Facial Disfigurement

FACIAL DISFIGUREMENT
Successful
Rehabilitation

Helen Collyer

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This book is dedicated to all those whose stories are here, and to Sam Gallop and his courageous friends in the Royal Air Force Guinea Pig Club.

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Introduction

‘What lies behind you, and what lies before
you, are tiny matters compared with what
lies within you’
Ralph Waldo Emerson

After many years’ experience in hospitals, I knew something of the severity of the problems faced by individuals suffering disfigurement. Having reached a stage when I could stand back from the daily round of nursing education, the opportunity occurred of undertaking a survey of disfigured people for a charity interested in rehabilitation. The aim was to see if we could learn more understanding from those thus afflicted, and to see if there were any ways, however small, in which others with similar problems might be helped to return to a full life.

Within the resources available and to maintain effectiveness it was necessary to limit this to those patients who had facial disfigurement because of burns, port wine stains, trauma and cancer. This does not take into account many other things: such congenital conditions as cleft lip and palate or skin conditions, to mention just two. In order to know whether the number of people involved warranted such a study, information was sought from the Department of Health and Social Security for England and Wales, the Department of Health and Social Services for Northern Ireland, and from the Scottish Home and Health Department about the number of patients suffering from facial cancer, burns and injury. The result for the year 1978 was a total of 39 189, and this did not include those patients treated in the Accident and Emergency Departments, only those receiving ‘in-patient’ treatment. Neither did it include people with port wine stains: no statistics were available for such people unless they were treated by surgery.

The total study, including the pilot study, took place in two of the

Health Regions, involving talking to patients either when they returned to a follow-up clinic or in their own homes.

This little book is an amalgam of the tales of many of the people who took part in this survey and shared their experiences so generously. The stories are as they told them and are not in answer to a series of questions, as it was important not to influence what they had to say. Four aspects of their rehabilitation – physical, emotional, social and financial – were explored. Because the common cold was likely to be within the experience of most people, this was used as an example: ‘If you have a cold your nose runs – this is physical; you feel awful – this is emotional; you have to keep out of everyone’s way – this is social; and for some it will have financial implications. I am interested in these four aspects ... Tell me when your trouble started/your accident occurred.’

Naturally, these stories are biased, they are personal accounts for this is how events appeared to these people at the time; there was neither the opportunity nor the need to check the other side of the story. No apology is made for this, because, like pain, no matter what actually happens, it is what it feels like to the patient that really matters.

Many of these patients will have ‘knocked on the door of death’ – whether it was when they were first told they had cancer; after an extensive operation; when they were involved in a road traffic accident; or when they were burned. Having survived, this is put behind them – at least it is seldom discussed – and it is then the little things that occur day after day that matter, and can sometimes ‘break the camel’s back’. These stories contain many little things which those learning to be doctors, nurses, physiotherapists, occupational therapists, dieticians, social workers and others concerned with the care of people could well benefit from considering; it is the reason for wishing you to share them, too.

The main aim of the book is to stimulate discussion and, it is hoped, to improve help for others in similar circumstances. This book does not attempt to answer questions, but rather to pose them. The answer must be found which is best suited to your patient’s problem; for example, it may be easier in some places than others to liaise with and utilise the very considerable expertise of the Red Cross and St John Ambulance Services.

All too often in the past, only what happened to the patient in hospital has been considered: here, that will be minimal. Where

possible, the individual will talk about his total experience, from the first symptoms until the day of interview. While the interviewer was interested in facial disfigurement, much of the material produced could apply to any condition. Also, the cause of the disfigurement often affected other parts of the body as well as the face. The patients were asked to talk about their problems, and this they did, not confining their remarks to their faces alone.

Because the subjects were only giving their own views, and 'others' were not available to reply, or to defend themselves or the good name of the hospitals, all names will be fictitious. As there was a limited amount of written material available in this country on facial disfigurement, the survey was both exploratory and descriptive, and may lead others to investigate this field further.

HOW TO USE THIS BOOK

Each story has at its end a portion labelled 'issues for discussion' which may contain one or more possible discussion topics. If read with empathy, each tale contains many more, and space has been left for you to write in your own topics. It is also hoped that these tales may prove to be a springboard for projects which will lead to a deeper understanding of anyone with a handicap.

WHAT OTHERS HAVE SAID

Erving Goffman (1979) reminds us that it was the Greeks who originated the term 'stigma' to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body, and advertised that the bearer was a slave, a criminal, or a traitor, a blemished person, ritually polluted, to be avoided, especially in public places.

Goffman also says that nowadays,

'While a stranger is present before us, evidence can arise of his

possessing an attribute that makes him different from others in the category of persons available for him to be. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one’.

Oliver Cape, in his foreword to the work of Bernstein (1976), maintains that

‘Any disfigurement is a source of embarrassment, but burn accidents are particularly traumatic and mutilating because they so often involve the unprotected face and hands. People stare, comment thoughtlessly, ask rude questions, are embarrassed into silence, or are unable to converse easily. Without intending to, strangers and friends in one way or another repeatedly make the disfigured person feel abnormal, out of place, unwelcome or unwanted’.

Bernstein (1976) wrote:

‘The public’s attitude is not helpful. We live in a society in which great emphasis is placed on appearance. The multi-million dollar advertising of the cosmetic industry overwhelms any charitable slogans about beauty being only skin deep, and leaves us with a cultural value pattern favouring a youthful and attractive exterior. Psychological studies may vary in emphasis, but it is clear that the face is our most important non-verbal instrument of communication and remains so throughout life.’

Safilios-Rothschild (1970) stated that ‘visible’ disabilities provoke greater discrimination and social stigma than do ‘invisible’ disabilities.

Rumsay *et al.* (1981) measured the ‘personal space’ afforded to a disfigured or non-disfigured confederate by 750 pedestrians in a busy street. In condition (1) the confederate had a birthmark (permanent disfigurement). In condition (2) this was replaced by trauma, scarring and bruising (temporary disfigurement). In condition (3) the confederate had no disfigurement. It was found that individuals stood further away from the confederate in the disfigured conditions than in the non-disfigured condition. In addition, indi-

viduals chose significantly more often to stand on the non-disfigured side of the confederate.

Gaston E. Blom (1982) reminds us that what is often overlooked is that the majority of people are able to adapt positively and lead satisfactory lives under conditions of chronic stress, adversity, and handicap: 'Coping is used to depict specific behaviour having the qualitative characteristics of active problem-solving and attempts to master situations which are stressful and challenging.'

These stories will show how well the individuals are adapting, but there is a need to recognise that any individual, even one who usually copes well with his/her disability, may not be able to cope at times, due to the onset and severity of new, additional, disadvantageous factors.