1	Appearance concerns, psychosocial outcomes, and the feasibility of implementing an online
2	intervention for adolescents receiving outpatient burn care
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#### ABSTRACT

28 The current study assessed the prevalence of appearance concerns, psychosocial difficulty, 29 and use of an appearance-focused social and psychological support resource (Young Person's Face 30 31 IT; YPF) within a population of teens (12-17 year-olds) receiving outpatient burn care with the goal to assess the feasibility of routine use of the resource in outpatient burn care. The study sample 32 33 included 78 patients ages 12-17 receiving outpatient care for burns at 1 hospital. Appearance concerns were measured via the Burn Outcomes Questionnaire Appearance Subscale, the 34 Appearance Subscale of the Body Esteem Scale for Adolescents, and a 2-part question which asked 35 36 participants directly about appearance concerns related to the burn injury. A large majority (70.0%) of study participants reported appearance concerns on at least 1 appearance measure and girls 37 reported more burn-related appearance concerns compared to boys. Psychosocial difficulty was 38 measured via the Pediatric Symptom Checklist-17 (PSC-17) and measures of social functioning 39 were collected and compared within the sample by burn size, burn location, sex, and appearance 40 41 concerns. Internalizing symptoms were prevalent on the PSC-17 (18.6% risk) and decreased selfworth and increased social anxiety symptoms were significantly associated with having 42 appearance concerns. Although interest in YPF was high (78.3%), actual use of the resource among 43 44 those who signed up to pilot it (n=46 participants) was low (19.4% use). Results indicate that there is a need for and interest in appearance-focused social anxiety resources for adolescents with burn 45 injuries such as YPF, but more research is needed to understand its feasibility in clinical practice. 46 47 Key words: Pediatric Burns, Appearance, Psychosocial Functioning, Young Person's Face IT,

Burn Outcomes Questionnaire, Body Esteem Scale

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Appearance-related concerns, including negative body image and worries about physical 52 characteristics, are prevalent across the lifespan, with estimates indicating that between 20-50% 53 of adults experience at least some concerns about their physical appearance.<sup>1,2</sup> Adolescence is a 54 developmental period in which concerns about appearance and negative body image are 55 particularly heightened.<sup>3-6</sup> The prevalence of appearance concerns and body dissatisfaction 56 among young people is estimated between  $50-80\%^7$ , with an ever higher prevalence of body 57 dissatisfaction among female youth.<sup>8</sup> Both adults<sup>9</sup> and young people experiencing concerns about 58 their appearance have been found to have significantly more social<sup>10</sup> and mental health problems 59 including depression, anxiety, suicidality, and eating disorders<sup>11-15</sup> compared to those without 60 61 appearance concerns. The experience of appearance concerns related to body size, weight, or physical characteristics in childhood and/or adolescence can be especially detrimental to a young 62 person's long-term social and emotional development.<sup>16</sup> Therefore, it is important to consider 63 64 ways to help support young people experiencing concerns about their appearance. A traumatic, appearance-altering injury, such as a burn injury, increases an individual's 65 risk for developing appearance-related concerns, making psychosocial difficulties such as social 66 67 anxiety, low self-esteem, depression, and engagement in risky health behaviors even more

68 likely.<sup>17-22</sup> Burn injuries are the third most common form of trauma to children<sup>23</sup> and often result

69 in scarring or other visible differences,<sup>24</sup> however, findings regarding the psychological impact

of visible differences have been mixed. Some studies have found that injury size, injury location,

and gender are risk factors for increased appearance concerns,<sup>25</sup> with higher risk for such

72 concerns in females with burn injuries,<sup>26</sup> and in females and males with larger burns<sup>27</sup> and/or

highly visible facial burns.<sup>28,29</sup> Other studies have reported that burn size, burn location, gender,

and cause of burn injury are less reliable predictors of appearance related concerns and postinjury psychological distress<sup>30,31</sup> than are socio-cognitive factors, including psychological
flexibility, social confidence, perceptions of social acceptance, and fear of negative
evaluation.<sup>32,33</sup>

Using the appearance subscale of the Burn Outcomes Questionnaire<sub>5-18</sub> (BOQ-AS), a 78 79 measure specifically designed for patients with burn injuries, recent studies have found that appearance concerns are relatively prevalent in 11-18-year-old patients receiving outpatient burn 80 care, with 15-20% of youth scoring at-risk on the appearance subscale.<sup>29,34</sup> Self-worth, on the 81 other hand, as measured by Harter's Self Perception Profile, has been found to be no different or 82 even better in adolescents with burn injuries than in those in the general population.<sup>35</sup> General 83 84 body esteem, as measured by the Body Esteem Scale for Adolescents (BE-A) has also been found to be more positive in youth with burn injuries compared to non-injured controls.<sup>36,37</sup> 85 Although injury-related appearance concerns and generalized body esteem are related domains, 86 there is some evidence to suggest that they may be distinct.<sup>38</sup> Little empirical evidence exists 87 related to assessing the distinction between more general rather than burn injury-related 88 appearance and body esteem concerns within the adolescent burn population. Especially for 89 90 clinicians, learning more about the prevalence of injury-related appearance concerns versus low generalized body esteem and the impact of both types of appearance concerns on psychosocial 91 functioning could help inform the creation and dissemination of appearance-related interventions 92 93 for youth with appearance-altering injuries.

Because previous studies have suggested that young people with all types of visible
differences are at an increased risk for developing psychosocial problems, clinicians and
researchers have continued to evaluate ways to assess and address their needs. Since individual

97 therapy and support groups can be difficult to access due to the lack of local and/or appearancespecific therapeutic services or due to the sensitive nature of the topic of appearance, recent 98 research has explored the possibility of developing and implementing online self-help 99 interventions focused on appearance-related distress.<sup>39</sup> For adult populations, internet-based 100 programs have been shown to help bridge geographical barriers to access and to encourage the 101 102 development of self-management skills – an important component shown to improve psychosocial wellbeing.<sup>40</sup> Until now, the evidence-base for psychosocial interventions that 103 address the specific needs of young people, and particularly adolescent patients with burn 104 injuries, has been sparse.<sup>41</sup> 105

The recent development of an online intervention designed specifically for young people 106 with conditions or injuries which affect their appearance provides an opportunity to explore 107 108 whether online appearance-focused tools can be useful within youth populations, and more specifically, within populations of youth with burn injuries. The online intervention, called "YP 109 Face IT" (YPF) is an interactive 7-session multimedia program containing automated text and e-110 mail reminders to facilitate intervention adherence.<sup>42</sup> The program targets appearance-related 111 distress by teaching young people strategies to manage challenging social interactions, negative 112 appearance-related thinking, and fear of rejection by others.<sup>43</sup> YPF utilizes approaches drawn 113 primarily from cognitive behavioral therapy (CBT) and Social Interaction Skills Training (SIST) 114 and is modeled after a similar program for adults called "Face IT" which was shown in a 115 116 randomized control trial (RCT) to produce significant reductions in appearance concerns among adults with no adverse effects and was comparable in its impact to a face-to-face CBT 117 intervention.<sup>44</sup> An RCT feasibility study of YPF recently found that it could be successfully 118 119 implemented in primary care settings, was acceptable to adolescents with a broad range of

visible differences including scarring, could address a gap in appearance-specific psychological
 care, and had no adverse effects.<sup>45</sup>

To better understand the prevalence of appearance concerns, psychosocial difficulties, 122 and potential utility of the YPF resource within an outpatient pediatric burn setting, the specific 123 goals of the current study included assessing: 1) the prevalence of general appearance concerns 124 125 as well as appearance concerns related directly to the burn; 2) the relationship between both types of appearance concerns and patient demographics (burn location, burn size, and patient 126 sex); 3) the prevalence of psychosocial difficulties including social anxiety and the relationship 127 128 between psychosocial difficulty and patient demographics and; 4) the feasibility of incorporating YPF into routine outpatient pediatric burn care for adolescents. Feasibility of YPF use was 129 evaluated by ascertaining interest in the program and comparing interest and use of YPF to other 130 available social and psychological support resources and assessing success in utilization of the 131 resource within a subset of study participants who signed up to use YPF with support from study 132 staff. 133

134 METHOD

135 Study Sample

Study participants were enrolled through the outpatient clinic of a pediatric burn hospital which serves more than 3,000 patients from the US and other countries each year. Using the daily outpatient appointment roster, patients were identified as eligible if they met the following criteria: (1) the patient had experienced a burn injury (with no restriction on time since injury); (2) the patient was between 12-17 years of age; (3) the patient presented with a parent or legal guardian; (4) both the parent or legal guardian and patient spoke English; (5) study staff received approval to approach the patient from a clinician familiar with the patient; and (6) the patient wasnot scheduled for surgery on the same day as their outpatient appointment.

## 144 **Procedures**

All procedures were reviewed and approved as human subject research by the hospital's 145 Institutional Review Board and the ethical principles outlined in the Declaration of Helsinki were 146 147 closely followed. Eligible patients and parents were approached in the outpatient waiting room by a member of the study staff who explained the goals of the study and obtained informed 148 verbal consent from the patient and parent. There were 2 phases of data collection during the 27-149 150 month recruitment period. In Phase I (17-months), the goal was to collect data on participant reported appearance concerns, patient-reported psychosocial functioning, and determine interest 151 in psychosocial support resources including YPF. In Phase II (10-months), participants 152 completed the same measures of appearance concerns and psychosocial functioning on a tablet 153 computer device that recorded all responses in real time using an application called Tonic and 154 had the opportunity to pilot the use of the YPF resource if interested. Tonic's application is 155 SSAE 16 SOC 1 certified and HIPAA compliant and allows for secure (encrypted) and 156 convenient survey administration anywhere that has internet access. 157

During Phase I, participants were asked about their interest in the following available psychosocial resources: (1) YPF; (2) an online educational resources for burn survivors focused on both physical and psychosocial recovery; (3) an online-chat group support for burn survivors and/or their families; (4) an in-person group support for burn survivors and/or their families at a local hospital; (5) an activities and outings social group for burn survivors at the same hospital where they were receiving outpatient care; (6) a corrective/reconstructive makeup clinic held at the hospital; and (7) a week-long healing retreat for female burn survivors. Participants were 165 provided with an information sheet about the resources and asked to circle or verbally indicate those that they were interested in. In the study's second phase, after determining interest in YPF 166 within the study population, participants were shown the same resource list and if interested in 167 any, were offered help in accessing them by study staff. Participants who were interested in 168 using YPF were shown how to log-in and navigate the site by a member of study staff. Parents 169 170 and adolescents were asked to provide their preferred contact information and received a weekly reminder via telephone or email from a member of study staff to encourage them to complete the 171 7 YPF sessions and discuss questions about use of the resource. Although automated reminders 172 173 to complete YPF sessions are available through the program, they were not utilized in the current study due to U.S. data security concerns. 174

175 Six-months post-study enrollment, participants and their parents who enrolled in the 176 study's second phase were contacted and asked to complete feedback surveys regarding the 177 adolescent's use of psychosocial support resources including YPF. Participants and parents of 178 participants who signed up to use YPF were also asked about the adolescent's use of the YPF 179 program and to provide feedback on how they thought the program could be improved.

180 Measures of Appearance Concerns

Appearance concerns were measured using 3 questionnaires to assess more general appearance concerns as well as concerns related directly to the burn injury. To measure more general appearance concerns, participants completed the ten-item Appearance Subscale of the Body Esteem Scale for Adolescents (BE-A) which evaluates general feelings about appearance.<sup>46</sup> Using a 5-point Likert scale ranging from 0 (never) to 4 (always), participants respond to the following prompts: (1) I worry about the way I look; (2) I like what I see when I look in the mirror; (3) I wish I looked like someone else; (4) I'm pretty happy about the way I look; (5) I 188 wish I looked better; (6) There are lots of things I'd change about my looks if I could; (7) I like what I look like in pictures; (8) I'm looking as nice as I'd like to; (9) I feel ashamed of how I 189 look; and (10) My looks upset me. The total score is computed by taking the mean of the item 190 scores, with higher scores indicating more negative feelings about appearance. The BE-A has 191 shown a high rate of internal consistency for both girls and boys ( $\alpha$ =0.94 and  $\alpha$ =0.90, 192 respectively).<sup>47</sup> Within the current study, a gender-specific cutoff score higher than the average 193 baseline scores of a comparison group of English school children (3.72 for boys and 3.22 for 194 girls) was used to assess the severity of general appearance concerns of participating patients.<sup>47</sup> 195 196 Burn-related appearance concerns were assessed using 2 different questionnaires – the 4item appearance subscale of the BOQ-AS which has been validated for use in 5-18-year-olds <sup>48-50</sup> 197 and a 2-part question created specifically for the study. On the BOQ-AS, adolescents are asked 198 199 to use a 5-point Likert scale ("definitely true" to "definitely false") to rate their agreement to the following questions: (1) I feel that the burn is unattractive to others; (2) I think people would not 200 want to touch me; (3) I feel unsure of myself among strangers; and (4) Changes in my 201 appearance have interfered with my relationships. Scores are computed using a t-score 202 transformation and compared to a standardized mean of 50 and standard deviation of 10.<sup>51</sup> A 203 204 score is considered "at-risk" (in this case, of having clinically significant appearance concerns) if it is 1 standard deviation or more below the mean of 50.48,52 Therefore, lower scores on the 205 BOQ-AS indicate more appearance concerns. 206 The 2-part question about appearance concerns was created to obtain a direct answer to 207

the question of whether the adolescent felt that they had a burn related appearance concern. It asked respondents if they had changes in their appearance due to the burn injury (yes, no, or maybe) and if so, if they felt worried or uncomfortable about those changes (yes, no, sometimes).

If participants answered "yes" or "maybe" to having changes in their appearance due to the burn
injury and answered "yes" or "sometimes" to feeling worried or uncomfortable about those
changes, they were categorized as having burn-related appearance concerns according to this
measure.

# 215 Measuring Psychosocial Functioning

## 216 The Pediatric Symptom Checklist

Psychosocial functioning was measured via the Pediatric Symptom Checklist. The 17-217 item version of the Pediatric Symptom Checklist (PSC-17)<sup>53</sup> measures overall psychosocial risk 218 and has a subscale that assesses internalizing (depression/anxiety), attention (ADHD), and 219 externalizing (conduct) symptoms. The youth-report PSC-17 form (PSC-17Y)<sup>54</sup> has been 220 validated in large samples and is used in a range of pediatric settings. The PSC-17Y global scale 221 222 measures symptoms related to internalizing, externalizing, and attention problems and has been shown to have a high degree of internal consistency ( $\alpha$ =0.85).<sup>54</sup> Respondents are asked to rate the 223 frequency of 17 symptoms on a 3-point scale (Never, Sometimes, or Often). Youth are 224 considered "at-risk" for general psychosocial problems if the score is  $\geq 15$ , "at-risk" for 225 internalizing or attention problems if the score is  $\geq$  5, and "at-risk" for externalizing problems if 226 the score is > 7. <sup>20,53,54</sup> 227

## 228 Measures of Social Functioning and Anxiety

Social functioning and anxiety were assessed via 4 scales: (1) the Social Anxiety Scale
for Adolescents (SAS-A)<sup>55</sup> which contains an overall scale and 3 subscales: Fear of Negative
Evaluation by others (FNE), Social Avoidance and Distress in New Situations (SAD-N), and
Social Avoidance and Distress in General Situations (SAD-G); (2) the Perceived Stigmatization
Questionnaire (PSQ); (3) Harter's Self-Perception Profile for Adolescents (SPPA)<sup>56</sup> which

includes a global measurement of self-worth and a romantic concerns subscale, and; (4) the Body
 Image Life Engagement Ouestionnaire (BILEO).<sup>47</sup>

236 *The Social Anxiety Scale for Adolescents* 

The 22-item SAS-A<sup>55</sup> measures social anxiety and contains 3 subscales (FNE, SAD-N, 237 and SAD-G) as well as an overall score. The SAS-A asks adolescents about the degree to which 238 they experience feelings such as shyness around others and worries about what other people are 239 saying about them. For example, the SAS-A asks youth to rate the degree to which they "get 240 nervous when [they] meet new kids," and "worry about being teased." The measure has been 241 used in samples of adolescents in public secondary schools<sup>57</sup> and has shown good internal 242 consistency across genders and grades (range  $\alpha$ =0.91-0.93) as well as across the 3 subscales and 243 the overall score ( $\alpha$ =0.90 for FNE,  $\alpha$ =0.83 for SAD-N,  $\alpha$ =0.77 for SAD-G, and  $\alpha$ =0.92 for the 244 SAS-A total).<sup>55</sup> Questions are answered on a 5-point Likert scale ranging from 1 (not at all) to 5 245 (all the time), with a total score  $\geq$  50 considered to be an indication of clinically significant levels 246 of social anxiety.<sup>58</sup> The current study focuses on the domains of social anxiety measured on the 3 247 subscales of the SAS-A. 248

## 249 The Perceived Stigmatization Questionnaire

The 21-item PSQ asks youth about stigmatizing behaviors related to appearance which are grouped into 3 categories: absence of friendly behavior, confused/staring behavior, and hostile behavior by others. The PSQ has been validated in populations of youth and adults with burn injuries and good internal consistency has been found within pediatric samples ( $\alpha$ =0.91). <sup>59,60</sup> Participants are asked to rate how often they experience a behavior (for example, "People don't know how to act around me" or "People seem embarrassed by my looks") on a 5-point Likert scale ranging from 1 (never) to 5 (always). An adolescent's score is calculated by taking the mean of the weighted item scores, with a higher score reflecting higher perceivedstigmatization.

## 259 Harter's Self-Perception Profile for Adolescents

Harter's Self-Perception Profile for Adolescents (SPPA) measures how adolescents 260 perceive themselves across various domains, including physical appearance, athletic competence, 261 romantic appeal, and global self-worth.<sup>56</sup> The current study administered the 5-item Romantic 262 Appeal subscale and 5-item Global Self-Worth scale which asks youth to identify with 263 statements such as whether they feel happy with themselves and feel that those who they are 264 265 romantically attracted to would like them back. Higher scores on the SPPA indicate more favorable ratings of self-worth and romantic appeal. Strong internal consistency has been found 266 on both of these SPPA scales ( $\alpha$ =0.75-0.85 for Romantic Appeal and  $\alpha$ =0.80-0.89 for Global 267 Self-Worth) within adolescent student populations.<sup>56</sup> 268 The Body Image Life Engagement Questionnaire 269

The BILEQ assesses the extent to which youth avoid activities across social, recreational 270 and educational domains because they feel bad or worry about how they look. The 10-item 271 measure asks adolescents to use a rating scale of 1 ("hasn't stopped me at all") to 4 ("stopped me 272 273 all the time") to rate how often worries about their appearance have stopped them from activities such as attending a social event, raising their hand in class, or spending time with friends and 274 family. For example, youth are asked to rate how often (in the past 2 weeks) they have felt 275 276 hindered from doing activities including going to the beach or pool, shopping for clothes, and trying out for a team or club because they had worries or felt bad about the way they looked. A 277 278 higher mean score across the summed items indicates lower life engagement. The measure has

been utilized to assess life engagement with high internal consistency ( $\alpha$ =0.93 in girls and 0.96 in boys).<sup>47</sup>

## 281 Burn Size and Location

Data regarding study participant's burn size (percent Total Body Surface Area; TBSA) 282 and location were collected from the electronic medical record and utilized to compare 283 284 prevalence of appearance concerns, psychosocial difficulty, and social functioning within groups of participants with similar injury types. Data related to burn size were available for 74 of the 78 285 participants. Participants were categorized as having either large (above 50.0% TBSA), medium 286 287 (between 25.1-49.99% TBSA) or small burns (below 25.0% TBSA). Data related to burn location was available for all participants. Participants were also categorized according to 288 whether or not they experienced a burn injury on the face, head, neck, or hands/wrist due to the 289 290 visibility of burns in those areas.

#### **Data Analysis**

Analyses were conducted using SPSS version 24.0 (IBM Corp. Armonk, NY, USA). 292 Descriptive statistics (frequencies) were utilized to assess prevalence of categorical (yes/no) 293 appearance concerns according to the 3 measures (BOQ-AS, BE-A, and the 2-part question), 294 295 prevalence of psychosocial problems on the PSC-17 (risk/no risk), and interest in using YPF (yes/no). Chi-square analyses were utilized to assess differences in prevalence of appearance 296 concerns, psychosocial difficulty, and resource interest based on categorical burn size (small vs. 297 298 medium vs. large), burn location (face, head, or neck vs. other and hand or wrist vs. other), and participant sex (male vs. female). Since scores on measures of social functioning and anxiety 299 300 (SAS-A, PSQ, SPPA, BILEQ) were non-normally distributed ordinal data, they were compared 301 across categorical burn size and location groups, participant sex, and appearance concerns groups using the Mann-Whitney U-test in the case of 2-group comparisons (burn location and sex). The
Kruskal-Wallis 1-way analysis of variance test was utilized to compare mean rank scores
amongst the 3 burn size groups. All significance tests were 2-tailed and statistical significance
was set to 0.05. Only data from subjects with complete PSC-17 and social functioning and
anxiety measures were included in the analyses. The prevalence of appearance concerns
according to the 3 measures, PSC-17 risk, and the median and interquartile range of scores on
measures of social functioning and anxiety are reported in Table 2.

309 RESULTS

# 310 Participant Enrollment and Demographics

A total of 5,634 patients were screened for study participation and 366 (6.5%) met study 311 eligibility requirements. A majority of ineligible patients (77.9%) did not fit age criteria and the 312 remainder did not speak English (14.2%), did not have a burn injury (3.7%), were not 313 accompanied by a legal guardian or did not receive clinician approval for study participation 314 (4.2%). Of the 366 eligible patients, 78 (21.3%) enrolled and completed a majority of measures 315 (n=32 in the first phase and n=46 in the second phase). Participant demographics are reported in 316 Table 1. The mean participant age was 14.84 (SD=1.92) years old, and participant Total-Body 317 318 Surface Area (TBSA) ranged from 0.20%-88.0% with a sample mean of 17.82% (SD=22.82). Most of the sample (77.0%; n=57) had burns that were less than 25.0% TBSA, 10.8% had 319 medium (25.1-49.9%) burns, and 12.2% had large (above 50.0% TBSA) burns. A total of 34.6% 320 321 of the sample had a burn injury on the face, head, or neck. The most frequently affected burn location within the sample was the hand and/or wrist (53.8%). 322

## **323 Prevalence of Appearance Concerns**

324 Appearance concerns were reported on at least 1 of the 3 measures by 70.0% (n=53) of the participants who enrolled. The largest proportion of appearance concerns were reported on 325 the BE-A, with 63.8% (n=44) of participants scoring above the gender-matched comparison 326 group of school-aged children without burn injuries. On the 2-part burn-related appearance 327 concerns questions, 34.2% (n=25) participants indicated experiencing appearance concerns. The 328 lowest prevalence of appearance concerns was reported on the BOQ-AS, where only 2 (3.1%) 329 participants scored at-risk. No significant differences in prevalence of appearance concerns were 330 found among participants with face, head, or neck burns versus those without, participants with 331 332 hand/wrist burns versus those without, or amongst the 3 burn size categories. However, females reported a significantly higher prevalence of appearance concerns on the 2-part question about 333 burn-related appearance concerns compared to males ( $X^2$ =5. 27; 46.2% vs. 20.6%, p<.05). 334

#### 335 **Psychosocial Functioning on the PSC-17**

The prevalence of general psychosocial problems within the participant sample as 336 measured by the PSC-17 overall risk score was 15.3%. On the internalizing subscale, 18.6% of 337 participants scored-at risk, compared to 9.1% risk on the externalizing and 6.1% risk on the 338 attention subscales. No significant differences were found in the proportion of participants with 339 340 risk on any PSC-17 scales when compared among sex, burn size group, or burn location categorized as face, head, or neck vs. other. Participants with hand burns were significantly more 341 likely to be at-risk on the PSC-17 internalizing subscale compared to participants without hand 342 burns (28.1% vs. 7.4%;  $X^2$ =4.14, p<.05). Psychosocial risk was more significantly related to the 343 endorsement of appearance concerns. The 2 participants who scored at-risk on the BOQ-AS were 344 345 at-risk on the PSC-17 internalizing subscale, therefore 100.0% of those who endorsed 346 appearance concerns on the BOQ-AS were at-risk on the PSC-17 internalizing subscale

compared to 15.8% of those who did not endorse appearance concerns on the BOQ-AS ( $X^2$ =9.03, *p*<.01). A significantly larger proportion of participants who endorsed appearance concerns on the 2-part question were at-risk on the PSC-17 internalizing subscale and the PSC-17 overall score compared to those who did not endorse appearance concerns (Internalizing:  $X^2$ =5.73; 33.3% vs. 8.3%, *p*<.05; Overall:  $X^2$ =4.10; 23.8% vs. 5.6%, *p*<.05).

## **Social Functioning and Anxiety**

Participants completed 4 measures related to social functioning and social anxiety, 353 including the Social-Anxiety Scale for Adolescents (SAS-A) which includes 3 scales (social 354 355 avoidance to new situations, general distress and social avoidance, and fear of negative evaluation), the Perceived Stigmatization Questionnaire (PSQ), Harter's Self-Perception Profile 356 for Adolescents (SPPA) which included a measure of self-worth and romantic appeal, and the 357 Body Image Life Engagement Questionnaire (BILEQ). Median and mean rank scores were 358 compared across burn size groups, burn location groups, sex, and appearance concerns which 359 was categorized to compare the 70.0% of the sample who endorsed appearance concerns on any 360 of the 3 measures versus the 30.0% who did not report appearance concerns. 361

No significant differences in median scores were found when comparing scores on measures of social functioning and anxiety across groups based on participant burn size, location, or sex. However, appearance concerns were significantly related to scores on the fear of negative evaluation scale of the SAS-A and the self-worth scale of the SPPA. Participants who reported appearance concerns had significantly more severe symptoms related to fear of negative evaluation on the SAS-A (Mdn=17.00) compared to those who did not report appearance concerns (Mdn= 11.50; U=302.50, p<.01). Reports of appearance concerns were also significantly associated with lower ratings of self-worth on the SPPA (Mdn=3.20) compared to participants who did not report appearance concerns (Mdn= 3.60, U=277.00, p<.01).

## 371 Assessing YP Face IT Feasibility

After completing measures of appearance and psychosocial functioning at the time of 372 study enrollment, participants were asked about their interest in the list of available support 373 374 resources including YPF. During the first phase of the study, of the 27 youth who reviewed the resource list, 11 (40.7%) indicated interest in 1 or more of the resources, which included 7 375 (26.0%) who said they would be interested in using YPF if it was available. During the second 376 377 phase of the study, 46 participants enrolled and 38 (82.6%) indicated interest in 1 or more of the resources, with 36 (78.3%) indicating interest in YPF specifically. These participants were 378 provided with sign in information, instructions on how to use the resource, weekly reminders, 379 and support from study staff in completing the sessions. Support included the initial review of 380 the resource at time of enrollment and reaching out to answer questions about resource use 381 during the study period. 382

Although 36 participants signed up to use YPF, in the 6-months following Phase II study 383 enrollment, only 7 (19.4%) of those who signed up completed at least some of the first session, 384 385 which introduces the content covered in YPF and is focused on describing common problems experienced by youth with visible differences. All participants who signed up were contacted (if 386 parents specified themselves as the primary contact, they were contacted) to encourage the use of 387 388 the YPF and to see if the participant had any questions. Outreach attempts via email, text, or telephone calls were terminated after 4 tries if there was no response or immediately if the 389 participant or parent indicated that they were no longer interested in use of YPF (2 adolescents). 390 391 For the 7 participants who used YPF, there were an average of 4.3 outreach attempts to

encourage session completion. At 6-months post-enrollment, only 1 participant had completed
more than half of the 7 YPF sessions. A majority (72.2%) of participants who signed up to use
YPF reported appearance concerns on at least 1 measure. However, rates of appearance concerns
reported on the 3 measures were not significantly higher in participants who signed up for YPF
(72.2%) compared to those who did not (70.0%).

Participants and parents of participants who enrolled in the second phase of the study 397 (n=46) were contacted 6-months post-enrollment to obtain more information about their use of 398 YPF and/or other available resources. Twenty participants and 21 parents (8 participant/parent 399 400 dyads) completed follow-up surveys. No demographic differences were found between study participants who completed follow-up surveys and those who did not. Four (20%) participants 401 who completed follow-up surveys indicated that they had used a psychosocial resource other 402 than YPF (burn camps and the corrective makeup clinic) in the 6-months following study 403 enrollment. Of the 7 participants who utilized YPF, 5 completed surveys about using it and 3 404 offered specific feedback about their experience. One participant cited not having access to a 405 device connected to the internet as barrier to using YPF. Another participant who was 17-years 406 old stated that YPF could be improved if it were tailored more to an older age group, and a 14-407 408 year-old participant suggested that having access to reviews of the resource by other youth with burn injuries would have helped her engage with the resource more, so she could decide whether 409 it was applicable to her. Parent feedback closely mirrored the information provided by study 410 411 participants. The parent of the 17-year-old YPF participant also noted that it may be useful to tailor the content to older teens and the parent of a 13-year-old participant noted that she would 412 413 be interested in having access to more parent-focused information mirroring the content covered 414 in YPF.

#### 415 DISCUSSION

## 416 **Prevalence of Appearance Concerns**

The current study assessed the prevalence of both general and burn-related appearance 417 concerns within a sample of adolescents receiving routine outpatient pediatric burn care in 1 418 hospital and explored the relationship between both types of appearance concerns and 419 420 psychosocial functioning, as well as the feasibility of implementing the YPF online resource within the population. Results indicated that the overwhelming majority (70.0%) of adolescents 421 receiving follow up care for burn injuries reported appearance concerns. Almost two-thirds 422 423 (63.8%) of all participants reported heightened general appearance concerns when scores on the Appearance Subscale of the Body Esteem Scale were compared to those of a non-burned 424 425 adolescent sample, compared to only 34.2% who reported appearance concerns related to the burn injury on a 2-part question and 3.1% who additionally reported appearance concerns on the 426 BOQ-AS. Reports of appearance concerns were not found to be significantly related to burn size 427 428 or location, however, girls in the sample reported more burn-related, but not general, appearance concerns on the 2-part question compared to boys. 429

Although there was evidence that most of the adolescents in this burn clinic sample had 430 431 some form of appearance concern, general concerns were more common than burn specific concerns and different measures of appearance concerns yielded varying levels of concerns 432 433 within the population. These findings suggest that estimates of the prevalence of appearance 434 concerns may be influenced by the measure used to assess them. One potential reason for such a range in appearance concern prevalence may be the content and order of questions within the 435 436 measures used. The BOQ-AS is a measure of appearance within the burn population and 437 includes 1 question which directly asks about the burn injury ("I feel that the burn is unattractive

to others") and 3 questions which ask about general appearance-related anxiety. Therefore, the 438 measure assesses both general and burn-related appearance concerns which may have affected 439 the prevalence of risk in the current study. If, for example, an adolescent was experiencing 440 general appearance concerns but did not have concerns directly related to their burn injury, they 441 may have qualified as at-risk on the BES-A and not at risk on the BOQ-AS since only 1 question 442 443 asks about general appearance concerns on this measure. Whatever the reason for the discrepancy, the findings obtained when using a more direct 2-part question about burn related 444 appearance concerns, and even more so when using this question as well as measures of general 445 446 appearance concerns combined, suggest that the prevalence of appearance concerns may be much higher in the adolescent burn population than some previous studies have reported. 447

### 448 Appearance Concerns and Psychosocial Functioning

Results confirm earlier research indicating that appearance concerns are associated with 449 significantly worse psychosocial outcomes in adolescents who are recovering from burn injuries. 450 451 In the current study, fear of negative evaluation and self-worth were particularly affected by the presence of appearance concerns. Concerns about appearance related to the burn injury were less 452 prevalent than general appearance concerns and only when considering combined general and 453 454 burn-related appearance concerns did significant differences in psychosocial functioning in those with versus without appearance concerns, particularly problems related to internalizing 455 symptoms, emerge. Therefore, findings confirm the high prevalence of appearance concerns 456 457 amongst the adolescent population and suggest that general appearance concerns and burnrelated appearance concerns are interrelated psychosocial domains. More research is needed to 458 459 determine which patients are most at-risk for increased general appearance concerns or the

460 development of burn-related appearance concerns post-burn injury so they can receive support461 earlier on during treatment.

## 462 Feasibility of Implementing YP Face IT

Given the previously reported prevalence of both appearance concerns and psychosocial 463 problems in adolescents who have experienced a burn injury, the current study also assessed 464 465 whether the YPF online resource could be feasibly implemented to fill the need for an accessible, evidence-based appearance-focused tool tailored to adolescents receiving outpatient burn care. 466 Results demonstrated strong interest in YPF during Phase I as well as Phase II of the study, 467 468 where nearly 80% (n=36) of enrolled study participants signed up to access the resource. However, in the 6-months following enrollment in the use of YPF, only 7 (19.4%) of the 469 adolescents who expressed interest in YPF utilized even a part of a session and none finished all 470 7 sessions, indicating that more research is needed to understand how to best support in-clinic or 471 at-home resource use. Follow-up surveys revealed that use of other available resources 472 mentioned to participants was also very low, which aligns with literature indicating that young 473 people appear to be reluctant to engage in psychological support.<sup>61,62</sup> Specific feedback from 3 474 adolescents who used YPF revealed that lack of at-home access and age-specific applicability 475 476 were deterrents to resource use. YPF requires an internet-enabled device, which according to the feedback surveys, was not consistently available to all participants. The YPF resource contains 7 477 sessions covering a range of topics such as navigating peer relationships, tools for combatting 478 479 social anxiety, how to reach out to social support networks, and dating and romantic relationships. Although each session was available to study participants before enrollment, users 480 481 may have benefited from more individual assessment and guidance on which YPF sessions 482 would be most applicable to them.

483 Although many adolescents signed up to use the YPF resource in the outpatient clinic, only a minority of them logged on at home to engage with the sessions. The reasons for this lack 484 of retention was not immediately apparent from our study. We were intrigued by a parent's 485 suggestion that it may be beneficial in future implementations of YPF to concurrently offer a 486 parent-focused version of the program since it would allow parents to learn and disseminate the 487 tools taught in YPF at a pace they find appropriate to their own child. In a recent study 488 completed by Heath and colleagues (2019) in the UK, a parent-focused resource prototype was 489 tested in a sample of parents of children with burn injuries.<sup>63</sup> The study's results showed that 490 parents rated the tool positively and appreciated having access to an online resource which 491 empowered them to seek out relevant information whenever it became necessary. It is possible 492 that offering parents the use of YPF could prove to be similarly beneficial within the current 493 study's outpatient population. Similar observations could be made about the potential for having 494 clinicians already working in settings where young people are recovering from burns use YPF in 495 a more tailored approach to treating appearance concerns post-injury. 496

There is some recent evidence to suggest that burn care clinicians would also value a 497 brief survey to assist in screening patients for appearance concerns and related psychosocial 498 distress within clinical burn settings.<sup>64</sup> Similarly, findings have demonstrated that outpatient 499 clinicians are able to routinely incorporate information about the patient's psychosocial 500 functioning into clinical care decisions within the context of outpatient burn care.<sup>34</sup> Therefore, if 501 502 patients were regularly screened for appearance concerns and/or more general psychosocial problems using brief measures such as the 2-part question or PSC-17, it might help clinicians 503 identify patients who have or are at-risk for developing appearance concerns and who might 504 benefit from referrals to traditional psychosocial care and/or the use of YPF. We conclude that 505

506 YPF could be a useful and accessible tool for adolescents in outpatient burn care, especially if 507 both their parents and their clinicians are given the opportunity to participate in offering them the 508 use of the resource as well as the chance to support the adolescent in completing the YPF 509 sessions.

#### 510 Future Research and Study Limitations

Based on the relatively high prevalence of appearance concerns and psychosocial 511 difficulties within the outpatient pediatric burn population and the amount of interest expressed 512 in the YPF online resource, we believe that with the right approach and support, YPF could be a 513 514 useful resource for adolescents and/or their parents/clinicians. The current study highlights the value of incorporating screening for both general and burn-specific appearance concerns into 515 routine outpatient burn care, and a need for caregiver-and/or clinician-oriented resources focused 516 517 on providing them with the vocabulary and tools needed to support young people through the social and emotional difficulties which may occur after a burn injury. 518

519 The current study had a number of limitations. First, for the most part, participants had smaller burns. Second, the YPF resource was created within a framework of Western cultural 520 norms and participants were only eligible to participate if they were English-speaking. The 521 522 applicability of the program to youth from other cultural or language groups was therefore untested. Third, the study was completed in a single outpatient burn clinic in which patients were 523 predominantly receiving surgical or wound care rather than psychiatric care or counseling. 524 525 Therefore, patients may not have been prepared to consider psychosocial as well as physical components of their care since their visits when recruited for the study were predominantly 526 527 focused on physical recovery. Fourth, fewer than half of the participants who enrolled in the 528 second phase of the study completed feedback surveys, limiting the generalizability of

529	conclusions drawn from them, although the cohort was found to be representative of the general
530	study population. Although our findings must be considered within the context of study
531	limitations, they nevertheless suggest a need for further research to investigate ways to prioritize
532	identifying and assessing adolescent appearance concerns and psychosocial problems within the
533	context of outpatient burn care.
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	$N^{l}$	M(SD)
Age at Survey (years)	78	14.84 (1.92)
TBSA (%)	74	17.82 (22.82)
Time Since Burn (years)	77	4.54 (5.42)
	$N^2$	%
Race/Ethnicity		
White/Caucasian	51	68.0
Black/African American	10	13.3
Hispanic/Latino	4	5.3
Asian/Pacific Islander	8	10.7
Other	2	2.7
Burn Location		
Face, Head, or Neck	27	34.6
Hand or Wrist	42	53.8
Other	9	11.5

<sup>1</sup>N of participants with available data <sup>2</sup>N of participants who fit the categorical criteria reported *Note:* Race/ethnicity was available for 75 participants and burn location data was available for all 78 participants.

Appearance Concerns	$N^{l}$	N (%) AC Reported
Burn Outcomes Questionnaire - Appearance	64	1 (3.1)
Body Esteem Scale for Adolescents	69	44 (63.8)
2-Part Burn Related Appearance Concerns Question	73	25 (34.2)
Psychosocial Functioning: PSC-17 Risk	$N^{l}$	N (%) Risk
Overall Psychosocial Problems	59	9 (15.3)
Internalizing Symptoms	59	11 (18.6)
Externalizing Symptoms	66	6 (9.1)
Attention Symptoms	66	4 (6.1)
Psychosocial Functioning: Categorical Risk	$N^{I}$	Median (IQR)
Self-Worth (SPPA)	71	2.80 (1.55)
Romantic Appeal (SPPA)	56	2.70 (1.10)
Social Avoidance to New Situations (SAS-A)	72	14.50 (7.00)
General Distress and Social Avoidance (SAS-A)	75	6.00 (3.00)
Fear of Negative Evaluation (SAS-A)	72	15.50 (10.50)
Life Engagement (BILEQ)	40	1.25 (0.78)
Perceived Stigmatization (PSQ)	67	1.93 (0.55)

Table 2. Appearance Concerns, Psychosocial Functioning, and Social Anxiety 

<sup>1</sup>N of participants with available data <sup>2</sup>N of participants who fit the categorical criteria reported

*Note:* AC= appearance concerns; IQR = Interquartile range