I wouldn't mind
	Asking in a horrible way
	Being excluded
	Feeling rejected
	Comments from strangers
	Boys care more
	Expect people to treat me differently
Coping with being treated differently	Tell someone
	Talk about my feelings
	Confront person
	Ignore them
	Walk away
	Don't cry in front of them or they will carry on
	Don't take it to heart
	Meet like-minded people
	Focus on hobbies
	Need to be confident

	Answer politely
	Explaining to others
	Messages from parents
Being different	Being different is good
	Different in a good or bad way
	Everyone is different
	Assume you have had a hard life
	Confusion about being different
	I am normal
	I am not normal
	I don't want it
Importance of friends	They don't treat me any differently
	They stick up for you
	Sit with them at lunch
	He made my life a bit better
	Understanding
	I feel vulnerable on my own
This is me	The way you look is who you are
	VFD has made me who I am
	I don't care what other people think
	It is not their business
	They have no right to question me
	I've got this for a reason
	Meeting others with a VFD
	Other difficulties

Responses of younger children	Ignorance of others
	Narrow minded
	Maturity
	Experiences at primary school
	Younger kids stare more
	It bothers me less now I am a teenager
People bully me because	They are jealous
	I am different
	To make you feel bad about yourself
	They see difference as bad
In the past I would feel	It makes me feel angry
	I am sick and tired of it
	It upset me
	Remember the mean things
	It is hard to live with
	I feel horrible about myself
	Lack of self-confidence
	Embarrassed
	Why me?
Value of appearance	Personality is more important
	Don't judge a book by its cover
	Appearance is not important
	It bothers me more as I get older
	It is important in relationships
	Worries about starting a family

	Worries about future career
	Adults are just the same as kids
	You shouldn't judge people on the way they look
	Appearance is important to some people
	Role of media
Experience of starting secondary school	I enjoy school
	It was scary
	I was worried people would say something

Appendix M

Table of Themes Following Re-Clustering

Table 3

Themes That Emerged Following Re-Clustering

Theme cluster	Supplementary elements	Themes
Different in a bad way	Viewed by others as different	Staring
		Name calling
		Repeated questions
		Curious questions
		Asking in a horrible way
		Being excluded
		Feeling rejected
		Comments from strangers
	Life is ten times harder	It is hard to live with
		It upset me
		Remember the mean things
		I feel horrible about myself
		Lack of self-confidence
		Don't cry in front of them or they will carry on
		Other difficulties
	I am sick and tired of it	It makes me feel angry
		I am sick and tired of it
		It is not their business
		They have no right to question me
	It is harder when you are younger	Experiences at primary school

		Younger kids stare more
		Ignorance of others
		Narrow minded
		Maturity
This is me	Being different is good	The way you look is who you are
		I am special
		I am unique
	I should be treated normally	I am normal
		Downward social comparisons
Growing acceptance	Learn to suck it up	It bothers me less now I am a teenager
		Focus on hobbies
		VFD as a part of me
		VFD has made me who I am
	My parents told me that	Messages from parents
	I don't care what people think	Ignore them
		Walk away
		Stand up for self
		Need to be confident
		You shouldn't judge people on the way they look
	Don't judge a book by its cover	Personality is more important Appearance is not important

		Appearance is important to some people
Worries about the future	I don't want it when I grow up	It bothers me more as I get older
		It is important in relationships
		Worries about starting a family
		Worries about future career
	Adults are just big kids really	Adults are just the same as kids
		Role of media

Appendix N

Thematic Map

Thematic Map

Appendix O

Letter to Participants to Disseminate Themes

"Date"

"Name and address of recipient"

Dear X,

Re: An exploration of peer relationships and difficult social experiences in young people who look different

Thank you for taking part in our project on difficult social experiences in young people who look different. I really enjoyed meeting you and was so impressed with how well you were able to talk about your experiences and some of the difficult things you have faced.

I have now met with 17 young people to talk about their experiences of looking different. This has been really useful and will help the doctors and nurses at ███████████████████ to support young people who find it difficult to cope.

At the end of our meeting I said that I would send you a summary of the themes which came out of these interviews. I have listed some of them here and would be interested to know your thoughts on them. As you will see everyone had different experiences so you may not agree with all the themes but that is ok! I would really like to hear your feedback but remember there are no right or wrong answers, I just want to know what you think!

Here are some of the themes that came up in the interviews…

This is me

Many young people saw themselves as different in a good way. They told me that looking different made them feel special and unique and meant they didn't look the same as everyone else. Although they looked different, lots of young people felt that they should be treated normally as they could do all the things that their friends could e.g., eat, drink, play sports and go to school.

A number of young people said that as they got older they started to worry less about the way they looked and felt that they had gotten used to looking different. Instead of worrying about how they looked,

many young people said they would spend their time doing the things they liked, such as going on the computer, reading or playing sports.

I also heard about the role some people's parents had played in helping them to accept their condition. Some young people told me that their parents had always told them that they were special and that their appearance did not matter.

Different in a bad way

A lot of young people told me about times where they were viewed badly by others, including people at school and strangers in the street. A number of young people told me that they were often stared at, called names or asked lots of questions about the way they looked. Some young people felt that the bullies were trying to make them feel bad and were not asking out of interest.

Everyone had different experiences. Some people said that they had experienced a lot of teasing whilst others said it only happened now and then.

Most people said that they felt sad and upset when someone teased them or called them names. A lot of young people also told me that they felt frustrated and angry particularly when a stranger stared at them or questioned them about the way they looked.

People had different ideas about how best to cope with being stared at or picked on. Some people would tell a friend or teacher, focus on something else or ignore them. Others would answer back and try their best to stand up for themselves. Most people said that they tried not to get upset in front of the bully as they thought that this would make them carry on.

It is harder when you are younger

A few people told me that they found things harder when they were at primary school. They said that they were teased and called names and found it difficult to deal with looking different. Some people said that they worried about how they looked more when they were at primary school compared to how they did now as a teenager.

I don't care what people think

Most people told me that they didn't care about what other people thought of them especially if they were complete strangers. A lot of people said that it was rude to judge people on the way they looked and believed that personality was much more important than appearance.

Although a lot of young people appeared to cope well with looking different and the negative comments they received from other people, some worried about how their condition would impact them in the future. A number of people worried about starting a relationship and having a family. Others worried about whether the way they looked would affect their future jobs. Not all young people felt this way and some people believed that if they worked hard enough at school they would be able to do whatever job they wanted.

What now?

It would be really useful to hear what you thought about some of the themes that I have talked about in this letter. I wondered if you would mind sharing these with me, either by sending me an email (suzy.beak.12@ucl.ac.uk) or talking to me over the phone (██████████).

I would be interested to know if….

- There were any things that you particularly agreed with?
- There were any things that you particularly disagreed with?
- There were any extra things that you think are important to tell me about your condition, or dealing with difficult social experiences that I may have missed out?
- And how it made you feel reading about other people's experiences of looking different?

Like I said before there are no right or wrong answers and everything you say will be kept confidential. This means that what you say will be kept private and your name will not appear anywhere in the write up of this project.

If you would rather not share your thoughts then that is absolutely fine, but I hope that you found it useful to read about how your ideas will help other people.

Thank you again for all your help with this project.

Best wishes,

Suzy Beak
Trainee Clinical Psychologist

Appendix P

Pie Graph to Represent Percentage of Quotations Used by Each

Participant

A Graph to Indicate Percentage of Quotations Used From Each Participant

1	
2	
3	
4	
5	
6	
7	
8	
9	
10	