Acceptability and feasibility of an online psychosocial intervention for Dutch adolescents with a visible difference: A mixed-methods study

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ABSTRACT

Adolescents with a visible difference can experience difficult social situations, (e.g., people staring or making unwanted comments) and are at risk for mental health problems. Unfortunately, interventions for adolescents with a visible difference experiencing appearance-related distress are scarce and lack an evidence-base. This study tests the acceptability and feasibility of YP Face IT, an innovative online psychological intervention using social skills training and cognitive behavioural therapy, to Dutch adolescents. Adolescents aged 12–17 with a visible difference and access to an internet-enabled computer or tablet participated. They completed YP Face IT (eight sessions) and questionnaires were administered pre- and post-intervention. After completing YP Face IT, participants were interviewed to assess the acceptability and feasibility of YP Face IT and study procedures. Overall, 15 adolescents consented to participation, one person dropped out after one session. Most adolescents appreciated the intervention and all would recommend it to other adolescents experiencing appearance-related distress. Everyone reported learning experiences after following the sessions. Some struggled with motivation, but reminders by the website and research team were helpful. The Dutch YP Face IT intervention may be acceptable and the current study design is feasible to use. An RCT should be conducted to assess the effectiveness of the intervention.

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1. Introduction

Living with a visible difference (i.e. disfigurement) can be very challenging, particularly in relation to social situations, which can be difficult as a result of people staring, asking unwanted questions or teasing and bullying (Jewett et al., 2018). It is estimated that 1 in 44 people have a visible difference to the face or body and 1 in 111 have a visible difference that solely affects the face (Changing Faces, 2010). A visible difference can be either congenital (e.g. cleft lip and palate, craniofacial conditions), result from a skin condition (e.g.

vitiligo, psoriasis), trauma (e.g. burns, scars), disease (e.g. cancer, meningitis) or medical treatment (e.g. radiotherapy).

Studies that have focused on the psychosocial aspects of living with a visible difference have produced contradictory findings. A small portion of studies found positive psychosocial outcomes. For instance, adolescents born with a cleft lip experienced no additional psychosocial problems (Berger & Dalton, 2009) and even perceived their friendships, social acceptance, appearance and emotional well-being in a more positive way than unaffected peers (Feragen, Kvalem, Rumsey, & Borge, 2010). In contrast, the majority of the literature showed poor psychosocial outcomes for adolescents with a visible difference. Literature reviews have highlighted that a significant number of adolescents with a visible difference can experience adverse psychosocial outcomes (Barankin & DeKoven, 2002; Rumsey & Harcourt, 2007; Thompson & Kent, 2001). More specifically, they experienced self-consciousness in public situations (Magin, Pond, Smith, Watson, & Goode, 2008), internalising

symptoms (Barankin & DeKoven, 2002; Pope & Snyder, 2005) and difficulties with social functioning (Bakker, Maertens, Van Son, & Van Loey, 2013). A recent meta-analysis showed that adolescents with a visible difference experienced more anxiety than unaffected peers (van Dalen et al., 2020).

While research has shown that people with a visible difference may experience adverse psychosocial outcomes, available interventions are scarce and have not been rigorously evaluated. This is true both for interventions aimed at adults (Bessell & Moss, 2007; Muftin & Thompson, 2013; Norman & Moss, 2015) and adolescents (Jenkinson, Williamson, Byron-Daniel, & Moss, 2015). Research often lacks a robust design and has poor methodological quality, yielding small effect sizes (Jenkinson et al., 2015). There is tentative support for interventions that include Social Skills Training (SST), Cognitive Behavioural Therapy (CBT; Bessell & Moss, 2007; Jenkinson et al., 2015; Norman & Moss, 2015) and anxiety management techniques (Muftin & Thompson, 2013). More research is needed to establish the effectiveness of these techniques when it comes to reducing psychological distress in individuals with a visible difference and helping them to manage challenging social experiences.

In order to provide adolescents with a visible difference with an intervention to address psychosocial issues, Young People's (YP) Face IT was developed in collaboration with adolescents, clinical experts and the British charity Changing Faces (www.ypfaceit.co.uk; Williamson, Griffiths, & Harcourt, 2015). YP Face IT was inspired by Face IT, a similar intervention for adults (Bessell, Clarke, Harcourt, Moss, & Rumsey, 2010) and combines SST and CBT strategies. More information about YP Face IT was included in the methods section and in a trial design paper by van Dalen et al. (2021). Face IT, designed for adults with a visible difference, was found to be effective at reducing anxiety, depression and appearance concerns in a Randomised Controlled Trial (RCT; Bessell et al., 2012). In a British acceptability and feasibility study YP Face IT was found to be acceptable to adolescents, with most reporting it would help improve their confidence and self-acceptance, and help develop new skills in dealing with difficult social situations (Williamson et al., 2015). Although YP Face IT may improve appearance-related distress (Williamson et al., 2019), the intervention has not been subjected to a RCT and there are concerns about whether adolescents have sufficient motivation to start and complete the full self-help programme (Riobueno-Naylor et al., 2020).

Recently, YP Face IT was translated to Dutch. To assess the acceptability of the Dutch version of YP Face IT (*Face IT voor jongeren*) in the Netherlands and the feasibility of an RCT design to assess its effectiveness, we conducted a mixed-methods study. Acceptability can be defined as reflecting *"the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive or emotional responses to the intervention"* (Sekhon, Cartwright, & Francis, 2017). In their theoretical framework Sekhon et al. (2017) considered acceptability to consists of the components affective attitude, burden, intervention coherence, ethicality, opportunity costs, perceived effectiveness and self-efficacy. A feasibility study asks whether *"something can be done, should we proceed with it and if so, how"* (Eldridge et al., 2016). Both acceptability and feasibility were tested in the current study.

We aimed to establish via in-depth interviews 1) the acceptability of the Dutch version of YP Face IT to Dutch adolescents and 2) the feasibility of using an RCT design to assess its effectiveness. More specifically, objectives of the current study were to establish:

1. The acceptability of therapeutic content to Dutch adolescents;
2. The acceptability of the structure and presentation of the intervention;
3. The perceived usefulness of the intervention;
4. And the feasibility of the study design and study procedures.

Objective 1, 2 and 3 focused on the acceptability of the intervention to Dutch adolescents. Objective 4 focused on the feasibility of using an RCT to test the effectiveness of the Dutch version of YP Face IT. We aimed to test the feasibility of recruitment procedures, administering questionnaires prior and directly after the intervention and contact procedures used by the research team.

2. Methods

This study was performed according to the SRQR guidelines (O'Brien, Harris, Beckman, Reed, & Cook, 2014). This study was registered prospectively in the Dutch trial register NL7138/NTR7335. Ethical approval was obtained from the medical ethics review committee in Rotterdam (MEC-2018-052/NL63955.078.18).

2.1. Participants

Participants were eligible if they a) had a self-declared visible difference due to any injury or condition, b) were aged 12–17 years old, c) had access to an internet-enabled computer or tablet. Patients were excluded from the study if they had either a) a learning disability that would interfere with their ability to follow and comprehend the intervention content, b) a visual impairment which prevented the participant from viewing the intervention, or c) reading skills below the level of a 12-year old. Patients did not have to experience appearance-related distress, as adolescents that are coping well were judged to be able to provide valuable information too. All criteria were assessed in a phone call with the young person or one of their parents.

If the adolescent was younger than 16 years old, informed consent was obtained from both legal parents/carers and assent was obtained from the adolescent. For adolescents aged 16 or older informed consent was obtained from the adolescent.

As shown in Fig. 1, 29 adolescents were assessed for eligibility. Five of them contacted the research team after hearing about the study from a patient organisation. Others were contacted by the research team during their appointment in the hospital. Thirteen adolescents declined to participate, and one participant was not able to be contacted for follow-up. A total of 15 adolescents were included in the study. Out of the five people that were informed through patient organisations, four (80%) were enroled in the study. Out of the 24 people that were informed through the Erasmus MC Sophia Children's Hospital, the Netherlands, 10 (41.67%) were enroled in the study. One person declined further participation after one session, considering YP Face IT irrelevant because she did not have any psychosocial problems. Overall, 14 adolescents participated (M_{age} = 15.35, SD = 1.73, 71.4% male). Seven participants were diagnosed with a cleft lip and/or palate (CL/P), two with a congenital melanocytic nevi, one with Apert syndrome, two with craniofacial microsomia, one with Goldenhar syndrome and scaphocephaly and one with a port-wine stain. Details, with pseudonymised names are shown in Table 1.

2.2. Materials

2.2.1. Interview

Semi-structured audio-recorded interviews were conducted by the first author (MvD) between May and June 2019. The interviewer was familiar to the participants, as she was the contact person during the entire study. The interview was based on an interview schedule used by the British YP Face IT study (Williamson et al., 2016). The interview schedule for the current study is shown in Table 2 and in Appendix A. The interview was used to elicit opinions on the intervention and on the study procedures. More specifically, questions focussed on: the acceptability of therapeutic content, its relatability and usefulness and presentation of the intervention,
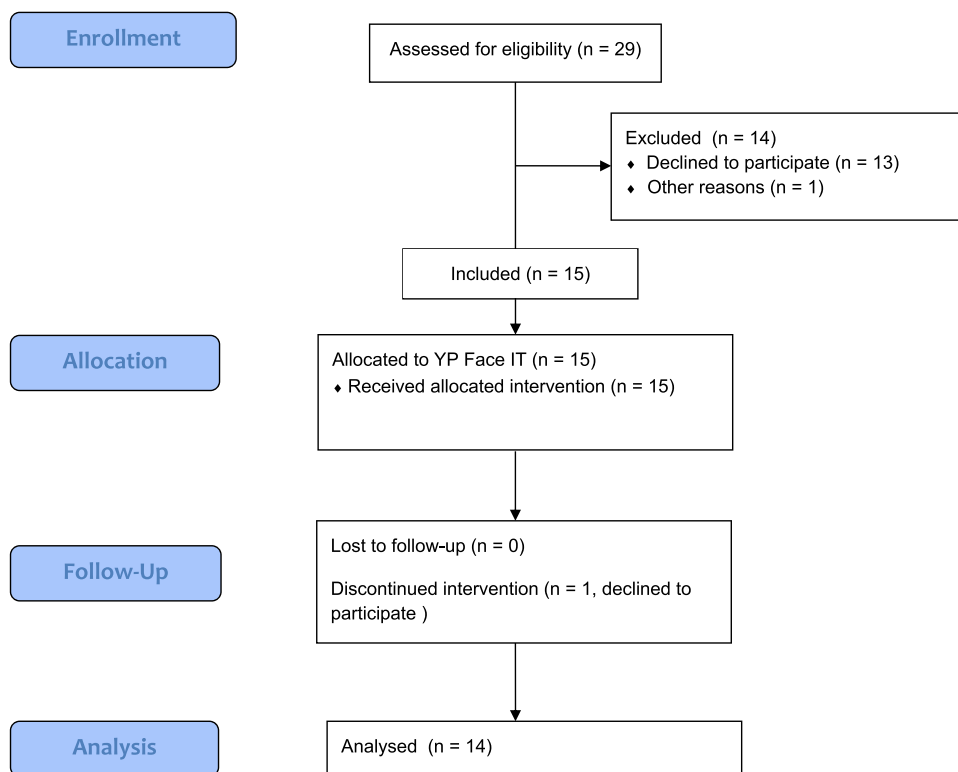
Fig. 1. Flow-chart based on CONSORT statement.

Table 1
Demographics and condition characteristics.

Name[a]	Medical diagnosis
Jack	Cleft lip/palate
Chloe	Congenital melanocytic nevi
Matt	Congenital melanocytic nevi
Samuel	Cleft lip/palate
Hannah	Cleft lip/palate
Daniel	Cleft lip/palate
Thomas	Cleft lip/palate
Emily	Apert Syndrome
Joshua	Craniofacial microsomia
Luke	Cleft lip/palate
Sophie	Cleft lip/palate
Oliver	Port-wine stain
Ben	Goldenhar syndrome & scaphocephaly
Ryan	Craniofacial microsomia

[a] All names were pseudonymised. To ensure anonymity of adolescents with a rare medical condition, age is not included in this table.

Table 2
Interview schedule used in this study.

Topic	Subtopic
Recruitment & Research procedures	How did you hear about the study?
	Posters and information provided
	Potential improvement of study procedures
Content of YP Face IT	Evaluation of sessions
	Evaluation of structure
	Evaluation of tasks and activities included
	Evaluation of quizzes
	Evaluation of videos
	Evaluation of homework activities
	Techniques learned
	Match with lived experience
Motivation	Motivation to complete YP Face IT
	Ways to increase motivation
Supervision	Content of supervision
	Duration of supervision
	Distance to supervisor
	Research team
Website & aesthetics	Navigation of the website
	Evaluation of forum
	Evaluation of diary
	Use of language
	Lay-out of the website

including use of language, structure and ease of navigation tools, views regarding adult supervision whilst completing the intervention, possible improvements, recruitment strategies and opinions on quantitative data collection procedures. Adolescents were also asked to rate YP Face IT on a scale of 1–10.

Participants were free to choose the means of interviewing (through a phone call, a video call, face to face in the hospital or at home) and whether they wanted a parent to be present. This potentially improves response rates and provides a means of interviewing that is comfortable to the participant (Heath, Williamson, Williams, & Harcourt, 2018). Interviews were scheduled to last around one hour.

Four members of the research team were involved with the interviews and data analysis. The first author who conducted the interviews was a PhD student at a Dutch university. She has a master's degree in clinical child and adolescent psychology, with no prior training on qualitative research methods. She was supported by

Dr. Okkerse who is a clinical psychologist and has 25 years of experience in treating children and adolescents with a visible difference and appearance-related distress. Dr. Williamson is a researcher with extensive experience in qualitative research methods and research into the well-being of people with a visible difference. Prof. dr. Utens is a clinical psychologist with considerable research experience in intervention studies aimed at reducing anxiety in children and adolescents. None of the members of the research team had a visible difference themselves.

Table 3
Content of the YP Face IT intervention.

Session	Content	Type	Week
1. Common problems	Common problems experienced by adolescents with a visible difference; bystander responses, teasing, bullying.	SST	1
2. Improve your social skills	Body language, verbal and non-verbal skills and building positive social interaction skills.	SST	2
3. Don't be SCARED, REACH OUT	Effect of own behaviour on other people. *REACHOUT* toolbox of techniques to cope with difficult social situations (Reassurance, Effort and Enthusiasm, Assertiveness, Courage, Humour, Over there, Understanding,and Try again).	SST	3
4. Think, Feel, Do	Relationship between thoughts, feelings and behaviours. Identifying negative thoughts and using a positive voice to challenges these thoughts. Different coping strategies for negative thoughts.	CBT	4
5. SMART goals	Using SMART goals to help achieve goals, dividing the end goal into sub goals. Dealing with concerns around romantic relationships.	CBT	5
6. Beating anxiety	Relaxation techniques. Exposure therapy in the form of a fear ladder.	CBT	6
7. Looking at your progress	Summary session of key learnings from previous sessions.	SST/CBT	7
8. Booster quiz	Quiz with 16 questions on all taught techniques.	SST/CBT	13

Note: SST = Social Skills Training; CBT = Cognitive Behavioural Therapy

Interviews lasted a mean time of 49 min (range 32 – 82 min). In total, two interviews were conducted via telephone and 12 interviews were conducted face-to-face (six in the participant's home and six at the hospital).

2.2.2. Questionnaires

For the purpose of studying the feasibility of administering outcome questionnaires, adolescents completed questionnaires on social anxiety (Social Anxiety Scale for Adolescents (SAS-A); La Greca & Lopez, 1998), body esteem (Body Esteem Scale For Adolescents and Adults (BESAA); Mendelson, Mendelson, & White, 2001), aspects of self-worth (Self-Perception Profiles for Adolescents (SPPA); Harter, 2012; Treffers et al., 2004), perceived stigmatisation (Perceived Stigmatisation Questionnaire (PSQ); Lawrence, Fauerbach, Heinberg, Doctor, & Thombs, 2006), quality of life (EuroQol-5D-5L (EQ-5D-5L); Herdman et al., 2011), life disengagement (Body Image Life Disengagement Questionnaire (BILD-Q); Atkinson & Diedrichs, 2021), depressive symptoms (Child Depression Inventory – 2 (CDI-2); Kovacs, 2016) and appearance-related distress (Spiegeltje, spiegeltje.; Okkerse & Dessens, 2016). The questionnaires were described in more detail in one of our previous papers (van Dalen et al, 2021).

2.3. Procedure

This study used a mixed-methods design to assess adolescents' opinions on the study and the intervention. An a priori sample size of 15 participants was set. This was deemed an appropriate number of participants to identify important themes and achieve data saturation (Guest, Bunce, & Johnson, 2006).

Participants were recruited via purposive sampling through the Erasmus MC Sophia Children's Hospital, the Netherlands and through Dutch patient organisations. Recruitment lasted 16 weeks. Participants recruited via hospital were first informed about the study by their treating clinician. A member of the research team was present in the waiting room to elaborate on the study and to provide an information package containing information letters and consent forms. When recruitment proceeded via patient organisations, patients were informed about the study by the patient organisation through social media, e-mail, magazine or the organisation's website. Interested parties received further information and consent forms after contacting the research team.

Fourteen days after receiving the information package, the research team phoned the adolescent or one of their parents to answer questions. After the research team received the signed informed consent forms, an online link to the questionnaires was sent. Adolescents were given two weeks to complete the questionnaires. After completing the questionnaires, adolescents received the login details for YP Face IT. Participants were asked to complete seven weekly sessions. An additional booster session was completed after six weeks.

Upon completion of the intervention, participants once again received an online link to the questionnaires. Participants were given two weeks to complete the questionnaires. An interview was scheduled. After the interview, participants received a gift card worth €10,-.

2.4. Intervention

YP Face IT is an online intervention developed for young people with a visible difference and experiencing appearance-related distress (Williamson et al., 2015). The intervention combines social skills training with cognitive behavioural therapeutic techniques. There are eight sessions; seven weekly sessions and one booster session six weeks after session 7. Each session uses text, videos, tasks and different interactive activities to encourage young people to develop new skills. In between sessions participants complete short homework assignments.

YP Face IT is an easy-to-access self-help programme, but progress is monitored in the background by psychologists to ensure progress and check for psychological issues that may need referral to face-to-face care. Adolescents can use the programme in their own time and are encouraged to apply the learned techniques in everyday life. Contrary to other versions of YP Face IT, the Dutch version of YP Face IT does not contain audio-recordings of the sessions. The content of the intervention is shown in Table 3.

To help facilitate adherence, the participants can set reminders via the website. The system will then send an automatic e-mail when a session is due. Reminders were also sent by the research team via WhatsApp if a next session was not started 10 days after the prior session.

To ensure the safety of all data on the website, a two-factor authentication was installed on the website. After logging in, participants received an e-mail with a pin code containing four digits.

2.5. Data analysis

Quantitative data were analysed using descriptive statistics. Due to the small sample size, no significance testing was performed. Also, the sample size was deemed too small to obtain an accurate estimate of the effect size (Albers & Lakens, 2018). The questionnaires were administered to elicit opinions about the study design during the interview. The study design could then be adjusted for a future RCT.

Interviews were audio-recorded and transcribed verbatim using MAXQDA 2018 software for qualitative data analysis (VERBI Software, 2017). Selected quotes for this article were translated from Dutch to English and edited for readability.

Inductive reflexive thematic analysis at a semantic level was used to analyse the qualitative data (Braun & Clarke, 2006, 2019). The first author used the six steps as described by Braun and Clarke (2006) to analyse and code the interviews. These steps include: familiarising yourself with the data, generating initial codes, searching for

Table 4
Means and standard deviations for total and subscale scores.

Construct	Baseline		Follow-up	
	N	Mean (SD)	N	Mean (SD)
Social anxiety total score	15	36.53 (13.59)	9	28.44 (10.58)
Fear of negative evaluation	15	15.20 (6.62)	9	12.11 (3.72)
Social anxiety and distress in new situations	15	14.07 (4.83)	9	10.78 (4.74)
Social anxiety and distress in general	15	7.27 (3.22)	9	5.56 (2.96)
Body esteem	15	2.89 (0.71)	10	3.37 (0.34)
Aspects of self-worth				
Scholastic competence	13	14.54 (2.57)	9	15.44 (3.61)
Social competence	13	16.31 (2.46)	9	17.11 (2.03)
Athletic competence	13	14.00 (4.18)	9	15.11 (2.89)
Physical appearance	13	14.00 (3.87)	9	16.44 (2.46)
Behavioural conduct	13	16.46 (2.53)	9	16.44 (2.46)
Close friendship	13	18.23 (2.28)	9	17.78 (3.83)
Global self-worth	13	16.54 (2.85)	9	17.22 (1.72)
Perceived stigmatisation total score	15	1.82 (0.41)	9	1.60 (0.37)
Confused and staring behaviour	15	1.82 (0.68)	9	1.71 (0.69)
Hostile behaviour	15	1.59 (0.55)	9	1.29 (0.39)
Absence of friendly behaviour	15	1.98 (0.45)	9	1.69 (0.42)
Quality of life				
Visual analogue scale	15	80.33 (11.68)	9	85.67 (9.95)
Mobility	15	1.07 (0.26)	9	1.00 (0)
Self-care	15	1.00 (0)	9	1.00 (0)
Usual activities	15	1.20 (0.42)	9	1.00 (0)
Pain/discomfort	15	1.40 (0.74)	9	1.11 (0.33)
Anxiety/depression	15	1.27 (0.59)	9	1.00 (0)
Life disengagement	15	1.15 (0.26)	9	1.01 (0.03)
Depressive symptoms total score	15	7.80 (4.21)	9	3.89 (2.31)
Negative mood	15	1.67 (2.29)	9	.78 (1.39)
Functional problems	15	4.27 (1.75)	9	3.00 (1.50)
Ineffectiveness	15	3.80 (1.57)	9	2.78 (1.30)
Interpersonal problems	15	.47 (1.75)	9	.22 (0.44)
Emotional problems	15	3.53 (2.97)	9	.89 (1.36)
Negative selfconfidence	15	1.87 (1.60)	9	.11 (0.33)

themes, reviewing themes, defining and naming themes and producing the report. All steps were done using MAXQDA 2018 (VERBI Software, 2017) as supportive software for collating and viewing pieces of text.

To ensure adequate coding and richer data, two researchers (MvD and JO) independently coded the first interview. They then discussed this interview to identify relevant codes. The first author (MvD) then coded all other interviews and generated the themes.

3. Results

3.1. Quantitative data

Quantitative data were used to inform the adherence and overall acceptability of YP Face IT. Means and standard deviations for the questionnaires are shown in Table 4. Due to the small sample size no significance testing was performed. Looking at the descriptive statistics, some scores seem to have improved after completing YP Face IT, but more research is needed to determine whether this is a structural change or a chance finding.

Of the 15 adolescents that started on YP Face IT, 13 (86.67%) completed all eight sessions, one person (6.67%) completed seven sessions and one person (6.67%) dropped out after one session. The completers took an average of 12.77 weeks (median 13) to complete YP Face IT. Everyone completed the questionnaires at baseline. Nine people (81.82%) completed the questionnaires at follow-up.

All adolescents indicated that they would recommend the programme to other adolescents with a visible difference and experiencing appearance-related distress. When asked how they would

rate YP Face IT on a scale of 1 (worst score) to 10 (best score) they evaluated the programme with a median of 7.9 (IQR = 7.0 – 8.0).

3.2. Qualitative data

Four main themes were identified through qualitative analyses, namely: "Therapeutic content matches lived experience", "Solid structure, but age-specific lay-out", "I wasn't really feeling like it: barriers to completing YP Face IT" and "A personal approach to inform participants". All themes were mentioned by all participants. The four themes and their subthemes are detailed below.

3.2.1. Therapeutic content matches lived experience

This theme reflects participants' experiences with the therapeutic content of YP Face IT. They felt that the content was relatable and that it created learning experiences.

3.2.1.1. I recognised myself in some of the examples. The first subtheme reflected the therapeutic content of the programme. Adolescents felt that the programme was relatable and matched their experiences of living with a visible difference, although some adolescents commented that they had not experienced bullying or name-calling by a group of strangers.

Several adolescents also commented that they liked the techniques and thought the explanation of these techniques was clear: *"Everything was explained well, there were good ways to solve problems or things like that, nice activities and nice homework activities that you can do and apply."* (Hannah, cleft lip/palate).

Some young people commented that learning about the think-feel-do technique was very helpful. This technique explains the relationship between thoughts, feelings and behaviour. One person said he thought the think-feel-do technique was the most helpful technique of the programme: *"I think especially the "think, feel and do" the little triangle, I liked that. Because I am a little lazy sometimes, so you have to force yourself to do things occasionally. […] You just have to think differently about things."* (Samuel, cleft lip/palate).

The adolescents thought that YP Face IT did not miss any useful information, although one person mentioned that information on social media could be useful, for instance information on how influencers perpetuate an image of beauty that does not reflect reality:

> "If you are struggling with something and you then see all those pictures [on social media] you think "oh, this person is perfect, I want to be like this". But they're really not perfect and they don't have the perfect life." (Samuel, cleft lip/late).

Opinions differed on which session was the best, but some adolescents commented on session 7 and 8: *"I liked that there was a sort of recap at the end. And also a quiz, so that you follow it better really."* (Daniel, cleft lip/palate).

The activities users were asked to complete during sessions and as homework helped embed key learnings: *"For me personally, you know if I write or type something myself, I will remember it better than when I read it and don't come back to it."* (Thomas, cleft lip/palate). The assignments did not take a lot of time, but the assignment in which a fear ladder was created was perceived as more strenuous: *"The one with the ladder, where you had to name different things. You have to think carefully, you have to name different steps, but if you only name three it's not enough for the entire ladder."* (Hannah, cleft lip/palate). Some adolescents skipped some of the homework assignments. However, we did not have sufficient data to establish whether there was a pattern in which homework assignments were skipped more often than others.

3.2.1.2. YP Face IT changed the way I think. Most adolescents reported learning something from completing YP Face IT. For most the changes were small: *"I learned things about body language. That you*

have to be open to other people and not slouching. You know, you always keep that in the back of your mind." (Jack, cleft lip/palate). Others reported a better understanding of other people's thoughts and intentions: *"Sometimes it [the visible difference] still bothers me and this might help to make it [YP Face IT] more fun. For example, that I understand better why some people look at me and how sometimes they laugh, while they are sometimes not laughing about me."* (Joshua, craniofacial microsomia).

One person in particular, reported a big change in her self-esteem. She had tried other programmes and psychological counselling to improve her self-esteem, which had not really helped her, whereas YP Face IT really helped her:

> "I did do the exercises and I dare to ask a lot more questions now. […] And I'm less afraid of walking up to strangers now. […] In the past I would have thought, yeah, they don't like me anyway. But now I don't think like that anymore." (Sophie, cleft lip/palate)

3.2.2. Solid structure, but age-specific lay-out

This second theme reflects participants' experiences with the way YP Face IT was set up, including the website and the choice to offer it as a self-help programme.

3.2.2.1. A logical structure in YP Face IT. Overall, the adolescents appreciated the way YP Face IT was laid out with social skills training presented before cognitive behavioural therapy: *"With the social skills you learn how you come across and of course thoughts go along with this too, so how you come across gives you thoughts, so I liked the link between the two."* (Hannah, cleft lip/palate) and several people described the structure as *"logical".* No one wanted to change the order of the sessions. They appreciated the way YP Face IT looked and the way the information was set up. Several adolescents commented on the interactive features in the programme. They liked the activities where you could select a response to see how others would react and the interactive videos playing out difficult social situations.

The length of the sessions was deemed appropriate and took the participants anywhere between 15 and 45 min. However, some participants commented that session 4 was very long:

> "There were no sessions that were too short, but especially at [session] 4 the text was really long. So that was kind of annoying, because you thought, oh the text is almost done and then there was a lot more text." (Sophie, cleft lip/palate)

Most adolescents indicated that they were able to complete the programme by themselves. Some adolescents, especially the younger adolescents, asked their parents for help when they encountered words or things they did not fully understand:

> "They [the parents] did not help, because I did it all by myself. But if there was something I didn't really understand, I asked them." (Luke, cleft lip/palate).

Some adolescents commented that there was repetition in the programme, but there was no consensus on whether this was a good or a bad thing:

> "No, it's not annoying, no, it's just, another repetition, because it's not like you can be a professional football player after playing keepie uppie just one time, you have to do it more often." (Oliver, port-wine stain)

> "Everything is maybe, yes, sometimes explained three times. Then I think, yeah, after one time I also understand this." (Jack, cleft lip/palate)

3.2.2.2. A colourful website, with room for improvement. The majority of adolescents thought the website was suited for adolescents aged 12–18. However, some adolescents older than 15 thought the website was tailored more towards the younger adolescents and thought some elements were childish. This was mostly due to the brighter colours and the use of avatars. Other adolescents liked the colours and avatars: *"The website was actually quite attractive. The colours, the puppets, I liked how that was done."* (Sophie, cleft lip/palate).

The website was deemed as ordered and structured by most adolescents, although some commented that a register or search function could help them find information more easily: *"If you had, separate from the sessions, a sort of register that you can just quickly search in. that you can just, just find a word or something and see that belongs to this session."* (Samuel, cleft lip/palate).

The website included a journal in which adolescents can document their progress or write about their day. Only a few adolescents used this function. Some suggested that it would be easier if the journal was always available, instead of at certain points in the session: *"I also think it would be handier if, when you want to use the journal, that it is already on the page."* (Oliver, port-wine stain).

The website also included a forum in which participants can talk to each other. This forum was not used by any of the adolescents in the current study. The majority of the adolescents indicated that a forum could be useful for some people, but not for them: *"It doesn't bother me, so I don't need it. But I think for people who are bothered by it. They would like to talk about other people's experiences"* (Matt, congenital melanocytic nevi). Some said they did not use the forum, because it did not have any messages on there. Others felt that they would prefer talking to someone directly, or using chat groups such as Facebook or WhatsApp.

When asked about things that they would change about YP Face IT, some commented on adding an audio-feature, because they preferred listening over reading: *"I personally like [audio fragments] better, that I can just put it in my ears, listen to it two or three times if necessary."* (Samuel, cleft lip/palate). Others commented on adding more videos and shortening some texts.

3.2.2.3. You can do YP Face IT in your own time; no appointment needed. Participants discussed what type of care they would prefer, if they had a choice. Overall, eight adolescents (57.14%) preferred YP Face IT, four (28.57%) face-to-face care and two (14.29%) felt that it depended on the type and severity of psychological issues they were experiencing. They felt that greater psychological distress or specific questions warrant more intensive face-to-face support. Adolescents identified that advantages of YP Face IT were the anonymity it afforded, being able to schedule the session when it was most convenient, not having to disclose personal information to someone they do not know and ease of access to support with no need to travel:

> "You can just do YP Face IT at home. That's just much easier than when you have to go somewhere or she comes to you and you have to make an appointment. And there you can just, on YP Face IT, log in and just, done." (Matt, congenital melanocytic nevi)

Some reflected that a limitation of YP Face IT is that it cannot be tailored to meet individual needs:

> "I think with a psychologist you have to build trust before you are really able to tell them something, but the advantage is that if you are able to tell it, this person can adjust the advice directly to you. A programme can too, but then it's less, it's just not personal." (Hannah, cleft lip/palate)

3.2.3. I wasn't really feeling like it: barriers to completing YP Face IT

Although most adolescents were highly motivated to complete YP Face IT because they found the programme interesting, others struggled. This theme reflects factors that limited engagement among this group and factors that increased motivation.

3.2.3.1. Too busy with school and forgetting about the sessions.
Participants identified several barriers that influenced their motivation to complete YP Face IT. Despite using the 'set reminder' function, two participants reported that they did not read their e-mail and subsequently forgot about the session. Other participants reported simply forgetting about the sessions, until they received an automated reminder or a reminder by the research team. Other barriers were a lack of time and motivation. As one person put it: *"I think I had the time, but I wasn't really feeling like it. [..] I would rather play games with my friends."* (Daniel, cleft lip/palate). Some participants also mentioned that the amount of text in the sessions was off-putting. Participants felt that sessions contained a lot of text, especially session 4.

When asked what they liked the least about the programme, some adolescents commented that the website did not always function properly. For instance, the code for two-factor authentication was not always e-mailed right away. This was solved by sending the code to their mobile phone instead of to their e-mail.

3.2.3.2. Sometimes it works and sometimes it doesn't.
Participants gave conflicting opinions on whether the two-factor authentication and questionnaires hindered or facilitated their motivation. The adolescents thought that the two-factor authentication did not influence the amount of times they logged into the website, although some participants had some issues with receiving the code: *"Sometimes it worked and sometimes it didn't, and then I would get five passwords in a row and then I tried one and it wasn't correct, and I thought okay, I will do it in an hour."* (Emily, Apert syndrome). Even though adolescents reported that it would not influence the amount of times they logged in, these technical issues could hinder their motivation to complete YP Face IT. Some participants reported that it would be easier without the two-factor authentication, even though it didn't matter how often they would use the website. Others reported that it made them feel secure, knowing that other family members could not access their account: *"I think some people would actually like it. If you just know, if you do it on the family computer or something, that your entire family doesn't have access to it."* (Chloe, congenital melanocytic nevi).

Completing the questionnaires took participants approximately 15–45 min. One person thought this was too long, but everyone else thought the length of the questionnaires was acceptable. Some reported that the questionnaires prompted self-reflection and self-awareness: *"I liked doing the questionnaires. And then you tick boxes that you wouldn't expect. [...] I liked doing it, because you learn from it."* (Sophie, cleft lip/palate).

3.2.3.3. Contact with the research team helped increase motivation.
Participants also reported facilitating factors that helped increase their motivation. For instance, the contact with and reminders by the research team were appreciated by everyone: *"I like to be reminded sometimes, you know. It was quite good. And WhatsApp is of course very convenient, because, yeah. everyone uses it. It's just fast."* (Chloe, congenital melanocytic nevi).

In response to previous studies finding motivation problems amongst participants, we investigated whether it would be helpful to send an extra e-mail after session 4. This e-mail stated that they were halfway and that other sessions would be shorter. This helped increase motivation for most participants: *"It was kind of motivating. I thought, wow, I'm actually quite far."* (Jack, cleft lip/palate).

3.2.3.4. It's not a problem for me, but if my experiences helps others. why not?.
Most adolescents cited altruism and helping others as a reason for being motivated to participate in the study. As one person put it: *"I just like participating in research. The more people participate, the better it is for other people in the end."* (Samuel, cleft lip/palate). Even though some participants professed not experiencing appearance-related distress, they still felt it was important to engage in research to help those who might: *"I think that I can give a different insight, because I don't experience any problems and maybe have a different view on it."* (Chloe, congenital melanocytic nevi) One person participated for personal reasons: *"I was curious, because I have done several things for my self-esteem before. So I really wanted to try it."* (Sophie, cleft lip/palate).

3.2.4. A personal approach to inform participants

This theme reflects participants' views on current and future research procedures.

3.2.4.1. I knew what I had to do.
Adolescents talked about the information they received prior to participating in the study. Some commented that they thought the language used in the information letters was not age-appropriate, *"child language"* (Sophie, cleft lip/palate and Oliver, port-wine stain), but others thought the information was clear: *"It was all explained well, what I was up to. It wasn't a lot, but I knew what I had to do and that you had to do a session each week."* (Hannah, cleft lip/palate). Despite the information being clear, some participants did not read all the information: *"I don't really like reading. So it was a lot of reading, so I scanned through it, to see what the study involves."* (Daniel, cleft lip/palate).

Those adolescents who were informed about the study before their hospital appointment appreciated this personal approach: *"It was nice, to hear about it face-to-face so that you know what you are up for and can ask questions immediately."* (Ben, Goldenhar syndrome & scaphocephaly).

3.2.4.2. Talk to people about your study.
When discussing ways to improve recruitment processes, some adolescents requested that we should retain current procedures. They mainly appreciated the personal approach used: *"It was good to hear about it face-to-face, because you know what you are up for and can ask your questions directly."* (Ben, Goldenhar syndrome & scaphocephaly). And stressed that it is important to address the potential participants directly: *"Just talk to people like you did for this study. I think they'll take up the offer more quickly than when they have to look things up themselves."* (Hannah, cleft lip/palate);.

Others commented that we should make a promo video or use social media: *"It is helpful to, for example, put it on platforms such as Instagram or Twitter."* (Oliver, port-wine stain);.

Or give some kind of reward: *"For example, if you give some kind of reward. [...] It could be anything. Like a gift card. But it could also be a fun day. It could also be a day here in the hospital."* (Jack, cleft lip/palate).

4. Discussion

This study investigated the acceptability and feasibility of the Dutch YP Face IT programme. Interviews with 14 adolescents with a wide range of visible differences were conducted. The data suggest that the YP Face IT intervention may be acceptable to Dutch adolescents and the study design is feasible. Despite formal tests not being conducted, the descriptive data seem promising. Everyone recommended the intervention for adolescents experiencing appearance-related distress. Qualitative data showed that the acceptability of the therapeutic content was generally high and apart from information on dealing with social media, no one thought there was

information missing from YP Face IT. The acceptability of the structure and presentation of the intervention was good, but opinions differed on the lay-out of the website. Adolescents appreciated the order of the sessions, particularly receiving social skills training before CBT. For the lay-out, some adolescents commented that it was more appropriate for younger adolescents (e.g., 12–15 year-olds) than older adolescents (e.g., 16 or 17 year-olds). The intervention was also perceived to be useful. Most adolescents reported learning something from the intervention, with one person mentioning YP Face IT having greatly improved her self-esteem.

Concerning the feasibility of our research procedures, results suggest that procedures can be retained, with the addition of using social media to aid recruitment and rewarding participation. Recruitment took place through Dutch patient organisations and through the Erasmus MC Sophia Children's Hospital, the Netherlands. Recruitment rates for adolescents informed by patient organisations were higher (80%) than recruitment rates for adolescents being informed by the hospital (41.67%). For a future RCT, it would be valuable to include both patient organisations and medical centres in recruitment. However, it appears that adolescents that are informed by their patient organisation are more likely to participate in the study.

This study also showed that around half of the adolescents preferred eHealth. So, despite the current generation being seen as digital natives with 93.5% of adolescents using the internet (almost) every day (Centraal Bureau voor de Statistiek, 2020), it is important to keep in mind that an eHealth intervention might not suit everyone. So, if YP Face IT were to become part of a stepped-care framework (see March, Donovan, Baldwin, Ford, & Spence, 2019), in which the intensity of care provided is determined by psychological aspects, factors that determine who should use eHealth and who receives face-to-face care should be examined.

Following this study, a number of minor changes were made to YP Face IT. First, the Dutch translation for journal was altered to reflect that the journal is not a diary (dagboek), but a notebook (notitieboek). Second, a number of grammatical errors were corrected throughout the intervention. The forum was maintained, as it could be helpful. Furthermore, the research team did not have the capacity to initiate and monitor WhatsApp or Facebook chat groups.

Our results are in line with previous research showing that YP Face IT is acceptable to British adolescents (Williamson et al., 2019). Contrary to other studies reporting high attrition rates for American adolescents completing YP Face IT (Riobueno-Naylor et al., 2020), adherence in Dutch adolescents was high with 13 (86.67%) adolescents completing YP Face IT and nine (81.82%) completing outcome questionnaires. However, the study by Riobueno-Naylor et al. (2020) did not use the automated reminder system. This might have also contributed to a higher attrition rate in comparison to our study, where adolescents received automated reminders and reminders by the research team. Second, Riobueno-Naylor et al. (2020) only included adolescents with burns, an acquired condition. Our study only included adolescents with congenital visible differences.

Despite YP Face IT being targeted to adolescents experiencing appearance-related distress, we opted to recruit both adolescents with and without appearance-related distress for this study. On the one hand, adolescents without appearance-related distress may also experience difficult social situations (e.g., Jewett et al., 2018) and may hold valuable opinions on how to cope with these situations. On the other hand, their opinions on YP Face IT may differ from opinions that adolescents with appearance-related distress have. For instance, one person dropped out because the programme was not relevant for her. It is unclear how this would impact a future RCT solely recruiting adolescents with appearance-related distress.

The current study has a number of strengths and limitations. A strength is the high number of adolescents that completed the entire programme (n = 13, 86.67%). Also, most adolescents completed YP Face IT within the advised 13-week timeframe. This improves the generalisability of current results to future clinical use. Furthermore, YP Face IT is an innovative, online psychological intervention. This is the first eHealth intervention specifically for adolescents with a visible difference living in the Netherlands.

A first limitation of this study is that all the visible differences were congenital and were present from birth. Despite contacting some adolescents with an acquired visible difference, none of them finished the study. One dropped out after one session and we were unable to reach another after sending the information package. Hence, we were unable to study adolescents with an acquired visible difference. The influence of this on our results remains unclear. To our knowledge, there are no studies that compare people with a congenital condition to those with an acquired condition. Previous research has shown that the subjective experience of the visibility of the condition is more important in predicting psychological adjustment than the objectively rated visibility (Moss, 2005). Whether adolescents with an acquired visible difference would report similar results is unknown. As people with an acquired visible difference experience similar social situations to those with a congenital visible difference, a future RCT should also recruit adolescents with an acquired visible difference (Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2019).

A second limitation is that the first author was involved in both the recruitment, data collection and conducting the interviews. This could have led to a social desirability bias (Paulhus, 1984), where adolescents could be prone to respond more positively to questions asked during the interview. However, participants shared numerous critical remarks during the interviews, so we think the extent of this bias is limited. Furthermore, the first author was trained in communication skills, which may have elicited more disclosure from participants.

A third limitation is the we could not obtain reliable data concerning the number of reminders that were sent and around homework adherence. Participants could set an automated reminder on the website, but the website overwrites these data points. We could thus not obtain a reliable estimate of how many reminders were actually set. Regarding homework, adolescents could enter their answers on the website. Not everyone opted to do this. For the people that did not enter answers to the homework assignments, it is unclear whether they did the assignment or whether they skipped it altogether.

As results show that the Dutch version of YP Face IT may be acceptable and feasible to Dutch adolescents, a RCT should be conducted to assess the effectiveness of the intervention. A RCT is currently being conducted in the Netherlands (van Dalen et al, 2021). If results from this study indicate that YP Face IT is effective in reducing appearance-related distress, it can be implemented in hospitals across the Netherlands.

Ethical approval

This study was approved by the Medical Ethical Research Committee (METC) Rotterdam (reference number MEC-2018-052/ NL63955.078.18). This study was conducted in accordance to the Declaration of Helsinki. This study has been registered prospectively in the Dutch trial register (Nederlands Trial Register), NL7138/ NTR7335.

CRediT authorship contribution statement

M. van Dalen: Conceptualization, Methodology, Formal Analysis, Investigation, Writing – Original Draft, Visualization, Project Administration. **S.G.M.A. Pasmans:** Writing – Review & Editing. **E.W.C. Aendekerk:** Writing – Review & Editing. **I.M.J. Mathijssen:** Writing – Review & Editing, **M.J. Koudstaal:** Writing – Review & Editing. **H. Williamson:** Writing – Review & Editing. **M.H.J. Hillegers:** Writing – Review & Editing. **E.M.W.J. Utens:** Supervision, Writing – Review & Editing, Funding acquisition. **J.M.E. Okkerse:** Conceptualization, Supervision, Writing – Review & Editing, Funding acquisition.

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Conflicts of interests

None declared.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.bodyim.2022.03.003.

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