

ROAR, the University of East London Institutional Repository: <http://roar.uel.ac.uk>

This article is made available online in accordance with publisher policies. Please scroll down to view the document itself. Please refer to the repository record for this item and our policy information available from the repository home page for further information.

Author(s): E Felicity Williams, Kenneth Gannon and Kristina Soon

Title: The experiences of young people with Epidermolysis Bullosa Simplex: A qualitative study

Year of publication: 2011

Citation: Williams, E., Gannon, K. and Soon, K. (2011) 'The experiences of young people with Epidermolysis Bullosa Simplex: A qualitative study'. *Journal of Health Psychology*, 16(5), pp. 701-710, doi: 10.1177/1359105310387954.

Link to published version:

<http://hpq.sagepub.com/content/16/5/701.abstract>

Publisher statement:

“© 2011 SAGE. The published version of this article from the *Journal of Health Psychology* is available at <http://hpq.sagepub.com/content/16/5/701>”

Information on how to cite items within roar@uel:

<http://www.uel.ac.uk/roar/openaccess.htm#Citing>

Running head: YOUNG PEOPLE'S EXPERIENCES OF EPIDERMOLYSIS BULLOSA

The Experiences of Young People with Epidermolysis Bullosa Simplex: A qualitative
study

E. Felicity Williams, DClinPsych, BSc Hons

University of East London

Kenneth Gannon PhD

School of Psychology, University of East London

Water Lane

London E15 4LZ

UK

k.n.gannon@uel.ac.uk

Kristina Soon DClinPsych

Clinical Psychologist

Department of Psychosocial and Family Services

Great Ormond Street Hospital for Children

London

UK

Word Count: 5988 (not including Abstract)

Acknowledgements

We would like to thank the participants and their families, whose contributions made this study possible.

Bio-bibliographical notes

E. Felicity Williams has recently completed the Professional Doctorate in CLinical Psychology at the University of East London.

Kenneth Gannon is Research Director for the Professional Doctorate in CLinical Psychology at the University of East London.

Kristina Soon is a clinical psychologist at Great Ormond Street Hospital for Children. She has a special interest in dermatological conditions.

Abstract

Objective: To explore the experiences of young people with Epidermolysis Bullosa Simplex (EBS).

Method: 11 participants aged 10 -14 years were interviewed. Interpretative Phenomenological Analysis was employed.

Results: A key theme was 'self as different'. This related to experiences of negative treatment and exclusion from peers; a lack of understanding of others about the condition; and a sense of the self as 'wrong'.

Conclusions: Findings indicate the importance of providing appropriate psychological and peer support, as well as wider community education and intervention, as part of the holistic treatment of young people with this chronic, painful and visible skin condition.

Keywords: Epidermolysis Bullosa; children; IPA; chronic conditions.

Introduction

Epidermolysis Bullosa (EB) is a group of hereditary chronic dermatological conditions in which the proteins necessary for the cohesion of the skin are missing. The principal clinical feature of EB is extremely fragile skin, which blisters very easily (Pye, 1992). Three main types of EB have been identified (Pye, 1992). Symptoms and severity vary within all categories of EB, with some children requiring little preventative or medical intervention and others requiring frequent inpatient care (Herod et al., 2002). EB Simplex (EBS) is generally considered to be the mildest form of EB. Blistering can either be localised to the hands and feet or found in areas of friction including the face, and the main clinical effects are pain and limited mobility (Sprecher, 2010). The most severe forms of EB are associated with a significant reduction in life expectancy (Pye, 1992). No cure for EB is currently available, and management of the condition predominantly involves minimising the damage caused to the skin, for example by the use of protective bandaging, or limitations to activities (Herod et al., 2002). EB is estimated to affect 1 in 40,000 live births (Horn et al 1997) and there are currently approximately 5,000 people with EB in the UK (DebRA).

Western culture attaches considerable significance to physical appearance and attractiveness and the ability of mass media to propagate particular norms of physical beauty has resulted in a great many people in developed countries experiencing dissatisfaction with their appearance (e.g. Groesz, Levine and Muernen, 2002).

People who are disfigured, deformed or visibly different in ways that depart markedly from established norms of attractiveness are likely to experience particular difficulties. The skin, particularly of the hands and face, is one of the most immediately noticeable aspects of our appearance. Even relatively transient alterations to the skin in these

areas, for example because of injury or acne, can result in psychological distress (Rumsey and Harcourt, 2007; Titman, 2005). Children and young people who are visibly different may develop a negative self image and experience psychological difficulties. For example, up to a half of 12-20 year olds with acne were reported to experience psychological or social problems (Smithard et al., 2001). For many children the appearance-related aspects of a skin condition are experienced as being more problematic than any associated physical limitations. Fox, Rumsey and Morris (2007) interviewed eight young people aged 11 to 18 years with psoriasis and identified a range of psychosocial concerns associated with the visibility of the condition. Other studies have reported higher rates of psychological difficulties in children with skin conditions than in healthy children (e.g. Smithard et al., 2001) and particular attention has been drawn to the impact of skin conditions on young people's self-esteem (e.g. Papadopoulos et al., 2000) and Quality of Life (QoL) (e.g. Chuh, 2003).

There is, therefore, reason to expect that EB is likely to pose particular problems and challenges to young people with this condition, both because of the impact on appearance and because of the very significant functional limitations associated with it. Horn and Tidman (2002) explored the impact of different types of EB on QoL in both adults (N = 90, age range 16-86 years) and children (N = 30, age range = 1-15 years) with EB employing the Dermatology Life Quality Index. Their findings indicated that all types of EB had a marked impact on QoL, although they found no clear relationship between symptom severity and QoL. Titman (2001) also employed standardised measures of symptom severity and quality of life and found no correlation between the severity of children's EB (as rated by the parents) and the child's psychological adjustment (as rated by the parents, children and school teachers). However, she also reported that children with EB (of all types) demonstrated reduced self-esteem in

comparison with norms on scales relating to athletic competence and physical appearance.

Concerns regarding physical appearance have been identified in research that sought to explore the impact of EB on parents of children with the condition. Qualitative studies by Lansdown et al., (1986) and van Scheppingen et al., (2008) reported mothers' concerns regarding others staring at their children and making negative comments relating to visible blisters. This is consistent with literature suggesting that adults and children with skin conditions can experience negative treatment by others (e.g. Gupta et al., 1998). van Scheppingen et al (2008) interviewed nine children suffering from different subtypes of EB and identified five main problems experienced by them. These concerned having itchy skin, pain, difficulties in joining in with others, the visibility of the condition and feelings about being different. The impact of these problems depended to an extent on the type of EB a child suffered from, with pain being a major issue for those with junctional and variants of dystrophic EB while children with EB simplex reported particular problems regarding difficulties joining in and concerns about appearance.

Overall, we have a limited understanding of the psychological impact of EB on children and much of what we do know is based on the views of parents. Whilst parental and carer perspectives are important, it must not be assumed that they represent the view of the child. The assumptions made by adults may be different from the views of children (Davies et al., 1991). Indeed, Woodgate (2000) stated that when the voices of children are not included in child-related health research, an understanding cannot be complete. Van Scheppingen et al (2008) interviewed children, but they recruited children with a variety of types of EB resulting in a limited understanding of the experiences associated with any single type.

The aim of our study was to explore children's experiences of living with EBS. It is considered to be a relatively mild form of EB and, possibly for this reason, it has received less research attention than other types. Given that there is no clear relationship between the severity of a disfiguring condition and its psychological impact (Rumsey and Harcourt, 2007) it is problematic to assume that those with more severe types of EB will necessarily experience more psychological distress than those with EBS.

Method

Participants

Potential participants all received their medical care at the same national children's hospital (a major centre for the care of children with EB) in the UK. They were required to have a diagnosis of EBS, to be fluent in spoken English and to be between 10 and 14 years of age. Twenty one young people met these inclusion criteria. They and their parents were sent a letter outlining the purpose of the study. This was followed up by a telephone call approximately ten days later in which the research was explained in more detail. Those who expressed an interest at this point were invited to attend for interview. Eleven young people chose to participate. Participants and non-participants were similar in terms of age, ethnicity and educational attainment. Six of the 11 participants were male. One of the participants identified themselves as 'Black British', two identified themselves as 'British Asian', and eight identified themselves as 'White British'. They ranged in age from 10 to 14 years with a median of 12 years.

Procedures and Interview Schedule

The study was approved by the UK National Health Service (NHS) and the University of East London ethics committees. Before the interview the study was explained in detail to

the child and accompanying parent(s), following which participants and their parent(s) signed a consent/assent form. Data were collected by means of individual, semi-structured interviews. The interview schedule covered the broad range of issues regarding psychological and social aspects of EB identified from the literature review. It was reviewed by a clinical psychologist familiar with the psychological aspects of dermatological conditions. The following areas were explored: illness severity, visibility, social experiences, others' views of EBS, the effect of EBS on feelings and ways of coping.

Ten participants chose to be interviewed in their homes, one chose to be interviewed at the hospital and three opted to have their parents present during the interview. While this may have influenced the willingness of these children to be open about certain issues it was considered to be good practice with this age-group. Interviews lasted between 15 and 70 minutes. . All interviews were audiorecorded and transcribed¹ for subsequent analysis. During the transcription process identifying details were removed and pseudonyms were used in order to maintain anonymity.

Data Analysis

Interpretative Phenomenological Analysis (IPA) was chosen because of its focus on the nature and meanings of people's experiences (Smith & Osborn, 2003), particularly its relevance to understanding how people "perceive and make sense of their lived experiences of illness (Eatough and Smith, 2008, P. 186). Following the transcription of all interviews, one transcript was read a number of times. Initially, wide-ranging notes (including summarising and preliminary interpretations) were recorded in accordance

¹ Key for transcript notation: (.) = noticeable pause; ... = text not relevant to the theme has been omitted; {abc} = text inserted for clarification. Punctuation has been added to facilitate reading.

with the process outlined by Smith and Osborn (2003). Following this, further reading of the same transcript aimed to categorise and name themes that were deemed to typify each section of text. Emerging themes were then amalgamated into meaningful clusters (Smith & Osborn, 2003). During this process the transcript was frequently referred to in order to check that emerging themes and clusters were grounded in the participant's actual response. Following this, a table of themes was produced. This list of themes was then used to inform the coding of each remaining interview, with themes being added to or altered in the process (Willig, 2001). When this first round had been completed for each transcript the analytic process was repeated in a second round in order to review each transcript for the presence of themes that had been identified in later transcripts during the first round of analysis (Smith et al, 1999). The first author (a trainee clinical psychologist working with children in the hospital in which the study was conducted, although not with this particular group of children) was primarily responsible for the data analysis. A number of analytic audits helped ensure the credibility of the analysis. These credibility checks included: a blind coding audit by someone familiar with IPA and the clinical population being studied; sending a summary of emerging themes to participants and inviting feedback; and providing an 'audit trail' for peer review. Disagreements identified by these checks were resolved in discussions among the three authors. Once each transcript had been analysed and credibility checks had been carried out, a table of themes was constructed.

Results

Four major themes resulted from the analysis: the self as different; physical activity and identity; independence and dependence, and coping. The 'self as different' was a

particularly salient theme in terms of the amount of material contributing to it and the proportion of interview time given to it and has therefore been selected for detailed consideration in this paper. Components of this theme related to visibility and contagion, normality and difference and a lack of understanding from others about the condition.

Visibility and contagion

Many participants described feeling peripheral to, or different from, their wider peer group. Two aspects of their experience were particularly related to this. One concerned the visibility of the condition, especially in relation to the socially significant areas of the face and hands. Visible difference in these areas was experienced as particularly problematic because it invited scrutiny, comment and questions and because of a sense that it was related to judgments about them as a person.

...say if I was normal, and someone was walking down the road and they had like all these (pointing to face) things I would just think they looked, they looked a little bit different. And you'd wonder why and you wouldn't know if the explanation was that they'd been in a car crash or something. All these patches all over your face and I don't (.) I wish it'd go away from my face cos that's what people see, when you look at someone you look at their face and not the rest of them (Rachel, 11 years).

For some children the reactions of others to their appearance made them conscious of their EB in ways they previously had not been: "I only started noticing about my EB when I, kind of people started to make comments, that's when I was about seven or eight, so, before then it didn't really matter because nobody cared" (Rachel, 11 years).

The second salient aspect of their experience was others' fear that EBS was contagious. Kathryn, for example, experienced the behaviour of her peers as

suggesting not only that she could infect them but that she should be excluded from their company:

He said 'I heard you got a disease'...like all the popular people at my school, cos they all follow each other, they think a disease has to be contagious...he always {says} 'she's got something wrong', he gives me like funny looks... as if we shouldn't be there or something (Kathryn, 14 years).

For adolescents such experiences could be particularly difficult:

I don't have no girlfriend... I think that's part of EB.... I think like, if I say to the mainstream girls like 'do you want to be friends with me', they say like 'er don't know', she would say like 'I don't know' or something. Cos, er ... they think about my EB...I think most of them think like, it spreads (Dilip, 12 years).

Participants also gave examples of a lack of understanding and sympathy by adults:

... He (the school teacher) says as well/ I don't know the name of it/ you know that big, circle blister, but I think they're worse, I don't know what they're called. He says that um... he says that they will spread and my mosque teacher says 'oh put your socks on cos when you walk around, like you could come to me and give me your blisters' (Zaman, 14 Years).

On occasion the responses of others were experienced as going beyond intrusion or exclusion: "They were all kind of like really rude and I had to sit at a table and people would call me like things like scabby" (Rachel, 11 years).

Participants' frequent references to the 'popular' and 'mainstream' people at their schools suggested a sense of isolation from the wider group. For some participants,

feelings of loneliness and experiences of isolation were related to the rarity of EB. Two participants described feeling happy and accepted on meeting someone else with EB:

I felt (.) happy in a way, cos I knew then that there was other people like me, cos before, like I'd never seen anybody else with it. So, I just felt really lonely and stuff, cos I thought no-one else was round there to support me with it...like, talk about how we both feel. 'Cos like if they have the same thing as me, they might have the same feelings... I think there should be like kind of a group type thing...like where there's like other people with, not just EB in general but like other disabilities (Kerry, 10 years).

Kerry's use of a collective voice indicates how meeting others with EB provided mutual support as well as a potential new group with whom to identify.

Normality and difference

Participants frequently spoke about how their visible differences and their inability to fully participate in activities marked them out as different and raised issues for them about what it meant to be normal. In the extract above Rachel briefly alludes to normality, but she returned to the issue later in the interview in order to assert her status as a normal person in spite of her appearance and the limitations she experienced: "I wouldn't want to be treated differently to everyone else cos, I am just normal I just happen to have like a skin problem, I am just like a normal person".(Rachel, 11 years).

Simon explicitly linked the issue of normality and appearing normal to experiences of being teased: "They just like taking the mickⁱ out of people who are, like, not normal. Well, not exactly not normal but (.) have something wrong with them...like a disorder or something" (Simon, 13 years). For some children their difference resulted in

physical separation from “normal” children and attracted a label of disability: “I work all day through the high school but I’m still part of {special needs school}... the disabled bit” (Dilip, 12 years).

The behaviour of others was an important factor in giving rise to a sense of being different. People would sometimes openly comment on their difference: ‘Once, when I was on a bus with this lady, she said, like, “What’s wrong with you?”’ (Rachel, 11 years). Even covert scrutiny could be the occasion for reflection on their failure to fit in: “I guess it {other people staring} is because I’m different...I can’t walk properly like the other people. And I can’t do things like the other people can”. (Kerry, 10 years). In saying “I’m different”, Kerry locates the ‘difference’ in herself, rather than viewing it as a relational construct. The use of the term ‘properly’ (a word used by many participants) is suggestive of a right and a wrong way to do things, and relates to the issue of what it is to be normal and indeed to be a fully realized person. Kerry experienced a sense of failure in relation to her inability to meet the standards to which she compared herself. This sense of failing to meet normative standards led participants to question the extent to which others could or would respect their personhood: “Some people might think that I’m not a full person ‘cos I can’t do anything, do like all the things that other people can do. ‘Cos I’m not like them they think that I don’t count as a proper person”. (Kerry, 10 years).

However, some children experienced a dilemma in relation to asserting their normality because in order for the difficulties associated with their EB to be acknowledged they sometimes found it necessary to highlight their ‘difference’.

I: it sounds like it’s important that people know what you’ve got.

Bella: yeah

I: what else, what's so good about that?

B: cos they know what you've got they know how hard, and how hard it is, and how it hurts as well. They say "so it's just like normal blisters" and I'm like 'no, it's different' (LAUGHS) (Bella, 13 years).

Bella's experience illustrates a particular consequence of a lack of knowledge concerning EBS among the general population. This issue is explored in more detail in the next theme.

Lack of Understanding

EB is a rare condition, one with which few people will have experience, and the resultant lack of knowledge sometimes left the participants feeling that others did not understand the limitations it imposed on them and, on occasion, to a failure to believe that anything was the matter. The fluctuating nature of EBS contributed to this:

"They said that I was making it up. Cos sometimes I can walk but most of the time I need a wheelchair, so I guess they saw me walking and then next saw me in a wheelchair so they thought I was making it up. And then they started calling me all names... like liar and things" (Kerry, 10 years).

The importance of others' understanding in terms of shaping participants' experiences of EBS was also conveyed by accounts suggesting increased difficulties at transitional periods, such as changing classes or schools: "I've moved up, I've got different teachers...they don't know it as well...and that's harder" (Bella, 13 years).

Rachel made a similar point:

"At my primary school, like people knew me and they knew not to just be like kind of, like rude about it, if you know what I mean? There's some people, they're just like all rude and it's just 'oh, look at your face' and things like that, say if you get

into an argument with someone and things like that. But at my primary school they will know not to say something like that" (Rachel, 11 years).

Participants were at times put in the position of having to "educate" others about the condition: "I just say it's a skin condition where you get blisters quite often...and just, that's it really. Cos, if they haven't got it they don't really need to know a lot about it cos, that's just like the basic thing of it" (Simon, 13 years). Such explanations could serve the purpose of accounting for some of their experiences and limitations:

"Because {if} they know what you've got they know...how hard it is, and how it hurts as well' (Bella, 13 years).

Discussion

The children in this study all suffered from what is generally considered to be a relatively mild form of EB. Nevertheless their accounts indicate a strong sense of being different from and, at times, actively excluded by their peers. They undoubtedly experienced pain, discomfort and a considerable degree of disability as a consequence of EB, but it was the social impact of their condition that emerged most strongly in their accounts. The impact centered on their visible difference, particularly in cases where the hands and/or face were affected and the consequences of this in terms of public scrutiny, shunning by others and negative and aversive social interactions. Such experiences led them to question their own normality and the extent to which others would accept their personhood. These are somewhat different from the findings reported by van Scheppingen et al (2008), in which itchy skin and pain emerged most strongly. van Scheppingen et al recruited children with various types of EB whereas we focused on children with a particular sub-type, indicating the importance of the relationship between experience and disease type.

Social comparison by children with EB and their exclusion from activities, coupled at times with negative treatment by others, appear to have contributed to the development of the idea of the self as different. Rumsey and Harcourt (2007) identified the important part played by social comparison in the development of self-image in children with visible differences and the negative impact of teasing on the development of a confident and secure sense of self. While both adults and children with skin conditions can experience difficulties in social relationships and negative treatment by others (e.g. Gupta et al., 1998) the period of adolescence is associated with a particularly strong focus on the importance of appearance (McCabe and Ricciardelli, 2005) and a marked relationship between appearance and sense of self (Harter, 1999; Seidah and Bouffard, 2007). Several of the young people in the present study identified a change in their experiences and awareness of their condition as they became older and changed schools. This was partly because they were exposed to a new set of peer pressures and partly because they were confronted by people, both young and adult, who they had to inform and educate about their condition. Visible differences, particularly of the face and hands, make blending into a new environment difficult or impossible. Fox et al (2007) identified visibility, contagion and lack of knowledge about psoriasis as issues for children with this condition. van Scheppingen et al (2008) also found difficulties joining in, visibility (including hiding hands), contagion, lack of understanding by others and normality to be concerns of the children with EB that they interviewed.

Experiences related to fears of contagion in the present study are consistent with literature suggesting that dermatological conditions, especially those with a disfiguring component, are frequently the subject of beliefs regarding a lack of hygiene and contagion (e.g. Papadopoulos, 2006; Fox et al, 2007). Our participants' accounts

indicated that instances of this kind were due to a lack of understanding from others regarding the condition, which is consistent with findings from van Scheppingen (2008) and studies of other dermatological conditions, such as psoriasis (Fox et al, 2007). A lack of knowledge and understanding from others (and associated difficult social experiences) seemed to be particularly evident in accounts of moving to a new environment, such as changing academic years or schools. This is consistent with literature suggesting that transitions can be difficult for a child with a skin condition, who often experiences negative reactions at such times, including curiosity and intrusive comments (Titman, 2005).

Participants described more negative experiences associated with the visibility of EBS when they had facial blisters. This finding is consistent with reports that young people with facial acne had lower self-esteem than those with acne on their bodies (Papadopoulos et al., 2000). Research has shown that body image plays an important role in adolescent self-esteem (e.g. Abell & Richards, 1996; Harter, 1999; Mintz & Betz, 1986) and perceived physical appearance has been shown to determine self-esteem in adolescents (Seidah and Bouffard, 2007). Additionally, 'peer bonding' has been highlighted as a central task of adolescence, with peer group norms becoming particularly important (e.g. Eiser, 1993). Our data too show that feeling (or being treated as) different to the 'norm' was a particularly difficult experience for some participants. The importance of the peer group was also evidenced in accounts suggesting that experiences of 'belonging' positively influenced participants' experiences of EBS. This was highlighted in accounts of meeting other young people with EB, which resulted in feelings of being 'supported'. The importance of establishing a shared identity with children who have had similar experiences is something that has been identified in research with children with skin conditions such as psoriasis (e.g. Fox, Rumsey and Morris, 2007).

Many participants referred to the role of physical activity in creating a sense of belonging, although they were frequently unable to participate in such activities. These findings are consistent with the view that physical activity provides 'normalizing experience(s)' in which 'social networks with peers are enhanced' (Taub & Greer, 2000, p. 395), and with Titman's (2001) findings that children with EB scored below norms on specific self-esteem scales related to athletic ability. In the present study low self-esteem was evident in other areas too, for example in references to the perceived negative views of others regarding the visibility of the condition, as well as expressed negative views about the self. The latter were salient in accounts in which participants seemed to subjugate themselves to the 'norm', once again indicating the importance of social comparison in young people's experiences of EBS and their developing sense of self.

Clinical Implications

Our findings are consistent with the view that the social context of the child, in particular the behaviour and attitudes of others, is fundamental in shaping their experience of chronic conditions (Kazak, 1992). Given this, psychological interventions targeted at the child, such as cognitive behavioural therapy, could be in danger of locating the causes of the distress associated with living with EBS within the individual while ignoring the wider context. Interventions aimed at addressing the negative attitudes and behaviours of others represent an alternative possibility. Such work might usefully include further development of anti-bullying policies in schools and a proactive approach to promoting and managing difference. There may be a role for community psychology in this regard, for example in the provision of outreach work to schools. Psychologists could also contribute to the compilation of information for teachers and peers about EBS.

Individual work with children with EBS could perhaps adopt a solution-focused approach to addressing issues such as bullying and stigma.

Papadopoulos (2006) notes that dermatological conditions rarely receive media attention and that the challenges they pose are often minimized. This resonates with some of our participants' accounts, who described having to educate others about the nature of their condition and its seriousness being trivialized by peers. This suggests the need for public health education campaigns about EBS and other dermatological conditions, highlighting in particular the physical, emotional and social challenges posed by them. As issues related to contagion have repeatedly been identified in studies on dermatological conditions this is an issue requiring special attention.

The provision and facilitation of informal support groups may be a useful step forward in allowing young people with EBS opportunities to talk to each other about their experiences of the condition and to reduce the associated sense of isolation. The introduction of summer camps for young people with EBS might also prove beneficial. These could allow participants to become involved in physical activity in a way that does not reinforce the young people's sense of difference or failure. Attendance at summer camps has been reported to lead to a number of benefits for young people with chronic conditions, (e.g. Briery & Rabian, 1999; Hunter, Rosnov, Koontz and Roberts, 2006). In addition, systemic approaches have highlighted the importance of peer support in helping chronically ill adolescents develop new coping techniques, in reducing isolation and the enhancement of social identity through group approval (Olsson et al., 2005).

Areas for Future Research

It would be valuable to conduct a longitudinal study of children with EBS in order to develop a clearer picture of developmental changes and the ways in which these relate to the experiences of children and young people as they engage in a wider variety of relationships and move further from the childhood focus on the relationship with the parents. The role of family relationships and social support generally in enabling children to successfully negotiate transitions could also be investigated in such a study. Other areas for investigation include comparisons of children with EBS with children diagnosed with other types of EB and formal evaluations of the intervention strategies considered above. It may also be helpful to include participants more actively throughout the research process (for example, collaborating with researchers in identifying research questions, conducting interviews and interpreting data), allowing them more opportunity for 'genuine participation' (Roberts, 2000, p. 225).

References

- Abell, S. C., & Richards, M. H. (1996). The relationship between body shape satisfaction and self-esteem: An investigation of gender and class differences. *Journal of Youth and Adolescence*, **25**, 691-703.
- Briery, B. G. & Rabian, B. (1999). Psychosocial Changes associated with Participation in a Pediatric Summer Camp. *Journal of Pediatric Psychology*, *24*, 183-190.
- Chuh, A. T. A. (2003). Quality of Life in Children with Pityriasis Rosea: a Prospective Case Control Study. *Pediatric Dermatology*, *20*, 474-478.
- Davies, W. H., Noll, R .B., DeStefano, L., Bukowski, W. M. & Kulkarni, R. (1991). Differences in the Child-Rearing Practices of Parents of Children with Cancer and Controls: The Perspectives of Parents and Professionals. *Journal of Pediatric Psychology*, *16*, 295-306.
- DebRA. (2010). Retrieved July 14th, 2010 from <http://www.debra.org.uk/>
- Eatough, V. and Smith, J.A. (2008). *Interpretative Phenomenological Analysis*. In C. Willig and W. Stainton Rogers (Eds.) *The Sage Handbook of Qualitative Research in Psychology*. London: Sage.
- Eiser, C. (1993). *Growing up with a Chronic Disease: The Impact on Children and their Families*. London: Jessica Kingsley Publishers Ltd.
- Fine, J. D., Johnson, L. B., Weiner, M., & Suchindran, C. (2005). Impact of Inherited Epidermolysis Bullosa on Parental Inter-Personal Relationships, Marital Status and Family Size. *British Journal of Dermatology*, *152*, 1009-1014.

Fox, F.E., Rumsey, N. & Morris, M. (2007). "Ur skin is the thing that everyone sees and you cant change it!": Exploring the appearance-related concerns of young people with psoriasis. *Developmental Neurorehabilitation* 10, 133-141.

Groesz, L. M., Levine, M. P., & Murnen, S. K. (2002). The effect of experimental presentation of thin media images on body satisfaction: A meta-analytic review. *International Journal of Eating Disorders*, 31, 1–16.

Gupta, M., Gupta, A. & Watteel, G. (1998). Perceived Deprivation of Social Touch in Psoriasis is Associated with Greater Psychological Morbidity: An Index of the Stigma Experienced in Dermatological Disorders. *Cutis*, 61, 339-342.

Harter, S. (1999). *The Construction of the Self: A Developmental Perspective*. New York: The Guildford Press.

Herod, J., Denyer, J., Goldman, A., & Howard, R. (2002). Epidermolysis Bullosa in Children: Pathophysiology, Anaesthesia and Pain Management. *Pediatric Anesthesia*, 12, 388–397.

Horn, H. M. & Tidman, M. J. (2002). Quality of Life in Epidermolysis Bullosa. *Clinical and Experimental Dermatology*, 27, 707-10.

Hunter, H.L., Rosnov, D.L., Koontz, D. & Roberts M.C. (2006). Camping Programs for Children with Chronic Illness as a Modality for Recreation, Treatment, and Evaluation: An

Example of a Mission-Based Program Evaluation of a Diabetes Camp. *Journal of Clinical Psychology in Medical Settings*, 13(1), 67-80.

Kazak, A. E. (1992). The Social Context of Coping with Childhood Chronic Illness: Family Systems and Social Support. In A.M. La Greca., L. J. Siegel., J. L. Wallander & C. E.Walker, C.E. (Eds.) *Stress and Coping in Child Health*. (pp. 262-278). London: The Guildford Press.

Lansdown, R., Atherton, D., Dale, A., Sproston, S. & Lloyd, J. (1986). Practical and Psychological Problems for Parents of Children with Epidermolysis Bullosa. *Child: Care, Health and Development*;12, 251-6.

Larkin, M., Watts, S. & Clifton, E. (2006). Giving Voice and Making Sense in Interpretative Phenomenological Analysis. *Qualitative Research in Psychology*, 3, 102-120.

Lavigne, J. V., & Faier-Routman, J. (1992). Psychological Adjustment to Pediatric Physical Disorders: A Meta-Analytic Review. *Journal of Pediatric Psychology*, 17, 133-157.

McCabe, M.P and Ricciardelli, L.A. (2005). A longitudinal study to explain strategies to change weight and muscles among normal weight and overweight children. *Appetite*, 45, 225-234.

Mintz, L. B., & Betz, N. E. (1986). Sex differences in the nature, realism, and correlates of body image. *Sex Roles*, **15**, 185-195.

Olsson, C. A., Boyce, M. F., Toumbourou, J. W. & Sawyer, S. M. (2005). The Role of Peer Support in Facilitating Psychosocial Adjustment to Chronic Illness in Adolescence. *Clinical Child Psychology and Psychiatry*, *10*, 78-87.

Papadopoulos, L. (2006). The Psychological Implications of Dermatological Conditions. *Dermatology in Practice*. *14*, 15-17.

Papadopoulos, L., Walker, C., Aitken, D. & Bor, R. (2000). The Relationship Between Body Location and Psychological Morbidity in Individuals with Acne Vulgaris. *Psychology, Health and Medicine*, *5*, 431-438.

Roberts, H. (2000). Listening to Children: and Hearing them. In P. Christensen, & A. James, (Eds), *Research with Children: Perspectives and Practices* (pp.225-241). London: Falmer Press.

Rumsey, N. & Harcourt, D. (2007). Visible difference amongst children and adolescents: Issues and interventions. *Developmental Neurorehabilitation*, *10*, 113-123.

van Scheppingen, C., Lettinga, A. T., Duipmans, J. C., Maathuis, K. G. B., & Jonkman, M. F. (2008). The Main Problems of Parents of a Child with Epidermolysis Bullosa. *Qualitative Health Research*, *18*, 545-556.

van Scheppingen, C., Lettinga, A.T., Duipmans, J.C., Maathuis, C.G.B. & Jonkman, M.F. (2008). Main problems experienced by children with Epidermolysis Bullosa: a qualitative study with semi-structured interviews. *Acta Dermato-Venereologica*, 88, 143-150

Seidah, A. & Bouffard, T. (2007). Being Proud of Oneself as a Person or Being Proud of One's Physical Appearance: What matters for feeling well in adolescence? *Social Behavior and Personality*, 35, 255-268

Smith, J. A., Jarman, M. & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In M. Murray. & K. Chamberlain, *Qualitative Health Psychology: Theories and Methods* (pp. 218-240). London: Sage.

Smith, J. A. & Osborn, M. (2003). Interpretative Phenomenological Analysis. In J. A. Smith (Ed.). *Qualitative Psychology: A Practical Guide to Methods* (pp.5-34). London: Sage.

Smithard, A., Glazebrook, C., & Williams, H. (2001). Acne Prevalence, Knowledge about Acne and Psychological Morbidity in Mid Adolescence: a Community Based Study. *British Journal of Dermatology*, 145, 274-279.

Sprecher, E. (2010). Epidermolysis bullosa simplex. *Dermatologic Clinics*, 28, 23-32.

Taub, D. E. & Greer, K. R. (2000). Physical Activity as a Normalizing Experience for School-Age Children with Physical Disabilities. Implications for Legitimation of Social Identity and Enhancement of Social Ties. *Journal of Sport & Social Issues*, 24,395-414.

Titman, P. (2001). *The Psychological Impact of Skin Disorders on Children and their Families* (unpublished DPhil thesis). University College London, London.

Titman, P. (2005). The Impact of Skin Disease on Children and their Families. In C. Walker, & L. Papadopoulos. *Psychodermatology: The Psychological Impact of Skin Disorders* (pp. 89-100). Cambridge: Cambridge University Press.

Waksler, F. (1991). *Studying the Social Worlds of Children*. London: Falmer Press.

Wardle, J. and Beales, S. (1986). Restraint, body image and food attitudes in children from 12 to 18 years. *Appetite*, 7, 209-217.

Willig, C. (2001). *Introducing Qualitative Research in Psychology*. Milton Keynes: Open University Press.

Woodgate, R. (2000). Part II: A Critical Review of Qualitative Research Related to Children's Experiences with Cancer. *Journal of Pediatric Oncology Nursing*, 17, 207-228.

ⁱ Colloquial English for tease or make fun of.