

Developing young person's Face IT: Online psychosocial support for adolescents struggling with conditions or injuries affecting their appearance

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Abstract

A participatory action approach with potential users and clinical experts was employed to design and evaluate the acceptability of young person's Face IT (YP Face IT), an online intervention incorporating cognitive behavioural therapy and social skills training for adolescents with appearance-related anxiety as a result of a visible difference. Workshops with adolescents and clinicians informed a prototype YP Face IT which underwent a usability analysis by 28 multidisciplinary health professionals and 18 adolescents, before 10 adolescents completed it at home. Acceptability data obtained online and via interview were analysed using content analysis. Participants found YP Face IT acceptable and believed it would provide much needed and easy access to psychosocial support. They requested that it should be made widely available either as a self-management tool requiring minimal supervision from a health professional or to compliment therapist-led care.

Keywords

adolescence, anxiety, appearance, cognitive behaviour therapy, Internet, intervention

Introduction

Approximately, one in 44 adolescents has a visible difference (disfigurement) to their face or body that is typically judged by society as undesirable (Changing Faces, 2010). Causes may be congenital (e.g. craniofacial conditions) or result from a skin condition (e.g. vitiligo), trauma (e.g. burns), disease (e.g. cancer) or treatment (e.g. surgery).

Increased awareness and preoccupation with physical features and sexual attractiveness, combined with social pressures to meet ever-narrowing beauty ideals and tendencies to engage in peer comparison, result in appearance assuming enormous importance during adolescence (Ricciardelli and Mellor, 2012). Appearance becomes central to self-worth (Harter, 1999), perceived social acceptance and romantic appeal (Griffiths et al., 2012). Society's pervading focus on appearance and tendency to mock or denigrate those deemed unattractive can therefore make life challenging for adolescents with an unusual appearance; up to half of those affected experience extensive and enduring psychosocial difficulties (Kent, 2000; Rumsey and Harcourt, 2012).

These include fear of negative evaluation by others, experiences of stigma and discrimination (e.g. intrusive questioning, staring, abuse, rejection by peers or family), leading to body dissatisfaction, self-consciousness, lower social self-efficacy and social avoidance, which can interfere with social and emotional development, academic performance and career aspirations (Masnaria et al., 2013; Rumsey and Harcourt, 2007). Health and health behaviours can also be affected (Rumsey, 2008). Body dissatisfaction is a component and predictor of disordered-eating, depression, smoking, exercise avoidance (All Party Parliamentary Group on Body Image and Central YMCA, 2012) and self-harming (Muehlenkamp and Brausch, 2012).

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Research consistently shows that location, size and cause of a visible difference do not reliably predict psychosocial adjustment, and that reliance exclusively on medical and surgical solutions to ameliorate distress is inadequate. Rather individuals may benefit from psychosocial interventions that promote self-management skills to tackle stigmatisation and body dissatisfaction (Bessell and Moss, 2007; Muftin and Thompson, 2013).

This view has been reinforced by the success of *Face IT* (Bessell et al., 2012), an eight-session online psychosocial intervention for adults with a visible difference. Informed by Kent's (2000) Integrated Model of Psychosocial Distress and Intervention for Individuals with Visible Differences, it utilises social interaction skills training (SIST) and cognitive behavioural therapy (CBT). Didactic materials, videos and homework activities are used to teach helpful verbal and non-verbal communication skills, positive strategies to manage social stigma (e.g. staring, unwanted questioning and abuse) and tools for skilful social interactions based on Changing Faces' 'REACHOUT' (Reassurance, Energy, Effort and Enthusiasm, Assertiveness, Courage, Humour, Over there, Understanding and Try again). Clients using *Face IT* are encouraged to develop self-awareness and engage in cognitive re-structuring exercises through the process of recognising and challenging unhelpful thinking styles that increase appearance-related distress. Goal-setting, anxiety management and a stepped approach to social exposure and dropping safety behaviours are taught to promote social confidence. Videos present socially challenging situations and ask clients to choose how they might think and respond. Implications resulting from their choices are explored, and the activity illustrates the social benefits of positive thinking and social skills.

In a randomised controlled trial, *Face IT* reduced levels of depression, anxiety and appearance-related distress compared to a non-intervention control. A systematic review by Jenkinson et al. (2015) reported a dearth of rigorously evaluated psychosocial interventions tailored to the needs of young people with a visible difference, but concluded that CBT and social skills-based interventions (akin to those within *Face IT*) show promise and are worthy of more rigorous development and evaluation.

The online mode of delivery of *Face IT* could also be particularly appealing to adolescents. With near universal access to and a growing dependence on computers (Purcell, 2013), adolescents are more comfortable seeking health-related support and information via the Internet (Gray et al., 2005) and can benefit from immediate and easy access to online psychological interventions (National Institute for Health and Clinical Excellence (NICE), 2005). Online access may also address barriers that typically prevent this group from seeking or accepting support, including social avoidance, perceived stigma associated with therapy and the sensitive nature of the topic (Gould et al., 2002).

Face IT has already overcome a significant challenge in translating theory and adapting in-person therapeutic activities to an Internet intervention. However, its acceptability to adolescents is unknown. This article describes two studies that used a participatory action approach to determine the acceptability of *Face IT* to adolescents with a visible difference, and to develop and maximise the acceptability of a YP *Face IT*: built on the theory and evidence underpinning the success of *Face IT*, but adapted to meet the specific needs of adolescents.

General method

A participatory intervention model (PIM; Nastasi et al., 2000), based on the principles of participatory action research (Greenwood et al., 1993), guided the design of both studies. Partnership-based models promote the formation of non-hierarchical collaborative relationships that acknowledge the expertise of both the relevant stakeholders (adolescents, health professionals (HPs) and parents) and the research team (Power et al., 2004). Ensuring that stakeholders find interventions acceptable is critical to their implementation, effectiveness and subsequent motivation to sustain intervention use (Nastasi et al., 2000). Researchers brought to the partnership their knowledge of evidence-based strategies and expertise of intervention development and evaluation; adolescents provided their cultural experiences and realities of living with a visible difference; HPs and parents contributed their expertise from working or living with those affected.

The authors' university research ethics committee approved both studies. Participants were given information sheets, provided written consent (parental consent was required for those under 16 years) and participant anonymity and confidentiality were ensured.

Study One: the acceptability of Face IT to adolescents with a visible difference and to clinical experts delivering appearance-related interventions to adolescents

Design

Face-to-face workshops were conducted with adolescents (both those with and without a visible difference) and individual interviews were conducted with clinical experts.

Participants

In all, 32 individuals participated in three groups. In Group one, there were 13 participants (seven males), aged 12–19 years (mean: 15.68; standard deviation (SD)=1.89) who were members of Changing Faces' Young Person's Council (CFYPC), a pre-existing voluntary group supervised by a

youth worker, invited to participate because they have a wide range of appearance-altering conditions (e.g. cleft lip, scarring) and are experienced at working together to improve services (see www.changingfaces.uk.org). In Group two, there were four female clinical psychologists, purposively selected for their expertise in delivering interventions to adolescents with visible differences. These groups were included to determine the acceptability of *Face IT* and to recommend any necessary changes or additions. In Group three, there were 15 adolescents (seven males), aged 13–16 years (mean: 14.5 years; SD=1.3), recruited via an advertisement at a local high school and supervised by their school teacher. This school group provided an adolescent's perspective on the graphic, navigation and information architecture design (the structure of website information) of *Face IT* and advised on the design of an appealing youth version. Group three were included to reduce the burden of 'work' on the CFYPC members whose tasks focused on evaluating and, if necessary, improving the website's therapeutic material.

Procedure

Data were collected via four separate workshops with adolescents and via telephone interviews with clinicians. To maximise engagement with the adolescents, the design of the workshops was informed by INVOLVE (part of the UK's National Institute for Health Research) guidelines for collaborating with young people (www.invo.org.uk), and by the school teacher or CFYPC youth worker who knew the participants' strengths and limitations.

Clinician interviews. After reviewing *Face IT*, each clinician participated in two semi-structured interviews (lasting 60–90 minutes) conducted by the lead author. In the first, clinicians were asked their views on whether *Face IT* addressed the problems and needs of adolescents struggling to cope with a visible difference, the extent to which its mode of delivery and content was acceptable, the supervision users would require in order to complete and benefit from the intervention, and any potential ways in which the intervention could be improved. In the second interview, clinicians were given the opportunity to comment on evidence- or practice-based solutions to improve the programme based on their group's and the CFYPC's feedback.

CFYPC workshops. The CFYPC participated in two 90-minute workshops facilitated by the authors and two Changing Faces youth workers. Participants were made aware of the project aims: to review the therapeutic content of *Face IT* and identify unaddressed support needs or strategies and features they would like added. Workshops used 'bite-size' interactive multimedia 'activities' (e.g. using computers, videos, posters) in the first workshop to present the extensive therapeutic content of *Face IT* and a summary of

participant feedback and possible solutions to improve *Face IT* in the second workshop.

In the first workshop, participants visited each activity in turn providing feedback verbally or via post-it notes before engaging in a small group work with facilitators who asked participants to share and discuss their views. In the second workshop, participants were invited to share their own and comment on the researchers' (and clinicians') solutions to the problems and deficits they had identified within *Face IT*.

School group workshops. The aims of these workshops were in response to the CFYPC's request to create a young person's version of *Face IT* with more interactive features and an age-appropriate presentation style and level of comprehension. The school group participated in two workshops. For each workshop, participants were divided into groups of three. Each smaller group was supervised by a researcher, briefed in the project aims and with significant experience of conducting research with young people.

In the first workshop, participants were introduced to the objectives of the project and each group was asked to review a session of *Face IT* on a computer and comment on its presentation, usability, language and comprehension and, if necessary, make suggestions for improvement. All *Face IT* sessions were reviewed. In the second workshop, to illustrate design preferences, participants were first asked to identify and provide a critique of websites they prefer and trust, including those that they seek advice from. To provide age-appropriate language and contemporary context for SIST sections, story boards of typical social situations that adolescents might be involved in were used to prompt group discussions related to their experiences of peer interactions and social networking behaviour.

Analysis

Workshop activities and interviews were audio-recorded, transcribed verbatim and analysed using a mix of inductive and deductive content analysis based on established guidelines (Elo and Kyngas, 2008; Hsieh and Shannon, 2005). First, a categorisation coding matrix was developed that reflected the information sought regarding the content and design of *Face IT* and allowed participants to raise new issues and permit the inclusion of new categories. The data were then read through several times and meaning units (words or statements related to a central meaning) were condensed and encoded using pre-existing or new category labels. Analysis was conducted at a manifest level staying close to the surface of the text and describing its visible and obvious components rather than interpreting the underlying meaning of the text (Graneheim and Lundman, 2004). Findings were scrutinised by the second author, which resulted in a 96 per cent inter-rater reliability. Differences were discussed and revisions cross-checked and fed back into the analysis.

Results and discussion

Five topic areas were identified and are presented and discussed below. Quotes are anonymised and pseudonyms are used.

'We need a website specifically for adolescents'

Participants unanimously requested an appearance-specific online intervention with similar content to *Face IT*, but designed for adolescents. Three new categories reflected their rationale.

Limited availability of appearance-specific psychosocial support. In all, 10 members of the CFYPC reported that there can be difficulties sourcing support to manage the social and psychological challenges associated with 'looking different'. Their experiences indicated that school and HPs lack the expertise to recognise their concerns or the resources to address them: 'me and mum tried ...but our school and doctor just didn't get it, they couldn't help' (John, 14 years). All clinicians concurred adding that adolescents seeking support from primary care often fail to meet criteria for secondary care referral, or appearance-specific support provided by primary or secondary care services is limited (see also Charlton, 2003).

Barriers preventing access to support. Half the members of the CFYPC and all of the clinicians identified that online support would overcome the practical or personal barriers and associated costs that reduce adherence to (or deter patients from accepting) face-to-face therapy. These included having to wait and travel large distances to access expert care, absence from school or work (for parents) to attend therapy, and concerns around discussing sensitive issues with an adult and/or psychologist. Adolescents reiterated that receiving counselling can be stigmatising, awkward and stressful (see also Moulding, 2007) and another burden that sets them aside from their peers: 'I wouldn't want mates knowing. They'd guess and ask why I skipped lessons' (Billy, 15 years).

Young Person's Face IT. The CFYPC and clinicians all valued *Face IT* as a tool that recognises issues faced by individuals with unusual appearance, but emphatically rejected its suitability for adolescents. They expressed that *Face IT* was 'academic' (Jill, 13 years); 'long and complicated' (Ann, 14 years); 'not meant for teenagers' (Bella, 14 years) and 'visually boring' (David, 15 years). They recommended the design of a young person's version of *Face IT* called YP Face IT.

Programme content

The core therapeutic elements (normalising/validating concerns, psycho-education, self-awareness exercises, training to improve social self-efficacy, anxiety, goal-setting, cognitive re-structuring strategies) and the chronology of *Face IT*

were broadly acceptable. However, substantial changes were discussed and the following incorporated into YPF.

Think, feel, do. The explanation and utilisation of CBT were reported as difficult to comprehend by over half of participants: 'that's very heavy going, I'm 16 and struggle, I'm not sure the younger ones will get it' (Lucy, 16 years). Elements of Stallard's (2002, 2007) model of CBT (*Think, Feel, Do; Catch it, Check It, Change It*), which has proved acceptable to 11- to 16-year olds, were proposed by the researchers, and subsequently preferred. The CFYPC and school groups provided age-appropriate language and social experiences to illustrate the model.

Age-appropriate social skills training and examples. Nearly all participants requested a simplified and reduced social skills training section, still incorporating the key verbal and non-verbal techniques of *Face IT*, to illustrate how to manage difficult social situations and negative reactions to their appearance, but utilising their own experiences.

Role models. Most adolescents recognised the potential power of positive role models to demonstrate skills and influence knowledge, attitudes, beliefs and values (Bandura, 2004). In particular, celebrities or public figures with a visible difference who have overcome or rejected the assumption that individuals with a visible difference cannot succeed in highly visible social roles. The CFYPC also expressed that non-celebrity role models, 'those slightly older who have survived' (Alice, 15 years) the transition of adolescence, often have useful advice or experience. All adolescents requested age-appropriate versions of the interactive videos within *Face IT* that simulate difficult social situations and ask users to practice positive behaviours in a safe environment before applying them in the real world. Since young people are more attentive to simulations and their associated health messages when characters are of a similar age and life context (Lieberman, 2001; Parrott, 2005), adolescents informed the design and script of the videos that members of the CFYPC enacted.

Exposure therapy: 'managing client expectations'. Strategies to target social avoidance and reduce social anxiety are a key feature of *Face IT* (Bessell et al., 2012). Three clinicians were concerned that exposure techniques within *Face IT* were ambitious and potentially unsafe for adolescents to complete at home without clinical support. However, the majority of adolescents highly valued elements of this section and requested that the techniques should be rewritten from an adolescent's perspective. Clinicians ensured the content engendered realistic expectations and provided guidance for seeking further support.

'You are not alone'. All members of the CFYPC reiterated previous research detailing how isolated one can feel as a result of looking different: 'I hate that I feel like I'm the

only one – they need to know they're not alone' (Jill, 13 years). Thus, their aspirations were to ensure that YPF engenders feelings of camaraderie, validates concerns and facilitates social support. Participants collaborated to achieve this by adding a friendly tone to the text, including avatars with various appearance-altering conditions that offer motivation, and a 'real-time' discussion forum to enable users to request or provide advice and social support.

Two clinicians raised ethical and safeguarding concerns regarding a forum. However, given adolescents' accounts of previous social networking experiences and evidence of their benefits to adolescents with chronic conditions (Love et al., 2012), the collaboration agreed on a moderated forum with established e-safety guidelines and rules of conduct (O'Keefe, 2008), that is restricted to those completing YPF. To increase YPF's accessibility to those with reading difficulties, videos explaining the aims and value of YPF were designed and filmed by the CFYPC, and optional audio facilities (read by a young adult) were added.

Romantic relations. All clinicians requested a section to target adolescent worries regarding the development and maintenance of romantic relationships. Most of the CFYPC agreed but all were reluctant to discuss this issue within workshops. As the evidence base to develop such an intervention is weak, a separate online study was conducted to inform this section of YPF (see Griffiths et al., 2012).

Reflective journal. Cognitive behavioural journaling, writing down thoughts and feelings about previous or current difficult situations while participating in an intervention, can increase insight and confidence to confront issues and to develop and reinforce skills (Clabby, 2006). While *Face IT* does not include a reflective journal, two clinicians and most adolescents valued its inclusion within YPF: 'for me it's hard to talk about embarrassing things, so yeah I agree, some will need to write stuff' (Phoebe, 14).

Booster session. Some adolescents suggested a revision session to reinforce learning and skill development. A review of computer-aided cognitive behavioural therapy (cCBT) for anxiety and depression suggests booster sessions can maintain and yield improved treatment effects among adolescents (Richardson et al., 2010). Participants therefore designed an interactive 'booster' quiz to be completed 6 weeks following completion of YPF.

Programme design

Language and comprehension. Although chronological age may not always reflect ability, the majority of adolescents rationalised that those under 12 years would prefer to talk to parent/carers, and 18-year olds could access *Face IT*. The collaboration therefore ensured the content was made meaningful to 12- to 17-year olds, with a reading age of 12 and readability levels between 90 and 100 per cent (Singh,

1994). During this process, participants provided ideas on the graphic design of the programme and reduced dependence on text by adding interactive activities, illustrations and videos.

Structure. Information architecture (IA) designs typically used for behaviour-change websites (Danahar et al., 2005) were discussed with web designers and participants. Feedback endorsed a hybrid IA design using a mix of tunnel IA (a linear model to guide the user and control the order and amount of content delivered within the weekly sessions) and matrix IA modules which allow the user to break free from the lock-step sequence of pages found in a tunnel design and offer different ways of interacting with content. Immediate automated progress feedback (e.g. tailored messages and visual displays) was included to personalise the programme.

Trust and relevance

The majority of adolescents stressed that the number and range of health-related information websites makes it difficult to identify which are the most relevant and trustworthy: 'there's so much out there, you gotta learn what sites you can trust' (Stuart, 15 years). They therefore insisted the YPF homepage should appear 'professional' and its purpose should be overt, with appealing visual anchors (photographs or videos). In order to foster trust in the information they suggested that the YPF homepage should include images of adolescents with visible differences, endorsements (including logos) by trusted charities, photographs and professional credentials of the YPF collaboration and personal recommendations by previous users (see also Crutzen et al., 2008). The collaboration also agreed that the homepage should provide information for parents and HPs regarding the issues adolescents struggle with and detail the rationale underpinning the intervention content and design.

Intervention delivery

Participants articulated the benefits of an online intervention to target barriers preventing access to support (described above) but identified caveats in relation to client safety and who might benefit from YPF.

Supervision and safety. Participants were ambivalent regarding adult supervision. A minority of older members of the CFYPC felt that some users might appreciate an empathetic adult available if difficulties or questions arose, but most members preferred a self-administered rather than therapist-assisted model. While all clinicians recognised the benefits of YPF in targeting hard-to-reach patients, two raised concerns around how to protect potentially vulnerable users and suggested that YPF should be accessible via, and supervised by, a HP capable of conducting a screening procedure to exclude complex cases (those requiring more

intensive face-to-face interventions). Exclusion criteria suggested included posttraumatic stress disorder (PTSD) resulting from traumatic injury (a risk associated with burn injuries; Yu and Dimsdale, 1999); clinical depression/suicidality (often associated with bullying and anxiety; Klomek et al., 2007) and eating disorders (a risk associated with low body image; Stice, 2002).

A supplement to current care. All participants argued that YPF should be viewed as an addition to current care provision, not a replacement for therapist-led counselling, or the support engendered via group activities.

Conclusion

Although psychosocial support is vital for many struggling with a visible difference, it can be difficult for young people to access, very often due to a host of barriers that clinicians and members of the CFYPC elucidated. These participants were confident that an online intervention would overcome these barriers and provide easy access to psychosocial support to complement current care provision. Through a rigorous process of evaluation and collaboration, adolescents and experts informed the design of a prototype young person's appearance-specific online support tool (YP Face IT), based on *Face IT* but tailored to appeal to adolescents and meet their therapeutic needs.

Study Two: the acceptability of YP Face IT to HPs, adolescents with a visible difference and their parents

Design

The YPF prototype underwent a usability analysis, employing the empirical testing approach (Olson and Olson, 2003) successfully utilised by Bessell et al. (2010), to establish its acceptability to its target audience in terms of therapeutic content, graphic and navigation design; efficiency (the time and effort required to use the system for the tasks that it is designed for); effectiveness, and the extent users feel and respond positively (or negatively) to the system (Williams, 2004). These methods involve assessors using the programme as users would in real life and providing opinions and detecting glitches (Smilowitz et al., 1994).

The acceptability of the YPF prototype was evaluated in two phases. Phase One determined its acceptability to adolescents with a range of visible differences and to multidisciplinary HPs, and the findings informed modifications to the prototype. Phase Two determined the acceptability of the amended prototype – with either real-time or remote (e-mail) adult supervision to 12- to 17-year olds with appearance-related distress and investigated their parents' perspectives on their using YPF.

Phase One

Participants and procedure

In all, 18 young people (seven males), aged 12–19 years (mean: 14.5 years) from across the United Kingdom, were purposively recruited via support groups that provide information for those with a range of appearance-altering conditions (e.g. the Cleft Lip and Palate Association). Five had craniofacial conditions (e.g. cleft lip); five had skin conditions (e.g. psoriasis); five had scarring and three had facial birthmarks. In all, 28 (four males) HPs who care for those with a range of appearance-altering conditions, were purposively recruited from around the United Kingdom. Four were consultants specialising in plastic surgery and laser therapy for craniofacial conditions and birthmarks, dermatology and general paediatrics; three were clinical nurse specialists working in oncology, burns and dermatology units; 12 were clinical psychologists working in burns, craniofacial, oncology and dermatology departments; four were general practitioners (GPs; family doctors) and five were youth counsellors/social workers working in oncology or the charities Changing Faces and DebRA (for people with epidermolysis bullosa).

Participants were provided with individual usernames and passwords to access the website, and guidelines on how to critically review YPF. To reduce their burden of work, adolescents reviewed three allocated sessions (each session was reviewed by at least three participants) while HP reviewed the full programme. Participants submitted feedback online and took part in audio-recorded, semi-structured, 40- to 80-minute telephone interviews conducted by the authors.

Interviews with all participants explored views regarding the suitability of the programme's design (What do you think of the way the programme looks? How can it be improved?); structure (What do you think of its layout and navigating around it? How could these features be improved?); language and comprehension (How easy is it to understand? Can you tell me about any difficulties?); realism (How does it reflect adolescent experiences? How can it be improved?); therapeutic content (What do you think about the strategies and activities used to help users, what would you add, or change?); appeal and motivation required to complete homework activities/full programme (What do you think about the activities? What will encourage adolescents to complete them?); confidentiality and privacy (What do you think of the security measures in place? How confident would users be to provide personal reflections in response to online activities?); mode of delivery (What do you think about online interventions? What are the positives and negatives?); and supervision (How much support would users need to complete it and from whom?). Interviews with HPs also explored their experiences of caring for adolescents with appearance-altering conditions, their use of appearance-specific interventions

and/or referral experiences and how they would imagine the programme could be used in their area and for whom. Adolescents were also asked, How would you feel if you were asked to complete YPF? Why would you use it, or why would you not?

Online feedback was examined weekly and text errors or glitches were addressed immediately. Interviews were also tailored to explore points raised by individuals within their online feedback.

Analysis

Qualitative data from adolescents and HPs were analysed separately with the content analytic procedure used in Study One, but their views are combined under six broad topic areas described below. Percentages are presented where useful, to indicate the extent to which participants shared opinions.

Website presentation and navigation

Adolescents discussed the appeal, realism and trustworthiness of the website: 100 per cent felt the programme reflected their experiences, endorsed the presentation style which was described as ‘age-appropriate’, ‘attention grabbing’ and ‘motivating’, and trusted the information and expertise of the development team: ‘I trust it, they look like they know what they’re doing’ (Chloe, 16 years). The majority of HP (94.5%) also approved of the presentation, structure and navigation and particularly liked the interactive activities, signposting, repetition and multimedia, describing the website as ‘easy to use’, with 5.5 per cent making small suggestions to improve navigation.

Comprehension and motivation

Most adolescents (94.5%) had ‘no difficulties understanding the text, instructions and homework activities’ (James, 14 years); with 30 per cent deciding they would use the audio facility, ‘I need the audio, my reading is slow’ (Will, 13 years). The majority of HP (88%) felt that the language, pace and tone were pitched appropriately for 12- to 17-year olds. However, some (12%) felt a minority of adolescents could find CBT and the length of sessions too challenging and users may have insufficient motivation to complete YPF. They suggested its suitability should be considered on an individual basis and the programme used flexibly, for example encouraging those with poor concentration to work through a session in two shorter sittings or to complete it with a psychologist present.

Therapeutic content

Adolescents did not make any negative comments about the therapeutic content. Totally, 80 per cent enthused about

the interactive elements such as quizzes, social skills videos, ‘Whiteboarding’ animations, avatars, audio and the real-life examples, because they showed that ‘there were other people going through the same experience’ (Peter, 15 years) and they could ‘get advice from people who had been through it’ (Lily, 16 years). The social skills training and anxiety beating skills were thought to be particularly helpful – because participants had previously used these to manage their own difficulties.

Adolescents endorsed the inclusion of a real-time forum to provide support and a sense of community: ‘I think it’s brilliant, I don’t actually know anyone with a birthmark like mine, so it’s kind of like I am on my own, they’ll be able to find others with the same thing and speak about it’ (Charlotte, 17 years). Some valued the anonymity of the forum: ‘you can talk to them over that and it’s less embarrassing than face-to-face’ (Will, 13 years). Most adolescents (88%) would complete homework activities, but 12 per cent were unsure or suggested parental support might be necessary (Will, 13 years).

All HPs endorsed the content, particularly its emphasis on practical strategies and inclusion of sensitive issues (e.g. intimacy). The psychologists felt it reflected interventions used in their own practice, was ‘incredibly valid’, ‘well-structured’ and ‘safe’, and the remaining HPs felt it was ‘intuitively sound’ (Nurse), ‘authoritative’ (GP), ‘trustworthy’ (Social Worker) and ‘comprehensive’ (Consultant). They also felt YPF would be a valuable addition to the care they provide because it addresses unmet needs, ‘access to expert appearance-specific psychosocial support is limited’ (GP); it has a wide audience and ‘synthesises all the information in one place’ (Consultant); and it includes ‘information for health professionals who may not know the area’ (Psychologist).

Mode of intervention delivery

All adolescents approved the online delivery with 88 per cent preferring access to YPF at home, as it offers the freedom to complete sessions in private, at their convenience and outside school hours. Many felt it would be ‘less pressurising and formal than a clinic environment’ (Harvey, 14 years) and ‘you could have the support of your family’ (Angus, 16 years). However, 12 per cent did not mind if access was provided at home, a clinic or school.

Likewise, most HPs (94.5%) valued online delivery to overcome barriers that prevent adolescents (and parents) from accepting or adhering to face-to-face therapy and to facilitate access to ‘hard to reach, isolated groups with social anxiety, low self-esteem, embarrassment’ (GP). It was considered suitable for patients awaiting secondary care interventions, to prepare adolescents for higher intensity psychological therapy and to provide immediate access to support that ‘empowers, fosters independence and reduces

isolation' (Psychologist). HPs also argued that YPF 'allows adolescents to work through a session at their own speed and not at a pace dictated by a health professional' (Psychologist) and permits psychologists to 'treat more patients and reduce healthcare costs' (Psychologist). However, a minority (5.5%) expressed that it may not be a suitable programme for all and were concerned that the content could trigger distress at a time when the user might not have access to expert support.

Supervision

Most adolescents (88%) would prefer to complete YPF without an adult present: 'I would be more honest' (Peter, 15 years), 'because the topics are sensitive' (Clara, 14 years). However, some (22%) wanted an adult available, 'if I wasn't sure of something' (Annie, 13 years).

For most HPs, the issue of supervision was a moot point. Most (60%) felt a supervision plan, where users could be monitored weekly via e-mail or telephone, would be appropriate, 12 per cent would 'tailor supervision levels to meet individual needs' (Clinical Psychologist), and 70 per cent requested research evidence to indicate the level of supervision users require as they work through the full programme. In addition, 85 per cent wanted YPF widely available via primary and secondary care and judged that, with brief training, supervisors could include psychologists, GPs, counsellors, assistant psychologists, practice, school or specialist nurses, and social and youth workers.

Improvements

Adolescents (64%) offered suggestions to increase user motivation including breaking down 'homework activities into smaller chunks' (Millie, 17 years); text/e-mail reminders to complete activities, weekly sessions and the booster quiz; advice on when to engage family/friend support; and making it explicit that the journal is confidential. A small number of HPs (10.5%) suggested changes including 'more ethnically diverse avatars' (Youth Worker), more examples of 'appearance changes post-chemotherapy' (Clinical Nurse Specialist), and engaging parental support to assist adolescents with poor motivation or concentration.

Phase One discussion

The design, therapeutic content, comprehension, mode of delivery and plans for delivering YP Face IT were broadly endorsed by adolescents and HPs who identified that it would be a valuable addition to the provision of care for young people with appearance-related distress, both in primary and secondary care. However, changes were recommended and minor concerns were raised.

Poor utilisation and high attrition rates due to loss of motivation and interest are fundamental characteristics of online interventions (Bennett and Glasgow, 2009). Participants'

suggestions to improve motivation and reduce attrition were adopted, including text and/or e-mail prompts that can be sent to the adolescent and/or parent and recommendations to engage parental/carer support. The supervision users require as they work through the programme, their experiences of using it, and the resources required to moderate the forum were investigated in Phase Two.

Phase Two

Participants and procedure

In total 10 adolescents' (five males), aged 12–17 years (mean: 14.5 years) with a range of visible differences (e.g. skin and craniofacial conditions and scarring) and self-reported appearance-related distress, plus a parent/carer of each adolescent ($n=10$), were recruited via UK support group websites (e.g. the Ichthyosis Support Group) and screened for inclusion according to the criteria suggested in Study One.

Adolescents completed YPF in their own home: one session per week and the booster session 6 weeks later. In order to examine users experiences of completing YP Face IT, including how much adult supervision they might require, 5 completed it in the presence of a health psychology researcher (first or second author). The researcher was in contact via Skype, with audio and visual facilities, and was able to see the users computer screen as they completed YP Face IT and respond to questions or difficulties. The researcher kept detailed field notes of any supervision provided. The remaining five completed the programme independently, with access to the research team via e-mail (monitored during working hours). Participants' experiences of using YPF were ascertained by way of a Likert-style evaluation questionnaire and a semi-structured telephone interview with the first or second author.

Throughout, a clinical psychologist provided supervision to the researchers and monitored data from users' online activities and journals, checking for safeguarding issues. The forum was moderated daily. Clinical supervision activities, safeguarding concerns, e-mail and forum uses were recorded. Parents provided feedback of their experience of their child completing the programme via a brief (30 minutes) semi-structured telephone interview. Questions explored parent's own and their child's motives for supporting the study. Parents were asked how their child found YP Face IT and about any feedback they had received. Views on the delivery of support via an online tool were explored, including enquiry into their preferences for support, past experiences of seeking and receiving support for their child, and how the programme and its delivery could be improved, including what they felt their role should be for supporting their child.

Analysis

Qualitative data from field notes and interviews were analysed using the content analytic procedure described in Study

One and quantitative data from the evaluation questionnaire are reported as percentages.

Results

Five broad topic areas were identified and within these, any differences between those receiving real-time versus e-mail supervision are represented.

Supervision

The ability to complete YPF at home was seen as a distinct advantage: 'It's nice to be able to relax in your own home, rather than a hospital clinic' (Bob, 12 years). Five completed YPF with a supervisor witnessing their progress and available for assistance. They worked independently and responded to self-reflective tasks within their online journal without raising any safeguarding concerns. Although two participants appreciated the attention (which supervisors believed had a positive impact on motivation and attrition), real-time supervision was not considered essential and three participants felt it may have been inhibiting: 'I think I might have found it easier if I was on my own' (Jane, 15 years).

Of the five who completed YPF with e-mail support, all completed the programme safely and were content with the level of support offered. Their utilisation of e-mail support was minimal (two e-mails requested advice on password retrieval), and two participants required four additional prompts via e-mail and telephone to complete homework activities and the booster session. Monitoring users' online data (quiz results, journal entries, reflective exercises) took 5 minutes/per user/per session.

Parental involvement

Eight participants reported that it would have been useful if their parents were more familiar with the content of the programme in order to support them when practicing new skills. However, two warned of the need to maintain users' independence: 'Be careful the parent doesn't get too involved and nag too much, or we won't want to do it' (Malik, 14 years); 'it's important to maintain independence ... because people with visible differences are very used to the hospital or parents being in control, that's what makes this program different' (Poppy, 17 years).

Forum use/online data checks

Feedback on the forum was positive and it was used appropriately. Participants in this study each posted 1–3 messages, but expressed that it would be more useful and that they would use it more, as the numbers using YPF increased and the content expanded: 'not many people are on it, because of the lack of people I didn't use it that much' (Malik, 14 years). Forum moderation by the authors took approximately 15 minutes per day.

Impact of YP Face IT on well-being

Users were asked to comment on how YPF had affected them either positively or negatively. The following categories were identified:

Confidence and self-acceptance. Eight participants discussed the positive impact YPF had on their confidence: 'it was a real confidence booster' (Dylan, 15 years) and 'it's helped me to be much more accepting of my difference' (Jane, 15 years). YPF was described as reassuring as it validated their concerns and helped them feel they were 'not alone' in struggling with appearance-related distress/bullying.

Developing new skills. Seven participants discussed new strategies that they were able to apply in real-life situations: 'I used some of the techniques at school already and now I don't really feel sad if people say nasty things to me anymore' (John, 12 years); 'what I use most is the goal setting and anxiety techniques' (Bill, 13 years); 'I had resigned myself to the fact that all people are like that, I was just going to have to deal with it. But YPF made me question, well, maybe they are not all bad, maybe it's just the way I'm thinking' (Jane, 15 years).

Dealing with difficult social situations. One of the most frequently discussed ways in which users felt YPF had helped them related to handling difficult social situations. Eight participants felt that they could now handle social situations better and were less nervous about them: 'it was good that I had been doing YPF, because otherwise I would have been completely stumped when I was being asked about my face' (Liz, 16, years).

Parent feedback

Parents functioned as gatekeepers with an important role in recruitment. It was often their encouragement that prompted adolescents to engage with the project, a view reiterated by participants: 'I know when Dad mentioned about doing it I wasn't the biggest fan. But I'm really pleased I have now' (Malik, 14 years). Parents were enthusiastic about YPF and relieved that 'at last there is support to help young people deal with their worries and the teasing and trouble they get' (parent of Bill). They did not express any concerns about their child using YPF and felt it was safe and helpful. While all believed it was important for adolescents to know they could contact a HP with knowledge of the programme if they experienced difficulties, some were concerned that access to YPF may be curtailed if 'supervision was mandatory but insufficient numbers of health professionals were willing to offer YPF' (parent of Jane).

Parents were motivated to offer support to their child to complete sessions; however, they did not believe that all parents would want to be involved and that, in these cases,

e-mail supervision and text/e-mail reminders would be essential. They also felt they would have benefitted from written information on how they could support their child while completing YPF. These parents have since collaborated with the research team to develop guidelines for parents of children using the programme, which are available on the website.

Adolescents were also asked to rate their satisfaction with YPF on a 5-point Likert scale, from 'strongly agree' to 'strongly disagree', in relation to its presentation, content, relevance, age-appropriateness, homework activities and feedback and comprehension. The majority, 90 per cent, strongly agreed that the programme was well-presented with appropriate therapeutic content, activities and support and did not want to change the programme.

Phase Two discussion

Participants safely self-administered YPF and completed all activities. Although some benefited from real-time supervision, the majority needed minimal supervision from a HP, namely to confirm the clients' suitability for the programme; monitor their progress and offer support via e-mail. However, observations that suggest some users may benefit from additional guidance supports assertions (by HPs in Study One) that supervision could be determined on an individual basis.

General discussion

Participants reiterated previous research that adolescents who struggle to adjust to the psychosocial consequences associated with a wide variety of appearance-altering conditions are at risk of reduced psychosocial well-being and may benefit from easily accessible interventions to address their unique needs and overcome barriers that limit access to care (Bessell et al., 2012).

As with *Face IT*, the therapeutic content of YP Face IT was informed by Kent's (2000) Model of Psychosocial Distress and Intervention for Individuals with Visible Differences. Kent integrates contributions made by the Social Anxiety (Baumeister and Leary, 1995), Stigma (Goffman, 1968), Social Skills (Bull and Rumsey, 1988) and Body Image Disturbance (Cash, 2001) models that describe some of the difficulties faced by individuals with a visible difference.

In essence, Kent's model acknowledges that an appearance that is unusual and perceived by the individual as unattractive (compared with highly valued cultural beauty ideals) can increase fear of rejection and negative appearance-related cognitions which, when combined with experiences of social stigma, can heighten social anxiety. Social anxiety can make individuals appear distracted, anxious or lacking in confidence and thus inhibit social interactions (Bull and Rumsey, 1988).

Kent therefore recommends SIST to improve communication skills that promote feelings of control, help individuals overcome negative reactions by others and ease social tension. CBT is advised to address negative thoughts and beliefs about one's own appearance and the assumptions individuals with visible differences make about the behaviour of others towards them (Thompson and Kent, 2001). CBT also offers individuals an opportunity to test out social situations they might fear due to negative past experiences. This process of exposure permits individuals to engage more fully in social situations and to reduce the limitations that they may be imposing upon their own lives (Kent, 2000). As social exposure, without first addressing any limitations in communication skills, might lead to more negative experiences and greater social withdrawal; SIST is therefore addressed prior to social exposure activities within YP Face IT.

There is some evidence, albeit limited, that SIST and CBT approaches may be effective for young people (Jenkinson et al. 2015). However, this project, which follows the Medical Research Council framework for the development of complex interventions (Craig et al., 2008), is the first to rigorously determine the acceptability of a therapeutic model that combines SIST and CBT, delivered in an age-appropriate, engaging and interactive way, to both potential service users and HPs working with this population. Adolescents who completed the programme also indicated that they had utilised and benefited from new skills taught within YP Face IT, suggesting that further trials to systematically evaluate its effectiveness are justified.

The Centre for Appearance Research in the United Kingdom has developed a pragmatic tiered model (The Centre for Appearance Research Framework of Appearance-Related Interventions) to classify and guide the development of interventions and ensure patients receive the most appropriate care (Rumsey and Harcourt, 2012). It recognises that while most benefit from low-level interventions (e.g. information booklets), far fewer require intensive and expensive higher level face-to-face interventions. Based on participant feedback and informed by the current gap in care provision, YP Face IT can be regarded as a mid-level intervention with a blended-care approach. It provides the benefits of a self-administered easily accessible intervention, with the additional safety of facilitation by a psychologist or other HP with brief training in its use (who can escalate care if necessary).

One of the strengths of this research is the use of a PIM. Although building meaningful and trusting relationships can be time-consuming, the research team successfully empowered stakeholders to develop an acceptable intervention that integrates the theoretical and current evidence base regarding intervention content, with the beliefs, motivations, language, culture and practices of potential service users and healthcare providers.

However, study limitations also warrant discussion. Participants were self-selected and highly motivated to

address a perceived deficit in support that they considered important. While a lack of participant representativeness could be considered a limitation of any participatory research (Entwistle et al., 1998), our findings may particularly reflect a degree of social desirability, especially as the design of the research did not permit anonymous responses. Reviewers in Study Two may have over-emphasised the positive aspects of YPF and been reluctant to criticise. In addition, despite efforts to recruit participants with a range of ages and conditions, the generalisability of findings is reduced by using small participant numbers only recruited via charity support groups. Further research is therefore need to evaluate the effectiveness of the programme, including its health economic evaluation, delivered via different primary and secondary healthcare settings and with a larger more diverse group of adolescents.

In conclusion, this research has resulted in the development of a highly acceptable and accessible psychosocial intervention. It is tailored to meet the specific needs of adolescents struggling with appearance-related distress and can be utilised either by secondary healthcare clinicians to support their current care provision or by primary care HPs with limited experience of delivering appearance-related support who require only minimal training to supervise adolescents' use of YP Face IT at home.

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