Patients with Facial Difference: Assessment of Information and Psychosocial Support Needs

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Abstract
Adults with congenital or acquired facial differences are a defined group of individuals in the community facing unique psychological and social issues. Despite multidisciplinary intervention, many individuals face lifelong challenges, which can adversely affect body image, self-esteem and quality of life. Nonprofit organizations such as AboutFace provide information and emotional support to individuals touched by facial differences. A pilot partnership project was proposed to qualitatively investigate the needs of adults with craniofacial deformities at Sunnybrook Health Sciences Centre. Questionnaires exploring epidemiology, issues and concerns, coping strategies and future program suggestions were mailed to 105 patients. Twenty-six patients (25%) responded, and 5 individuals participated in an in-depth focus group. Approximately equal numbers of males and females (mean age 34 years, range 16 to 54 years) with facial differences arising from congenital (46%), post-traumatic, (46%), or postablative (8%) means responded. Strategies used by patients to cope with their facial difference differed significantly from current services offered by AboutFace. While enthusiastic interest was expressed for the development of information and support programs, it is clear that several nonsurgical needs of patients with facial difference are not currently being met. An alliance between clinical and community programs is proposed to aid in the development of a comprehensive treatment plan for patients with facial differences.

Introduction

Facial Difference
In a society that encourages conformity to an idealized standard of beauty, individuals with facial disfigurements or ‘facial difference’, are a defined group of individuals who may experience psychological difficulties and social stigma as a result of their appearance. In Canada, approximately 10,000 babies are born with a facial difference annually, while 52,000 individuals acquire a new facial difference each year as the result of injury, disease or illness. People with facial difference, whether present at birth, or due to illness or trauma, may suffer poor body image or self-esteem, creating barriers to friendship, education and employment opportunities.

Multidisciplinary Treatment of Facial Difference

The goal of treatment of facial difference by multidisciplinary teams is to improve functional and cosmetic needs while fostering psychological adjustment, positive self-esteem, and healthy interpersonal skills. While reconstructive surgery aims to improve physiologic function and satisfaction with appearance, complete restoration of a disfigurement is rare. Physicians who operate on patients with facial difference are increasingly recognizing the importance of support in treating the ‘whole patient’; “It is becoming clear...that surgery alone is not sufficient; such patients also require informed supportive counseling...such intervention should not be an optional extra but an integral part of quality care and rehabilitation.” As a complement to the vital role of surgery in addressing facial difference, it is equally important to recognize the

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Community supports for patients with facial differences include AboutFace, a Toronto-based nonprofit organization where objectives include providing information on issues related to facial difference, networking individuals for information sharing and emotional support and educating the public about the abilities and challenges in facial difference. Other regional agencies addressing issues related to facial difference include Changing Faces (London, England), Smiles (USA), Let's Face It (Washington), and The Disfigurement Guidance Centre.

A pilot partnership project was proposed in order to explore the potential for an alliance between AboutFace and the Craniofacial Program at the Sunnybrook Health Science Centre (SHSC). Objectives of the project were (1) to investigate the needs of adults with craniofacial disorders, (2) to establish a link between AboutFace and the SHSC Craniofacial Program, (3) to help plan for services which best meet the identified needs of adults with facial differences, and (4) to make recommendations for the initiation of future AboutFace-community partnerships.

Method
Patients with facial differences treated by a single craniofacial surgeon at Sunnybrook Health Science Centre, a Level I trauma unit, served as the study population. All participants were adults with congenital or acquired facial differences. Patients with significant cognitive dysfunction were excluded. A four-page questionnaire was used to qualitatively investigate epidemiology (age, sex, cause and duration of facial difference), coping strategies and suggestions for future support programs. Five-point visual analogue scales were used to semi-quantitatively assess attitudes about self, and issues and concerns related to facial difference. Questions for evaluation were based on data obtained from literature review and agency experience of significant issues expressed by individuals with facial difference. Approval from the SHSC Research Ethics Board was obtained for this study. One hundred and five questionnaires were mailed to patients treated between 1996 and 1998. Data was collected and entered into the FileMaker Pro 3.0 Program for Macintosh. Written responses were recorded as they appeared on the questionnaire. Numerical scores of respondents were averaged and presented as the mean.

A two-hour focus group was conducted at SHSC and facilitated by two of the authors (KMH, LR) in order to gain additional insight into the unique issues and needs of adults with facial difference. A consent form acknowledging and accepting audio-taping of the session was signed by participants at the beginning of the focus group, for the purpose of recall and summary of the discussion. Participants were encouraged to speak freely and share their thoughts and ideas in a non-threatening, comfortable environment.

Results
Questionnaire Response
Of 105 questionnaires, 26 were completed and returned, yielding a 25% response rate (summarized in Table I). Another 31 packages were returned unopened due to a change in address, and the remaining 48 were unaccounted for. The respondents included 12 males and 14 females. Respondent age ranged from 16 to 54 years with a mean age of 34 years. Cause of facial difference was categorized as congenital, post-traumatic or post-ablative. Twelve patients each had a congenital (46%) or traumatic (46%) cause of their facial difference, while two patients (8%) had ablation of a malignancy (Table I). The average duration of acquired facial difference was 3 years (range 2.0 - 6.5 years).

Of the 26 respondents, none had personal involvement with AboutFace, but 23% were aware of the organization’s existence. Ninety percent (23 participants) indicated interest in future involvement with support organizations. Fifty-four percent (14 participants) were interested in further involvement in the study (focus group), and 5 were able to participate in the focus group.

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<th>Table 1 Questionnaire Response</th>
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<td>Response rate</td>
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<td>Post-traumatic</td>
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<td>Post-ablative</td>
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Surgical Experience
Patients were asked "What helped or would have helped you to prepare for your surgery?". Strategies included preoperative explanations by the physician, the opportunity to ask questions, support from family and friends, counseling, and religion. One patient stated: "I never had any [preparation] throughout my childhood - it was a total nightmare". This experience was echoed among other respondents who had undergone multiple surgeries during childhood, revealing that surgeries were "not asked for, not understood, and explanations were not adequately given". When asked about recovery and needs after surgery, typical responses included emotional support, reassurance, rest and time. Many patients described surprise and frustration at the length of time taken to recover following surgery.

Emotional, social and work-related effects of surgery varied. Some individuals reported improved self-esteem and more self-confidence following surgery, enabling them to lead a more normal life: “I was able to attend school, church, Brownies and Girl Guides”. However, other individuals expressed that although they were satisfied with the results of their surgery, their facial difference still affected their life in terms of self-concept, socially or professionally: "Sometimes when I look in the mirror, it's hard to see myself"; "There are still people staring at me and making mean comments"; "I still can't find permanent employment in a public field".

When asked: "What would you say to someone dealing with facial difference for the first time?" and "What did you learn from your experience?", responses included: "I learned how cruel people can be to people with deformities and how ignorant they are of their
Patients were asked about interest in future services related to facial difference. Significant interest was expressed for information and resources about facial differences, networking with other adults with a facial difference, information about congenital syndromes at SHSC. Unequivocal interest was demonstrated for the establishment of a monthly support group in the community.

Attitudes About Self
A five-point visual analogue scale was used to assess participants’ attitudes about themselves. Categories included (1) feelings of attractiveness (overall, facial, sexual), (2) social skills (handling new situations, meeting new people, letting people know me, feelings of belonging), and (3) self-esteem (feeling good about myself, confidence in abilities, recognizing my strengths, giving myself credit).

Twenty-six scores were averaged, and the mean score was plotted on a scale from 0 to 4 (poor to excellent). A score of 2 was considered average (Figure 1). Respondents scored slightly below average in feelings of attractiveness, average in social skills and scores varied in self-esteem.

Issues and Concerns
A five-point visual analogue scale was used to assess issues and concerns with respect to self-concept, body image, social and professional situations (Figure 2). High scores (‘frequently’ or ‘always’ difficult) were common in interacting with new people, dating or socializing, self-consciousness with appearance, and looking at myself in photos or in the mirror. However, overall numerical trends for issues and concerns related to facial difference were not striking. Individual responses accompanying the numerical scores included forthright statements such as: “People still stare at me all the time”; “I’m tired of doctors saying You’re in your forties, have a family and work - so what’s the problem? Accept yourself?”; and “People still look for physical perfection, especially employers. You learn the hard way to hide your feelings”.

Coping Strategies and Program Suggestions
The vast majority of respondents reported that past strategies used to cope with facial difference consisted of talking with family and friends, pursuing hobbies and educating themselves (Figure 3). Fewer patients talked to their physician, avoided social contact or sought counseling as means of coping. A smaller percentage used alcohol or drugs or pursued employment with minimal face-to-face contact. Of special interest was that the most infrequent coping strategies included talking with other adults with a facial difference and attending support groups.

Patients were asked about interest in future services related to
Table 2
Support and Information Needs Suggested by Participants (n=26)

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<th>Need</th>
<th>Percentage</th>
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<td>Information and resources about facial differences</td>
<td>54%</td>
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<tr>
<td>Networking with other adults with a facial difference</td>
<td>46%</td>
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<tr>
<td>Information sessions (speakers, videos, workshops)</td>
<td>46%</td>
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<td>Syndrome-specific information</td>
<td>38%</td>
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<td>Support groups or meetings</td>
<td>35%</td>
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Discussion

Although reconstructive surgical techniques have made extraordinary advancements in the surgical management of facial differences, inherent psychosocial issues of living and coping with a disfigured face are not always addressed.12 The aim of this project was to qualitatively investigate the information and support needs of adult patients with facial difference at SHSC, and to help plan for community services which best meet these needs.

Over one third of respondents were in the 35 to 44 year age range. It is interesting that many telephone callers to AboutFace and organization members themselves are in this age range,2 indicating the similarity between this subset of the study population and individuals in the community with facial difference who currently seek support services. Furthermore, the wide range of participant ages illustrates that having a facial difference can have an impact at any age, with issues and challenges remaining significant throughout the decades.

It is clear that many adults with facial difference are not aware of organizations such as AboutFace, and only a minority of those who are aware of their existence take advantage of their services. From the interest shown in this study, the lack of awareness is likely a consequence of inadequate access to information, rather than disinterest. Perhaps by targeting individuals with newly acquired facial difference directly at trauma centres and introducing support services early, utilization of community resources would be more effective.

The majority of past coping strategies reported by respondents were largely activities that did not involve community programs and which could be achieved independently. Strategies used most frequently included talking with other adults with a facial difference and attending support groups and services offered by community agencies. This is in contrast to the respondents’ significant interest in information and support services.

Results obtained from the focus group confirmed the findings of the questionnaire, namely that despite minimal previous use of information and support resources, many patients with facial difference have a strong interest in the services of a support group. Such a link would directly provide patients with access to these services, with the opportunity to take advantage of these programs, support themselves and facilitate self-education about facial difference.

The diverse attitudes toward surgical outcome and issues related to facial difference imply that although reconstructive surgery aims to improve physiologic function and satisfaction with appearance, many people still experience difficulties in their life not directly addressed by surgery. In order for tertiary care centres to best care for post-surgical patients, it is important for the individual undergoing craniofacial surgery, as well as their family members, friends, and health care professionals to recognize, anticipate and understand these needs. By doing so, an effective support network can be built for the patient, both at treatment centres and in the community.

The results of this study suggest that many of the nonsurgical needs of patients with facial difference are not currently being met. These needs include access to information about their condition, access to general resources related to having a facial difference, and support programs. To date, the clinical focus in facial difference has often been on surgical treatment and ancillary services to address functional difficulties.1 Organizations founded specifically to support individuals touched by facial difference, provide programs and services that specifically address these issues, such as networking, education, support and outreach in the community.

Direct outcomes of this study have included the initiation of communication between the SHSC Craniofacial Program team and AboutFace, and the establishment of a monthly support group for people with facial difference. Future plans include regional distribution of informational materials and organization of educational evenings and workshops.

Initiation of further alliances between tertiary care centres specializing in craniofacial differences and community support agencies will be strongly advantageous in developing a comprehensive treatment plan for these patients. Individuals with facial difference will be encouraged to build supportive networks, participate in their communities and become more self-sufficient through awareness, knowledge and self-realization. Physicians, nurses and other health care providers may develop heightened awareness and a greater understanding of their needs, to better care for patients with facial differences.

Acknowledgements

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References