Facial Disfigurement in Patients With Head and Neck Cancer: The Role of Social Self-Efficacy

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This study investigated the moderating role of social self-efficacy (i.e., the belief that one is capable of exercising control over the reactions and openness of other people) with respect to the link between facial disfigurement and psychological and social functioning. Facial disfigurement was rated by patients (n = 76) as well as their physicians. In line with the hypotheses, the results revealed that the degree of facial disfigurement, as judged by patients as well as their physicians, was positively related to psychological distress and distress in reaction to unpleasant behavior of others, but only when patients did not feel self-efficacious in social encounters. Furthermore, social self-efficacy mitigated the positive link between facial disfigurement as judged by patients and social isolation.

Keywords: facial disfigurement, social self-efficacy, psychological distress, social isolation, head and neck cancer

One of the major concerns reported by patients with head and neck cancer is the disfigurement associated with their disease and subsequent treatment (Gamba et al., 1992; Koster & Bergsma, 1990). Owing to their altered facial appearance and the loss or impairment of important functions, such as speech and swallowing, these patients are prone to psychological and social problems (Breitbart & Holland, 1988; see also Charlton, Rumsey, Partridge, Barlow, & Saul, 2003; Clarke, 1999; for a review, see De Boer, McCormick, Pruyn, Ryckman, & van den Borne, 1999). For example, a considerable number of patients feel stigmatized and are confronted with the unpleasant behavior of other people, including negative remarks, naked stares, and avoidance (Clarke, 1999; Gamba et al., 1992; Strauss, 1989). Such negative behavior of others is likely to result in psychological distress as well as social isolation (Gamba et al., 1992; Vardy et al., 2002). It is noteworthy that other research has shown that the subjective experience of being avoided can be objectively demonstrated (Houston & Bull, 1994; Kleck, 1969; Rumsey, Bull, & Gahagan, 1982; Silver, Wortman, & Crofton, 1990). It is also important to note that patients become socially isolated not only because other people avoid them, but also because they isolate themselves from their family and friends out of concern for their appearance and fear of the reactions of others (De Boer et al., 1995; Dhooper, 1985).

The present study aims to add to the knowledge about associations between facial disfigurement and psychological distress, distress in reaction to unpleasant behavior of other people, and social isolation. It seems plausible that more severe facial disfigurement is associated with more serious psychosocial problems. However, the findings of previous studies that investigated the relationship between the degree of facial disfigurement and distress and social functioning in patients with head and neck cancer have been inconclusive (Gamba et al., 1992; Katz, Irish, Devins, Rodin, & Gullane, 2000; Rapoport, Kretlter, Chaitchik, Algur, & Weissler, 1993). As pointed out by Katz et al. (2000), these inconsistent findings may be partly due to methodological constraints on the measurement of disfigurement. Most of the studies used the surgical procedure as a proxy for the degree of disfigurement, which does not take into account individual differences in the cosmetic result attributable to, for example, differences in reconstructive technique and previous radiotherapy. Also, ratings that were based on photographs may fail to account for disfigurement that becomes more apparent when patients are observed during dynamic interaction (i.e., affected facial expression). Therefore, the present study assesses physicians’ subjective evaluations of patients’ facial expression (i.e., observer-rated disfigurement). Furthermore, self-reports of visibility of (the treatment of) cancer were obtained (i.e., patient-rated disfigurement). Most studies used so-called “objective” measures of facial disfigurement, but patients’ own subjective evaluations of facial disfigurement may be more strongly related to distress and social isolation.

Moreover, we assume that not all patients are affected by facial disfigurement to the same degree (cf. Katz, Irish, Devins, Rodin, & Gullane, 2003; Leary, Rapp, Herbst, Exum, & Feldman, 1998; Thompson & Kent, 2001). Whether individuals experience more distress and social isolation as a consequence of severe rather than minor facial disfigurement may be influenced (i.e., moderated) by psychological factors. The few studies that looked into this issue...
found empirical evidence for the mitigating role of social support (Katz et al., 2003) and the strengthening role of negative evaluation by others (Kent & Keohane, 2001; Leary et al., 1998).

An important moderator that has been neglected so far is **social self-efficacy**. Social self-efficacy is the extent to which patients believe that they are capable to exercise control over the reactions and openness of other people. Patients with severe facial disfigurement who feel self-efficacious in social interactions are likely to feel more confident that they can control and handle the unpleasant behavior of others and, as a result, they are expected to become less distressed than patients with severe facial disfigurement who do not feel self-efficacious in social interactions. Patients with severe facial disfigurement who feel self-efficacious in social interactions will probably also be less inclined to withdraw from social situations and be more successful in social integration by using, among other things, more proactive social skills. In general, people tend to avoid situations that are believed to exceed their capacities, and self-efficacy determines how much effort and persistence people will expend when they face an obstacle or failure (Bandura, 1986, 1997). Following Bandura (1986, 1997), we defined self-efficacy beliefs with respect to a task-specific personal ability; that is, the ability to exercise control over social interactions. Previous studies have examined the relationship between general self-efficacy and patient adjustment and found that patients with high self-efficacy showed less distress than those with low self-efficacy (e.g., Cunningham, Lockwood, & Cunningham, 1991). Moderating effects, however, have not been studied.

To summarize, we test three hypotheses. Hypothesis 1 is that social self-efficacy mitigates the positive relation between facial disfigurement as judged by patients, as well as their physicians, and psychological distress. In a similar vein, it is hypothesized that the degree of facial disfigurement as judged by patients and their physicians is positively associated with distress in reaction to unpleasant behavior of other people (Hypothesis 2) and social isolation (Hypothesis 3), especially when patients do not feel self-efficacious in social encounters.

**Method**

**Participants and Procedure**

During a check-up visit at the hospital, consecutive patients who met the inclusion criteria of the study were invited to participate by their physician. The inclusion criteria were (a) a tumor in the head and neck region (e.g., in the oral cavity, larynx, oropharynx, hypopharynx, or jaw), treated with surgery and/or radiotherapy; (b) a life expectancy of at least 6 months; (c) and an age between 18 and 70 years. Directly after this visit, a member of the research team met with the patient to answer any questions about the study. With patients who were willing to participate, an appointment for a house visit was made. Part of the data was collected by means of a structured interview (e.g., on social support). The other part, which is reported in the present article, was collected by means of a questionnaire that was filled out during the house visit. The study was approved by the Institutional Review Board of the Groningen University Hospital.

In total, 76 patients agreed to fill out the questionnaire (response = 72%). The sample was representative of the population of head and neck cancer patients at this hospital in terms of age and gender. The average age of the 44 male and 32 female patients was 58 (SD = 12.69) years. Most patients shared a household with their partner (84%), either with or without children. The education of most patients consisted of primary education (23.7%) or vocational training at the lower (39.5%) or average (15.8%) level. Patients had been diagnosed 1 to 62 months ago (M = 1.12 years, SD = 1.05 years). The majority underwent surgery (80%) and a large group received radiotherapy, with or without surgery (58%). T-classifications (tumor size) were available for 48 patients: 43.8% patients received a T1 classification, 31.3% received a T2; 8.3%, a T3; and 16.7%, a T4.

**Measures**

Facial disfigurement was judged by both patients and their physicians. Patients answered two questions, namely (a) “Do you believe that other people can see that you are ill or have been ill?” (1 = not at all, 2 = somewhat, 3 = fairly well, 4 = very well) and (b) “Do you believe that your appearance has changed owing to your disease?” (1 = not at all, 2 = somewhat, 3 = rather, 4 = very). The two item scores were averaged into a single score for facial disfigurement (Cronbach’s alpha was .78, r = .65, p < .001). Physicians judged the degree of impairment of patients’ facial expression on a 7-point scale ranging from 1 (not at all impaired) to 7 (very much impaired; cf. Katz et al., 2000).

To measure social self-efficacy, we asked patients to answer 12 questions about the extent to which they believe that they are capable to exercise control over the reactions and openness of other people. Example items are as follows: (a) “Whether people are open and honest to me depends on my attitude”; (b) “I can reassure people, when they are nervous to talk to me”; (c) “I can make sure that other people like to associate with me”; and (d) “How others react to me is under my own control.” The answer alternatives were 1 (never), 2 (usually no), 3 (usually yes), and 4 (always). The items were averaged into a single index for social self-efficacy (α = .63; M = 3.64, SD = 0.41).

Psychological distress was assessed with nine items of Spielberger’s State–Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1969; van der Ploeg, Defares, & Spielberger, 1980). All items reflected either positive or negative mood states experienced during the last couple of days. The items were tense, restless, at ease, afraid, pleasant, agreeable, depressed, satisfied, and happy (1 = not at all, 2 = somewhat, 3 = rather, 4 = very much). We added one item: abandoned. The positive mood states were reverse-coded, and all items were then averaged into a single index, with a higher score indicating more distress (α = .90). The mean level of distress (M = 1.64, SD = 0.66) is within the normal range.

Distress in reaction to unpleasant behavior of others was assessed with four items. All items started with the general stem: “When someone I know well behaves unpleasantly toward me, . . .” This stem was followed by the following items: (a) “I keep ruminating about it,” (b) “I become grumpy,” (c) “I become tense,” and (d) “I become depressed” (α = .76). The answer alternatives were 1 (seldom or never), 2 (sometimes), 3 (usually), and 4 (very often). Higher scores on this scale indicated more distress in reaction to unpleasant behavior of others (M = 1.58, SD = 0.75). This measure showed a correlation of .40 (p < .001) with psychological distress.

Social isolation was assessed with 12 items that were answered on a 4-point scale: 1 (never), 2 (usually no), 3 (usually yes), 4 (always). Example items are the following: (a) “Acquaintances rather not talk about my disease”; (b) “It is difficult to keep friends, because of my disease”; (c) “When it comes down to it, you face things alone”; (d) “Most people know about which attitude to adopt toward someone who is ill” (reverse-scored; α = .70; M = 1.83, SD = 0.46). Social isolation correlated .26 (p < .05) with both psychological distress and distress in reaction to unpleasant behavior of others.

**Data Analysis**

Correlations between patients’ and physicians’ judgment of facial disfigurement and medical variables (i.e., T-classification and time since symptoms were first experienced) and demographic variables (i.e., age, gender, and education level) were calculated. Indices of facial disfigure-
ment should be correlated with medical variables but not with demographic variables (Katz et al., 2000). Furthermore, there should be a moderate correlation between patients' and physicians' judgment (Katz et al., 2000). An alpha level of .05 was used for all statistical tests.

We performed linear regression analyses to determine whether the associations between facial disfigurement and outcome variables (i.e., psychological distress, distress in reaction to unpleasant behavior of others, and social isolation) were moderated by social self-efficacy. Because none of the medical and demographic variables were associated with one or more of the independent variables as well as one or more outcome variables, these variables did not need to be included in the regression analyses as covariates. Also, no significant interactions with gender were found. In consecutive steps, main effects (i.e., facial disfigurement, either patients' or physicians' judgment, and social self-efficacy), and the interaction between facial disfigurement and social self-efficacy (i.e., the product of the “centered” scores) were entered (Aiken & West, 1991). We calculated and plotted the regression slopes for patients high (+1 SD) and low (−1 SD) on social self-efficacy, separately (Aiken & West, 1991). Following Cohen (1988), $\Delta R^2 = .02$ (i.e., $f^2 = .02$) represents a small effect, $\Delta R^2 = .13$ (i.e., $f^2 = .15$) represents a medium effect, and $\Delta R^2 = .26$ (i.e., $f^2 = .35$) represents a large effect.

Results

Facial Disfigurement

The mean score of patient-rated disfigurement was 1.97 (SD = 0.97, range = 1–4), indicating that, on average, patients felt that the consequences of the cancer treatment was somewhat visible. The average score on physician’s judgment of disfigurement was 2.17 (SD = 1.62, range = 1–7), indicating minor impairment of facial expression. There was a moderate correlation between patients’ and physicians’ perceptions of facial disfigurement ($r = .42, p < .001$). As expected, patients’ perception of facial disfigurement was significantly associated with medical variables, including T-classification ($r = .44, p < .01$) and time since symptoms were first experienced ($r = .26, p = .03$), but not with demographic variables, including age ($r = −0.12, p = .32$), gender ($r = .14, p = .23$), and education level ($r = .11, p = .34$). Similarly, physicians’ judgment of facial disfigurement was significantly related to T-classification ($r = .52, p < .001$) and time since symptoms were first experienced ($r = .25, p = .03$), but not with age ($r = .04, p = .76$), gender ($r = .20, p = .09$), and education level ($r = −0.01, p = .90$).

Facial Disfigurement and Psychological Distress

The regression analyses revealed an interactive effect of facial disfigurement, as judged by either the patient or the physician, and social self-efficacy on psychological distress (see Table 1). In line with Hypothesis 1, the positive association between facial disfigurement and psychological distress was significant only when social self-efficacy was low. Because the two interactions assumed the same form, only the interaction with patients’ perception of disfigurement was plotted (see Figure 1).

Facial Disfigurement and Distress in Reaction to Unpleasant Behavior of Others

The analyses also showed interaction effects with respect to distress in reaction to unpleasant behavior of others. In support of Hypothesis 2, we found a significant positive link between patients’ perception of facial disfigurement and distress in reaction to unpleasant behavior of others only when social self-efficacy was relatively low (see Figure 2). When social self-efficacy was high, patients perceived relatively little distress in reaction to negative behavior of others, regardless of the degree of facial disfigurement. The interaction between physicians’ judgment of disfigurement and social self-efficacy merely approached significance ($p = .058$) but assumed the same form.

Table 1

Results of the Regression of Psychological Distress, Distress in Reaction to Unpleasant Behavior of Others, and Social Isolation on Facial Disfigurement, Social Self-Efficacy (SSE), and Facial Disfigurement by SSE

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Psychological distress</th>
<th>Distress in reaction to others’ unpleasant behavior</th>
<th>Social isolation</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>$B^*$</td>
<td>$\Delta R^2$</td>
<td>$\Delta F$</td>
</tr>
<tr>
<td>Patient-rated disfigurement (PaD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PaD</td>
<td>0.30***</td>
<td>0.17</td>
<td>7.30</td>
</tr>
<tr>
<td>SSE</td>
<td>-0.00</td>
<td></td>
<td></td>
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<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PaD × SSE</td>
<td>-0.43**</td>
<td>0.08</td>
<td>7.32</td>
</tr>
<tr>
<td>Physician-rated disfigurement (PhD)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PhD</td>
<td>0.08</td>
<td></td>
<td>2.36</td>
</tr>
<tr>
<td>SSE</td>
<td>0.01</td>
<td></td>
<td></td>
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<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PhD × SSE</td>
<td>-0.21*</td>
<td>0.06</td>
<td>4.70</td>
</tr>
</tbody>
</table>

Note. With respect to distress and social isolation, $n = 76$. Concerning negative emotions, $n = 65$.

* Unstandardized regression coefficient.

* $p < .05$. ** $p < .01$. *** $p < .001$. 
Facial Disfigurement and Perceived Social Isolation

With respect to social isolation, we again found a significant interaction between patients’ judgment of disfigurement and social self-efficacy. As expected, a significant positive link between disfigurement and social isolation was present, but only when social self-efficacy was relatively low. Patients perceived relatively little social isolation when social self-efficacy was high, regardless of the degree of facial disfigurement. The interaction, thus, takes a similar form, as depicted in Figure 2. The interaction between physicians' judgment of disfigurement and social self-efficacy was not significant. Thus, Hypothesis 3 was partly supported.

Discussion

The present study contributes to the existing literature on psychological and social consequences of facial disfigurement in that it shows that social self-efficacy moderates the positive link between the degree of facial disfigurement and psychological distress, distress in reaction to unpleasant behavior of others, and social isolation. More specifically, patients with more (rather than less) severe facial disfigurement experienced more psychological distress, more distress in reaction to unpleasant behavior of other people, and more social isolation, but only when they believed that they were not very capable of exercising control over the reactions and openness of other people. Because the belief that one is disfigured is subjective and not necessarily congruent with the actual “objective reality,” it is noteworthy that most of our findings were consistent with respect to facial disfigurement defined as visibility of the disease rated by patients and facial disfigurement defined as impairment of facial expression rated by physicians.

Previous research has revealed that disfigurement associated with head and neck cancer and subsequent treatment is one of the major concerns reported by patients (Gamba et al., 1992; Koster & Bergsma, 1990). However, findings concerning the link between the degree of disfigurement and distress were inconclusive, and only a few studies have investigated psychological factors that may mitigate the impact of disfigurement on distress and social functioning (Katz et al., 2000; Thompson & Kent, 2001). Our findings are in line with, and add to the results of, the few studies that did investigate psychological factors, including social support and fear of negative evaluations by others, as moderators of the link between facial disfigurement and distress (Katz et al., 2003; Kent & Keohane, 2001; Leary et al., 1998).

The present study has a number of limitations that need to be kept in mind when interpreting the findings. First, we mainly used newly developed questionnaires that have not been validated. Furthermore, the internal consistency of the social self-efficacy measure was not very high and could be further improved. Second, although the response rate was satisfactory, the sample size was rather small. It has to be noted, however, that despite these limitations, our study revealed very consistent moderating effects. That is, four of six expected interactions were found to be significant, and one approached significance. This is especially noteworthy because it is much more difficult to detect interaction effects in naturalistic than in experimental samples, particularly in small samples (McClelland & Judd, 1993). A third limitation is the cross-sectional design of our study, which does not allow causal inference. Although our argument may suggest that social self-efficacy prevents distress in individuals with relatively severe facial disfigurement, such a causal effect needs to be investigated in intervention studies specifically designed to increase social self-efficacy. Fourth, on average, the sample consists of patients with relatively minor facial impairment, indicating that we have to be cautious in generalizing the results to people with more severe facial impairment.

Although the sample consisted of a specific group of patients, we believe that the associations found in our study may be true also for other groups with facial disfigurement and perhaps also for individuals with other physical handicaps; all the more, as our results are in line with other work regarding patients with psoriasis and other facial disfigurements (e.g., Kleve, Rumsey, Wyn-Williams, & White, 2002; Leary et al., 1998). Apparently, social self-efficacy is an important asset, especially for patients with severe facial disfigurements.

References


