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E. M. Ackuaku-Dogbe, MBChB, DO (Glasg), FWACS, FGCPs, Senior lecturer, Department of Surgery, Eye Unit, R. B. Biritwum, MBChB, MPH, MSc (Biostat), MD, FWACS, FGCPs, Department of Community Health, Z. I. Briamah, MBChB, FWACS, FGCPs, Lecturer, Department of Surgery, Eye Unit, University of Ghana Medical School, P. O. Box 4236, Accra, Ghana

Request for reprints to: Dr. E. Ackuaku-Dogbe, Department of Surgery, Eye Unit University of Ghana Medical School, P. O. Box 4236, Accra, Ghana

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E. M. ACKUAKU-DOGBE, R. B. BIRITWUM and Z. I. BRIAMAH

ABSTRACT

Objective: Orbital exenteration results in devastating functional, aesthetic and psychological losses. We studied the psycho-social challenges of patients following orbital exenteration.

Design: Retrospective descriptive study

Setting: Korle-Bu Teaching Hospital, eye clinic, Accra

Subjects: Ten surviving patients, at least six months post orbital exenteration.

Results: Though all the patients were satisfied with the medical results of the surgery, 50% felt strongly uncomfortable or dissatisfied with the cosmetic effect of the surgery. Sixty percent of the patients suffered unwelcome comments and 50% uncomfortable stare from close friends and relations. Sixty percent were not uncomfortable in the company of friends and close relations.

Conclusion: Our findings call for a counseling plan for our patients while it is also necessary to find ways of improving their cosmesis.

INTRODUCTION

Orbital exenteration (OE) is a disfiguring procedure which typically involves removal of the entire contents of the orbit including the periorbita, appendages, eyelids and, sometimes, a varying amount of surrounding skin. OE results in devastating functional, aesthetic and psychological losses. It is usually reserved for the treatment of potentially life-threatening malignancies (1,2). Often the orbit is reconstructed to improve cosmesis and also to facilitate the application of prosthesis. However in some cases the orbit is left to granulate leaving a shallow depression with no prosthesis resulting in gross facial disfigurement. Some of the patients hide their deformities in various ways including dark glasses or head scarf extending over the face when in public.

Patients often experience social problems and may find it embarrassing to interact with friends and family members. Some experience excessive interference with their lives from people offering unsolicited assistance. Three others are haunted by fear of recurrence of cancer. The relations and acquaintances of these patients who are involved in

the lives of these patients react differently in different circumstances to either re-enforce these challenges or mitigate them.

From the year 2004 to 2009, we performed 25 exenterations in Korle-Bu Teaching hospital, Accra all of them left to granulate. Currently there is no formal comprehensive counseling for these patients other than a brief pre-operating counseling emphasising the lifesaving nature of the surgery. Exenterations are still ongoing mainly for malignant orbital and peri-orbital tumours. This study aimed at finding out the social challenges of patients following orbital exenteration in order to plan counseling and support programmes to mitigate the effects of their facial disfigurement.

The literature is scarce in reports on facial disfigurement and psycho-social problems. The only published study in the literature on psycho-social challenges in patients with orbital exenteration included some patients who have had some form of surgery to improve cosmesis (3) To our knowledge no such study has been performed within the West African sub-region where patients present with late disease and are less likely to have any kind of plastic surgery or prosthesis to improve cosmesis.

MATERIALS AND METHODS

All surviving patients who had exenteration and whose telephone numbers could be retrieved were called to give consent for an interview between January and June 2012. Twenty three telephone numbers of patients operated on from January 2004 to February 2012 were recovered. Following informed consent, 12 patients who were available were invited to the eye clinic for the interview. Included in the study were patients who were at least five months post operation with no local recurrence of tumour. The patients were all 16 years or above. Two of the patients interviewed were excluded because they were less than five months post-surgery at a stage where the wound was still being dressed and not exposed to the public view. All the other patients called up either could not be reached, were dead or bed ridden.

The interviewer was a research assistant who used a semi-structured questionnaire. The patients were interviewed in the presence of one close family member each to confirm some of the answers to the questions. The patients were asked about pre-surgical counseling and satisfaction with surgical outcome cosmetically. The questionnaire also contained questions related to demography, how comfortable the patients were among friends and relations as against strangers, and the attitude and reaction of people towards them. The types of reactions investigated included show of unsolicited sympathy, embarrassing stare or remarks made and benign intentional neglect. Patients were then asked what they wanted done for them to ameliorate their current condition.

The study was approved by the Ethical and Protocol Review Committee of the University of Ghana Medical School. The results were analysed using SPSS version 17.0. Continuous numerical data was captured as mean and standard deviation and categorical data as percentages.

RESULTS

Demography: A total of 12 patients interviewed were included in the study. They ranged between 16 and 65 years. The majority (7; 70%) were between the ages of 40 years and 65 years with a mean of 44.9 years and standard deviation of 15.6. The male to female ratio was 1:4. Seven (70%) were educated up to Junior High School level, only one had tertiary education. Two (20%) were educated up to Senior High School. Three (30%) were unemployed, two each were traders and retired. One each was an orderly, a teacher and a student. Majority of the patients were of low income level (70%) or lower middle income level (30%). Five (50%) were married, 4 (40%) single and one divorced. Three of the patients were from outside Accra, the majority (70%) from Accra.

Pre-operative counseling: All ten patients were five to 48 months post operation with a mean of 19.8 months and a standard deviation of 15.6. Eight patients were more than 12 months post operation

Seven (70%) of the patients confirmed that they had been counseled. Of the seven, six (85.7%) clearly understood the counseling. All six said they were counseled only about the benefits of surgery and the consequences of not having surgery. The interval between the time of counseling and time of deciding to have surgery ranged from one to 365 days, with a mean of 66.2 days and a standard deviation of 110.5. Six (60%) decided on having surgery within 15 days, two (20%) made their decision at three months, one at six months and one at one year.

Eight (80%) of the patients had to seek approval from close relations and out of these, six (75%) said these approvals were very influential in their decision making. Most of the patients (7, 70%) said they had no fear of the surgery because they had confidence in their doctor and they just wanted to be free of their pain. The rest had fear of losing their eyes or sight and one had fear of surgery because he had never had any surgical procedure previously.

Post-operative events: Asked how the patients felt when they first saw their deformity post operation, 5 (50%) felt good to see the tumour out, the rest felt "worried", "uncomfortable", "very unhappy" or "dreadful". Sixty percent had no immediate post-operative fears two had fears of recurrence and one had fears of death. One patient had fear of being ridiculed. After healing all ten patients felt satisfied with the surgery.

When among close friends and relatives, 60% of the patients were not uncomfortable. Nine (90%) regularly conceal their defects, eight of them with dark glasses and one with an eye patch. Eight (88.9%) of the patients who conceal their defects do so only when out of their homes; only one conceals it at all times. One person does not find the need to hide his defect. When among strangers only 30% said they were treated differently; people would usually stay away from them. One said he was no longer considered an important personality in his community.

Table 1 shows people's reaction towards the patients when they were with friends and relations they are familiar with and also reactions from people they were not familiar with. Asked what they thought could have been done for them following surgery, all 6 patients who responded indicated that they wished something had been done to improve their looks during surgery or immediately following surgery. Table 2 catalogues the responses of the patients when asked what they wanted done for them currently.

The responses of the patients were all confirmed by the accompanying relations

Table 1
Reaction of people towards patients after surgery

Reactions	Close friends	and relations	Unfamiliar	persons
	Yes (%)	Total	Yes (%)	Total
Unwanted remarks	6 (60%)	10	2(20%)	10
Unspoken stare	5(50%)	10	5(50%)	10
Benign Intentional neglect	1(10%)	10	1(10%)	10
Sympathetic attention	2(20%)	10	2(20%)	10
Unwanted questions	2(20%)	10	2(20%)	10

Table 2
Patients' Responses When Asked What They Wanted Done For Them Currently

Patient	Response
1.	I can't tell
2.	I think you can still give me something that will make me look good cosmetically
3.	I think I will need plastic surgery to give me a good or better outlook
4.	I think you can put an artificial eye in place for me
5.	I think you can still put a prosthesis on my eye to make me look good
6.	I would be happy if my doctor can give me some drug to calm down the pains I sometimes experience on my eyes
7.	I would like the hole to be filled
8.	I would prefer a prosthesis in place of the exenterated eye
9.	If you place a prosthesis in my eye I will be very grateful
10.	Well, I think you can put something on my eye to make it better on my face

DISCUSSION

Facial disfigurement has long been viewed as one of the most potentially distressing aspects of head and neck cancer because of the vital importance of the facial region to self-concept, interpersonal relationships, and communication and the fact that facial disfigurement is highly visible (4).

In this study, most of the patients are from low income group (70%) and of low level of education, which may explain why they reported with advanced disease requiring exenteration. Again about 40% delayed for three months or later to decide on surgery. Eight (80%) of the patients had to seek approval from close relations and out of these, (5) (75%) said these approvals were very influential in their decision making. These results reveal some complexity in the decision making of these patients to take up exenteration. Even more intriguing is the fact that only 60% had any form of meaningful counseling and even this was limited to the benefits of surgery and the consequences of not having surgery and nothing about cosmesis. Yet 70% had no fear of surgery because

they trusted their doctor would give them the best especially to relief them of their pain. At the time of surgery this majority were more concerned about getting rid of the tumour than the cosmetic effects of the surgery. Those who had any fears at all had fears of losing the eye or of the surgical process.

Post operatively however, though all the patients were satisfied with the surgery, having achieved their aim of getting rid of the tumour, 50% felt strongly uncomfortable or dissatisfied with the cosmetic effect. Some even had other fears: death, recurrence or ridicule. On hind sight, the patients wished something could have been done at surgery to improve their looks and were still hoping that their looks could be improved.

Konradsen and others performed a study to explore and explain how disfigurement is addressed in interactions between patient and nurse during the period in hospital immediately after undergoing disfiguring facial surgery (6). They discovered that pre-operatively, survival was more important to the patients than appearance. Immediately after the cancer had been diagnosed, the question of

survival had been foremost in the minds of both patients and professionals. None of the patients had hesitated or had any doubt about whether to accept the operation. Disfigurement was a luxury problem before surgery and immediate post-surgical period. They also noted that once a patient was on 'the other side', re-socialisation in the new situation began; the patient had to get on with the life they had left, but with the experience of having had cancer and having undergone a change in their appearance. At this stage, cosmesis and recurrence of cancer became an issue. In the study by Alessandro *et al* (3), they found out that both patients and family members were concerned about cancer and its recurrence more than disfigurement. However, as time passed, their preoccupation with disfigurement became more relevant. Our patients seem to have behaved similarly.

Research suggests that individuals with disfigurements are treated differently because of how they look. Studies report staring, comments and questions (6) verbal and physical abuse and avoidance (7). Most of our patients were only uncomfortable when outside their homes and would hide their defect with dark glasses. There was very little difference between close friends and relatives and strangers in their reaction towards these patients. Alessandro and others in their study among 12 patients who have had exenterations concluded that ultimately, acquaintances are sources of stigmatization and support alike as they intrude in the everyday existence of patients but also provide sympathy to cancer survivors (3). They also found that all of the patients were almost always comfortable in interactions with their family members and friends. This seems to be the trend in our study where 60% of the patients suffered unwelcome comments and 50% uncomfortable stare from close friends and relations but 60% were not uncomfortable in the company of friends and close relations.

It has been suggested that adjustment to adult-acquired impairments may be more difficult than disfigurement acquired from childhood. Those with congenital defects may display greater confidence and effectiveness in adulthood, when dealing with the challenges of looking different (8). However those who become disfigured during adulthood may benefit from a more positive self-image prior to the disfiguring event but must adjust to sudden body image changes as well as the disease or trauma giving rise to that change (9). So though our patients from their responses seemed to be braving it out, all of them wanted something done currently to improve their looks. Some have actually admitted that they have lost their self-esteem in society. When among strangers only 30% admitted they were treated differently. People would usually stay away from them. One said he was no longer considered an important personality in his community. These responses suggest an unspoken deep seated difficulty of these patients in

copied with the change in their facial appearance. Coping with social stress is a complex phenomenon. In their review of disfigurement issues, Rumsey and Harcourt (10) noted that social sequelae of visible difference depend upon a complex combination of social and individual factors. Folkman *et al* have suggested that individuals with disfigurement may unintentionally reduce social activity for fear of stigmatisation (11). Coping strategies are central to understanding the impact of disfigurement upon individuals and predicting distress and adjustment (12). These factors were not explored in this study. In a study among patients with facial surgery by Furness and his colleagues, a range of outcomes was found, from long-term anxiety, isolation and depression, through little impact upon activities and well-being, to perceived benefits in relationships, self-perception and outlook (12). Most of their patients however had surgeries for mouth and jaw cancers with only three out of the 29 having enucleation for eye cancer. The patients in this study with highly visible ocular cancers rated their appearance as considerably altered as opposed to the rest of the patients. These studies suggest that our patients with facial disfigurement due to exenteration may be going through psychosocial problems but we are unable through this study to determine the complexities of their problems. This study however clearly shows that these patients have some psychosocial problems that would explain why 90% of them have to conceal their defects especially when outside their homes.

Our findings call for a counseling plan for our patients while also finding out ways of improving their cosmesis. Furness in a study to determine adaptation to facial surgery in adulthood concluded that health care professionals may need to extend the emotional and educational support currently given to facial surgery patients to promote positive adaptation (12). Alessandro suggested that cancer patients scheduled to undergo orbital exenteration should be warned about the possibility of difficulties when interacting with strangers or acquaintances. Educating healthcare personnel to become more aware of these issues and to be prepared to intervene at various levels and time points during the period before and after orbital exenteration is equally important (3). This is probably how all centres dealing with patients undergoing orbital exenterations should go.

LIMITATIONS OF STUDY

Though orbital exenteration is not a common procedure, more accurate results could have been obtained from larger samples. The study design, though established that our patients had social challenges, the specific challenges were not determined.

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