

Congenital melanocytic naevus (CMN) through the lens: Using photo-elicitation interviews to explore adjustment in adolescents with a rare birthmark condition

Ella Guest^{*}, Heidi Williamson, Diana Harcourt

Centre for Appearance Research, University of the West of England, Bristol BS16 1QY, United Kingdom

ARTICLE INFO

Keywords:

Congenital melanocytic naevus
Birthmark
Psychosocial adjustment
Photo-elicitation
Interpretative phenomenological analysis
Optimism
Positive body image
Body appreciation
Broad conceptualisation of beauty

ABSTRACT

Adolescents with the rare birthmarks congenital melanocytic naevi (CMN) experience physical and psychosocial challenges, many of which stem from looking different from the 'norm'. However, some adjust and have positive experiences. Understanding the lived experiences of adolescents who have adjusted to CMN can provide a holistic picture of adjustment and inform the development of support and interventions for others with the condition. Open, participant-driven photo-elicitation interviews were conducted with four White females (15–17 years) who self-identified as having adjusted to CMN. Participants chose five photographs which were used to guide the interviews (47–80 min). Interpretative phenomenological analysis (IPA) was used to analyse the transcribed interview data. Three superordinate themes were identified: 'Accepting My 'True' Self' (1), 'I am Not Alone in This' (2), and 'Developing as a Person' (3). The themes related to accepting CMN as part of their identity, developing a positive body image (e.g., body appreciation, broad conceptualisations of beauty, body image flexibility), feeling supported and accepted by family, friends, and others with CMN, and developing adaptive coping skills. Findings suggest positive body image may be important for adjustment and can be determined by an individual. The benefits of using photo-elicitation within appearance research are discussed.

1. Introduction

Congenital Melanocytic Naevi, known as 'CMN', are black or brown raised birthmarks, which can affect any part of the body but commonly present on the torso, face, arms, and legs and make an individual look visibly different from the 'norm' (Kinsler et al., 2009). CMN are categorised by diameter as small (<1.5 cm), medium (1.5–19.9 cm), or large/giant (>20 cm; Macneal & Patel, 2023). Small CMN are fairly common, with a prevalence of 1 in 100 births; whereas, giant CMN are rare, occurring in approximately 1 in 20,000 births (Kinsler & Bulstrode, 2009). CMN is thought to occur equally across genders and racial/ethnic groups (Macneal & Patel, 2023).

Some individuals do not experience any symptoms from CMN; however it can cause discomfort, including pain and itching due to skin sensitivity (Masnari et al., 2019; Neuhaus et al., 2020). Furthermore, in a small number of cases, there are serious implications associated with larger CMN, such as central nervous system abnormalities and malignant melanoma (Masnari et al., 2019; Neuhaus et al., 2020). CMN treatment involves self-monitoring for changes in shape or texture, using

sun protection, and specialist hospital appointments to assess whether CMN is present in the brain or spinal cord and the risk of developing skin cancer (Kinsler et al., 2009). Surgical removal of giant CMN is carried out if there is considered to be significant risk of melanoma and is generally not recommended for improving cosmetic outcomes. Reasons for this include it often being difficult to remove all of the CMN, issues with wound healing, and the potential for re-growth (Ott, 2019).

The physical symptoms of CMN, having to self-monitor and attend hospital appointments, and concerns about developing malignant melanoma can affect health-related quality of life. For example, cross-sectional research ($n = 235$) identified that poorer health-related quality of life was related to having more visible CMN (i.e., larger size, noticeable locations on the body) and malignant melanoma (Masnari et al., 2019). Although CMN can cause physical symptoms and require treatment/monitoring, the psychosocial challenges, including those stemming from how the condition affects appearance, are found to have a greater impact of an individual's quality of life and psychosocial adjustment (Masnari et al., 2019). For example, Masnari et al. (2019) found children aged 2–18 years with CMN had significantly poorer

^{*} Correspondence to: Centre for Appearance Research, University of the West of England, Frenchay Campus, Coldhambour Lane, Bristol, United Kingdom.
E-mail address: Ella.Guest@uwe.ac.uk (E. Guest).

emotional functioning and peer relationships than their unaffected peers. Similarly, Neuhaus and colleagues (2020) identified over half of young people (14–18 years) with CMN in their sample felt their condition had a moderate to large impact on their life. Specifically, many felt self-conscious about the appearance of their CMN, which limited their choice of clothing and led them to cover up their birthmarks. These body image and appearance concerns can become particularly problematic during adolescence, when appearance and romantic relationships become the focus of many social interactions and appearance-related bullying and teasing is prevalent (Gattario & Frisé, 2019; Griffiths et al., 2012; Neuhaus et al., 2020; Strauss et al., 2007).

Despite the differing physical characteristics, the psychosocial impact of living with a condition that affects appearance is similar across conditions (Bundy, 2012; Gee et al., 2020; Jenkinson et al., 2015a; Rumsey, 2018). Cognitive, emotional, and behavioural quality of life is affected in between one third and one half of children and young people with conditions that affect their appearance (Jenkinson et al., 2015a). Unfortunately, many challenges stem from the value society places on appearance ideals and negative attitudes towards appearance difference, which can lead to unwanted attention, appearance-based discrimination, bullying, and teasing, particularly during childhood (Masnari et al., 2013; Montgomery & Thompson, 2018; Stock et al., 2013; Strauss et al., 2007). These negative experiences can hinder the adjustment process and lead to negative outcomes including body image concerns, disordered eating, poor self-esteem, social anxiety, and depression (Jenkinson et al., 2015; Montgomery et al., 2016; Rumsey & Harcourt, 2012; Williamson et al., 2016). They can also have a long-term impact on social factors such as forming peer and romantic relationships and career aspirations (Jenkinson et al., 2015a).

Adjustment relates to how well someone adapts to and copes with the physical and psychosocial challenges of their condition. It is a complex and varied process, involving various physical, psychosocial, and cultural factors; concerns about appearance difference are found to be one of the biggest barriers to adjustment (Gee et al., 2020; Masnari et al., 2012; Rumsey, 2018; Stock et al., 2018, 2020). Nonetheless, while children and young people with CMN face appearance-related stigma, many cope well with these challenges and adjust to their condition (Bundy, 2012; Rumsey, 2018). Moreover, some individuals with appearance-altering conditions report experiencing positive body image, greater appearance satisfaction, and more positive experiences than the general population (Alleva et al., 2023; Berger & Dalton, 2009; Feragen & Stock, 2016). Additionally, some research has identified adults and young people with appearance-altering conditions can experience psychological growth due to their condition, including becoming more accepting, seeing appearance as less important, and being better able to support others (Egan et al., 2011; Garbett et al., 2017; Wallace et al., 2007; Williamson et al., 2010). Nevertheless, how these positive experiences develop is not well understood and further exploration of factors that are associated with adjustment and positive outcomes is necessary to inform the development of support and interventions and to foster positive outcomes in all adolescents with CMN.

Gee and colleagues (2019) developed a model to explain adjustment to appearance-altering conditions in children and adolescents. The model proposes four predisposing influences on adjustment (developmental, significant others, individual characteristics, and sociocultural) which impact five domains (psychological wellbeing, social experiences, life engagement, appearance evaluation, and treatment/care) that determine how well an individual adjusts. However, a major limitation of the model is that it was developed using data from health professionals. Indeed, most research into adjustment to appearance-altering conditions, has relied on accounts from adults, parents, or health professionals (e.g., Gee et al., 2020; Koot et al., 2000; Masnari et al., 2019). Moreover, the limited research that has included the perspectives of children and adolescents has focussed on adjustment and quality of life as constructs or outcomes, neglecting to explore nuances in individual experiences and adjustment as a dynamic process (Brocki & Wearden,

2006; Neuhaus et al., 2020; Rumsey, 2018; Thompson et al., 2002a).

For this reason, in-depth qualitative explorations of children and young people's experiences of overall adjustment are needed to better understand the process, including individual differences and the influence of context-specific risk and protective factors (Brocki & Wearden, 2006; Gee et al., 2020; Hefferon et al., 2017; Rumsey, 2018; Willig, 2013). This would enable a better understanding of adjustment models and help support individuals to achieve adjustment, positive outcomes, and become comfortable with their appearance.

One novel qualitative method of data collection which suits explorations into lived experiences relating to appearance is participant-driven photo-elicitation interviews, whereby participants select photographs that have meaning for them in relation to the research question and these are used to facilitate and guide the interview process (Bates et al., 2017). Researchers have highlighted numerous benefits of using photo-elicitation interviews with young people, including making the process more interesting and engaging, which can reduce the researcher-participant power imbalance (Armstrong-James et al., 2019; Cappello, 2005; Prosser, 2011). Moreover, photographs facilitate the interview by helping the young person articulate complex experiences, centring the interview on their own world, and encouraging collaboration and rapport building (Frith et al., 2005; Pain, 2012).

Visual research methods, including photo-elicitation and photovoice (Wang & Burris, 1997), have been used to explore the experiences and perceptions of children and young people with a range of chronic conditions including cancer (Pini, 2019), type 1 diabetes (Melton & Johnson, 2015), spinal cord injury (Singh et al., 2021), and renal failure (Wells et al., 2013). In relation to appearance-altering conditions, photovoice has been used to explore quality of life in adults with the craniofacial condition Crouzon Syndrome (Wheeler & Early, 2017) and photo-elicitation has been used to understand the experiences of children who attended burn camps (Armstrong-James et al., 2019). Additionally, photo-elicitation has been used to explore body image in women with and without multiple sclerosis (Bailey et al., 2021).

Photo-elicitation interviews also complement research using interpretative phenomenological analysis (IPA), a qualitative method used to understand how individuals make sense of their lived experiences. Specifically, photographs can help understand meaning, attitudes, values, and beliefs, which is fundamental to the nature of IPA research (Frith & Harcourt, 2007; Harper, 1986; Prosser & Schwartz, 1998; Richard & Lahman, 2015). The inductive nature of photo-elicitation also lends itself to this and photographs can help a participant and researcher collaborate, which complements the double hermeneutic IPA process (i.e., the process whereby the researcher interprets the participant's own interpretation of their experience; Bates et al., 2017; Pain, 2012). Additionally, the reflective process of photo-elicitation interviews can encourage meaning making from lived experience for a participant (Bates et al., 2017; Pyle, 2013; Radley & Taylor, 2003).

The aim of the study was to use photo-elicitation interviews and interpretative phenomenological analysis (IPA) to understand the lived experiences of young people who self-identified as having adjusted to having CMN.

2. Method

2.1. Design

This qualitative study used open, participant-driven photo-elicitation interviews and interpretative phenomenological analysis (IPA) to gain an in-depth understanding of the lived experiences of four female adolescents (15–17 years) who self-identified as having adjusted to CMN. University research ethics approval was gained prior to recruitment. The Economic and Social Research Council (ESRC) Visual Ethics Guidelines (Wiles et al., 2008) were used for guidance on the ethical issues relating to anonymity in photo-elicitation research. Given that the participants in the study have a rare, visible condition, including the

photographs in the manuscript may make them identifiable even if methods such as blurring are used. Therefore, to maintain anonymity, the photographs themselves have not been included (see Clark (2019) for guidance on making ethical decisions when using visual research methods). A table describing the participants' photographs can be found in the [supplementary materials](#).

2.2. Theoretical position

The research was informed by a relativist ontology, which posits truth is subjective and bound to a particular framework, paradigm, or context (Hugly & Sayward, 1987; Taylor, 1978). Consistent with the aim of understanding lived experience, the epistemological underpinnings were hermeneutics and phenomenology, concerned with gaining knowledge through the interpretation of experience, and idiography, which relates to focussing on particular nuances in experience (Smith et al., 2009). The theoretical underpinnings of IPA are outlined in Fig. 1.

2.3. Research Team

The first author is a White female who was in her late twenties when the research was carried out. She has experience of carrying out qualitative research into the psychosocial impact of appearance-altering skin conditions. The second and third authors are White females in their mid-fifties, with no personal experience of skin conditions. The second has over 15 and the third over 25 years' experience of psychosocial mixed-methods research into appearance-affecting conditions and injuries with adolescents. The first author kept reflexive notes during the research process, including bracketing off potential assumptions throughout the process. In particular, the first author had experience of living with a visible skin condition during childhood and adolescence, which meant that she had some perspective on the experiences of the participants. However, the condition was eczema, which is different to a birthmark condition and is transient in nature, meaning that there are periods of remission and relapse. The author made notes about their experiences of having eczema during childhood in an attempt to bracket off assumptions. A full reflexive essay can be found in the researcher's doctoral thesis: Congenital Melanocytic Naevus (CMN) through the lens: Exploring the positive experiences of young people with CMN using photo-elicitation interviews (worktribe.com). A summary of the reflexive notes made during the data analysis process can be found in the [supplementary materials](#). Supervision with the research team was used to discuss the findings at each stage of the analysis process and a full audit trail of the analysis was kept on NVIVO to increase the transparency of the research (Smith et al., 2009).

2.4. Participants and recruitment

Purposive recruitment was carried out from January – October 2020 by Caring Matters Now, a UK-based charity supporting individuals with

CMN. The charity sent an email advertising the study to their mailing list and posted information about it on their social media pages. The information provided to participants stated "Are you aged 15–17 years old and have CMN on your face and/or hands? Do you think that having CMN can be a positive experience in some ways? Researchers at the University of the West of England want to talk to young people with CMN. They know that having CMN can be difficult at times, but they are interested in finding out if, and how, having CMN could affect young people's lives in a positive way". Additionally, a video of the first author explaining the study was also included.

Four females in mid-late adolescence with CMN on parts of their body that are visible during everyday interactions (i.e., face, neck, hands, legs, arms) took part (Table 1 includes further participant information). This criterion was imposed to maintain homogeneity in social/demographic factors, which is necessary to explore convergence and divergence in experience with IPA (Smith et al., 2009). Four is a suitable sample size for an IPA study, allowing for an in-depth exploration of the data, which focuses on both converging and diverging experiences (Smith et al., 2009).

2.5. Materials

Although there is guidance on combining photo-elicitation and IPA (e.g., Bates et al., 2017), there is currently no practical information on carrying out photo-elicitation and IPA interviews. Prompts used in the open interviews were informed by photo-elicitation and IPA literature, including open questions that were driven by the photographs (e.g., 'Can you describe this photograph to me?', 'Why have you chosen this photograph?') and using IPA prompts to encourage reflection and meaning making (e.g., 'Why?', 'How did that make you feel?'; Bates et al., 2017; Burton et al., 2017; Slavin & Smith, 2009; Smith, 2004, 2007) to fit the interpretive, phenomenological nature of the research question. The existing guidance for photo-elicitation and IPA has been used to develop guidance on combining photo-elicitation interviews with IPA, which is presented Fig. 2.

2.6. Pilot Interview

The interview questions were piloted with the first participant to assess whether they were both suitable for the photo-methodology and would address the research question in sufficient depth for IPA. The pilot interview lasted 50 min and the open format of the interview, driven by the photographs, was successful. Therefore, after discussion with the research team, it was decided that it would be suitable to use the pilot interview as part of the sample, as no major changes to the protocol were made. The first author noted that it was necessary to use numerous prompts during the interview to elicit reflection from the participant, which differed from her experience of interviewing adults. Feedback on the interview was given by a colleague with experience of carrying out IPA.

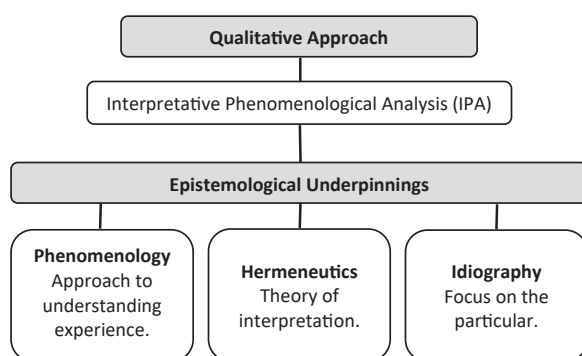


Fig. 1. Visual Representation of the Theoretical Underpinnings of IPA.

Table 1
Participant Characteristics.

Pseudonym	Age	Location of CMN	Interview Format
Charlotte	17	Large CMN on back and satellites on face, arms, and legs.	Video
Alice	15	Large CMN on back and satellites on arms and legs.	Audio
Olivia	15	Large CMN from shoulder blades to knees.	Audio
Robyn	16	Some scarring from CMN removal surgery on face, CMN and satellites on face, arms, legs, and torso.	Video

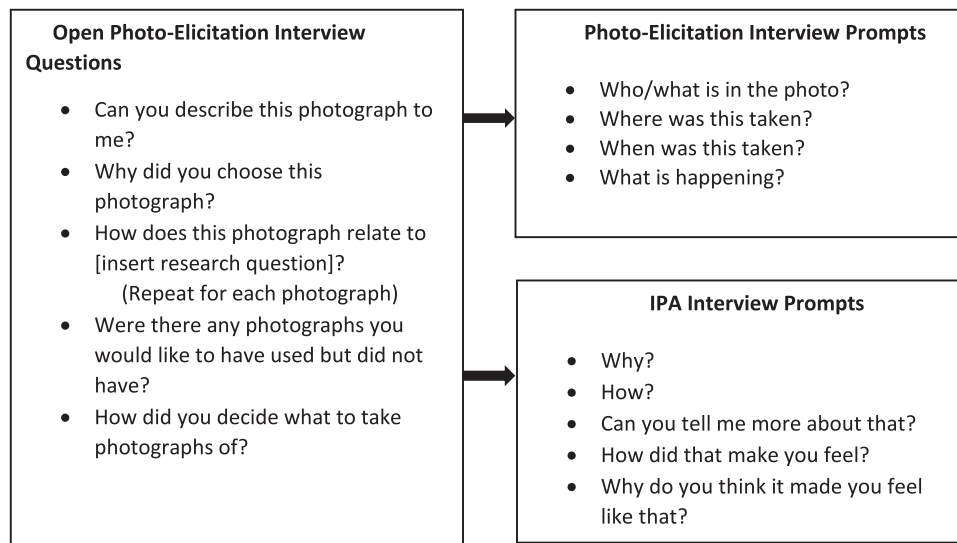


Fig. 2. Process for Developing Interview Schedule to Combine Photo-Elicitation and IPA.

2.7. Photo-Elicitation Interviews

Open, participant-driven photo-elicitation interviews involve participants selecting or taking photographs relating to the research question, which are used to guide the interview process (Frith & Harcourt, 2007; Richard & Lahman, 2015).

2.8. Procedure

Public involvement (PI) from the charity, parents, and young people with CMN was used when developing the research question and methodology, as well as to gain feedback on the study materials, and when determining how to conceptualise adjustment in a way that young people with CMN would be able to understand and relate to (e.g., positive experiences and coping; Hayes et al., 2012). Participants were asked to bring five photographs that they felt showed the positive aspects of having CMN to be used in the interviews. As adjustment is a process that occurs over time, the authors felt it was important to give the participants the option of taking photographs (which is typical of photo-elicitation) and to use existing photographs. Indeed, all of the photographs used in the study by participants were existing and reflected times of importance in relation to adjustment to CMN. It was stipulated that they could be old or new, could have the participant or other people in them, or include a place or thing that reminds them of the positive aspects of CMN. Five photographs were chosen because previous research has used 5–15 photographs with children and young people (Armstrong-James et al., 2019; Pyle, 2013) and as IPA interviews require in-depth data on experience and meaning, it was decided that choosing a higher number of photographs might make the interviews very long or compromise the depth of discussions (Pyle, 2013).

The first author carried out open interviews with each participant over the telephone ($n = 2$) or video conferencing ($n = 2$), which ranged from 47 to 80 min. The participants emailed their photographs to the researcher ahead of the interview. The interviewer began by introducing themselves and asking general questions about the participant's interests, what they were doing at school or college, and what they had been doing that day to build rapport and reduce the power imbalance. Once the participant seemed comfortable with talking to the researcher, the study began. Participants were asked to select one photograph at a time and describe it. They were then asked open questions relating to why they had chosen it, how it made them feel, and how it related to the research question. The researcher noted down any interesting or relevant comments to revisit with the participant. Participants were also

asked whether there were any experiences they would like to have talked about but did not have photographs of. They were given a £ 10 shopping voucher for their time. The researcher made reflective notes after each interview and attempted to bracket off any initial assumptions that might influence the analytic process.

The first author transcribed the interviews verbatim at the semantic level, recording spoken words and significant features including pauses and laughter (Pietkiewicz & Smith, 2012; Smith et al., 2009). The interview transcripts were imported into NVIVO 12 qualitative analysis software. Raw data is not available for this manuscript because the nature of the in-depth interviews from a small sample of young people with a rare condition could make participants identifiable and therefore breach participant anonymity. Detailed examples of themes and quotes are available as a supplementary file.

2.9. Analysis

IPA, an inductive method of qualitative analysis, concerned with interpretations of lived experiences by both the participant and researcher, known as a 'double-hermeneutic', was carried out by the first author between 7th November 2020 and 1st March 2021 (Smith et al., 2009). An audit trail of the analysis was kept on NVIVO 12, and themes were discussed and agreed by all authors. IPA was chosen because its hermeneutic (interpretative) and phenomenological (experience) epistemological underpinnings lend themselves to explorations of lived experience and personal sense-making (Braun & Clarke, 2020; Smith et al., 2009). Moreover, IPA enables a dual focus whereby individual divergent experiences and shared experiences between participants are given attention, which is beneficial when understanding complex and varied aspects of health (Chamberlain & Murray, 2017).

Some researchers advocate for incorporating photographs in the analysis process (Collier & Collier, 1986; Papaloukas et al., 2017), including using photos within the IPA bracketing process and deriving literal and metaphorical themes from the contents of the photographs (Papaloukas et al., 2017). However, others argue that photographs lack meaning without the context of the interview and cannot be assumed to 'speak for themselves'; therefore, they serve the purpose of elicitation and do not add to the narrative (Bates et al., 2017; Frith et al., 2005; Frith & Harcourt, 2007). Furthermore, Pyle (2013) cautions that adult researchers who attempt to interpret children's photographic data may distort or overlook a child's interpretations and consider it outside the child's own world. Therefore, within the current study, the photographs were treated as an elicitation tool and not analysed.

Smith et al.'s (2009) six steps for carrying out IPA were utilised:

1. Reading interview transcript numerous times and bracketing off any initial preconceptions.
2. Carrying out initial noting - a detailed set of notes including descriptive, linguistic, and conceptual comments.
3. Developing emergent themes using initial notes.
4. Identifying connections between emergent themes to develop superordinate themes.
5. Moving on to analyse the next participant's data and bracketing off assumptions from first participant to retain idiographic focus.
6. Looking for patterns across all data and focusing on theoretical interpretations of lived experience.

3. Results

Three recurrent superordinate themes 'Accepting my 'true' self', 'I am not alone in this', and 'Developing as a person' were identified in relation to the participants' experiences (Fig. 3). Each is discussed with reference to convergence and divergence and presented alongside supporting interview excerpts. Additional excerpts for each theme can be found in Table 1, and full image descriptions in Table 2, of the supplementary materials.

3.1. Theme 1. Accepting my 'true' self

The first theme relates to the participants coming to accept and appreciate their CMN.

3.1.1. Theme 1.1: 'A Part of Me'

Participants felt that accepting CMN as an important part of their identity, which had shaped them as people, was necessary to adjust and have a positive relationship with their birthmarks. For example, Robyn (16) explained "I've kind of always had quite a positive outlook on CMN...it's a part of me and I can't change it, so I may as well, you know, embrace it". Conversely, acceptance had been a complex process for the others. Charlotte, Alice, and Olivia recalled becoming increasingly self-conscious of their birthmarks as they progressed through childhood. However, now in mid-to-late-adolescence, they had formed a positive relationship with their birthmarks, seeing them as an important part of their identity, which they did not need to conceal from others. For example:

When I first started becoming aware of it, I was a bit, like, I wanted to hide it a bit. But as I've grown up, I've - I understand that it's who I am, and I can't cover it up because it's just who I am (Olivia, 15).

The shift in Olivia's perception of her birthmarks can be seen in other parts of the interview, where she describes herself as a "proud CMN

owner", a phrase that suggests she now sees CMN as a valued possession, worthy of care and respect. These participants discussed how they felt in-tune with their bodies as children, but later became disconnected and critical of them during adolescence. However, now in emerging adulthood, they had begun to reconnect with their bodies, forming a more holistic relationship with them. This is illustrated in Alice's interview, where she reflects on how far she has come when looking at a photograph of herself with her siblings smiling together at a festival where she is wearing a short-sleeved t-shirt that shows her CMN (photograph 1). She describes the realisation that "I was...hiding from myself because the birthmarks make me who I am and if I'm hiding that then I'm kind of hiding from myself" (Alice, 15).

Additionally, while Robyn and Olivia felt that acceptance had developed naturally, it was a very conscious process for Charlotte and Alice. Both described an internal struggle whereby they wanted to accept their 'true' selves but were concerned about the repercussions of being outwardly 'different'. Both overcame this by using personal milestones. For Charlotte, starting college gave her an opportunity to embrace her true self in a new environment and live to her own values, rather than the values of others. This contrasts the time and energy she had devoted to concealing her CMN at school, which had jeopardised her relationships with others. When discussing a selfie where she is leaning back on a radiator casually and showing the CMN on her arm to the camera (photograph 2), she explained "in college I met a lot of friends, because I've been happier with myself, so I feel like I show my personality a bit more to other people and let them in, instead of blocking other people out" (Charlotte, 17).

Alice found summer particularly challenging because concealing her CMN became more difficult in warmer weather; however, she overcame this by working towards becoming more confident of showing her CMN for a summer biking holiday. While discussing a photograph of herself smiling on the beach while wearing a bikini (photograph 2) she recalled:

We had paniers so we couldn't have a lot of stuff, so a bikini was a lot less bulky and I guess I was planning on wearing it because I was quite confident with how I looked at that moment because it was summer and I'd got ready for summer (Alice, 15).

In addition to the having a less 'bulky' bag, this is also a metaphor for Alice shedding the psychological weight of concealing her condition. Finally, although Alice and Charlotte felt that they had come to accept their true selves, they emphasised that it is not a linear process and they experience temporary setbacks but, importantly, recognise they will feel positive again:

Sometimes you have a day when you're like 'uhh [I am] too tired to do anything' and just feeling a bit down and don't really have the energy to just urr like I don't know have the confidence to have your head held high and all that. Whereas there are other days where you feel like you can just walk around in shorts and feel comfortable with who you are I guess (Alice, 15).

3.1.2. Theme 1.2: Appreciating my difference

In addition to accepting CMN as part of their identity, the participants had also come to appreciate looking 'different'. For the young people, CMN gave them an opportunity to be unique, stand out from the crowd, and break free from pressures to conform to sociocultural beauty ideals. When discussing a photograph of herself stood outside a photography exhibition showcasing images of people with CMN (photograph 4), Alice (15) discusses how "[Society] it's all a bit samey samey - like the way you should look and the way you should dress. I'm different in a good way and I have the chance to stand out". In contrast with many of her friends who don't have CMN, Robyn appreciates her appearance. In reference to a photograph of her lying on a rubber ring on holiday, smiling and showing the CMN on her legs (photograph 5), she explained "I like my legs, you know, I'm proud of them. Yeah, so having my legs out which do have prominent CMN on them, yeah, I'm happy with them, I'm happy with myself in terms of confidence".

For Alice, attending the photography exhibition of people with CMN

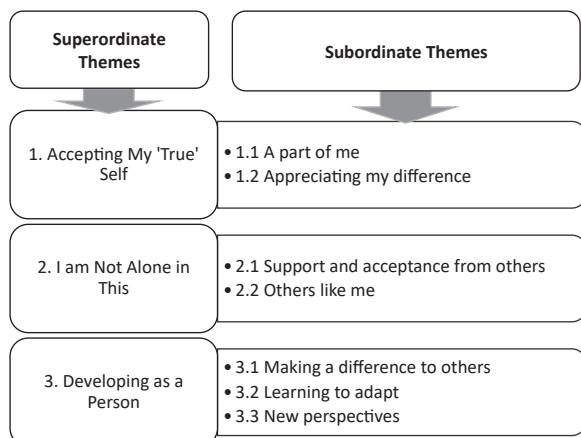


Fig. 3. Visual Representation of Superordinate and Subordinate Themes.

had encouraged her to view CMN from an outsider's perspective, which had allowed her to appreciate the beauty in her condition. This can be seen in Alice's interview, where she shifts from talking about the models to talking about herself: "well like they're - we're so beautiful - the people that had CMN - and I...shouldn't have a time when I'm doubting myself because um it's a chance to be unique" (Alice, 15). Similarly, through seeing others with CMN in a positive and confident light, Charlotte was able to appreciate the beauty in being different. When discussing a photograph where she is in public and wearing no makeup after modelling for a photo shoot (photograph 3), she explains "I just feel like I look more genuine because when I cover my face in makeup it kind of looks like, not fake, but it's like I'm trying to cover something. But my natural self looks a lot better" (Charlotte, 17).

On the other hand, although Robyn does discuss appreciating looking different, she also moves her attention away from being different and focuses on the aspects of her life that make her no different to anyone else:

I think a really important part of making someone feel comfortable is bringing awareness that they are different but at the same time making them feel the same as everybody else, because at the end of the day you are the same as everybody else, it doesn't really matter about your appearance (Robyn, 16).

When sharing a photograph of her lacrosse team, where everyone is standing together for a team photo in their uniforms and smiling at the camera (photograph 1), she discusses how playing sport can bring the focus away from appearance. In particular this is an environment where the role of appearance is minimised and everyone is focussed on playing the game, rather than what their body looks like. This levels the playing field and allows people to connect and focus on achieving the same goal:

I think other people with CMN, it's really important from a young age to, you know, like enjoy a physical activity...for any child it's empowering but for someone with CMN it's just like, it feels like an achievement, you know, and you're the same as everybody, you're the same as everybody playing on the pitch, you know (Robyn, 16).

In summary, all of the participants felt that accepting their CMN as a central part of their identity was necessary to adjust and have positive experiences in relation to their condition. Moreover, having learnt to embrace their CMN, they had also come to appreciate having a condition that made them different to their peers.

3.2. Theme 2 – I am not alone in this

The second theme surrounds the importance of the participants feeling that they were not facing the challenges associated with CMN alone. This included practical and emotional support and acceptance from family, friends, and others with CMN.

3.2.1. Theme 2.1: Support and acceptance from others

The participants felt that having support and acceptance from close family and/or friends enabled them to form a positive relation with their CMN. For example, Robyn (16) recounted "that's what my parents did from a young age...they just made me feel like any other child, the same as my brothers, same as my cousins, I'm just a kid and it doesn't matter what I look like" (Robyn, 16). However, she also discusses feeling uncomfortable when others focus heavily on appearance, which may be because this causes an internal conflict by threatening her own values around appearance:

That does make me kind of uncomfortable when people do talk about appearance because to be honest, I don't think about it a massive amount. So, when people do like you now bring up the subject or go in depth about it, I'm a bit like 'hmm, is it really that important?' (Robyn, 16).

Similarly, Alice's parents shared her journey and played a key role in helping her to build confidence and learn to accept her CMN. Alice progresses from discussing her achievements in relation to showing her CMN as a joint achievement (e.g., "we were very proud of ourselves").

This suggests that as she has become more confident, her parents have been able to remove the scaffolding that was supporting her, even in a potentially vulnerable situation. "We had been on the waiting list for a while, and I think I needed more confidence in my birthmarks and so we signed up to that and it was really helpful" (Alice, 15) In relation to a photograph of herself with her siblings without their parents at a festival, where she is smiling and wearing shorts (photograph 1), she explained:

We weren't with our parents [at the festival] so that was a big step, and it was a very like busy place, so like if I did it a few years ago, not last year, I would have felt too overwhelmed (Alice, 15).

Conversely, Olivia and Charlotte were largely supported by their friends. As with Robyn's parents, Olivia's friends made her feel like she was no different to them, explaining "they don't really see me as any different to them, they just see me as another person" (Olivia, 15). However, for Charlotte, opening herself up to her friends and allowing them to support her had taken time. By realising that her friends accept and value her, she had been able to accept herself and embrace her CMN. She also discusses her friends 'uplifting' her which, in addition to building her confidence, is a metaphor for her allowing her friends to carry some of the weight of her condition.

They [friends] just like uplift you and want to hang out with you, like invite you places, make you feel like you are loved and stuff like that, which makes you even more confident because like it proves that the care about you by them asking you to hang out and not you having to ask them. It makes you feel like more welcome (Charlotte, 17).

3.2.2. Theme 2.2: Others like me

Alongside support from friends and family, the participants felt that knowing others with CMN was extremely important for their adjustment because it made them feel like they were not alone and that others understood their experiences. When sharing a group photograph from a charity Family Weekend for young people with CMN (photograph 2), Robyn explained "It's nice being around other people that look like you, I think. It's comforting to know that you're not the only one out there that looks and experiences the same things that you do" (Robyn, 16). Alice (photograph 5) and Olivia (photograph 3) also shared group photos from the charity events, explaining "It's encouraging to know that others go through the same thing" (Alice, 15) and that knowing others with CMN "...just makes you feel like you're not alone" (Olivia, 15).

In addition, Olivia discusses the benefits of knowing others who *look* like her. Indeed, as a characteristically visible condition, CMN makes individuals look *different*. However, meeting peers with CMN at charity events allows the young people to blend into the crowd and feel "extra comfortable" (Olivia, 15). When looking at the group photograph (photograph 3), she explained how when she is with other people with CMN "I don't care like what other people around me think or because I'm with a massive crowd of people that have the same condition as me" (Olivia, 15).

The participants also felt that they were able to relate to their friends with CMN on a deeper level because they understood each other's experiences and struggles. These relationships were viewed as reciprocal, allowing both the giving, and receiving of support. Specifically, Robyn explained how "two people with physical differences can talk to each other and really empower each other because they really know what each other have gone through. They can give each other pointers on how to feel comfortable". Further to this, Alice described a sense-making quality within her peer relationships, whereby "we share our experiences and, yeah, like make sense of each other in case one [of us] is over-reacting" (Alice, 15).

On the other hand, Charlotte did not know other people with CMN but she, along with the other participants, gained benefits from seeing others with CMN, for example at a photography exhibition called 'How Do you C Me Now?'. "It [the exhibition] made me feel like relieved for once, because people were actually admiring my skin condition, rather

than judging it if that makes sense” (Charlotte, 17).

The second theme relates to the importance of having both social and emotional support in order to adjust and develop a positive relationship with their CMN. While support from family and friends was important, the participants expressed the additional benefit of knowing others with the same condition who have a unique understanding of their experiences and the challenges they face living with CMN.

3.3. Superordinate Theme 3 – Developing in myself

The final superordinate theme centres on how CMN helped the participants develop important life skills which helped them to cope with their condition adaptively, provide support to others, and changed their outlook on life and appearance.

3.3.1. Subordinate Theme 3.1 - Making a difference to others with CMN

After coming to accept and appreciate CMN as an important part of their identity, the young people were empowered to raise awareness of their condition, including through campaigns and on social media. This took the form of both correcting misconceptions and educating people. Charlotte explained “there’s a stereotype that people with skin conditions are infectious or something, or you can catch it, yeah. I think I’ve brought more knowledge to their lives and taught them that you can’t actually catch it” (Charlotte, 17). Additionally, when discussing a photograph of herself standing with a certificate whilst giving a talk about CMN (photograph 3), Robyn explained she “...was very proud and I felt proud also that I was educating other people about it as well” (Robyn, 16) There is a strong sense of optimism from the young people that their voices can make a difference to how the general population sees CMN and “...that there needs to be more awareness of my skin condition” (Charlotte, 17). In conjunction with being able to raise awareness, some of the participants also believed that having CMN had enabled them to directly support others with CMN who are struggling. Alice recounted this when sharing a photograph of her stood smiling with a group of friends with CMN (photograph 5):

I’m the oldest one in the group. They don’t always look up to me, but I feel like I’m the mother [laughs]... I feel like because I don’t think any of them get counselling, so I have more reason when I remember when someone was walking past us, they were like ‘ohh, they’re thinking really bad thoughts about me’ and I was like ‘ah, they could not be’ you know. But, yeah, so I guess I have a more levelled understanding about what other people may be thinking (Alice, 15).

During her adjustment journey, Alice progresses from sharing the process with her parents to becoming more independent and able to cope with challenges alone, to finally coming to the point where she can help and support others. This can be seen by her use of the word ‘mother’ when she describes her relationship with other members of the charity how she has become ‘levelled’ and able to provide support from a stable and balanced position. This supportive role is also highlighted by Robyn, who feels a sense of duty to support others who are struggling and impart her own coping skills to benefit them. She believes she “...can’t just be accepting and then just let other people suffer. You know – got to help them along. They’re just like me” (Robyn, 16). Moreover, she described the two-way benefit of supporting others:

I felt really proud about it. It just made me want to do it more to be honest. I wanted to keep meeting up and help other people because they’re just like me and they just need a little boost you know, to feel comfortable and you know, I would love to keep doing that and keep helping people (Robyn, 16).

3.3.2. Subordinate Theme 3.2: learning to adapt

This theme also relates to the way that having CMN had enabled the young people to adapt to their condition in a positive way and develop new skills and abilities. Firstly, the participants recounted how having CMN had allowed them to deal with negative experiences relating to their appearance positively. For example, Charlotte explained “I just

ignore it. Sometimes I stare back at them and then they usually stop staring” (Charlotte, 17). Whereas, Alice expressed “I would just think that they’re just – they don’t know what they are talking about in a way. So, I shouldn’t be concerned about what they think”.

Further to adapting their behaviour in response to others, the participants had learnt to reframe their thoughts and perceptions and identify and reappraise potentially negative biases in their thinking. Alice explained “I think I’ve become more like I guess I’m more lenient about what people think about me when they’re looking at me and I feel more positive about what they’d be thinking” (Alice, 15). Similarly, Olivia had learned to realise that “although people stare they probably don’t have as much of a negative thought about it as I may deem that they do.” (Olivia, 15). On the other hand, Robyn discussed using humour as a tool to manage situations and reorient them in a positive way.

I think people are more accepting about something when they’re laughing and about it and you know people will accept it if they laugh about it... “If you are willing to joke about it you can show it’s not like a touchy subject and you’re more comfortable with it so then they feel more comfortable with speaking it or asking questions about it (Robyn, 16)

Using humour, Robyn can address any power imbalance by having ownership over her own condition and how others perceive her. Additionally, there is the sense that she also uses humour to show others that they do not need to feel awkward and to put them at ease.

Finally, Charlotte and Alice also discuss using the behavioural technique graded exposure to slowly become more confident about their CMN and to gauge others’ reactions. Each positive experience builds their confidence and helps them to expose more of their CMN. When discussing a photograph where she is leaning against a radiator posing for the camera with her CMN showing (photograph 1), Charlotte described how “I’ve started wearing tops that are shorter and showing my arms a tiny bit more and going out with my arms on show sometimes – not completely, but you know those half ones” (Charlotte, 17). Similarly, Alice recalled how “...last summer was a really good summer for revealing my birthmarks because I’ve been doing counselling last year. I started in last November I think so umm yeah I like received like tasks to do and different challenges to do that helped me work up to the summer” (Alice, 15).

3.3.3. Subordinate theme 3.3: new perspectives

Finally, the participants discussed how CMN had given them a more positive outlook on life. For Robyn, having CMN had put appearance into perspective for her and allowed her to focus on other aspects of her life, which contrasted a lot of her friends who did not have appearance-altering conditions. This enabled her to be resilient and cope with significant life challenges:

I think it has actually helped me and my confidence. Because obviously it’s kind of that thing where you put things in perspective, you know, and I think it has helped me to put things into perspective like you know if you had a bad day with your skin or something, like a couple of spots, acne, or something, I’m not going to be like it’s ‘ah the worst day of my life! (Robyn, 16).

When discussing a photograph of herself as a guest of a TV show where she had been raising awareness of CMN (photograph 2), Olivia explained that having CMN gave her the ability to be more understanding of others and gave her the ability to empathise with them:

I think it’s [CMN] made me quite an understanding person. Like a lot of my friends come to talk to me about stuff because I tend to listen and understand, and I feel like I’ve got that experience through being with the charity and hearing other people’s stories. (Olivia, 15).

The participants also felt that having CMN had afforded them unique opportunities that they otherwise would not have had:

I feel like there’s more diversity in the modelling industry as well nowadays. So I feel like CMN will kind of help me get like, get in the

modelling industry easier. Maybe not easier, but like it will be raising awareness through it and how people can treat people with my skin condition much better than they are usually treated (Charlotte, 17).

In summary, the third theme relates to the coping and life skills that the participants had developed due to their condition. They felt that these helped them to adjust to CMN and have positive experiences in relation to it and that it helped them with other aspects of their lives.

4. Discussion

Using photo-elicitation interviews and IPA, this study provides a detailed account of the lived experiences of four female adolescents who identify as having adjusted to the birthmark condition CMN. The term 'adjustment' relates to understanding how someone copes with their condition; however, it is not well-defined and is likely to vary between individuals. Therefore, we allowed the participants to self-identify as having adjusted and having positive experiences relating to their condition. Nonetheless, although there were nuances in their experiences, all felt that coming to accept and appreciate their CMN and having support and acceptance from family, friends, and others with CMN was central to adjusting to their condition. Moreover, having CMN had given them the opportunity to develop important life skills and learn to cope with challenges. One key finding was that the participants' experiences strongly echo the concept of positive body image, a multifaceted construct which relates to being able to love, appreciate, and take care of one's body, including its uniqueness and functional abilities, which is associated with physical and psychosocial health (Tiggemann, 2015; Halliwell, 2015).

The first theme related to the participants coming to accept CMN and see it as an important part of their identities. This has also been identified in qualitative research with adults with a range of appearance-altering conditions (Egan et al., 2011; Stock et al., 2016) and adolescents with Silver-Russell syndrome (Ballard et al., 2021). Moreover, qualitative research into positive body image with emerging adults suggests that body acceptance, and seeing the body as an integral part of the self, is key to developing a positive body image (Gattario & Frisén, 2019).

There were notable differences between participants in relation to the acceptance process. Namely, while Robyn felt that she had always been accepting of her condition, the others had more complex relationships with the appearance of their birthmarks, which changed throughout childhood and adolescence. These experiences echo Piran, (2002) Theory of Embodiment, which posits that young girls are connected and in tune with their bodies, later becoming disconnected in adolescence where appearance comparisons and sociocultural pressures become salient, and finally reconnecting with them to form a holistic relationship in adulthood.

Further to acceptance, the participants had come to appreciate looking 'different' and described their CMN as making them 'unique' and 'special'. In line with this, Stock and colleagues (2016) found interpreting difference positively related to lower psychological distress in individuals with the craniofacial condition cleft lip and/or palate. Again, these experiences closely link to positive body image and the participants expressed body appreciation, broad conceptualisation of beauty (rejecting narrow sociocultural appearance ideals and believing a diverse range of appearances are attractive), body image flexibility, body activism, and the developing the ability to protect themselves from harmful appearance-related messages and (Tylka & Wood-Barcalow, 2015; Alleva et al., 2023).

While Olivia and Robyn had always felt positive about their CMN, Alice and Charlotte had worked to become comfortable in their own skin. This is important because it supports the notion that individuals do have some control over their adjustment trajectory, which is promising in relation to intervention development (Rumsey, 2018). Moreover, while adjustment is often conceptualised as a linear process, the participants experienced fluctuations in their acceptance levels, but had

come to understand that these setbacks were temporary, which has been found in qualitative research with adults (Egan et al., 2011). Again, this closely links to recent research into positive body image, which suggests that individuals can harness the development of positive body image and that this can 'ebb and flow' rather than being a constant state (Alleva et al., 2023; Gattario & Frisén, 2019). These findings suggest that developing a positive body image may be an important part of overall adjustment to CMN, and potentially other appearance-altering conditions.

Positive body image is not currently included in models of adjustment to appearance-altering conditions, which consider body image concerns and appearance investment as potential risk factors for poor adjustment. However, the findings of this research suggest it may be pertinent to consider whether positive body image might serve as a protective factor for adjustment. In this case, positive body image interventions, such as the Expand Your Horizon writing intervention, may be beneficial for young people with CMN and other appearance-altering conditions (Alleva et al., 2015).

Interestingly, while previous research has often found milestones and transition periods (e.g., starting a new school, entering adolescence) to be challenging times for adjustment, the participants in this study had used adversity as a motivation to overcome their concerns (Gee et al., 2020). This links closely to optimism, whereby individuals are able to interpret situations using positive emotions, which is linked to health outcomes and adjustment to appearance-altering conditions (Fortune et al., 2005; Tugade & Fredrickson, 2004). Many of the participants' experiences did relate to optimism and being able to appraise situations positively (Scheier et al., 1994). Optimism is included in models of adjustment to visible difference and has been identified as a protective factor in individuals with cleft lip and/or palate (Feragen & Stock, 2016; Stock et al., 2016). While optimism is often thought of as a trait, or dispositional, factor these findings support the notion that optimism can be learned by shifting from negative attentional biases as the participants had learned to have a more optimistic attitude (Clarke et al., 2013; Seligman, 1999). Therefore, optimism may also serve as an important part of interventions, rather than just being considered a predictor in adjustment models, and could be explored in relation to developing positive body image.

The second theme relates to the importance of social support and acceptance from family, friends, and others with CMN, who facilitate adjustment by providing a safe environment for the participants to become confident in their own skin. The importance of social support and acceptance is reflected in Gee and colleagues' (2020) model of adjustment to appearance-altering conditions and in other literature (e.g., Egan et al., 2011; Stock et al., 2016). During childhood, parents/caregivers provide practical and emotional support relating to a condition, including modelling acceptance, helping them to navigate challenges and develop coping strategies (Costa et al., 2021, 2022; Thornton et al., 2021). Similarly, friends are found to help an individual develop problem- and emotion-focussed coping skills, particularly during adolescence (Thompson et al., 2002b). In line with previous research into adults, the participants described two different approaches used by their friends and family: (a) emphasising the positive aspects of being different or (b) making them feel that they were the same as everyone else by focussing on non-appearance-related characteristics that they shared (Egan et al., 2011; Meyerson, 2001; Stock et al., 2016). Moreover, these findings are similar to those of Alleva and colleagues (2023) who identified that finding friends who support and accept you (and your appearance) is an important part of the journey towards positive body image.

As found in other research, the participants felt that knowing others with CMN was particularly important (Ballard et al., 2021; Egan et al., 2011; Stock et al., 2016). This included spending time with friends they had made through the national charity, and seeing others with CMN on social media or at the 'How do you C Me Now?' CMN portrait exhibition in London. These experiences made the participants feel like they were

not alone and having friends with CMN provided a reciprocal relationship where they could give and receive support from others who had a unique understanding of what it is like to be a young person with CMN. This is similar to children who attend burn camps, who report feeling able to forget about their appearance concerns and become more confident showing their scarring in front of others (Armstrong-James et al., 2019). Current models of adjustment include social support and acceptance, but the findings of this study suggest that knowing others with the same condition might be particularly important and could be considered separately.

In relation to the third theme, the participants felt that having CMN gave them various unique opportunities and skills. Finding meaning in adversity is something that has been found in individuals with chronic conditions, which facilitates the acceptance process and can lead individuals to gain a more positive outlook on their condition (Fortune et al., 2005). Broadly, this included having the opportunity to support others, being able to develop adaptive coping skills, and being given opportunities and experiences they would otherwise not have had.

Similarly, to the teenagers with cancer in Williamson and colleagues' (2010) qualitative study, the young people were able to raise awareness of CMN, educate others, and challenge misconceptions and appearance-related stigma. Moreover, having personally adjusted to CMN, they felt it was their duty to adopt a supportive role and use what they had learned to help others adjust. Again, this desire to help others has been found in other research exploring positive outcomes in visible difference (Garbett et al., 2017).

Another key part of the adjustment process was developing adaptive coping skills to deal with challenging experiences with others including behaviourally (e.g., staring back, ignoring them, providing information) and cognitively (e.g., reappraising the situation, challenging negative thinking patterns) and becoming gradually more confident showing their CMN. These adaptive skills include techniques such as thought challenging, cognitive reframing, and graded exposure which form part of CBT-based interventions and are used with adolescents with appearance-altering conditions (Clarke et al., 2013; Jenkinson et al., 2015b; Williamson et al., 2015). Participants in Alleva and colleagues (2023) interview study, which included individuals with appearance-altering conditions, also reported learning techniques to become more accepting of their bodies which helped them to self-protect from harmful appearance-related messages, support others, and value themselves beyond their appearance.

Finally, the participants felt that having CMN had given them a unique outlook on life and their condition had helped them in other aspects of their lives. This included being less self-critical, appraising situations rationally, being able to understand and empathise with others, being less concerned about small things in life, and worrying less about their appearance. These findings suggest adolescents have similar experiences to adults with visible differences (Egan et al., 2011; Feragen & Stock, 2016; Garbett et al., 2017; Thompson et al., 2002a; Wallace et al., 2007).

4.1. Photo-elicitation in body image and appearance research

There are a number of unique benefits of using photo-elicitation interviews in research exploring experiences of appearance and body image. In the case of this study, the participants' adjustment largely related to coming to accept, appreciate and embrace *looking* different. Moreover, this experience was naturally captured over time in family photographs and from posts on social media which marked key milestones. Having these photographs within the interviews allowed the participants to reflect on their experiences and triggered memories about how they felt when each of the photographs were taken, which helped to build a clear picture of how their relationship with their appearance and birthmarks developed over time. This could be particularly useful for other research in the area exploring appearance-related processes that occur over time, such as the development of positive body

image, and there are clear benefits of using a visual method to explore a visual topic.

Nonetheless, it may not be appropriate for all research in the area, including with individuals who are experiencing body image concerns or disordered eating, who may find it upsetting to reflect on images or may not have photographs of themselves to draw upon. Indeed, one reflection from Bailey and colleagues (2021) who used photo-elicitation to explore body image, was that looking at photographs can elicit negative reactions and feelings from participants about their appearance. Furthermore, it is necessary to consider potential ethical and legal issues of using photographic data, such as anonymity and ownerships from the outset of a research project, including how data will be recorded and disseminated and use published guidance to inform these decisions (Reavey, 2020; Wiles et al., 2008).

4.2. Methodological considerations

This study has numerous methodological strengths and limitations. First, the inductive nature of the study enabled an in-depth exploration of the lived experiences of four young people with CMN. This provides further context and nuanced understanding of the adjustment process, adding to current quantitative, outcome-focussed literature. Moreover, this is the first study to explore experiences of CMN from the perspective of young people themselves and the use of photo-elicitation aided this by putting their personal experiences and understandings at the forefront of the research, facilitating participant expression, and allowing the researchers to access the worlds of the participants (Burton et al., 2017; Carter & Ford, 2013; Frith et al., 2005; Pyle, 2013).

A small, homogeneous sample is necessary for IPA research and garnered rich experiential data, which allowed for the identification of both convergent and divergent themes in relation to a process that may vary from the 'norm'. However, the findings do not reflect the experiences of all young people with CMN and make it difficult to identify salient issues for a specific group (Pringle et al., 2011). Similarly, the participants were all White adolescent females who were actively engaged with a national charity that supports people with CMN. Therefore, their lived experiences may differ from other young people with CMN, including individuals who are male or non-binary, and from other racial and cultural backgrounds. It is necessary to understand the experiences and needs of young people from a range of backgrounds in order for charities to provide suitable support for everyone. Members of charitable support organisations are largely White, middle class, and educated. Therefore, it is important to consider other avenues for recruitment, such as through the National Health Service (NHS), or the social media platform Reddit, which can be a more anonymous source of support and includes members from a range of socio-economic and educational backgrounds and minority groups (Luong & Lomanowska, 2021; Shatz, 2017).

Nonetheless, the findings help build understanding of positive adjustment to CMN, have theoretical transferability to other groups, and may usefully inform further quantitative research into factors associated with adjustment, such as informing the measurement of factors such as positive body image and body image flexibility (Brocki & Wearden, 2006; Smith et al., 2009).

4.3. Future research recommendations

In future, research should be carried out with other groups of young people with CMN, including children of different ages, boys, and with a more racially diverse sample or those from different cultural backgrounds to ensure the voices of all young people are represented in research. Additionally, the findings of the study could be used to inform qualitative research into concepts such as positive body image in young people with CMN, and longitudinal research considering factors associated with adjustment to CMN in relation to developmental and contextual factors, which could help understand variation in the process

and how to best foster positive adjustment.

4.4. Conclusions

In summary, this photo-elicitation study has provided an insight into the experience of four adolescents who identify as having positively adjusted to CMN. It provides a novel contribution to the literature by focussing on adjustment from the perspective of young people themselves. The findings illustrate the importance of acceptance, social support, and coping skills in adjustment, but also highlight the individual and varied adjustment pathway. The findings suggest adjustment should be considered as a dynamic process and potential protective factors such as positive body image should be further explored.

Funding

This research was supported by Vocational Training Charitable Trust Foundation, United Kingdom.

CRediT authorship contribution statement

Williamson Heidi: Conceptualization, Supervision, Writing – original draft, Writing – review & editing. **Guest Ella:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Software, Writing – original draft, Writing – review & editing. **Harcourt Diana :-** Conceptualization, Funding acquisition, Supervision, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

In accordance with Body Image policy, the authors declare that they have no conflicts of interest.

Data Availability

The data that has been used is confidential.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.bodyim.2023.101656](https://doi.org/10.1016/j.bodyim.2023.101656).

References

- Alleva, J. M., Martijn, C., Van Breukelen, G. J., Jansen, A., & Karos, K. (2015). Expand Your Horizon: A programme that improves body image and reduces self-objectification by training women to focus on body functionality. *Body Image, 15*, 81–89. <https://doi.org/10.1016/j.bodyim.2015.07.001>
- Alleva, J. M., Tylka, T. L., Martijn, C., Waldén, M. I., Webb, J. B., & Piran, N. (2023). I'll never sacrifice my well-being again: The journey from negative to positive body image among women who perceive their body to deviate from societal norms. *Body Image, 45*, 153–171. <https://doi.org/10.1016/j.bodyim.2023.03.001>
- Armstrong-James, L., Cadogan, J., Williamson, H., Rumsey, N., & Harcourt, D. (2019). Using photo-elicitation to explore families' experiences of burn camp. *Journal of Family Nursing, 25*(1), 81–108. <https://doi.org/10.1177/1074840718817630>
- Bailey, K. A., Dagenais, M., & Gammage, K. L. (2021). Is a picture worth a thousand words? Using photo-elicitation to study body image in middle-to-older age women with and without multiple sclerosis. *Qualitative Health Research, 31*(8), 1542–1554. <https://doi.org/10.1177/10497323211014830>
- Ballard, L. M., Jenkinson, E., Byrne, C. D., Child, J. C., Inskip, H., Lokulo-Sodipe, O., Mackay, D. J., Wakeling, E. L., Davies, J. H., & Temple, I. K. (2021). Experiences of adolescents living with Silver-Russell syndrome. *Archives of Disease in Childhood, 106*(12), 1195–1201. <https://doi.org/10.1136/archdischild-2020-321376>
- Bates, E. A., McCann, J. J., Kaye, L. K., & Taylor, J. C. (2017). Beyond words: A researcher's guide to using photo elicitation in psychology. *Qualitative Research in Psychology, 14*(4), 459–481. <https://doi.org/10.1080/14780887.2017.1359352>
- Berger, Z. E., & Dalton, L. J. (2009). Coping with a cleft: Psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *The Cleft Palate-Craniofacial Journal, 46*(4), 435–443. <https://doi.org/10.1597/08-093.1>
- Braun, V., & Clarke, V. (2020). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research. https://doi.org/10.1002/capr.12360*
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*(1), 87–108. <https://doi.org/10.1080/14768320500230185>
- Bundy, C. (2012). Visible difference associated with disease: Skin conditions. In D. Rumsey, N., & Harourt (Ed.), *Oxford handbook of psychology. The Oxford handbook of the psychology of appearance* (pp. 398–413). Oxford University Press.
- Burton, A., Hughes, M., & Dempsey, R. C. (2017). Quality of life research: A case for combining photo-elicitation with interpretative phenomenological analysis. *Qualitative Research in Psychology, 14*(4), 375–393. <https://doi.org/10.1080/14780887.2017.1322650>
- Cappello, M. (2005). Photo interviews: Eliciting data through conversations with children. *Field Methods, 17*(2), 170–182. <https://doi.org/10.1177/1525822x05274553>
- Carter, B., & Ford, K. (2013). Researching children's health experiences: The place for participatory, child-centered, arts-based approaches. *Research in Nursing & Health, 36*(1), 95–107. <https://doi.org/10.1002/nur.21517>
- Chamberlain, K., & Murray, M. (2017). Health psychology. In *The SAGE Handbook of qualitative research in psychology* (pp. 421–449). Sage Publications Ltd.
- Clark, A.J. (2019). Visual ethics beyond the crossroads. (<https://salford-repository.wor.ktribe.com/output/1361723/visual-ethics-beyond-the-crossroads>).
- Clarke, A., Thompson, A.R., Jenkinson, E., Rumsey, N., & Newell, R. (2013). *CBT for appearance anxiety: Psychosocial interventions for anxiety due to visible difference*. John Wiley & Sons.
- Collier, J., & Collier, M. (1986). *Visual anthropology: Photography as a research method*. UNM Press.
- Costa, B., Ardouin, K., & Stock, N. M. (2022). Factors associated with psychological adjustment in adults with cleft lip and/or palate: Findings from a national survey in the United Kingdom. *The Cleft Palate-Craniofacial Journal, 59*(4 suppl2), S7–S17. <https://doi.org/10.1177/10556656211028494>
- Costa, B., Thornton, M., Guest, E., Meyrick, J., & Williamson, H. (2021). The effectiveness of interventions to improve psychosocial outcomes in parents of children with appearance-affecting health conditions: A systematic review. *Child: Care, Health and Development, 47*(1), 15–30. <https://doi.org/10.1111/cch.12805>
- Egan, K., Harcourt, D., Rumsey, N., & Collaboration, A. R. (2011). A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference. *Journal of Health Psychology, 16*(5), 739–749. <https://doi.org/10.1177/1359105310390246>
- Feragen, K. B., & Stock, N. M. (2016). A longitudinal study of 340 young people with or without a visible difference: The impact of teasing on self-perceptions of appearance and depressive symptoms. *Body Image, 16*, 133–142. <https://doi.org/10.1016/j.bodyim.2016.01.003>
- Fortune, D., Richards, H., Griffiths, C., & Main, C. (2005). Adversarial growth in patients undergoing treatment for psoriasis: A prospective study of the ability of patients to construe benefits from negative events. *Psychology, Health & Medicine, 10*(1), 44–56. <https://doi.org/10.1080/13548500512331315352>
- Frith, H., & Harcourt, D. (2007). Using photographs to capture women's experiences of chemotherapy: Reflecting on the method. *Qualitative Health Research, 17*(10), 1340–1350. <https://doi.org/10.1177/1049732307308949>
- Frith, H., Riley, S., Archer, L., & Gleeson, K. (2005). Imag (in) ing visual methodologies. *Qualitative Research in Psychology, 2*(3), 187–198. <https://doi.org/10.1191/1478088705qp037ed>
- Garbett, K., Harcourt, D., & Buchanan, H. (2017). Using online blogs to explore positive outcomes after burn injuries. *Journal of Health Psychology, 22*(13), 1755–1766. <https://doi.org/10.1177/1359105316638549>
- Gattario, K. H., & Frisén, A. (2019). From negative to positive body image: Men's and women's journeys from early adolescence to emerging adulthood. *Body Image, 28*, 53–65. <https://doi.org/10.1016/j.bodyim.2018.12.002>
- Gee, C., Maskell, J., Newcombe, P., Kimble, R., & Williamson, H. (2020). Australian health professionals' perspectives of psychosocial adjustment to visible differences: A qualitative analysis of pediatric populations. *Body Image, 33*, 13–26. <https://doi.org/10.1016/j.bodyim.2020.02.004>
- Griffiths, C., Williamson, H., & Rumsey, N. (2012). The romantic experiences of adolescents with a visible difference: Exploring concerns, protective factors and support needs. *Journal of Health Psychology, 17*(7), 1053–1064. <https://doi.org/10.1177/1359105311433909>
- Halliwel, E. (2015). Future directions for positive body image research. *Body Image, 14*, 177–189. <https://doi.org/10.1016/j.bodyim.2015.03.003>
- Harper, D. (1986). Meaning and work: A study in photo elicitation. *Current Sociology, 34*(3), 24–46. <https://doi.org/10.1177/001139286034003006>
- Hayes, H., Buckland, S., & Tarpey, M. (2012). Briefing notes for researchers: Public involvement in NHS, public health and social care research. *INVOLVE: Eastleigh*.
- Hefferon, K., Ashfield, A., Waters, L., & Synard, J. (2017). *Understanding optimal human functioning-The 'call for qual' in exploring human flourishing and well-being*. Taylor & Francis.
- Hugly, P., & Sayward, C. (1987). Relativism and ontology. *The Philosophical Quarterly (1950-), 37*(148), 278–290.
- Jenkinson, E., Williamson, H., Byron-Daniel, J., & Moss, T. P. (2015a). Systematic review: Psychosocial interventions for children and young people with visible differences resulting from appearance altering conditions, injury, or treatment effects. *Journal of Pediatric Psychology, 40*(10), 1017–1033. <https://doi.org/10.1093/jpepsy/jsv048>
- Jenkinson, E., Williamson, H., Byron-Daniel, J., & Moss, T. P. (2015b). Systematic review: Psychosocial interventions for children and young people with visible differences resulting from appearance altering conditions, injury, or treatment

- effects. *Journal of Pediatric Psychology*, 40(10), 1017–1033. <https://doi.org/10.1093/jpepsy/jsv048>
- Kinsler, V. A., Birley, J., & Atherton, D. J. (2009). Great Ormond Street Hospital for children registry for congenital melanocytic naevi: Prospective study 1988–2007. Part 1—Epidemiology, phenotype and outcomes. *British Journal of Dermatology*, 160(1), 143–150. <https://doi.org/10.1111/j.1365-2133.2008.08849.x>
- Kinsler, V., & Bulstrode, N. (2009). The role of surgery in the management of congenital melanocytic naevi in children: A perspective from Great Ormond Street Hospital. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 62(5), 595–601. <https://doi.org/10.1016/j.bjps.2008.12.016>
- Koot, H. M., De Waard-van der Spek, F., Peer, C. D., Mulder, P. G. H., & Oranje, A. P. (2000). Psychosocial sequelae in 29 children with giant congenital melanocytic naevi. *Clinical and Experimental Dermatology*, 25(8), 589–593. <https://doi.org/10.1046/j.1365-2230.2000.00712.x>
- Luong, R., & Lomanowska, A. M. (2021). Evaluating Reddit as a crowdsourcing platform for psychology research projects. *Teaching of Psychology*, Article 00986283211020739. <https://doi.org/10.1177/00986283211020739>
- Macneal, P., & Patel, B. C., (2023). Congenital Melanocytic Nevi. *National Library of Medicine*.
- Masnari, O., Landolt, M. A., Roessler, J., Weingaertner, S. K., Neuhaus, K., Meuli, M., & Schiestl, C. (2012). Self- and parent-perceived stigmatisation in children and adolescents with congenital or acquired facial differences. *Journal of Plastic, Reconstructive & Aesthetic Surgery: JPRAS*, 65(12), 1664–1670. <https://doi.org/10.1016/j.bjps.2012.06.004>
- Masnari, O., Neuhaus, K., Aegerter, T., Reynolds, S., Schiestl, C. M., & Landolt, M. A. (2019). Predictors of health-related quality of life and psychological adjustment in children and adolescents with congenital melanocytic nevi: Analysis of parent reports. *Journal of Pediatric Psychology*, 44(6), 714–725. <https://doi.org/10.1093/jpepsy/jsz017>
- Masnari, O., Schiestl, C., Rössler, J., Gütlein, S. K., Neuhaus, K., Weibel, L., Meuli, M., & Landolt, M. A. (2013). Stigmatization predicts psychological adjustment and quality of life in children and adolescents with a facial difference. *Journal of Pediatric Psychology*, 38(2), 162–172. <https://doi.org/10.1093/jpepsy/jss106>
- Melton, S. T., & Johnson, N. (2015). Using photo-elicitation to explore young adult perspectives on coping with type 1 diabetes. *PLAID: People Living with And Inspired by Diabetes*, 40–48. <https://doi.org/10.17125/plaid.2015.7>
- Meyerson, M. D. (2001). Resiliency and success in adults with moebius syndrome. *The Cleft Palate-Craniofacial Journal*, 38(3), 231–235. https://doi.org/10.1597/1545-1569.2001.038.0231_rasiaw.2.0.co.2
- Montgomery, K., Norman, P., Messenger, A. G., & Thompson, A. R. (2016). The importance of mindfulness in psychosocial distress and quality of life in dermatology patients. *British Journal of Dermatology*, 175(5), 930–936. <https://doi.org/10.1111/bjd.14719>
- Montgomery, K., & Thompson, A. R. (2018). The potential role of mindfulness in psychosocial support for dermatology patients. *Clinics in Dermatology*, 36(6), 743–747. <https://doi.org/10.1016/j.clindermatol.2018.08.010>
- Neuhaus, K., Landolt, M. A., Theiler, M., Schiestl, C., & Masnari, O. (2020). Skin-related quality of life in children and adolescents with congenital melanocytic naevi—an analysis of self-and parent reports. *Journal of the European Academy of Dermatology and Venerology*, 34(5), 1105–1111. <https://doi.org/10.1111/jdv.16131>
- Ott, Hagen, et al. (2019). Multidisciplinary long-term care and modern surgical treatment of congenital melanocytic nevi—recommendations by the CMN surgery network. *JDDG: Journal der Deutschen Dermatologischen Gesellschaft*, 17(10), 1005–1016. <https://doi.org/10.1111/ddg.13951>
- Pain, H. (2012). A literature review to evaluate the choice and use of visual methods. *International Journal of Qualitative Methods*, 11(4), 303–319. <https://doi.org/10.1177/160940691201100401>
- Papaloukas, P., Quincey, K., & Williamson, I. R. (2017). Venturing into the visual voice: combining photos and interviews in phenomenological inquiry around marginalisation and chronic illness. *Qualitative Research in Psychology*, 14(4), 415–441. <https://doi.org/10.1080/14780887.2017.1329364>
- Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii. *Czasopismo Psychologiczne*, 18(2), 361–369.
- Piran, N. (2002). Embodiment: A mosaic of inquiries in the area of body weight and shape preoccupation. *Ways of Knowing in and through the Body: Diverse Perspectives on Embodiment*, 211–214.
- Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*, 18(3). <https://doi.org/10.7748/nr2011.04.18.3.20.c8459>
- Prosser, J. (2011). Image-based educational research: Childlike perspectives. *LEARNing Landscapes*, 4(2), 257–273. <https://doi.org/10.36510/learnland.v4i2.399>
- Prosser, J., & Schwartz, D. (1998). Photographs within the Sociological. *Image-Based Research: A Sourcebook for Qualitative Researchers*, 115.
- Pyle, A. (2013). Engaging young children in research through photo elicitation. *Early Child Development and Care*, 183(11), 1544–1558. <https://doi.org/10.1080/03004430.2012.733944>
- Radley, A., & Taylor, D. (2003). Images of recovery: A photo-elicitation study on the hospital ward. *Qualitative Health Research*, 13(1), 77–99. <https://doi.org/10.1177/1049732302239412>
- Reavey, P. (Ed.). (2020). *A handbook of visual methods in psychology: Using and interpreting images in qualitative research*. Routledge.
- Richard, V. M., & Lahman, M. K. E. (2015). Photo-elicitation: Reflexivity on method, analysis, and graphic portraits. *International Journal of Research & Method in Education*, 38(1), 3–22. <https://doi.org/10.1080/1743727X.2013.843073>
- Rumsey, N. (2018). Psychosocial adjustment to skin conditions resulting in visible difference (disfigurement): What do we know? Why don't we know more? How shall we move forward? *International Journal of Women's Dermatology*, 4(1), 2–7. <https://doi.org/10.1016/j.ijwd.2017.09.005>
- Rumsey, N., & Harcourt, D. (Eds.). (2012). *Oxford handbook of the psychology of appearance*. Oxford.
- Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A reevaluation of the Life Orientation Test. *Journal of Personality and Social Psychology*, 67(6), 1063. <https://doi.org/10.1037/0022-3514.67.6.1063>
- Shatz, I. (2017). Fast, free, and targeted: Reddit as a source for recruiting participants online. *Social Science Computer Review*, 35(4), 537–549. <https://doi.org/10.1080/09638288.2019.1709911>
- Singh, H., Scovil, C. Y., Yoshida, K., Oosman, S., Kaiser, A., Jaglal, S. B., & Musselman, K. E. (2021). Capturing the psychosocial impacts of falls from the perspectives of wheelchair users with spinal cord injury through photo-elicitation. *Disability and Rehabilitation*, 43(19), 2680–2689. <https://doi.org/10.1177/0894439316650163>
- Slavin, R., & Smith, D. (2009). The relationship between sample sizes and effect sizes in systematic reviews in education. *Educational Evaluation and Policy Analysis*, 31(4), 500–506. <https://doi.org/10.3102/0162373709352369>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39–54. <https://doi.org/10.1191/1478088704qp0040a>
- Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-Being*, 2(1), 3–11. <https://doi.org/10.1080/17482620601016120>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage.
- Stock, N. M., Feragen, K. B., Moss, T. P., & Rumsey, N. (2018). Toward a conceptual and methodological shift in craniofacial research. *Cleft Palate-Craniofacial Journal*, 55(1), 105–111. <https://doi.org/10.1177/1055665617721925>
- Stock, N. M., Feragen, K. B., & Rumsey, N. (2016). Adults' narratives of growing up with a cleft lip and/or palate: Factors associated with psychological adjustment. *The Cleft Palate-Craniofacial Journal*, 53(2), 222–239. <https://doi.org/10.1597/14-269>
- Stock, N. M., Whale, K., Jenkinson, E., Rumsey, N., & Fox, F. E. (2013). Young people's perceptions of visible difference. *Diversity and Equality in Health and Care*, 10(1), 41–51.
- Stock, N. M., Zucchelli, F., Hudson, N., Kiff, J. D., & Hammond, V. (2020). Promoting psychosocial adjustment in individuals born with cleft lip and/or palate and their families: Current clinical practice in the United Kingdom. *The Cleft Palate-Craniofacial Journal*, 57(2), 186–197. <https://doi.org/10.1177/1055665619868331>
- Strauss, R. P., Ramsey, B. L., Edwards, T. C., Topolski, T. D., Kapp-Simon, K. A., Thomas, C. R., Fenson, C., & Patrick, D. L. (2007). Stigma experiences in youth with facial differences: A multi-site study of adolescents and their mothers. *Orthodontics & Craniofacial Research*, 10(2), 96–103. <https://doi.org/10.1111/j.1601-6343.2007.00383.x>
- Taylor, M. C. (1978). Toward an ontology of relativism. *Journal of the American Academy of Religion*, 46(1), 41–61. <https://doi.org/10.1093/jaarel/XLVI.1.41>
- Thompson, A. R., Kent, G., & Smith, J. A. (2002a). Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, 7(2), 213–225. <https://doi.org/10.1348/135910702169457>
- Thompson, A. R., Kent, G., & Smith, J. A. (2002b). Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, 7(2), 213–225. <https://doi.org/10.1348/135910702169457>
- Thornton, M., Harcourt, D., Deave, T., Kiff, J., & Williamson, H. (2021). Have we done enough? A cross-condition exploration of the experiences of parents caring for a child with an appearance-affecting condition or injury. *Developmental Neurorehabilitation*, 24(6), 418–428. <https://doi.org/10.1080/17518423.2021.1901150>
- Tiggemann, M. (2015). Considerations of positive body image across various social identities and special populations. *Body Image*, 14, 168–176. <https://doi.org/10.1016/j.bodyim.2015.03.002>
- Tugade, M. M., & Fredrickson, B. L. (2004). Resilient individuals use positive emotions to bounce back from negative emotional experiences. *Journal of Personality and Social Psychology*, 86(2), 320. <https://doi.org/10.1037/0022-3514.86.2.320>
- Tylka, T. L., & Wood-Barcalow, N. L. (2015). What is and what is not positive body image? Conceptual foundations and construct definition. *Body Image*, 14, 118–129. <https://doi.org/10.1016/j.bodyim.2015.04.001>
- Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *f*, 24(3), 369–387. <https://doi.org/10.1177/109019819702400309>
- Wallace, M. L., Harcourt, D., Rumsey, N., & Foot, A. (2007). Managing appearance changes resulting from cancer treatment: Resilience in adolescent females. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 16(11), 1019–1027. <https://doi.org/10.1002/pon.1176>
- Wells, F., Ritchie, D., & McPherson, A. C. (2013). It is life threatening but I don't mind'. A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies. *Child: care, Health and Development*, 39(4), 602–612. <https://doi.org/10.1111/j.1365-2214.2012.01399.x>
- Wiles, R., Prosser, J., Bagnoli, A., Clark, A., Davies, K., Holland, S., & Renold, E. (2008). *Visual ethics: Ethical issues in visual research*.
- Williamson, H., Griffiths, C., & Harcourt, D. (2015). Developing young person's Face IT: Online psychosocial support for adolescents struggling with conditions or injuries affecting their appearance. *Health Psychology Open*, 1–12. <https://doi.org/10.1177/2055102915619092>

- Williamson, H., Hamlet, C., White, P., Marques, E. M. R., Cadogan, J., Perera, R., Rumsey, N., Hayward, L., & Harcourt, D. (2016). Study protocol of the YP Face IT feasibility study: Comparing an online psychosocial intervention versus treatment as usual for adolescents distressed by appearance-altering conditions/injuries. *BMJ Open*, 6(10), Article e012423. <https://doi.org/10.1136/bmjopen-2016-012423>
- Williamson, H., Harcourt, D., Halliwell, E., Frith, H., & Wallace, M. (2010). Adolescents' and parents' experiences of managing the psychosocial impact of appearance change during cancer treatment. *Journal of Pediatric Oncology Nursing*, 27(3), 168–175. <https://doi.org/10.1177/1043454209357923>
- Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-hill education (UK).