

Improving Adolescents' Adjustment to the Psychosocial Impact of
Living With a Visible Difference: Understanding the Role of
Communication with Parents and Adolescents' Use of Web-Based
Support

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A long-held dream of mine has been to delve deeper into the world of research and learn the craft of using quantitative and qualitative methods to generate new insights into social phenomena. This dream led me to a quest for a position that would enable me to enrol in a formal PhD research education, which was finally realised in the spring of 2019. The path towards completing a PhD required three long years, an extensive amount of self-discipline, self-efficacy, and endurance, and it has been characterised by excitement and uncertainty. If I were to convey only one message about how these three years have affected me on a personal level, it would be that my understanding of how we acquire knowledge about social phenomena has truly expanded.

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Table of Contents

Summary	ix
List of Papers	xiii
Abbreviations	xv
1. General Introduction	1
1.1. Appearance Ideals and Social Consequences of Having a Visible Difference	1
1.1.1. Defining ‘Visible Difference’	2
1.2. Theoretical Perspectives on Psychosocial Aspects of Having a Visible Difference.	2
1.2.1. Understanding Individual Experiences	2
1.2.2. Negative Responses and Social Reactions to a Visible Difference	3
1.2.3. Changing Existing Attitudes and Perceptions in the General Population.....	4
1.3. Adolescence and the Impact of Having a Visible Difference	5
1.3.1. Challenges of Living With a Visible Difference	6
1.3.2. The Role of Adolescents’ Age, Gender, and Type of Visible Difference	7
1.4. Promoting Adjustment to Appearance-Related Distress	8
1.4.1. The Role of Parents’ Influences and Open Communication	10
1.4.2. Biomedical and Psychosocial Support.....	11
1.4.3. Barriers Related to Provision of Support.....	12
1.5. Internet Interventions	13
1.5.1. Young Person’s Face IT.....	14
1.6. Summary of Knowledge Gaps and Research Aim	17
3. Methods	19
3.1. Young Person’s Face IT–Norway	19
3.2. Recruitment and Eligibility Criteria	19
3.3. Procedures	20
3.3.1. Attrition.....	23
3.4. Samples	23

3.4.1. Paper I.....	23
3.4.2. Paper II.....	24
3.4.3. Paper III	24
3.5. Data Collection	24
3.5.1. Semi-Structured Interviews	24
3.5.2. Outcome Measures.....	25
3.5.3. Predictor Variables.....	26
3.6. Thematic Analysis	28
3.6.1. Paper I.....	28
3.7. Statistical Analyses.....	29
3.7.1. Paper II.....	29
3.7.2. Paper III	29
3.8. Ethical Considerations	30
4. Results	33
4.1. Summary of Papers I–III	33
4.1.1. Paper I.....	33
4.1.2. Paper II.....	33
4.1.3. Paper III	34
5. General Discussion.....	35
5.1. Parents’ Influences on Adolescents’ Adjustment to Having a Visible Difference	35
5.2. The Role of Web-Based Self-Help in Treating Appearance-Related Distress	37
5.2.1. Demographic and Intervention-Related Predictors of Intervention Effects	38
5.2.2. How Does Intervention Engagement Influence Intervention Effects?	38
5.2.3. Do Intervention Effects Vary by Gender?	39
5.2.4. Negative Effects.....	40
5.2.5. Parental Involvement	41
5.3. Methodological Considerations: Strengths and Limitations	42

5.3.1. Study Design and Data Collection.....	42
5.3.2. Recruitment Strategies and Sample	44
5.3.3. Outcome Measures.....	45
5.3.4. Analyses.....	46
5.3.5. Influences of COVID-19.....	48
5.4. Implications	49
5.4.1. Clinical Practice	49
5.4.2. Future Directions	50
6. Conclusions.....	53
References.....	55
Appendix 1: Interview guide for Parents of Adolescents Randomised to the waiting-list CAU group.....	79
Appendix 2: Interview guide for Parents of Adolescents Randomised to the Intervention Group	83
Papers I–III.....	89

Summary

Living with a condition or injury that affects one's appearance can be challenging, especially during adolescence. A visible difference can be congenital (e.g. a cleft lip and/or palate and differences in sex development) or acquired (e.g. alopecia and burns). Irrespective of the type, having a visible difference can become a barrier to adolescents' psychosocial adjustment by negatively affecting body image, and it may put some adolescents at risk for stigmatising experiences, including teasing and staring. Although many adolescents manage to use effective coping strategies to deal with social challenges, some need additional support to strengthen their psychosocial adjustment. However, local healthcare systems have few specialists with clinical expertise in addressing appearance concerns, which makes tailored support difficult to access. Parents consequently often become the main source of support, but they may find it challenging to address appearance issues with their adolescents. Some evidence suggests that Young Person's Face IT (YPF), a self-guided web-based intervention, has the potential to promote adolescents' psychosocial adjustment to having a visible difference. This evidence is promising, because it suggests that the intervention can help adolescents' access tailored support more easily.

To date, little research has explored the role of parents' communication with their adolescents about appearance issues. Furthermore, studies have explored only the feasibility and acceptability of YPF, which provide limited evidence of effectiveness. This dissertation therefore aims to improve the understanding of parents' perceptions of communicating about appearance-related issues with their adolescents and of how the use of YPF may influence adolescents' psychosocial adjustment to having a visible difference. This aim is addressed and concretised in three papers based on data collected from a larger project and a randomised control trial (RCT) conducted in Norway, the Young Person's Face IT–Norway (YPF–N) project. The YPF–N project aimed to evaluate the effectiveness of YPF. Adolescents were randomly assigned to an intervention group or a waiting-list care-as-usual (CAU) group. Participants in the intervention group received access to YPF immediately after randomisation, and participants in the waiting-list CAU group received access to YPF three months after randomisation. Moreover, qualitative interviews were conducted with both parents and adolescents throughout the project.

Paper I qualitatively explored parents' perceptions of communicating about appearance issues with their adolescents. Semi-structured interviews were conducted by telephone with 18 parents (3 fathers and 15 mothers) of adolescents with a wide range of

visible differences. Inductive thematic analysis revealed that parents carefully considered the time and context before raising the subject of appearance with their adolescents, for instance when adolescents expressed a need for emotional care or were perceived to be upset. Parents highlighted the choice of setting as important, because some hesitated to raise appearance issues with their adolescents for fear of causing further distress. Notably, adolescents' use of YPF facilitated their interest in talking with their parents about topics related to their visible difference. Talking openly about such topics enabled parents to better comprehend their adolescents' thoughts and feelings and to stay informed about their adolescents' adjustment.

Paper II was a parallel-group RCT that evaluated YPF's effectiveness in improving adolescents' body esteem and reducing their social anxiety, perceived stigmatisation, and life disengagement. The adolescents ($N = 189$, aged 11–18, 60% girls) were drawn from two study sites (YPF–N and the Netherlands). The adolescents from both the intervention group (who had access to YPF) and the waiting-list CAU group (who had not yet access to YPF) completed outcome measures at baseline and three-month follow-up. Compared with the waiting-list CAU group, the social anxiety levels of the adolescents in the intervention group decreased from T1 to T3. No significant improvements were found for the other outcomes. Analyses of predictors of intervention effects only revealed gender differences in social-anxiety levels at T3, indicating that boys had greater reductions in social anxiety levels compared with girls.

Paper III continued the investigation of the effectiveness of YPF by exploring whether demographic (age and gender), psychosocial (frequency of teasing experiences and depressive and/or anxiety symptoms), and intervention-related (minutes spent on YPF) variables predicted intervention effects. Only adolescents ($N = 71$, aged 11–18, 61% girls) who had access to YPF were included. The analyses revealed that boys, participants who experienced higher levels of teasing and depressive and/or anxiety symptoms before access to YPF, and participants who devoted more minutes to YPF obtained higher overall intervention effects.

As a whole, this dissertation brings to light the important role played by parents' openness to communicating about appearance issues with their adolescents, in their ability to stay informed about their adolescents' adjustment to having a visible difference. Adolescents' engagement with YPF also eased initiatives to raise and discuss appearance-related topics. The findings further demonstrate that YPF can be effective in reducing social anxiety levels associated with having a visible difference. The design of YPF makes the intervention easily accessible for adolescents who need support, and it lowers the barriers historically associated

with face-to-face therapy, such as waiting lists, lack of local expertise, and costs. Finally, the findings underscore that adolescents who experience higher levels of psychosocial distress associated with having a visible difference and who spend more time on YPF may obtain stronger intervention effects. This dissertation shows that web-based support can promote adolescents' adjustment to the psychosocial impact of living with a visible difference. Moreover, it shows that parents find communication about appearance-related issues with their adolescents helpful in learning about their adjustment.

List of Papers

- I. Zelihić, D., Williamson, H., Kling, J., & Feragen, K. B. (2021). “It’s tough because I see that it’s upsetting her ...”: A qualitative exploration of parents’ perceptions of talking with their adolescents about having a visible difference. *Body Image*, 38, 306–316. <https://doi.org/10.1016/j.bodyim.2021.05.006>

- II. Zelihić, D., van Dalen, M., Kling, J., Pripp, A. H., Nordgreen, T., Kvalem, I. L., Pasmans, S. G. M. A., Mathijssen, I. M. J., Koudstaal, M. J., Hillegers, M. H. J., Williamson, H., Utens, E. M. W. J., Feragen, K. B., & Okkerse, J. M. E. (2022). Reducing social anxiety in adolescents distressed by a visible difference: Results from a randomised control trial of a web-based intervention. *Body Image*, 40, 295–309. <https://doi.org/10.1016/j.bodyim.2022.01.008>

- III. Zelihić, D., Feragen, K. B., Nordgreen, T., Pripp, A. H., & Kling, J. (submitted). Predictors of adolescents’ response to a web-based intervention to improve psychosocial adjustment to having an appearance-affecting condition (Young Person’s Face IT). <http://doi.org/10.2196/preprints.35583>

Abbreviations

ANCOVA	Analysis of covariance
ARC	Appearance research collaboration
BE-Appearance	Appearance esteem subscale of the BESAA
BESAA	Body esteem scale for adolescents and adults
BILD-Q	Body image life disengagement questionnaire
CAU	Care as usual
CBT	Cognitive behavioural therapy
ICBT	Internet-based cognitive behavioural therapy
ITT	Intention to treat
MI	Multiple imputation
PSQ	Perceived stigmatisation questionnaire
RCT	Randomised control trial
SAS-A	Social anxiety scale for adolescents
SPSS	Statistical package for the social sciences software
SST	Social skills training
T1	Baseline assessment
T2	Seven-week follow-up
T3	Three-month follow-up
T4	Six-month follow-up
TSD	Service for sensitive data
YPF	Young Person's Face IT
YPF-N	Young Person's Face IT-Norway

1. General Introduction

‘The perception of the bodies of others and of their expression of emotions is as primary as the perception of our own body and its emotions and expressions’.

(Schilder, 1950, p. 226)

1.1. Appearance Ideals and Social Consequences of Having a Visible Difference

As articulated in the quote above, our perceptions of our own body and appearance are influenced by how we perceive and interact with other individuals, which implies that our image of ourselves is dynamic in nature. Physical appearance has been a subject of great interest across cultures and history (Blanco-Dávila, 2000), and some believe it mirrors the inner self (Etkoff, 1999). It is not uncommon for individuals to evaluate others based on their appearance and unjustifiably use their degree of attractiveness as a measure of their competence (Langlois et al., 2000). Individuals also base their recognition of others’ emotions (Hess et al., 2004) and personalities (Naumann et al., 2009) on aspects of appearance. The belief that appearance plays an important role in life has existed since ancient times and is illustrated well by Aristotle, who concluded in his *Nicomachean Ethics* that a certain level of attractiveness was necessary to achieve happiness (Cashen, 2012).

Having an appearance that is culturally devalued (Kent & Thompson, 2002, p. 103) and considered to deviate from normative standards has in many cases involved negative consequences for the affected person (Rumsey & Harcourt, 2004; Sharratt et al., 2020; Parnell et al., 2021). Historical examples (Shaw, 1981) and, in some cultures and contexts, current ones (Bradbury-Jones et al., 2018) show that individuals have reacted with shock and fear and turned to superstitious beliefs when seeing a person with an appearance that is visibly different from the rest of the community. Attempts to explain the causes of unusual physical-appearance characteristics have included beliefs that the affected individual was cursed or under the influence of ghosts (Shaw, 1981; Bradbury-Jones et al., 2018). It is concerning but unsurprising that looking different can become a significant barrier to engagement in social activities and relationships and can negatively affect self-esteem (Sharratt et al., 2020).

1.1.1. Defining 'Visible Difference'

Several terms historically found in the medical literature, including 'disfigurement', 'abnormality', and 'deformity', are used to denote an unusual appearance (Rumsey & Harcourt, 2007). When such terms are used to categorise someone on the basis of their appearance, they may convey a stigma, which places significance on 'attribute[s] that [can be considered] deeply discrediting' because they fail to meet normative expectations (Goffman, 1963, p. 3). 'Visible difference' is now generally considered a more appropriate term (Rumsey & Harcourt, 2007; What is Visible Difference?, n.d.) and refers to the myriad of conditions, injuries, and medical and surgical interventions that can render an appearance visibly different. Some people are born with a congenital condition that alters their bodily or facial appearance, including craniofacial conditions (e.g. a cleft lip and/or palate and craniosynostosis) and skin conditions (e.g. epidermolysis bullosa and ichthyosis). Other conditions that lead to a visible difference may manifest later in life (e.g. vitiligo and eczema). Some people may experience accidental injuries (e.g. burns), traumatic events (e.g. traffic accidents), or illness (e.g. cancer) or undergo medical interventions (e.g. surgery) that leave lasting marks on their physical appearance (Rumsey & Harcourt, 2007).

The number of individuals living with a visible difference is unknown and may be impossible to estimate, given the substantial variation in the conditions that lead to visible difference as well as in the location, severity, visibility, and nature of visible differences. However, estimates from the United Kingdom suggest that around 1 in 44 people (2.3%) have a visible difference located on their face or body (Changing Faces, 2010). Based on these estimates, and considering current national statistics indicating that there are approximately 400 000 adolescents aged 12 to 17 years in Norway, around 8000 of them may live with a visible difference (Statistics Norway, 2021).

1.2. Theoretical Perspectives on Psychosocial Aspects of Having a Visible Difference

1.2.1. Understanding Individual Experiences

Few theoretical frameworks are devoted to understanding the impact of a visible difference. Kent (2000), however, integrated four perspectives drawn from the sociological (stigma) and psychological (social anxiety, social skills, body image) literature to better understand the psychosocial aspects of having a visible difference. The first perspective asserts that feeling discomfort or social anxiety in social encounters is not uncommon but

rather a pancultural human emotion (Leary & Kowalski, 1995, pp. 2–3). An individual's thoughts about and perceptions of how they are evaluated by others, whether in prospective, imagined, or current situations, lie at the core of experiences of social anxiety (p. 6). The second perspective suggests that those who have an attribute that differs from social expectations and norms and is considered undesirable (i.e. a stigma) may be exposed to experiences of social exclusion (Goffman, 1963). An important distinction is made between enacted and felt stigma. Whereas enacted stigma is actual discrimination or exclusion, felt stigma involves fears of enacted stigma and the feelings of shame experienced by some because they possess a deviant attribute (Scambler & Hopkins, 1986). The third perspective argues that the level of social skills displayed by individuals with visible differences plays an important role in how they are perceived by others, which affects the quality of their social interactions (Rumsey et al., 1986; Partridge, 1998). The idea is that many can become too self-conscious about their appearance during social interactions; this may result in noticeable behaviours (e.g. avoidance and absence of eye contact), which may in turn cause others to retreat, triggering perceptions of stigmatisation (Partridge, 1998). As noted by Masnari et al. (2013b) and Parnell et al. (2021), attitudes towards and evaluations of those with a visible difference (in their studies, children) can be more negative than attitudes towards and evaluations of those without a noticeable difference. Social skills training (SST) therefore encourages and enables individuals to initiate positive changes by managing and improving their own social interactions (Partridge, 1998). The fourth perspective maintains that society's increasing focus on appearance has been the main driver of people's pursuit of physical perfection, which may reinforce dissatisfaction with specific or general aspects of the body (Cash, 1996). Certain experiences or social interactions may cause some to develop a negative body image that becomes integrated into a body image schema (Altabe & Thompson, 1996). Events like social comparisons or unwanted changes to appearance (Cash, 1996) can activate such body image schemas and negatively affect psychosocial well-being (Altabe & Thompson, 1996).

1.2.2. Negative Responses and Social Reactions to a Visible Difference

Individuals with a visible difference may experience negative social reactions (Ablett & Thompson, 2016), and evolutionary theory can identify some of the underlying causes of others' reactions. Symmetrical features have been thought to act as markers of facial attractiveness (Mealey et al., 1999) and of health and genetic quality (Thornhill & Gangestad,

1993; Grammer et al., 2003). In contrast, because genetically and environmentally induced stressors can result in developmental changes to specific parts of the body and lead to fluctuating asymmetrical features (FA) (Rhodes & Simmons, 2007, p. 33), FA is thought to indicate disease or infections (Møller, 2006; Van Dongen & Gangestad, 2011). It is a widespread belief that humans may have an evolved predisposition to avoid contact with individuals who show signs of infectious disease (Park et al., 2003). In fact, viewing a visible difference has been shown to trigger the same mechanisms (e.g. avoidance behaviours) that have evolved to enable humans to avoid potential threats from infectious diseases (Jewett et al., 2018). As such, it is imperative to raise public awareness of the daily social challenges experienced by many individuals with a visible difference by challenging negative attitudes (Jewett et al., 2018).

1.2.3. Changing Existing Attitudes and Perceptions in the General Population

Some evidence suggests that general attitudes towards and perceptions of individuals who have a visible difference can be changed. For instance, Edwards et al. (2011) presented video vignettes portraying adolescents with craniofacial conditions using positive and negative social skills to a general community sample of students and adults to assess the sample's first impressions. The first impressions significantly improved when adolescents used positive social skills and significantly worsened when adolescents used negative social skills. Moreover, Masnari et al. (2013b) found that children and adolescents who had previous contact with someone with a visible difference gave more positive ratings of digitally altered pictures of children with a facial difference. Another intervention, delivered by teachers during class and designed to promote positive body image attitudes, significantly altered negative body image attitudes in children (Damiano et al., 2018). On the other hand, it has been recognised that interventions aimed at changing implicit prejudices and stereotypes demonstrate limited effectiveness (FitzGerald et al., 2019), meaning that it can be difficult to change such attitudes. Nonetheless, because negative social attention can be difficult for some individuals with a visible difference (Nicholls et al., 2019), changing negative attitudes towards and perceptions of those who have a visible difference is important. However, as advocated by Kent (2000), strengthening social coping skills is also imperative and can significantly contribute to the improvement of psychosocial well-being. Hence, the principal objective of this dissertation is to investigate how strengthening social coping skills in adolescents with a visible difference may improve their psychosocial well-being and

adjustment. Exploring the possible effects of changing attitudes and perceptions in the general population is unfortunately beyond the scope of this dissertation.

1.3. Adolescence and the Impact of Having a Visible Difference

Adolescence can be defined as the phase of life from 10 to 19 years (World Health Organisation, n.d.) and is characterised by biological, cognitive, and emotional growth, including identity formation and major social role transitions (Erikson, 1968; Steinberg, 2005; Sawyer et al., 2018). Forming and maintaining social relationships and experiencing a sense of belonging and group affiliation are central needs for all individuals (Baumeister & Leary, 1995), and they may become increasingly important as adolescence emerges (Tomova et al., 2021). In fact, adolescents spend more time with their peers than with their family (Larson et al., 1996), and interpersonal peer relationships exert important influences on their mental health (La Greca & Harrison, 2005; Finan et al., 2018), including regulation of behaviours (Farley & Kim-Spoon, 2014) and emotions (Herd & Kim-Spoon, 2021).

Adolescence can be a vulnerable period, because attention to and interest in appearance is particularly high and looks may contribute to the determination of social relationships (Pivnick et al., 2021) and acceptance among peers (Vannatta et al., 2009; Di Giunta et al., 2018). Adolescents increasingly engage in various types of social media use involving appearance-related content, and this activity may influence how they view their appearance (Steinsbekk et al., 2021) and negatively affect psychological well-being (Hawes et al., 2020). Indeed, body image, which involves subjective perceptions of and attitudes towards one's physical-appearance characteristics (Cash, 2012, p. 334), undergoes major shifts in adolescence (Rosenblum & Lewis, 1999; Gattario & Frisén, 2019) and is sensitive to influences from one's experiences during this period of life. For instance, experiences of appearance-related teasing from peers can negatively affect body image (Menzel et al., 2010; Gattario & Frisén, 2019) and especially the aspect of body esteem (Lunde et al., 2006). Having a self-perceived difference in appearance can also be an influential factor in the development of a negative body image (Gattario & Frisén, 2019). This is concerning, because a negative body image has been prospectively linked to elevated symptoms of social anxiety, among other problems (Vannucci & Ohannessian, 2018).

Self-esteem, which relates to positive and negative attitudes adolescents may have about themselves (Rosenberg, 1965), also plays a crucial role in adolescents' lives. Self-esteem has important influences on psychological well-being, relationships with others, and

other outcomes that may emerge later in life, such as job satisfaction (Orth et al., 2012). Moreover, self-esteem may ease the impact of adverse events such as COVID-19 on psychological well-being (Rossi et al., 2020). In contrast, having low self-esteem during adolescence can make adolescents more vulnerable to experiences of peer victimisation (van Geel et al., 2018) and can pose a risk for poorer physical and psychological health in adulthood (Trzesniewski et al., 2006). Adolescents with body image concerns may also be at risk for developing low self-esteem (Williams & Currie, 2000). It is evident that the phase of adolescence is marked by important changes, and adolescents' interpersonal relationships with peers, as well as their perceptions of and attitudes towards themselves, may significantly influence their lives. Consequently, the increasing focus on appearance during this phase can be especially impactful and can constitute a significant challenge for many adolescents who have a visible difference.

1.3.1. Challenges of Living With a Visible Difference

Previous research has provided extensive evidence regarding the psychological and psychosocial impacts of living with a visible difference during adolescence (Griffiths et al., 2012; Maskell et al., 2013; Feragen & Stock, 2016; Barke et al., 2016; Brierley et al., 2019; van Dalen et al., 2020; Keys et al., 2021). Having a visible difference may increase the risk of appearance concerns (Maskell et al., 2013) and of low body esteem (Barke et al., 2016), and it can be a source of anxiety (van Dalen et al., 2020) and depression (de Oliveira Freitas et al., 2020). For adolescents who acquire a visible difference, the impact of changes in appearance may also result in a loss of identity (Brierley et al., 2019). Some adolescents have general worries about being negatively evaluated by society because of their difference (Tiemens et al., 2013; Macleod et al., 2016), which may grow to include fear of negative evaluations by potential intimate partners (Griffiths et al., 2012). Many such adolescents are involuntarily faced with social challenges, such as being teased, bullied, or stared at (Tiemens et al., 2013; Nicholls et al., 2019) or receiving unwanted questions or comments from others (Moss et al., 2020). The range of potentially stigmatising experiences to which adolescents can be exposed can affect health-related quality of life (Masnari et al., 2013a; 2019) and make it difficult to engage in ordinary life activities, such as speaking in public, being photographed, or participating in school (Nicholls et al., 2019). Enduring experiences of negative social attention can have profound implications and negatively impact adolescents' self-esteem (Willemsse et al., 2021), including their body image and appearance satisfaction (Crandall et

al., 2020). This is particularly concerning, because many develop a feeling of being different because of negative social experiences associated with their visible difference (Tiemens et al., 2013; Anderson et al., 2019).

1.3.2. The Role of Adolescents' Age, Gender, and Type of Visible Difference

Several factors, especially adolescents' age, gender, and type of visible difference, have been thought to be associated with variations in individual experiences related to having a visible difference. First, regarding age, the onset of negative social experiences, such as being the object of teasing, seems to be particularly impactful when it occurs from middle to late adolescence (Feragen & Stock, 2016). Feragen and Stock (2016) found that experiences of teasing related to adolescents' visible differences had a greater negative impact on appearance satisfaction and symptoms of depression when they occurred between the ages of 10 and 16 than when they occurred before or until the age of 10. Additionally, studies have found that experiences of stigmatisation (Masnari et al., 2012), lower self-esteem, lower appearance satisfaction, and lower sociability (Wolf et al., 2019) occurred more frequently in middle and late adolescence. It is also noteworthy that Wolff et al. (2019) found that the onset of an acquired visible difference, such as alopecia areata (hair loss), had a lower impact on self-esteem when acquired in childhood than when acquired in adolescence. Because adolescence may be a period of increased investment in appearance, experiences of teasing and stigmatisation related to having a visible difference may have a particularly strong influence on psychosocial well-being and adjustment during this phase. Also, adolescents between middle and late adolescence may be more likely to have negative social experiences. It is, however, still unclear how age relates to adolescents' adjustment (Clarke et al., 2014, p. 11), although some studies including adults have found that adolescents became more accepting of their visible difference over time (Stock et al., 2016; Jones et al., 2017).

Second, adolescents' gender seems to play an important role. Among adolescent community samples, it is a general finding that girls have higher symptoms of social anxiety (Asher et al., 2017) and depression (Shorey et al., 2021), including greater disengagement in ordinary life activities, compared with boys (Atkinson & Diedrichs, 2021). Studies have consistently shown that girls with a visible difference tend to have a more negative body image and lower appearance satisfaction (Crerand et al., 2020), encounter more teasing related to their appearance, and have fewer positive social experiences (Feragen & Stock, 2016) compared with boys. Girls with a visible difference are also more likely to have a

stronger investment in their appearance (Crerand et al., 2017) and to experience more challenges related to social interactions and psychological adjustment compared with boys (Wolf et al., 2019), which could make girls vulnerable to elevated symptoms of anxiety (Shapiro et al., 2015). Some studies have found that among adults with a visible cleft, women may experience more distress related to their appearance (Paganini et al., 2021) and more frequently undergo secondary cleft surgery to improve aesthetic features compared with men (Paganini et al., 2018). However, it is important to note that not all studies have discovered gender differences in experiences of stigmatisation (Masnari et al., 2012), psychological adjustment (Masnari et al., 2013a), or physical, psychological, and social functioning (Klassen et al., 2012) among adolescents with a visible difference; in fact, some studies have shown that such difficulties are more prevalent among boys than among girls (Klassen et al., 2012). Nonetheless, considering the body of evidence, it is likely that girls represent an especially vulnerable subgroup of adolescents in relation to the impact of a visible difference on psychosocial experiences and adjustment.

Third, it has been widely established that the presence of a visible difference can affect adolescents' social experiences and be a source of distress. Although the size of a visible facial difference may be related to increased experiences of stigmatisation in adolescents (Masnari et al., 2012), several studies have determined that neither the type (Masnari et al., 2012; Griffiths et al., 2012; Bradbury, 2012) nor the size or visibility of a visible difference (Moss, 2005; Ong et al., 2007; Hotton et al., 2020) are significant determinants of psychosocial well-being or adjustment in general. In other words, individuals' subjective perceptions and the importance they assign to their difference are the strongest determinants of their psychosocial well-being and subsequent adjustment (Moss, 2005; Ong et al., 2007; Lawrence et al., 2012). It is therefore likely that the type and size of a visible difference are weak predictors.

1.4. Promoting Adjustment to Appearance-Related Distress

As discussed in the previous paragraph, several factors influence how adolescents may be affected by their visible difference, and the research has not always provided a consistent picture of the impact of each factor. Furthermore, the process of adjusting to a visible difference is characterised by large variations between individuals (Thompson & Kent, 2001), and it is therefore important to understand the factors that influence individual adjustment. According to one model, the adjustment process can be viewed as having three facets that exert a reciprocal influence on one upon another. The three facets consist of

predisposing, cognitive, and outcome-related factors (see Table 1; Clarke et al., 2014, pp. 34–47).

Table 1

The Appearance Research Collaboration model of examples of factors affecting adjustment

(adapted from Clarke et al., 2014)

Predisposing factors	⇒	Cognitive factors	⇔	Outcomes
Age and gender		<i>Dispositional style</i> <ul style="list-style-type: none"> ○ Optimistic ○ Pessimistic 		Social anxiety
Relationship status, parental and peer influences		<i>Sociocognitive processing</i> <ul style="list-style-type: none"> ○ Satisfaction with social support ○ Fear of negative evaluation ○ Social acceptance 		Social avoidance Anxiety
Treatment history, ethnicity, social visibility, influences from society and social media		<i>Appearance-specific cognitions</i> <ul style="list-style-type: none"> ○ Social comparisons ○ Salience and valence ○ Appearance discrepancy ○ Subjective visibility 		Depression Mood
				Aggression Shame/inadequacy Intimacy

The first facet includes predisposing factors such as demographic and generic factors (e.g. age, gender, and family environment) and previous treatment history, which influence core beliefs and experiences related to having a visible difference. The second facet includes cognitive processes and dispositional styles (e.g. perceptions of social acceptance and social comparisons), which are involved in forming body image schemas or general cognitive schemas. The third facet includes both positive and negative outcomes of having a visible difference (e.g. negative body image and social anxiety). As Table 1 shows, predisposing factors influence adolescents’ cognitive processes, which may have implications for adolescents’ psychosocial well-being and adjustment, which in turn affect cognitions. For example, compared to children, adolescents (i.e. a predisposing factor) tend to engage more frequently in social comparisons and become more invested in their appearance, which may trigger feelings of inadequacy (i.e. cognitions) and negatively affect engagement in social activities (i.e. outcomes). Lower engagement in social activities may in turn contribute to negative cognitions among adolescents, because some may develop fears of experiencing

negative appearance evaluations, which may have led to lower social engagement in the first place. Notably, the Appearance Research Collaboration (ARC) model postulates that because cognitive schemas are mental representations of information related to oneself and others, they are dynamic structures influenced by experiences. The second facet therefore acts as a mediator between the first and the third, because it can be modified by psychosocial support employing therapeutic content and techniques (Clarke et al., 2014).

1.4.1. The Role of Parents' Influences and Open Communication

As adolescents' main caregivers, parents commonly play a major role in adolescents' psychological (Mak et al., 2021) and psychosocial (Liu et al., 2020) well-being. A parent–adolescent relationship characterised by intimacy and cohesion may positively influence adolescents' development (Hochgraf et al., 2021) and adjustment in early adulthood (Fosco et al., 2012). In particular, open communication with parents has been found to positively predict adolescents' psychological well-being (Finan et al., 2018), and a close parent–adolescent relationship seems to be important for fostering more openness and disclosure of information to parents (Kapetanovic et al., 2019). A recent study found that, in families in which parents discussed the COVID-19 pandemic with their adolescents, the adolescents displayed less psychological stress, including fewer symptoms of depression and anxiety (Tang et al., 2021). Thus, parents can be an important source of support for adolescents and can promote adjustment through open communication.

Despite the benefits of open communication, there is a dearth of research on communication patterns between parents and their adolescents in relation to a visible difference. Some recent studies (Thornton et al., 2021; Feragen et al., 2021) have suggested that open communication is important both for parents' ability to understand their child's thoughts and feelings about their visible difference and for facilitating children's own understanding of their appearance. However, some parents may find it difficult to raise appearance-related issues with their child or adolescent, because they fear doing so will trigger new problems or because they lack the confidence to do so (Thornton et al., 2021; Feragen et al., 2021). Doubts about how and when to initiate such conversations may impede parents' initiative to communicate openly with their children or adolescents about their visible difference (Feragen et al., 2021). It is possible that adolescents, compared to children, use their parents to a lesser degree or in other ways when raising and discussing sensitive appearance-related issues. There is thus a need for more research on parents' experiences of

talking with their adolescents about their visible difference; such research may result in a better understanding of how open communication about appearance-related issues contributes to adolescents' adjustment.

1.4.2. Biomedical and Psychosocial Support

The main sources of support for adolescents with a visible difference have revolved around biomedical and psychosocial treatment procedures. Biomedical procedures may include reconstructive or aesthetic surgery (Rumsey & Harcourt, 2007). The benefit of reconstructive surgery is its potential to improve functional outcomes and prevent later complications (Piper et al., 2016; Sadeq et al., 2020), whereas cosmetic and aesthetic surgery may be more strongly dictated by psychosocial motivators. For example, stigmatising experiences may be the main motivator of undergoing aesthetic surgery, and such surgery may contribute to the reduction of experiences of teasing and bullying (Johns et al., 2017; Jones et al., 2020) or improve health-related quality of life (Jones et al., 2020). The decision to undergo surgery can stem from a strong wish to achieve a normal appearance and from the hope that surgical procedures may reduce social visibility (Myhre et al., 2021). However, studies have demonstrated that despite undergoing surgery to improve aesthetic features, individuals may continue to experience negative social attention (Johns et al., 2017) and appearance satisfaction may not increase to desired levels (Niemelä et al., 2008; Bemmels et al., 2013; Myhre et al., 2021). Moreover, some may continue to pursue surgery in the hope of achieving the 'perfect' appearance (Bemmels et al., 2013). Consequently, biomedical procedures have been criticised for their lack of attention to the psychosocial aspects of looking different (Rumsey & Harcourt, 2007; Clarke et al., 2014; Gee et al., 2019; Myhre et al., 2021).

Because the type, size, or visibility of a visible difference does not reliably predict adjustment, a focus on developing social skills and changing unhelpful cognitive schemas through psychosocial support can promote adjustment. This view is in line with the frameworks offered by Kent (2000) and ARC. Psychosocial support includes individual- or group-level interventions that focus on changing behaviours, thoughts, and attitudes, and it can be offered as an adjunct or alternative to biomedical treatment (Rumsey & Harcourt, 2012). Psychosocial interventions at the individual level focus on improving psychological well-being and social interaction skills, and they may include residential social camps, techniques based on SST or cognitive behavioural therapy (CBT), or a combination of SST

and CBT techniques delivered face-to-face (Jenkinson et al., 2012). Specialised psychosocial support is eclectic and includes a wide range of therapeutic approaches and techniques (e.g. SST, CBT, psychoeducation, mindfulness, and acceptance and commitment therapy) (Harcourt et al., 2018). To date, two systematic reviews have evaluated the quantitative literature on the effectiveness of psychosocial interventions in improving adjustment to a visible difference in children and adolescents (Jenkinson et al., 2015) and adults (Norman & Moss, 2015). Both reviews found positive but limited evidence for the effectiveness of interventions employing a combination of SST and CBT techniques. General limitations across studies were the lack of randomised control trial (RCT) designs and small effect sizes (Jenkinson et al., 2015; Norman & Moss, 2015), including small sample sizes, and the lack of long-term measurements (Jenkinson et al., 2015). Both reviews concluded that more methodological rigor was needed to evaluate the effectiveness of existing psychosocial interventions (Jenkinson et al., 2015; Norman & Moss, 2015).

Psychosocial support delivered at the group level mainly includes school-based interventions and educational resources aimed at improving body image in adolescent community samples (Diedrichs & Halliwell, 2012). School-based interventions have the benefit of reaching a broader audience simultaneously, and some interventions have been shown to positively influence adolescents' body image (Diedrichs et al., 2021; Bell et al., 2021). However, a general challenge of school-based interventions involves the lack of specific content with which to increase knowledge about and improve attitudes towards adolescents with visible differences (Diedrichs & Halliwell, 2012). Moreover, *Everybody's Different: The Appearance Game*, one of the few interventions that incorporates content designed to reduce negative perceptions of visible difference among community samples of children and young adolescents, did not significantly change perceptions of visible difference (Guest et al., 2021).

1.4.3. Barriers Related to Provision of Support

As underscored above, psychosocial support can promote adolescents' adjustment to their visible difference, but there is little evidence of the effectiveness of existing interventions (Jenkinson et al., 2015). A survey (Harcourt et al., 2018) demonstrated that access to relevant psychosocial support varied across countries in Europe, including Norway, where many healthcare professionals expressed that they lacked sufficient training to address appearance-related issues. Qualitative findings have revealed that appearance-related issues

may not be sufficiently addressed in the healthcare system and that some healthcare professionals may feel they lack the knowledge and confidence to raise appearance-related issues with children and adolescents (Gee et al., 2019). Several barriers seem to obstruct healthcare professionals' opportunities to deliver psychosocial support to children and adolescents with a visible difference, including a lack of hospital resources and insufficient time. In some countries, long travel distances may also obstruct access to relevant care (Gee et al., 2019).

1.5. Internet Interventions

Mental health disorders affect a significant number of children and adolescents, with an estimated prevalence of 13.4% worldwide (Polanczyk et al., 2015); moreover, such disorders can significantly undermine health-related outcomes (Otto et al., 2021). For adolescents in general, several barriers may impede access to and choice in seeking psychological support. These include a personal preference for discussing mental health difficulties with family members and friends, concerns about disclosing sensitive information to unknown healthcare professionals, perceptions of stigma related to seeking help, difficulties accessing relevant support, limited availability of support, excessive waiting time, and costs (Radez et al., 2021).

Through the delivery of healthcare and interventions via the internet, the ongoing advances in digital health technology can mitigate many of the barriers that limit access to traditional face-to-face psychosocial support (Hollis et al., 2015). Psychosocial support delivered via the internet can, for instance, potentially reach more adolescents and reduce travel time and costs (Andersson, 2018). This is especially pertinent to elongated countries such as Norway, where access to specialised support can vary depending on geographical place of residence. Internet interventions have existed for nearly 20 years and utilise the internet as a mode of delivering psychological treatment (Andersson, 2018). The therapeutic content of internet interventions is typically based on CBT, which is then referred to as internet-based cognitive behavioural therapy (ICBT) (Andersson et al., 2016). The content is usually accessed on a secure and encrypted online platform, which may require a password, presented as text material, and may include video and audio files (Andersson et al., 2016). The duration of treatments with ICBT may vary between programmes and may range from under or above 10 weeks (Andersson et al., 2016). ICBT programmes can be classified as guided or unguided/self-guided; the first type involves therapist guidance, and the second is

characterised by the absence of therapist support (Andersson & Titov, 2014). Some evidence suggests that ICBT can be more effective and have higher completion rates when involving guidance (Baumeister et al., 2014), although guided ICBT is less cost-effective than unguided ICBT (Andersson & Titov, 2014). However, both forms of ICBT can be more cost-effective than face-to-face interventions, and they positively impact psychological outcomes when compared with waiting-list controls (Axelsson et al., 2018).

Mounting evidence shows that ICBT can be effective in reducing symptoms of anxiety (Stjerneklar et al., 2019a) and depression (Stjerneklar et al., 2019a; Topooco et al., 2019) and treat general mental health challenges in adolescents (Vigerland et al., 2016). In the context of using digital health technology to treat psychosocial challenges related to having a visible difference, only one full-scale RCT has been conducted to evaluate Face IT, a web-based intervention based on techniques from SST and CBT and designed to improve adjustment in adults (Bessell et al., 2012). Bessell et al. (2012) demonstrated that Face IT successfully reduced symptoms of anxiety and depression and general appearance-related distress compared to a control group, and they showed that its intervention effects were comparable to those of face-to-face delivery of the intervention (Bessell et al., 2012). Notably, studies have also suggested that adolescents with a visible difference endorse intervention techniques based on SST and CBT (Riklin et al., 2020) and may prefer internet-delivered support (Williamson et al., 2015).

1.5.1. Young Person's Face IT

Based on the positive findings outlined above, Young Person's Face IT (YPF), an intervention based on Face IT, has been developed and adapted to a web-based platform for adolescents with a visible difference. YPF was developed at the Centre for Appearance Research, based at the University of the West of England, Bristol, in close collaboration with adolescents who have a visible difference, their parents, clinical experts, and healthcare professionals (Williamson et al., 2016; Williamson et al., 2019). The therapeutic framework of YPF has been informed largely by the principles described in Kent's (2000) framework, and it provides adolescents with the opportunity to improve social interactions by learning new coping strategies and social skills (i.e. SST). The content of YPF focuses on teaching adolescents techniques they can use to change existing negative thoughts about and perceptions of their appearance (i.e. CBT techniques; see Figure 1 and Table 2).

Figure 1

Screenshot of the YPF website (overview of sessions)



Table 2

Overview of YPF sessions and contents (adapted from Williamson et al., 2019)

Session	Session focus
1: Common problems	Common difficulties and feelings, shared experiences with other adolescents, review of positive and negative coping strategies
2: Improve your social skills	Using positive body language and talking skills to promote self-confidence and manage negative reactions from others
3: Don't be SCARED, REACH OUT	Recognising the impact of one's behaviour on others and using the REACHOUT (reassurance, effort, enthusiasm, assertiveness, courage, humour, over there, understanding, try again) toolbox to manage social stigma and challenging situations
4: Think, Feel, Do	Focusing on the link between thoughts, feelings, and behaviours, misconceptions adolescents may have about others' perceptions, challenging negative thoughts using the <i>catch it; check it; change it</i> technique
5: SMART goals	Engaging in realistic and achievable goal setting to overcome social anxiety and tackle self-imposed limitations
6: Beating anxiety	Anxiety management techniques (<i>testing the water, fear ladder</i>)

7: Looking at your progress	Review of all previous sessions
8: Booster quiz	Interactive quiz on key learning points

As Figure 1 and Table 2 show, YPF includes seven sessions and one booster session completed six weeks later to maintain the therapeutic effect (Williamson et al., 2016). Each session is intended to take 30–40 minutes to complete, and participants work through YPF independently, although they may ask for advice and guidance from others (e.g. parents/primary caregivers) if needed. Each session provides advice and guidance on how to adjust to common challenges related to having a visible difference in written, audio, and video formats. Through interactive and homework activities, the sessions focus on teaching and encouraging adolescents to practice strategies such as managing staring, bullying, and anxiety (Williamson et al., 2016). Participants can record their own reflections and experiences in their YPF diary. To support participants who struggle with reading, audio recordings of all the written texts are available on the English and Norwegian YPF intervention website.

Several studies across the world have explored the feasibility and acceptability of the intervention (Feragen, 2017; Gee et al., 2018; Williamson et al., 2019; Riobueno-Naylor et al., 2019; 2021; van Dalen et al., 2021b), and YPF consequently exists in English (<https://www.ypfaceit.co.uk>), Norwegian (<https://www.ungfaceit.no/>), and Dutch (<https://www.faceitvoorjongeren.nl/>). The British version of YPF was evaluated in a feasibility trial by Williamson et al. (2019) and was delivered to adolescents with a wide range of conditions leading to a visible difference. YPF was found to be a safe and acceptable intervention, and when compared to a control group, it demonstrated preliminary results indicating that the intervention could improve body esteem and reduce social anxiety (Williamson et al., 2019). Similarly, the Dutch version of YPF was evaluated in an acceptability and feasibility study, but without the use of a randomisation procedure and a control group (van Dalen et al., 2021b). Adolescents generally found that YPF was relevant and contained pertinent techniques and stated that the intervention had made a positive impact on them and that they would recommend YPF to other adolescents with a visible difference. Some endorsed the anonymity afforded by the design of the intervention and the intervention's ease of access, but some cited lack of time and motivation as barriers to engagement with YPF (van Dalen et al., 2021b). The studies by Riobueno-Naylor et al. (2019; 2021) explored the feasibility of incorporating YPF into routine outpatient paediatric

burn care in the United States and enrolled adolescents with a visible difference due to burns. Adolescents expressed high levels of interest in using YPF, although only a few actively engaged with and used the intervention, suggesting that there is a need for more knowledge about how adolescents' engagement with YPF can be supported (Riobueno-Naylor et al., 2021).

Taken together, YPF can provide adolescents with the opportunity to access relevant support in a timely manner and may eradicate barriers related to accessing face-to-face psychosocial support. Such benefits can be considered essential, because psychosocial care for adolescents with a visible difference can be limited and difficult to access (Rumsey & Harcourt, 2007; Harcourt et al., 2018; Gee et al., 2019). Despite these potential benefits, no studies have evaluated YPF in a full-scale RCT that includes a larger sample of adolescents with a wide range of conditions leading to a visible difference.

1.6. Summary of Knowledge Gaps and Research Aim

Despite the fact that previous research has identified many of the challenges associated with having a visible difference, critical knowledge gaps remain in several areas. First, there is a lack of knowledge about how parents experience raising and discussing appearance-related issues with their adolescents. Because parents play a central caregiving role for their adolescents and are often their first line of support, it is essential that they have the security, confidence, and knowledge necessary to raise difficult appearance-related topics with their adolescents. Second, a growing number of studies have suggested that adolescents may benefit from increasing their range of social coping skills, and CBT-based techniques seem indicated to strengthen adolescents' coping strategies for difficult situations related to their visible difference. However, relevant face-to-face support is sometimes inaccessible, and studies have identified several barriers experienced by healthcare professionals when they attempt to address appearance-related issues with adolescents, which may limit access to psychosocial support. Additionally, there is currently a lack of evidence-based evaluations of the effectiveness of interventions developed specifically for adolescents with visible differences who are in need of psychosocial support. Third, little is known about which variables that are associated with adolescents' response to web-based interventions such as YPF that incorporates SST and CBT-based techniques and that are made to improve adjustment to a visible difference. Hence, the overarching aim of this dissertation is to contribute to a better understanding of how adolescents' psychosocial well-being and

adjustment to having a visible difference can be improved. More knowledge about the type of support that may promote adolescents' adjustment may be of central importance to healthcare professionals seeking to aid adolescents in need of support. The following research questions were addressed in three papers that comprise this dissertation:

- I. How do parents experience communicating about appearance-related issues with their adolescent who has a visible difference? (Paper I)
- II. Does YPF improve body esteem and/or reduce social anxiety in adolescents with a visible difference? Does YPF reduce perceived stigmatisation or life disengagement in adolescents with a visible difference? (Paper II)
- III. Which variables predict intervention effects among adolescents with a visible difference who have access to YPF? (Paper III)

3. Methods

3.1. Young Person's Face IT–Norway

The research conducted for this dissertation was based on data collected from the four-year Young Person's Face IT–Norway (YPF–N) project (2019–2023), which was funded by the Research Council of Norway (Grant number: 287243) and coordinated by the Centre for Rare Disorders at Rikshospitalet, Oslo University Hospital. The YPF–N project consists of a larger project and a preregistered parallel-group RCT (trial registration number: NCT03165331) that aim to evaluate the effectiveness of YPF in improving psychosocial outcomes in adolescents with a visible difference. Quantitative data were collected in multiple waves, and qualitative interviews were conducted with both parents and adolescents at different time points to explore experiences with using YPF (see Figure 2). This dissertation builds upon both qualitative (Paper I) and quantitative (Papers II and III) data, and Papers I–III therefore consist of overlapping samples. Paper II also builds upon data collected as part of an RCT conducted in the Netherlands that explored the effectiveness of YPF. The Dutch RCT was developed independently of the RCT conducted in the YPF–N project, and there were consequently some differences in study procedures (these differences are described in detail in Paper II). More information about the data included in the papers that comprise this dissertation is provided in the paragraphs below.

3.2. Recruitment and Eligibility Criteria

Participants were recruited nationwide between April 2019 and February 2021 from university hospitals, specialist treatment units, local educational and healthcare services, and patient organisations as well as through media and social media platforms (for details regarding recruitment in the larger YPF–N, see Kling et al., 2021). For participants who wished to participate in the YPF–N project, they and/or their parents/primary caregivers contacted the research team by telephone or email. Following the initial contact, all the participants (and/or their parents, if the adolescent was under 16 years of age) were contacted via telephone by the research team and answered questions in order to confirm eligibility. The participants also provided demographic information (e.g. birth date, gender, type of visible difference, and parental occupation/education), either during the initial screening conversations and/or as part of the baseline assessment.

The inclusion criteria were (1) age between approximately 12 and 17 years, a visible difference, and self-identified appearance-related distress, teasing, or bullying; (2) access to the internet and a home computer or tablet; (3) minimum reading level corresponding to that of a 12-year-old; and (4) normal or corrected-to-normal vision. Exclusion criteria were (1) a diagnosis of clinical depression, psychosis, eating disorder, or post-traumatic stress disorder (PTSD) or within 12 months of traumatic injury; (2) learning disabilities that would impede understanding of the intervention content; and (3) current participation in any face-to-face psychological intervention (e.g. therapist-delivered CBT).

3.3. Procedures

After assessing the participants for inclusion and exclusion criteria, informed consent was obtained from the eligible participants. After the consent forms were secured, the outcome measures were administered prior to randomisation at T1 (baseline assessment). The participants were consecutively randomly assigned to either an intervention group or a waiting-list care as usual (CAU) group; the members of the latter were provided with access to the intervention three months after randomisation. A single randomisation procedure was performed in a 1:1 ratio, and the participants were informed about their group allocation by either telephone or by email. Neither the members of the research team nor the participants were blinded to the randomisation outcome.

The participants randomly assigned to the intervention group received a username and password to access YPF and completed the intervention on a computer or tablet, either at home or another self-selected location. During the course of the intervention, some adolescents contacted the research team because they needed technical support to log in to the intervention website, to change a password, or to deal with technical issues associated with the intervention website. No participants or parents contacted the research team because of concerns related to psychological well-being, because they wanted a referral to the healthcare system, or because participants needed support with the YPF sessions.

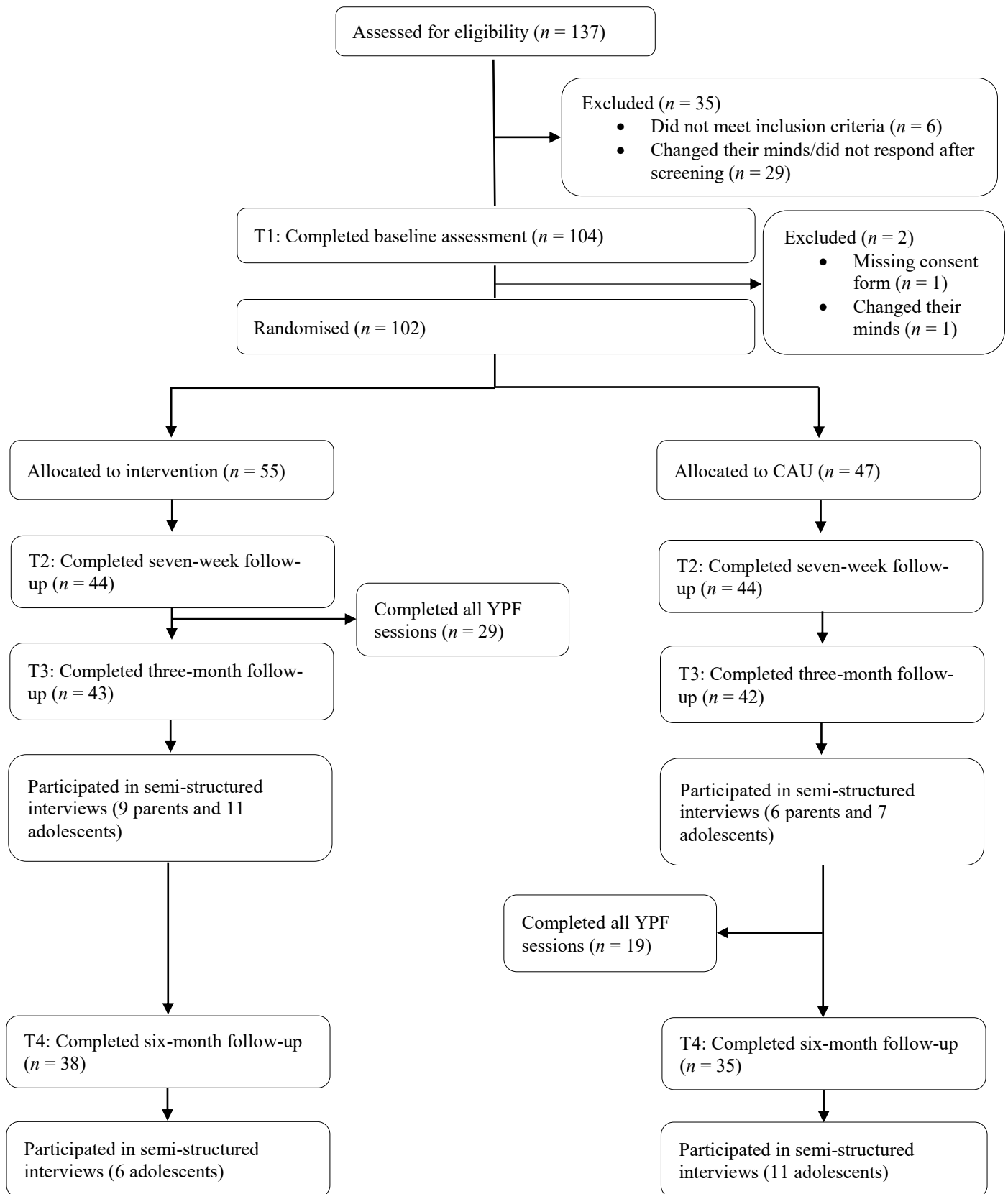
The participants randomly assigned to the waiting-list CAU group received access to YPF after three months. Because there is no standardised psychological or psychosocial treatment for adolescents with a visible difference in Norway, Norwegian CAU varied according to the needs, resources, and expertise within local healthcare services. For example, CAU could include routine consultations at the hospital for medical treatment of skin conditions, such as eczema or other congenital conditions. The participants randomly

assigned to the waiting-list CAU group knew they would wait three months before receiving access to YPF and would complete a new set of outcome measures after completion of YPF for the purpose of the larger YPF–N project.

Following T1, the participants completed outcome measures again at T2 (seven-week follow-up, after completion of YPF's seven sessions), T3 (three-month follow-up), and T4 (six-month follow-up). After T3, the participants randomly assigned to the waiting-list CAU group were provided with access to YPF (see Figure 2). Parents were systematically invited to participate in semi-structured interviews at T3, and the adolescents were invited at T3 and T4. Interviews with parents and adolescents continued until it was determined that no new information about experiences with using YPF–N had emerged.

Figure 2

Flow chart of YPF–N study procedures



3.3.1. Attrition

As Figure 2 shows, a total of 137 participants were assessed for eligibility for the YPF–N project, of which 104 completed the baseline assessments and 102 underwent randomisation. Two participants did not undergo randomisation, and 14 did not complete the outcome measures at T2 (intervention group $n = 11$; CAU group $n = 3$), three did not complete the outcome measures at T3 (intervention group $n = 1$; CAU group $n = 2$), and 12 did not complete the outcome measures at T4 (intervention group $n = 5$; CAU group $n = 7$). Hence, a total of 29 participants were lost to follow-up after randomisation.

Attrition analyses were conducted to explore whether participants who were not randomised and were lost to follow-up (noncompleters) differed from those who completed the measures at all time points (completers) in terms of several characteristics. These included demographic (age, gender, type of condition), group (intervention or CAU group), and baseline (scores on the BE–Appearance Subscale and SAS-A Total Scale) characteristics. The analyses showed no significant differences in age ($t(102) = -.950, p = .344$), gender (chi square: $X^2(1, N = 104) = .064, p = .831$), type of condition (Fisher’s exact test, $p = .060$), or frequency of participants in each group (chi square: $X^2(1, N = 102) = .360, p = .548$) between noncompleters and completers. Moreover, noncompleters and completers did not significantly differ in terms of baseline characteristics on the BE–Appearance Subscale ($t(99) = .456, p = .650$) or the SAS-A Total Scale ($t(100) = .329, p = .743$).

3.4. Samples

The final sample of the YPF–N project consisted of 102 participants. Participants age ranged between 11 and 18 years ($M = 13.85$ years; $SD = 1.71$), and over two-thirds were adolescent girls ($n = 58$; 57%). Two-thirds of the participants had a craniofacial condition ($n = 63$; 64%), under one-third had a condition affecting the body form ($n = 22$; 22%) or a skin condition ($n = 10$; 10%), and some had a scarring condition ($n = 4$; 4%). Details pertaining to the samples corresponding to Papers I, II, and III are presented below.

3.4.1. Paper I

Paper I was an exploratory qualitative study guided by a critical realist perspective (Bhaskar, 1975) and consisted initially of 15 parents (2 fathers and 13 mothers) of adolescents with a visible difference. The recruitment of participants was extended to include three parents of adolescents who had declined to participate in the YPF–N project, a decision

prompted by a request from a mother of an adolescent who had declined a direct invitation to join the RCT. Including parents of adolescents who chose not to engage in the RCT contributed to the diversity of the sample. At the time when the interviews were conducted, participating adolescents had completed the outcome measures at T3. Nine adolescents were from the intervention group (and had access to YPF), and six were from the waiting-list CAU group (and had not yet access to YPF).

3.4.2. Paper II

Paper II was a parallel-group RCT that enrolled participants drawn from the YPF–N project and participants living in the Netherlands who were also part of an independent parallel-group RCT evaluating the effectiveness of YPF. The combined sample consisted of 189 adolescents ($M = 14.35$ years, $SD = 1.82$, 60% girls) who had completed the outcome measures at T1 and underwent random assignment to the intervention group to complete YPF ($n = 100$) or waiting-list CAU group ($n = 89$) and who had completed the outcome measures at T3. The a priori sample-size calculation performed to estimate the required number of participants showed that 62 participants were needed per group to achieve at least 80% for detecting treatment effects. A Cohen's d effect size of .50 was considered to represent a clinically meaningful effect (Norman et al., 2003). The study reported in Paper II was therefore considered sufficiently powered to detect statistically significant results.

3.4.3. Paper III

Paper III was a prospective study that built upon the RCT reported in Paper II and enrolled 71 participants ($M = 13.98$ years, $SD = 1.74$, 61% girls). The sample included only participants who had access to YPF, from both the intervention group and waiting-list CAU group. At the time of their inclusion in Paper III, the participants from the intervention group had completed the outcome measures at T1 and T3, and the participants from the waiting-list CAU group had completed the outcome measures at T1 and T4.

3.5. Data Collection

3.5.1. Semi-Structured Interviews

The interviews presented in Paper I were conducted via telephone with parents. They lasted 35 minutes on average (range: 17–56 minutes). A semi-structured-interview guide initially developed by Heidi Williamson, who developed the original English version, was

used (Williamson et al., 2016), and it was translated into Norwegian by the author of this dissertation.

The questions in the interview guide explored parents' perceptions of their adolescents' thoughts and feelings about having a visible difference. To explore parents' perceptions of appearance-related conversations, two open-ended questions were added to the translated interview guide before initiating data collection (see Appendix 1). Note that parents of adolescents in the intervention group were asked additional questions concerning the intervention (see Appendix 2). Questions were followed up by a range of probes for the purpose of gathering more information about how parents perceived appearance-related conversations to unfold with their adolescents, parents' perceptions of how such conversations affected them and their adolescents, and potential barriers to or facilitators of the dialogue. Examples of follow-up questions were 'How often do you have conversations with your son/daughter about his/her appearance?', 'What do you think is the reason for not talking about appearance-related topics with your son/daughter?', and 'Do you have any examples of appearance-related situations that you could talk with your son/daughter about?' No changes were made to the interview guide as data collection progressed.

3.5.2. Outcome Measures

Body Esteem. The Appearance Esteem (BE-Appearance) Subscale of the Body Esteem Scale for Adolescents and Adults (BESAA; Mendelson et al., 2001) was used to assess body esteem in Papers II and III. The BE-Appearance Subscale contains 10 items rated on a 5-point Likert scale ranging from 0 (never) to 4 (always). Statements include 'I worry about the way I look' and 'I look as nice as I'd like to'. After negatively worded items have been reversed, higher mean values indicate greater appearance esteem.

Social Anxiety. The Social Anxiety Scale for Adolescents (SAS-A; La Greca & Lopez, 1998) was used to assess subjective experiences of social anxiety in Papers II and III. The SAS-A contains 17 items divided into three subscales that are rated on a 5-point scale ranging from 1 (never) to 5 (always). The first subscale, Fear of Negative Evaluation, contains eight items (e.g. 'I worry about being teased'). The second subscale, Social Avoidance and Distress Specific to New Situations or Unfamiliar Peers, contains six items (e.g. 'I feel shy around people I don't know'). The third subscale, Social Avoidance and Distress in General, contains four items (e.g. 'It's hard for me to ask others to do things with me'). Higher scores indicate higher levels of social anxiety.

Perceived Stigmatisation. The Perceived Stigmatization Questionnaire (PSQ; Lawrence et al., 2006) was used to assess perceptions of stigmatisation behaviours in Papers II and III. The PSQ consists of 21 items divided into three subscales that are rated on a 5-point Likert scale from 1 (never) to 5 (always). The subscales evaluate the Absence of Friendly Behaviour, Experiences of Confused and Staring Behaviours from Others, and the extent to which respondents encounter Hostile Behaviour. Examples of items are ‘Strangers are polite to me’, ‘People do not know what to say to me’, and ‘People laugh at me’. After positively worded items are reversed, higher scores indicate higher levels of perceived stigmatisation.

Life Disengagement. The Body Image Life Disengagement Questionnaire (BILD-Q; Diedrichs et al., 2016; Atkinson & Diedrichs, 2021) was used in Papers II and III to assess the extent to which engagement or intention to engage in various life activities (e.g. ‘going to a social event’ and ‘spend time with friends and family’) impacted appearance-related worries. The current BILD-Q (Atkinson & Diedrichs, 2021) consists of nine items rated on a 4-point Likert scale from 1 (‘hasn’t stopped me at all’) to 4 (‘stopped me all the time’); a previous 10-item version of the BILD-Q was used in the current study (Diedrichs et al., 2016). Higher scores indicate greater life disengagement.

Health-Related Quality of Life. The EQ-5D-5L (Herdman et al., 2011) was used to measure health-related quality of life in Paper III. The measure defines health in five dimensions: mobility (e.g. ‘I have no problems in walking about’), self-care (e.g. ‘I have no problems with washing or dressing myself’), usual activities (e.g. ‘I have no problems doing my usual activities’), pain/discomfort (e.g. ‘I have no pain or discomfort’), and anxiety or depression (e.g. ‘I am not anxious or depressed’). Each dimension is rated on one of five different levels (‘no problems’, ‘slight problems’, ‘moderate problems’, ‘severe problems’, and ‘unable to’). Respondents also self-rate their overall health from 0 (‘the worst health you can imagine’) to 100 (‘the best health you can imagine’) on a visual analogue scale (EQ VAS).

3.5.3. Predictor Variables

In addition to using age and gender (coded as 0 = male and 1 = female) as predictor variables in Papers II and III, the variables described below were included as predictors.

Type of Visible Difference. The participants' type of visible difference was categorised into four broad groups (craniofacial conditions, skin conditions, conditions affecting body form, and scarring conditions) and used as a predictor variable in Papers II and III.

Experiences of Appearance-Related Teasing. The frequency of teasing experiences and subsequent distress was assessed with two items drawn from Project Eat-III (Neumark-Sztainer et al., 2007) and was included as a predictor variable only in Paper III. The items assessed the frequency of teasing experiences related to 'weight and shape' and 'the way you look' and feelings of distress from teasing related to 'weight and shape' and 'the way you look'. Distress was scored on a 5-point scale (ranging from not upset to very upset), with higher scores reflecting greater distress.

Engagement With YPF. Engagement was measured in two ways. Paper II assessed engagement based on the number of weeks participants spent on completing YPF, irrespective of the number of sessions completed. Paper III assessed engagement based on the number of sessions completed and the mean time spent on YPF sessions (in minutes). The YPF programme automatically records the time each participant spends on each session. However, the recorded time may not always represent the actual time devoted to sessions, because participants may forget to log out, which leads to an invalid measurement of the time spent on a particular session. However, each session consists of several subsessions, and the time spent on each subsession is recorded as well. Therefore, to control for potential errors in the measurement of total time spent and to obtain a more precise and correct measure of time, participants' time usage was inspected for each subactivity of each session. When unrealistic time usage was suspected for any subactivity of a given session, a mean was calculated based on the time recorded for the other subactivities of the same session, and the time usage suspected as unrealistic was replaced with this mean.

Session Usefulness. Following the completion of YPF sessions 1–6, the participants were asked to rate the degree to which they perceived the specific session as helpful on a 5-point Likert scale ranging from 1 ('strongly agreed') to 5 ('strongly disagreed'). Based on this information, a sum score for sessions 1–6 was calculated and a variable was computed to assess perceived session usefulness. Perceived session usefulness was included as a predictor variable only in Paper III.

3.6. Thematic Analysis

3.6.1. Paper I

A six-phase inductive and data-driven approach to thematic analysis was used (Braun & Clarke, 2006), and the themes were constructed by identifying patterns in the data.

Phase 1: A verbatim transcription of the interviews was performed (15 interviews were transcribed by the first author and three by a research assistant). All the transcriptions were read several times, and data were extracted from the full interviews. The first and last author highlighted excerpts containing information about the conversations or lack of conversations between parents and adolescents. Unless they contained relevant information about potential conversations, excerpts about parents' perceptions of their adolescent's experience of living with a visible difference or of their adolescent's experiences with participating in the YPF–N project were excluded.

Phase 2: The first author then coded the data on a semantic level (by writing descriptive words or phrases adjacent to associated excerpts from the transcripts). The first five interviews were coded in tandem with the last author. Disagreements that arose during the analysis process were discussed and resolved between the first and last author. This was done by systematically going through all the coding for the first five interviews until an agreement on the level of coding was reached. This process ensured consistent coding.

Phases 3–4: After coding the material, the first author categorised codes into broader units on a latent level (by interpreting emerging patterns and categories). Thematically related codes were grouped into categories and were identified as candidate subthemes. Subthemes were checked for thematic similarities and grouped under overarching themes. Codes, subthemes, and overarching themes were generated iteratively and continuously compared to the initial codes and excerpts. This analysis generated four overarching themes and seven subthemes that were clearly defined and named.

Phases 5–6: Finally, the analysis was formed into a coherent story with distinct names for overarching themes and subthemes, supported by evidence from data extracts. After the initial construction of themes, all the transcripts were reread with the intention of searching for new information related to parents' experiences of communicating about appearance-related issues with their adolescents, because such information had the potential to inform the themes. No new information was discovered, and considering the review of all the transcripts and the study's exploration of a relatively unexplored area, it was determined that the 18 parents provided enough information about the topic under investigation.

3.7. Statistical Analyses

All the statistical analyses were conducted using the IBM Statistical Package for the Social Sciences Software (SPSS), version 26.

3.7.1. Paper II

An analysis of covariance (ANCOVA) was used to test whether T3 outcome scores (dependent variable) were statistically significantly different between the intervention group and the waiting-list CAU group (independent variable), after accounting for T1 outcome scores and country (covariates). Country was defined as ‘Norway’ and ‘the Netherlands’. Partial eta squared (η_p^2) was used to measure effect size and was interpreted using Cohen’s (1988) guidelines for small ($\eta_p^2 = .01$), moderate ($\eta_p^2 = .06$), and large ($\eta_p^2 = .14$) effects. To avoid issues with multiple comparisons, the Benjamini–Hochberg correction (Benjamini & Hochberg, 1995) was applied for the ANCOVA models to reduce the risk of Type 1 errors. Intention-to-treat (ITT) analyses were conducted to account for missing T3 data, which were missing at random, using a multiple imputation procedure (MI; Rubin, 1987). One MI model was constructed separately for each outcome variable, and the pooled mean of the imputed dataset consisting of five iterations was used. To improve model precision, the variables ‘gender’ and ‘group’ were entered into each MI model together with T1 and T3 total-scale outcome scores.

Hierarchical regressions were conducted to explore whether demographic (age, gender, country, type of visible difference) and intervention-related (weeks spent on YPF) variables and T1 outcome scores predicted T3 outcome scores (dependent variable). A one-level independent variable consisting only of participants from the intervention group was used. The hierarchical multiple regression models were evaluated using R^2 , adjusted R^2 (R_{adj}^2), and R^2 change (ΔR^2).

3.7.2. Paper III

Backward multiple regressions were used to select candidate predictors of outcomes (dependent variable) following adolescents’ use of YPF; the p -value threshold was set at .20 (two tailed) following recommended procedures (Royston et al., 2009; Heinze & Dunkler, 2017). The predictors included demographic (age and gender), psychosocial (frequency of teasing experiences and depressive and/or anxiety symptoms), and intervention-related

(minutes spent on YPF) variables. Paper III used a one-level independent variable consisting of all the participants who had access to YPF, regardless of whether they were originally enrolled in the intervention group or the waiting-list CAU group (i.e. the intervention group had completed the outcome measures at T1 and T3, and the waiting-list CAU group had completed the outcome measures at T1 and T4). To assess the degree of change in outcomes associated with the demographic, psychosocial, and intervention-related predictors following participants' use of YPF, difference scores were calculated for the dependent variables based on assessments conducted before and after participants' use of YPF. All the regression models were evaluated using adjusted R^2 (R^2_{adj}).

3.8. Ethical Considerations

The research conducted in Papers I–III was carried out with the approval of the Regional Committee for Medical and Health Research Ethics (Health Region South-East, reference number: 2015/2440) and was accepted by the Data Protection Office based at the Oslo University Hospital. The participants and, if participants were under 16 years of age, their parents were provided with written and oral information about the YPF–N project. The written information contained a consent form and a detailed description of the aim of the project and study procedures, and it specified that participants could withdraw their consent to participate at any time without specifying any reasons and that all personal information would be handled confidentially and securely. Consent was obtained in written form. The parents of participants under 16 years of age were provided with a short document including questions they could ask their adolescent after each YPF session, to facilitate engagement with the intervention. Incentives for completing the outcome measures at T2 (NOK 100), T3 (NOK 300), and T4 (NOK 300) were offered to the participants.

All the data were collected and analysed within Service for Sensitive Data (TSD). TSD is a service designed for storing and processing data in compliance with the Norwegian Data Protection Authority and the Health Research Act, and it was developed and is maintained by the University Center for Information Technology at the University of Oslo. TSD provides virtual servers, backup systems, storage systems, a high-performance computing facility, and databases, all within in a highly secure environment. The outcome measures were administered using a secure and encrypted version of the web-based platform Nettskjema, which is interfaced with TSD and the governmental ID-portal for login, enabling a secure data harvesting and strong identification of the respondents. Safeguarding routines were also established, such that all the data entered by participants in the YPF platform (e.g.

diary entries, personal reflections, assignments), were reviewed weekly by the author of this dissertation to check for signs of psychological distress. The YPF–N research team was also available to offer support to participants via telephone if needed. All data entry and storage performed on the YPF platform has hypersecure online data protection (VeriSign®) and complies with Oslo University Hospital’s data processing agreement regarding the storage, sharing, and accessibility of data.

In 2016, before the initiation of the YPF–N project, a pilot study (Feragen, 2017) with a sample of adolescents with a visible difference living in Norway was conducted to evaluate the acceptability and feasibility of YPF. The 29 adolescents in the sample were randomly assigned to either an intervention group receiving YPF or a non-waiting-list CAU group. The pilot revealed that some parents and adolescents struggled with the fact that YPF would not be offered to those randomly assigned to the CAU group, which weakened both the parents’ and their adolescents’ motivation to participate. In view of this issue, the YPF–N project implemented a waiting-list CAU group to reduce ethical concerns, improve recruitment, and handle potential psychological distress associated with being randomly assigned to a non-waiting-list CAU group.

An advisory group was established for the YPF–N project (Kling et al., 2021). It consisted of representatives from 18 patient organisations representing diverse conditions leading to a visible difference, (e.g. craniofacial and skin conditions, burns, and overweight). The representatives of the advisory group were regularly invited to take part in project meetings to discuss recruitment strategies, research findings, and considerations related to the future implementation of YPF in the healthcare system. The advisory group was involved to facilitate user involvement in the research process and to draw from the experiences of individuals with experiences with visible difference. The aim was to give users the opportunity to influence the research process, which could increase the probability of making the research as relevant as possible for users’ requirements and needs.

4. Results

4.1. Summary of Papers I–III

4.1.1. Paper I

Parent–adolescent communication about sensitive topics such as appearance may potentially facilitate positive adjustment in adolescents, but it can be challenging for parents of adolescents with a visible difference. Semi-structured interviews were therefore conducted to explore how parents experience of communicating about appearance-related issues with their adolescent who has a visible difference. The parents ($n = 18$) were drawn from the larger YPF–N project. Inductive thematic analysis revealed four overarching themes: (1) *conversational settings*, (2) *understanding adolescents’ feelings and thoughts*, (3) *providing parental guidance and encouragement*, and (4) *when the dialogue becomes difficult*. The themes showed that parents resorted to specific settings when initiating conversations about appearance, such as when their adolescents expressed a need for emotional care, seemed to be upset, or during treatment-related settings. The choice of setting was carefully considered, because some parents generally felt uncomfortable raising appearance-related issues with their adolescent due to worries that they would trigger appearance-related concerns. Interestingly, engagement with YPF sparked adolescents’ interest in talking about their visible difference with their parents. The themes also suggested that open communication enabled parents to stay informed about their adolescent’s psychosocial adjustment to having a visible difference.

4.1.2. Paper II

Preliminary findings indicate that YPF may be effective in improving body image and reducing social anxiety in adolescents with a visible difference. However, no previous study has gone beyond the feasibility phase. For Paper II, a parallel-group RCT was conducted with 189 adolescents (aged 11–18 years) from two countries (Norway and the Netherlands) who had a visible difference. The aim was to establish the effectiveness of YPF in improving body esteem and in reducing social anxiety, perceived stigmatisation, and life disengagement. A one-way ANCOVA showed that, compared to a care-as-usual group, adolescents randomly assigned to the intervention group who had access to YPF had reductions in social anxiety symptoms ($\eta_p^2 = 0.06$). No significant group differences were found for the other outcomes. The follow-up analyses, which included only the intervention group, revealed that after access to YPF, girls had more social anxiety symptoms compared to boys and adolescents

living in the Netherlands had more social anxiety symptoms compared to those living in Norway. Neither age, time spent on the intervention (measured in weeks and irrespective of the number of sessions completed), nor type of visible difference predicted intervention effects. Future studies should investigate how the effects of YPF on social anxiety symptoms vary over time and the potential long-term effects of YPF.

4.1.3. Paper III

YPF has the potential to support adolescents' adjustment to living with a visible difference using a web-based platform, but more knowledge is needed to establish which adolescents benefit the most from the intervention. This study investigated predictors of intervention effects after adolescents with a visible difference ($n = 71$, aged 11–18) received access to YPF. Backward multiple regression revealed that higher intervention effects were predicted by demographic (gender), psychosocial (frequency of teasing experiences related to body and appearance and levels of depressive and/or anxiety symptoms), and intervention-related (minutes spent on YPF) variables. Specifically, the results suggested that adolescent boys, adolescents who reported higher levels of psychosocial distress before receiving access to YPF (baseline), and/or adolescents who spent more minutes on YPF obtained better overall intervention effects. However, the results were limited by low levels of explained variance (ranging from 1.6 to 24.1%). More knowledge about the role of other variables (e.g. adolescents' initial motivation and previous history of web-based and/or biomedical support) in predicting effects of YPF is therefore required.

5. General Discussion

The overall aim of the research conducted for this dissertation was to improve the knowledge and understanding of variables that may promote adolescents' psychosocial adjustment to their visible difference. The current research explored the role of parents' experiences of communicating about sensitive appearance-related topics with their adolescents (Paper I) and adolescents' use of web-based support that employs SST and CBT techniques (Papers II and III). What follows is a general discussion of the results from all three papers in light of previous research.

5.1. Parents' Influences on Adolescents' Adjustment to Having a Visible Difference

Previous research has underscored the significant impact of parents' contributions to adolescents' well-being and general adjustment (Fosco et al., 2012; Mak et al., 2021; Liu et al., 2020; Hochgraf et al., 2021). Importantly, the quality of the parent–adolescent relationship, which can be assessed based on the degree to which parents and adolescents enjoy spending time together, including perceived connectedness and parental awareness and supportiveness, also matters for adolescents' development and mental health (Hair et al., 2008). Strong parent–adolescent relationships likely facilitate open communication (Kapetanovic et al., 2019), which enables parents to gain more knowledge about their adolescent's whereabouts. Ultimately, parents are the most common source of support for many adolescents with a visible difference (Riklin et al., 2020). Hence, as demonstrated by another study including parents of younger children (Feragen et al., 2021), staying informed about adolescents' thoughts and feelings can be especially important for parents' ability to offer timely support for their adolescent and promote their adolescent's adjustment. The findings of Paper I align with those reported by Feragen et al. (2021), and they underscore that communicating openly about appearance-related issues can play an important role in parents' ability to provide guidance, advice, and positive reinforcement to their adolescents. Furthermore, close relationships characterised by openness seemed to ease parents' initiation of conversations about sensitive appearance-related topics with their adolescents. Previous research with community samples has also suggested that relationship quality may be linked to better communication between parents and their adolescents (Solís et al., 2015; Keijsers et al., 2016) and has stressed that adolescents' own perceptions of their parents' openness to

communicate represents an important factor of their psychosocial adjustment (Xiao et al., 2011).

Paper I also points to the fact that for some parents, raising an appearance-related issue can be difficult because they perceive or fear it will be a sensitive topic for their adolescent. Moreover, uncertainty about the appropriate occasions in which raise appearance-related issues and a lack of interest from adolescents to engage in appearance-related conversations can also contribute to the creation of conversational boundaries. These findings suggest that raising appearance-related issues is not a straightforward process and that parents may lack the confidence to initiate appearance-related conversations; that is, they may feel insecure about which words to use and may be afraid they will trigger negative thoughts in their adolescents by talking about their visible difference (Thornton et al., 2021; Feragen et al., 2021). More research on the factors that may strengthen parents' confidence and facilitate their initiation of conversations about appearance-related issues is therefore needed.

As Paper I shows, adolescents' participation in the YPF–N project and engagement with YPF seemed to facilitate the initiation of appearance-related conversations with their parents. Thus, low-level interventions developed to support adolescents' psychosocial adjustment to their visible difference and perhaps other appearance-related interventions may stimulate appearance-related conversations by increasing adolescents' interest in and motivation for discussing appearance-related topics with their parents. Other studies have endorsed the notion that parent-based interventions (Diedrichs et al., 2016; Widman et al., 2019) and parents' viewing of social media content depicting real-life issues (Cingel et al., 2021) may facilitate parents' openness to and comfort with communicating about sensitive topics (e.g. appearance, mental health, and sexual health) with their adolescents. Additionally, some studies have suggested that involving parents in interventions developed to improve body image (Hart et al., 2015; Diedrichs et al., 2016) and treat depression and anxiety (Grist et al., 2019) in adolescent community samples can positively influence adolescents' outcomes. Taken together, the findings of Paper I suggest that parents of adolescents with a visible difference should use conversations to support their adolescents' adjustment process and that the quality of the parent–adolescent relationship likely plays a key role in adolescents' openness to discussions of sensitive appearance-related issues.

5.2. The Role of Web-Based Self-Help in Treating Appearance-Related Distress

Although specialised psychosocial support for adolescents with a visible difference is eclectic and includes a variety of therapeutic approaches (Harcourt et al., 2018), previous research has shown that interventions combining techniques from SST and CBT can be effective in treating appearance-related distress (Bessell et al., 2012; Jenkinson et al., 2015; Norman & Moss, 2015). A lingering issue, however, has been the limited evidence of effectiveness to fully support the use of available interventions based on these techniques into practice (Jenkinson et al., 2015). Paper II therefore makes an important contribution by showing that web-based interventions such as YPF can successfully support adolescents with psychosocial challenges related to having a visible difference. These findings are consistent with those of other studies that include adolescent community samples, which have demonstrated that ICBT interventions can be effective in treating mental health challenges (Vigerland et al., 2016; Stjerneklar et al., 2019a; Topooco et al., 2019). Moreover, Bessell et al. (2012) demonstrated that the intervention effects of Face IT (the adult version of YPF) on reducing appearance-related distress were comparable to those of standard face-to-face therapy. Taken together, Paper II and Bessell et al. (2012) contribute evidence to the growing body of research that has identified benefits of self-help interventions for individuals with visible differences (Rumsey & Harcourt, 2007; Shah et al., 2014; Williamson et al., 2015; Pasterfield et al., 2019; Gee et al., 2019) and for those with experiences of social anxiety (Bessell et al., 2012; Shah et al., 2014; Williamson et al., 2019) and general appearance-related distress (Muftin & Thompson, 2013).

Digital health technologies can significantly improve access to mental healthcare for adolescent in general (Hollis et al., 2015) and can facilitate the search for support. This is essential, because some adolescents may refrain from seeking psychological support from mental healthcare services because of a perceived stigma surrounding mental health issues (Radez et al., 2021). Especially for adolescents with a visible difference, digital health technologies may be preferable because of the benefits of increased anonymity, confidentiality, and ease of access (Griffiths et al., 2012). Moreover, because some healthcare professionals may lack sufficient training (Harcourt et al., 2018) or confidence (Gee et al., 2019) to address appearance-related issues, self-help tools requiring no therapist support, such as YPF, can attenuate some of the barriers associated with traditional face-to-face support.

5.2.1. Demographic and Intervention-Related Predictors of Intervention Effects

Although web-based interventions may be effective in treating appearance-related distress in both adolescents and adults with a visible difference, there is very limited evidence about whether certain factors, such as demographic variables and baseline distress levels, predict intervention effects (Muftin & Thompson, 2013). One exception is the YPF feasibility study, which indicated that adolescents' intervention engagement predicted stronger intervention effects (Williamson et al., 2019). Hence, Paper III attempts to determine whether some adolescents could benefit more from using YPF by exploring the role of available demographic, psychosocial, and intervention-related variables. The analyses in Paper III support the notion that adolescents who experience higher levels of psychosocial distress and spend more minutes engaging with YPF may obtain better overall intervention effects. Indeed, higher baseline levels of anxiety (Stjerneklar et al., 2019b) and depressive symptoms (Spence et al., 2020; Stjerneklar et al., 2019b) have been found to predict increased intervention effects of guided ICBT in adolescent community samples. Given that some adolescents with a visible difference may be vulnerable to social attention they perceive as negative (Tiemens et al., 2013; Nicholls et al., 2019) and to anxiety (van Dalen et al., 2020), providing early intervention is imperative, because psychological distress may increase and/or persist into adulthood and significantly affect health-related outcomes if left untreated (Winning et al., 2018).

5.2.2. How Does Intervention Engagement Influence Intervention Effects?

When it comes to the importance of intervention engagement for predicting intervention effects, previous evaluations of ICBT with adolescent community samples have had mixed results. Whereas one study did not find that the number of completed sessions predicted intervention effects (Spence et al., 2020), other studies have demonstrated that higher numbers of completed sessions were associated with better therapeutic effects (March et al., 2018; Spence et al., 2019). Regarding the predictive power of intervention engagement, mixed results were observed across Papers II and III. Whereas variables potentially related to engagement predict higher intervention effects of YPF in Paper III, this is not the case in Paper II. However, Papers II and III employ different measures of engagement: number of weeks spent on YPF (irrespective of the number of sessions completed) and minutes spent on YPF, respectively. This may explain the difference in results. For instance, because there are many ways to measure intervention engagement (Molloy & Anderson, 2021), different

measurements likely capture different aspects of engagement. It could be that Paper III's use of minutes spent on YPF as an indicator of intervention engagement better captures adolescents' actual use of specific intervention contents. In contrast, Paper II's use of weeks spent on YPF as an indicator offers no information about adolescents' actual use of specific session contents. Still, this indicator provides useful information about how long time the adolescents' spent on YPF, despite not being a significant predictor of intervention effects.

Variations in how engagement is operationalised and assessed across studies may limit the understanding of the importance of engagement in predicting the effects of interventions based on digital health technologies and may limit the generalisability of results (Molloy & Anderson, 2021). To facilitate comparisons, future studies of how adolescents' engagement relates to the effectiveness of YPF should therefore aim to consistently include identical measures of engagement. As recommended by Molloy and Anderson (2021), measures of engagement should include both objective indicators (e.g. sessions completed and the time devoted to each session) and subjective indicators (e.g. qualitative interviews regarding participants' experiences with intervention use) of user engagement to determine their effects on outcome changes.

5.2.3. Do Intervention Effects Vary by Gender?

Papers II and III offer some evidence that suggests that intervention effects varied by gender, such that adolescent boys obtained somewhat better effects from using YPF than did girls. Could this be taken to mean that boys benefit more from using YPF than girls? There is a possibility that boys on a general basis obtain better intervention effects than do girls, and this could be tied to the content of YPF. For example, the YPF sessions focus strongly on teaching adolescents how to become more confident in social contexts and how to handle social anxiety, but they offer very little content targeting adolescents' body image. In view of findings that girls' body image tends to be more vulnerable during adolescence than that of boys (Nelson et al., 2018), the gender differences reported in Paper II and Paper III could be tied to the lack of content directed at improving body image.

It is also important to note that the regression models used in Paper III are characterised by low levels of explained variance, indicating that although gender effects were present, variables that were not accounted for need to be included to improve the understanding of intervention effects. Other variables that may help to explain variations in intervention effects are adolescents' incentive to use YPF, level of parental support, previous

history of biomedical and/or psychosocial support, comorbid conditions, engagement-related factors, and perceptions of intervention design. The analyses in Paper III are also limited by the fact that, due to limitations in sample size, they do not investigate potential interactions between the predictors and dependent variables. For instance, Paper II explores only the main effect of group (i.e. whether T3 outcome scores are significantly different between the intervention group, the members of which had received YPF, and the waiting-list CAU group) and not whether the main effects varied depending on adolescents' gender. Inconsistent findings regarding gender differences in response to ICBT for anxiety have been reported in previous studies (Stjerneklar et al., 2019b; Spence et al., 2020), including a study comparing standard CBT to child-centred therapy (Silk et al., 2018). Again, in the context of adolescents who have a visible difference, more research is needed to determine if and how gender moderates the intervention effects of YPF.

5.2.4. Negative Effects

Papers II and III did not investigate whether differential effects could be found across potential subgroups, which could have introduced greater nuance into the understanding of individual variations in adolescents' response to the intervention. Hence, subgroups with positive or negative intervention effects may be hidden behind calculations of means, and complicate our understanding of intervention effects. The negative effects associated with ICBT seem to have received increasing attention in the past few years (Rozenal et al., 2014; Rozenal et al., 2017; Andersson et al., 2019). As pointed out by Gullickson et al. (2019), it is not uncommon for negative effects to appear after treatment with ICBT, which may result from lack of symptom improvement, technical difficulties with the intervention itself, problems with the intervention's content, or experiences of psychological distress due to the intervention. Uncovering potential negative effects associated with YPF is important to learning more about any negative outcomes and highlighting aspects of the intervention that could be improved, such as session contents and user experience. To establish whether certain variables (e.g. demographic or intervention-related variables) explain any adverse outcomes, it is equally important to identify potential risk factors for negative effects. Future studies undertaking this task should be careful to precisely define what they count as a negative effect, because different types of negative effects exist (e.g. an increase in symptom severity is different from an experience of novel symptoms) (Rozenal et al., 2014).

Ultimately, monitoring adolescents who use YPF for potential negative effects can facilitate early responses from healthcare professionals.

5.2.5. Parental Involvement

As discussed above in relation to the findings reported in Paper I, parents may be an invaluable source of support for adolescents' adjustment to living with a visible difference. Unfortunately, YPF does not include content tailored to parents, although parents were provided with a short document that contained information about the content of each YPF session and questions they could ask their adolescents after each session. Facilitating parent involvement during adolescents' use of YPF could possibly contribute to strengthen intervention engagement and intervention effects. For instance, parent involvement could include additional activities in YPF that require parents and adolescents to discuss and reflect on topics together. As noted by Williamson et al. (2015), some adolescents would have appreciated stronger parental familiarity with the YPF content because it would have supported their training in new coping skills. Similarly, Riobueno-Naylor et al. (2021) suggested that developing a parent-focused version of YPF would enable parents to learn and disseminate tools taught in YPF and would facilitate adolescents' engagement and learning process.

Findings from other studies with adolescent community samples offer a varied picture of the effects of involving parents in ICBT for anxiety. Stjerneklar et al. (2019b) did not find that parental support predicted intervention effects, whereas Carnes et al. (2019) concluded that standard CBT was equally as effective as CBT involving some sort of parental involvement. On the other hand, Spence et al. (2019) found that stronger support from family members predicted increased intervention engagement (as indicated by the number of sessions completed) and increased intervention effects. Other studies have also revealed that both healthcare professionals (Weineland et al., 2020) and adolescents themselves (Lenhard et al., 2016) have been supportive of the idea of involving parents during adolescents' use of ICBT. Because this dissertation does not investigate the possible effects of parental involvement during adolescents' use of YPF, researchers are encouraged to explore whether greater parental involvement influences intervention effects, and if so, how adolescents' access to parental support in YPF can be facilitated.

5.3. Methodological Considerations: Strengths and Limitations

The research conducted for this dissertation must be interpreted in relation to the strengths and limitations of the chosen methods. The methodological approach leverages many of the benefits of using both quantitative and qualitative methods to explore an under-researched area (Lund et al., 2012; Feters et al., 2013). The qualitative part of the dissertation (Paper I) offers an in-depth understanding of how parents, as adolescents' nearest caregivers, can support their adjustment to common challenges associated with having a visible difference through communication about sensitive appearance-related topics. A particular strength of the dissertation is its quantitative part, which involves an RCT that formally investigates the effectiveness of YPF (Paper II) and a closer investigation of variables that predict adolescents' intervention effects (Paper III).

5.3.1. Study Design and Data Collection

The qualitative approach of Paper I permits an in-depth exploration of parents' perceptions of communicating with their adolescents about their visible difference, which is a relatively unexplored area of visible difference research (Feragen et al., 2021; Thornton et al., 2021). The use of the telephone to conduct interviews enabled the inclusion of participants who were geographically hard to reach, and it may have given participants more confidence to disclose sensitive information (Ward et al., 2015). A possible limitation of conducting interviews by telephone was the inability to observe and respond to participants' visual cues (e.g. body language and facial expressions), which may have enhanced the richness of the data, resulted in more information about the interview context, and facilitated rapport (Novick, 2008). However, the loss of information about visual cues may not have negatively affected the research conducted for Paper I, because the absence of visual cues may result in increased focus on the interview conversation and reduce misinterpretations of facial expressions (Ward et al., 2015). Nonetheless, conducting face-to-face interviews may have increased the depth of detail in the information provided by the interviewees (Johnson et al., 2021).

A notable strength of Paper II is the RCT design, which enabled inferences to be made about the effectiveness of YPF in improving psychosocial outcomes in adolescents with a visible difference. Specifically, the design of the RCT followed a pragmatic approach, in the sense that YPF was evaluated in a setting similar to that of real-life clinical practice (Dal-Ré et al., 2018), and to promote generalisability, it ensured that the sample resembled the

population for which the intervention was intended (Williams et al., 2015). The outcome measures were selected based on their clinical relevance for the population under consideration, and participants were analysed in the group to which they were initially randomly assigned (i.e. ITT), both of which are considered key components of pragmatic RCTs (Roland & Torgerson, 1998; Williams et al., 2015). In general, RCT designs are considered essential when evaluating the effectiveness of interventions (Jones & Podolsky, 2015). Through the randomisation process, both known and unknown variables that may influence intervention effects are evenly distributed across the intervention and control groups, which ensures strong internal validity (Frieden et al., 2017). Importantly, the RCT reported in Paper II achieved sufficient power to detect statistically significant intervention effects, where $N = 189$ participants were included and randomised.

A limitation of the chosen RCT design, however, was the lack of blinding of participants and of research-team members involved in recruitment, data collection, and statistical analyses to the outcome of the randomisation (i.e. group allocation). The lack of blinding may have introduced several methodological flaws, including performance bias (knowledge of group allocation may have affected participants' thoughts and behaviour) and detection bias (inconsistent outcome assessment may have resulted from the investigator's knowledge of participants' group allocation) (Schulz & Grimes, 2002; Higgins et al., 2011). Yet, as highlighted in previous studies (Roland & Torgerson, 2002; Williams et al., 2015; Dal-Ré et al., 2018), blinding in a pragmatic RCT is not always warranted or possible. For instance, participants' uncertainty about whether they will receive the intervention may affect their intervention response in real-life clinical practice (Roland & Torgerson, 2002; Dal-Ré et al., 2018). Moreover, in Paper II, blinding participants to their group allocation would not have been possible, because those randomly assigned to the intervention group had to receive instructions on how to access and use YPF and were followed up by research-team members by telephone if needed. Hence, the pragmatic nature of the RCT in Paper II necessitated the lack of blinding.

Papers II and III are based on a longitudinal design in which data were collected at two assessment waves, namely before and after the participants had access to YPF. A strength of longitudinal data, as opposed to cross-sectional data, is the ability to estimate individual changes over time (Hedeker & Gibbons, 2006). In Paper III, the longitudinal data also enable a calculation of change scores in order to explore predictors related to intervention effects for adolescents' who had access to YPF, which would not have been possible with a cross-sectional design. The longitudinal designs used in Papers II and III are

limited by the inclusion of data from only two assessment waves. Studies with data from three or more waves allow for the use of more flexible statistical models with less restrictive assumptions, such as linear mixed models (Singer & Willett, 2003), as well as for the examination of more long-term effects. Although data were collected in four waves in the larger YPF–N project, including all the waves was not possible, because data collection was ongoing when Paper II and Paper III were finalised. Furthermore, as noted in Paper II, participants recruited for the Dutch RCT were included and merged with the Norwegian sample, which meant that only data collected at identical waves of assessment could be used.

5.3.2. Recruitment Strategies and Sample

As demonstrated by Kling et al. (2021), the recruitment of participants for the YPF–N project required extensive effort. The most successful recruitment channels proved to be targeted letters sent to the homes of eligible participants by patient organisations, hospital departments, and specialised resource centres. Recruitment via primary healthcare institutions was unsuccessful; this may have reflected the fact that healthcare professionals have a high workload, lack sufficient time, or may not feel confident in raising the subject of appearance when attempting to recruit adolescents for appearance-based research (Hamlet et al., 2017). Taken together, these results suggest that adolescents with a visible difference are a population that can be hard to reach, and they underscore the significance of resorting to specialised recruitment channels when recruiting adolescents for participation in research (Kling et al., 2021). Nonetheless, a relatively large and heterogeneous sample was still recruited, which can be considered a strength of all the research reported in the papers of this dissertation.

It is also important to emphasise that the participants in YPF–N did not have to satisfy specific cutoff criteria regarding the level of appearance-related concerns or psychosocial distress in order to be included for participation. In contrast, and as reported in Paper II, participants recruited for the Dutch RCT were screened for subclinical symptoms of low body esteem, social anxiety, and depression, and only adolescents with subclinical levels of distress were randomised. To get a clearer picture of the populations for which YPF might be suitable, recruiting a heterogeneous sample of adolescents who self-identified as having a visible difference was prioritised for the YPF–N project, which also aligns with the pragmatic evaluation of the intervention. Questions could therefore be raised as to whether some participants were motivated to participate by reasons other than need for support (e.g. to help

others by contributing to research or in response to incentives offered for the completion of outcome measures at T2, T3, and T4). Moreover, it is important to consider the findings of Paper III, which indicates that YPF may have stronger therapeutic effects for adolescents who experience higher levels of psychosocial distress related to their visible difference. Future evaluations of YPF should therefore conduct a more thorough screening for subclinical symptoms during the recruitment of participants.

5.3.3. Outcome Measures

Some considerations related to the outcome measures used in Papers II and III must be acknowledged. The BE-Appearance Subscale, SAS-A, PSQ, BILD-Q, and EQ-5D-5L were selected to provide a comprehensive picture of adolescents' psychosocial well-being and adjustment related to having a visible difference following YPF. The measures are well-known and have demonstrated good psychometric properties in use with adolescent (BE-Appearance Subscale: Mendelson et al., 2001; SAS-A: La Greca & Lopez, 1998; BILD-Q: Diedrichs et al., 2016) and adult (EQ-5D-5L: Feng et al., 2021) community samples. Furthermore, the total BESAA (Lawrence et al., 2011) and the PSQ (Lawrence et al., 2010; Crerand et al., 2020) have shown good psychometric properties in use with adolescents with a visible difference. However, the BE-Appearance subscale, SAS-A, BILD-Q, and EQ-5D-5L do not measure specific challenges known to be relevant for individuals with a visible difference. For instance, items do not make reference to a visible difference or to experiences specific to people with a visible difference when assessing respondents' appearance esteem, social anxiety levels, life disengagement, or self-rated health, which may have reduced the sensitivity of the measures in assessing these constructs in Papers II and III. On the other hand, Paper II found significant postintervention changes in social anxiety levels, which was not the case for perceived stigmatisation, even though the PSQ was developed for adolescents with a visible difference. This may indicate that the selected measures, or at least the SAS-A, are sensitive enough to detect potential intervention effects from YPF. Nonetheless, future studies are encouraged to conduct more extensive validations of the measures used in Papers II and III in populations consisting of adolescents with a visible difference.

A general challenge in appearance-related research has been a lack of both condition-specific measures (e.g. items referring to a specific type of visible difference) and cross-condition measures (e.g. items that do not distinguish between the type of visible difference) developed to assess appearance-related distress in adolescents with a visible difference (Moss

et al., 2014). However, it is also important to consider the trade-off between using condition-specific measures and using more generic measures. For instance, measures assessing specific constructs may have challenges with generalisability across different conditions, whereas generic measures may generate results that are more comparable across populations and conditions (Patrick & Deyo, 1989). On the other hand, condition-specific measures may be more sensitive to detect particular concerns attributed to a specific condition, whereas generic measures may lack this sensitivity (Patrick & Deyo, 1989). Considering that Papers II and III include participants with a wide range of conditions leading to a visible difference, a condition-specific measure may have contributed to the limited generalisability of the results.

5.3.4. Analyses

The inductive thematic analysis conducted in Paper I allowed for the identification of themes to be derived from the data itself. Choosing a deductive approach to thematic analysis would have required a preconceived coding scheme, and existing theory would have guided theme construction more extensively (Braun & Clarke, 2006). A deductive approach would perhaps also have provided a less comprehensive description of the themes inherent in the entirety of the data, because this approach focuses on specific aspects of the data (Braun & Clarke, 2006). Because knowledge about parents' experiences of communicating about appearance-related issues with their adolescents is relatively limited, it was deemed more important to conduct an inductive (data-driven) analysis and focus on identifying themes representing the entirety of the data. This approach also allowed the research question to evolve both during the coding process and as new themes were identified. It should be noted, however, that thematic analysis is not well suited to exploring aspects of language use when compared to methods such as discourse and conversation analysis (Braun & Clarke, 2006). The themes identified in Paper I therefore provide a limited understanding of parent–adolescent communication about appearance, because the themes do not consider in detail how parents' communication style and choice of words affect their adolescents (and vice versa).

As pointed out in previous debates (Yardley, 2000), a lack of standardised and unified criteria for evaluating the quality of findings produced by qualitative research can make it difficult to know which criteria should be used. This is not to say that quality criteria developed to guide evaluations of qualitative research do not exist (e.g. Lincoln & Guba, 1985; Tracy, 2010). In Paper I, particular attention is given to the ability to demonstrate the

trustworthiness of findings, and showing transparency surrounding the choices made at each step of the thematic analysis and how these may have affected construction of themes. For instance, all the steps surrounding the construction of themes, from data collection to coding, have been acknowledged and described. Moreover, to enhance the trustworthiness of the results, a summary of the findings of Paper I was sent to the YPF–N advisory group, who confirmed that the themes resonated with their members' experiences.

Turning to Paper II, some issues pertaining to intervention effects need to be considered. First, main effects were found at the T3 assessment (i.e. three-month follow-up), when the intervention group displayed lower levels of social anxiety. However, it remains unclear whether intervention effects are maintained over time, because only the data from one postintervention assessment wave (i.e. three-month follow-up) were included. Including data from the assessment conducted at T4 (i.e. six-month follow-up) would have provided an estimate of the long-term intervention effects of YPF. Although data from two assessment waves can be used to detect linear changes, the use of three or more waves is better suited to modelling changes over time and determining the course and stability of intervention effects (Singer & Willett, 2003). Thus, more studies are needed to investigate the temporal nature of intervention effects that may be obtained from completing YPF and whether these vary considerably or remain stable over time. Relatedly, Paper II investigates only main effects, without considering interactions. Potential interaction effects may have elucidated whether the main effect observed for the intervention group on levels of social anxiety at T3 varied between boys and girls and/or between participants living in Norway and the Netherlands. The fact that we do not explore possible interactions limits the overall understanding of the observed effects of YPF.

Second, there is no single way to define what counts as a clinically significant change (Jacobson et al., 1999), that is, whether an intervention makes a practical and noticeable difference in the lives of those by whom it was completed (Kazdin, 1999). In Paper II, an effect size of .50 (Cohen's *d*) is used as a benchmark to define a clinical meaningful change (Norman et al., 2003), and a partial eta squared of $\eta_p^2 = 0.06$ was obtained for the observed change in levels of social anxiety among adolescents in the intervention group at T3. According to Cohen (1988, p. 26), a medium effect size represents an effect which is visible to the naked eye. This may suggest that YPF made a clinically significant impact on adolescents' social anxiety levels. However, as previously debated (Jacobson & Truax, 1991; Kelley & Preacher, 2012; Pogrow, 2019), statistical effects and their magnitude (i.e. effect

sizes) do not necessarily equate to clinically meaningful effects, which means that a particular intervention does not necessarily make a real-world impact despite showing statistically promising results. Additionally, an effect size, or the magnitude of effects from an intervention, may be dynamic and vary across contexts and populations (Kelley & Preacher, 2012). In other words, the impact of YPF on adolescents' social anxiety levels may vary across contexts and between adolescents who have different experiences related to living with a visible difference. Hence, future studies of how YPF influences adolescents' lives should consider using one of the methods for defining a clinically meaningful change outlined by Jacobson and Truax (1991).

5.3.5. Influences of COVID-19

In part, the research conducted for this dissertation was carried out during the outbreak of the COVID-19 pandemic, which was an additional and unexpected variable that the YPF–N project was not prepared for. A major limitation of this research is that possible influences of the pandemic were not systematically controlled for due to a lack of resources and because the project had to go on. Hence, participants were recruited before, during, and after consequential events of the pandemic, such as periods of restrictions and lockdowns. Additionally, efforts of the Norwegian government to control the spread of the virus (e.g. implementing social restrictions and lockdowns) varied significantly among municipalities across the country. Hence, controlling for possible influences of the pandemic would have been extremely challenging, but it may have provided a better understanding of how the pandemic may have affected the research. It may be that the pandemic influenced participants' adherence to and engagement with YPF, because social restrictions and lockdowns may have hindered opportunities to actively practice the social skills taught by the intervention. However, because YPF is delivered and completed through a web-based platform, social restrictions and lockdowns did not impede participants' access to YPF or their opportunity to participate in the studies reported in Paper II and Paper III.

Emerging evidence suggests that adolescents' mental health was negatively impacted during the COVID-19 pandemic, and studies have found increases in symptoms of depression, anxiety, and social anxiety (Hawes et al., 2021; Panchal et al., 2021), including increased psychological distress resulting from school concerns and home confinement (Hawes et al., 2021). For some adolescents, psychosocial difficulties were exacerbated during the pandemic (Branje & Morris, 2021; Panchal et al., 2021). Although research on how the

COVID-19 pandemic has affected the lives of individuals with a visible difference is still scarce, preliminary evidence suggests that wearing face coverings may have been difficult for some because doing so provoked a feeling of identity loss (Changing Faces, 2021). In contrast, for others, the pandemic may have provided temporary relief from social pressure and social interactions (Harcourt et al., 2021). In sum, given the extensive influence of the COVID-19 pandemic on both the individual and societal levels, the pandemic remains a factor that was not controlled for and that may have introduced bias into the research conducted for this dissertation.

5.4. Implications

5.4.1. Clinical Practice

By drawing attention to the experienced benefits of open communication about appearance-related issues, the findings of Paper I brings to light the likely importance of parents' contributions to their adolescents' adjustment to their visible difference. Talking openly about such issues may help parents stay informed about their adolescents' thoughts and feelings and enable them to provide timely support through encouragement and emotional relief. Given that some adolescents may find it difficult to communicate about sensitive appearance-related topics, parents' openness to communicate may serve to promote their adolescents' motivation to engage in conversations. Conversely, some parents may feel that it is difficult to initiate conversations because they fear exacerbating appearance-related concerns or creating new problems by placing a negative focus on aspects of their adolescents' appearance. As such, healthcare professionals working with parents of adolescents with a visible difference can boost parents' confidence in initiating conversations by informing them of the benefits of communicating openly about appearance-related issues. Healthcare professionals should also consider referring adolescents to available interventions designed to support their adjustment (e.g. YPF), because such interventions may create a setting for appearance-related conversations.

Further, Paper II points to the fact that YPF may successfully support adolescents' adjustment by reducing levels of social anxiety. The primary benefits of YPF are that the content of the intervention is specifically tailored to adolescents with a visible difference and is designed to teach adolescents how to practice social skills that will help them overcome experiences with unwanted attention. The content of YPF also focuses on teaching adolescents techniques for altering negative thought patterns and setting realistic goals for

handling appearance-related anxiety. Furthermore, the web-based design of YPF makes the intervention available to all adolescents in need of support, irrespective of geographical location, and can be accessed at any time. The ease of access also mitigates barriers associated with face-to-face therapy, such as a lack of expertise with appearance-related issues, long waiting lists, the need for referrals, and the time and expense associated with travel. Because YPF is a low-level intervention, adolescents (or their parents/primary caregivers) can self-refer, thus eliminating the need to wait for referrals from healthcare professionals (e.g. a psychologist). However, healthcare professionals should also be aware that YPF was developed for adolescents who do not require intensive clinical support, although the intervention may be used as an adjunct to face-to-face therapy and could perhaps also support adolescents who have a clinically diagnosed mental condition. It is therefore recommended that healthcare professionals carefully consider whom they choose to refer to YPF. Ideally, healthcare professionals would also have time allocated to monitoring adolescents' progress and would be available to offer support upon request.

The findings of Paper III are a reminder that although YPF may positively impact adolescents' adjustment, the intervention may not benefit all adolescents equally. Those who experience greater psychosocial distress, especially in the form of self-reported teasing about appearance and depressive and/or anxiety symptoms, may benefit from increased intervention effects. This may also be the case for adolescents who devote more minutes to the YPF intervention sessions, because increased engagement may facilitate more stable therapeutic effects. In the process of referring adolescents to YPF, healthcare professionals are therefore encouraged to conduct a screening to assess the degree of psychosocial distress and to encourage adolescents to engage as much as possible with the intervention. Importantly, the findings also suggest that intervention effects attributable to YPF may vary between boys and girls; that is, boys may to some degree benefit from increased intervention effects. However, more studies are needed to establish how and to what extent intervention effects of YPF vary by gender.

5.4.2. Future Directions

Several important issues that are not investigated in this dissertation should be addressed in future studies. For instance, more knowledge is needed to understand how the quality of adolescents' relationships with their parents affects parent-adolescent communication (e.g. perceived parental openness to discussing appearance-related issues).

Because only parents were interviewed for Paper I, interviews could be conducted with parent–adolescent dyads to explore the shared experiences of having conversations about appearance-related topics. Such interviews could also explore parents’ and adolescents’ perceptions of how their relationship influences conversations. Given parents’ main caregiving role, future studies should examine how parents who find it difficult to discuss appearance-related issues with their adolescents could be supported to be more confident to engage in conversations.

Future studies should also give special attention to the fact that the research conducted in Papers II and III explores only the short-term effects of YPF. That is, it uses only data from assessments conducted at baseline and the three-month follow-up. It may be that adolescents need to practice the skills taught by YPF for a longer period in order for intervention effects to appear. Hence, more research is needed to identify the potential immediate and long-term intervention effects of YPF. This could be explored with data from assessments conducted immediately after participants complete the seventh YPF session and three to six months after completion of the eighth session. A more comprehensive picture of whether intervention effects from YPF decrease or are maintained over time could then be established.

Importantly, the research conducted for Papers II and III does not substantiate the existence of negative effects of YPF. As a previous study highlighted, it is not uncommon for negative effects to appear as a result of treatment with ICBT (Gullickson et al., 2019). Future studies should therefore investigate whether certain subgroups of adolescents experience negative effects as a result of completing YPF, and healthcare professionals in charge of referring adolescents could consider monitoring them for negative effects. Semi-structured interviews conducted before and after adolescents’ access to YPF may offer complementary information about their experiences of using YPF and possibly spotlight aspects of the intervention that could be improved. Such interviews have been conducted as part of the YPF–N project.

Finally, Paper III provide early evidence that adolescents who experience higher levels of psychosocial distress before receiving access to YPF and who spend more minutes on YPF may obtain stronger intervention effects. However, these results are preliminary. More research is required to support this claim, and studies should ideally investigate the role of other variables that may influence intervention effects, including adolescents’ body esteem, initial motivation to complete YPF, and previous history with psychosocial support. Research also need to explore whether the development of a parent-specific version of YPF or another type of parental involvement during adolescents’ use of YPF promote increased intervention effects. Investigating the issues raised in this section would represent the next

step towards a better understanding of how YPF could benefit adolescents' adjustment to living with a visible difference.

6. Conclusions

This dissertation advances the understanding of how adolescents' adjustment to living with a visible difference can be supported. The findings indicate that parents' openness to communicate about appearance-related issues may enable them to offer timely support that provides adolescents with the opportunity to express difficult thoughts and feelings. For some parents, however, considering the time and context before raising the subject of appearance may help them initiate conversations, because some may worry that they will further distress their adolescents by talking about issues related to their visible difference. Hence, parental support may be indicated and needed by some. Further, the findings highlight the benefit of offering web-based support based on SST and CBT techniques to adolescents who experience psychosocial challenges related to their visible difference. YPF has the potential to reduce social anxiety levels, and help adolescents increase their range of social coping skills and anxiety-management techniques. YPF also counteracts barriers traditionally associated with face-to-face therapy, including lack of specialised support, geographical distance, long waiting lists, and strict criteria for referral.

Another central conclusion of this dissertation is that adolescents who experience increased levels of psychosocial distress and devote more minutes to YPF sessions may benefit from increased intervention effects. The analyses also suggest that boys may benefit from increased intervention effects compared with girls, but more research is needed to clarify whether and to what extent gender and other variables, such as adolescents' motivation, influence intervention effects. The development of a parent-specific version of YPF may potentially facilitate parent–adolescent conversations about appearance-related issues and adolescents' engagement with intervention content, which may in turn strengthen intervention effects. In sum, the knowledge produced by this dissertation moves the field of appearance psychology one step closer to understanding how the role of parents and web-based psychosocial support may promote adolescents' adjustment to challenges associated with having a visible difference. Hopefully, this knowledge will benefit adolescents in need of support, their parents, and healthcare professionals who wish to help adolescents strengthen their adjustment.

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**Appendix 1: Interview guide for Parents of Adolescents
Randomised to the waiting-list CAU group**

INTERVJUGUIDE – FORELDRE – KONTROLL

INNLEDNING:

Etter 3 måneder: På vegne av hele prosjektteamet vil vi si tusen takk for at dere deltar i studien vår og for at du tar deg tid til dette intervjuet. Samtalen vil antakelig vare i ca. 30 minutter. Hvis du ikke ønsker å svare på et spørsmål eller ikke ønsker å fortsette intervjuet så er det helt i orden, gi meg i så fall beskjed. Samtalen blir tatt opp, slik at den kan skrives ned i etterkant. Materialet fra dette intervjuet blir anonymisert og det er bare den fagpersonen som skal skrive ned intervjuet som vil høre det i etterkant. Hvis du trenger pause under intervjuet er det bare å si ifra. Har du noen spørsmål før vi begynner?

GENERELLE SPØRSMÅL OM DELTAKELSEN I PROSJEKTET:

ETTER 3 MÅNEDER (PRE INTERVENSJON)

- Vi ønsker å høre hva du syns om
 - *Informasjonen som ble gitt fra oss (brevene/informasjon)? Kan vi forbedre disse på en eller annen måte? **Hvis ja**, hvordan?*
 - *Dersom du så en plakat/brosjyre, hva syns du om disse?*
 - *Har du forslag til hva vi kunne gjort annerledes for å forbedre måten vi når barn/ungdom og deres foresatte til en slik studie som vår?*
- Dersom din sønn/datter bekymrer seg for utseendet, har dere fått annen informasjon eller støtte fra hjelpeapparatet utenom Ung Face IT?
 - *Hva syns dere om støtten eller rådene dere fikk? Var det til hjelp? **Hvis ja**, hvorfor? **Hvis ikke**, hva kunne blitt gjort annerledes?*

FORELDRENES TANKER OM BARNETS UTSEENDE:

ETTER 3 MÅNEDER

- Hva tror du at din sønn/datter tenker om sitt eget utseende?
- Har dere opplevd at dette med utseendet har vært et problem for ham/henne?
- Tenker dere at dette med utseendet har påvirket hans/hennes sosiale erfaringer?
- Tenker dere at dette har endret seg på en eller annen måte de siste månedene?
- Vet du om han/hun har opplevd en eller flere situasjoner relatert til utseendet i løpet av de tre siste månedene som har vært vanskelig å håndtere?
 - *Diskuterte dere situasjonen med han/hun i etterkant?*
 - *Hvordan opplever du at han/hun håndterer slike situasjoner?*
- Hvordan er det for deg som mor/far å snakke om utseendet med din sønn/datter?
- Hvordan tenker du det er for din sønn/datter å snakke om utseendet med dere som foreldre?

AVSLUTTENDE ORD:

Etter 3 måneder: Det var alle spørsmålene vi hadde. Er det noe du ønsker å tilføye?

Tusen takk for at du ville svare på alle spørsmålene; deres deltakelse i studien vil bidra til at ungdommer med diagnoser som påvirker utseendet vil få et bedre hjelpetilbud i fremtiden.

Hvis du kommer på noe eller skulle ha spørsmål er det bare å kontakte meg eller Kristin Feragen som er prosjektleder. Jeg minner også om at det kan hende dere blir kontaktet på nytt for et nytt, men kortere intervju om 3 måneder.

**Appendix 2: Interview guide for Parents of Adolescents
Randomised to the Intervention Group**

INTERVJUGUIDE – FORELDRE – INTERVENSJON

INNLEDNING:

Etter 3 måneder: På vegne av hele prosjektteamet vil vi si tusen takk for at dere deltar i studien vår og for at du tar deg tid til dette intervjuet. Jeg regner med at samtalen vil vare i ca. 30 minutter. Hvis du ikke ønsker å svare på et spørsmål eller ikke ønsker å fortsette intervjuet så er det helt i orden, gi meg i så fall beskjed. Samtalen tatt opp på bånd og deretter skrevet ned i tekst. Materialet fra dette intervjuet blir anonymisert og det er bare den fagpersonen i prosjektgruppa som skal skrive ned intervjuet som vil høre det. Hvis du trenger pause under intervjuet er det bare å si ifra. Har du noen spørsmål før vi begynner?

DELTAKELSE I PROSJEKTET OG ARBEIDET MED UNG FACE IT:

ETTER 3 MÅNEDER

Vi vil gjerne høre hva dere tenker om at barnet deres har vært med i prosjektet og fått jobbet med Ung Face IT

- Hva er hovedgrunnen til at dere ønsket å delta i prosjektet?

- Var det dere foresatte eller han/hun som først tok initiativ til deltakelse i prosjektet?
 - *Hva tror dere han/hun syns om programmet?*
 - *Diskuterte eller fortalte han/hun om programmet eller aktivitetene han/hun gikk gjennom med dere eller med noen andre? Hvis ja, hva diskuterte de?*
 - *(Sjekk før intervjuet om informantene har fullført alle kapitler). Hvis ikke, hvordan kunne vi bedre ha motivert han/hun til å gjennomføre Ung Face IT?*
 - *Hadde han/hun noen vanskeligheter med programmet? Hvis ja, hva?*

- Hjalp dere han/hun med å komme seg gjennom Ung Face IT?
 - *Hvis ja, hva slags hjelp og hvordan?*

- Øvde han/hun på noen av aktivitetene med dere? **Hvis ja**, hvilke aktiviteter dreide det seg om?
- Tenker dere at Ung Face IT hjalp ham/henne?
 - *Kan du si noe mer om det? (Hvis ja, hvordan? Hvis nei, hvorfor?)*
- Vet du om han/hun har opplevd situasjoner relatert til utseendet i løpet av de siste tre månedene som han/hun syns var vanskelig å håndtere?
 - *Diskuterte dere situasjonen med ham/henne i etterkant?*
 - *Vet du om han/hun brukte noen av teknikkene som ble presentert i programmet for å håndtere situasjonen?*
 - *Er dere noe annet dere ønsker å si om Ung Face IT?*
- Hva syns dere om skrivet med retningslinjer som dere foresatte fikk?
 - *Hva fungerte støttende og hva kan forbedres?*
 - *Følte dere som foresatte at dere kunne støtte ungdommen? Har du noen tanker om hvordan vi bedre kunne involvert dere foreldre?*
 - *Vi ønsker å høre mer om hva dere som foresatte syns om informasjonen som ble gitt fra oss (brevene/informasjon)? Kan vi forbedre disse på en eller annen måte? Hvis ja, hvordan?*
 - *Dersom du så en plakat/brosjyre, hva syns du om disse?*

FORELDRENES TANKER OM BARNETS UTSEENDE:

ETTER 3 MÅNEDER

- Hva tror du at din sønn/datter tenker om sitt eget utseende?
- Har dere opplevd at dette med utseendet har vært et problem for ham/henne?
- Tenker dere at dette med utseendet har påvirket hans/hennes sosiale erfaringer?
- Tenker dere at dette har endret seg på en eller annen måte de siste månedene?

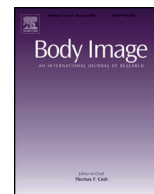
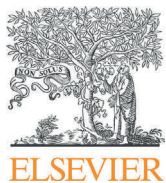
- Hvordan er det for deg som mor/far å snakke om utseendet med din sønn/datter?
- Hvordan tenker du det er for din sønn/datter å snakke om utseendet med dere som foreldre?

AVSLUTTENDE ORD:

Etter 3 måneder: Det var alle spørsmålene vi hadde. Er det noe du ønsker å tilføye?

Tusen takk for at du ville svare på alle spørsmålene; deres deltakelse i studien vil bidra til at ungdommer med diagnoser som påvirker utseendet vil få et bedre hjelpetilbud i fremtiden. Hvis du kommer på noe eller skulle ha spørsmål er det bare å kontakte meg eller Kristin Feragen som er prosjektleder. Jeg minner også om at det kan hende dere blir kontaktet på nytt for et nytt, men kortere intervju om 3 måneder.

Papers I–III



“It’s tough because I see that it’s upsetting her. . .”: A qualitative exploration of parents’ perceptions of talking with their adolescents about having a visible difference

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ABSTRACT

Many adolescents live with a visible difference that affects their lives in profound ways, but studies investigating parents’ perceptions of raising appearance issues during conversations with their adolescent are lacking. As part of a larger study exploring the effectiveness of a web-based intervention (YP Face IT), semi-structured interviews were conducted with 18 parents of adolescents with a visible difference. Thematic analysis revealed four overarching themes: (1) *Conversational settings*; (2) *Understanding adolescents’ feelings and thoughts*; (3) *Providing parental guidance and encouragement*; and (4) *When the dialogue becomes difficult*. Results showed that parents resorted to specific settings when instigating conversations about appearance, such as when their adolescents expressed a need for emotional care, were perceived to be upset, or whilst managing their condition. The choice of setting was also important as some parents generally felt uncomfortable raising appearance issues with their adolescent, for fear of fueling appearance concerns. Results further suggest that open communication can enable parents to stay informed about their adolescent’s psychosocial adjustment to a visible difference. These results stress the need to make available support to facilitate open communication about appearance-related topics between parents and adolescents.

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1. Introduction

Multiple conditions, injuries and treatment side effects can affect an individual’s appearance. For example, some acquire a visible difference as a result of an accidental injury (e.g. burn), a skin condition (e.g. psoriasis), or medical intervention (e.g. chemotherapy). Others are born with a visible difference, including those with a craniofacial condition (e.g. cleft lip and palate) or a missing limb (Rumsey & Hamlet, 2017). Living with a noticeable visible difference that is not “culturally sanctioned” (Kent & Thompson, 2002, p.103), can be particularly challenging for adolescents in societies where appearance is highly valued (Bradbury, 2012; Rumsey & Harcourt, 2012).

The exact number of adolescents living with a visible difference is unknown, however, estimates from the UK suggests that around one in 44 adolescents have a visible difference located on their face or body (Changing Faces, 2010). Research and clinical experience suggests that these adolescents may experience a range of

social challenges that can be psychologically demanding, such as teasing and bullying from peers (Van Geel et al., 2014; Feragen & Stock, 2016), being stared at by others (Tiemens et al., 2013), or name-calling and impersonation (Carroll & Shute, 2005). Children and adolescents who are visibly different may also be perceived more negatively by their peers and rated as less attractive (Masnari et al., 2013; Jacobs et al., 2020). Fear of being negatively evaluated by potential romantic partners may also deter adolescents from engaging in romantic relationships, a key developmental task and potential source of self-esteem (Griffiths et al., 2012). Given the many social challenges and potentially stigmatising experiences, it is not surprising that anxiety levels may be more elevated in adolescents with a condition that affects their appearance (van Dalen et al., 2020).

Adolescence is a time when young people usually start to form their own identities (Erikson, 1968). Identity development is typically related to relationships with family members, especially parents (Crocetti et al., 2017). During this stage, developing secure attachments and forming and maintaining stable social relationships with, for example, parents and peers, can also positively impact psychosocial functioning (Bowlby, 1973) and in particular the development of self-esteem (Harris & Orth, 2019). Self-esteem may be especially important during adolescence, because of its

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crucial impact on adolescents' lives and well-being, (e.g. through its influence on the quality and size of adolescents' social support networks) (Marshall et al., 2014), and its close relation with, and prediction of, depression and anxiety (Sowislo & Orth, 2013).

Satisfaction with appearance seems to be a key contributor to levels of self-esteem, with previous studies (DuBois et al., 2000; Barker & Bornstein, 2010) suggesting that appearance dissatisfaction predicts lower self-esteem among adolescents. For example, the longitudinal study by Barker and Bornstein (2010) found that 10-year-olds who were less satisfied with their appearance reported declines in self-esteem aged 14. Adolescence is also a time when appearance ideals are especially high and unrealistic (Thompson et al., 2017) and when appearance criticism from peers is ubiquitous. Appearance conversations with peers can influence how individuals view their appearance, with adolescents being particularly susceptible to negative appearance-related comments (Jones et al., 2004).

Given that looking different can constitute an extra psychological burden for some adolescents, receiving relevant support, including emotionally supportive conversations with parents/carers, is therefore important (Keating et al., 2013; Middleton et al., 2018). However, although evidence suggests that family conversations about appearance more generally (e.g. about interchangeable appearance aspects such as clothes and hairstyle) are not typically challenging for adolescents without a congenital or acquired visible difference (Frisén & Holmqvist, 2010), discussing experiences associated with having a visible difference may be more challenging. Adolescents with an "undesirable" aspect to their appearance may avoid drawing attention to, talking about, or disclosing their difference to others for fear of being negatively evaluated or ridiculed (Griffiths et al., 2012), or because others minimise or fail to understand the impact of their visible difference on their lives (Williamson & Rumsey, 2017; Rasmussen et al., 2018). Responsibility to initiate supportive appearance-related conversations is therefore likely to rest with parents/carers. However, as children transition into adolescence and demand greater autonomy and more privacy from their parents (Hawk et al., 2013), communication patterns also shift and adolescents typically disclose less information about their activities and whereabouts (Padilla-Walker et al., 2018). Although parents may have to adjust to changes in communication routines during this developmental phase, promoting a culture of open communication within the family seems to have important implications for adolescents' psychosocial adjustment (Xiao et al., 2011).

Little is known about parents' perceptions of talking with their adolescents about their visible difference, although there is some evidence to suggest that parental support can focus on the facilitation of practical coping strategies, for example by advising on how to answer appearance questions from peers (Klein et al., 2006). In general, previous studies have mainly investigated parents' experiences of having and parenting a child or adolescent with a visible difference (Klein et al., 2010; Nelson et al., 2012; Leemreis et al., 2014; Moss et al., 2020). Results suggest that parents have worries and concerns related to the visibility of their child's or adolescent's condition (Leemreis et al., 2014), and how peers and other peoples' perceptions could affect their adolescent's self-esteem and confidence (Klein et al., 2010). Parents also go through their own phase of emotional experiences related to the social consequences of having a child or adolescent with a visible condition (Nelson et al., 2012). They may find it difficult to raise appearance-related issues, feel insecure about how and when to address such issues, and which words to use (Thornton et al., 2021). Evidence also suggests that health professionals, who may also play significant roles in the lives of adolescents with a visible difference, have similar concerns (Hamlet et al., 2017; Williamson & Rumsey, 2017; Gee et al., 2019). Due to a lack of knowledge about the psychosocial impact of living

with a visible difference and fear of causing harm by raising sensitive questions, many lack confidence in engaging adolescents in conversations about their visible difference within clinical settings. The subject is also often avoided, which can constitute a significant barrier to addressing appearance concerns (Hamlet et al., 2017; Williamson & Rumsey, 2017; Gee et al., 2019).

As parents in main care-giving roles are often a significant source of support, it is essential to gain a better understanding of their experiences of raising and discussing appearance issues with their adolescents and factors that facilitate or hinder this dialogue. Knowledge about parental experiences may shed light on unmet support needs and provide guidance to social workers and health-care professionals on how to support parents who may struggle to discuss appearance with their adolescent, and educate parents about the potential perceived benefits of such conversations.

1.1. Aim

The aim of the current study was to conduct an in-depth exploration of parents' perceptions of talking with their adolescent about appearance and their visible difference. This aim is encapsulated in the following research question: *How do parents experience communicating about appearance issues with adolescents who have a visible difference?*

2. Methods

2.1. Ethical considerations

Ethical approval was given for the study from the Regional Committee for Medical Research Ethics (Health Region South-East, reference number: 2015/2440) and accepted by the Data Protection Office based at Oslo University Hospital. All participants provided a signed consent form before enrolment. In order to preserve anonymity, pseudonyms were given to participants when using direct extracts and quotes. Furthermore, when referring to adolescent characteristics such as age and condition, only broad categories are provided (e.g. craniofacial condition, age 14–16 years).

2.2. Research team

The research team consisted of four members with similar professional backgrounds, three of whom have experience of conducting research in appearance and body image. The first author is a PhD candidate with a master's degree in educational-psychological counselling and one year of professional counselling experience. The first author has experience of publishing qualitative research and underwent qualitative research training as part of a PhD programme in psychology. The second author is a health psychologist with extensive experience of conducting visible difference research with young people and their families. The third author is a licenced clinical psychologist with a PhD in developmental psychology and experience of conducting body image research with adolescents. The last author is also a licenced clinical psychologist and expert in appearance research on congenital craniofacial differences. The first and last authors designed the aim of the present study, in close collaboration with the second author.

2.3. Study design

A critical realist approach based on the philosophy of Bhaskar (1975) underpinned the study design and interpretation of research results. This approach assumes that an external and objective world exists independently from our perceptions (Sayer, 2000, p. 7), yet acknowledges the meaning of individuals' subjective understandings and interpretations (Wynn & Williams, 2012). Importantly,

critical realism asserts that this authentic, but socially influenced, reality can be accessed via research in order to bring about progressive change (Houston, 2001). A critical realist approach is therefore compatible with the aims of this research; to gain a practically useful insight into the personal experiences of parents as well as the social mechanisms that influence their lives and perceptions, with the overall objective of identifying any unmet needs.

Given the limited evidence base, and in line with a critical realist approach, a qualitative exploratory approach using semi-structured interviews was utilised (Green, & Thorogood, 2018). Semi-structured interviews provided a basis for a systematic exploration of topics using pre-set open-ended questions (DiCicco-Bloom & Crabtree, 2006), which remained focused on the key topic whilst allowing for participant-led exploration.

The study was conducted at the Centre for Rare Disorders, Rikshospitalet, Oslo University Hospital, Norway, as part of an ongoing larger mixed methods study and randomised control trial (RCT) in Norway to assess the effectiveness of the Norwegian version of a web-based psychosocial intervention for adolescents with a visible difference aged 12–17, Young Person's Face IT Norway (YP Face IT-N). Adolescents were informed about the YP Face IT-N trial via direct invitations sent from specialised medical treatment teams (e.g. craniofacial) and advertisements in local health care settings and via patient organisations or social media. Those who were interested and eligible for inclusion provided informed consent. As part of the RCT (Trial registration number: NCT03165331) design, participating adolescents and one of their parents were invited for interviews three and six months from baseline to provide qualitative feedback on their experiences of the study.

2.4. Recruitment and participants

The majority of participants in this study were parents of adolescents who were enrolled in the YP Face IT-N RCT between October 2019 and February 2020. During this period $n = 15$ parents were invited to take part in the current study and all 15 accepted. At the time of the interviews, adolescents had been in the trial for 3 months, nine were in the intervention group and had completed YP Face IT-N, and six were in the control group and had not completed the intervention.

In addition, the research team extended recruitment to parents of adolescents who had declined to participate in the RCT. This decision was prompted by a request from a mother of an adolescent who had received, and declined, a direct invitation to join the RCT. This parent wanted to share her thoughts regarding the impact of this invitation on communication about appearance within her family. The team decided that diversifying the sample, by including parents of adolescents who chose not to engage in the RCT, could potentially add depth to the data and greater understanding of the topic under investigation. The YP Face IT-N trial advisory group, which consists of 15 parents of children and adolescents with visible differences and representing different patient organisations related to diverse conditions leading to a visible difference, therefore agreed to disseminate a further invitation to parents of adolescents not participating in the study. Our intention was to give parents the opportunity to share their experiences of talking about appearance-related topics with their adolescents, whether their adolescent was part of the study or not. Three parents of non-participating adolescents were recruited.

The final sample included 18 parents (three fathers and 15 mothers). Adolescents were eight males and ten females with a range of different appearance-altering conditions, such as missing limbs and craniofacial (e.g. cleft lip and palate) and skin conditions (e.g. ichthyosis). Differences in parental experiences as a result of their adolescent's allocation to either intervention and control groups, or non-participation in the trial, were considered. Notably,

to facilitate adolescent engagement with YP Face IT-N, parents of adolescents in the intervention group were provided with a short document including questions they could ask their adolescent after each YP Face IT-N session. As this document did not include content on parental support skills or how to improve parent-adolescent interactions and/or communication, parents of adolescents in both groups were included. Nonetheless, consideration of adolescents' experiences in relation to the YP Face IT-N RCT was considered during the analysis of parent data.

2.5. Data collection

Semi-structured in-depth interviews were conducted via telephone and lasted on average 35 minutes (range: 17–56 minutes). Telephone interviews were chosen in order to increase geographical reach. Most interviews were performed by the first author ($n = 11$), two by a research assistant, and five by the last author.

A semi-structured interview guide was used. Parents of adolescents in the intervention group were asked additional questions concerning the intervention. The interview guide was originally developed by Dr. Heidi Williamson, who also developed the original English version of YP Face IT (Williamson et al., 2016). The interview guide was translated into Norwegian by the first author. Questions explored parents' perceptions of their adolescents' experiences with having a visible difference, including questions such as: "What do you think your son/daughter thinks about his/her appearance?", "Have you experienced that appearance is a problem for your son/daughter?", "Do you think that your adolescent's appearance has influenced his/her social experiences?" and "Do you know whether he/she has experienced any challenging situations related to his/her visible difference for the last three months that were difficult to manage?".

For the purpose of the present study, two open questions were added in the Norwegian version before initiating data collection, to more specifically explore parents' perceptions of appearance-related conversations: "How do you, as a father/mother, feel about talking about appearance with your son/daughter?" and "What do you believe your son/daughter feels when talking about appearance with you as a parent?"

Questions were followed-up by a range of probes, with the purpose of gathering more information about how parents perceived appearance conversations to unfold, how they believed such conversations affected the adolescent, and potential barriers or facilitators hindering the appearance dialogue. Examples of follow-up questions were: "How often do you have conversations with your son/daughter about his/her appearance?", "What do you think is the reason for not talking about appearance-related topics with your son/daughter?" and "Do you have any examples of appearance-related situations that you could talk with your son/daughter about?". No changes were made to the interview guide as data collection progressed.

2.6. Data analysis

An inductive, data driven approach to thematic analysis was chosen based on the six phases outlined by Braun & Clarke (2006), and themes were constructed through identified patterns in the data. The first phase in the analytic procedure involved transcribing the interviews verbatim (15 interviews were transcribed by the first author and three by a research assistant). All transcriptions were read several times and data was extracted from the full interviews. The first and last author highlighted excerpts containing information about conversations or lack of conversations between parents and adolescents. Excerpts about parents' perceptions regarding their child's experience of living with a visible difference or experiences with participating in the YP Face IT-N RCT were excluded,

Table 1

Overview of overarching themes, subthemes, example codes and number of parents represented in the subgroups (i.e. intervention, control or non-participating).

Overarching theme	Subtheme	Example codes	Subgroups: Intervention, Control, Non-participating
Theme 1: Conversational settings	Finding the right occasions to raise appearance issues	Safe context (need for care)	9/9; 5/6; 1/3
	Young Person's Face IT: enabling conversations	Basis for conversation (YP Face IT)	5/9; 2/6; 1/3
Theme 2: Understanding adolescents' feelings and thoughts	Being different	Feeling different, otherness	8/9; 6/6; 3/3
	Treatment-related talks	A wish for corrective surgery	5/9; 1/6; 2/3
Theme 3: Providing parental guidance and encouragement	Dealing with difficult situations	Unwanted comments at school	2/9; 4/6; 1/3
		Encouragement and support	5/9; 2/6; 2/3
		Creating a sense of accomplishment	
Theme 4: When the dialogue becomes difficult	Parents' feelings when engaging in appearance talk	Tough when appearance becomes a subject	9/9; 6/6; 3/3
	Reflecting on conversational boundaries	Adolescent's openness to talk	8/9; 3/6; 3/3

unless they contained relevant information about potential conversations. The first author then coded the data on a semantic level (i.e. writing descriptive words or phrases adjacent to associated excerpts from the transcripts). The first five interviews were coded in tandem with the last author. Disagreements during the analysis process were discussed and resolved between the first and last author. Specifically, this was done by systematically going through all coding for the first five interviews until agreement on the level of coding was reached. This process ensured consistent coding. After the material had been coded, the first author categorised codes into broader units on a latent level (i.e. interpreting emerging patterns and categories). Thematically related codes were grouped into categories and were identified as candidate subthemes. Subthemes were checked for thematic similarities and grouped into overarching themes. Codes, subthemes, and overarching themes were generated iteratively and continuously compared back to the initial codes and excerpts. This analysis generated four overarching themes and seven subthemes that were clearly defined and named (see Table 1). Finally, the analysis was formed into a coherent story with distinct names for overarching themes and subthemes, supported by evidence from data extracts. Overarching themes and associated subthemes are illustrated with excerpts from the transcripts. In order to increase transparency, the number of parents describing a particular phenomenon is provided in the results section, with the purpose of precisely characterising the diversity of perceptions among parents and the amount of evidence that supports a particular theme (Maxwell, 2010).

After initial theme construction, all transcripts were re-read with the intention of searching for potentially new information related to parents' experiences of communicating about appearance issues with their adolescents that could inform the themes. No new information was discovered and, considering the review of all transcripts and the study's exploration of a relatively unexplored area, it was determined that the 18 parents provided enough information about the topic under investigation.

To enhance the trustworthiness of the study (Tracy, 2010), a summary of the study findings was sent to the YP Face IT-N RCT advisory group, for their review and to check that the analysis resonated with their members' experiences. The advisory group provided feedback that was accordant with the themes identified.

3. Results

Four overarching themes and seven subthemes were constructed from the inductive thematic analysis (see Table 1).

The themes describe how and under what circumstances parents engage in conversations with their adolescent about different

topics related to appearance and experiences in daily life. The themes also illustrate how parents experience this communication. Table 1 includes the proportion of parents from each of the three subgroups (who had adolescents in the intervention group, control group, or non-participating adolescents).

All parents were asked how often appearance-related conversations were taking place with their adolescent. Eight of the 18 parents reported that conversations happened frequently, often when the adolescent experienced a difficult situation. Eight of the 18 parents described having less frequent conversations, also often prompted by the adolescent's experiences, whereas two parents described not talking about appearance-related topics with their adolescent at all.

3.1. Conversational settings

This theme captures the parents' experiences of the different settings and circumstances in which conversations about appearance-related topics occurred with their adolescents. This theme was present in all three subgroups.

3.1.1. Finding the right occasions to raise appearance issues

Ten of the 18 parents explicitly described settings in which conversations occurred. Although parents acknowledged the ideal setting to raise appearance issues did not exist, having enough time and being in the right context, such as when relaxing on the couch in the evening, was deemed important: "...you kind of have to have a nice setting. . .it opens up the possibility to bring up such [appearance-related] themes" (Lisa, son, 12-14 years, skin condition). Other appropriate settings could arise if the adolescents expressed a need for emotional care, when managing or discussing the adolescents' condition, or when discussing future treatment options.

Of the parents who mentioned the conversational settings they used when raising appearance issues, three parents (all from the intervention group) expressed that conversations occurred "naturally", when and if a topic arose that could be discussed further. These parents had the impression that it was important for them not to raise the topic of appearance "out of the blue". They elaborated this as a need to feel "right" about raising the issue, because they were aware that talking about appearance could potentially affect their adolescent's current mood by evoking negative thoughts and feelings. For example, one of the fathers described how he might tentatively attempt to engage in appearance talk if he noticed that his daughter's condition caused physical discomfort:

When we see that she struggles, [then we ask] are you in [physical] pain?', [that's when] it becomes a topic and then we just try

in a humble way to start a dialogue and see whether she is interested in talking about it. So, we don't force [the conversation]. . . (Ethan, daughter, 12-14 years, bone condition)

When discussing who initiates appearance conversations, parents had different experiences. Some had adolescents who instigated conversations, whereas other parents felt they had to raise the subject themselves:

. . . She [the adolescent] only answers my questions and says that everything is ok, and maybe she doesn't have any need to talk about it with us. . . I have thought for myself that if she did have a need [to talk] she would have initiated conversations herself. . . (Emma, daughter, 15-17 years, skin condition)

Other opportunities to talk about appearance were also described. In all three subgroups (12 of 18 parents in total), there were descriptions of how the parents monitored their adolescent's behaviours or feelings, looking for evidence of distress, and carefully judging when to intervene and initiate appearance conversations. For instance, Christina (daughter, 14-16 years, craniofacial condition) said: ". . . if she is a little bit angry (. . .) if I observe it early enough, then I can go up and talk to her. . ." Thus, the adolescent's body language, behaviours, and emotional state were described as important signals for the parents in terms of reaching out and approaching them for a conversation.

3.1.2. *Young Person's Face IT: enabling conversations*

Eight of the 18 parents reported that their adolescent's experience of the YP Face IT-N project created a starting point for conversations about appearance. One of the mothers of an adolescent from the intervention group expressed how her daughter's interest in talking about her appearance increased with participation in the project: ". . . [The adolescent benefited from] being heard and actually have an interest in talking about it. Because usually, we don't talk that much with [her] about this" (Natalie, daughter, 14-16 years, craniofacial condition). Another mother described that her daughter had mentioned that completing YP Face IT had helped her become more analytical about her own reactions and strategies in past situations: ". . . she has seen for herself that 'I reacted in this way there'. . . a little bit like that, her experiences, she has understood herself and situations a bit more. She has specifically talked to me about this. . ." (Meryl, daughter, 13-15 years, craniofacial condition). Completing YP Face IT also generated conversations about the adolescents' own experiences:

He was working with the project [YP Face IT] yesterday, started with it, and then he said 'Mom, come and look', and then he said that some people say they think adults shouldn't stare, that they should know better. I replied 'Yeah, don't you feel the same way?', 'No, people should be allowed to stare if they want to, I too can stare sometimes'. (Cecilia, son, 12-14 years, craniofacial condition)

In contrast, one mother described how her daughter reacted negatively after receiving an invitation letter to participate in the YP Face IT-N project: ". . . it was impossible for me to talk sensibly with her afterwards [after opening the invitation letter] about participation in the study, or discussing getting some help around this. . . because this [appearance] is so vulnerable for her, it just became so difficult" (Sophie, daughter, 13-14 years, craniofacial condition).

3.2. *Understanding adolescents' feelings and thoughts*

This theme illustrates parents' experiences of how conversations enabled them to better comprehend their adolescent's feelings, thoughts, and adjustment to having a visible difference.

Parents from all three subgroups were similarly represented in this theme and its subthemes.

3.2.1. *Being different*

Sixteen of the 18 parents described that their adolescents often expressed feelings about having a visible difference during conversations. This is exemplified by a mother who recounted a conversation where her son shared his thoughts about his appearance: ". . . when I have asked him earlier, he tells me that he is ashamed of his [body part]" (Lisa, son, 12-14 years, skin condition). One topic that was particularly present and described by eight of the 18 parents was their adolescent's disclosure of feeling different: ". . . she doesn't want to be any different than others" (Jane, daughter, 12-14 years, craniofacial condition). One of the mothers described how conversations had revealed a developmental change in her daughter's feelings about being visibly different. When younger, her daughter shared how proud and special she felt because of her difference. When older and in response to negative reactions from other children to her difference, she shared her shift in perspective with her mother:

. . . she came home one day and said, 'You know what mom? When the other kids ask me if they can see [body part] (. . .), I don't want to [show them] anymore, because now they just tell me 'ugh'. So, from then on it was that thing about being different (. . .) So from that time, she began to hide that she was [different and] had a prosthesis. (Linda, daughter, 12-14 years, skin condition)

3.2.2. *Treatment-related talks*

Eight of the 18 parents recounted conversations with their adolescents about treatment-related issues, such as reconstructive surgery or other surgical interventions, which in turn gave parents a clearer picture of how their adolescent felt about their appearance and/or condition, and future treatment: ". . . she is going to ask for a [surgical] correction on her [body part]. She has said that she looks forward to getting it done" (Natalie, daughter, 14-16 years, craniofacial condition). Another mother described how conversations could also provide an opportunity to discuss treatment options, and potentially help the adolescent reflect upon such issues:

. . . when she asked whether it was possible to 3D-print an [body part], then we could talk about the possibility that this would turn out to be fine and very good in the future, one cannot know now, because new research is [bringing improvements] all the time. We can talk about it like that. . . (Jane, daughter, 12-14 years, craniofacial condition)

Hence, the parents described that treatment-related conversations helped them to better understand their adolescent's emotional response to aspects of their visible condition.

3.2.3. *Dealing with difficult situations*

Seven of the 18 parents provided detailed accounts of their adolescents recalling challenging social experiences at school or during social interactions with peers. Parents described these experiences as emotionally taxing for the adolescent which triggered disclosure about the course of the event:

Yeah, she [the adolescent] talked about [the experience] at home. She told about it immediately when she came home, because it affected her. Yeah, so she is very open with us at home around such things. It is at least how we [parents] experience her. . . she can tell about such things without me needing to ask, 'What happened today?' . . . (Meryl, daughter, 13-15 years, craniofacial condition)

One of the fathers recounted a dialogue with his daughter who was worried that her appearance affected one of her friendships. In this particular conversation, the father gained insight into how appearance concerns influenced his daughter's interpretation of her relationship with her friend:

...But as I try to explain to her, it is just the way it is with these friend-groups, they [adolescents] switch back and forth between friends all the time. It can be times where she has been a lot with one [of her friends] and then suddenly she wants to be with someone else, and then after some time they're back together, right. So, it has nothing to do with her facial appearance, but clearly, she draws those conclusions, right, because she often has low self-confidence because of [her appearance]. (Ethan, daughter, 12-14 years, bone condition)

3.3. Providing parental guidance and encouragement

The third theme reveals parents' experiences of how talking openly about different appearance issues enabled them to encourage, positively reinforce, and guide their adolescents, helping them to adjust to their visible difference and cope with difficult situations. When talking about these experiences parents perceived openness to be a crucial strategy that contributed to their adolescent's positive psychosocial adjustment. This theme was present in all three subgroups.

Nine parents expressed that conversations became a tool used to provide support for their adolescents. These parents seemed to shift the topic of conversation consciously to a more positive focus, as exemplified by one of the mothers: "...we have kind of focused on positive aspects and talked a lot about the fact that everyone has something [that is different]" (Jane, daughter, 12-14 years, craniofacial condition). Engaging in dialogue provided the ideal occasion for one of the fathers to encourage his daughter whenever she was feeling disheartened. This father emphasised the need for him to be more attentive to his child's support needs, because of the additional challenges associated with feeling different to peers:

...So that's how we're continuously working with her and encourage her and support her with all our strength in order for her to feel a desire and have a will to do things, because it is so easy to get in that [state], in that "basement" where everything is dark and sad and 'I hate everybody' and 'I hate myself' and 'I look ugly' and 'No one wants to be with me'... So we [parents], we lift her up. She can fall down into that "basement" sometimes, but we lift her up. (Ethan, daughter, 12-14 years, bone condition)

Another mother highlighted how talking openly with her daughter gave her the opportunity to provide guidance on the importance of being open with her friends about situations she felt were difficult. After considering her mother's guidance, the mother described her daughter's sense of accomplishment: "...she experienced appreciation [from her friends]. She felt that it helped her a lot, [being open] was something that provided a little relief..." (Sophie, daughter, 13-14 years, craniofacial condition). As such, the parents felt that conversations enabled them to provide personalised guidance and support to their adolescents.

3.4. When the dialogue becomes difficult

The fourth and last theme encapsulates the parents' experiences of and reflections on managing the more challenging aspects related to talking to their adolescent about their appearance and condition, and the impact of these conversations on the parents. This theme, in which parents from all subgroups were equally rep-

resented, explores parents' reflections on how adolescents perceive talking about appearance issues.

3.4.1. Parent's feelings when engaging in appearance talk

Sixteen parents talked about how they felt when having appearance conversations with their adolescents. Eight of these parents found it challenging to raise appearance issues, because they observed that it was a burdensome topic for their adolescent. One of the mothers expressed this in specific words: "...it's tough because I see that it's upsetting her..." (Meryl, daughter, 13-15 years, craniofacial condition). The two parents that described not talking about appearance with their adolescent (one from the intervention group and one from the non-participating group), found the lack of conversations to be emotionally difficult for themselves and wished for appearance conversations: "I feel that it's sad that she really doesn't want to talk about it" (Eliza, daughter, 12-14 years, craniofacial condition).

Conversely, for eight of the parents (i.e. from the intervention and control group), raising appearance issues was not perceived as an intrinsically difficult task because of the good and open relationship they experienced with their adolescent. One mother clearly expressed how the positive relationship she shared with her adolescent underpinned their ability to discuss appearance issues openly: "I experience it [talking about appearance] to be rather easy (...) in fact, we are quite open around different topics, so maybe it is the fact that we have a good relationship with him that makes it easy" (Kate, son, 15-17 years, congenital limb condition).

3.4.2. Reflecting on conversational boundaries

Two mothers, one from the intervention group and one from the non-participating group, described that it was difficult to talk openly about appearance issues, due to a perceived lack of interest or motivation from the adolescent. One of the mothers recalled a situation when she was surprised to overhear her son talking about his appearance and condition with friends, because he had previously shown no interest in discussing these topics with her. As a result, she had the perception that she was not invited into her son's "conversational zone". Similarly, another mother shared this experience when trying to talk with her daughter about her appearance:

I try to bring it up and I try to talk it up, right (...) but it's like she won't comment on anything and doesn't say anything, usually she prefers not to respond to my questions. I think it is obvious that [appearance] is sensitive. (Eliza, daughter, 12-14 years, craniofacial condition)

Because talking about appearance was experienced as a sensitive endeavour and described in all subgroups (by 11 parents), parents expressed the need to be attentive and considerate about the adolescent's motivation to engage in a dialogue: "...I think that there is a clear boundary on how much I should ask and when it turns out to be pestering, like if I ask the same things many times, it can be perceived as nagging" (Emma, daughter, 15-17 years, skin condition).

One of the mothers (from the intervention group) also described that she was very conscious about the way she talked with her son and reflected upon the importance of being cautious about not using words that could potentially cause appearance concerns.

Although 11 parents from all three subgroups perceived that their adolescent did not find it challenging to talk about their visible difference, attempting to engage in appearance talk could still be difficult. For instance, one of the mothers felt that when approaching her son to talk about appearance issues, it was not unlikely that he would feel that she was: "...making a deal out of something he initially didn't think was a problem" (Kate, son, 15-17 years, congenital limb condition). Similarly, another mother had

the impression that her son carried more thoughts than he was able to share with her, because she perceived that he felt that: “. . . [appearance] was not really something to talk about” (Julia, son, 14–16 years, skin condition).

4. Discussion

The current study examined parents' perceptions of talking with their adolescent about topics related to appearance and their visible condition. Very few studies have investigated how parents experience talking with their child or adolescent about their visible difference, and the challenges and benefits of having such conversations. Therefore, this study provides a unique contribution by highlighting the different settings and contexts that facilitate appearance conversations, how conversations enable parents to elicit information about their adolescent's psychosocial adjustment to a visible difference and provide support through advice and guidance, and presents barriers that may hinder constructive appearance conversations. Overall, parents from all three subgroups were similarly represented across most themes. Still, a somewhat higher proportion of parents from the intervention group talked about the need to find the right context for appearance conversations, providing guidance and encouragement, and reflecting on conversational barriers.

Irrespective of whether or not their adolescent had experience of completing YP Face IT, findings revealed that some parents took care to ensure that they mitigated the risk of exacerbating distress when taking the decision to instigate conversations about appearance. They considered the timing and setting of the event, such as when their adolescent expressed a need for care, when helping their child to manage their condition, and when observing behaviours that indicated the adolescent was struggling. Similar findings were reported in a study by [Middleton et al. \(2018\)](#), where parents of children with sickle cell disease were alert to their child's physical and emotional well-being in order to initiate conversations.

The finding that parents in the current study were cautious or hesitant about initiating conversations reflects their apprehension about randomly raising a potentially sensitive topic that may not be perceived as welcome or helpful by their adolescent. Previous studies have also illustrated that parents use of language when describing their adolescent's appearance or condition may cause emotional distress ([Puhl & Himmelstein, 2018](#)) and that conversations may be perceived by the adolescent as a reminder of his or her difference ([O'Toole et al., 2016a](#)). Indeed, evidence of adolescents ignoring or responding negatively to such approaches was reported by parents in this study and suggests parental concern is well-founded, but ultimately may impede initiatives to instigate conversations that could ameliorate adolescent concerns.

To encourage supportive dialogue, parents may therefore need to identify and exploit contexts and settings that facilitate appearance conversations. For example, current findings showed that the YP Face IT-N RCT provided a conversational setting for parents in all three subgroups. Although tentatively, this result indicates that adolescents' affiliation with an appearance-specific RCT, regardless of the degree of participation, can facilitate a dialogue about appearance among some parent-adolescent dyads. This is also consistent with results from another study, the Dove Self-Esteem Project, where participation led to increased conversations about body image between mothers and daughters ([Diedrichs et al., 2016](#)). Intervention studies may therefore have the potential to facilitate conversations between parents and adolescents about sensitive topics such as appearance.

In three subthemes, descriptions from parents in the intervention group were proportionally more frequent than descriptions from the control- and the non-participating group. This could

indicate that positive conversational experiences may have been influenced by the intervention content. YP Face IT teaches and encourages adolescents to practice coping strategies in order to manage staring, bullying, and anxiety, and changing negative thoughts about their own appearance ([Williamson et al., 2016](#)). Although parents do not have access to YP Face IT, and the intervention does not include information about how to improve interaction and communication skills between parents and adolescents, it does provide parental guidelines that encourage parents to discuss intervention content with their adolescent. The intervention may have therefore, indirectly, facilitated conversations about appearance. Relatedly, it could also be the case that the interviews conducted with the parents and/or adolescents impacted their experience of participating in the YP Face IT-N RCT. Nonetheless although completion of the intervention might have helped some adolescents or parents to take the initiative for a conversation, the results still indicate that parents from all subgroups had relatively similar experiences.

Interestingly, almost half of the parents in the current study, and all parents from the control group, expressed that they were confident to discuss and address appearance issues, because they experienced a good and open relationship with their adolescent. Similar results were found in previous studies ([Frisén & Holmqvist, 2010](#); [Wilson et al., 2010](#)), with community samples of adolescents. For instance, the study by [Frisén and Holmqvist \(2010\)](#) showed that, during appearance conversations with their parents, adolescents often felt that their parents viewed their appearance positively. However, conversations were typically related to clothes and hairstyle, rather than aspects concerning the physical body. Moreover, the study by [Wilson et al. \(2010\)](#) indicated that developing a good relationship was important for parents and their adolescents when facilitating conversations about sex-related topics, another potentially sensitive conversational topic. When combined, these results suggest that the relationship parents have with their adolescents may be a vital component when instigating difficult conversations and may constitute a prerequisite in parents' initiative to talk about sensitive issues.

The current study demonstrates that talking openly about appearance issues may benefit both parents and their adolescents. Parents in this study expressed that having conversations enabled them to explore the adolescent's thoughts and feelings related to having a visible condition and coping mechanisms used in difficult situations, which in turn strengthened the parents' ability to support their adolescents in suitable ways. Conversations also provided opportunities for parents to acknowledge their adolescent's difficult feelings, and provide encouragement, guidance, and advice. For example, one of the mothers encouraged her daughter to talk openly with her friends about difficult experiences related to her visible difference. As a result, her daughter felt that being open with her friends provided emotional relief. Other studies looking into parents', children's, or adolescents' experiences with talking about sensitive issues, have revealed several benefits of open communication, such as improved management and adjustment to having a congenital condition ([DeBoer et al., 2017](#); [Middleton et al., 2018](#); [O'Toole et al., 2019](#)), and more confidence in peer interactions ([O'Toole et al., 2019](#)). Additionally, talking openly allows parents to educate their adolescent on how their congenital condition makes them different from peers ([Middleton et al., 2018](#)), which may increase the adolescents' awareness about their own situation. [Pariera and Brody \(2018\)](#) also found that older adolescents perceived openness and honesty to be their parents' strengths when talking about sex-related topics. Open and honest communication is therefore not only highlighted as a strength in parents' conversational approach, but may also be favoured by adolescents when discussing a sensitive topic. This assumption is supported by a study that found better psychosocial adjustment in adoles-

cents who perceived higher levels of open communication with their parents (Xiao et al., 2011).

However, having open conversations about sensitive issues is not without its challenges. Present findings reveal barriers that parents faced when trying to initiate appearance-related conversations. Some parents perceived that adolescents were not always open to talk about their thoughts, feelings, and social encounters, and avoided responding to questions about appearance. Resorting to avoidance when faced with difficult questions is not uncommon among adolescents and may reflect a desire to regulate personal boundaries (Golish & Caughlin, 2002). For instance, adolescents may feel that parents become overprotective or have unnecessary concerns when confronted with questions (e.g. about their condition or appearance) that they themselves do not necessarily perceive as problematic (O'Toole et al., 2016a). At worst, frequent questioning may be perceived by adolescents as obtrusive and an invasion of privacy, which may in turn impede future conversations and restrict parents' future knowledge about their adolescent's experiences (Hawk et al., 2013). This does not mean that parents should be afraid of asking questions and engaging in conversations. However, parents should attempt to be attentive to how their language and overall communication is perceived by the adolescent. For instance, a recent study by Lydecker et al. (2018) found that parents' fat talk (e.g. negative comments about weight and body image) directed towards their child negatively influenced the child's eating behaviours and weight. Similarly, another study showed that increased levels of fat talk and old talk (e.g. age-related appearance concerns) between mothers and daughters were indicative of higher levels of body dissatisfaction (Arroyo & Andersen, 2016). Hence, studies demonstrate the unfortunate consequences that parents' language use may have on adolescents' own appearance perceptions and stresses the importance for parents to be considerate when raising sensitive issues. Almost half of the parents in the current study, most of them from the intervention group, also described that their adolescent felt different as a result of their visible difference. One of the mothers, in particular, described how her daughter became less open to reveal her visible difference to others as she became older, because of stigmatising responses from peers. Thus, in addition to the importance of being attentive to how they communicate with their adolescents about appearance issues, parents may also have to consider how to navigate conversations as their adolescent's transition from childhood to adolescence and become more aware of and worried about how they differ from peers (Ballard et al., 2019).

In the current study, across all subgroups, talking about the adolescent's visible difference was also emotionally difficult for some of the parents. These parents found it challenging when adolescents did not want to engage in appearance conversations. Studies point to several barriers that parents face when raising sensitive topics with their adolescents, including concerns about causing worries when discussing the condition (O'Toole et al., 2016b), feeling uncomfortable and lacking knowledge or communication skills about the topic for discussion (Wilson et al., 2010), and lack of confidence to instigate conversations (Morawska et al., 2015). These barriers may potentially act as stressors for parents and impede constructive conversations with their adolescent. However, although talking about sensitive issues can be uncomfortable for parents and adolescents, these difficult conversations often provide emotional relief for adolescents, enable support from family members, and can improve parent-adolescent relations (Keating et al., 2013).

4.1. Parents' perceptions in light of a critical realist perspective

From a critical realist viewpoint, it could be argued that different settings, openness to talk, and the relationship between

parents and their adolescents, constitute important mechanisms that enable conversations about appearance. Although parents perceived conversations as an approach to explore their adolescent's thoughts and feelings, their knowledge of adolescents' inner experiences will remain limited. Correspondingly, exploring parents' experiences of addressing appearance issues with their adolescents through qualitative interviews may provide an in-depth, albeit limited, understanding of the parental perceptions.

4.2. Limitations

Although the current study provides unique insight into parents' experiences of appearance conversations with their adolescent, some limitations require consideration when interpreting the results. First, interviews were conducted by telephone, which may hinder the interviewer's potential to respond to visual cues (Holt, 2010). Video calling was not used due to regulations of ethics for data collection placed by the Oslo University Hospital. Additionally, because thematic analysis (Braun & Clarke, 2006) did not necessitate gathering of visual cues, data collection via telephone calls was deemed appropriate. Although video calls or face-to-face interviews would have provided visual cues, participants can prefer the greater sense of anonymity afforded by telephone calls, particularly when discussing sensitive issues (Fenig et al., 1993). Telephone interviews also facilitated participation for those who were geographically hard-to-reach (Drabble et al., 2016).

Second, although most interviews (73%) were performed by the first author, two other interviewers also collected data. While multiple interviewers can increase the efficiency of data collection, multiple interviewers bring their own experience, expertise and style into the interview setting. Interviewers' knowledge in a certain field or interviewing skills may for example determine the amount of relevant follow-up questions that are asked, which may in turn affect the quality and depth of the data. Interviewers may also differ in how comfortable and confident they feel exploring sensitive questions (Rosenblatt, 2012), or leading participants through the interview guide.

Third, the study sample consisted mainly of mothers and no systematic efforts were made to recruit more fathers. We interviewed the parent who had contacted the research team when enrolling the adolescent into the study. It is well known from the research literature that men are underrepresented in qualitative health research (Polit & Beck, 2008). This is unfortunate because fathers may provide different perspectives of a certain phenomenon and may have other experiences to share. However, although gender differences were not explored, results did not indicate any differences between fathers and mothers in their approach to conversations about appearance. Still, future research on the present topic should aim to include a representative sample of fathers and investigate this issue more explicitly.

Fourth, the majority of the study sample were parents of adolescents that had participated in a larger RCT study evaluating a psychosocial intervention aimed at reducing appearance-related distress. Regardless of which group adolescents were allocated to in the larger study (i.e. intervention, control or non-participating group), the study may have influenced parents' experiences and perceptions in relation to the topic explored. Since 15 of the 18 families had decided to participate in an appearance-related intervention study, it could be that this group of parents were more receptive and less anxious about discussing topics related to a different appearance than parents in general. To address this potential limitation we also invited parents of non-participating adolescents. Interestingly, although only three parents were recruited, their experiences did not seem to differ significantly from the other parents, which may indicate that the present sample still represents parents of adolescents in general.

Fifth, inter-coder reliability (ICR) was not calculated during the analytic phase. While including metrics of ICR may increase the transparency surrounding the coding process (O'Connor & Joffe, 2020), this method is widely debated among qualitative scholars (Yardley, 2000; Braun & Clarke, 2013; O'Connor & Joffe, 2020). For example, a high ICR may not guarantee that a study is rigorous and trustworthy (O'Connor & Joffe, 2020), as this number may only represent how much researchers agree on a set of codes (Yardley, 2000). To maximise the trustworthiness of findings, quality criteria used to guide qualitative research were employed. These included transparent reporting of all analytical steps in the construction of themes and subthemes, analysis validation checks by the RCT trial advisory group (parents of children and adolescents with diverse conditions leading to a visible difference), independent review of the first author's codes and themes by the last author. In addition, the extent of participant support for each theme and subtheme was quantified in the result section (see Table 1).

4.3. Clinical relevance and future research

The results of this study could inform the practice of healthcare professionals and social workers wishing to help parents address sensitive topics with their adolescent and, given some parents' inherent fear of making things worse, give them more confidence to highlight the potential benefits of talking about sensitive issues. For example, parents may be informed that, although some topics are difficult to talk about, conversations may ultimately enable them to provide emotional relief, guidance, and encouragement to their adolescents. Future studies should aim to investigate how adolescents' age, type of condition, and gender may relate to experiences of appearance conversations and consider the impact of developmental changes in communication patterns, for instance from childhood into adolescence. It would also be interesting to explore if parents' gender and body image perceptions influence appearance conversations with adolescents. Future studies should also seek to explore how adolescents themselves experience discussing their visible difference with their parents, and how they benefit from talking about appearance issues. Lastly, in our study, being interviewed about appearance-related concerns may have made parents more attentive to these kinds of concerns in their adolescents, and in turn made them more eager to support their adolescents in completing YP Face IT. Further investigation is therefore warranted on how participation in an appearance-specific intervention might influence interviews conducted in parallel, as well as on how the knowledge gained from interviewing parents and/or adolescents that are actively part of intervention studies may feed back into the intervention and its commencement.

5. Conclusion

The current study explored parents' experiences of talking with their adolescents about their visible difference, which is a rarely investigated subject within visible difference research. Findings indicate that parents carefully consider timing and context before broaching the topic of appearance with their adolescent and can limit conversations to specific settings, for example when perceiving a need for emotional care after a difficult social experience. Appearance conversations can help parents to learn more about their adolescent's adjustment to living with a visible difference, and how they cope with difficult situations. Findings also draw attention to the benefits of communicating openly about appearance issues; parents reported that open and constructive conversations enabled them to provide their adolescents with encouragement, emotional relief, and guidance, which in turn helped their adolescents to reflect upon their situation and strengthen coping skills. However, talking about appearance issues was also reported to be

an emotionally taxing endeavour, for parents as well as for their adolescents. This suggests a need to focus on developing interventions that may support both parents and adolescents in talking more openly about sensitive appearance issues.

Author statements

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Dr. Johanna Kling: Writing – Review & Editing, Supervision

Dr. Kristin Billaud Feragen: Conceptualisation, Methodology, Formal analysis, Investigation, Writing – Review & Editing, Supervision, Project administration, Funding

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Reducing social anxiety in adolescents distressed by a visible difference: Results from a randomised control trial of a web-based intervention[☆]



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ABSTRACT

A visible difference to the face or body may challenge adolescents' adjustment and engagement in life activities, where some require psychosocial support. However, evidence is limited for whether existing interventions for this adolescent group reduce social or appearance-related distress. We therefore conducted a parallel-group, randomised control trial to evaluate the effectiveness of Young Person's Face IT, a self-guided web-based psychosocial intervention developed for adolescents with a visible difference who experience distress. Adolescents ($N = 189$, aged 11–18) from two countries (Norway and the Netherlands), were randomly allocated to an intervention group or care as usual (CAU). Outcomes were body esteem, social anxiety, perceived stigmatisation, and life disengagement. Compared with CAU, participants who completed Young Person's Face IT showed reductions in social anxiety symptoms ($\eta_p^2 = 0.06$). No significant improvements were found for the other outcomes. This study endorses web-based psychosocial support in reducing social anxiety in adolescents distressed by a visible difference. Future studies are needed to confirm the effectiveness of Young Person's Face IT and to explore potential long-term effects.

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1. Introduction

1.1. Living with a visible difference

Having a sense of normality and belonging is central to the psychological well-being of all individuals, and is especially important during adolescence. A visible facial or bodily difference can therefore have a profound psychological impact (Ablett & Thompson, 2016; Feragen & Stock, 2017) irrespective of the type of visible difference (Griffiths, Williamson, & Rumsey, 2012).

Approximately one in 44 people live with a visible difference that deviates from the norm and is considered socially undesirable (Changing Faces, 2010). A visible difference can be congenital or acquired, and includes a range of different conditions (Rumsey & Harcourt, 2007). Congenital differences include craniofacial conditions (e.g. cleft lip and palate or craniosynostoses) and skin conditions (e.g. epidermolysis bullosa or ichthyosis). Acquired visible differences can result from accidental traumas (e.g. burn scars or injuries from traffic accidents), disease (e.g. meningitis), or medical interventions (e.g. hair loss from chemotherapy or scars).

Previous studies suggest that the presence of a visible difference increases adolescents' risk of low self-esteem (Tiemens, Nicholas, & Forrest, 2013) and particularly of developing anxiety (van Dalen et al., 2020), and increases concerns regarding the chances of being involved in romantic relationships (Griffiths et al., 2012). Adolescents who are worried or dissatisfied with their appearance may also experience challenges in peer relationships (Shapiro, Waljee, Ranganathan, Buchman, & Warschausky, 2015), fear of negative evaluations (Griffiths et al., 2012), and reduce their engagement in different life activities, such as school attendance, sports, and socialising with friends (Atkinson & Diedrichs, 2021). Many adolescents also encounter stigmatising experiences or intrusive behaviours (e.g. teasing, bullying, staring, or unwanted questioning and attention from others) (Tiemens et al., 2013), which have been linked to reduced psychological adjustment and health-related quality of life (Masnari et al., 2013).

The timing of negative social experiences seems to be particularly influential. Feragen and Stock (2016) found that experiences of teasing after the age of 10, and measured again at age 16, predicted lower appearance satisfaction and higher levels of depressive symptoms in adolescents with visible differences. Considering that many adolescents also become increasingly invested in and self-conscious about their appearance (Knauss, Paxton, & Alsaker, 2007; Gattario & Frisé, 2019), looking different can become especially challenging during this developmental phase. A gender difference also exists, in adolescents with or without a visible difference, where adolescent girls consistently report higher dissatisfaction with their appearance or lower appearance esteem than boys (Feragen & Borge, 2010; Frisé, Lunde, & Berg, 2015). Levels of social anxiety have also been shown to be higher in adolescent girls with or without a visible difference compared to boys (Berk, Cooper, Liu, & Marazita, 2001; Ohannessian, Milan, & Vannucci, 2017).

While some adolescents manage to cope by acknowledging and accepting their situation (Egan, Harcourt, Rumsey, & Appearance Research Collaboration, 2011), others adjust to the consequences of being visibly different by employing techniques to conceal their difference (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010). Psychological adjustment appears to be more strongly related to subjective appearance perceptions rather than objective appearance ratings (Moss, 2005). Social experiences may also act as a contributing factor, where close friendships and social acceptance can positively influence adolescents' adjustment (Feragen, Kvalem, Rumsey, & Borge, 2010). In other words, positive social experiences, including close relationships with peers, may improve adolescents' adjustment to and buffer against the impact of negative influences and social stigma (Feragen et al., 2010; Tiemens et al., 2013).

In contrast, some social experiences may make adolescents with a visible difference more vulnerable and put an additional strain on their psychological well-being (Stock & Feragen, 2016). More recently, the COVID-19 pandemic presented new and unique challenges and studies have shown that social anxiety levels increased during the pandemic in adolescent community samples (Hawes, Szency, Klein, Hajcak, & Nelson, 2021). Research on how COVID-19 may have affected the lives of adolescents with a visible difference in particular is still scarce. For some, wearing face coverings may have been difficult because it provoked a feeling of identity loss, whereas

others may have felt relief by being able to cover their visible difference (Changing Faces, 2021). Also, for some, the pandemic may have worked to provide a temporary relief from social pressure (Harcourt, Tollow, Hamlet, Zucchelli, & Williamson, 2021).

1.2. Interventions and support

Evidence-based interventions and support alternatives that could help adolescents develop effective coping strategies and strengthen psychological well-being may be of central importance in the process of adjusting to a visible difference. However, evidence for the short- and long-term effectiveness of existing interventions for adolescents who experience appearance-related distress is scarce (Jenkinson, Williamson, Byron-Daniel, & Moss, 2015). Several methodological issues need to be taken into account, such as small sample sizes and lack of experimental designs (Jenkinson et al., 2015). Moreover, existing interventions have mainly included samples of adults with visible differences when testing the effectiveness of psychosocial interventions (Norman & Moss, 2015). Evidence-based interventions tailored specifically for adolescents with visible differences are therefore needed.

Some psychosocial approaches and therapeutic techniques have shown promise in supporting adolescents with visible differences. Evidence-based approaches are Social Skills Training (SST; Blakeney et al., 2005; Pell, 2019) and SST in combination with Cognitive Behaviour Therapy (CBT; Maddern, Cadogan, & Emerson, 2006). Blakeney et al. (2005) evaluated an SST-based intervention workshop with English-speaking adolescents with burn injuries ($N = 64$). Compared to controls, participants reported less withdrawal from social situations and fewer behavioural problems one year after the intervention. However, the study was limited by a relatively small sample size, and could have been strengthened by including a broader set of measures. Pell (2019) also evaluated an SST-based workshop in the United States, in this case attended by parents of children with craniofacial conditions, adults with burn injuries, and individuals' with skin conditions ($N = 46$). After completing the workshop, participants felt better prepared to cope with negative social experiences such as staring (Pell, 2019). The study was however descriptive in nature and limited by the lack of a control group, a relatively small sample size, and did not include pre- and post-intervention measurements (Pell, 2019).

Maddern et al. (2006) evaluated an intervention based on a combination of SST and CBT with adolescents with craniofacial and scarring conditions living in England. After completing the intervention, participants ($N = 29$) reported fewer experiences of teasing and felt less distressed by actual teasing, and parents reported a reduction in anxiety levels. Again, this study was limited by the lack of a control group and a small sample size (Maddern et al., 2006). Residential social camps have also shown potential in positively affecting appearance satisfaction and perceptions of stigmatising behaviours among adolescents with a visible difference living in the United Kingdom, as was demonstrated in the study by Armstrong-James, Cadogan, Williamson, Rumsey, and Harcourt (2018). Although the study included pre- and follow-up measurements, a high level of attrition at follow-up and lack of a control group limits the interpretation of results (Armstrong-James et al., 2018).

Evidently, interventional techniques such as SST and/or CBT techniques may assist adolescents in strengthening coping mechanisms when dealing with difficult situations, and recognising and changing negative thoughts and feelings about their own appearance (Blakeney et al., 2005; Maddern et al., 2006; Jenkinson et al., 2015). Having good social skills may also benefit adolescents in several ways, such as being rated more positively by others and being perceived as more social and confident (Edwards, Topolski, Kapp-Simon, Aspinall, & Patrick, 2011). In summary, promising results regarding the usefulness of SST and/or CBT approaches need to

be tested with more robust methodology, such as large-scale randomised control trials (RCT), in order to build stronger evidence for their effectiveness in strengthening coping in adolescents with a visible difference.

1.3. Web-based psychosocial support

Despite research showing the potential psychological benefit of SST and CBT-based interventions for adolescents with a visible difference, the general availability of psychological treatment and interventions for these adolescents is limited (Harcourt et al., 2018). Local health care systems may have few psychologists with clinical expertise in appearance psychology and related to living with a visible difference in many countries, combined with geographic and demographic characteristics that may contribute to make specialised psychological treatment difficult to reach (Harcourt et al., 2018). Given the variation in accessibility of appearance-related care, research needs to address the potential benefits of alternative ways of delivering interventions and reaching adolescents in need for support.

Increasing evidence points to Internet-delivered Cognitive Behaviour Therapy (ICBT) as being potentially effective in treating psychological difficulties such as anxiety and depression (National Institute for Health and Clinical Excellence, NICE, 2005; Nordgreen, Gjestad, Andersson, Carlbring, & Havik, 2018). For instance, a recent review and meta-analysis (Carlbring, Andersson, Cuijpers, Riper, & Hedman-Lagerlöf, 2018), has suggested that guided ICBT in many instances is equally effective as standard face-to-face CBT in treating social anxiety and depression in adults. ICBT has also shown promise in adolescent community samples in reducing symptoms of anxiety (Stjerneklar, Hougaard, McLellan, & Thastum, 2019) and depression (Topooco et al., 2019), and negative body image (Franko, Cousineau, Rodgers, & Roehrig, 2013; Rodgers et al., 2018). Stjerneklar et al. (2019) randomised adolescents with anxiety disorders ($N=70$) to a 14-week guided ICBT or to a waitlist group. Adolescents who completed the ICBT programme showed significant improvements in their anxiety symptoms post-intervention, compared with the waitlist group. In the study by Topooco et al. (2019), adolescents with depressive symptoms ($N=70$) were also randomised to an 8-week guided ICBT or to a control group, with those receiving ICBT showing significant improvements in their symptom levels.

Web-based support has also improved body image perceptions in older adolescents (Franko et al., 2013; Rodgers et al., 2018). Franko et al. (2013) and Rodgers et al. (2018) evaluated BodiMojo, an unguided intervention to promote positive body image. In both studies, adolescents from community settings were randomised to an intervention group that received BodiMojo or a control group. Adolescents in the intervention group showed improved body image (Franko et al., 2013) and appearance esteem (Rodgers et al., 2018). Collectively, results from these intervention studies are encouraging. It is also noteworthy that, since the rise of COVID-19, there has been an increased demand for ICBT-based approaches, which has proved to be effective in reducing anxiety and depression in adults during the pandemic (Mahoney, Li, Haskelberg, Millard, & Newby, 2021).

Little is currently known about the effectiveness of ICBT-interventions specifically developed for individuals with a condition affecting their appearance. Previous studies have indicated that adolescents may find it difficult to raise appearance concerns face-to-face with healthcare professionals (Williamson et al., 2010), and may prefer more easily accessible support that offers a greater degree of anonymity and confidentiality when discussing appearance issues (Griffiths et al., 2012). ICBT-based approaches have the potential to fulfil this need, including in extraordinary times where pandemics such as COVID-19 may cause lockdowns and inhibit access to support due to social distancing (Mahoney et al., 2021).

1.4. The Young Person's Face IT (YPF) intervention

One self-guided web-based intervention, Face IT, for adults with a visible difference and integrating SST and CBT approaches, was developed and evaluated via a RCT by researchers at the Centre for Appearance Research at the University of the West of England, Bristol, UK. Compared with controls, the trial demonstrated that standard face-to-face intervention and Face IT equally reduced anxiety, fear of negative evaluations, depressive symptoms, and appearance-related distress (Bessell et al., 2012).

Based on evidence of Face IT's effectiveness among adults with a visible difference (Bessell et al., 2012; Norman & Moss, 2015), a similar self-guided intervention for adolescents, Young Person's Face IT (YPF), was developed by researchers at the Centre for Appearance Research, in close collaboration with adolescents with visible differences, their parents, and clinical experts and health professionals (Williamson et al., 2016). The therapeutic content of YPF is based on the adult version, Face IT (Bessell et al., 2012), and consists of seven weekly sessions and one booster session completed six weeks later to maintain therapeutic effect (Williamson et al., 2016). Each session takes around 30–40 min to complete and participants are encouraged to work through YPF independently, although they may also ask for advice and guidance from others (e.g. parents/primary caregivers) if needed. Each session provides advice and guidance in written, audio, and video formats, and focuses on teaching and encouraging adolescents to practice strategies such as managing staring, bullying, and anxiety, through interactive and homework activities (Williamson et al., 2016). A detailed description of the intervention content is published elsewhere (see Williamson et al., 2016). Additionally, participants can record their own reflections and experiences in their YPF diary. To support participants who may struggle with reading, audio recordings for all written text are available on the English and Norwegian YPF intervention website.

The feasibility and acceptability of YPF has been explored in several studies across the world (Feragen, 2017; Gee, Williamson, Maskell, Kimble, & Newcombe, 2018; Williamson et al., 2019; Riobueno-Naylor et al., 2019; 2021; van Dalen et al., 2021), and the programme therefore exists in English (<https://www.yppfaceit.co.uk>), Norwegian (<https://www.ungfaceit.no/>) and Dutch (<https://www.faceitvoorjongeren.nl/>). The British study by Williamson et al. (2019) was a feasibility trial that delivered YPF online to adolescents with a wide range of appearance-affecting conditions, and found YPF to be a safe and acceptable programme and demonstrated preliminary results indicating that the intervention could improve body esteem and reduce social anxiety (Williamson et al., 2019). The studies by Riobueno-Naylor et al. (2019, 2021) included adolescents with burns and aimed to explore the feasibility of incorporating YPF into routine outpatient paediatric burn care in the United States. Although adolescents expressed interest in using YPF, few engaged actively with the programme, and the authors concluded that more knowledge is needed on how adolescents' engagement with the intervention can be supported (Riobueno-Naylor et al., 2021).

In summary, YPF may potentially provide a cost-effective alternative to traditional face-to-face psychological treatment for adolescents that experience appearance-related distress as a result of their visible difference, and be easily accessed by adolescents in need of relevant support, irrespective of their geographical location (Williamson, Griffiths, & Harcourt, 2015). Several studies also suggest that the intervention is a safe, relevant, and acceptable tool (Feragen, 2017; Williamson et al., 2019; Riobueno-Naylor et al., 2021; van Dalen et al., 2021). However, no previous studies on YPF have moved beyond exploring the feasibility and acceptability of the intervention with larger sample sizes. Hence, one of the main limitations of the previous research on YPF was the lack of a full-scale RCT to evaluate the effectiveness of the intervention. RCTs evaluating YPF in other languages than English are also lacking. Informed by

previous research on YPF, the primary purpose of the present study was therefore to strengthen the evaluation of the intervention, with the intention of filling the existing gap in the availability of evidence-based support for adolescents with visible differences.

1.5. Aim

The aim of the current study was to evaluate the effectiveness of YPF compared with care as usual (CAU) in improving psychological well-being in adolescent with a visible difference living in Norway and the Netherlands. We had three specific aims:

- 1) Examine whether YPF improves body esteem and/or reduces social anxiety compared with CAU (primary outcomes).
- 2) Examine whether YPF reduces perceived stigmatisation and/or life disengagement compared with CAU (secondary outcomes).
- 3) Explore variables that could potentially influence post-intervention outcome scores for the intervention group. We therefore examined whether age, gender, country, time spent on YPF, and/or type of visible difference, predict changes in body esteem, social anxiety, perceived stigmatisation, and life disengagement, when controlling for baseline outcome scores.

2. Method

2.1. Trial design

This study was a parallel-group RCT. Participants were recruited from two independent studies conducted in two countries (i.e. Norway and the Netherlands) and the samples were merged for the present study. Participants were allocated to either an intervention group (YPF) or a control group receiving CAU, and completed outcome measures prior to randomisation (baseline assessment) and thirteen weeks later (post-intervention assessment). The Norwegian study was reviewed by the Regional Committee for Medical Research Ethics (Health Region South-East, reference no.: 2015/2440) and accepted by the Data Protection Office based at Oslo University Hospital. For the study in the Netherlands, approval was obtained from the Medical Research Ethics Committee in Rotterdam, Netherlands (Reference no.: MEC-2018-052/NL63955.078.18). This trial followed the CONSORT 2010 guidelines (Schulz, Altman, & Moher, 2010).

2.2. Recruitment and procedure

In Norway, participants were recruited between April 2019 and February 2021 nationwide from University Hospitals, specialist treatment units, local healthcare services, patient organisations, and through social media (see Kling, Nordgreen, Kvale, Williamson, & Feragen, 2021). In the Netherlands, participants were recruited between August 2019 and October 2020 from a University/City hospital and nationwide through patient organisations, and through social media. In both countries, participants were recruited before, during, and after lockdowns and/or restrictions following from COVID-19.

Participants and/or participants' parents/primary caregivers contacted the research team by telephone or email if they wished to participate in the study. Following initial contact, all participants (and/or parents if adolescent < 16 years) were contacted via telephone by the research team, and answered questions in order to confirm eligibility. Inclusion criteria were: 1) age between approximately 12–17 years with a visible difference and self-identified appearance-related distress, teasing or bullying; 2) access to the internet and a home computer or tablet; 3) minimum reading level corresponding to that of a 12-year-old; 4) normal or corrected-to-normal vision. Exclusion criteria were: 1) a diagnosis of clinical depression, psychosis, eating disorder (see details below for differences

in assessment procedures between the two participating countries), and post-traumatic stress disorder (PTSD), or within 12 months of traumatic injury; 2) learning disabilities that would impede understanding of the intervention content; 3) currently receiving any psychological face-to-face intervention (e.g. therapist-delivered CBT). In order to protect potentially vulnerable participants and given the research team's limited ability to provide extended psychological support to those in need, exclusion criteria 1) and 2) were employed as to exclude participants requiring more intensive face-to-face interventions (Williamson et al., 2015). Ultimately, YPF constitutes an addition to existing support for adolescents with appearance-related distress and is not intended to replace psychological face-to-face treatment when needed (Williamson et al., 2015). Exclusion criterion 3) was employed to eliminate any influences that could impede interpretation of intervention effects resulting from YPF.

After assessing participants for inclusion and exclusion criteria, informed consents were obtained from eligible participants. For participants < 16 years, consents were also obtained from both parents/primary caregivers, and only from the participants if they were 16 years or older. After consent forms were obtained, baseline outcome measures were administered through secure online data collection platforms, accepted by the University Hospitals in Norway and the Netherlands. Participants also provided demographic information (e.g. birth date, gender, type of visible difference, and parental occupation/education) either during the screening conversations and/or as part of the baseline assessment. Consecutively, participants in both countries were randomised to either the intervention group or CAU in a 1:1 ratio, and were informed about their group allocation either by telephone or by email. Participants in the intervention group were informed about the outcome measures they would be asked to complete and given verbal instructions on how to access YPF, whereas participants in the CAU group were only informed about the outcome measures.

As the studies in Norway and in the Netherlands were developed independently, there were some differences in procedures between the two study sites: 1) In Norway, a single randomisation procedure was performed by the first author using envelopes containing a random sequence and research team members were not blinded to the randomisation. In the Netherlands, randomisation was performed using a computer generated list with a random sequence, where research team members were blinded to the randomisation, and was stratified by age (12–13, 14–15 or 16–17 years); 2) Participants living in the Netherlands were screened for subclinical symptoms of low body esteem, social anxiety, and depression, using questionnaires at baseline (see the section on assessment for details about the screening), and only randomised in cases of subclinical symptoms. This screening was performed in order to offer YPF to adolescents at the worrying end of these scales, as suggested to be beneficial by previous research (Williamson et al., 2019). In contrast, participants living in Norway were not screened for subclinical symptoms and all those that fulfilled the inclusion criteria were enrolled in the trial; 3) Although participants from both Norway and the Netherlands were randomised either to an intervention group or CAU, there were some differences between the CAU groups in the two countries. In Norway, a waiting list CAU group was used. Participants randomised to this group knew that they would wait three months before they would receive access to the intervention, and complete a new set of outcome measures after completion of YPF for the purpose of the larger Norwegian RCT study. In the Netherlands, participants randomised to CAU were offered access to the intervention after participation in the study (after final completion of outcome measures at six months). However, adolescents choosing to do so were not included in a follow-up study; 4) In Norway, progress with YPF was followed-up by a research team member; 5) All participants were offered incentives for completing outcome measures.

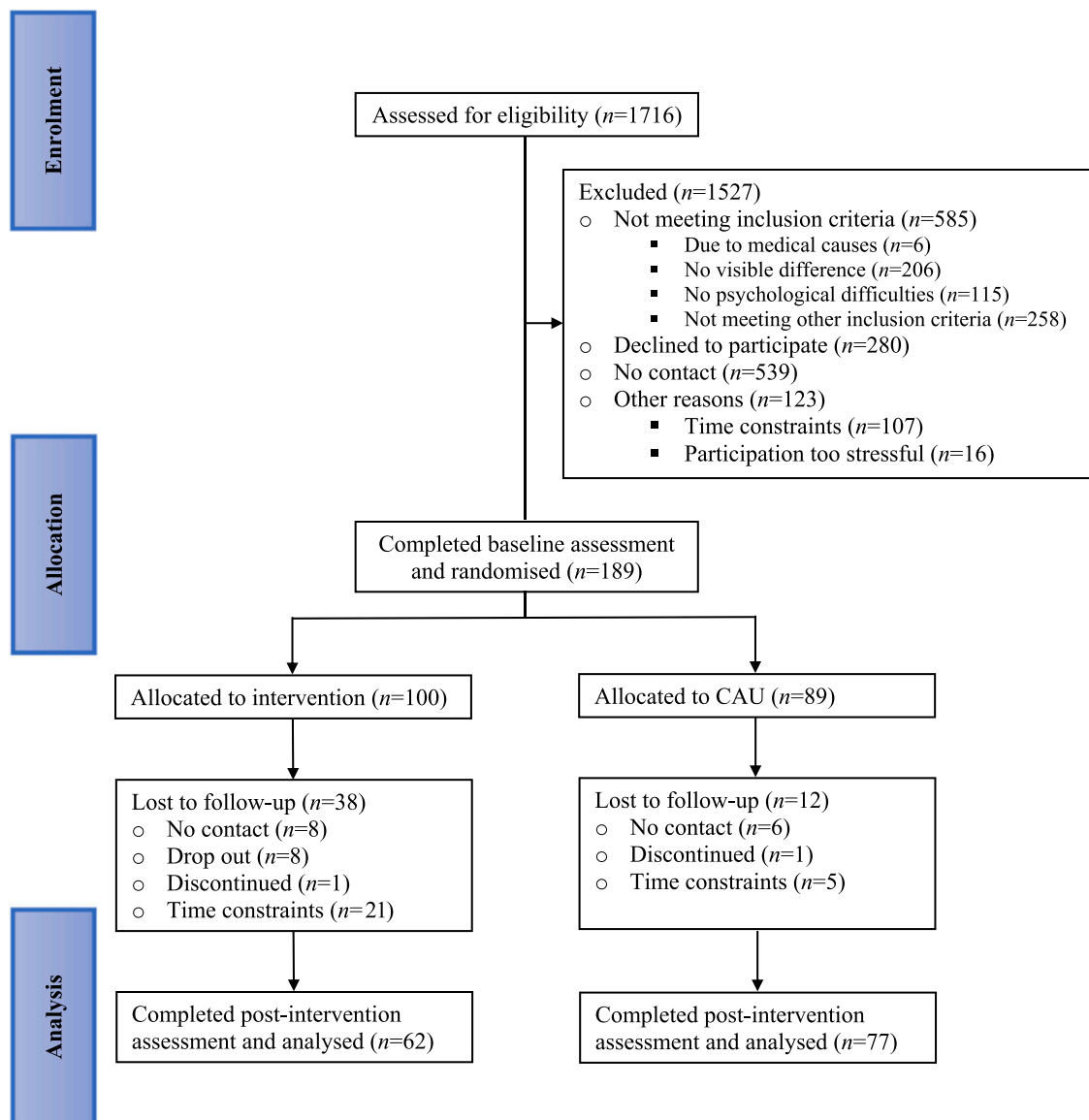


Fig. 1. Flow chart of study procedures. BESAA = Body-Esteem Scale for Adolescents and Adults; SAS-A = Social Anxiety Scale for Adolescents; CDI-2 = Child Depression Inventory 2 (Kovacs, 2016). Only participants living in the Netherlands were screened for subclinical symptoms of low body esteem, social anxiety, and depression at baseline and before randomisation. All randomised participants ($N = 189$) were included in intention-to-treat (ITT) analyses.

In line with standard recommendations provided by the ethics committees in both countries, participants living in Norway received a €30 gift card for completion of the post-intervention measure and participants living in the Netherlands received a €10 gift card after study completion.

2.3. Participants

A total of 1716 participants were assessed for eligibility. After screening, 1527 were excluded (see Fig. 1). The final study sample consisted of 189 participants randomised to the intervention group ($n = 100$) or CAU ($n = 89$). An a priori sample size calculation revealed that 62 participants were needed per group to achieve at least 80% for detecting treatment effects when a Cohen's d effect size of .50 was considered to represent a clinically meaningful effect (Norman, Sloan, & Wyrwich, 2003). Therefore, this study was considered sufficiently powered to detect statistically significant results.

2.4. Intervention (YPF)

Participants in the intervention group received a username and password to access YPF and completed the intervention on a computer or tablet at home or another self-selected location. During the course of the programme, some adolescents contacted the research team because they needed technical support with logging in to the intervention website, support with changing passwords, or because of technical issues with the intervention website. No participants or parents contacted the research team because of concerns related to psychological well-being, or because they wished referral to the healthcare system.

2.5. CAU

All participants received CAU, with those in the intervention arm also receiving YPF. However, none of the two participating countries offer standardised psychosocial or psychological treatment for adolescents with a visible difference, and CAU would therefore vary according to needs, resources, and expertise within local health care

services. CAU could for example include routine consultations at the hospital for medical treatment of skin conditions, such as eczema or other type of congenital conditions.

2.6. Assessment

2.6.1. Primary outcomes

2.6.1.1. Body esteem. To assess body esteem, the Appearance Esteem Subscale (BE-Appeal) of the Body-Esteem Scale for Adolescents and Adults (BESAA; Mendelson, Mendelson, & White, 2001) was used. This subscale contains ten items rated on a five-point Likert scale from 0 (*never*) to 4 (*always*). Statements include “I worry about the way I look” and “I like what I see when I look in the mirror”. After negatively worded items have been reversed, higher mean values indicate greater appearance satisfaction (Mendelson et al., 2001). Good internal consistency of the BE-Appeal Subscale has been demonstrated in a community sample of adolescents (Nelson, Kling, Wängqvist, Frisén, & Syed, 2018), as well as for all three subscales of the BESAA with adolescents with a visible difference (Lawrence, Rosenberg, Mason, & Fauerbach, 2011). In this study, Cronbach's alpha was $\alpha = .91$ for the total sample.

2.6.1.2. Social anxiety. The Social Anxiety Scale for Adolescents (SAS-A; La Greca & Lopez, 1998) was used to assess subjective experiences of social anxiety. SAS-A contains 18 descriptive self-statements divided into three subscales, with items rated on a five-point scale ranging from 1 (*never*) to 5 (*always*). All subscales were used in the present study. The first subscale, Fear of Negative Evaluation (FNE), contains eight items (e.g. “I worry about what other kids think about me”). The second subscale, Social Avoidance and Distress Specific to New Situations or Unfamiliar Peers (SAD-New), includes six items (e.g. “I get nervous when I meet new kids”). The third subscale, Social Avoidance and Distress in General (SAD-General), contains four items (e.g. “I feel shy even with kids I know well”). Higher scores indicate higher levels of social anxiety (La Greca & Lopez, 1998). Good psychometric properties of the SAS-A have been demonstrated in a Finnish adolescent community sample (Ranta et al., 2012). In this study, Cronbach's alpha was high for all subscales (FNE, $\alpha = .91$; SAD-New, $\alpha = .86$; SAD-General, $\alpha = .78$) and high for the overall scale ($\alpha = .93$).

2.6.2. Secondary outcomes

2.6.2.1. Perceived stigmatisation. The Perceived Stigmatization Questionnaire (PSQ; Lawrence, Fauerbach, Heinberg, Doctor, & Thombs, 2006) was used to evaluate participants' perceptions of stigmatisation behaviours. PSQ consists of 21 items, divided into three subscales, that are rated on a five-point Likert scale from 1 (*never*) to 5 (*always*). All subscales were used in the present study. The subscales evaluate the Absence of Friendly Behaviour (AFB), Experiences of Confused and Staring Behaviours from Others (CSB), and the extent to which respondents encounter Hostile Behaviour (HB). Example of items include, “People are relaxed around me”, “People avoid looking at me”, and “People call me names”. After reversing positively worded items, higher scores indicate higher levels of perceived stigmatisation. Acceptable psychometric properties have been demonstrated for the PSQ with children and adolescents with a visible difference (Lawrence, Rosenberg, Rimmer, Thombs, & Fauerbach, 2010). The PSQ has also previously been translated and used with Dutch adults with burn injuries (Willemse, Geenen, & Van Loey, 2021). In this study, Cronbach's alpha was acceptable for two of the subscales (AFB, $\alpha = .79$; CSB, $\alpha = .75$), and good for the third subscale (HB, $\alpha = .90$) and the overall scale ($\alpha = .88$).

2.6.2.2. Life disengagement. The Body Image Life Disengagement Questionnaire (BILD-Q) (Diedrichs et al., 2016; Atkinson & Diedrichs, 2021) was used to measure the extent to which

adolescents' worries and negative feelings directed towards their appearance impact engagement or intention to engage in different life activities (e.g. “going to a social event” and “giving an opinion”). The current BILD-Q (Atkinson & Diedrichs, 2021) consists of nine items rated on a four-point Likert scale from 1 (“Hasn't stopped me at all”) to 4 (“Stopped me all the time”). However, a previous ten-item version of the BILD-Q was used in the present study (Diedrichs et al., 2016). Higher scores reflect greater life disengagement. Acceptable psychometric properties of the BILD-Q have been demonstrated in an adolescent community sample (Atkinson & Diedrichs, 2021). In this study, Cronbach's alpha was good ($\alpha = .83$).

2.6.3. Screening measures

In the Netherlands, screening for subclinical symptoms of low body esteem, social anxiety, and depression, was carried out using BESAA, SAS-A and the Child Depression Inventory 2 (CDI-2; Kovacs, 2016). For SAS-A, 0.5–2 standard deviations above average was used as a cut-off value (Inderbitzen-Nolan & Walters, 2000). The same approach was used for BESAA (i.e. 0.5–2 standard deviations under average). For the CDI-2, the 70th and 90th percentile was used as a cut-off value (Kovacs, 2016). Participants that showed subclinical symptoms on one or several of these measures were included in the study and subsequently randomised.

2.6.4. Translations

BESAA, SAS-A, PSQ, and BILD-Q did not exist in Norwegian and were translated, and only BILD-Q had to be translated to Dutch. The translation of BILD-Q to Dutch was performed by the second author and double-checked by the last author, both of which are native speakers of Dutch. Back-translations were performed for all measures following recommended procedures (Brislin, 1970), except for the translations of BILD-Q to Norwegian and to Dutch.

2.7. Statistical analysis

Data were analysed using the IBM Statistical Package for the Social Sciences Software (SPSS, version 26). First, data were screened for outliers and distribution of data that may have violated assumptions of the statistical analysis. No outliers were found that could impede analyses and data quality was considered satisfactory for the main analyses. Due to human error, one item in the PSQ (i.e. “People are nice to me”) was omitted in the Norwegian version. This error was taken into account when calculating the AFB subscale and total scale. An independent samples t-test was used to assess differences in age between the intervention group and CAU.

To test research questions 1) and 2), whether YPF improves body esteem, and reduces social anxiety, perceived stigmatisation, and life disengagement, a series of ANCOVA's were conducted for each outcome. Group allocation (i.e. intervention or CAU) was used as the independent variable and baseline scores on the outcome measures and country (defined as Norway or the Netherlands) were used as covariates. Effect sizes (partial eta squared; η_p^2) were interpreted using Cohen's (1988) guidelines for small ($\eta_p^2 = .01$), moderate ($\eta_p^2 = .06$), and large ($\eta_p^2 = .14$) effects. To test research question 3), whether gender, age, country, time spent on YPF, and/or type of visible difference, predict post-intervention body esteem, social anxiety, perceived stigmatisation and/or life disengagement for the intervention group only, four separate hierarchical multiple regressions were conducted. Post-intervention outcome scores were used as dependent variables. In Step 1, we entered baseline scores of the respective outcomes. In Step 2, we entered gender, age, country, time spent on YPF, and type of visible difference. The hierarchical multiple regression models were evaluated using R^2 , adjusted R^2 (R^2_{adj}), and R^2 change (ΔR^2).

Table 1
Mean levels of body esteem, social anxiety, perceived stigmatisation, and life disengagement by group and time.

Variable	Intervention Group		CAU	
	Baseline <i>M</i> (SD; <i>n</i>)	Post-intervention <i>M</i> (SD; <i>n</i>)	Baseline <i>M</i> (SD; <i>n</i>)	Post-intervention <i>M</i> (SD; <i>n</i>)
Body Esteem	2.29 (0.86; 100)	2.53 (0.81; 62)	2.34 (0.84; 89)	2.44 (0.81; 77)
Social Anxiety				
FNE	20.86 (8.35; 100)	17.69 (6.42; 62)	21.26 (7.10; 89)	20.16 (7.05; 77)
SAD-New	17.27 (5.63; 100)	15.71 (4.86; 62)	17.07 (5.30; 89)	16.88 (5.76; 77)
SAD-General	8.67 (3.43; 100)	8.29 (2.90; 62)	8.94 (3.52; 89)	9.52 (3.69; 77)
Total SAS-A	46.80 (15.19; 100)	41.69 (12.11; 62)	47.27 (13.41; 89)	46.56 (14.06; 77)
Perceived Stigmatisation				
AFB	2.22 (0.54; 100)	2.13 (0.55; 61)	2.21 (0.57; 86)	2.13 (0.52; 74)
CSB	2.14 (0.66; 100)	1.92 (0.64; 61)	2.17 (0.69; 86)	2.10 (0.65; 74)
HB	1.74 (0.77; 100)	1.66 (0.67; 61)	1.82 (0.83; 86)	1.74 (0.78; 74)
Total PSQ	2.07 (0.50; 100)	1.94 (0.47; 61)	2.10 (0.52; 86)	2.02 (0.51; 74)
Life Disengagement	1.50 (0.52; 99)	1.36 (0.42; 61)	1.55 (0.48; 88)	1.51 (0.43; 74)

Note. Body Esteem = BE-Appearance Subscale; FNE = Fear of Negative Evaluation; SAD-New = Social Avoidance and Distress Specific to New Situations or Unfamiliar Peers; SAD-General = Social Avoidance and Distress in General; Total SAS-A = Social Anxiety Scale for Adolescents Total Scale; AFB = Absence of Friendly Behaviour; CSB = Confused and Staring Behaviours from Others; HB = Hostile Behaviour; Total PSQ = Perceived Stigmatisation Questionnaire Total Scale; Life Disengagement = Body Image Life Disengagement Questionnaire; CAU = Care as usual.

An alpha level of $\alpha = .05$ (two-tailed) was used for all statistical tests. To avoid issues with multiple comparisons, a correction (i.e. the Benjamini-Hochberg adjustment; Benjamini & Hochberg, 1995; reported as “corrected p ”) was applied to the main analyses including participants from both the intervention group and CAU (i.e. the ANCOVA’s) to reduce the risk of Type 1 errors. Intention-to-treat (ITT) analyses were run, as data were missing at random, using multiple imputation (MI; Rubin, 1987) to account for missing post-intervention data (Allison, 2000). One MI model was constructed separately for each outcome variable and the pooled mean of the imputed dataset consisting of five iterations was used. To improve model precision, gender and group were entered in each MI model together with baseline and post-intervention total scale scores. For transparency, the analyses were conducted using both the original dataset and with a dataset containing imputed values (i.e. ITT), and are reported accordingly in the results section. For the dataset containing the imputed values, only values based on pooled estimates are reported. As such, for the analyses conducted to test research question 3, pooled estimates were only available for the regression coefficients (see Table 4).

3. Results

3.1. Sample characteristics

Participants were 189 adolescents ($M = 14.36$ years, $SD = 1.82$, range: 11–18), with more girls ($n = 114$, 60%, $M = 14.43$ years, $SD = 1.82$) than boys ($n = 75$, 40%, $M = 14.24$ years, $SD = 1.82$). Approximately half of the participants had a craniofacial condition ($n = 100$, 53%), almost a fifth had a skin condition ($n = 42$, 22%), or conditions affecting body form such as missing limbs or fused fingers/toes ($n = 36$, 19%). The remaining participants had a scarring condition resulting from for example surgery or burns ($n = 11$, 6%). Approximately two thirds of the participants’ parents had completed primary, secondary, and/or high school as their sole education ($n = 112$ fathers, 59% and $n = 111$ mothers, 59%). The remaining parents had a university degree (i.e. Bachelor’s; $n = 21$ fathers, 11% and $n = 39$ mothers, 21%), or had an advanced degree (i.e. Master’s and/or Ph.D.; $n = 24$ fathers, 13% and $n = 20$ mothers, 11%).

3.2. Preliminary analyses

Baseline and post-intervention means and bivariate correlations for all outcome variables are presented in Tables 1 and 2. As randomisation was stratified by age only for participants living in the Netherlands, the relationship between age and group

Table 2
Bivariate correlations between all outcome variables across each group at baseline.

Variable	Intervention Group				CAU			
	1	2	3	4	1	2	3	4
1. Body Esteem	–				–			
2. Social Anxiety	–.64 ^a	–			–.46 ^a	–		
3. Perceived Stigmatisation	–.50 ^a	.58 ^a	–		–.29 ^a	.54 ^a	–	
4. Life Disengagement	–.54 ^a	.56 ^a	.51 ^a	–	–.30 ^a	.43 ^a	.43 ^a	–

Note. Body Esteem ($n = 189$) = BE-Appearance Subscale; Social Anxiety ($n = 189$) = Social Anxiety Scale for Adolescents Total Scale; Perceived Stigmatisation ($n = 186$) = Perceived Stigmatization Questionnaire Total Scale; Life Disengagement ($n = 187$) = Body Image Life Disengagement Questionnaire; CAU = Care as usual.

^a $p < .01$.

allocation for participants living in Norway was explored. For participants living in Norway, an independent samples t-test showed that age did not significantly vary between participants in the intervention group and CAU, $t(85) = 1.17$, $p = .25$. Intervention fidelity was measured by the amount of sessions completed, and around 62% of participants in the intervention group completed the seven main YPF sessions.

3.3. The effectiveness of YPF in improving primary and secondary outcomes

To explore differences between the intervention group and CAU, ANCOVA analyses were performed, using baseline primary and secondary outcome scores and country (i.e. country of residence) as covariates (see Table 3).

3.3.1. Body esteem and social anxiety

For body esteem, there was no statistically significant main effect of group post-intervention, $F(1, 135) = 0.727$, $p = .395$, $\eta_p^2 = 0.005$; corrected $p = .609$; ITT $p = .456$.

For the social anxiety total scale, there was a significant main effect of group post-intervention, with a moderate effect size, $F(1, 135) = 7.95$, $p = .006$, $\eta_p^2 = 0.06$; corrected $p = .04$; ITT $p = .017$. The adjusted post-intervention mean for the intervention group ($M = 42.09$, $SE = 1.10$) was lower compared with CAU ($M = 46.24$, $SE = 0.99$), demonstrating that social anxiety was reduced in the intervention group ($b = 4.16$). For fear of negative evaluation, there was a statistically significant main effect of group post-intervention, with a moderate effect size, $F(1, 135) = 7.26$, $p = .008$, $\eta_p^2 = 0.05$; corrected $p = .04$; but not in the ITT analyses ($p = .061$). For social avoidance

Table 3

Mean between-group difference (intervention–CAU) at post-intervention for all outcome variables, as well as standard errors, and confidence intervals. One-way analysis of covariance (ANCOVA).

Variable	Between-group difference			
	B (SE)	p-values	95% CI	η_p^2
Body Esteem	–0.08 (0.10)	.395	–0.27, 0.11	0.005
	–0.08 (0.10)	.456	–0.30, 0.14	
Social Anxiety				
FNE	2.10 (0.78)	.008*	0.56, 3.64	0.051
	1.71 (0.87)	.061	–0.09, 3.50	
SAD-New	1.14 (0.57)	.048	0.01, 2.26	0.029
	1.18 (0.55)	.033	0.10, 2.27	
SAD-General	1.01 (0.48)	.037	0.06, 1.96	0.032
	0.77 (0.42)	.069	–0.06, 1.59	
Total SAS-A	4.16 (1.48)	.006*	1.24, 7.08	0.056
	3.96 (1.56)	.017	0.77, 7.16	
Perceived Stigmatisation				
AFB	–0.01 (0.07)	.938	–0.14, 0.13	0.000
	–0.00 (0.07)	.972	–0.13, 0.13	
CSB	0.07 (0.08)	.426	–0.10, 0.23	0.005
	0.06 (0.08)	.422	–0.09, 0.22	
HB	0.02 (0.07)	.734	–0.12, 0.17	0.001
	–0.00 (0.07)	.970	–0.14, 0.13	
Total PSQ	0.02 (0.06)	.692	–0.09, 0.13	0.001
	0.00 (0.05)	.940	–0.09, 0.10	
Life Disengagement	0.11 (0.06)	.063	–0.01, 0.22	0.027
	0.09 (0.05)	.077	–0.01, 0.18	

Note. Numbers in bold indicate ITT analyses and included all participants that underwent initial randomisation (intervention group, $n = 100$; CAU, $n = 89$). b = mean between-group difference; Body Esteem ($n = 139$) = BE-Appearance Subscale; FNE ($n = 139$) = Fear of Negative Evaluation; SAD-New ($n = 139$) = Social Avoidance and Distress Specific to New Situations or Unfamiliar Peers; SAD-General ($n = 139$) = Social Avoidance and Distress in General; Total SAS-A ($n = 139$) = Social Anxiety Scale for Adolescents Total Scale; AFB ($n = 132$) = Absence of Friendly Behaviour; CSB ($n = 132$) = Confused and Staring Behaviours from Others; HB ($n = 132$) = Hostile Behaviour; Total PSQ ($n = 132$); Life Disengagement ($n = 133$) = Body Image Life Disengagement Questionnaire. Baseline scores and centre (i.e. Norway or Netherlands) served as covariates in each analysis.

* Significant at $p < .05$ after Benjamini-Hochberg adjustment.

specific to new situations or unfamiliar peers, there was a statistically significant main effect of group post-intervention with a small effect size, $F(1, 135) = 3.99$, $p = .048$, $\eta_p^2 = 0.03$; ITT $p = .033$, but not after correction ($p = .120$). For social avoidance and distress in general, there was a statistically significant main effect for group post-intervention with a small effect size, $F(1, 135) = 4.43$, $p = .037$, $\eta_p^2 = 0.03$, but not after correction ($p = .120$) and in the ITT analyses ($p = .069$).

3.3.2. Perceived stigmatisation and life disengagement

There were no statistically significant main effects post-intervention for the perceived stigmatisation total scale score ($F(1, 128) = 0.158$, $p = .692$, $\eta_p^2 = 0.001$; corrected $p = .816$; ITT $p = .940$), absence of friendly behaviour ($F(1, 128) = 0.006$, $p = .938$, $\eta_p^2 = .000$; corrected $p = .938$; ITT $p = .972$), confused/staring behaviour ($F(1, 128) = 0.639$, $p = .426$, $\eta_p^2 = 0.005$; corrected $p = .609$; ITT $p = .422$), or hostile behaviour ($F(1, 128) = 0.116$, $p = .734$, $\eta_p^2 = 0.001$; corrected $p = .816$; ITT $p = .970$). Country was significantly related to the hostile behaviour subscale post-intervention ($F(1, 128) = 5.879$, $p = .017$), indicating that participants in the Netherlands had higher perceptions of hostile behaviours compared with participants living in Norway. However, the main effect of country was not significant in the ITT analyses ($p = .077$).

For life disengagement, there was a non-significant main effect for group post-intervention ($F(1, 129) = 3.519$, $p = .063$, $\eta_p^2 = 0.027$; corrected $p = .126$; ITT $p = .077$).

3.4. Underlying predictors related to potential intervention improvements

To explore variables (i.e. baseline outcome scores, age, gender, time spent on YPF, and type of visible difference) that could potentially influence post-intervention outcome scores for the intervention group, while controlling for baseline scores, hierarchical multiple regression were conducted (see Table 4 for values from the original dataset and pooled estimates from the ITT analyses).

3.4.1. Predictors of primary outcomes

3.4.1.1. Body esteem. In Step 1, baseline scores significantly accounted for 51.7% of the variance in body esteem post-intervention, $F(1, 60) = 64.34$, $p < .001$. In Step 2, adding age, gender, country, time spent on YPF, and type of visible difference did not significantly improve the model, indicating that these variables did not explain variations in body esteem.

3.4.1.2. Social anxiety. In Step 1, baseline scores significantly accounted for 58.7% of the variance in social anxiety post-intervention, $F(1, 60) = 85.12$, $p < .001$. In Step 2, an additional 10.4% of the variance was significantly accounted for after introducing age, gender, country, time spent on YPF, and type of visible difference, into the model, $F(7, 53) = 2.55$, $p = .025$. Gender ($p = .016$) and country ($p = .046$) emerged as statistically significant predictors of overall levels of social anxiety post-intervention, where girls reported higher levels of social anxiety compared with boys, and participants living in the Netherlands had higher levels of social anxiety compared with participants living in Norway.

3.4.2. Predictors of secondary outcomes

3.4.2.1. Perceived stigmatisation. In Step 1, baseline scores significantly accounted for 54.4% of the variance in perceived stigmatisation post-intervention, $F(1, 59) = 70.27$, $p < .001$. In Step 2, adding age, gender, country, time spent on YPF, and type of visible difference did not significantly improve the model.

3.4.2.2. Life disengagement. In Step 1, baseline scores significantly accounted for 46.4% of the variance in life disengagement post-intervention, $F(1, 58) = 50.14$, $p < .001$. In Step 2, adding age, gender, country, time spent on YPF, and type of visible difference did not significantly improve the model.

4. Discussion

The current study is the first large-scale RCT to evaluate the effectiveness of Young Person's Face IT in improving body esteem, and/or reducing social anxiety, perceived stigmatisation, and life disengagement in adolescents with a visible difference. In general, results indicated that, compared with CAU, levels of social anxiety for the total scale were lower in the intervention group post-intervention. However, the intervention group did not significantly differ from CAU on levels of body esteem, perceived stigmatisation, or life disengagement post-intervention.

4.1. Web-based psychosocial support to reduce social anxiety

Research on adolescent samples with a visible difference has demonstrated higher levels of anxiety and fear of negative evaluations in this population (Griffiths et al., 2012; van Dalen et al., 2020). The results from the present study are therefore interesting and promising in that adolescents who completed the YPF programme displayed lower levels of social anxiety post-intervention, compared with CAU. This finding is also in line with Williamson et al. (2019).

Reduced levels of social anxiety may indicate that participants who completed YPF learned new social skills and anxiety-

Table 4

Hierarchical multiple regressions predicting changes in body esteem, social anxiety, perceived stigmatisation, and life disengagement, from baseline outcome scores, age, gender, country, time spent on YPF and/or type of visible difference of participants in the intervention group.

Step	Variable	Body Esteem			R ²	R ² _{adj}	ΔR ²	ΔF
		B (SE)	β	B 95% CI				
Step 1	Baseline body esteem	0.69 (0.09) ^a .066 (0.09)^a	0.72	0.52, 0.86 0.47, .085	0.52	0.51	0.52	64.34 ^a
Step 2	Baseline body esteem	0.65 (0.09) ^a 0.65 (0.10)^a	0.68	0.47, 0.84 0.44, 0.86	0.59	0.52	0.07	1.23
	Gender	-0.31 (0.16) -0.18 (0.13)	-0.19	-0.62, 0.00 -0.43, 0.07				
	Age	0.03 (0.04) 0.03 (0.03)	0.08	-0.05, 0.12 -0.31, 0.10				
	Country	-0.32 (0.16) -0.18 (0.15)	-0.19	-0.64, 0.01 -0.48, 0.12				
	Time spent on YPF	0.00 (0.01) 0.00 (0.01)	0.00	-0.02, 0.02 -0.02, 0.02				
	Skin condition	-0.05 (0.22) -0.03 (0.19)	-0.03	-0.49, 0.40 -0.41, 0.35				
	Craniofacial condition	0.13 (0.20) 0.07 (0.16)	0.08	-0.27, 0.53 -0.25, 0.38				
	Scarring condition	-0.03 (0.45) 0.14 (0.37)	-0.01	-0.92, 0.87 -0.59, 0.86				
Social Anxiety								
Step	Variable	B (SE)	β	B 95% CI	R ²	R ² _{adj}	ΔR ²	ΔF
Step 1	Baseline social anxiety	0.59 (0.06) ^a 0.60 (0.06)^a	0.77	0.46, 0.72 0.49, 0.71	0.59	0.58	0.59	85.12 ^a
Step 2	Baseline social anxiety	0.55 (0.07) ^a 0.58 (0.06)^a	0.71	0.42, 0.68 0.45, 0.71	0.69	0.64	0.10	2.55 ^b
	Gender	5.06 (2.03) ^b 4.27 (1.66)^b	0.21	0.99, 9.13 1.00, 7.54				
	Age	0.12 (0.55) 0.08 (0.52)	0.02	-0.98, 1.22 -0.97, 1.14				
	Country	4.45 (2.18) ^b 1.59 (2.46)	0.18	0.08, 8.81 -3.67, 6.85				
	Time spent on YPF	-0.09 (0.13) -0.09 (0.13)	-0.05	-0.35, 0.18 -0.37, 0.18				
	Skin condition	1.90 (2.86) 1.86 (2.55)	0.07	-3.85, 7.64 -3.14, 6.85				
	Craniofacial condition	-2.50 (2.59) -1.05 (2.36)	-0.10	-7.69, 2.69 -5.72, 3.62				
	Scarring condition	-7.54 (5.76) -3.90 (5.02)	-0.11	-19.10, 4.02 -13.78, 5.98				
Perceived Stigmatisation								
Step	Variable	B (SE)	β	B 95% CI	R ²	R ² _{adj}	ΔR ²	ΔF
Step 1	Baseline perceived stigmatisation	0.67 (0.08) ^a 0.70 (0.07)^a	0.74	0.51, 0.83 0.57, 0.83	0.54	0.54	0.54	70.27 ^a
Step 2	Baseline perceived stigmatisation	0.66 (0.09) ^a 0.72 (0.07)^a	0.73	0.49, 0.84 0.58, 0.86	0.58	0.52	0.04	0.73
	Gender	0.06 (0.09) 0.07 (0.08)	0.06	-0.12, 0.24 -0.09, 0.23				
	Age	0.01 (0.03) 0.00 (0.02)	0.03	-0.04, 0.06 -0.04, 0.05				
	Country	0.08 (0.10) 0.01 (0.07)	0.08	-0.11, 0.27 -0.13, 0.15				
	Time spent on YPF	0.00 (0.01) -0.00 (0.01)	0.04	-0.01, 0.01 -0.01, 0.01				
	Skin condition	-0.21 (0.13) -0.12 (0.11)	-0.21	-0.47, 0.05 -0.34, 0.10				
	Craniofacial condition	-0.20 (0.12) -0.10 (0.10)	-0.22	-0.43, 0.03 -0.29, 0.10				
	Scarring condition	-0.39 (0.26) -0.12 (0.24)	-0.15	-0.91, 0.13 -0.62, 0.37				

(continued on next page)

Table 4 (continued)

		Life Disengagement			R ²	R ² _{adj}	ΔR ²	ΔF
		B (SE)	β	B 95% CI				
Step 1	Baseline life disengagement	0.55 (0.08) ^a 0.52 (0.06)^a	0.68	0.39, 0.70 0.41, 0.63	0.46	0.45	0.46	50.14 ^a
Step 2	Baseline life disengagement	0.47 (0.08) ^a 0.49 (0.06)^a	0.59	0.31, 0.63 0.38, 0.60	0.56	0.49	0.10	1.62
	Gender	0.19 (0.09) ^b 0.16 (0.06)^b	0.23	0.02, 0.37 0.04, 0.29				
	Age	0.01 (0.02) 0.01 (0.02)	0.04	-0.04, 0.06 -0.02, 0.04				
	Country	0.03 (0.09) -0.03 (0.06)	0.04	-0.15, 0.22 -0.15, 0.09				
	Time spent on YPF	0.01 (0.01) 0.00 (0.00)	0.15	-0.00, 0.02 -0.01, 0.01				
	Skin condition	0.08 (0.12) 0.09 (0.10)	0.09	-0.16, 0.32 -0.11, 0.30				
	Craniofacial condition	-0.04 (0.11) 0.02 (0.08)	-0.04	-0.25, 0.18 -0.15, 0.18				
	Scarring condition	0.04 (0.24) 0.06 (0.20)	0.02	-0.45, 0.52 -0.33, 0.46				

Note. Numbers in bold indicate ITT analyses and included all participants that were initially randomised to the intervention group ($n = 100$). Body Esteem ($n = 62$) = BE-Appearance Subscale; Social Anxiety ($n = 62$) = Social Anxiety Scale for Adolescents Total Scale; Perceived Stigmatisation ($n = 61$) = Perceived Stigmatization Questionnaire Total Scale; Life Disengagement ($n = 60$) = Body Image Life Disengagement Questionnaire

^a $p < .001$.

^b $p < .05$.

management techniques over the course of the programme that contributed to a reduction in anxiety during social interactions. For instance, sessions in YPF specifically includes advice and guidance on how adolescents can handle teasing and bullying, and deal with unwanted attention such as staring and inappropriate questions, with opportunities to practice new social interaction skills via the programme's interactive videos, that they can then test in real-life situations (Williamson et al., 2019). YPF also includes CBT-based sessions that teach adolescents how to challenge negative thoughts and feelings, how to set realistic goals to overcome self-imposed limitations, and how to overcome social anxiety using anxiety-management techniques (Williamson et al., 2019).

The reduction in social anxiety among participants who completed YPF is consistent with the aim of the programme and aligns with previous research demonstrating that adolescents can adjust more positively to their visible difference by increasing their social skills repertoire, which may help them appear more confident, interesting, social and friendly to peers (Blakeney et al., 2005; Edwards et al., 2011). Additionally, CBT-based interventions, delivered face-to-face to adolescents with a visible difference (Maddern et al., 2006) or delivered online to adolescent community samples (Stjerneklar et al., 2019), have also proved effective in reducing anxiety. Thus the most important finding from this study is that YPF, an easily accessible self-guided intervention providing context-specific training in social skills to manage challenging social interactions combined with anxiety management and CBT-techniques to challenge unhelpful thought patterns, can contribute to reduced levels of social anxiety. However, it should also be noted that although our results regarding social anxiety were significant on a total scale level, results were a bit more inconclusive on a subscale level. For instance, although we did find statistically significant reductions in the three subscales of the SAS-A, these were found to be non-significant after corrections were applied (for social avoidance in new and unfamiliar situations, and distress in general), and in the ITT-analyses (for fear of negative evaluation).

4.2. Measuring body esteem, perceived stigma, and life disengagement in adolescents with a visible difference

In contrast to the present study's encouraging results regarding the effectiveness of YPF in reducing social anxiety, our results also showed

that YPF did not improve body esteem, or reduce perceived stigmatisation and life disengagement among adolescents who completed the intervention. This is in contrast to Williamson et al. (2019), who found positive changes for body esteem post-intervention in a much smaller sample. Although results from this larger RCT indicate that YPF is not being effective in improving these outcomes, factors that may have contributed to this result warrant discussion.

Although this study included acknowledged, reliable, and valid measures tested with the general population, chosen measures may not be sensitive enough to identify challenges specific to adolescents living with a visible difference. For instance, the Appearance Subscale of the BESAA (Mendelson et al., 2001) that was included in our study is primarily aimed at assessing adolescents' general appearance satisfaction, without specifically addressing concerns related to the presence and nature of a visible difference. A generic measure was chosen, since the large variation in included types of visible differences impeded the use of condition-specific measures. A general challenge within appearance-related research is the lack of validated psychometric cross-condition instruments that assess appearance concerns specifically in adolescents with a visible difference (Moss, Bailey, Griffiths, Lawson, & Williamson, 2014). It might therefore be the case that existing measures were not sensitive enough to capture variations in individuals' experiences of living with a visible difference and some measures therefore missed potential interventional benefits. Nonetheless, body esteem levels are generally found to be higher in adolescent community samples (e.g. Frisén et al., 2015) compared to the current study sample. This could indicate that the Appearance Subscale of the BESAA did capture some dissatisfaction with body esteem in our sample of adolescents with visible differences, even if differences between the intervention group and CAU were not found post-intervention.

Participants' degree of engagement with YPF may also have played a role. In the study by Williamson et al. (2019), engagement with YPF (defined as number of YPF sessions completed) was significantly related to positive changes in body esteem and reduced fear of negative evaluation post-intervention. In the present study, a slightly different measurement of engagement was included, that is, how many weeks participants spent completing YPF, irrespective of whether they completed all sessions or not. Both variables may indicate participants' engagement and

motivation in slightly different ways, and engagement with the intervention may presumably include additional aspects. These may include adolescents' own motivation to comply with intervention sessions, number of sessions completed and the amount of time spent on each session, and whether participants were prompted to complete the programme by the research team and/or by caregivers. It could be that increased intervention engagement is associated with increased intervention effects (Williamson et al., 2019). Future studies should therefore aim to capture how to measure engagement and also include different aspects of engagement, in order to obtain a more correct picture of how engagement with YPF relates to intervention effects.

4.3. Predictors related to intervention improvements

Hierarchical multiple regressions were conducted to explore variables that could have had an impact on post-intervention outcome scores among the intervention group. Overall, results did not provide support for age, country (i.e. country of residence), time spent on YPF, nor type of visible difference, in predicting possible improvements in adolescents that completed YPF, while controlling for baseline outcome scores. The presence of a visible difference is well known to be a cause of appearance-related distress in adolescents (Griffiths et al., 2012; van Dalen et al., 2020), irrespective of variations in size and location of the visible difference (Moss, 2005). This overall finding from general appearance research on the psychology of visible differences was confirmed in the present study, since variations in outcome measures were not related to types of included conditions or diagnoses.

Gender, however, significantly predicted social anxiety post-intervention, after accounting for baseline levels. Although social anxiety decreased from baseline to post-intervention for both boys and girls in the intervention group and CAU (as shown in Table 1), the hierarchical multiple regressions conducted only with the intervention group showed that gender differences in levels of social anxiety that were present at baseline (where girls reported more social anxiety than boys), were further increased after completing YPF. These results might potentially indicate that YPF is more effective in reducing social anxiety among boys than girls with a visible difference. Further investigation on the potential impact of gender on the effectiveness of an intervention such as YPF is therefore warranted.

4.4. Clinical implications and future research

Taken together, this study demonstrates that web-based psychosocial support, combining SST and CBT techniques, may contribute to reduced levels of social anxiety in adolescents with a visible difference. The usefulness of YPF is further supported by the fact that these changes also were clinically meaningful. Although, the effects of YPF on body esteem, perceived stigmatisation, and life disengagement were not significant, we propose that these findings require further investigation, with consideration to the included measures and aspects related to adolescents' engagement with the intervention, as discussed above. Nonetheless, our results suggest that YPF may benefit adolescents who struggle with social anxiety, a common challenge related to living with a visible difference.

It is important to note that other views exist in contrast to the definition of a clinically meaningful change used in the present study (i.e. a medium effect size). Some suggest that statistically significant group differences and effect sizes cannot provide information about clinical or practical relevance (Ogles, Lunnen, & Bonesteel, 2001; Pogrow, 2019), owing to a lack of information about the variety of individual responses to treatment. However, there are no standardised ways of defining a clinically meaningful change and

several approaches exist (Jacobson, Roberts, Berns, & McGlinchey, 1999). Additionally, BESAA, for instance, is not thoroughly validated in clinical populations (Kling et al., 2019) and we currently have no evidence of what the expected clinically meaningful change is for adolescents with a visible difference that have completed a web-based intervention based on SST and CBT. No normative data therefore exist with which to compare the results from the present study.

Nonetheless, the present study demonstrates that YPF seems to positively impact adolescents' social anxiety. This is a promising finding, since research and clinical experience indicate that many adolescents with a visible difference have limited access to specialised, evidence-based, and tailored interventions (Williamson et al., 2019), highlighting the usefulness of easy accessible treatment offers such as YPF for those who experience appearance-related anxiety. Combined with ease of accessibility, the content of YPF also makes the intervention attractive. YPF provides adolescents with the opportunity to learn and incorporate social coping skills that can be easily practiced and applied to real-life settings, and encourages adolescents to challenge negative appearance-related thoughts. Web-based psychosocial support may also become especially relevant when access to traditional face-to-face support is particularly limited. For example, psychosocial support was demonstrated to be restricted for many adolescents with chronic health conditions during the COVID-19 pandemic (Serlachius, Badawy, & Thabrew, 2020). This makes YPF an especially useful and accessible alternative for adolescents with a visible difference in need of immediate support.

In clinical settings, YPF may be incorporated as a low-level independent intervention for those who do not require complex clinical support and adolescents could self-refer, or used as an adjunct to support face-to-face therapy. However, incorporating web-based psychosocial support into the healthcare system is not straightforward. In a comparative case study, Folker et al. (2018) identified several barriers in implementing ICBT-based services in routine care settings, including financing, intake of patients, and scepticism from general practitioners towards ICBT. Lack of knowledge by stakeholders about the effectiveness of web-based psychosocial support and concerns about implementation also seem to constitute significant barriers towards integration of such services in the healthcare system (Topooco et al., 2017). It is therefore important to clarify aspects such as who should be in charge of monitoring patients, how patients should be recruited/referred, where financial resources should come from, and whether YPF should be implemented only in local support systems or across the healthcare system. Disseminating information to stakeholders about how ICBT-based interventions work and could be implemented, may perhaps also work to avoid unnecessary delays in the implementation process. More research is needed to shed light on these important questions regarding the implementation of web-based interventions such as YPF.

Future studies are also needed to investigate the potential short-term and long-term effectiveness of YPF in improving body esteem and reducing social anxiety, perceived stigmatisation, and life disengagement. Additionally, future research should consider investigating whether YPF could be offered as an early intervention to pre-adolescents who are at risk of developing symptoms of social anxiety and/or dissatisfaction with appearance due to a visible difference, and who may benefit from increasing their range of social skills and challenge negative appearance-related thoughts. YPF may also constitute an available alternative to traditional face-to-face treatment for adolescents who have conditions without regular medical follow-up and who may need psychosocial support, and for those who are not receiving psychological treatment elsewhere. We therefore also encourage further investigation on the cost-effectiveness of implementing the intervention.

4.5. Strengths and limitations

The main strength of the current study was the RCT-design, which made it possible to eliminate many potential confounders and thus improve internal validity. The study was also a result of an international collaboration and included participants from two countries, which strengthens the generalisability of results to a broader population. Additionally, we secured a large enough sample size to reach sufficient power to detect statistically significant changes in outcomes, which is often a general challenge within the visible difference research field (Gee et al., 2018; Williamson et al., 2019) and in intervention studies (Axén, Brämberg, Bakken, & Kwak, 2021).

Despite the study strengths, several limitations need to be considered. First, our study only included two points of assessment. Including an assessment after participants' completed the seven main YPF sessions, and before the booster session, could have provided an estimate of immediate intervention effects. Additionally, including an assessment to measure long-term intervention effects (e.g. three to six months post-intervention) would have provided an estimate of participants' outcome levels in the longer term, and determined the course and stability of intervention effects. Future research should therefore test the potential immediate and long-term effect of YPF, and evaluate whether improvement levels differ over time.

Second, although we used validated outcome instruments, included measures were not constructed specifically for a population consisting of adolescents with visible differences, and were therefore possibly not sensitive enough to capture changes in the adolescents' adjustment to their visible difference following completion of the intervention. However, there are currently no cross-condition measures that possibly would assess such changes. We therefore encourage future studies to identify measures that are sensitive enough to capture potential distress in adolescents with a visible difference across conditions, and/or consider developing new instruments specifically tailored to examine relevant outcome variables, in mixed groups such as in the present study. Additionally, outcome measures that were translated into Norwegian and/or Dutch for this specific study have not undergone language-specific psychometric evaluations, which is a methodological limitation. Relatedly, to the authors knowledge, no studies have tested measurement invariance for the Norwegian and Dutch version of BESAA, SAS-A, PSQ, or BILD-Q, which indicate whether the construct measured by a questionnaire has the same meaning to the same or different groups across different measurements (Putnick & Bornstein, 2016), which we acknowledge as a study limitation.

Third, there were some methodological differences between the two study sites that could have impacted on the results. Waiting-list control groups may prompt expectations influencing outcome scores. On the other hand, this solution was chosen in the Norwegian sample in order to secure recruitment and reduce ethical concerns, since the pilot study (Feragen, 2017) indicated that participants and parents found it difficult to accept that YPF would not be offered to participants in the control group. Moreover, no screening for subclinical symptoms was done in the study site in Norway and participants were therefore included irrespective of levels of body esteem, social skills, and/or symptoms of depression. However, the randomisation procedure and ANCOVA models should account for systematic baseline differences between participants and no differences were found for gender or type of visible difference between the two experimental groups. Nonetheless, variations in baseline outcome levels between the two study sites could mean that participants had different experiences of appearance-related distress and support needs, which may in turn have affected intervention effects.

Fourth, we only explored main effects when testing our research questions. Exploring interaction effects could have provided a better understanding of whether intervention effects differed between

boys and girls among those that completed YPF. Furthermore, although we found that gender predicted changes in social anxiety and life disengagement for the intervention group post-intervention, it could be that the main effect of gender was dependent on another moderating variable. Larger samples are therefore needed in order to shed light on this important issue.

Fifth, when reporting intervention fidelity and measuring adolescents' engagement with YPF we included only one possible aspect of engagement, namely how many weeks adolescents spent completing the intervention, irrespective of the number of sessions completed. Future studies should report other aspects related to fidelity, such as time spent on each intervention session, and include a closer investigation on how different aspects of adolescents' engagement with YPF could relate to intervention effects.

Sixth, strict exclusion criteria were employed when recruiting participants. Excluding adolescents with clinically diagnosed conditions (i.e. depression, psychosis, eating disorders, and PTSD), or those receiving another type of psychological treatment, may have limited the generalisability of our results to the sub-group of adolescents with comorbid mental health conditions. We therefore suggest that future studies also aim to include adolescents who may have a clinically diagnosed mental health condition and/or are receiving another type of psychological support, in order to evaluate the effectiveness of YPF also for this group. Furthermore, although we consistently reported how many participants were excluded from the analyses, reasons for exclusion of participants who did not meet eligibility criteria were only described using main categories (i.e. not meeting other inclusion criteria). As such, we encourage future RCTs to report information about exclusion of participants in detail.

Another limitation concerns socio-economic status (SES). Even though parents' SES has been previously found to influence adolescents' health-related quality of life (Kim, Wallander, Depaoli, Elliott, & Schuster, 2021), we did not control for SES in our analyses. This was due to the fact that parents' SES was assessed differently in Norway versus the Netherlands, and these different assessments could not be reliably equated. However, we recommend that future studies include indicators of SES in analyses of the YPF intervention to explore its potential influence.

Finally, the lockdown that ensued in both participating countries from COVID-19 might have negatively impacted participants' psychological well-being and/or influenced results. We were not able to systematically control for possible influences of COVID-19 due to several reasons, including a lack of resources and because participants were enrolled in the study before and during the pandemic. Additionally, the pandemic presented unique challenges to both countries and governmental efforts to control the virus were different. Hence, participants who completed the intervention during lockdown may not have had the same opportunity to apply new social skills as adolescents completing YPF with fewer social restrictions. Considering the impact that the COVID-19 lockdown may have had on adolescents' body image (Vall-Roqué, Andrés, & Saldaña, 2021), future studies should investigate how the pandemic might have affected the psychological well-being of adolescents with a visible difference.

5. Conclusion

This is the first study to experimentally test the effectiveness of Young Person's Face IT, a web-based psychosocial intervention developed for adolescents experiencing appearance-related distress and social challenges as a result of living with a visible difference. Our results showed that participants who completed YPF reported reduced social anxiety symptoms post-intervention, compared to participants receiving CAU. We found no intervention effect on body esteem, perceived stigmatisation, or life disengagement. To conclude, our study supports the notion of a web-based intervention

such as YPF having the potential to provide adolescents with knowledge and skills to manage the adverse social consequences of having a visible difference. Future studies are encouraged to further explore the effectiveness of YPF and its potential in reducing social anxiety, as well as investigating its long-term effects.

Declaration of interests

None.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Predictors of adolescents' response to a web-based intervention to improve psychosocial adjustment to having an appearance-affecting condition (Young Person's Face IT)

Abstract

Background: Adolescents with a condition affecting their appearance that results in a visible difference can be at risk of psychosocial distress and impaired adjustment. Evidence for the effectiveness of existing interventions in improving psychosocial outcomes is limited and relevant treatment can be difficult to access. Young Person's Face IT (YPF), a novel self-guided web-based intervention, has demonstrated potential in reducing social anxiety in adolescents with visible differences. However, more knowledge is needed regarding factors that contribute to variations in intervention effects in order to identify which adolescents may benefit most from YPF. **Objective:** This study aimed to identify predictors related to overall intervention effects following adolescents' use of YPF. **Method:** N=71 adolescents (61% girls; mean age 13.98, range 11–18 years) with a wide range of visible differences completed primary (body esteem and social anxiety symptoms) and secondary (perceived stigmatization, life disengagement, and self-rated health) outcome measures, at baseline and post-intervention. Predictor variables were demographic (age and gender), psychosocial (frequency of teasing experiences related to aspects of body and appearance, and depressive and/or anxiety symptoms), and intervention-related (time spent on YPF) factors. **Results:** Backward multiple regression revealed that higher intervention effects were predicted by gender, baseline frequency of teasing experiences, levels of depressive and/or anxiety symptoms, and time spent on YPF. However, the results were limited by low proportion of explained post-intervention variance, ranging from 1.6 to 24.1%. **Conclusions:** This study suggests that adolescent boys, adolescents who experience higher levels of psychosocial distress related to their visible difference, and adolescents that spend sufficient time on YPF, may obtain better overall intervention effects.

Trial registration number: NCT03165331.

Keywords: visible difference; web-based-interventions; e-health; body esteem; social anxiety; adolescents

Introduction

Background

Physical appearance can be a source of psychological and social distress, especially during adolescence. A heightened focus on appearance and pressures to conform to appearance ideals may negatively affect adolescents' psychological health in terms of anxiety, depression, and low self-esteem.^[1] Moreover, negative peer influences, including teasing related to appearance and weight, may put adolescents at a particular risk of psychosocial distress, including body dissatisfaction.^[2] Consequently, having an appearance that is not accordant with societal norms may make some adolescents particularly vulnerable to appearance concerns and stigmatizing experiences.^[3, 4]

A range of congenital and acquired conditions may affect facial or bodily appearances and lead to what is referred to as a visible difference.^[5] Congenital conditions may include craniofacial (e.g., cleft lip/palate or differences of sex development) and skin conditions (e.g. eczema or psoriasis).^[5, 6] Acquired conditions may result from medical interventions (e.g., hair loss from radiation therapy) or accidental traumas (e.g. traffic injuries and burn scars). Prevalence rates of those living with a visible condition are uncertain, although estimations show that around 2.27 % of individuals have a visible difference, with a significant yearly incidence of an acquired visible difference.^[7]

Demographic and psychosocial influences on adolescents' adjustment to a visible difference

Some of the main challenges encountered by many adolescents with a visible difference include experiences of being stared at and questioned about their appearance by others,^[3] and teased or bullied by peers because they look different.^[8-10] Some studies also suggest that age may play a role in experiences of having a visible difference. As children transition into adolescence, they

may become increasingly aware of their condition and how it affects their appearance.^[11]

Longitudinal findings also show that experiences of teasing during adolescence may have a negative impact on appearance satisfaction and emotional well-being.^[12] Additionally, more frequent stigmatization has been predicted by higher age in children, as reported by their parents.^[3]

Experiences of teasing can negatively influence adolescents' self-esteem and lead some to choose behavioural avoidance, refraining from engagement in social activities, as a coping strategy for fear of being teased for their difference^[9, 10] or negatively evaluated by others.^[13] Moreover, studies show that stigmatizing experiences attributable to a visible difference can negatively influence adolescents' psychological adjustment and health-related quality of life.^[14] It is therefore not surprising that adolescents with a visible difference, irrespective of type and severity, may report increased symptoms of anxiety compared to unaffected peers.^[15] These findings underscore that challenging peer interactions, and particularly those of a stigmatizing nature, may be especially impactful on psychosocial well-being during adolescence.

It is generally recognized from adolescent community samples that adolescent girls tend to experience lower body esteem than adolescent boys^[16] and also report greater disengagement in activities such as school attendance and spending time with friends and family.^[17] There is also evidence suggesting gender differences within samples affected by a visible difference.^[4, 8, 18] For instance, studies have found higher levels of emotional and social challenges,^[19] higher levels of anxiety,^[18] and lower appearance satisfaction in girls compared to boys.^[4, 8]

Available support to promote adolescents' adjustment

Support for adolescents with a visible difference currently consists of biomedical and psychosocial alternatives.^[5] Biomedical interventions can include medical and surgical procedures to correct or "fix" appearance differences, and may not necessarily lead to enhanced psychosocial functioning or solve underlying challenges such as experiences of teasing.^[5, 20] Developing successful psychosocial interventions should therefore be acknowledged as a priority.^[5, 21] Psychosocial support has typically been based on an eclectic approach and included a wide range of therapeutic

approaches and techniques, such as Social Skills Training (SST), techniques based on Cognitive Behavioural Therapy (CBT), psychoeducation, mindfulness, and acceptance and commitment therapy.^[22] Psychosocial interventions incorporating techniques based on SST and CBT have specifically shown potential in improving psychosocial well-being and promoting adjustment in adolescents challenged by their visible difference,^[23, 24] and may be offered as an alternative or adjunct to biomedical support.^[5] Specifically, Blakeney et al^[25] demonstrated that adolescents with burn injuries reported less withdrawal from social situations, after completing an intensive SST intervention. Similarly, Maddern et al^[26] demonstrated that children and adolescents with craniofacial and scarring conditions reported fewer experiences of teasing and a reduction in anxiety levels, after completing an intervention based on SST and individual face-to-face CBT sessions. Study designs describing benefits associated with SST and CBT-techniques need to be strengthened by more stringent research methods, such as randomized controlled trials (RCT) evaluating the short- and long-term effects of existing interventions.^[23]

Emerging research also indicates that guided Internet-Delivered Cognitive Behavioural Therapy (ICBT) can be effective in treating psychological difficulties such as anxiety^[27] and depression^[28] in adolescent community samples. Higher levels of baseline anxiety and depression have also been found to predict increased intervention response to ICBT.^[29] ICBT has shown intervention effects on mental health outcomes that are comparable to standard face-to-face CBT, and may represent a more cost-effective and accessible treatment alternative.^[30] ICBT could also offer several benefits for adolescents experiencing challenges related to their visible difference. For instance, since raising appearance issues face-to-face with healthcare professionals may be experienced as too personal and difficult,^[31] some adolescents could favor more easily accessible support that offers a greater degree of anonymity and confidentiality when discussing appearance concerns.^[13]

Young Person's Face IT (YPF)

To date, YPF is the only self-guided internet intervention utilizing a web-based platform developed for adolescents with a visible difference. YPF was developed at the Centre for Appearance Research based at the University of the West of England, UK, in close collaboration with adolescents with visible differences and their parents, clinical experts, and health professionals.^[24, 32] The therapeutic content is based on SST and CBT-techniques, and consists of seven weekly sessions and one booster session completed six weeks later to maintain therapeutic effect.^[32] Each session is completed independently and is intended to take around 30-40 minutes. Sessions provide advice and guidance on how to adjust to common challenges related to having a visible difference in written, audio, and video formats, and encourage adolescents to practice strategies to manage staring, bullying, and anxiety, through interactive and homework activities (for a more detailed description of the intervention, see Williamson et al^[32]).

The feasibility and acceptability of YPF has been explored in several countries (Unpublished report),^[24, 33-35] and a smaller feasibility trial found increased post-intervention levels of body esteem and lower levels of social anxiety in adolescents' who completed YPF, compared with a control group.^[24] Intervention engagement (defined as number of YPF sessions completed) was also found to be a contributory factor in the smaller feasibility trial, with higher number of sessions completed predicting a positive intervention effect.^[24] The effectiveness of YPF in improving body esteem and reducing symptoms of social anxiety, perceived stigmatization, and life disengagement, was also recently evaluated in a RCT (Author et al., under review). The RCT showed that adolescents' in the intervention group had significantly lower levels of social anxiety compared with the control group post-intervention. The RCT also indicated a gender difference, showing that the intervention response to YPF appeared to be stronger for boys compared with girls for social anxiety and life disengagement (Author et al., under review).

Study objectives

The objective of this exploratory study was to contribute to the accumulating body of research on the effectiveness of YPF in promoting adolescents' adjustment to their visible difference (Author, Under review; Unpublished report),^[24, 33-35] by further investigating which adolescents that are likely to benefit from the intervention. Based on knowledge about variables of importance from previous research, we specifically investigated whether demographic (age and gender), psychosocial (frequency of teasing experiences and depressive and/or anxiety symptoms), and intervention-related (time spent on YPF) variables, predict changes in body esteem and social anxiety (primary outcomes), and perceived stigmatization, life disengagement, and self-rated health (secondary outcomes) in adolescents with a visible difference following completion of YPF.

Methods

Study design

The current study utilized longitudinal data collected as part of a larger ongoing mixed-methods project and RCT study investigating the effectiveness of the [Language] version of YPF (Trial registration number: NCT03165331). The study was conducted at the [Centre], [City] University Hospital, reviewed by the Regional Committee for Medical Research Ethics (Health Region South-East, reference number: [Number]), and accepted by the hospital's Data Protection Office.

Procedure

Participants were recruited between April 2019 and February 2021. In addition to new participants, participants in the current study were partly the same as those included in the study by Author et al. (under review), which was also conducted as part of the larger project in [Country]. Participants were recruited nationwide from University Hospitals, specialist treatment units, local healthcare services, patient organisations, and through social media platforms.^[36] Participants and/or participants' primary caregivers contacted the research team by telephone or email if they wished to participate in the study. Following initial contact, all participants (and/or parents if

adolescent <16 years) were contacted via telephone by the research team, and were screened for eligibility. Inclusion criteria were: 1) age between approximately 12-17 years with a visible difference and self-identified appearance-related distress, teasing, bullying; 2) access to the internet and a home computer or tablet; 3) minimum reading level corresponding to that of a 12 year-old; 4) normal or corrected-to-normal vision. Exclusion criteria were: 1) a diagnosis of clinical depression, psychosis, eating disorder, and post-traumatic stress disorder (PTSD), or within 12 months of traumatic injury; 2) learning disabilities that would impede understanding of the intervention content; 3) currently receiving a psychological face-to-face intervention. After screening for inclusion and exclusion criteria, informed consents were obtained. For participants < 16 years, consents were also obtained from both primary caregivers. After consent forms had been received, participants completed outcome measures (baseline) and were subsequently randomized to an intervention group receiving YPF or to a waiting list control group. Participants in the latter group received the intervention (YPF) thirteen weeks after the intervention group and completed outcome measures before commencing intervention start-up. Participants from both groups completed outcome measures thirteen weeks after completing YPF (post-intervention). In the current study, all participants who had completed YPF (from both the intervention group and the waiting list control group) were included. Outcome measures were administered through a secure online data collection platform (Services for Sensitive Data; [Acronym]) accepted by [City] University Hospital.

Participants

We assessed 137 participants for eligibility of which 102 were randomized. Of these 102 participants, we excluded 31 due to missing post-intervention data. One was identified as an outlier and one did not commence intervention start-up, and both were removed from the data set. The final sample included 71 participants (61% girls) aged 11–18 years (mean=13.98 years, SD=1.74). Over two-thirds of participants had a craniofacial condition (69%), such as a cleft lip and/or palate or a craniosynostosis. Under one-third of participants had a condition affecting body form (17%), such

as missing limbs or changes due to disease, a skin condition (11%) such as ichthyosis or psoriasis, or an acquired condition (3%), such as scarring due to surgery.

Measures

Outcomes

Body esteem. The appearance esteem subscale (BE-Appearance) of the Body Esteem Scale for Adolescents and Adults (BESAA) assessed body esteem.^[37] The subscale contains ten items rated on a five-point Likert scale ranging from 0 (*never*) to 4 (*always*). Statements include “I worry about the way I look” and “I look as nice as I’d like to”. After negatively worded items have been reversed, higher mean values indicate higher levels of appearance esteem. The BESAA has shown good psychometric properties among adolescent community samples^[16] and among adolescents with a visible difference.^[38] In this study, for the BE-Appearance subscale, Cronbach alpha was $\alpha=.89$ for boys and $\alpha=.95$ for girls.

Social anxiety. The Social Anxiety Scale for Adolescents (SAS-A) assessed experiences of social anxiety.^[39] SAS-A contains 22 items (four filler items not included in calculations) divided into three subscales that are rated on a five-point scale ranging from 1 (*never*) to 5 (*always*). The first subscale, fear of negative evaluation (FNE), contains eight items (e.g. “I worry about being teased”). The second subscale, social avoidance and distress specific to new situations or unfamiliar peers (SAD-New), includes six items (e.g. “I feel shy around people I don’t know”). The third subscale, social avoidance and distress in general (SAD-General), contains four items (e.g. “It’s hard for me to ask others to do things with me”). A total scale score is also computed based on 18 items. Higher scores indicate higher levels of social anxiety. The SAS-A has shown good psychometric properties among adolescent community samples.^[40] In this study, Cronbach alpha was calculated for all subscales and the total scale (FNE: $\alpha=.95$ for boys and $\alpha=.92$ for girls; SAD-new: $\alpha=.89$ for boys and $\alpha=.89$ for girls; SAD-General: $\alpha=.77$ for boys and $\alpha=.84$ for girls; Total scale: $\alpha=.95$ for boys and $\alpha=.93$ for girls).

Perceived stigmatisation. The Perceived Stigmatization Questionnaire (PSQ) measured perceptions of stigmatisation behaviours.^[41] PSQ consists of 21 items divided into three subscales

that are rated on a five-point Likert scale from 1 (*never*) to 5 (*always*). The subscales evaluate the absence of friendly behaviour (AFB), experiences of confused and staring behaviours from others (CSB), and the extent to which respondents encounter hostile behaviour (HB). A total scale score is also computed based on all items. Example of items include, “Strangers are polite to me”, “People do not know what to say to me”, and “People laugh at me”. After positively worded items are reversed, higher scores indicate higher levels of perceived stigmatisation. One item in the PSQ (“People are nice to me”) was omitted from the measure due to human error. This error was accounted for when calculating the AFB subscale and the total scale. The PSQ has shown acceptable psychometric properties among adolescents with a visible difference^[42] and has been previously translated and used with Dutch adults with a visible difference.^[43] In this study, Cronbach alpha was calculated for all subscales and the total scale (AFB: $\alpha=.68$ for boys and $\alpha=.75$ for girls; CSB: $\alpha=.69$ for boys and $\alpha=.68$ for girls; HB: $\alpha=.89$ for boys and $\alpha=.87$ for girls; Total scale: $\alpha=.87$ for boys and $\alpha=.87$ for girls).

Life disengagement. The Body Image Life Disengagement Questionnaire (BILD-Q) assessed the extent to which appearance-related worries impact engagement or intention to engage in different life activities (e.g. “going to a social event” and “spend time with friends and family”).^[17, 44] The current BILD-Q^[17] consists of nine items rated on a four-point Likert scale from 1 (“*Hasn’t stopped me at all*”) to 4 (“*Stopped me all the time*”); a previous ten-item version of the BILD-Q was used in the current study.^[44] Higher scores indicate higher levels of life disengagement. The BILD-Q has shown acceptable psychometric properties in an adolescent community sample.^[17] In this study, Cronbach alpha was $\alpha = .76$ for boys and $\alpha=.87$ for girls for the total scale.

Health-related quality of life. The EQ-5D-5L^[45] was used to measure self-rated health satisfaction in five dimensions: Mobility (e.g., “I have no problems in walking about”), Self-care (e.g., “I have no problems with washing or dressing myself”), Usual activities (e.g., “I have no problems doing my usual activities”), Pain/discomfort (e.g., “I have no pain or discomfort”), and Anxiety or depression (e.g., “I am not anxious or depressed”). Each dimension is rated on one of five different levels (“no problems”, “slight problems”, “moderate problems”, “severe problems”, and “unable

to”). For the purpose of the current study, participants’ ratings on the five health dimensions are descriptively reported in the results section, with only the dimension of anxiety/depression included as a predictor in our analyses. Participants also self-rated their health from 0 (“the worst health you can imagine”) to 100 (“the best health you can imagine”) on a visual analogue scale (EQ VAS), which was used as a secondary outcome in the analyses.

Predictors

Experiences of appearance-related teasing. We assessed the frequency of teasing experiences and subsequent distress with two items drawn from Project Eat-III.^[46] Items assessed frequency of teasing experiences related to “weight and shape” and “the way you look” and feelings of distress from teasing related to “weight and shape” and “the way you look”. Distress was scored on a 5-point scale (*not upset to very upset*), with higher scores reflecting greater distress. To reduce the number of variables that would be included in our analyses, correlations between frequency of teasing experiences about body form and weight and about appearance were calculated and showed a moderately strong positive association ($r=0.475$, $P < .001$). Correlations between distress experienced from teasing about body form and weight and from teasing about appearance were also calculated and showed a strong positive association ($r=0.670$, $P < .001$). Hence, we computed two single variables assessing frequency of teasing experiences and teasing-related distress. Cronbach alpha was calculated for both computed variables (frequency of teasing experiences in general: $\alpha = .59$ for boys and $\alpha = .63$ for girls; general teasing-related distress: $\alpha=.70$ for boys and $\alpha=.83$ for girls).

Engagement with YPF. Engagement was measured in two different ways. First by the number of sessions completed, and second by calculating mean time spent on YPF (in minutes). The YPF programme automatically records time spent on each session for each participant. Still, recorded time may not always represent actual time usage, as participants might forget to log out, which leads to non-valid measurement of time spent on a particular session. However, each session consists of several sub-sessions, and time spent is recorded also for each sub-session. Therefore, in order to control for possible errors of total time spent and to obtain a more precise measure of time, we

inspected participants' time usage on each sub-activity within each session. When unrealistic time usage was suspected for any given sub-activity within a given session, we calculated a mean based on those sub-activities that had representative time usage and replaced the suspected time with this mean.

Session usefulness. In YPF, following completion of session one to six, participants are also asked to rate the degree to which they perceive the specific session to be helpful on a 5-point Likert scale from 1 ("Strongly agreed") to 5 ("Strongly disagreed"). Based on this information, a sum score for session one to six was calculated to compute a variable for perceived session usefulness.

Translations

BESAA, SAS-A, PSQ, and BILD-Q had not been translated to [Language] prior to the project. BESAA, SAS-A and PSQ were translated following recommended procedures, including translation and back-translation.^[47] Back-translation was not performed for the BILD-Q measure.

Statistical analysis

All analyses were conducted with the IBM Statistical Package for the Social Sciences Software (SPSS, version 26), and included preliminary and main analyses. Difference scores were calculated based on baseline and post-intervention scores for primary and secondary outcomes and used in all analyses in order to assess the degree of change associated with YPF. Preliminary analyses included inspection of missing data and outliers, and a descriptive exploration of participants' frequency of teasing experiences, self-rated health state on all dimensions from EQ-5D-5L, intervention engagement, and bivariate correlations between prognostic factors and primary and secondary outcomes. The strength of associations were interpreted using Cohen's^[48] guidelines, defined as weak (.10), moderate (.30), and strong (.50) relationships.

Main analyses were conducted to investigate predictors of intervention effects. This included identification of predictors following recommended procedures,^[49, 50] using backward multiple regressions with a p -value threshold of .20 (two-tailed). All regression models were evaluated using adjusted R^2 (R^2_{adj}). Demographic (age and gender), psychosocial (frequency of teasing experiences

and depressive and/or anxiety symptoms), and intervention-related (time spent on YPF) variables were entered in all regression models. Body esteem and social anxiety were defined as primary outcomes. Secondary outcomes were perceived stigmatization, life disengagement, and self-rated health (i.e. EQ VAS), selected to evaluate how YPF affects other influential aspects of adolescents' adjustment to a visible difference. A 95% confidence interval (two-tailed) was used in all main analyses. Listwise deletion was used to handle missing data for the main analyses and pairwise deletion was used for the bivariate correlations. Owing to the exploratory nature of the current study, no adjustment for multiple comparisons was made.^[51]

Results

Preliminary analyses

Rates of missing data for the psychosocial and intervention-related factors were small (baseline depressive and/or anxiety symptoms, 1%; time spent on YPF, 3%). There were no missing data for the primary and secondary outcomes, except for 1% missing for the BILDQ- post-intervention.

A total of 66% (n = 47) of the participants completed all seven YPF sessions and the booster session, spending on average 265 minutes (SD=125) on the intervention (see Table 1).

Table 1. Overview of YPF sessions completed, time spent on each session, perceived session usefulness by demographic characteristics^a.

YPF session (N)	Time spent on session mean (SD)	Session usefulness mean (SD) ^b	Boys ^a	Girls ^a	Age mean (SD)	Type of condition represented (n, %) ^a
0 (1)	N/A ^c	N/A	1/28, 4%	N/A	17.00 (N/A)	Craniofacial (1/49, 2%)
1 (8)	20.14 (24.32)	1.67 (.58)	4/28, 14%	4/43, 9%	14.25 (1.83)	Craniofacial (7/49, 14%), Body form (1/12, 8%)
2 (3)	50.67 (60.18)	2.00 (N/A)	1/28, 4%	2/43, 5%	13.00 (1.73)	Craniofacial (2/49, 4%), Scarring (1/2, 50%)
3 (1)	183.30 (N/A)	1.00 (N/A)	N/A	1/43, 2%	15.00 (N/A)	Craniofacial (1/49, 2%)

4 (5)	144.60 (93.27)	3.02 (1.04)	3/28, 11%	2/43, 5%	14.80 (1.64)	Craniofacial (3/49, 6%), Scarring (1/2, 50%), Body form (1/12, 8%)
5 (2)	127.25 (39.24)	4.13 (.53)	2/28, 7%	N/A	13.00 (1.41)	Craniofacial (2/49, 4%)
6 (N/A)	N/A	N/A	N/A	N/A	N/A	N/A
7 (4)	235.00 (144.76)	3.08 (1.88)	1/28, 4%	3/43, 7%	14.00 (2.45)	Craniofacial (2/49, 4%), Skin (2/8, 25%)
8 (47)	264.61 (125.30)	3.21 (1.11)	16/28, 57%	31/43, 72%	13.87 (1.70)	Craniofacial (31/49, 63%), Skin (6/8, 75%), Body form (10/12, 83%)

^aThe mean age of the total sample was 13.98 years, and there were more girls (n=43, 61%) than boys (n=28, 41%). Most participants had a craniofacial condition (n=49, 69%), followed by a condition affecting body form (n=12, 17%), a skin condition (n=8, 11%), or an acquired condition (n=2, 3%).

^bSession usefulness (n=63)=Scores range from 1 (Strongly agreed) to 5 (Strongly disagreed)

^cN/A=Not applicable

For the total sample, irrespective of whether all sessions were completed, participants' spent 215 minutes on average completing YPF (SD=140, range 1–612 minutes), with girls spending some more time on the intervention (mean=232 minutes, SD=146) than boys (mean=187 minutes, SD=128). Generally, participants reported that the sessions helped them or they were uncertain (mean=3.09, SD=1.18, n = 63), with boys (mean=2.96, SD=1.25) having slightly more positive perceptions of session usefulness compared with girls (mean=3.16, SD=1.16).

Two-thirds of the participants (68%) had no experiences of teasing related to body weight or body form, while one-third experienced this rarely (28%) or sometimes (4%). No teasing related to appearance was reported by 41% or rarely by 37%, while 17% experienced this sometimes or often (4%). Almost half of the sample (48%) did not experience teasing-related distress related to body shape or weight, some reported a little distress (16%), were moderately upset (11%), quite upset (6%) or very upset (3%). More than one-third (35%) were not upset by teasing related to their appearance, while the remaining sample were a little (17%), moderately (14%), quite (9%) or very upset (14%).

Participants reported no problems with mobility in 82% of cases, self-care (93%), usual activities (73%), pain and discomfort (52%), or anxiety or depression (47%). Other participants had slight problems with mobility (10%), self-care (6%), usual activities (20%), pain and discomfort (30%), and anxiety or depression (30%). Moderate problems with mobility were reported by 6% of the sample, self-care (1%), usual activities (6%), pain and discomfort (16%), and anxiety or depression (21%). Severe problems were reported regarding mobility (3%), usual activities (1%), pain and discomfort (1%), and anxiety or depression (1%). Extreme problems with pain and discomfort were reported by one participant.

Generally, significant correlations were moderate to strong (see Table 2). For the psychosocial factors, and for boys, frequency of teasing experiences correlated strongly with teasing-related distress ($r=0.696$, $P<.01$), social anxiety and distress in general ($r=0.535$, $P<.01$), and life disengagement ($r=0.507$, $P<.01$). Depressive and/or anxiety symptoms correlated strongly with life disengagement ($r=0.570$, $P<.01$). For girls, frequency of teasing experiences also correlated strongly with teasing-related distress ($r=0.716$, $P<.01$).

Table 2. Baseline and post-intervention means for primary and secondary outcomes, and bivariate correlations between all study variables by gender^a.

	14	15	16	17
	-0.144	-0.126	0.135	-0.038
	0.123	0.355	0.507**	0.260
	0.241	0.318	0.463*	0.278
	0.196	0.352	0.161	0.192
	0.186	-0.033	0.004	0.155
	0.210	0.377	0.570**	-0.062
	0.386*	0.251	0.473*	0.513**
	0.458*	0.631**	0.420*	0.492**
	0.365	0.670**	0.489**	0.497**
	0.451*	0.434*	0.179	0.355
	0.429*	0.516**	0.405*	0.433*
	0.847**	0.762**	0.516**	0.594**
	0.292	0.538**	0.199	0.313
	0.192	0.426*	0.487**	0.570**
	0.180	0.408**	0.524**	0.434*
	0.192	0.138	0.184	0.453*

2	3	4	5	6	7	8	9	10	11	12	13
0.152	-0.115	-0.134	-0.585**	0.073	0.093	0.029	0.103	-0.014	-0.073	-0.251	-0.346
	0.696**	0.046	0.188	0.322	0.295	0.334	0.426*	-0.061	0.535**	0.246	0.172
	0.716**	0.052	0.053	0.362	0.018	0.443*	0.426*	0.207	0.605**	0.375	0.389
	-0.223	-0.011	0.242	0.060	0.203	0.278	0.388	0.181	0.054	0.278	0.143
	-0.328*	0.384*	0.173	0.136	0.136	0.045	0.041	0.068	-0.007	0.131	0.057
	0.351*	-0.155	-0.073	0.418*	0.118	0.418*	0.476*	0.391*	0.132	0.265	0.083
	0.102	0.330*	0.376*	0.002	0.408*	0.429*	0.429*	0.297	0.321	0.396*	0.235
	0.285	0.436**	0.118	-0.230	0.610**	0.963**	0.857**	0.784**	0.784**	0.668**	0.556**
	0.312*	0.440**	0.136	-0.243	0.712**	0.889**	0.749**	0.714**	0.714**	0.588**	0.453*
	0.038	0.070	0.037	-0.098	0.247	0.708**	0.414**	0.454*	0.454*	0.602**	0.556**
	0.242	0.352*	0.064	-0.149	0.255	0.685**	0.391**	0.417**	0.593**	0.593**	0.490**
	0.219	0.218	0.053	-0.101	0.355*	0.387*	0.443**	0.194	0.139	0.696**	0.696**
	0.184	0.191	0.050	0.181	0.155	0.115	0.142	-0.012	0.095	0.728**	0.728**
	-0.084	-0.053	0.121	-0.179	0.390**	0.401**	0.456**	0.233	0.118	0.672**	0.672**
	0.470**	0.365*	-0.098	-0.221	0.171	0.300	0.330*	0.208	0.076	0.757**	0.757**
	0.200	0.146	0.130	-0.185	-0.013	0.221	0.200	0.091	0.212	0.435**	0.435**
	-0.048	-0.223	-0.031	-0.233	-0.040	0.342*	0.286	0.236	0.280	0.146	-0.033

Variable ^b	Baseline mean (SD)	Post-intervention mean (SD)	1
1. Age	13.89 (1.73) 14.05 (1.77)	N/A ^c	
2. Frequency of teasing	1.57 (.52) 1.62 (.68)	N/A	0.065
3. Teasing-related distress	1.98 (1.12) 2.24 (1.29)	N/A	0.352*
4. Time	N/A	N/A	-0.148
5. Perceptions of session usefulness	N/A	N/A	-0.222
6. Depressive and/or anxiety symptoms	1.44 (.70) 1.98 (.86)	N/A	0.063
7. BE-Appearance	2.69 (.78) 2.06 (1.01)	2.92 (.65) 2.41 (.89)	0.157
8. SAS-A Total	35.32 (14.33) 48.05 (15.11)	5.57 (1.81) 8.74 (3.15)	-0.188
9. FNE	15.71 (7.62) 21.26 (7.99)	13.14 (4.95) 17.77 (6.38)	-0.175
10. SAD-New	12.93 (5.70) 18.05 (5.85)	11.39 (4.45) 17.07 (6.31)	-0.198
11. SAD-General	6.68 (2.82) 8.74 (3.81)	5.57 (1.81) 8.74 (3.15)	-0.047
12. PSQ Total	1.98 (.54) 2.04 (.51)	1.79 (.38) 1.96 (.47)	-0.141
13. AFB	2.02 (.55) 2.02 (.59)	1.82 (.49) 2.05 (.50)	0.064
14. CSB	2.23 (.64) 2.33 (.61)	2.07 (.55) 2.12 (.59)	-0.200
15. HB	1.51 (.69) 1.62 (.68)	1.31 (.41) 1.55 (.56)	-0.144
16. BILD-Q	1.21 (.30) 1.57 (.54)	1.11 (.22) 1.57 (.58)	-0.128
17. Self-rated health state	83.75 (15.79) 75.47 (21.26)	88.75 (9.29) 74.88 (19.26)	-0.458**

^aNumbers in bold indicate male sample, including correlations above the diagonal.

^bFrequency of teasing=frequency of teasing about body form, body weight, and/or appearance;

Teasing-related distress=Degree of upset experienced as a result of experiences of teasing about

body form, body weight, and/or appearance; Perceptions of session usefulness=Participants ratings

of how useful the YPF sessions (1–6) were; Time=Mean time spent on YPF sessions (1–8); BE-

Appearance=BE-Appearance subscale of the Body Esteem Scale for Adolescents and Adults (BESAA);

FNE=Fear of negative evaluation (SAS-A subscale); SAD-N=Social avoidance and distress specific to

new situations (SAS-A subscale); SAD-G=Social avoidance and distress in general (SAS-A subscale);

Total SAS-A=Total scale score of the SAS-A; AFB=Absence of friendly behaviour (PSQ subscale);

CSB=Confused and staring behaviours from others (PSQ subscale); HB=Hostile behaviour (PSQ subscale); Total PSQ=Total scale score of the PSQ; Life disengagement=BILD-Q; Self-reported health state=EQ VAS.

^cN/A=Not applicable.

^d* $P < 0.05$, ** $P < 0.01$.

Analyses of predictors related to intervention effects

To test our research question, backward multiple regressions were used to identify predictors of changes in body esteem, social anxiety, perceived stigmatization, life disengagement, and self-rated health, following adolescents' use of YPF (see Table 3 for details).

Table 3. Selection of predictor variables using backward multiple regression^a.

Outcomes and predictors ^b	Full model			R^2_{adj}	Final model			R^2_{adj}
	Coefficient (B)	<i>P</i> value	95% CI		Coefficient (B)	<i>P</i> value	95% CI	
BE-Appearence				.111				.139
Age	.064	.147	-0.023 to 0.152		.064	.142	-0.022 to 0.149	
Gender	.001	.995	-0.327 to 0.329					
Frequency of teasing	.214	.101	-0.043 to 0.470		.206	.087	-0.031 to 0.443	
Depressive and/or anxiety symptoms	-.017	.868	-0.217 to .183					
Time spent on YPF	.002	.002	0.001 to 0.003		.002	.002	0.001 to 0.003	
SAS-A Total				.134				.138
Age	-.579	.400	-1.945 to 0.786					
Gender	-3.895	.134	-9.016 to 1.226		-4.059	.116	-9.153 to 1.034	
Frequency of teasing	4.386	.032	0.382 to 8.389		4.327	.034	0.337 to 8.318	
Depressive and/or anxiety symptoms	2.897	.068	-0.225 to 6.019		2.822	.075	-0.288 to 5.931	
Time spent on YPF	.016	.074	-0.002 to 0.033		.017	.055	0.000 to 0.034	
FNE				.147				.167
Age	-.245	.548	-1.055 to 0.565					
Gender	-.635	.677	-3.673 to 2.402					

Frequency of teasing	3.415	.006	1.040 to 5.789	3.803	.001	1.607 to 6.000	
Depressive and/or anxiety symptoms	.998	.286	-0.854 to 2.850				
Time spent on YPF	.011	.029	0.001 to 0.022	.011	.024	0.002 to 0.021	
SAD-New				.017			.036
Age	-.216	.375	-0.698 to 0.267				
Gender	-1.481	.107	-3.291 to 0.328	-1.402	.116	-3.162 to .358	
Frequency of teasing	-.331	.641	-1.746 to 1.083				
Depressive and/or anxiety symptoms	1.086	.054	-0.018 to 2.189	.924	.075	-0.095 to 1.944	
Time spent on YPF	.002	.525	-0.004 to 0.008				
SAD-General				.134			.143
Age	-.119	.559	-0.522 to 0.285				
Gender	-1.778	.022	-3.291 to - 0.265	-1.695	.026	-3.177 to -0.213	
Frequency of teasing	1.302	.031	0.119 to 2.485	1.218	.041	0.052 to 2.385	
Depressive and/or anxiety symptoms	.813	.083	-0.109 to 1.736	.778	.094	-0.137 to 1.693	
Time spent on YPF	.002	.366	-0.003 to 0.007				
PSQ Total				.112			.105
Age	-.042	.120	-0.095 to 0.011	-.046	.085	-0.099 to 0.007	
Gender	-.188	.062	-0.387 to 0.010	-.168	.092	-0.365 to 0.028	
Frequency of teasing	.113	.149	-0.042 to 0.268	.102	.192	-0.053 to 0.257	
Depressive and/or anxiety symptoms	.118	.056	-0.003 to 0.239	.115	.062	-0.006 to 0.237	
Time spent on YPF	.000	.220	0.000 to 0.001				
AFB				.072			.087
Age	-.021	.533	-0.086 to 0.045				
Gender	-.303	.017	-0.550 to - 0.057	-.297	.016	-0.537 to -0.057	
Frequency of teasing	.091	.349	-0.102 to 0.284				
Depressive and/or anxiety symptoms	.135	.078	-0.016 to 0.285	.150	.035	0.011 to 0.289	
Time spent on YPF	.000	.391	0.000 to 0.001				
CSB				-.024			.016
Age	-.052	.195	-0.132 to 0.027	-.055	.156	-0.132 to 0.022	
Gender	-.051	.736	-0.349 to 0.248				
Frequency of teasing	-.017	.885	-0.250 to 0.216				

Depressive and/or anxiety symptoms	.072	.434	–0.110 to 0.254				
Time spent on YPF	.000	.352	–0.001 to 0.001				
HB				.237			.241
Age	–.052	.144	–0.122 to 0.018	–.056	.113	–0.125 to 0.013	
Gender	–.227	.088	–0.489 to 0.035	–.209	.111	–0.467 to 0.049	
Frequency of teasing	.352	.001	0.147 to 0.557	.342	.001	0.139 to 0.545	
Depressive and/or anxiety symptoms	.164	.045	0.004 to 0.324	.161	.048	0.002 to 0.321	
Time spent on YPF	.000	.393	–0.001 to 0.001				
Life disengagement				.159			.158
Age	–.022	.472	–0.082 to 0.038				
Gender	–.232	.044	–0.457 to –0.006	–.244	.034	–0.469 to –0.019	
Frequency of teasing	.111	.214	–0.066 to 0.287				
Depressive and/or anxiety symptoms	.209	.003	0.072 to 0.347	.235	.001	0.106 to 0.364	
Time spent on YPF	.001	.135	0.000 to 0.001	.001	.142	0.000 to 0.001	
Self-reported health state				.059			.088
Age	–3.595	.012	–6.380 to –0.809	–3.691	.008	–6.385 to –0.997	
Gender	–5.326	.312	–15.771 to 5.120				
Frequency of teasing	2.701	.511	–5.465 to 10.867				
Depressive and/or anxiety symptoms	–1.437	.654	–7.805 to 4.932				
Time spent on YPF	–.002	.929	–0.037 to 0.033				

^aGender=Boys coded as 0 and girls as 1

^bFrequency of teasing=frequency of teasing about body form, body weight, and/or appearance; Time spent on YPF=Mean time in minutes spent on YPF sessions (1–8); BE-Appearance subscale=BE-Appearance subscale of the Body Esteem Scale for Adolescents and Adults (BESAA); FNE=Fear of negative evaluation (SAS-A subscale); SAD-N=Social avoidance and distress specific to new situations (SAS-A subscale); SAD-G=Social avoidance and distress in general (SAS-A subscale); SAS-A Total=Total scale score of the SAS-A; AFB=Absence of friendly behaviour (PSQ subscale); CSB=Confused and

staring behaviours from others (PSQ subscale); HB=Hostile behaviour (PSQ subscale); PSQ Total=Total scale score of the PSQ; Life disengagement=BILD-Q; Self-rated health=EQ VAS.

Primary outcomes

For body esteem (BE-Appearance), age ($\beta=.170$), frequency of teasing ($\beta=.199$), and time spent on YPF ($\beta=.375$) were retained in the final model, which was significant ($P=.006$), accounting for 13.9% of the variance in difference scores. For social anxiety (SAS-A), four different models were developed (total scale and three subscales). For the total scale, gender ($\beta=-.191$), frequency of teasing ($\beta=.265$), depressive and/or anxiety symptoms ($\beta=.230$), and time spent on YPF ($\beta=.226$) were retained in the final model, which was significant ($P=.009$), accounting for 13.8% of the variance. For the subscale fear of negative evaluation (FNE), teasing ($\beta=.389$) and time spent on YPF ($\beta=.261$) were retained in the final model, which was significant ($P=.001$), accounting for 16.7% of the variance. For the subscale social anxiety and distress in new situations (SAD-New), gender ($\beta=-.199$) and depressive and/or anxiety symptoms ($\beta=.227$) were retained in the final model, which was not significant ($P=.112$), accounting for 3.6% of the variance. For the subscale social anxiety and distress in general (SAD-General), gender ($\beta=-.270$), frequency of teasing ($\beta=.252$), and depressive and/or anxiety symptoms ($\beta=.214$) were retained in the final model, which was significant ($P=.005$), accounting for 14.3% of the variance.

Secondary outcomes

For perceived stigmatization (PSQ), four different models were developed (total scale and three subscales). For the total scale (PSQ Total), age ($\beta=-.204$), gender ($\beta=-.207$), frequency of teasing ($\beta=.163$), and depressive and/or anxiety symptoms ($\beta=.245$) were retained in the final model, which was significant ($P=.027$), and accounted for 10.5% of the variance. For the subscale, absence of friendly behaviour (AFB), gender ($\beta=-.301$) and depressive and/or anxiety symptoms ($\beta=.263$) were retained in the final model, which was significant ($P=.019$), and accounted for 8.7% of the variance. For the subscale confused and staring behaviours (CSB), only age ($\beta=-.174$) was retained in the final

model, which was not significant ($P=.156$), and accounted for 1.6% of the variance. For the subscale hostile behaviour (HB), age ($\beta=-.173$), gender ($\beta=-.180$), frequency of teasing ($\beta=.383$), and depressive and/or anxiety symptoms ($\beta=.240$) were retained in the final model, which was also significant ($P<.001$), and accounted for 24.1% of the variance. For life disengagement (BILD-Q), gender ($\beta=-.257$), depressive and/or anxiety symptoms ($\beta=.428$), and time spent on YPF ($\beta=.169$) were retained in the final model, which was significant ($P=.003$), and accounted for 15.8% of the variance. Finally, for self-rated health (EQ VAS), only age ($\beta=-.319$) was retained in the final model, which was also significant ($P=.008$), and accounted for 8.8% of the variance.

Discussion

In order to obtain a better understanding of which adolescents that are likely to benefit from Young Person's Face IT, this study explored how demographic (age and gender), psychosocial (baseline frequency of teasing experiences and depressive and/or anxiety symptoms), and intervention-related (time spent on YPF) variables, predicted changes in a range of outcomes. Our sample included 71 adolescents (61% girls) with a wide range of conditions affecting appearance, with craniofacial conditions being the most common. A total of 66% of participants completed all eight YPF session and generally agreed, or were uncertain, that the intervention sessions were helpful.

Results showed that different combinations of demographic, psychosocial, and intervention-related variables, predicted intervention effects on primary and secondary outcomes. In general, explained variance was higher in analyses including primary outcomes than for secondary outcomes. Nonetheless, it is important to note that explained variance overall was relatively low for the regression models (ranging from 1.6 to 24.1%), which should be taken into account when interpreting our results. Principal findings are discussed in more detail below.

Principal findings

Adolescents who reported greater baseline psychosocial distress, in the form of higher frequency of teasing and depressive and/or anxiety symptoms, had stronger effect of YPF on primary

and secondary outcomes compared to adolescents with lower levels of psychosocial distress. These results could indicate that adolescents who experience higher levels of psychosocial distress may benefit more from YPF than adolescents' who experience relatively lower distress. Indeed, similar to our findings, studies with adolescent community samples have found that higher pre-test symptoms of anxiety^[29, 52] and depression^[29] have predicted greater reductions in post-test symptoms of anxiety following ICBT. Although speculative, it could be possible that adolescents' who experience higher psychosocial distress may have more potential for improvement and/or may be more motivated to engage with the intervention content.

Moreover, frequent experiences of different types of teasing in childhood, including teasing about appearance, have been linked to symptoms of social anxiety in adulthood,^[53] and adolescents who frequently experience peer victimization are also more likely to develop an anxiety disorder compared to non-victimized adolescents.^[54] Also, symptoms of depression and anxiety developed during adolescence,^[55] and higher psychological distress in childhood and adolescence in general,^[56] may persist into adulthood and increase the risk of poorer health. Hence, providing evidence-based support for adolescents with a visible difference who experience higher levels of psychosocial distress seems imperative to promote psychosocial well-being and adjustment. However, more studies are required to further investigate whether higher levels of psychosocial distress consistently predicts stronger effect of YPF in adolescents with a visible difference, and whether stronger intervention effects are maintained over time for this group.

The current study also found that time spent on YPF predicted stronger intervention effects on primary and secondary outcomes, suggesting that adolescents who spend more time on YPF, and thereby engage more with the content of the intervention, achieve a higher intervention response. This aligns with Williamson et al,^[24] which found that increased engagement with YPF (i.e., number of YPF sessions completed) predicted positive changes in body esteem and social anxiety. The number of weeks participants spent completing YPF, irrespective of number of sessions completed, did not predict any changes post-intervention in the study by Author et al. (under review). Our

results are also in line with other studies with adolescent community samples, showing that intervention engagement seems to be important for adolescents' response to ICBT,^[52, 57] suggesting that increased engagement allows for greater therapeutic effects.

We found that gender was significantly related to intervention effects, as girls had consistently lower changes in primary and secondary outcome scores compared with boys. This corroborates some of the findings reported in Author et al. (under review), that included partly the same participants as in this study, where girls had higher post-intervention scores on symptoms of social anxiety. Combined, these results could suggest that boys benefit more from YPF than girls. Again, these results should be interpreted with caution considering that our prognostic models were limited by relatively low explained variance. Previous studies with adolescent community samples offer contrasting results on how gender relate to the effectiveness of interventions based on ICBT,^[29, 58] as girls tend to have better effect.^[29] Future studies should therefore further investigate whether boys truly benefit more from YPF, as well as whether other factors (e.g. motivation to complete YPF, changes in the YPF content) contribute to predict girls' intervention response.

Age did not provide a consistent picture of intervention effects. Whereas higher age predicted higher changes in body esteem, lower age predicted higher changes in perceived stigmatization and self-rated health. Generally, studies with adolescent community samples also offer inconsistent results regarding the importance of age in predicting intervention effects of standard CBT and ICBT.^[59, 60] More research on the role of age as a predictor of intervention effects of YPF and other types of psychosocial support for adolescents with a visible difference is therefore needed. For instance, it could be that mental age is a better predictor than biological age.

Clinical implications

The current study has two important implications that may guide the referral of adolescents to YPF. Our results indicate that YPF may have an increased benefit for adolescents who experience high levels of psychosocial and/or psychological distress, due to for example appearance-related teasing or high levels of depressive and/or anxiety symptoms. It is therefore important to note that

YPF may not benefit all adolescents with a visible difference, and future studies should further investigate which indicators that may consistently predict intervention effects. Our results also suggest that time spent on YPF matters for intervention effects, in line with previous testing of YPF.^[24] Hence, adolescents referred to YPF should be encouraged to spend enough time on each session, in order to hopefully increase therapeutic effects, as has been demonstrated in recent research.^[52, 57]

Limitations

There are some limitations to the current study that needs to be addressed. First, the regression models generally showed low explained post-intervention variance in primary and secondary outcomes (Range: 1.6 to 24.1%). In other words, other unknown variables, not included in our study, could contribute to explain adolescents' overall response to YPF. As such, we encourage further studies to include additional variables (e.g., incentives to complete YPF, perceptions of user-interface design, level of family support, previous history of surgery and/or psychosocial support). We also need a better understanding of how adolescents' baseline levels of body esteem, perceived stigmatization, and life disengagement prospectively predicts intervention effects of YPF.

Second, there is a lack of cross/condition-specific measures developed for adolescents with a wide range of visible differences that are sensitive to different stages of adolescence or other aspects than those related to body image that may influence adolescents' adjustment.^[61] The PSQ has, however, been specifically developed to assess stigmatizing experiences in children, adolescents, and adults with appearance changes following burn injuries. Nonetheless, it is possible that the other measures used in this study failed to capture other central aspects that are salient to adolescents' experiences and adjustment to their visible difference. We therefore encourage the development and psychometric evaluation of cross-condition measures that could be used across different studies in research with adolescents with a visible difference. Moreover, none of the included measures had undergone previous psychometric evaluations in [Language], a common problem in non-English

countries with small populations, which also underscores the importance of interpreting our results with caution.

Third, assessing the degree of clinically important change is vital to understand how a treatment may affect a particular group of individuals.^[62] However, there are no standardized procedures to assess clinically important changes, and those proposed by Jacobson and Truax^[62] require available norms or aggregation of samples from different studies to establish norms, in order to assess clinically important change. Normative data on the measures used in the current study for adolescents with a visible difference are lacking. Hence, it is not clear whether the impact of YPF on adolescents with a visible difference represent clinically important changes.

Fourth, a larger sample size would have increased statistical power and made it possible to use more stringent statistical analyses, by for example exploring interaction effects in our sub-groups. Nonetheless, given the lack of research on web-based interventions for adolescents with a visible difference, we believe that our study provides support for the evidence-base for the effectiveness of YPF.

Finally, we were not able to systematically control for possible negative influences of the COVID-19 pandemic on intervention effects of YPF, mainly due to the fact that participants were enrolled in the study before, during, and after COVID-19 lockdowns and restrictions (which also differed from districts in [Country]). Emerging number of studies have found that the pandemic had a significant negative impact on the mental health of many adolescents, including increased levels of social anxiety^[63] and depression,^[64] and may have exacerbated mental health difficulties for some adolescents.^[65] However, recent research also indicates that for some individuals with a visible difference, the COVID-19 pandemic may also have provided a temporary relief from social pressure,^[66] possibly with a corresponding beneficial psychological health effect. The intervention effects of YPF on adolescents in the current study could therefore have been both negatively and positively affected by the influence of the COVID-19 pandemic. Nonetheless, research on how COVID-19 may have impacted the lives of adolescents with a visible difference is still scarce and we

encourage future studies to specifically control for possible influences of a factor such as the COVID-19 pandemic.

Conclusion

This study explored predictors of intervention effects of Young Person's Face IT, a web-based psychosocial intervention designed to promote adolescents' adjustment to a visible difference. We specifically examined how demographic, baseline psychosocial, and intervention-related variables, prospectively explained post-intervention improvements in body esteem, social anxiety, perceived stigmatization, life disengagement, and self-rated health. Our results suggest that boys, and adolescents with higher levels of psychosocial distress, may have increased intervention effects of YPF. Our results also suggest that time spent on YPF play a role in intervention effects. In sum, although more studies are needed to further investigate intervention effects of YPF and similar intervention programmes, our study advances the understanding of how web-based psychosocial support may benefit adolescents who may experience challenges with adjusting to the impact of having a visible condition.

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