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**A RETROSPECTIVE STUDY OF SUBJECTS
USING FACIAL PROSTHESES**

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School of Dental Studies
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September 1994

CANDIDATE'S CERTIFICATE

This is to certify that the work presented in this thesis was carried out by the candidate in the School of Dental Studies, University of Sydney, and has not been submitted to any other university or institution for a higher degree.

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USING FACIAL PROSTHESES**

JAMES R FISHER

A thesis submitted in fulfilment
of the requirements for the degree of
Master of Science in Dentistry

School of Dental Studies
University of Sydney

September 1994

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ACKNOWLEDGEMENTS

I am indebted to the following people for their assistance during the course of this study.

The subjects who participated in the study. They gave their time, submitted to questions about their personal lives and related details of experiences which were sometimes painful to recall. Without their contribution this study would not have been possible.

Professor Iven Klineberg, my supervisor, for his understanding and guidance in seeing this project to its completion.

Dr Wendy-Louise Walker, co-supervisor, for her lively enthusiasm, encouragement and help at all stages throughout this project, much of which was given in a voluntary capacity.

Dr William Walsh and Dr Luise Martin, for making available the details of patients for whom they had made facial prostheses, and for the valuable professional assistance they have given me.

Dr Ross Sparks and Dr Nick Fisher, Division of Mathematical Statistics, CSIRO. Dr Sparks for his advice and work on the statistical analysis, and Dr Fisher for making this work possible, for helping with data preparation and for many other forms of assistance.

Emeritus Professor Campbell Graham who introduced me to maxillofacial prosthetics and the particular social and emotional concerns of patients who need facial prosthetic treatment.

Dr Nanette Dominguez, with whom I was fortunate to work for 2 years, for her friendship and for the opportunity to discuss how she approached the writing of her own thesis, without which this project may never have been completed.

Dr Herbert Smartt for his interest and help.

The librarians of the Dental Library, University of Sydney, and the Library of the Institute of Dental Research over the years of this work, for their help and for the considerable time they spent locating and obtaining books and articles from other libraries on my behalf.

The United Dental Hospital Administration, in particular Dr William Winspear and Dr John Wilkinson, for their moral support and for the hours when I was exempted from my regular job to allow me to work on this project.

The members of my family for their help, encouragement and unfailing support throughout this very prolonged venture.

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ABSTRACT

Facially-disfigured people may encounter numerous social and emotional problems, particularly when they also have maxillofacial cancer. The ability to cope psychosocially has an important effect on the quality of life achieved by these people after rehabilitation. This study was undertaken to investigate two aspects of the experiences of a group of facially-disfigured subjects who had received facial prostheses. The first was to identify factors that affected the psychosocial coping ability of the subjects from the time of onset of disfigurement (or most often, the time of diagnosis of cancer), through treatment, rehabilitation and to the present. The second was to ascertain the value of the facial prostheses in rehabilitation and to identify factors that affected this. Interviews were recorded with 41 subjects about their experiences, the subjects completed a personality assessment questionnaire and other data about the prostheses were also collected. The data were summarised, tabulated and analysed. A number of factors were found to affect the psychosocial coping of different subjects, including the manner of presentation of the diagnosis, the delay caused by misdiagnosis, the degree of personal interest the doctor showed for the subject and how well the subject was informed before surgery about possible outcomes. Other factors were the manner of presentation of the disfigurement to the subject, the radiotherapy treatment and its side effects and adverse comments or behaviour of others towards the disfigured person. Family support and the subject's personality were also important. Prostheses were important for promoting a return to social functioning and 61% of subjects were using their prostheses regularly. Significant problems occurred due to inadequate retention, soft tissue trauma and difficulty handling skin adhesives. The recent advent of osseointegrated implants for anchorage of facial prostheses would alleviate many of these problems, but the limitations of material service life and colourant stability remain and need further research and development.

LIST OF ABBREVIATIONS

Acrylic or acryl.	polymethylmethacrylate
adh	adhesive
BCC	basal cell carcinoma
CT	computerised tomography
F	female
GP	general medical practitioner
HTV	high temperature vulcanising
km.	kilometre
M	male
op.	operation
part.	partial
16PF	16 Personality Factor Questionnaire
prob.	problem
pros. or prosth.	prosthesis
psych.	psychological or psychiatric
PVC	polyvinylchloride
radiother.	radiotherapy
ref'd	referred
Repat. Dept.	Repatriation Department
RSL	Returned Servicemans League
RTV	room temperature vulcanising
silic.	silicone
subj.	subject
SCC	squamous cell carcinoma
TV	television
tiss	tissue undercuts
v.	very
WWII	World War II

CHAPTER 1

INTRODUCTION AND REVIEW OF LITERATURE

1.1 Introduction

The social and emotional problems experienced by facially-disfigured people are partly due to the discrimination they experience from other members of society (Macgregor, 1951). Surgical reconstruction may diminish or alleviate these problems, but if this is not possible the only alternative may be a facial prosthesis. Cancer, with its connotations of death, is a complication for many of these people. The capacity of a patient to cope psychosocially with these combined problems is a major factor affecting the quality of life he or she will have after rehabilitation.

This literature review will cover the psychosocial consequences of facial disfigurement and head and neck cancer and their treatment, with particular reference to patients who are rehabilitated with facial prostheses.

1.1.1 PSYCHOSOCIAL IMPORTANCE OF THE MAXILLOFACIAL REGION

The structures and functions of the maxillofacial region are uniquely important in human development from the time of birth and throughout life (Bailey and Edwards, 1975). Organs of the mouth and face perform many important sensory and motor functions: sight, hearing, smell, taste, touch, intake of nutrition and communication through speech and facial expression (Klineberg, 1991). The importance of this region is reflected by its disproportionately large area of representation in the cerebral cortex compared with that of other body parts (Ball and Paoletti, 1986).

Bailey and Edwards (1975), and Ball and Paoletti (1986) have reviewed the psychosocial importance of the orofacial region. For the infant it is primarily through the mouth and face that communication and interaction with the environment occur. Early physical, social and emotional experiences take place with the mother, with whom the child's first relationship is formed, particularly during breastfeeding. At this time the child learns about deprivation and gratification, and emotions of pleasure or pain are expressed verbally or by facial expressions such as smiling, laughing or crying. The mouth and teeth are important for exploration of the environment and are the child's first weapon. Throughout life the mouth is directly or symbolically associated with fundamental instincts and needs such as self preservation, recognition, identity, love and sexual expression, aggression and hatred (Bailey and Edwards, 1975; Meerloo, 1956).

The child also develops an awareness of self as distinct from the environment. The sense of body image, "the sum of one's experiences" (Bailey and Edwards, 1975, p.534), is said to be defined by the time a child has reached school age (Ball and Paoletti, 1986). It is derived from the individual's perception of him- or herself physically and psychologically, how this compares with others and the reaction of others to him or her. The socialisation experiences within the family also influence the body image (Kolb, 1974). Facial appearance is uniquely representative of the individual's identity and has an important effect on body image. The most vital area of the face in this respect lies within the facial triangle ie the area including the eyes and the point of the chin. Other features are less important unless highly abnormal. "'Acceptable appearance' depends on subjective judgements based on society's value systems" (Ball and Paoletti, 1986, p.187). Body image and self concept are associated with a person's sense of adequacy and competence, and with one's acceptability to other members of society (Bailey and Edwards, 1975). "Few researchers dispute the importance of a positive self concept for a person's well being and effective social behaviour" (Bull and Rumsey, 1988, p.200).

Owing to one's lifelong dependence on the orofacial region, strong emotions of love and need are attached to it. Hence mutilation or loss occurring in this area disrupts the body image and the sense of identity causing anxiety, depression, and mourning responses of grief, bitterness and anger (Bailey and Edwards, 1975; Stricker, Clifford, Cohen, Giddon, Meskin and Evans, 1979).

1.1.2 ATTITUDE OF SOCIETY TO FACIAL APPEARANCE

There is a preoccupation in society with physical attractiveness and facial beauty, and these values are idealised by advertising and the movies (Macgregor, 1951; Meerloo, 1956; Bernstein, 1976; Bull and Rumsey, 1988). There is also a common tendency to regard the appearance of the face and facial features as symbolically significant, and indicative of particular personality characteristics, intelligence and social adjustment (Macgregor, 1951; van Doorne, 1980-82; Addison, 1975). Macgregor reported a patient whose face was disfigured by radical cancer surgery who said "People think I've changed because my face is changed" (Macgregor, 1951, p.631). Research by Dion, Berscheid and Walster (1972) supports this belief, and is described by Berscheid (1981, p.10) as showing "a very robust physical attractiveness stereotype". Bull and Rumsey (1988) found that the concept that facial appearance has a strong influence on certain aspects of social interaction came from research that was anecdotal (lacking methodological rigour) or that lacked relevance to the situation in real life. Nevertheless, they suggest that the "crucial" effect may be in how facial attractiveness affects "the dynamics of encounters" (Bull and Rumsey, 1988, p.5).

Within our culture people agree to a remarkable extent about a person's physical level of attractiveness (Kalick, 1978). Children seem to be aware of differences in attractiveness from age 6 years, and demonstrate negative stereotyped beliefs about disfigured people, by the age of 11 to 12 years (Rumsey, Bull and Gahagan, 1986). This glorification of

beauty places the facially-disfigured in our society at a greater disadvantage.

1.2 Facial Disfigurement

Facial disfigurements may be either congenital in origin or acquired at some time after birth. Inherited genetic defects, mutation, or environmental effects during pregnancy may cause a range of facially-disfiguring congenital abnormalities (Chalian, Drane and Standish, 1972). Examples are cleft lip and palate, occurring in approximately 1 in 600 live births (Albery, Hathorn and Piggot, 1986), ear malformations occurring in 1 in about 5,250 live births (Conway and Wagner, 1965) and port wine stain, capillary haemangioma of the skin, (Collyer, 1984).

Acquired disfigurement may be caused by trauma eg from burns or violent injury, or by destructive diseases, particularly cancer, or their treatment. Disfigurements for which a facial prosthesis is needed are occasionally due to congenital factors or trauma but most often result from the treatment of epithelial tumours by radical surgery or radiotherapy, particularly in older patients (Beumer J *et al.*, 1979).

Facial disfigurement is defined by Chalian *et al.* (1972, p.351) as "an abnormality of the face that is sufficiently marked to set the individual aside from other members of society". It varies greatly in

form and degree, from a minor skin blemish or crooked teeth which may not always be noticed, to the more gross and shocking disfigurements of severe burns, radical cancer surgery or some congenital deformities. Although the social and emotional consequences of the disfigurement are almost always negative, they are not necessarily equivalent in degree to its severity, (Chalian *et al.*, 1972; Macgregor, 1951).

Macgregor (1951) describes facial disfigurement as essentially a social or psychological problem that differs from most other types of physical handicap in which problems result mainly from functional disability. Also, facial disfigurement is always visible, being on the face which must be kept uncovered for communication and social interaction. If the disfigured person is to seek social contact, he or she cannot avoid the inevitable aversive reactions of other people. Deformities of other parts of the body, in contrast, can usually be concealed by clothing.

1.2.1 REACTIONS OF SOCIETY TO FACIAL DISFIGUREMENT

Society defines standards of beauty, acceptable appearance and the acceptability or otherwise of deviations (Bull and Rumsey, 1988). Anyone whose appearance falls outside our tacit standards of normality, for whatever reason, may be regarded as "bad, peculiar or somehow not quite human" (Addison, 1975, p.147). Society's attitudes to disfigurement are generally "disapproval, repulsion and rejection" (Kolb, 1974, p.818). Research by Richardson, Goodman, Hastorf and Dornbusch (1961) and Richardson (1970) showed a cultural preference for normal people over

the handicapped. Comparing different types of bodily handicap, facial disfigurement was among the most disliked, and liking for individuals with other forms of handicap increased with increasing distance of the handicap from the face. Furthermore, with increasing age of the raters (children from 5 to 12 years), dislike for functional handicaps decreased, but dislike for facial disfigurement increased. In a study by Macgregor (1951), facially-disfigured patients complained that what was most damaging to their self esteem and caused most selfconsciousness and unhappiness were the reactions of other people towards them. These were manifested by "staring, remarks, curiosity, questioning, pity, rejection, ridicule, whispering, nicknames, discrimination", (Macgregor, 1951, p.633).

The high premium on physical attractiveness and facial beauty (discussed above) places even mildly disfigured people under pressure to re-establish a "normal" appearance to conform to society's physical standards and to avoid stereotyped judgements about their personality. Failure to do this sets them apart both in the estimation of others and themselves (Bull and Rumsey, 1988).

Myths and superstitions are prevalent about the origin or symbolic significance of different types of facial disfigurement. Such ideas are said to have persisted from times when catastrophes were thought to have a spiritual cause, and disfigurement was ascribed to wickedness or punishment for vice (Addison, 1975). Macgregor describes a patient disfigured by cancer who said "I feel others shy away from me because

they think it's contagious. I don't understand why I got it when I've always led a good, clean life", (Macgregor, 1951, p.631). Another patient who had a child born without an ear said "People have asked me if it runs in the family, or if I were unfaithful to my husband", (Macgregor, 1951, p.631).

Depending on the particular type of deviation, the kind of stereotyped response evoked may involve judgements about the affected person's personality, intelligence, sexual orientation, ethnic or social background, criminality or contact with contagious disease (Kolb, 1974). Less conspicuous types of deformity may stimulate jokes, ridicule or antipathy. More gross disfigurements elicit surprise, pity, curiosity and horror (Macgregor, 1970). Stereotyped ideas or characters appearing in folklore, cartoons, literature and films reinforce the belief that certain forms of ugliness and disfigurement are synonymous with inferiority, low intelligence, immorality, evil, contagious disease or punishment for past sins (Macgregor, 1951; Kolb, 1974; Meyer and Knorr, 1977; Shaw, 1981, in Bull and Rumsey, 1988). Such misconceptions are held not only by ignorant or uneducated but also by well-educated and highly intelligent people (Kolb, 1974). These false rationalisations provide someone or something to blame for the deformity. Parents may use them as an excuse to deflect blame for the deformity onto another source, to strengthen guilt feelings or to justify rejection of disfigured people (Macgregor, Abel, Bryt, Lauer and Weissmann, 1953).

Deformities due to congenital causes or disease seem to arouse more

disapproval than those due to trauma. One patient was anxious to explain to new acquaintances that his facial scars were due to trauma, in case they might think he "was an ex-convict or led an immoral life" (Chalian *et al.*, 1972, p.353). Another chose to attribute her jaw deformity to an accident rather than endure the pity and aversion evoked when the actual cause, cancer, was given (Chalian *et al.*, 1972).

In special circumstances a disfigurement which resulted from some socially approved action eg war service, may earn kudos for the bearer, aversive reactions being consciously overruled by the observer (Ball and Paoletti, 1986).

1.2.2 INTERPERSONAL INTERACTIONS INVOLVING DISFIGURED PEOPLE

Disfigured people are at a disadvantage in social encounters and particularly when meeting strangers. The presence of a facial disfigurement interferes with the smooth flow of conversation and social interaction. Normal people, when dealing with someone who is handicapped, tend to concentrate on the handicap to the exclusion of the rest of the personality (Addison, 1975; Chalian *et al.*, 1972). The disfigurement then becomes a focus for the observers' attention, and contributes disproportionately to the overall impression gained (Bernstein, 1976). The disfigured face may be like a mask, incapable of conveying subtle changes of expression, so that communication is

hindered and it is more difficult for the disfigured person's personality to be revealed to others (Chalian *et al.*, 1972). These effects apply also to the users of facial prostheses, particularly where the critical area for facial expression - the facial triangle (including eyes, nose and mouth) - is disturbed. The observer may be disconcerted by the presence of the prosthesis and unsure of where to fix his or her gaze (Addison, 1975).

Macgregor (1951) has described how a handicapped person may often be deprived of social contact due to the typical mechanism of first encounters between people. Impressions are formed rapidly, both consciously and unconsciously, and are significantly influenced by the other person's appearance. We use "manifold subjective factors which are influenced by our past experiences, social attitudes and prejudices" to assess the person's personality. "When prejudice exists, ... visible traits which set the individual apart from the majority group may serve as a barrier to further social interaction and prevent further knowledge of the man himself. If he looks different, he must, ipso facto, be different. And herein lies the tragedy of a facial deformity" (Macgregor, 1951, p.630).

1.2.3 PSYCHOSOCIAL ADJUSTMENT BY THE DISFIGURED PERSON

Addison describes the normal process of adjustment for a newly-disfigured person as involving acceptance of the fact of the deformity, a mourning process for the lost part or lost body image, adaptation to a new body image, and "acquisition of a set of techniques for dealing with normal people" (Addison, 1975, p.148). A productive and satisfying social life depends on acceptance of the new structure and development of a new body image (Kolb, 1974).

The mourning process, similar to that seen in other forms of sudden deprivation, normally follows a fairly well-defined pattern (Addison, 1975). At first there is disbelief, numbed emotions, and denial that it has happened. As the truth is realised there is increasing distress and social withdrawal to work through the grief and implications of the loss. After weeks or months of withdrawal the mood improves, the threads of life are picked up again with a degree of acceptance of the loss and new sources of fulfillment are found.

How well the disfigured person succeeds in adapting to this depends on his or her personality, social circumstances, the reaction of others, particularly the immediate family (Macgregor, 1951) and the aetiology and duration of the disfigurement (Frank, 1975). A person who felt rejected, inferior or isolated prior to being disfigured would not be expected to cope well afterwards (Addison, 1975). For people who have relied heavily on physical attractiveness for maintaining their self

esteem and body image, facial disfigurement may mean the end of an enjoyable life (Kolb, 1974; Addison, 1975).

The family and cultural attitudes are more important in affecting the social adaptation of the disfigured person than the presence of the defect. Where the family and social attitude is supportive and constructive, the chances of compensatory development without personality disorder are enhanced (Kolb, 1974).

Discussing adaptation to acquired disfigurement, Kolb (1974) describes the bodily change being experienced as a "distortion of the self".

Others describe a sense of changed personality or identity (Frank, 1975; Bailey and Edwards, 1975). Other responses commonly observed include

1. Anxiety - This is always present according to Kolb (1974), due partly to fears of separation from or rejection by people upon whom the disfigured person is emotionally dependent. There may also be hostility due to the expected negative responses of others to the disfigurement, This is influenced by the person's own former attitude to that type of disfigurement prior to becoming disfigured him- or herself.

2. Depression - This is almost universal, being a feature of the normal mourning process (Addison, 1975), and may be either overt or concealed, and minor or profound (Ball and Paoletti, 1986). It may be due to over-expectation of rejection by people on whom the patient depends, or to repression and turning towards the self of hostile impulses to close family or other people (Kolb, 1974).

3. Self devaluation - Disfigured people are well aware of the negative attitudes of society, and those who have acquired disfigurement are likely to have shared those views before they themselves were disfigured. The disfigured person may adopt society's negative view of him as different or inadequate and behave according to this evaluation (Addison, 1975; Bull and Rumsey, 1988; Macgregor, 1951).
4. Social withdrawal and isolation - One of the commonest reactions, it may be minor or profound (Frank, 1975).
5. Anger - External people or events may be blamed for the disfigurement or for not helping. Anger may be directed at Fate, the surgeon, people who are not involved, or those who are trying to help (Frank, 1975).
6. Aggression - This may help the disfigured person to cope with difficult social situations, for example, responding to curious stares by staring back, hence seeking to embarrass the inquisitive person (Frank, 1975).
7. Denial - The patient may diminish the importance of the deformity or pretend it doesn't exist and expect others to do the same, (Ball and Paoletti, 1986), due to a wish to maintain the pre-existing body image (Kolb, 1974). Unconscious denial may cause an unwillingness to accept devices that aid rehabilitation (Kolb, 1974). This may be manifested by a hypercritical response to or rejection of a facial prosthesis (Frank, 1975). Some patients may prefer to use a dressing as this implies a temporary condition, whereas acceptance and use of a facial prosthesis may imply a permanent facial defect (Addison, 1975).

In a study of facially-disfigured people and plastic surgery, Macgregor *et al.* (1953) found that problems arose due to society's attitude to disfigurement, the negative value associated with it, and the damaging effect of this on the individual's social interaction with others, and hence damaged self concept. Forms of adjustment differed in every case but personality, family and social setting were found to be important influences on the victim's attitude to the deformity and the type of adjustment made. They also had difficulty with finding jobs, friends and marriage partners and some developed psychological disturbances out of proportion to the degree of their disfigurement. Most had behavioural problems such as "feelings of inferiority, self consciousness, frustration, preoccupation with the deformity, hypersensitivity, anxiety, hostility, paranoia, social withdrawal, antisocial and psychotic behaviour". In a follow up study by Macgregor three types of coping strategies were identified. These included first, social withdrawal to avoid social contact; second, aggression to counter anticipated negative reactions of others; and third, overcoming the other person's aversion by using charm and actively sustaining the positive aspects of the interaction (Bull and Rumsey, 1988).

Macgregor (1979) also reported that the severity of disfigurement was not directly related to the degree of emotional disturbance or how well each person adjusted to the problem. In fact, those more severely afflicted tended to have less difficulty coping emotionally with the curiosity, pity or revulsion of others because these responses were predictably negative. Whereas, less conspicuous disfigurements may not

be noticed in some encounters and hence the response would be normal as for a non-disfigured person. If they were noticed, however, they were more likely to evoke laughter, ridicule or antipathy than pity or revulsion. People with the less obvious deviations complained more bitterly about the emotional strain and anxiety caused by the erratic, unpredictable and humiliating nature of the reactions, and had more difficulty adapting to their disfigurement. Macgregor (1979) reported anger among the patients at the amount of time and mental energy spent coping with these problems which may otherwise have been devoted to more positive aspects of living.

1.2.4 ADJUSTMENT FOR CONGENITALLY DISFIGURED PEOPLE

Kolb (1974) discusses the effect of congenital deformity on the body image, self image and personality development of a disfigured child and the family. While it is normal for the parents of a disfigured newborn baby to experience such feelings as humiliation, grief, guilt and depression, it is their subsequent attitudes and behaviour, particularly those of the mother, to the child and the deformity which determine the child's own psychosocial adjustment. A mother who develops a healthy response to the defect does not consider it a stigma, nor a punishment for her own past behaviour. She does not hide her concern about it and is able to seek help from others about it. Psychopathological responses of the mother may take various forms but basically seem to result either from her attempts to deny anxiety about the defect, or having a sense of stigma about it.

The concept of self begins at the time when the baby first distinguishes "self" from "not self" in the first few months after birth (Bull and Rumsey, 1988). Disfigured children become aware of being different from peers even at the toddler stage (Lefebvre and Barclay, 1982). When they encounter people outside the family circle, images in books and on television depicting what peers are doing, many of their experiences will be negative. They may be assumed to be less intelligent by adults, may receive less praise and have less expected of them than nonhandicapped children. They may be teased or rejected by playmates, tend to play alone and perhaps lack skills for reciprocal play (Bull and Rumsey, 1988). They usually dislike looking in mirrors, going outside the home, being seen in public or involvement in social activities (Kolb, 1974).

It is on the basis of family responses, in particular those of the parents, that the development of body image and "consequent ego attitudes" take place in the disfigured child (Kolb, 1974). If the family is supportive and positive the child is likely to develop a positive self image. It may then be possible for peers to interact more with the child's personality than with the disfigurement (Bull and Rumsey, 1988). However, it may well be difficult for this positive and supportive atmosphere to be maintained in the family if there is little support for other family members from outside.

1.2.5 THE SOCIAL SUPPORT GROUP

Addison (1975), Kolb (1974), Frank (1975), Collyer (1984), Ball and Paoletti (1986) and others stress that it is vital that close family members provide social and emotional support for the patient, particularly during the period of adjustment to the disfigurement.

Addison points out that, in contrast to more common forms of loss, such as bereavement, the consequences and effects of facial disfigurement on a person are not understood by most people, such as members of the social support group. The mourning period and social rehabilitation are complicated by the patient's feeling that his or her appearance is socially unacceptable, by others finding the person's appearance upsetting and perhaps by an uncertain future due to the possibility of recurrent malignancy. It is much easier for the patient to adapt and cope when supported by close family.

However, members of the support group are subject to the prejudices that exist in society and they may have difficulty in hiding their aversion. They may be uncertain about how to behave and hence withdraw from the patient, or they may prevent the patient from expressing his or her feelings. This prevents adequate mourning of the loss by the disfigured person and "hinders social recovery" because the patient is not able to interact with others in a realistic way (Addison, 1975).

Coping by members of the support group has a large effect on how the

patient copes. Counselling may be needed by them as much as the patient (Ball and Paoletti, 1986). Although the patient and family may deny having any problems of readjusting to daily life, it is important that these be pursued and worked through by a rehabilitation counsellor for mature coping to occur (Ball and Paoletti, 1986).

Health care workers may also feel aversion to the disfigured patient. They may cope with this by keeping a professional distance, avoiding emotionally-charged issues, being authoritarian, and depersonalising the patient by viewing him or her as a clinical problem rather than as a person. These approaches can be emotionally damaging for the patient. In order to help with coping it is important for the patient not to feel alienated (Ball and Paoletti, 1986).

1.2.6 TREATMENT OF FACIAL DISFIGUREMENT

Macgregor (1951) and Kolb (1974) suggested that plastic surgery and/or psychological evaluation and treatment should be provided as early as possible for facially disfigured people to minimise the social and emotional suffering and to prevent irreversible psychological changes. Most authors (for example Macgregor, 1951; Agerakis, 1990; Addison, 1975; Collyer, 1984) suggest that public misconceptions and attitudes to disfigurement should be changed.

Whether a facial defect is treated by surgery, prosthesis or a combination of the two, a team approach to the planning of treatment is

essential in order that the points of view of all clinicians involved can be expressed (Westbury, 1983; Clarke, 1983; Beumer *et al.*, 1979). Most congenital and traumatic defects are reconstructed surgically except where the defect is too large or the structures to be replaced are too complex eg the external ear, eye or nose (Beumer *et al.*, 1979). Surgery is also preferred for reconstructing small tissue defects resulting from cancer. Even for larger defects many people, particularly the young, prefer it because of the permanence it provides compared with a prosthesis even though the latter may be a better shape and colour (Beumer *et al.*, 1979). Defects which perforate through the skin into the oral cavity below the level of the occlusal plane of the teeth are best treated surgically to prevent leakage of saliva (Westbury, 1983). However surgery may be contraindicated by many factors such as the size and location of the defect, the condition of adjacent tissues, the likelihood of tumour recurrence, the patient's preference, age and general health (Beumer *et al.*, 1979; Bulbulian, 1973; Westbury, 1983; Clarke, 1983). In these cases prosthetics can offer the advantage of quick, reversible and medically uncomplicated rehabilitation (Rahn and Boucher, 1970; Chalian *et al.*, 1972; Bulbulian, 1973; Chalian, 1979).

Surgical and prosthetic reconstruction may be used in combination. A defect may be partly closed by surgery or modified to enhance its suitability to accommodate a prosthesis (Chalian *et al.*, 1972; Blenkinsopp, 1983; Clarke, 1983). On the other hand a prosthesis may be used to temporarily restore a defect pending an observation period for tumour recurrence, and be surgically reconstructed later (Beumer *et al.*,

1979; Westbury, 1983).

Ball and Paoletti (1986) also state that it is important for the success of the surgery for both patient and support group to feel that they are ready for it, and to minimise inappropriate expectations. Helping patients with unrealistic expectations of surgical reconstruction to face reality must be done sensitively and skillfully. However, clear instructions and descriptions of expected outcomes of surgery are often misinterpreted by patients (Ball and Paoletti, 1986; Macgregor, 1977; Meyer and Knorr, 1977). It has been reported that a high rate of postoperative dissatisfaction can be expected if adolescent patients are not involved in making the decision to have surgery, as well as the parents (Phillips and Whitaker, 1979).

Ball and Paoletti (1986) report that after successful surgery there is a reduced need for former coping mechanisms such as denial and anger. There is a sense of psychological and intellectual freedom, improvement in relationships, increased comfort in public, reduced selfconsciousness with strangers, increased interest in appearance, and a sense of increased attractiveness to others.

1.2.7 REHABILITATION AND THE REHABILITATION TEAM

The treatment of patients with head and neck cancer by eradication of physical disease and surgical or prosthetic reconstruction is incomplete without also seeing to the psychosocial adjustment of the patient and family (Gillis, 1979; Chen, Udagama and Drane, 1981; Côté, 1978; David and Barritt, 1977; van Doorne, 1983). Rehabilitation to an acceptable quality of life should be held as a central concept throughout the whole process of cancer treatment, and not introduced as an afterthought (Udagama, 1983).

These days patients with head and neck cancer or craniofacial deformities are treated by multidisciplinary teams consisting of specialists from the many different fields which may be involved with treatment. A head and neck cancer team might consist of various surgical and medical specialists, dental specialists or a dentist, a psychiatrist or psychologist, a social worker, speech therapist, vocational counsellor and others. According to Agerakis (1990) all hospital staff who contact the patient should be regarded as part of the team. Members of the team consult together at regular clinics to examine, assess and jointly plan treatment for patients.

Several authors state that rehabilitation should start at the time of diagnosis of cancer and if possible before disability occurs (Ordway, 1977; David, Barritt, 1977; Agerakis, 1990).

Agerakis describes different phases or categories of rehabilitation as preventive, restorative, supportive and palliative. The best candidates for rehabilitation have had good previous general health and surgical experience, good family and social relationships, good relationships with doctors, good adaptation to anxiety and an ability to express anxiety openly, and good work records.

Both Addison (1975) and Frank (1975) have discussed how the prosthetic clinician can play an important role in managing psychosocial problems for patients disfigured by radical cancer surgery during the rehabilitation phase. The patient must be allowed to mourn the loss (Addison, 1975). When first seen by the prosthetic clinician, about 4 to 6 weeks postoperatively, the patient will generally have begun to grieve. During the next few weeks of prosthetic treatment, while in the sheltered hospital environment, the patient has time to think deeply about the implications of the disfigurement and how to cope with it when leaving hospital to return to the community. He or she can be greatly assisted at this time if there is freedom to express and discuss feelings in a supportive environment. Some staff, such as the nurse, prosthetic clinician and speech therapist, are in a good position to develop this type of supportive relationship with the patient, owing to the long periods of time they spend with the patient during treatment. One patient has described this relationship as "vitally important" (Piff, 1983). These staff members are likely to be seen by the patient as working to restore normality - whereas the surgeon may be regarded as the one who removed it - and being less elevated than medical staff, may

seem to be more approachable. The patient can be allowed or gently encouraged to express feelings which may have been difficult to express to others (Addison, 1975). This may include grief or anger and may be unpleasant or distressing for staff to experience. Some patients do not want to confide in their spouse or family for fear of causing worry, and so are isolated. They may or may not have been told they have had cancer, may suspect it, or may resist any suggestion of it (Frank, 1975). Some patients react well to the truth, there is a drop in anxiety which parallels the reduction in uncertainty. In some cases there is a catastrophic emotional reaction. Sensitivity and skill is needed in deciding how much a person who is asking for "the truth" about the nature and prognosis of the disease wants or needs to know (Ball and Paoletti, 1986). "The art is to allow the patient to proceed at his own pace" (Frank, 1975, p.145). The patient will usually give a clue in ordinary conversation as to whether he or she needs more information or needs to continue to deny the possibility of a serious condition (Frank, 1975).

Addison (1975) suggests further guidelines for assisting these patients.

Each patient is a unique individual with his or her own thoughts and feelings and must be treated with dignity and respect always. The experience of being in hospital can be humiliating, alienating and dehumanising. The inevitable loss of autonomy and regression to a dependent status which occur when a person enters hospital for major surgery may be a problem at the time of rehabilitation. Some patients,

of independent mind, will find this difficult to accept and perhaps degrading and intolerable. Others may welcome this situation in which all decisions are made for them but are difficult to rehabilitate later. It is important that the self respect, particularly of patients who have suffered recent facial disfigurement, is not further damaged by staff treating them "merely as an adjunct to their medical condition" (Addison, 1975, p.150). Collyer (1984) stresses that staff must remember that every contact with the patient can improve or diminish the patient's self esteem. The attitude of all staff in contact with the patient is vital (Coté, 1978).

The concerns of the patient's family and relatives should be considered. They should be encouraged to visit the patient while he or she is in hospital to give emotional support during the postoperative period. The family should have an opportunity to discuss what is entailed in the prosthetic treatment and the problems that may be encountered daily with the defect or prosthesis.

Each member of staff who has contact with the patient can play a part in helping with the social and emotional adjustment to the disfigurement. Patients may relate better to and confide in some members of staff more than others. Staff should be aware of when the patient needs referral to the social worker, psychologist or psychiatrist. Members of staff who must listen to the grief and anger expressed by patients during the course of their work need to be able to share their own pain and irritation with sympathetic colleagues.

1.3 Psychosocial Effects of Maxillofacial Cancer

Head and neck cancers form 4.7% of all cancers registered annually in the United States . Due to the psychosocial and functional importance of this part of the body the effects of radical cancer treatments, such as surgery or radiotherapy, are more devastating to these patients and their families than for those with cancer in other sites (Agerakis, 1990). Head and neck cancer has been described as "probably the greatest ego threat of all malignancies because of its visibility" ... "even at best the body image is damaged" (Cobb, 1974, p.419).

Psychosocial aspects of maxillofacial cancer and its treatment have been discussed by a number of authors (Turns and Sands, 1978; Agerakis, 1990; Ross, 1979; Strauss, 1988 and 1989; Addison, 1975; Frank, 1975; Gillis, 1979; Rozen, Ordway, Curtis and Cantor, 1972; Sykes, Curtis and Cantor, 1972; David and Barritt, 1977; Udagama, 1983, and Cobb, 1974).

The majority of people confronted with a diagnosis of cancer in the head and neck region cope constructively. However, a minority do not and become unco-operative, clinging, psychotic or suicidal (Turns and Sands, 1978). To most people, a cancer diagnosis is associated with treatment involving pain and suffering, mutilation and possible death. For those who survive cancer life may be permanently changed. The extent to which this happens depends largely on the person's own psychological resources and on the support received from family and medical staff.

When the full extent of the cancer is known and plans for its treatment are being considered, the patient must be informed. It is important that the patient be counselled as to the extent of surgical resection and postoperative disfigurement (Macgregor, 1977) and the steps leading to definitive rehabilitation should be described. This gives the patient confidence (Blenkinsopp, 1983). Cobb (1974, p.420) states "...the patient must have an important role in the decisions of treatment". The aim is for the patient to be well-informed and to have realistic expectations before surgical resection (Beumer *et al.*, 1979). David and Barritt (1977) describe the preoperative interview as "the key" to successful rehabilitation by revealing potential psychosocial problems.

The sequence of emotional responses which occurs when a person receives a diagnosis of cancer is similar to that described above for a newly-disfigured person. At first there is a tendency to disbelieve or deny the diagnosis. The patient may use bargaining to help deny the fact that the disease may be fatal, for example saying "I'm sure it's going to turn out all right because I'll be doing whatever you say" (Turns and Sands, 1978, p.69). Moving on from this phase anxiety and depression are common when it is realised that cure may not be possible in spite of everyone's best efforts. Patients may become withdrawn or tearful. Guilt feelings are experienced due to the superstitious belief that catastrophes such as cancer are punishment for transgressions of the past. There may also be anger and hostility (Turns and Sands, 1978).

Anxiety underlies most of the patient's behaviour at this stage. There

may be fear of rejection by or of altered relationships with friends or family, fear of pain, impending surgery, or of disfigurement. Also there is anxiety about separation from family, abandonment and above all death, which is the ultimate separation from all that one knows and loves (Turns and Sands, 1978; Allen, 1984; Ordway, 1977).

With the prospect of these losses an anticipatory mourning process occurs. Patients at this stage may reminisce about the past, put their affairs in order and in symbolic ways say goodbye to those close to them. If the condition is terminal, over a period of months they may come to accept impending death (Turns and Sands, 1978).

These phases may vary in their order, overlap or occur more than once in the process. This sequence represents a healthy response to life-threatening illness. It is important for the hospital staff and the family to understand that the patient is undergoing an emotional crisis and to be receptive and supportive (Turns and Sands, 1978). Working through these conflicts is an essential part of the diagnosis and planned treatment (Rozen *et al.*, 1972).

For the patient whose cancer is terminal, the construction of sometimes quite a large facial prosthesis to restore appearance can be important to allow a return to a relatively normal life for the remaining few months (Cantor, Curtis and Rozen, 1968; Udagama, 1983).

For patients who do not die there will be emotional relief and the possibility of a future. However, their lives may be irrevocably changed. They may face chronic illness and prolonged treatment, limitation of activities, alteration of social status and role and uncertainty about cancer recurrence. Patients should be prepared for these possibilities before surgery (Turns, Sands, 1978). "Rehabilitation is the adjustment of the survivor to an altered reality" (Udagama, 1983, p.197). Successful adjustment depends more on an ability to cope with anxiety, a good self image and acceptance of the dependence associated with chronic illness than on the severity of disfigurement (Coté, 1978; Rozen *et al.*, 1972; Bailey and Edwards, 1975). The patient may be forced to limit involvement in some activities within the family and the community, which may provoke an episode of anxiety or depression.

Several authors refer to problems that occur due to the dependent status forced on people who are admitted to hospital (Turns and Sands, 1978; Addison, 1975; Ross, 1979). (This has been discussed above under "Rehabilitation").

Social problems develop due to the aversive attitudes of society to both cancer and facial disfigurement. The public views cancer as a stigma and associates it with mystery, horror, punishment, fear of contamination and repulsion. Patients are aware that the signs of cancer are difficult to conceal and, due to self consciousness and loss of self esteem, may withdraw from social contact and become isolated and depressed (Rozen *et al.*, 1972). The face is important in body image, self image and identity

and facial features have symbolic sexual significance (Bailey and Edwards, 1975) . After surgical reconstruction of a facial disfigurement family and friends may be disconcerted by the patient's altered appearance. Turns and Sands quote the wife of a man whose face was surgically reconstructed after a car accident: "He is not the man I married. I know it's really silly, but I feel I am going to bed with a stranger" (Turns and Sands, 1978, p.70).

After cancer people may be forced to give up work or change their job. Rozen *et al.* (1972) in a study of head and neck cancer patients, found that after treatment the number working had dropped by one third and the number financially dependent on their spouses had doubled. Many of these patients' financial and emotional resources had been exhausted by the cancer and its treatment. Sykes *et al.* (1972) in a follow up study suggested that those with a more positive self image tended to be in professions or self employment rather than semi- or unskilled occupations, and were more highly motivated to overcome obstacles to return to work than lower skilled workers. Agerakis (1990) in a survey of head and neck cancer patients reported a similar pattern of return to employment. Ability to work is highly valued (Strauss, 1989) and deprivation of it may be the hardest aspect of the illness to accept (Turns and Sands, 1978).

Pathological psychological responses to cancer include severe depression, and less commonly paranoid psychosis, acute brain syndrome and delirium tremens. However less extreme reactions are more common,

such as clinging dependence, unco-operativeness, regression or multiple somatic complaints. If the patient is to be referred to a psychiatrist, it is important that the referring doctor maintains an interest and involvement in the patient's progress and that the patient knows this will happen. The attitude of the doctor has an important influence on the outcome of rehabilitation. Patients are very sensitive to verbal and nonverbal cues that may suggest hopefulness, hopelessness or rejection. Referral to a psychiatrist could be interpreted as abandonment (Turns and Sands, 1975).

Difficulty in psychosocial adjustment to cancer may be expected for those with a narcissistic personality, a history of psychiatric disorders or pre-existing sources of anxiety (Turns and Sands, 1978; Addison, 1975; Kolb, 1974; Coté, 1978). Narcissistic people rely heavily on physical attractiveness, strength or sexual prowess for maintaining their self image and self esteem, and are likely to be severely threatened by facial cancer and disfigurement. The mutilation caused by facial cancer also damages the sexual symbolism of facial structures and causes sexual aversion in others (Udagama, 1983). Loss of self esteem and alienation may lead to social isolation.

Of particular importance in helping the patient cope with his or her emotional crisis is a close and trusting relationship with one or more of the rehabilitation team members, and good support from the immediate family (Turns and Sands, 1975; Addison, 1975; Frank, 1975). The doctor should work to preserve and enhance family relationships. The quality of

the patient's life and death is dependent on this (Turns and Sands, 1975). Agerakis (1990) describes quality of life as "the yardstick" by which the success of rehabilitation should be judged. In successful rehabilitation the patient should feel able to return to normal, productive daily activities, and should have self esteem and social relationships with family and friends functioning at a similar level as they were prior to the cancer diagnosis. In short, he or she should feel useful, needed and wanted, and without stigma or undue anxiety.

1.4 Facial Prosthetics

Social bias against the disfigured (Goffman, 1963; Burr, 1935, and Shaw, 1981) and the use of artificial parts by disfigured people to restore their appearance go back thousands of years (Udagama, 1983). Numerous materials were used such as ivory or wax, enamelled or painted precious metals, porcelain and glass, and in the last century rubber, Vulcanite, cellulose nitrate and gelatin-glycerine compounds (Trester, 1983). The means devised to keep them in position included straps, adhesives, fitting into tissue undercuts, attachment to teeth and later attachment to spectacles. This century there have been considerable advances in materials and retentive devices and these will be discussed further below.

1.4.1 PROSTHETIC DEVICES IN GENERAL

Bulbulian (1973) defines the problems peculiar to the construction of facial prostheses. For other commonly-used types of prostheses, such as the prosthetic leg, eyeball or denture, the local anatomy provides good retention, suitable materials are readily available and soft tissues or clothing help to hide conspicuous edges. However for facial prostheses, the following problems exist:

1. Local anatomy is frequently not a favourable shape for providing retention of a prosthesis. Whatever form of retention is used should not alter the natural appearance of the face.
2. The natural appearance of skin is very difficult to reproduce with artificial materials and once achieved is difficult to maintain over long periods of time due to material or colourant deterioration.
3. The prosthesis is lifeless and immobile and cannot move in response to muscular contraction like a normal nose, ear or eye.
4. The exposed location of the prosthesis, particularly of a nose prosthesis, means that it is not protected from environmental influences such as heat, ultraviolet light, dust, chemical fumes etc, which will contribute to its soiling and degradation. Furthermore, the nose and eye prostheses particularly are in the facial triangle which is the focus of attention of others (Addison, 1975), so that an extremely high aesthetic standard is necessary for the prosthesis to pass unnoticed.
5. The prosthesis has a fixed colour. The colour of the face normally changes, sometimes in seconds, due to circulatory alterations in the skin after physical exertion or emotional changes. Exposure to solar or

therapeutic radiation may cause darkening or tanning of the skin. Also the colour of the prosthesis may match the skin in one set of lighting conditions, but may not match under lighting of a different spectral composition due to metamerism effects (Johnston, 1992).

1.4.2 REQUIREMENTS OF A FACIAL PROSTHESIS

Bulbulian (1973) defines these as:

1. Natural appearance. The prosthesis must look natural and normal while being worn.
2. Comfortable retention. It must be able to be placed in position easily and held there securely and comfortably for many hours at a time.
3. Reasonable durability. It must be made of a material that is durable in shape and colour.

He discusses these in more detail as follows.

1. Natural appearance involves a number of factors. These include correct matching and distribution of skin colours and the correct degree of translucency. Light penetrates the surface layers of the skin and is reflected back through those layers giving characteristic translucency (van Oort, 1983).

Gross form and shapes must be correct, suit the adjacent structures and provide bilateral symmetry. A degree of asymmetry is also desirable as a more natural effect is achieved in this way (Hulterstrom, 1983). Correct

surface topography, pores, creases and wrinkles are also important.

2. Comfortable retention may depend on a number of factors. In general the weight of the prosthesis should be as light as possible, particularly for prostheses relying on spectacle attachment for retention. Prosthesis size and location are significant. Some restorations such as an ocular prosthesis or a plug prosthesis for an isolated small defect (Beumer *et al.*, 1979), will be adequately retained by interlocking against surrounding soft tissues. Very large facial defects may present considerable problems for retention (Conroy, 1983; Marunick, Harrison and Beumer, 1985). Surface irregularities of the defect assist with location of and resistance to dislodgement of the prosthesis. For orofacial defects, a connection between the intraoral and the facial prosthesis allows either or both prostheses to contribute to the support and retention of the other. The frame of spectacles has been commonly used for retaining nose, eye and occasionally ear prostheses.

3. The useful life of a prosthesis ends when it is broken, torn or distorted beyond repair, or when the colour changes to a noticeable extent. Most materials in current use deteriorate in some respect in 6 months to 2 years. This problem can be minimised if the defective aspect can be rectified (eg recolouring of a discoloured prosthesis) or if reproducible fabrication is possible (Firtell and Bartlett, 1969). A brief discussion of materials follows.

1.4.3 FACIAL PROSTHETIC MATERIALS

Lewis and Castleberry (1980) are the latest of a number of workers (for example, Lewis, Cowper, Castleberry and Fischer, 1977; Sweeney, Fischer, Castleberry and Cowperthwaite, 1972; Cantor, Webber, Stroud and Ryge, 1969) to have defined criteria for the ideal characteristics of a facial prosthetic material. Ma (1992) reviewed research on colour, and on physical and mechanical properties of 5 groups of facial prosthetic materials:

- . Poly(methyl methacrylate)
- . Latexes
- . Vinyl polymers and copolymers
- . Polyurethane elastomers
- . Silicone elastomers - HTV (high temperature vulcanising) and
RTV (room temperature vulcanising).

None of these materials satisfies all of the requirements of an ideal material. Common clinical problems were identified:

1. Discolouration occurred over time due to environmental factors and loss of externally-applied colours. External environmental factors caused discolouration of elastomers and colourant materials (pigments and flocking). Loss of externally-applied colours from the prosthesis surface was caused by loss of adhesion, patient handling, cleaning or use of adhesives.

2. Degradation of physical and mechanical properties was demonstrated by tearing at margins, change of surface texture, elongation at margins, incompatibility with medical adhesives, weakening of margins by colourants, adhesives, solvents and cleansers, and deterioration of static and dynamic mechanical properties.

At present regardless of materials used the average life of a facial prosthesis is 6 months to 2 years (Ma, 1992).

Ma (1992) suggests that future research should concentrate on improving the physical and mechanical properties of materials to make them more like those of human tissue and to increase the service life of the material. Colour stable colourants should be sought and scientific methods for colour matching to human skin should be developed. Having reviewed recent research on these materials he suggests that research should be conducted to indicate more clearly the clinical performance of materials rather than only results of laboratory testing.

In another recent review of literature, Andres, Haug, Munoz and Bernal (1992) referred to a series of studies (Craig, Koran, Yu and Spencer, 1978; Koran, Powers, Lepeak and Craig, 1979; Koran, Yu, Powers and Craig, 1979; Yu and Koran, 1979; Yu, Koran and Craig, 1980) which concluded that MDX 4-4210¹ was the best of a number of materials tested due to its ease of manipulation and processing. The other materials included RTV silicones, an HTV silicone, a polyvinylchloride (PVC)

¹ RTV silicone elastomer. Dow Corning Corporation, Midland, MI, USA.

material and a polyurethane material. Abdelnabi, Moore and Sakamura (1984) reached a similar conclusion when they compared certain physical properties of MDX 4-4210 and a new material, polydimethyl siloxane silicone. Wolfaardt, Chandler and Smith (1985) found that Cosmesil², an RTV silicone product, was superior to MDX 4-4210 and two other RTV silicones in all physical properties tested. Kouyoumadjian, Chalian and Moore (1985) and Farah, Robinson, Koran, Craig and Hood (1987) attempted to soften MDX 4-4210 by mixing it with other materials such as silicone oil and Silastic medical adhesive silicone type A³. This resulted in a softer material but other desirable properties were adversely affected.

Andres *et al.* [b](1992) concluded that the ideal material is not available, and that research should be directed towards laminating different materials to combine their desirable properties. An example of this type of application has been suggested by Udagama (1987).

A subsequent international survey by Andres, Haug, Brown and Bernal (1992) investigated the usage of materials by members of two large United States-based prosthodontic professional organisations. Materials most used by respondents were MDX 4-4210, Medical adhesive type A and mixtures of these. Most used dry earth pigments, artists oil pigments, coloured flocking and kaolin mixed intrinsically with the silicone base material. External colour modifications mostly consisted of Medical

² Cosmedica, UWIST, Cardiff, Wales, UK.

³ Methyl triacetoxysilane crosslinked silicone. Dow Corning Corporation, Midland, Michigan, USA.

adhesive type A thinned with xylene and mixed with pigments, and applied to the surface of the cured prosthesis. Although most respondents preferred flexible materials, a small number were still using rigid acrylic resin which has advantages in durability and ease of cleaning, altering and recolouring (Bulbulian, 1973).

1.4.4 FACTORS AFFECTING PROSTHESIS DESIGN

The design of a facial prosthesis depends on the patient's requirements, the physical characteristics of the tissue defect, and the form of retention that will be used.

The patient's requirements will be determined by his or her age, level of manual skills, occupation, preference for treatment options, degree of acceptance of an existing prosthesis, availability for treatment, the climate, heavy smoking, problems with control of saliva or mucus, the patient's life expectancy or prognosis of malignant disease (Conroy, James and Rowe, 1975).

A number of factors need to be considered when assessing the tissue defect. The location and size of the defect and likely changes in tissue shape due to recent surgery or radiotherapy are significant. The availability of tissues within the defect which are suitable for providing support, stability and retention for the prosthesis is also a fundamental consideration. Where this is insufficient it may be necessary to extend the prosthesis over normal tissues adjacent to the

defect or make use of auxiliary devices such as the frame of spectacles. The health and load-bearing capacity of the defect tissues are important, and would be affected by such factors as whether surgical wound healing is still in progress and whether the tissues were irradiated. The submucosal thickness and resiliency of soft tissues, the type of covering epithelium, the presence or absence of underlying, supporting bone and its surface smoothness or irregularity must be assessed. Also the mobility of tissues within and adjacent to the defect during muscle activity and the orientation of supporting tissue surfaces with respect to the direction and degree of anticipated forces on the prosthesis must be evaluated. The bulk or distortion of tissues both within and adjacent to the defect may make normal anatomical contour of the prosthesis impossible and compromise the appearance of the prosthesis. Problems with control of saliva or mucus may also affect prosthesis design. The principles of assessment of defects have been discussed by Conroy (1983). Bulbulian (1973) discusses how aesthetic requirements may affect prosthesis design for different types of defects of nose, ear and eye.

Retention (Bulbulian, 1973; Beumer *et al.*, 1979) of the prosthesis may be achieved by the use of skin adhesives, engagement of tissue irregularities or undercuts by the prosthetic material (Pratt, 1975; Parel, 1980), attachment to another device such as the frame of spectacles, a headband or an intraoral prosthesis (in orofacial defects) (Conroy, 1983), or by implantation of magnets in soft tissue (Swartz, Udagama and Spira, 1982) or titanium implants in bone (Tjellström,

Jansson and Brånemark, 1992). The advent of osseointegrated titanium implants, allowing direct prosthetic anchorage to bone, has enabled the rehabilitation of these patients to a level hitherto not considered possible (Parel, Holt, Brånemark and Tjellström, 1986; Henry, 1992).

1.4.5 CLINICAL AND TECHNICAL PHASES OF FACIAL PROSTHESIS CONSTRUCTION

While the precise procedures involved in prosthesis construction vary greatly depending on the nature and complexity of the case at hand, the following are the fundamental stages. These processes are discussed in detail by Bulbulian (1973), Chalian *et al.* (1972), Beumer *et al.* (1979) and others.

1. History-taking, examination and treatment planning.

Writers have stressed that it is important for a quiet, unhurried atmosphere to be established in which these emotionally-stressed patients will feel free to discuss problems and in which they can be fully informed about proposed treatment (Conroy *et al.*, 1975; Addison, 1975; Frank, 1975; Beumer *et al.*, 1979).

2. Impression.

The impression records the facial defect, adjacent structures and perhaps contralateral facial structures. Impression material is applied to the face, and coverage of the eyes and/or nose is often necessary. As this can be an unpleasant experience steps must be taken to minimise physical discomfort or causes of anxiety for the patient during the

procedure. From the impression a plaster cast of the defect area and face is made and a pattern for the prosthesis is formed in wax or clay.

3. Prosthesis pattern and mould.

The pattern is placed on the patient's face, evaluated, and the shape and margins are corrected and refined. Skin colours may be selected at this stage. A 2- or 3-part plaster (or in some cases metal) mould is formed around the completed pattern and afterwards the pattern material is removed from the mould. This leaves a mould cavity which is then filled with the prosthetic material in a fluid or dough state, suitably coloured by admixture of colouring agents. The mould is closed and curing of the material to its solid state often involves application of heat in an oven or water bath.

4. Completion of the prosthesis.

After curing the formed prosthesis is recovered from the mould and trimmed to fit the patient. Surface colouring or addition of eyelashes or eyebrows, or attachment to a spectacle frame may be needed to complete the prosthesis. The patient is instructed in the use and cleaning of the prosthesis, and some counselling is advised to help the patient during the critical first few days of using the prosthesis (Beumer *et al.*, 1979). The patient is placed on a program of regular review.

1.4.6 ACCEPTANCE AND USAGE OF FACIAL PROSTHESES BY PATIENTS

Macgregor stated "For the person who must accept a prosthetic device designed to conceal or replace a lost part of the face, adjustment is difficult and emotionally taxing. Besides the deep psychologic implications of a prosthesis on the maintenance of body integrity and the self-image, there is the fear of being unmasked should the appliance become dislodged" (Macgregor, 1977, p.568). Studies which have been published on the usage and acceptability of facial prostheses to patients are reviewed below.

Jani and Schaaf (1978), in a survey of 76 facial prosthesis patients, found that half of the patients were using their prostheses. Of the latter, 79% of the prostheses were retained with skin adhesive, 79% of the patients liked the colour and 89% the shape of the prosthesis, and 84% thought their prostheses were excellent. Few (18%) used their prostheses at night, or had skin irritation (13%). Of the 50% of patients not using their prostheses, the main problems were poor retention (which also affects comfort and appearance) and poor aesthetic appearance. Other problems were caused by changes in the defect tissues, discomfort or skin irritation. The main causes of prosthesis replacement within 12 months were colour change, material deterioration or changes in the shape of the defect tissues. They concluded that there was a need for more durable materials, better colouring techniques and adhesives that do not irritate irradiated tissues. They also stated that aesthetic appearance of the prosthesis is an important factor in acceptance and

that it is important to ensure that patients and their families had appropriate expectations prior to starting treatment. Family members should understand that adverse comments about the appearance of the prosthesis make acceptance of it by the patient more difficult.

Jebreil (1980) surveyed 18 patients who had been given orbital prostheses (12) or eye patches (6) to determine whether those dissatisfied with their orbital prostheses would more readily accept eye patches. Reasons for not using the prosthesis included discomfort, poor retention, poor fit, skin irritation by adhesive, tissue shape changes and surgical reconstruction of the area. Reasons for prosthesis replacement included colour change, marginal breakdown, changes in the defect and surgical reconstruction of the defect. Tabulated figures of patient responses to some survey questions are inaccurate or do not total correctly. The conclusions drawn by the author about the patients' preferences for orbital prosthesis or eye patch are inconsistent with the figures. Nevertheless, it was shown that 10 (56%) of the subjects preferred an orbital prosthesis, 4 (22%) preferred an eye patch, 3 subjects did not respond and 1 (6%) preferred no patch or prosthesis. Of the 6 eye patch wearers, 4 (67%) would have preferred an eye prosthesis.

Sela and Lowenthal (1980) studied the changes in patients' self image, optimism or pessimism, and feelings of being healthy or sick after the provision of facial prostheses. A questionnaire of 25 true or false statements was designed indicating responses to these parameters, and was completed by 39 patients immediately prior to facial prosthetic

treatment and again 3 months after the completion of this treatment. For 33 patients the scores increased, indicating improved self image and optimism, but no clear association was found between these changes and patient age, sex or ethnic origin. However a clear correlation was found between the aetiology of the defect and the degree of improvement in the score. The greatest improvement occurred for those with traumatic defect origin, somewhat less improvement was seen in those with congenital defects, and the least improvement occurred for those whose defects resulted from cancer. The authors attributed the result for the cancer patients to their persistent fear of recurrence and a sense of doom.

In a follow up study, Lowenthal and Sela (1982) used a modified questionnaire which was completed by 52 patients both before and 2 months after the completion of facial prosthetic treatment. They investigated whether the objectively-judged aesthetic improvement provided by the prosthesis (rated separately by a prosthodontist, a physician and a sculptor) was matched by a corresponding improvement in the patients' sense of health and self image, as measured by the questionnaire responses. Objective ratings by the physician and the sculptor were made from photographs of the patients. Results showed that, on average, there was an improvement both in questionnaire scores (39%), and in the objectively-judged aesthetic change (30% to 44%) ie aesthetic improvement rated by investigators seemed to be matched with the benefit shown by patients' psychological test results. The average improvement both subjectively and objectively, was higher in men (42%) than women (34%). Subjectively, improvement was greater in younger

patients (14 to 50 years; 45%) than in older patients (51 to 75 years; 33%). However, judged objectively, on average, the old (53%) benefitted more than the young (48%). The prosthodontist was found to be more critical of the aesthetic results than the physician and the sculptor.

In 1981 Chen *et al.* published a survey of 73 cancer patients who had been given facial prostheses. The most commonly made prosthesis was for the nose (47%). The ear prosthesis had the highest percentage of success, perhaps because of partial coverage by hair, compared with the eye (69%) and nose prosthesis (68%). Most patients preferred a prosthesis to a patch. Prostheses lasted an average of 10 months and needed replacement due to material deterioration or colour change. Double-faced adhesive tape was the most favoured form of adhesive because of its convenience in use and for cleaning. The two most important causes of concern to the greatest number of patients were the limited prosthesis service life and prosthesis appearance. Other factors of concern, in order, were: cost, overall fit, softness, cleaning, skin comfort and of least concern, friends comments. The authors stressed the importance of early detection of psychosocial problems in the diagnosis and treatment of these patients, and of cooperation between those treating the disease and those responsible for the emotional welfare of the patient.

Roefs, van Oort and Schaub (1984) studied factors affecting the acceptance of facial prosthesis by 14 patients.

Objective ratings were made of:

1. Patient responses to specified aspects of a semistructured interview covering the patient's experiences of cancer treatment from diagnosis, through hospital treatment and recovery, the return home, prosthetic rehabilitation and to the present.
2. The physical aspects of the prosthesis.
3. The type and amount of hospital treatment.
4. The degree of facial mutilation.

No correlation was found between the patients' subjective ratings of their prostheses (as positive, neutral or negative) and any of the rated factors above. Although firm conclusions could not be drawn due to the small sample size the authors noted that:

1. Subjects seemed to give neutral rather than negative responses about their prostheses or treatment due to a sense of "social desirability".

The survey was conducted in the hospital where treatment had been given.

2. "In general all respondents were positive about the support of the medical team which may have alleviated early negative feelings and improved acceptance" (Roefs *et al.*, 1984, p.851).
3. Personality, self esteem, self concept and social environment may be important factors affecting prosthesis acceptance.

1.5 The Purpose of this Study

1. The aim of this study is to evaluate a group of subjects who have been given facial prostheses.
2. It is intended to study what aspects of the subjects' experiences of the diagnosis of cancer (or occurrence of trauma or from earliest memories for the congenitally disfigured), treatment, rehabilitation and of life through to the present time significantly affected their ability to cope socially and emotionally.
3. Of particular interest is the value of the facial prostheses in the rehabilitation of the subjects and what factors affected this.

CHAPTER 2

MATERIALS AND METHODS

2.1 Preliminary Interviews

Gently guided interviews were conducted with several subjects about their experiences of coping socially, emotionally and physically with facial disfigurement and their facial prostheses. This covered the period from when the person first became aware of the possibility of being facially disfigured - usually at initial cancer diagnosis - through surgery, hospital treatment, rehabilitation, prosthetic treatment and up to the time of interview.

Factors affecting coping were hypothesised to include family background and current social circumstances, personality type and significant aspects of the diagnosis, treatment and rehabilitation experiences. The significant aspects were :

1. the diagnosis of cancer;
2. the management of the diagnosis and preoperative period by the doctors;
3. the operation and postoperative period in hospital;
4. radiotherapy or chemotherapy treatment;
5. counselling;

6. the return to home, community and job;
7. the facial prosthetic treatment;
8. the social support available during these experiences, and
9. factors related to the appearance and use of the facial prosthesis.

From these observations the items of data to be collected in the main study were identified.

2.2 Forms for Data Collection for the Main Study

Based on the findings of the preliminary study the following forms were designed or selected for data collection.

1. Demographic data form

This covered biographical information, and certain aspects of the medical, prosthetic and social history (Appendix 1).

2. Interview schedule

The main periods in the subject's experience from the time of diagnosis to the time of interview were covered. A semi-structured format allowed free discussion by the subject about periods of the experience as well as answering specific questions. The questions covered issues which had been significant for subjects in the preliminary study and other issues thought to be relevant. The subject was free to mention aspects of concern which were not covered in the schedule (Appendix 2).

3. Quantitative questionnaire about the facial prosthesis

To allow quantitative comparisons of the prostheses, 15 aspects of prosthesis appearance and usage were listed for rating by the subject and the interviewer. Opposite each aspect was an analogue scale from "good" on the left to "bad" on the right. Ranged between these were the words

"very" "slightly" "neither/nor" "slightly" "very"
or "equally"

showing the degree of "good" or "bad". The subject was to decide whether the aspect rated good, bad or in between and then circle the word that described how good or bad. An instruction sheet was given to the subject to read before filling in the questionnaire (Appendix 3).

4. Prosthesis and defect assessment forms

These forms were designed to allow objective rating of different aspects of the prosthesis material, means of retention, appearance and usage, any dressing or patch that was used, and the disfigured area of the face. For some aspects a response by the subject was required instead of objective rating by the interviewer (Appendix 4).

5. 16 Personality Factor Questionnaire (16PF), Form C

This 25-35 minute personality assessment test (IPAT Staff, 1979) covers 16 essentially independent personality factors (Appendix 5).

2.3 Population and Sampling

The group under study consisted of patients who had received facial prostheses from any of 3 treatment centres in Sydney, and whose personal details were available so that they could be contacted. The treatment centres were the Dental Clinic, Prince of Wales Hospital, High Street, Randwick, NSW, 2031; the Dental Department, Royal Prince Alfred Hospital, Missenden Road, Camperdown, NSW, 2050; and the Department of Prosthetic Dentistry, United Dental Hospital of Sydney, Chalmers Street, Surry Hills, NSW, 2010.

Letters requesting participation (Appendix 6) were sent to 57 patients. Those who had not made contact after 2 weeks were followed up with a telephone call and another letter. Forty-two subjects agreed to take part in the study and were interviewed. For each subject an arrangement was made to meet for an interview, usually in the subject's home, and consent was sought to use a tape recorder and to take photographs of the subject and prosthesis. Due to a faulty tape recording the data for one subject had to be excluded. This left a total of 41 subjects who were ultimately included in the study.

2.4 Data Collection Procedure

The subject was requested to read, fill in and sign a form consenting to take part in the survey and allowing hospital records to be viewed (Appendix 7).

The tape recorder was switched on and lapel microphones were attached to subject and interviewer.

The demographic data sheet (Appendix 1), items 1, 2, 3, 6, 7 and 8 were completed. It was found that these items made an appropriate introduction to the interview. If other demographic data items were asked at this stage they tended to stimulate explanations about matters which were to be covered in detail in the interview. These items were better left until after the interview was finished.

The interview was then commenced following the order set out in the interview schedule (Appendix 2). However in later interviews when the third question in section 7 was reached the quantitative questionnaire about the prosthesis was completed. This saved the repetition of information about the prosthesis that occurred if the quantitative questionnaire was done separately later. After it was completed the remaining interview questions were asked.

In practice, the order of interviewing rarely followed the schedule exactly. When the first one or two questions had been asked the subject would usually launch into the story in his or her own words. During this account some of the interview questions could sometimes be slipped in where appropriate. This allowed the story to flow naturally and the subject could spontaneously emphasise aspects that were important. When the story was finished the interviewer would return to the beginning of the interview schedule and ask any questions that had not already been

answered. Although occasionally a question would be overlooked using this method, it was preferred to the alternative of forcing the subject to keep strictly to the order and content of the interview schedule.

The quantitative questionnaire about the prosthesis (Appendix 3), in later interviews was carried out during the interview when the prosthesis was being discussed (as was mentioned above). The subject was given the instruction sheet to read and then the questionnaire. The last 3 of the 15 items were introduced after all subjects had been visited once, because items 9 and 11 were felt to be lacking specificity. These 3 items were rated at a second visit to the subjects or by telephone.

The prosthesis and defect data sheet (Appendix 4) was filled in at the second visit to subjects. This sheet was not completed for 35% of the subjects because they could not be visited a second time (subjects 1, 4, 5, 6, 10, 13, 17, 19, 22, 24, 27, 29 and 32).

For the 16 Personality Factor Questionnaire, Form C (Appendix 5), the subject first read the preliminary instructions. To facilitate completion of the test the subject would read each question and state the selected answer (a), (b) or (c), and the interviewer would mark this on the answer sheet.

Photographs were taken when consent had been given.

CHAPTER 3

RESULTS

The results presented and analysed include demographic data of the subjects, descriptions of the tabulated interview data, the 16PF Test results and data about the prostheses.

3.1 Demographic Data

Details of the demographic data for each subject are presented in Appendix 8. Some characteristics of the sample are tabulated below.

(a) Age (years)

	Male	Female
Range	21 - 87	43 - 89
Mean	63	73

(b) Sex

Male	29
Female	12

(c) Cause of disfigurement

	Male	Female	Total
Trauma	1	-	1
Birth defect	2	-	2
Tumour	26	12	38
Total	29	12	41

Of 41 subjects, 29 (71%) were male, 12 (29%) were female and their average age was over 60 years. For 38 (93%) subjects the cause of disfigurement was a tumour, whereas only 2 (5%) were caused by congenital deformities and 1 (2%) was due to a traumatic accident.

3.2 Interview Data

For each subject the recorded interview was transcribed in note form. The data were then summarised and categorised. Each subject's experiences were summarised and under the heading of each interview category significant responses were listed, particularly those to do with psychosocial coping. For specific aspects under each category the subject's response was tabulated and rated positive, neutral or negative (Appendix 9). The quantitative and qualitative results obtained for each specified aspect (column) of each of the interview tables are summarised below.

3.2.1 DIAGNOSIS AND PREOPERATIVE PERIOD (TABLE 9.1, APPENDIX 9)

(a) Subject reaction to manner of doctors' presentation of diagnosis

Of the total of 39 respondents there were 10 positive, 2 negative, 2 equivocal¹ and 25 unclear ratings. For 2 subjects this aspect was irrelevant.

Reasons for positive ratings were that the doctor explained everything clearly; was direct, even blunt, and to the point; was gentle or was sincere.

Reasons for negative ratings were that the doctor was too forward or blunt, or that he told the subject about the cancer diagnosis loudly in front of other patients.

(b) Rating of subject coping with diagnosis and prospect of treatment

(* NOTE - This column comprised a global rating by the author and a psychologist of the coping of each subject in the preoperative period). There were 22 positive, 2 equivocal, 7 negative and 8 unclear ratings. For 2 subjects this aspect was irrelevant.

Positive ratings were given for subjects who coped well emotionally, with only transient or no emotional disturbance.

Equivocal ratings were given where subjects coped both poorly and well at different times. Neutral ratings were given where the coping level was unclear.

Negative ratings indicated significant emotional coping problems such as a prolonged anxiety crisis.

¹ These subjects reported both positive and negative experiences.

(c) Support group rating

There were 38 positive, 1 equivocal and 2 unclear ratings.

Reasons for positive ratings were that there were expressions of emotional and social support from close relatives, friends or doctors. Overall most subjects described themselves as well-supported emotionally.

The reason for the equivocal rating was that although the relatives were supportive and well-intentioned one of them gave the subject incorrect advice which subsequently made emotional coping for him more difficult.

(d) Whether adequate period of prior notice of operation was given

There were 20 positive, 1 negative, and 18 unclear ratings. For 2 subjects this aspect was irrelevant.

Of those who were rated positively, 2 subjects who had 4 and 3 days notice respectively felt this was adequate and were glad to not to wait longer.

The single negative rating was because only 1 day of notice was given, but the subject accepted that this was unavoidable under the circumstances.

(e) How well informed subject felt beforehand about nature of operation

There were 30 positive, 3 negative and 5 unclear ratings. For 3 subjects this aspect was irrelevant.

Some of the positive ratings were given for subjects who felt fully informed about the procedure to be done. Some were given for subjects who felt as fully informed as possible accepting that the nature of the

operation could vary depending on the circumstances found during surgery. In one extreme case, the subject had been told preoperatively that she would have cosmetic reconstruction of her nose although at operation this was changed to surgical resection.

The negative rating was given for one subject who felt he had been led to believe that much less tissue would be removed than actually was taken over a series of 4 operations; for another subject who was expecting the resection to be much bigger than it was, and for a third subject who was not told before the operation that she would be left with a facial defect afterwards.

(f) How well the subject felt informed preoperatively about the degree to which appearance and function would be affected

There were 22 positive, 5 negative and 11 unclear ratings. For 3 subjects this aspect was irrelevant.

Positive ratings were given where patients felt well enough informed. Three of the 5 negative ratings occurred because unexpected conditions were encountered at operation and hence the outcome was different from what had been expected.

(g) Subject reaction to management by doctor(s) of this early period

There were 20 positive, 2 negative, 13 equivocal and 4 unclear ratings. For 2 subjects this aspect was irrelevant.

Negative ratings were given in cases where the subject perceived misdiagnosis or mismanagement by the doctor, which was considered the cause of unnecessary delay resulting in worse disfigurement or even in

the tumour becoming inoperable; blunt presentation of the diagnosis or treatment plan; a prolonged waiting period (4 - 5 weeks) to be told the diagnosis and treatment plan, due to complexity of the case; a perceived impersonal or uncaring attitude of the doctor; and the subject not being fully informed about effects of radiotherapy when he was given the option to decide whether to have radiotherapy or surgery.

3.2.2 AFTER OPERATION (TABLE 9.2, APPENDIX 9)

(a) Reaction to first sight of defect

There were 12 positive, 12 negative, 2 neutral and 13 unclear ratings. For 2 subjects this aspect was irrelevant.

Reasons for positive ratings being made were that the subject liked the manner of presentation of the disfigured area; or that he or she reacted positively to the defect or was not upset by it.

Reasons for negative ratings being made were that there was no attempt by the medical or nursing staff to prepare the patient for what to expect before seeing the defect; that the manner of presentation of the defect by staff was insensitive; that the subject was scared to look in the mirror; that seeing the defect for the first time was an unpleasant shock; that the amount of tissue that had been taken was more, or that the defect was bigger, than the subject had expected.

(b) Subject coping overall in hospital

(* NOTE - This column comprised a global rating by the author and a psychologist of the coping of each subject in the postoperative period).

There were 29 positive, 4 negative, 2 neutral and 4 unclear ratings. For 2 subjects this rating was irrelevant.

Positive ratings were given where the subject had a positive view of, or was not significantly upset by the hospital experiences; or where in spite of unpleasant hospital experiences the subject seemed able to continue to function normally without excessive or prolonged emotional or social disturbance.

Negative ratings were given for subjects who felt unhappy because the defect was larger than had been expected; due to a perceived lack of concern by medical staff who did not provide spectacles so that the subject could read, watch television and occupy himself during his hospital stay; due to the outcome of surgery being the opposite to that planned ie radical resection of the nose instead of surgical reconstruction, and further, with inadequate explanation of what had happened, the subject being shown the area for the first time in front of a large group of medical students; due to failure by the surgeon, after the disfiguring surgery, to arrange for prosthetic reconstruction of the defect area, surgical reconstruction having been contraindicated); and due to perceived derogatory comments between other patients in the ward about the subject's disfigurement.

(c) Support for subject by support group

There were 30 positive, 1 negative, 4 equivocal and 4 unclear ratings. For 2 subjects this aspect was irrelevant.

Positive ratings indicated that the subject felt adequately emotionally and socially supported by the support group.

The negative rating was given for the subject who did not receive support because she did not want to worry her relatives and so did not tell them about her disfiguring surgery.

Equivocal ratings were given for cases in which some members of the family were accepting and supportive and one or more others could not accept the disfigurement and did not provide useful support. In one case the false expectations about the surgical outcome created by supportive, well-intentioned but misguided family members (in spite of good advice about what to expect from the surgeon) caused the subject to be shocked and depressed when he saw the defect.

(d) Nursing staff in hospital

There were 29 positive, 2 negative, 3 equivocal and 5 unclear ratings. For 2 subjects this aspect was irrelevant.

Positive ratings were given for subjects who appreciated treatment received from the nursing staff.

Negative ratings were given for subjects who complained about the inefficiency of members of the nursing staff; the neglect of giving medications at the correct times; the taking of the subject's pulse every half hour day and night; the incorrect use of dry gauze in a wound dressing which then required a prolonged and painful removal; or uncaring, insensitive or bullying behaviour by certain members of the nursing staff.

3.2.3 RETURN TO HOME, COMMUNITY AND JOB (TABLE 9.3, APPENDIX 9)

(a) Readjustment to home life

There were 24 positive, 3 negative, 2 equivocal, 3 neutral and 9 unclear ratings.

Positive scores were given for subjects who returned to a daily life at home similar to that prior to the illness with no disruption or only transient and minor disruption to normal social, emotional and physical functioning.

Negative ratings were made for subjects who had prolonged (period of months or years) or permanent marked change in the quality of their home lives after the operation compared with the period prior to the illness. This was due to a significant disruption of social, emotional or physical functioning eg due to depression; emotional problems caused by having to clean and dress the facial defect; social isolation at home because of shame about the disfigurement being seen in public; or multiple and gross disabilities requiring constant and longterm care by a spouse.

Neutral ratings were given for subjects who had minor to moderate changes in the quality of home life compared with the period prior to the illness. For example, this may have been due to limitation of arm movement and reduced physical strength; due to taking a long time (12 months) to regain physical strength; or due to being prevented from resuming an activity (gardening) because of disability.

Equivocal ratings indicated a combination of positive and negative responses by the subject.

(b) Return to job

Fourteen subjects were known to have been working up to the time of surgery, 25 subjects had not been working and for 2 subjects this was unclear.

Of the 14 subjects who had been working up to the time of surgery, 9 returned to work after returning home from hospital (with a variable delay for convalescence of up to 12 months), 2 returned to work but were forced to retire earlier than they would have otherwise due to factors related to the illness and surgery, and 3 did not return to work at all due to residual disabilities after the surgery. One subject who had not been working prior to the surgery took up voluntary work after her rehabilitation.

(c) Resumption of normal social activities and outings

There were 31 positive, 6 negative, 1 equivocal and 3 unclear scores.

A positive score was given when the subject indicated that he or she had returned to essentially presurgical levels of social functioning using either a cover or a prosthesis. This meant that the subject had a similar frequency of shopping, visiting friends, clubs, sporting activities etc after the return home as had existed prior to the illness.

A negative score was given when the subject indicated that he or she went out or took part in social activities significantly less after the return home from hospital than before due to embarrassment about the disfigurement (most cases); or due to reduced physical strength or severe disability and mobility problems. A negative score was also given

to a male subject who attributed his marriage breakdown to his disfigurement.

An equivocal score was given where the subject indicated a long delay in returning to normal social activities.

(d) Overall subject coping

(* NOTE - This column comprised a global rating by the author and a psychologist of the coping of each subject in the period after returning home). Positive ratings were made for 31 subjects, negative ratings for 5 subjects, neutral ratings for 4 subjects and there was no rating for 1 subject.

Positive ratings were given for subjects who coped during this period without significant disruption of their normal social and emotional functioning, ie they returned to normal activities and roles within the home and socially out of the home, often with the help of support groups.

Negative ratings were given where there was significant disruption to social or emotional functioning eg due to self-imposed social isolation due to shame about the disfigurement; due to residual weakness or physical disability after the operation; due to marriage breakdown after returning home, which the subject attributes to the disfigurement; due to a psychiatric problem developing postoperatively related to work (but judged by a clinical psychologist as a depressive response to having cancer and radical surgery).

A neutral rating was made where the subject made a slow return to a level of emotional, physical, social, and vocational functioning below

that which had existed prior to surgery.

(e) Support group reaction to appearance

There were 24 positive, 1 negative, 8 equivocal and 8 unclear ratings. Positive ratings were given to subjects who indicated a positive reaction of the support group to their appearance.

The negative rating was given to a subject who indicated a lack of support by support group because his wife left him which he attributes to the disfigurement.

Equivocal ratings were given either to subjects for whom individuals in the support group reacted differently (some positively, some negatively), or to those whose support group had a shock on seeing the defect but who were still supportive of the subject.

3.2.4 RADIOTHERAPY AND CHEMOTHERAPY (TABLE 9.4, APPENDIX 9)

(A) RADIOTHERAPY

(a) Experience of having the treatment and of the staff

Of the 23 subjects who had radiotherapy, there were 13 positive, 2 negative and 8 unclear ratings.

Positive ratings were given to subjects who were happy with or had no problem with the treatment they received and with the staff.

Negative ratings were given because one subject had not had anything explained about the treatment and panicked when the large machine was moved towards her. Another subject found the physical surroundings and treatment "disgusting", frightening, dehumanising and debilitating. He

felt that one member of staff seemed inexperienced, frivolous and not responsible enough to be operating a dangerous machine. Also there seemed to him to be little care by staff for patients in the waiting room, who had to help each other if they were ill and vomiting.

(b) How well informed about treatment side-effects

Of the 23 subjects who had treatment, 1 responded positively indicating the subject felt well-enough informed, and 2 responded negatively because they did not feel they had been adequately informed. One subject was not told about the increased risk of tooth decay and of infection in the jaw caused by radiotherapy, when asked to choose between radiotherapy and surgery for his treatment; the other felt inadequately informed about the severity of the effects of the radiotherapy. The response of 20 subjects was unclear.

(c) Impact of side effects and longterm effects

There were 4 positive, 13 negative, 4 neutral and 2 unclear ratings. Positive ratings indicated that the subjects found the side effects insignificant.

Negative ratings were given for subjects who had adverse side effects eg mild to extreme fatigue; dryness, inflammation and ulceration of mucous membranes of mouth and throat; burns of skin; nausea, vomiting; difficulty eating and swallowing; slowed mental processes and memory loss; loss of hair, double vision.

Neutral ratings were given where the subjects had a minor degree of side effects which caused the subject little or no discomfort.

(d) Emotional coping overall

(* NOTE - In this column coping of subjects with the experience of radiotherapy overall was rated by the author and a psychologist).

There were 13 positive and 3 negative ratings. For 7 subjects no rating could be made because of insufficient information.

Positive ratings indicated that the subjects coped well with the treatment.

Negative ratings indicated that the subjects did not cope well for reasons such as a perceived lack of consideration for the subject by the medical profession because of the difficulty in getting to the treatment rooms in the city for repeated visits; finding the longterm effect of slowed thought processes distressing; and finding all aspects of the treatment and its effects unpleasant.

(e) Support for subject by support group

Fourteen subjects indicated positive support during this period; for 9 subjects there was no clear response.

(B) CHEMOTHERAPY

Only 5 subjects received this treatment.

(a) Having the treatment

There were 4 negative ratings and one unclear rating.

Negative ratings were given for subjects who had adverse side effects during treatment eg severe nausea and vomiting, fatigue, malaise, pain, hunger, thirst and slowed thinking.

(b) Subject coping

Only 1 subject responded clearly for this aspect. His spirits improved when he saw that the treatment caused the lesion to shrink.

3.2.5 PROSTHESES (TABLE 9.5, APPENDIX 9)

(This data was combined from interview responses and ratings in the quantitative questionnaire forms completed by subjects).

(a) Having the prosthetic treatment

There were 29 positive, 4 negative, 1 neutral and 7 unclear ratings. Positive ratings indicated no concerns about the prosthetic treatment procedures.

Reasons for giving negative ratings included that treatment methods were described as "cumbersome" and "old-fashioned" compared with those of other treatment centres; that treatment took too long or there were too many visits; and that the subject found having the facial impression was an unpleasant experience.

The neutral rating was given because after the facial impression this subject had 2 remnants of impression material which remained lodged in the nasal cavity for some months.

(b) Retention

There were 30 positive, 11 negative, 2 neutral ratings and 1 unclear rating. (NB There was a total of 44 prostheses, and 41 subjects.)

Positive ratings were given because retention was good or moderately

good. For one subject there was some skin soreness caused by removing a prosthesis fixed with adhesive; and for another the adhesive lost its hold in the presence of sweat.

Neutral ratings were given for subjects who experienced slight slipping of the prosthesis; and a tendency for the prosthesis to fall when the subject leaned forward.

Negative ratings were given for subjects who described the prosthesis slipping down and exposing the defect margin (3 patients, for prostheses retained by spectacles). For those subjects using adhesive retention for their prostheses, a negative rating was given for skin irritation on removal of the prosthesis (3 patients); ineffective adhesive agent; retention with adhesive ineffective due to changes in the shape of the tissue bed; and where retention by engaging soft tissue undercuts was ineffective.

(c) Shape

There were 37 positive, 4 negative, 2 neutral and 1 unclear ratings.

Positive ratings were given for subjects who were happy with this aspect of the prosthesis, or happy with the prosthesis even though this aspect may not have been perfect eg 3 subjects noted that the marginal fit of their prostheses was not perfect but were still happy with the prostheses overall.

The reasons for the neutral ratings were that there were aesthetic aspects of the shape of the prosthesis that could have been better, but the patients accepted them as they were.

The reasons for the negative ratings were that the tissue surface of the

prosthesis no longer fitted due to changes in the shape of the tissue bed; that the prosthesis was not large enough to cover the defect, and that the shape of the prosthesis was defective due to deterioration of the prosthetic material with age and usage.

(d) Colour

There were 35 positive, 2 negative, 6 neutral and 1 unclear ratings.

Positive ratings were given for subjects who approved of the colour of the prosthesis, (although one of these subjects uses make up to improve the colour).

Neutral ratings were given for cases in which there could be some improvement in the colour of the prosthesis, and one of these subjects also used makeup to improve the colour.

The reasons for giving negative ratings included that the colour of the prosthesis did not match the skin; that the incorrect colour attracted attention in public, and that the colour had changed due to the age of the prosthesis and deterioration of the prosthetic material.

(e) Comfort

There were 33 positive, 9 negative and 2 neutral ratings.

The reason for giving a positive rating was that the subject was comfortable or not conscious of the prosthesis (although one subject scored positive for this even though there was skin soreness due to the use of adhesive).

Negative ratings were given because the prosthesis was uncomfortable or heavy; the prosthesis was resting on unhealed tissues; the adhesive

caused discomfort or the prosthesis engaged the nasal cavity for retention and made the nostril feel blocked.

(f) Putting the prosthesis on

There were 28 positive, 11 negative, 3 neutral and 2 unclear ratings. Positive ratings were given for subjects who found that putting the prosthesis on was not a problem. (These included 4 subjects who needed another person to put the prosthesis on for them).

One subject who was given a neutral rating required another person to put the prosthesis on, and felt ambivalent about this.

Negative ratings were given for subjects who found the prosthesis was difficult to put on; that it had to be done by another person and that this was a problem (2 subjects); that it was too time-consuming and that glue would get stuck in the adjacent hair.

(g) Protecting the prosthesis from damage when it is not in use

There were 31 positive, 3 negative, 1 neutral and 9 unclear ratings.

Positive ratings were given for subjects who found this no problem.

A neutral rating indicated less inconvenience than a negative rating.

Negative ratings were given because the prostheses were made of brittle acrylic resin and were easily broken. However many others in the study had acrylic resin prostheses and did not respond negatively in this aspect.

(h) Cleaning

There were 30 positive, 8 negative, 4 neutral and 2 unclear ratings.

A positive rating indicated no problem.

A neutral rating indicated less problem than a negative rating.

Reasons for the negative ratings were that the glue was difficult or inconvenient to remove without causing damage to prosthesis or skin; or that adhesive got stuck in hair.

(i) Family/friends reaction

There were 35 positive, 4 negative, 3 equivocal and 2 unclear ratings.

Positive ratings were given for subjects who indicated approval for the prosthesis and/or that it was a source of some inoffensive joking.

Negative ratings were given because a member of the subject's immediate family did not like the prosthesis (4 subjects).

(j) How well the prosthesis escapes public notice

There were 33 positive, 6 negative, 1 equivocal and 4 unclear ratings.

A positive rating was given for subjects who found that the prosthesis was not readily noticed in public; and for 1 subject who said that although the public did look at it, they did not say anything and he was not concerned about it.

Negative ratings were given because the prostheses attracted attention in public, particularly from children.

(k) Benefit to subject

There were 29 positive, 7 negative, 5 neutral and 3 unclear ratings.

A neutral rating indicated an ambivalent attitude of the subject.

Negative ratings were given to subjects who found that it was too

conspicuous; that the adhesive caused skin irritation; that retention was a problem; that putting the glue and prosthesis on and taking them off each day and cleaning were far too time-consuming for the patient to bother using them; that the subject could not use the adhesive without getting it in her hair; that the expression of the prosthetic eye was unsuitable, and that the subject did not want a facial prosthesis from the beginning, but had been forced to have it because his family and the surgeon wanted it.

(1) Whether a patch or dressing was preferred to a prosthesis

The preferences of 27 subjects were for a prosthesis, of 3 subjects for a patch, of 2 subjects for a dressing, of 3 subjects for no cover and of 6 subjects were unclear.

(■) Coping with the prosthesis

(* NOTE - In this column a global rating of the subjects' coping with the prosthesis was made by the author. Difficulty was experienced in establishing a satisfactory basis for making these ratings.)

There were 32 positive, 4 negative and 5 neutral ratings.

Positive ratings were given for subjects who were able to accept and use their prostheses, even in the presence of some problems.

Neutral ratings were given for those who did not use their prostheses for long enough for an assessment of their coping to be made.

Negative ratings were made for subjects who experienced a negative reaction from their spouse and/or the public, or who found the prosthesis unacceptable for some reason such as its appearance,

discomfort or difficulty using adhesive.

3.2.6 COUNSELLING (TABLE 9.6, APPENDIX 9)

(a) Counselling offered at what stage and by whom

Thirteen subjects were offered counselling. This occurred before operation and was made by the surgeon, and by another patient who had previously been through a similar operation and rehabilitation. It occurred after operation in hospital and was made by a social worker (for 4 subjects), psychologist, psychiatrist, surgeon, doctors and a minister. After return home, it was offered by a surgeon (at a recall appointment), in a hospice for the terminally ill by a counsellor, by cancer care counsellors at the hospital, by a "healing" service at church, and by a counsellor at a local hospital.

For 5 subjects it was not offered and for 23 it was unclear.

(b) Whether the subject wanted counselling

There were 8 positive, 25 negative and 8 unclear ratings.

A positive score was given if the subject felt he or she needed counselling. Reasons included that "it would be hard if you didn't have someone to lean on", that it would have been good to speak to another person who had previously been through the same experience (2 subjects).

A negative score was given if the subject felt he or she did not want counselling, because there was enough support from the family (2 subjects), because he/she was able to solve his/her own problems, because it would not have made any difference, because one should be

able to cope by oneself and for one subject because she wanted to "fight it" herself.

(c) Value of counselling received

There were 9 positive, 1 equivocal and 31 unclear ratings.

A positive rating was given for subjects who found the counselling "excellent", very good or helpful in assisting them with coping after the operation.

The one negative response by the subject was rated equivocal, was due to a minister who visited him in hospital to give counselling but whom the subject found to be inexperienced, "useless" and "a wreck".

(d) Subject suggestions

These included

- * Counselling about how to clean and dress the facial defect would have helped.

- * It would have been useful to talk to another person who had been through the same experience (5 subjects), and one subject specified that this was providing it was the right kind of person. Two subjects said they would like to help others in this way.

- * People facing disfiguring surgery should be warned that it may need to be more extensive than they expect.

- * Two subjects said that the years they had spent in the army in World War II had helped them learn to cope with adversity.

- * Counselling is needed to help the person receiving a facial prosthesis to cope with the negative reactions they will encounter from others.

3.2.7 CURRENT CONCERNS, SOCIAL ACTIVITY, LIFE SATISFACTION

(TABLE 9.7, APPENDIX 9)

(a) Current concerns and subject coping overall

(* NOTE - This column comprised global ratings of the subjects' level of coping with their current daily life by the author and a psychologist).

There were 36 positive, 4 negative ratings and 1 neutral rating.

Positive ratings were given for subjects who had returned to a similar pattern of daily life to that which existed prior to the illness, in which there seemed to be a level of self esteem, family and social contact, including outings and interests, consistent with maintaining an enjoyable life. Together with this, subjects receiving positive ratings seemed to have no predominant anxiety, depression or social isolation associated with the disfigurement or prosthesis.

The reason for the neutral rating of one subject was her greater tendency towards impatience with the family over minor annoyances than would have occurred before the illness.

Negative ratings were given where social activity, outings and capacity to enjoy life were limited due to the need to use a dressing or prosthesis over the disfigured area, and for one subject because of difficulty accepting an arm and shoulder disability caused by the disfiguring operation.

(b) Coping with inquisitive children

There were 26 positive, 3 negative, 2 neutral and 10 unclear ratings.

Positive ratings were given for subjects who accepted the child's curiosity, often with amusement, and gave an explanation.

The 2 neutral scores were given for subjects who had found incidents with children unpleasant previously but had since learned not to be worried by them.

Negative scores were indicated where the subject avoided children, and experienced embarrassment, anxiety or emotional upset. Several subjects described incidents of tactless or openly offensive behaviour by older children and adolescents.

(c) Social activity

There were 34 positive, 4 negative, 2 neutral ratings and 1 unclear ratings.

Positive ratings were recorded where social activity had returned to a similar level as prior to illness, assuming that this was at a normal level.

Neutral scores were given where social activity is reduced but due to factors other than disfigurement or the prosthesis eg residual physical disability.

Negative ratings were recorded where social activity was markedly reduced due to the presence of disfigurement and or the prosthesis.

(d) Daily life now compared with before illness

There were 24 positive, 12 negative, 2 irrelevant and 3 unclear ratings. Positive scores were given for subjects whose current daily life was the same or similar to the pre-illness level.

Negative scores were given for subjects whose daily life was markedly different from the pre-illness level due to either limited social

activity (due to the disfigurement or prosthesis), or to a lower level of activity generally due to physical incapacity, or difficulty controlling outflow of nasal secretions.

3.2.8 SURGICAL RECONSTRUCTION (TABLE 9.8, APPENDIX 9)

For 36 subjects this category was irrelevant.

(a) Subject rating of surgical result

There were 5 positive ratings.

(b) Support group rating of result

There was 1 positive rating and 4 unclear ratings.

(c) Feeling in public compared with when using the prosthesis

There were 5 positive ratings which indicated that the subject felt no adverse effects, felt normal, or felt better or more relaxed after surgical reconstruction than with the prosthesis.

(d) Social activity compared with when using prosthesis

There were 2 positive ratings, 2 neutral ratings and 1 unclear rating.

The positive ratings indicated that social activity after surgical reconstruction was better than it had been with the prosthesis.

The neutral ratings indicated that social activity after surgical reconstruction was no different from how it had been with the prosthesis.

3.3 16 Personality Factor Questionnaire Results

For each subject the 16PF Answer sheet (Appendix 5) was scored and the raw scores age-corrected. The raw scores were converted to sten² scores using "Norms for General Population. Male + Female: Form C" based on the U.S.A. population (IPAT Staff, 1972). The sten scores were then plotted on the 16PF Test Profile sheet. Copies of the subjects' Test Profiles are in Appendix 10.

3.3.1 HYPOTHESIS AND DATA PREPARATION

The psychologist hypothesised that a given subject's scores for the 16PF factors C, O, Q₃ and Q₄ would be significantly associated with the subject's capacity to cope emotionally with the diagnosis, operation and rehabilitation with prosthesis (Walker, 1993). In order to assess whether such an association existed two sets of data were prepared, one from the subjects' scores for the four 16PF factors mentioned above and one from ratings of subjects' coping at different stages of their experience from the interview material. These were then analysed statistically as described below. It should be noted that the validity of the results of this analysis is flawed because a minority (unknown percentage) of the coping ratings were derived with reference not only to the interview responses, but to the 16PF scores as well.

² An explanation of this term appears in footnote 1, pages 104 and 105.

Scores for the four 16PF factors mentioned above for the 34 subjects who completed the 16PF Test are tabulated in Appendix 11. The sten score of each of these subjects for each test factor was categorised as low, average or high according to the scheme shown in Appendix 11.

Subjects 4, 9, 11, 22, 29, 32 and 33 did not complete the 16PF Test.

Coping ratings for each subject for five interview categories are tabulated in Appendix 12. These interview categories, tabulated in Appendix 9, are the diagnosis and preoperative period (Table 9.1), after operation (Table 9.2), return home (Table 9.3), prosthesis (Table 9.5) and current concerns, social activity and life satisfaction (Table 9.7). For subjects 6 and 24 insufficient data was available and these were excluded from the data before it was submitted for statistical analysis.

For subject 13 a coping score for the after operation period was unavailable and was estimated in the following way, which was recommended by a statistician (Fisher, 1993). Fourteen other subjects with an identical pattern of coping scores for the other 4 interview categories were found. Of these, 13 scored "+" and 1 scored "-" in the after operation period. Accordingly the missing score for subject 13 was estimated as "+".

Using the same technique a coping score for subject 15 for the return home period was estimated as "+". Of other subjects with an identical pattern of coping scores in other aspects, 13 scored "+" for the return

home period.

This method could not be used to estimate a value for the coping score for the after operation period for subject 27 because no other subjects with an identical pattern of coping scores in other aspects could be found. Therefore the data from this subject was excluded from statistical analysis.

Data for 31 subjects was submitted for statistical analysis, having excluded data from subjects 4, 6, 9, 11, 22, 24, 27, 29, 32 and 33.

3.3.2 METHOD OF STATISTICAL ANALYSIS

Statistical analysis was carried out by a statistician using correspondence analysis (Greenacre, 1984). The multidimensional relationships between the coping period score data and the personality factor score data of the subjects were projected into 2 dimensional space and represented graphically (Appendix 13). Graphs of the following are presented.

1. Association between coping during the preoperation period and the test factors (Graph 13.1);
2. Association between coping during the after operation period and the test factors (Graph 13.2);
3. Association between coping during the return home period and the test factors (Graph 13.3);

4. Association between coping with the prosthesis and the test factors (Graph 13.4);
5. Association between coping during the present period and the test factors (Graph 13.5);
6. Association between emotional stability factor and coping periods (Graph 13.6);
7. Association between confidence and serenity factor and coping periods (Graph 13.7);
8. Association between socially precise factor and coping periods (Graph 13.8);
9. Association between relaxed, unfrustrated factor and coping periods (Graph 13.9).

Analysis of these graphs was carried out with the guidance of the statistician and the psychologist (see "Notes on the interpretation of graphs" in Appendix 13).

3.3.3 RESULTS OF STATISTICAL ANALYSIS

The following coping period scores and personality test factor scores were found to be significantly associated ($p < 0.05$):

1. Low coping score during preoperation period and low score for socially precise test factor (Graphs 13.1 and 13.8).
2. Low coping score during preoperation period and low score for emotional stability test factor (Graphs 13.1 and 13.6).
3. Average coping score during preoperation period and average score for relaxed/unfrustrated test factor (Graphs 13.1 and 13.9).

4. Low coping score during after operation period and low score for socially precise test factor (Graphs 13.2 and 13.8).
5. Average coping score during after operation period and average score for relaxed/unfrustrated test factor (Graphs 13.2 and 13.9).
6. Low coping score during return home period and low score for emotional stability factor (Graphs 13.3 and 13.6).
7. Low coping score for present period and low score for emotional stability factor (Graphs 13.5 and 13.6).

3.4 Prosthesis Evaluation

Factors affecting the value of the prosthesis are analysed using the collective data from

- (1) the interview responses and responses to the quantitative questionnaire about the prosthesis. This data was combined and described above in section 3.2.5;
- (2) the prosthesis data form for subjects for whom this could be completed.

Tables were compiled from the above sources of data and are described below.

3.4.1 PROSTHESIS MATERIAL AND LOCATION (APPENDIX 14)

There was a total of 44 prostheses comprising 19 prostheses of the nose, 14 of the ear and 11 of the eye. Of these 1 nose prosthesis and 4 eye prostheses involved the organ specified and an adjacent area of the face. Twenty were made of acrylic resin, 22 of silicone rubber and 2 of a combination of these materials. Approximately half of the nose prostheses were of acrylic resin (10) and half (9) of silicone rubber. Almost all (13) ear prostheses were of silicone rubber and 1 was made of acrylic resin. Nine eye prostheses were made of acrylic resin and 2 were a combination of acrylic resin and silicone rubber.

3.4.2 DAILY USAGE OF THE PROSTHESIS (APPENDIX 15)

Tables 15.1, 15.2 and 15.3 present the pattern of daily usage of the nose, ear and eye prostheses respectively. This includes the time at which each prosthesis was used and whether there was any difficulty in protecting it from damage when it was not in use.

Overall, of 44 prostheses, 27 (61%) were in use and 17 (39%) were in use rarely or not at all. Of the 27 prostheses in use 9 (33%) were used continuously for periods of from 2 to 21 days, 9 (33%) were used for the waking hours each day, and 8 (30%) were used at certain times of the day, in the presence of other people, in some cases excluding close family. Of the 9 prostheses used in excess of 1 day without removal, 1 (11%) was a silicone rubber nose prosthesis, 7 (78%) were silicone

rubber ear prostheses and 1 (11%) was an acrylic resin orbital prosthesis. For 1 (9%) prosthesis the period of use was unclear. Four (31%) of a total of 13 subjects who had acrylic resin prostheses fixed to glasses found storage of the prosthesis difficult because of its fragility.

In a total of 19 nose prostheses (Table 15.1), 14 (74%) were partial prostheses and 5 (26%) were complete. Thirteen (68%) prostheses were in use and 6 (32%) were not in use. Of the 13 prostheses in use, 1 (8%) prosthesis was used continuously for 2 days or more, 5 (39%) were used during the waking hours each day and removed at night, 6 (46%) were used at specific times, during certain activities or in the presence of particular people. For 1 (8%) prosthesis the usage was not clear.

Of the 14 ear prostheses (Table 15.2), there were 3 (21%) partial and 11 (79%) complete prostheses. Nine (64%) were in use and 5 (36%) were rarely or not in use at the time of interview. Of the 9 prostheses in use, 7 (78%) were used for periods of 2 to 21 days continuously, 1 (11%) was removed each night, being rigid acrylic, and for 1 prosthesis the response was unclear.

Of a total 11 orbital prostheses (Table 15.3), 7 (64%) were in use and 4 (36%) were not in use. Of the 7 prostheses in use 1 (14%) was used for up to 3 days at a time, 3 (42%) were used most of the day and removed at night, and 3 (42%) were used at certain times of the day or in the presence of visitors.

3.4.3 PROSTHESIS RETENTION (APPENDIX 16)

Table 16.1 displays the number of prostheses for which the different types of retention were used in different locations. Tables 16.2, 16.3 and 16.4 show the effectiveness of retention for each prosthesis (identified by subject number), for nose, ear and eye prostheses respectively.

Attachment to glasses (Table 16.1) was used for 13 (30%) of the total 44 prostheses in the study. These included 6 nose prostheses (that is 32% of the total 19 nose prostheses), and 7 eye prostheses (64% of the total 11 eye prostheses). Skin adhesive was used for 25 (57%) of the total 44 prostheses. These included 9 nose prostheses (47% of the total 19 nose prostheses), 14 (100%) of the ear prostheses and 2 eye prostheses (18% of the total 11 eye prostheses). Tissue undercuts were used to retain 3 (16%) of the nose prostheses. This represented 7% of the total 44 prostheses. For 3 other prostheses a combination of methods were used. One nose and one eye prosthesis had attachment to, or contact with glasses as well as skin adhesive for retention. One eye prosthesis used tissue undercuts and adhesive.

Table 16.2 shows that for the nose prostheses retention problems occurred with 10 (53%) of the total 19 prostheses. These comprised 3 (50%) of the 6 fixed to glasses, 5 (56%) of the 9 used with adhesive, 1 (33%) of the 3 using tissue undercuts and the one using a combination of attachment to glasses and adhesive.

For ear prostheses (Table 16.3) retention problems were experienced with 2 (14%) of the 14 prostheses. For 1 (7%) prosthesis the effectiveness of retention was unclear. All were retained with adhesive.

In Table 16.4, there was a retention problem with 1 (9%) of the total 11 eye prostheses. This prosthesis was retained with adhesive.

3.4.4 PROSTHESES USED WITH ADHESIVE FOR RETENTION (APPENDIX 17)

The tables in this appendix show the subjective responses to positioning the prosthesis, removing the prosthesis and removing the adhesive for the 28 prostheses used with skin adhesives (including those using a combination of forms of retention). Individual prostheses are specified by number, and the brand of adhesive and prosthetic material are also shown. Tables 17.1, 17.2 and 17.3 present the results for nose, eye and ear prostheses respectively.

Of a total 28 prostheses used with adhesive (including the 3 prostheses using combined forms of retention), 16 (57%) were positioned by the subject and 12 (43%) by another person. Those positioned by the subject included 10 nose prostheses, 3 eye prostheses and 3 ear prostheses. For 7 (44%) of these prostheses (2 ear and 5 nose prostheses) some degree of problem was experienced in positioning the prosthesis, and for 2 others (a nose and an ear prosthesis) it is unclear whether there was a problem. Twelve prostheses were positioned by another person and with six (50%) of these (1 eye and 5 ear prostheses) some sort of problem was

experienced. For one prosthesis it was unclear whether there was a problem.

Of the total 28 prostheses, there was difficulty experienced in removal of the prosthesis in 5 (18%) cases, which included 2 nose, 1 eye and 2 ear prostheses. It is not clear whether there was a problem in 6 (21%) cases.

For 12 (43%) of the total of 28 prostheses there was some degree of problem with adhesive removal, either from the prosthesis or the skin. These consisted of 6 nose, 1 eye and 5 ear prostheses. There was 1 prosthesis for which this was unclear.

3.4.5 PERFORMANCE OF DIFFERENT ADHESIVES (APPENDICES 16 AND 17)

Skin-Bond Cement³ was used with 15 prostheses, including 1 nose, 3 eye and 11 ear prostheses. Retention was satisfactory for 13 (87%) of these, but some degree of problem with retention occurred with 2 (14%) prostheses (1 nose and 1 ear prosthesis). Removal of the prosthesis was no problem with 9 (60%) prostheses, but was a problem with 2 (13%) prostheses (1 eye and 1 ear prosthesis), and for 4 (27%) prostheses it is unknown whether there was a problem. Removal of the Skin-Bond adhesive was no problem for 10 (67%) cases, but was a problem for 4 (27%) cases (3 ear and 1 eye prosthesis), and was unclear in 1 case.

³ Skin-Bond Cement, Smith and Nephew United, Inc. Largo, Florida, USA.

Uro-Bond 5000 Medical Adhesive⁴ was used with 7 prostheses and there was no problem in 4 (57%) of these. Some degree of problem occurred in 3 cases (42%, 2 nose and 1 ear prosthesis). Six (86%) prostheses were removed without problem, and for 1 prosthesis it is unclear whether there was a problem or not. Adhesive removal was no problem for 3 (43%) cases but some degree of problem in 4 (57%) cases.

Medical Adhesive B⁵ was used with 4 prostheses. For 2 prostheses (50%) there were no retention problems, but there was a problem with the retention of 1 prosthesis, and for 1 prosthesis the result is unclear. Removal of the prosthesis was a problem for 2 (50%) prostheses, and removal of the adhesive was also a problem in 2 cases using this adhesive.

For 2 (7%) prostheses the type of adhesive used was unclear.

3.4.6 PROSTHESES THAT WERE NOT IN USE (APPENDIX 18)

This table lists 17 prostheses not being used at the time of interview and the problems or reasons that were associated with each prosthesis. The most common problems involved adhesives (10 subjects), discomfort or tissue injury (9 subjects), tissue shape changes (8 subjects) and poor retention (8 subjects). Others included cleaning problems (6 subjects),

⁴ Uro-Bond 5000 Medical Adhesive, Urocare Products, Inc. So. El Monte, California, USA.

⁵ Medical Adhesive B, Dow Corning Corporation, Midland, Michigan, USA.

bad public reaction (5 subjects), tissue changes due to surgery (4 subjects), bad family reaction (3 subjects), material deterioration (2 subjects), that the prosthesis was not needed or wanted (2 subjects) and that there was difficulty storing the prosthesis when it was not in use (1 subject).

CHAPTER 4

DISCUSSION AND CONCLUSIONS

4.1 Limitations in the Interpretation of Results

The evaluation of the results of this study should not exceed the limitations imposed by the nature of the data, the mode of data collection and the data analyses that were carried out.

The interview data are subjective and retrospective and hence are subject to omissions and possible distortions that may occur when recalling past events. The interviews were conducted, transcribed, summarised and evaluated by the author who is untrained in psychology. Hence significant information to do with the subjects' emotional coping may have been missed. Similarly, assessments of the subjects' emotional coping skills may be subject to error.

In spite of these limitations, general conclusions about the trend of responses of the subjects can be made and the qualitative details of their experiences are of considerable value.

4.2 Evaluation of the Results

The social and emotional coping of subjects with their cancer treatment and prostheses was affected by different aspects of these experiences for different subjects. In several instances the effect was marked and its duration fairly clear. However for many of these disturbances either the degree and/or the duration of the impact is not clear. Overall, 29% (12 of a total of 41) indicated no apparent psychosocial coping problems (this does not include problems using the prosthesis). Sixty-eight percent reported psychosocial problems and for one subject (subject 6) this was not clear.

4.2.1 DIAGNOSIS AND PREOPERATIVE PERIOD

Subjects described a range of emotional responses during this phase of the treatment which corresponded to reports by a number of authors (Turns and Sands, 1978; Addison, 1975; Frank, 1975; Strauss, 1988 and 1989; Ross, 1979). These included manifestations of anxiety, often acute (subjects 1, 2, 9, 12, 15, 17, 25, 31, 33, 39, 40 and 41), denial (subject 4), disbelief (subjects 8 and 27), numbed emotions, depression (subject 12) and grief as the possible implications of the disease were realised. These reactions are normal.

Some (subjects 3, 16, 18, 20, 21, 22, 30, 36) coped remarkably well and seemed to minimise the emotional disruption during this phase by rapidly accepting the diagnosis and its possible implications and having faith

in their doctors' competence and treatment.

Two aspects in which some significant problems affecting emotional coping did occur were misdiagnosis, and the advice given preoperatively to subjects about the expected degree of disfigurement after the operation. Several subjects (subjects 1, 10 and 38) had post-operative outcomes which differed from what they had been expecting, as discussed in the next section (After Operation in Hospital). A number of subjects were resentful about misdiagnosis and inappropriate treatment (subjects 7, 8, 10, 19, 23, 31, 35, 37 and 40), which preceded the correct diagnosis of cancer and treatment, usually by another specialist. The period of delay was resented because it allowed tumour growth, hence requiring more radical treatment and in one case (subject 19) reduced the chance of preventing the condition from becoming terminal. Two other reasons for treatment being delayed were that the pathology report on a biopsy was very slow in being returned to the doctor (subject 27), and that a hospital bed was unavailable (subjects 5 and 13) resulting in a larger resection of tissue than had originally been described by the surgeon as being necessary.

Most subjects were sensitive to the doctors' manner and disliked having their concerns disregarded or treated with contempt (eg subject 31). Patients should feel respected as individuals when in hospital, and not merely be treated as "an adjunct to their medical condition" (Addison, 1975). The presentation of the diagnosis of cancer was described as being blunt by 2 subjects (subjects 1 and 14). Subject 8 resented being

told about her cancer loudly and in the hearing of other patients. As described by Addison (1975) and Collyer (1984) doctors who treated their patients with respect, "as a person" (subject 25) or who "took a personal interest" (subject 13) were appreciated and long remembered.

4.2.2 AFTER OPERATION IN HOSPITAL

Most subjects coped successfully with their time in hospital with the support of family, friends, doctors and/or nursing staff. The most significant social and emotional problems seemed to be due to the disfigurement, how it was presented to the patient and the anxiety that subjects experienced before seeing it, and also to when there was a discrepancy between the expected and the actual outcome of surgery which the subject felt should have been advised beforehand.

Some surgeons took care to advise the subject before removing the dressing of the degree of disfigurement to expect (subjects 3, 9, 16, 25 and 38) and to provide emotional support to help the person cope with the anxiety and depression associated with seeing the disfigurement. In some cases this was done by a member of the nursing staff (subjects 10, 28 and 31) and in some other cases it seems to have been neglected. Addison (1975) described how patients at this difficult time of coping with grief should be monitored by a counsellor or psychologist to help them if needed.

One of the most striking cases of psychosocial coping problems in this

study was subject 34 who entered hospital for cosmetic surgery to correct a slightly misshapen nose resulting from previous cancer treatment. At operation tumour was found subcutaneously and instead of cosmetic reconstruction, the operation became a radical surgical resection. Postoperatively this was not explained clearly enough to the subject, and she agreed to allow a group of medical students to be present when the dressing was to be removed. The combined emotional impact of the unexpected, gross disfigurement and the presence of strangers caused her to become very depressed for some time, until a prosthesis had been made. Her mood then improved and she returned home and to normal daily life, taking up voluntary work in the hospital cafe. However she avoided returning for a new prosthesis even after the existing one had faded to a white colour, due to the unpleasant memories associated with the time when the first prosthesis was made.

Another subject (subject 1) was concerned to discover after an operation that she had a facial defect which would remain for at least 12 months and which required daily cleaning and dressing and the use of a facial prosthesis. These were the cause of considerable distress, physical discomfort and social embarrassment. She had not been warned of this possibility prior to surgery.

Subject 10 understood that a small amount of tissue was to be removed from the nose in a series of procedures over 4 days under local anaesthetic. However, when this subject discovered that the lower half of the nose had been removed he was very angry that the possibility of

such an extensive resection had not been made clear before the operations. A third subject (subject 38) was correctly informed by the surgeon that there would be a defect at the operation site on the nose. However, a well-meaning relative insisted that the subject had misunderstood and that there would be no defect left after the operation. This made emotional coping for the subject more difficult when the defect was seen.

Other subjects who had difficulties were a former photographic model (subject 8) and a former opera singer (subject 9) whose adjustment may have been made more difficult by their reliance on physical attractiveness for maintaining self esteem (Addison, 1975; Kolb, 1974; Bailey and Edwards, 1975).

A number of subjects coped remarkably well at this time, communicating little if any concern about their disfigurement.

Most subjects had support from family and friends, doctors and/or hospital staff. Also most subjects appreciated their treatment by the nursing staff, although there were some complaints of inefficiency (subjects 13 and 25), insensitivity (subject 41) and disturbed sleep due to beeping monitors and persistent nursing attention (subject 15).

Extraordinarily, 2 subjects (subjects 10 and 28) reported derogatory remarks made by nursing sisters about the appearance of their disfigurements at the moment when the subject was about to see it for

the first time. Subject 37 was upset when he realised that patients in the ward had made remarks about his disfigurement between themselves.

4.2.3. RETURN TO HOME, COMMUNITY AND JOB

For 19 subjects (49% of a total of 39) the surgery and disfigurement caused little or no impediment to their return to normal daily life. They used either a dressing, facial prosthesis or no covering over the disfigurement. Five subjects (subjects 16, 17, 25, 33 and 38) reported minor degrees of social, emotional or physical problems in adapting. Significant disruption of the return to a normal daily life due to psychosocial disturbances was caused by having cancer (subject 14), the appearance of or home care procedures for the disfigured area (subjects 1, 5, 8, 9, 34 and 37), terminal disease (subjects 19 and 32), physical disabilities resulting from the treatment (subjects 12, 27, 31 and 40) and/or enforced retirement from work (subjects 7, 12, 15 and 19).

Although most support group members were able to accept the disfigurement after the initial shock, this was not so for some of them (subjects 25, 32, 34, 39 and 41). Five subjects mentioned that coping would have been difficult without the emotional support they received (subjects 8, 16, 34, 39, 41).

The importance of the social support group is particularly evident in 2 cases (subjects 37 and 38). Subject 37 lost a major part of his social support after he became disfigured, as his wife then left him. He

attributed his marriage breakdown, subsequent loneliness, depression and suicidal tendencies to his wife's inability to live with the disfigurement. Subject 38 avoided returning home for several weeks after his operation due to fear of rejection by an important part of his support group - his small grandchildren. When they welcomed him back he "started to live again".

4.2.4. RADIOTHERAPY

There was a large number of unclear responses in this category and the data on chemotherapy were insufficient to provide useful conclusions. Predictably 13 of the 23 subjects had moderately to extremely unpleasant short- or long-term side effects following radiotherapy, although only 2 subjects (subjects 39 and 40) found these emotionally disturbing. Four subjects in this group did not clearly indicate whether they had experienced emotional disturbances.

Subject 15 was concerned to discover (years later) that he had not been fully informed about the consequences of radiotherapy causing susceptibility of the jaw to osteoradionecrosis, before he was asked to decide whether he wanted surgery or radiotherapy treatment for his tumour. Subject 40 reported finding the manner of the staff, the facilities, the treatment and the side effects all highly unpleasant or unsatisfactory. Subject 39 found the effects of radiotherapy in causing slowed thought processes, and the lack of energy and motivation, very distressing. The subject described being "more or less a vegetable for 6

months" and says her husband's support was essential at this time.

4.2.5 FACIAL PROSTHESES

The prosthetic treatment procedures were acceptable to most subjects although subjects 1 and 28 found the facial impression procedure unpleasant or frightening. One subject reported that alginate impression material had flowed into his nasal cavity and had not been retrieved. His doctor was able to dislodge a large piece of alginate material into the pharynx from which it was coughed up. About 4 months later another large piece appeared in the pharynx and was coughed up. The subject was "in no way critical" but this highlights the problem of protecting the nasal cavity when taking an impression of a nasal defect.

Retention, putting the prosthesis on, cleaning and discomfort were the aspects with the highest incidence of reported problems (Appendix 9).

Retention (Appendix 16) was a problem in 30% of prostheses (13 of a total 44). More than half of the nose prostheses (10) were affected, including 5 used with adhesive, 3 fixed to glasses and 1 using soft tissue undercuts. These problems were due to poor adhesion of prostheses used with skin adhesive and the tendency of a prosthesis mounted on glasses to slip forwards if a relatively horizontal area of supporting tissue, such as the nasal bridge, is not present to resist it. The alar prosthesis engaging soft tissue undercuts was not retentive due to the mobility of the tip of the nose. In the author's experience nasal

defects are usually not well suited to the use of adhesives due to the very limited area of skin for adhesion and the delicate and easily-damaged defect skin. Two silicone rubber ear prostheses were not retentive, due to ineffective adhesive (Urobond 5000) and tissue shape changes in the defect area. For the one nonretentive eye prosthesis the problem was due to loss of adhesion in the presence of sweat.

Application of the prosthesis (Appendix 17) was a problem or received an equivocal response (which implies a degree of negativity) in 33% of cases (14 of a total 42). This problem occurred with 1 spectacle-mounted prosthesis and otherwise was only associated with the use of adhesives. Prosthesis positioning when using adhesive was particularly difficult with ear prostheses, and for those with poor eyesight or manual skills.

Cleaning (Appendix 17) was a problem or was rated equivocal for 29% of prostheses (12 of a total 42). Most of these involved adhesive, which many subjects found difficult to clean from their prostheses or skin without causing damage, or to remove from their hair. Figures for silicone rubber (43%) and acrylic resin (43%) suggest the same rate of problems with adhesive removal from both materials.

Comfort (Appendix 9) received negative or equivocal ratings for 25% of prostheses. These were nose and ear prostheses used with adhesive, nose prostheses fixed to glasses which would slip, and a silicone rubber alar prosthesis that blocked the nostril.

Other characteristics of the prostheses which caused lower rates of problems than the above were colour, shape, removal of the prosthesis, the reaction of family and friends and how well the prosthesis escaped notice in public.

Due to ambiguity the question about prosthesis shape was interpreted by some to include the whole external surface of the prosthesis including the fitting surface, and by others to include only the surface visible when the prosthesis was positioned on the face. Neutral and negative responses totalled 14%.

Negative and neutral responses about the colour totalled 19%.

Discrepancies in matching skin colour may have been due to a mismatch during prosthesis construction, or a change in the colour of pigments due to exposure to the ultraviolet light in sunlight. Facial prostheses need recolouring or replacement every 6 months to 2 years for this reason.

Difficulty with removal (Appendix 17) of 5 prostheses was due to trauma to the underlying skin by the pull of the adhesive, adjacent hair being caught in adhesive, and difficulty raising the fine edge of an acrylic eye prosthesis.

The reactions of family and friends (Appendix 9) were negative or neutral for 7 prostheses, and 5 of these were not in use. The 2 prostheses that were in use could not easily be substituted with a

dressings because this would have been large and obtrusive, so the subjects were forced to use the prostheses they had. These figures suggest that the support group reaction influenced the subject's attitude to the prosthesis.

Escaping notice in public (Appendix 9) was negative or neutral in 18% of cases (7 of a total 40). One subject became socially isolated after being stared at the first time she went out with her prosthesis in place. It seems that although most prostheses escaped notice to some degree, most subjects had to accept that at times their prostheses would be noticed. The fact that the general public know little about facial prostheses (Addison, 1975) and are not expecting to see one would help to reduce the likelihood of the prosthesis being noticed by strangers.

Approximately 61% of the prostheses (27 of a total 44) in the study were in use (Appendix 15). Those used for the longest periods of time between application and removal were complete silicone ear prostheses. These prostheses usually had a large flat surface for adhesion and could remain in position for many days without apparent trauma to the underlying tissues. Being flexible they could be left in place overnight without interfering with head position on the pillow (as with a rigid prosthesis). Most other prostheses had to be removed before the subject lay down to sleep or for cleaning, particularly those used for defects of the nasal or oral cavity.

Of the total 27 prostheses in use, 9 (31%) were used only when necessary

ie when going out or in the presence of others. Of the 17 prostheses which were not in use, 8 (47%) had previously been accepted and used, but were no longer in use for such reasons as surgical reconstruction of the defect, ageing and deterioration of the prosthetic material, tissue contour changes in the defect area, and defective skin adhesive. The other 9 prostheses were unacceptable to the subjects and were little used from the time they were received. Overall the most common reason for not using the prostheses (Appendix 18) was tissue shape changes due to healing processes or reconstructive surgery. The next most frequently occurring problems were difficulties using skin adhesive or cleaning it from the prosthesis or the skin. Less common reasons for not using the prostheses included that the subject either did not want the prosthesis from the beginning (the surgeon and subject's family wanted it) or found that it wasn't needed, that the prosthetic material had deteriorated or that there were aesthetic problems.

Of the subjects who gave clear responses (41), 71% (29) felt that the prosthesis had been beneficial. Twenty-nine percent indicated equivocal or negative responses about its value. Seventy-seven percent of subjects preferred a prosthesis, 9% preferred a patch, 5% preferred a dressing and 9% preferred no cover. A total of 35 subjects responded.

4.2.6 COUNSELLING

Although it is not clear how many subjects were offered counselling, only about 23% (8) of those who responded (total 35) actually wanted it,

the others preferring to cope on their own. Seventy-seven percent (10 of a total of 13) of those who said they had counselling found it helpful, except 1 subject who had an inexperienced and nervous counsellor.

Several subjects agreed that the opportunity to speak to another person who had been through the same experience would have been helpful, and 2 offered to do this for others. Two of those who coped well felt that their war experiences had helped them in coping. It was also suggested that counselling about coping with the reactions of others to the facial prostheses would be helpful.

4.2.7 CURRENT CONCERNS, SOCIAL ACTIVITY AND LIFE SATISFACTION

Most subjects seemed to be leading relatively normal daily lives with normal levels of social activity and social support.

Incidents with children noticing and commenting on the prosthesis in public were a problem to several subjects (subjects 13, 15, 32, 34, 35 and 37) but did not seem to correlate with difficulty coping emotionally with the cancer and disfigurement, except for one subject (subject 37). There were 2 subjects (subjects 8 and 37) for whom the disfigurement and prosthesis caused significant problems of social isolation.

Of the subjects who felt that their current daily life was similar to their pre-illness life, 2 subjects (subjects 20, nasal defect, and 21, auricular defect) did not bother to use a cover of any kind and 1

subject (subject 10, nasal defect), used only a small dressing or no cover. For subject 21, the defect area was effectively covered by bushy hair. Subjects 10 and 20 seemed to have robust enough self esteem to be unaffected by the disfigurement. Another in this category (subject 22) had had surgical reconstruction. Eighteen subjects who felt their daily life was back to normal used the prosthesis regularly. Four subjects whose quality of daily life was not as good as prior to illness indicated post-treatment physical disability as the main reason, whereas 3 felt it was due to the disfigurement and/or the prosthesis.

4.2.8 SURGICAL RECONSTRUCTION

All subjects who had surgical reconstruction seemed to return to a similar quality of daily life as before disfigurement except one subject for whom the reconstruction was incomplete.

4.3 16PF Data Statistical Analysis

Statistical analysis of the association between the subjects' scores for 16PF factors C, O, Q₃ and Q₄ and coping ratings derived for different periods of their diagnosis and treatment experience was carried out. Significant associations were found between low, medium and high sten scores¹ for factors C, O and Q₃, and low, medium and high interviewer

¹ Raw scores for 16 personality factors are obtained from the subject's completed 16PF answer sheet. "... before these raw scores can be evaluated and interpreted, they must be converted into a system which places the examinee's

ratings respectively for emotional coping at the preoperative period. There were significant associations between low scores for C and low coping rating at the return home and the present periods; between low scores for factor Q_3 and low coping ratings for the after operation period; and between average scores for factor Q_4 and average coping ratings at the pre-operation and after operation periods. This suggests that subjects with low ego strength (low sten score for factor C), guilt proneness (high sten score for factor O) and undisciplined self conflict (low sten score for factor Q_3), tended to cope badly during the pre-operation period of their illness. Those with low ego strength also coped badly on their return home and through to the present.

Conversely those with high ego strength (high sten score for factor C), self assurance (low sten score for factor O), and high self-concept control (high sten score for factor Q_3) tended to cope well during the preoperative phase.

score in relation to scores obtained by other people in some defined population (normal adults, college students, adult males only, etc). The standardisation tables convert raw scores to ..." *sten* ("standard ten") scores. The sten scores "...are distributed over 10 equal-interval standard score points (*assuming normal distribution*) from 1 through 10, with the population average (or mean) fixed at 5.5. Stens 5 and 6 extend, respectively, a half standard deviation below and above the mean, constituting the solid centre of the population, while the outer limits for stens 1 and 10 are $2\frac{1}{2}$ standard deviations below and above the mean. One would normally consider sten scores of 4 though 7 to be *average*, since they fall within one standard deviation of the population mean and therefore represent approximately two-thirds of all the obtained scores. Sten scores of 1, 2, 3 and 8, 9 and 10 are generally considered to be of greater importance for profile interpretation since they are more extreme and occur far less frequently in a normal population." (IPAT Staff, 1979, p.17).

The association between factor C (low ego strength - high ego strength) and coping ability was expected and "makes good psychological sense" (Walker, 1994). Hence this result may have been significantly contaminated when the 16PF results were consulted to help derive the coping ratings for some subjects. Another study with completely independent data sets would be needed to test this association again.

The direct relationship between the high factor Q_3 sten score and the high coping rating at the pre-operation period and for the low Q_3 score and poor coping at the after operation period were unexpected and therefore are less likely to have been affected by the contamination that occurred between the two data sets referred to above.

The association between average scores for factor Q_4 and average coping at the pre- and after operation periods may indicate that an association between this factor and high or low scores for coping may only be revealed by a study involving a larger number of subjects.

No significant association was found between any of the four 16PF factors and coping with the prosthesis.

Scores for factors C, O and Q_3 could be used to help identify people in greater need of counselling before, during and after their cancer treatment, but not to help predict coping with a facial prosthesis. These relationships would need to be defined more precisely with a study in which the data sets were larger and completely independent.

4.4 Conclusions

The following conclusions are drawn from the analysis of the results. In general, psychosocial coping problems affecting the different subjects were caused by a range of different factors. Except for a few cases (such as subjects 8, 34 and 38) the severity and duration of the social or emotional disturbance could not be judged by the author.

The handling by doctors and hospital staff of a number of phases in the diagnosis, treatment and rehabilitation process were found to be important in adversely affecting the emotional coping of about 68% of the subjects. These included the manner in which the diagnosis and treatment were explained, the delay caused by misdiagnosis and inappropriate treatment, the amount of respect and care the subject felt was accorded him or her as an individual and how well the subject was informed before surgery about possible outcomes. Other factors were the style of presentation of the disfigured area, the subjects' anticipatory anxiety about the disfigurement and about the possible support group reaction to it, the radiotherapy treatment and its side effects, and discriminatory comments or behaviour by others towards the disfigured person. Family support and the subject's personality were also important in how well subjects coped. Only 23% of a total of 35 respondents wanted counselling and most of those who received it found it beneficial. The 16PF questionnaire could be used before, during or after cancer treatment to help identify people in greater need of counselling. However further research is needed to determine clearly whether there is

a statistically significant relationship between certain 16PF scores and a person's ability to cope emotionally with cancer treatment and disfigurement.

It is the opinion of the author that, as suggested by Bailey and Edwards (1975) and Rozen *et al.* (1972), emotional coping and successful psychosocial adjustment depended mostly on 4 aspects of the subjects' personalities. These were

- (a) the subjects' pre-existing self image which needed to be strong enough to survive the impact of disfigurement;
- (b) the capacity to cope with anxiety;
- (c) the ability to accept the dependence imposed by chronic illness; and
- (d) the ability to adapt to physical disability and altered social role.

The prostheses were important in promoting a return to social functioning and many subjects (61%) used their prostheses regularly for social activities. However, more than one third of the subjects had problems mainly due to inadequate retention, soft tissue trauma or difficulty handling skin adhesives. The suggestion was made that it would be helpful to receive counselling about coping with the reactions of people to a facial prosthesis. These problems have recently been overcome by the advent of osseointegrated implants for prosthesis fixation (Worthington and Brånemark, 1992). The limitations of material service life and colourant stability (Ma, 1992) need further research and development.

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APPENDICES

APPENDIX 1

DEMOGRAPHIC DATA FORM

1. Subject number
2. Date of interview
3. Date of birth
4. Occupation at time of diagnosis
5. Occupation at time of interview
6. Education, school level attained
7. Marital status
8. Who are the people you are close to
 ...in the family?
 ...among friends?
9. Original cause of disfigurement
10. Date of original diagnosis
11. Date of first operation
12. Date of subsequent operations
13. Total period of hospitalisation for treatment of condition
14. Radiotherapy, dosage, date?
15. Chemotherapy, dosage, date?
16. Prosthesis number received?
 date first one received?
 date current one received?
17. Do you think you
 ...drink alcohol more, less or the same now as before
 diagnosis?
 ...smoke more, less or the same now as before diagnosis?
18. Would your financial position be better, worse or the same now as
 before diagnosis?
19. Were you taking tablets for nerves (tranquilisers) or for
 sleeping
 ...before diagnosis?
 ...now?

APPENDIX 2

SEMI-STRUCTURED INTERVIEW SCHEDULE

1. Let's talk about the period leading up to the surgery.
 - . How did you first notice the problem?
 - . What early treatment was given?
 - . How did you and your family cope with the diagnosis?
 - . Looking back, how well do you think the doctors handled this early period?
 - . Were you offered any counselling to help you cope?
2. When you were told that an operation would be needed,
 - . did you have enough notice before the day it was due?
 - . How long were you in hospital before the operation?
 - . How much did you know about what was to be done at the operation?
 - . Did you expect your appearance to be affected? How?
 - . How did you find the treatment by the doctors and nursing staff?
 - . How were you and your family coping at this time?
3. I'd like to ask you about the period after the surgery.
 - . How did you cope in the first days after the operation?
 - . How did you find the care by the doctors and nursing staff?
 - . How was the result of the operation first explained and shown to you?
 - . How did your family cope with this period?
 - . Was anyone particularly helpful (or unhelpful) at this time?
 - . At this point had anyone discussed with you how the area would be reconstructed?
4. How did you cope when you came home from hospital?
 - . How did other members of the family react?

- . What about getting out of the house and seeing friends?
Did you do that as much as you had before?
How did you cope in public, for example, shopping?
 - . Some people who have this type of surgery find that they have problems with their employment, and financially. Were you affected in this way?
5. Regarding the radiotherapy (chemotherapy) treatment given to you,
- . did you know what to expect when you went to have the treatment?
 - . How did the treatment go? Any side effects?
If so, tell me about them. How long did it take you to recover?
 - . How did you find the staff?
6. Who sent you to have the prosthesis made?
- . How did you find the stages of treatment during the making of the prosthesis?
 - . How did you get on with the staff?
7. Now I'd like to ask you some questions about using the prosthesis.
- . Did you have any problems getting used to it?
 - . Do you have any particular likes and dislikes about it?
 - . I would like you to comment on some particular points:
 - how well it stays in position
 - the appearance
 - the comfort
 - handling and manipulating it
 - keeping it clean
 - . Tell me how people have reacted to it, such as your family, and people in public?
 - . How would you feel about using a dressing (or patch) instead of the prosthesis, when at home, and when out?
 - . How do you cope with inquisitive children?
 - . Is your daily life now much the same as it was before you became ill? If not, how has it changed?

Looking back, do you think that there was any time when you would have been glad of extra help, either a talk with a professional counsellor, or with another patient who had been through the same experiences?

8. Now let's talk about the surgical reconstruction.
 - . Tell me about how this came about.
 - . How do you feel about the result?
 - . How does your family feel?
 - . How do you feel in public?
 - . How does your social life now compare with when you had the prosthesis? Or with before you had any surgery on your face?
 - . Do you prefer the surgical reconstruction or the prosthesis?

APPENDIX 3

QUANTITATIVE QUESTIONNAIRE INSTRUCTION SHEET AND FORMS



THE UNIVERSITY OF SYDNEY

DEPARTMENT OF PROSTHETIC DENTISTRY

2 CHALMERS STREET
SYDNEY 2010
NEW SOUTH WALES
AUSTRALIA
TELEPHONE
(02) 211 4322

YOUR EXPERIENCE OF THE PROSTHESIS.

I would like you to make some ratings of different aspects of the prosthesis to indicate how good or bad things have been for you.

You will see that I have listed on the left side a number of different aspects of use of the prosthesis, such as comfort, colour and shape.

For each aspect you have a scale that goes from GOOD to BAD, with words in between.

So, for each aspect, decide whether you are rating good, bad or in between, then find the word that tells you how good or bad.

Circle that word.

For example, if you had a prosthesis with a very bad colour, you would show that as follows:

	<u>G O O D</u>					<u>B A D</u>
Colour ?	very	slightly	neither/nor equally	slightly	<u>very</u>	

Date

G O O D

B A D

HOW GOOD OR BAD IS
PROSTHESIS FOR

1. Staying in position?	very	slightly	neither/nor equally	slightly	very
2. Comfort?	very	slightly	neither/nor equally	slightly	very
3. Fit at edges?	very	slightly	neither/nor equally	slightly	very
4. Colour?	very	slightly	neither/nor equally	slightly	very
5. Shape?	very	slightly	neither/nor equally	slightly	very
6. Appearance?	very	slightly	neither/nor equally	slightly	very
7. How well glue holds?	very	slightly	neither/nor equally	slightly	very
8. Convenience to clean?	very	slightly	neither/nor equally	slightly	very
9. Convenience to handle?	very	slightly	neither/nor equally	slightly	very
10. Reaction of family/friends?	very	slightly	neither/nor equally	slightly	very
11. Reaction of public?	very	slightly	neither/nor equally	slightly	very
12. Benefit to you?	very	slightly	neither/nor equally	slightly	very

Date

G O O D B A D

HOW GOOD OR BAD IS
PROSTHESIS FOR

13. How well it escapes notice in public?	very	slightly	neither/nor equally	slightly	very
14. Convenience to put on?	very	slightly	neither/nor equally	slightly	very
15. Convenience to protect from damage when not in use?	very	slightly	neither/nor equally	slightly	very

APPENDIX 4

PROSTHESIS AND DEFECT ASSESSMENT FORMS

PHOTOS AND DEFECT DATA

Subject _____

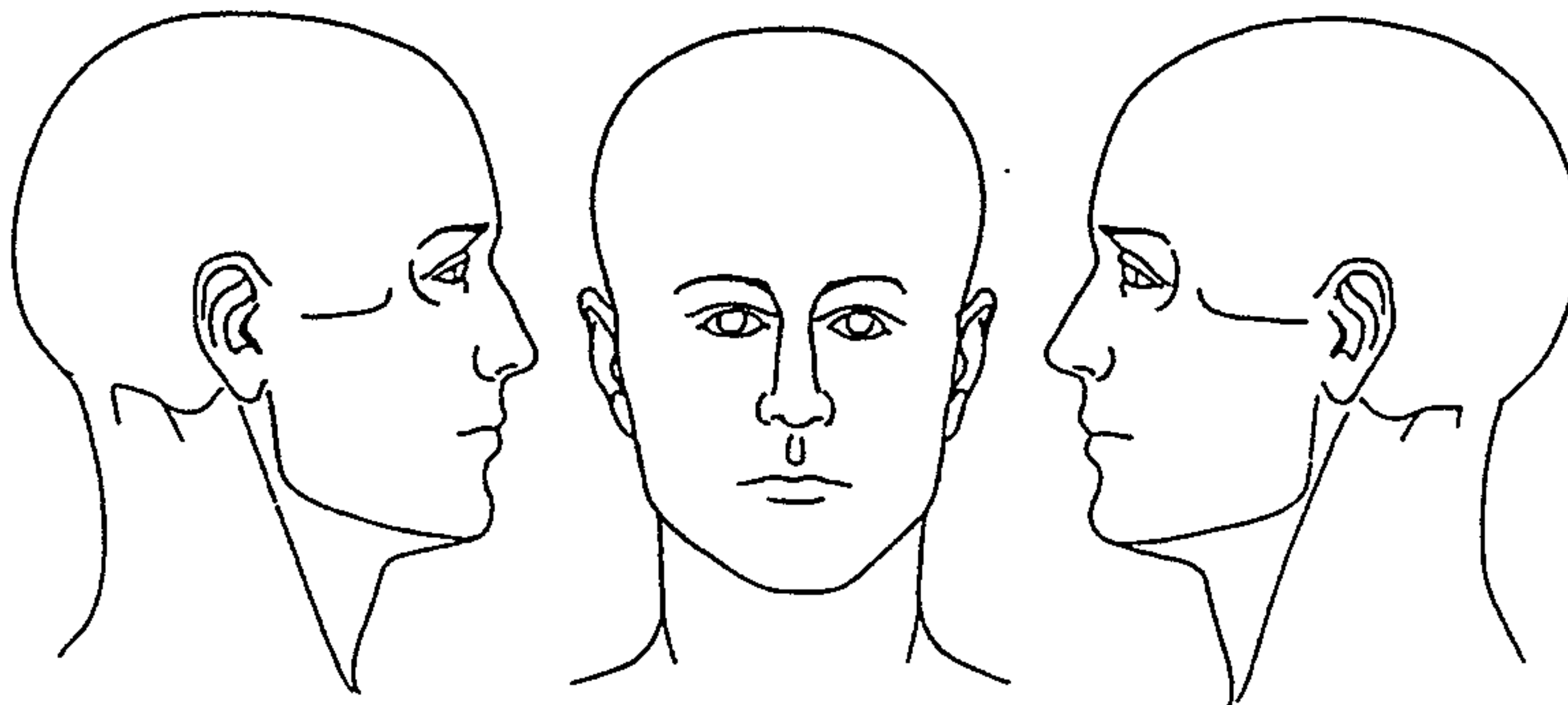
PHOTOS

Date _____

1. Portrait - Bracket flash, card, background
(Front, side or back view)
 - with prosth
 - without prosth
 - patch
 - dressing (if used in public)
2. Close up - Double flash, cm scale, background
 - prosthesis - external
 - fitting
 - patch

DEFECT AREA

1. Diagram - Outline defect and/or skin graft
 - Openings



2. Description - (if no photo)
 - Defect area....
 -
 - Colour, contour variations....
 -
 - Conspicuousness ☐ inconspic ☐ btwn ☐ conspic
3. Functional losses

PROSTHESIS DATA

Subject _____

1. GENERAL

Date _____

Prosth. _____

_____ Prosthesis off _____

1.1 Base material type ☐ silicone ☐ acrylic

Name/brand....

1.2 Struct. deterioration base

Fitting surface	☐	☐	☐
External surface	☐	☐	☐
Margins	☐	☐	☐
	none	minor	signif.

Comment....

1.3 Surface applied layer

Present ☐ yes ☐ ? ☐ no

1.4 Struct. deterioration surface layer

☐ none ☐ minor ☐ signif.

Comment....

1.5 Usage (e.g. awake/asleep; at home/ out)

When used....

or Period of wear(hrs/days)....

1.6 Removal ☐ no problem ☐ problem

Comment....

1.7 Main reason why removed

☐ loss of retention ☐ discomfort ☐ to sleep ☐ to clean ☐ other

Comment....

1.8 When not using- protection from damage

☐ problem ☐ no problem

Where?....

Comment....

1.9 Cleaning

Agents/insts used....

Method....

Time taken....

Comment....

1.10 Colour method ☐ base ☐ external ☐ internal

Comment....

PROSTHESIS DATA

Subject _____

1. GENERAL

Date _____

Prosth. _____

_____ Prosthesis ON _____

1.11 Prosth. colour cf skin colour

Prosth. is....

....

....

☐ Not easily noticed ☐ noticeable ☐ than skin.
attracts attention

1.12 Lighting

☐ artificial ☐ natural
☐ dim ☐ average ☐ bright

1.13 Marginal fit - as in normal use

Adaptation at rest ☐ no gap ☐ gap ...location...
dimensions...

Change during speech, smiling ?

1.14 Edge thickness visible margins

☐ not easily noticed ☐ noticeable ☐ attracts attention

Comment....

1.15 External shape

Symetry ☐ good ☐ problem

Comment....

Proportions
of face ☐ good ☐ problem

Comment....

Life like ?

☐ good ☐ problem

Comment....

PROSTHESIS DATA

Subject _____

2. RETENTION - ADHESIVE

Date _____

Prosth. _____

_____ Prosthesis OFF _____

2.1 Adhesive type ☐ Skin Bond ☐ Med Ad "B" ☐ Urobond 5000

2.2 Adhesive application

Who ? ☐ patient ☐ other

How ? ☐ brush ☐ spray ☐ other

Where ?
-Prosth fitting surface
☐ most/all ☐ about $\frac{1}{2}$ ☐ less than $\frac{1}{2}$

-Skin area....
How area located....

....

Waiting period ?....

2.3 Positioning prosthesis

Who ? ☐ patient ☐ other

Method....

....

_____ Prosthesis ON _____

2.4 Position correctness ☐ seems OK ☐ seems wrong

Comment....

2.5 While fixed

☐ no problem ☐ slippage ☐ detachment part ☐ detachment whole

Comment....

PROSTHESIS DATA

Subject _____

3. RETENTION - GLASSES

Date _____

Prosth. _____

_____ Prosthesis OFF _____

3.1 Fracture

Glasses frame

-location....

-cause....

-approx date....

Glasses/prosth joint

-location....

-cause....

-approx date....

-no. of times....

Prosthesis

-location....

-cause....

-approx date....

-no. of times....

_____ Prosthesis ON _____

3.2 Headband ☐ ☐
yes no

Type ☐ ☐ ☐
Hat elastic Hooks Other

Problems....

3.3 Position during use

Coincide with "ideal" position? ☐ ☐
yes no

If "no," distance moved(mm)....
direction ideal--normal....

Problem to patient? ☐ ☐
yes no

Comment....

PROSTHESIS DATA

Subject _____

4. RETENTION - OTHER MEANS

Date _____

Prosth. _____

_____ Prosthesis OFF _____

4.1 Means of retention....

....

....

4.2 Insertion- problem? ☐ yes ☐ no

Comment....

_____ PROSTHESIS ON _____

4.3 Retention

☐
no
problem

☐
slippage

☐
detachment
part

☐
detachment
whole

Comment....

PROSTHESIS DATA

Subject _____

5. PATCH

Date _____

Prosth. _____

_____ PATCH OFF _____

5.1 Material

☐	☐	☐	☐
cloth	cardboard	plastic film	other

Comment...

5.2 Colour...

_____ PATCH ON _____

5.3 Retention

Type ☐ ☐ ☐
 elastic adhesive on
 tape glasses

Comment...

Retention adequate? ☐ yes ☐ no

Comment...

5.4 Defect coverage

☐ complete ☐ incomplete

Problem to patient? ☐ yes ☐ no

Comment...

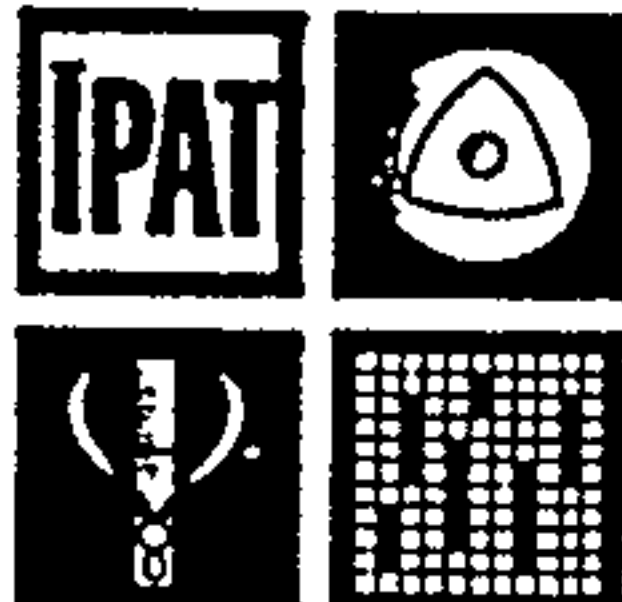
5.5 When used

☐ at home ☐ out ☐ other

comment...

APPENDIX 5

16 PERSONALITY FACTOR QUESTIONNAIRE, FORM C AND TEST PROFILE SHEET



Form C
1969 EDITION R

16 PF

WHAT TO DO: Inside this booklet are some questions to see what interests you have and how you feel about things. On most items there are no "right" or "wrong" answers because people have the right to their own views. All you have to do is answer what is true for *you*.

If a separate answer sheet has *not* been given to you, turn this booklet over and tear off the answer sheet on the back page. Write your name and other information asked for on the answer sheet.

First, read the four **EXAMPLES** below and mark your answers *on the answer sheet* where it says **EXAMPLES**. Fill in the box completely:

EXAMPLES:

1. I like to watch team games.
a. yes, b. occasionally, c. no.
2. I prefer people who:
a. are reserved,
b. (are) in between,
c. make friends quickly.
3. Money cannot bring happiness.
a. yes (true),
b. in between,
c. no (false).
4. Adult is to child as cat is to:
a. kitten, b. dog, c. baby.

In the last example there is a right answer—kitten. But there are very few such reasoning items.

Ask *now* if something isn't clear.

When the examiner tells you, start with number 1 and answer the questions. Keep these four things in mind:

1. Give only answers that are true *for you*. It is best to say what you really think.
2. Don't spend too much time thinking over each question. Give the *first, natural* answer as it comes to you. Of course, the questions are too short to give you *all* the information you might like, but give the best answer you can under the circumstances.
3. Answer *every* question one way or the other. Don't skip any.
4. You should mark the *a* or *c* answer *most* of the time. Mark the middle *b* answer *only* when you feel you have to, because neither *a* nor *c* seems to be right for you.

DO NOT TURN PAGE UNTIL TOLD TO DO SO

1. I think my memory is better than it ever was.
a. yes, b. in between, c. no.
2. I could happily live alone, far from anyone, like a hermit.
a. yes, b. occasionally, c. no.
3. If I say the sky is "down" and winter is "hot," I would call a criminal:
a. a gangster, b. a saint, c. a cloud.
4. When going to bed, I:
a. drop off to sleep quickly,
b. in between,
c. have difficulty falling asleep.
5. When driving a car in a line of traffic, I feel satisfied:
a. to remain behind most of the other cars,
b. in between,
c. only after I've reached the front of the line.
6. At a party I let others keep the jokes and stories going.
a. yes, b. sometimes, c. no.
7. It's important to me not to live in messy surroundings.
a. true, b. uncertain, c. false.
8. Most people I meet at a party are undoubtedly glad to see me.
a. yes, b. sometimes, c. no.
9. I would rather exercise by:
a. fencing and dancing,
b. in between,
c. wrestling and baseball.
10. I smile to myself at the big difference between what people do and what they say they do.
a. yes, b. occasionally, c. no.
11. In reading about an accident I like to find out exactly how it happened.
a. always, b. sometimes, c. seldom.
12. When friends play a joke on me, I usually enjoy it as much as the others, without feeling at all upset.
a. true, b. in between, c. false.
13. When someone speaks angrily to me, I can forget the matter quickly.
a. true, b. uncertain, c. false.
14. I like to "dream up" new ways of doing things rather than to be a practical follower of well-tried ways.
a. true, b. uncertain, c. false.
15. When I plan something, I like to do so quite alone without any outside help.
a. yes, b. occasionally, c. no.
16. I consider myself less "high strung" than most people.
a. true, b. in between, c. false.
17. I get impatient easily with people who don't decide quickly.
a. true, b. in between, c. false.
(End, column 1 on answer sheet.)
18. I have sometimes, even if briefly, had hateful feelings towards my parents.
a. yes, b. in between, c. no.
19. I would rather tell my innermost thoughts to:
a. my good friends,
b. uncertain,
c. a diary.
20. I think the opposite of the opposite of "inexact" is:
a. casual, b. accurate, c. rough.
21. I always have lots of energy at times when I need it.
a. yes, b. in between, c. no.

22. I am more annoyed by a person who:
 a. tells off-color jokes and embarrasses people,
 b. uncertain,
 c. is late for an appointment and inconveniences me.
23. I greatly enjoy inviting guests and amusing them.
 a. true, b. uncertain, c. false.
24. I feel that:
 a. some jobs just don't have to be done so carefully as others,
 b. in between,
 c. any job should be done thoroughly if you do it at all.
25. I have always had to fight against being too shy.
 a. yes, b. in between, c. no.
26. It would be more interesting to be:
 a. a bishop, b. uncertain, c. a colonel.
27. If people cheat me in small things, I'd rather humor them than show them up.
 a. yes, b. occasionally, c. no.
28. I like friends who:
 a. are efficient and practical in their interests,
 b. in between,
 c. seriously think out their feelings about life.
29. It bothers me if I hear others expressing ideas that are contrary to those that I firmly believe.
 a. true, b. in between, c. false.
30. I'm over-conscientious and worry over my past acts or mistakes.
 a. yes, b. in between, c. no.
31. If I were good at both, I'd rather:
 a. play chess,
 b. in between,
 c. go bowling.
32. I like to join with people who show lively group enthusiasm.
 a. yes, b. in between, c. no.
33. I put my faith more in:
 a. insurance,
 b. in between,
 c. good fortune.
34. I can forget my worries and responsibilities whenever I need to.
 a. yes, b. sometimes, c. no.
 (End, column 2 on answer sheet.)
35. It's hard for me to admit it when I'm wrong.
 a. yes, b. sometimes, c. no.
36. In a factory it would be more interesting to be in charge of:
 a. machinery or keeping records,
 b. in between,
 c. talking to and hiring new people.
37. Which word does not belong with the other two?
 a. cat, b. near, c. sun.
38. Minor distractions seem:
 a. to irritate me,
 b. in between,
 c. not to bother me at all.
39. I am quite happy to be waited on, at appropriate times, by personal servants.
 a. often, b. sometimes, c. never.
40. I would rather live in a town:
 a. artistically laid out, but relatively poor,
 b. uncertain,
 c. that is rough, prosperous, and booming.
41. People should insist more than they now do that moral laws be followed.
 a. yes, b. sometimes, c. no.
42. I have been told that, as a child, I was rather:
 a. quiet and kept to myself,
 b. in between,
 c. lively and always active.

43. I enjoy routine, constructive work, using a good piece of machinery or apparatus.
a. yes, b. in between, c. no.
44. I think most witnesses tell the truth even if it becomes embarrassing.
a. yes, b. in between, c. no.
45. When I meet new people, I'd rather:
a. discuss politics and social views,
b. in between,
c. have them tell me some good, new jokes.
46. I try to make my laughter at jokes quieter than most people's.
a. yes, b. in between, c. no.
47. I never feel so wretched that I want to cry.
a. true, b. uncertain, c. false.
48. In music I enjoy:
a. military band marches,
b. uncertain,
c. violin solos.
49. I would rather spend two weeks in the summer:
a. bird-watching and walking in the country with a friend or two,
b. uncertain,
c. being a leader of a group in a camp.
50. The effort taken in planning ahead:
a. is never wasted,
b. in between,
c. is not worth it.
51. Inconsiderate acts or remarks by my neighbors do *not* make me touchy and unhappy.
a. true, b. uncertain, c. false.
(End, column 3 on answer sheet.)
52. When I know I'm doing the right thing, I find my task easy.
a. always, b. sometimes, c. seldom.
53. I would rather be:
a. in a business office, organizing and seeing people,
b. in between,
c. an architect, drawing plans in a quiet room.
54. "House" is to "room" as "tree" is to:
a. forest, b. plant, c. leaf.
55. Things go wrong for me:
a. rarely, b. occasionally, c. frequently.
56. In most things in life, I believe in:
a. taking a gamble,
b. in between,
c. playing it safe.
57. Some people may think I talk too much.
a. likely, b. uncertain, c. unlikely.
58. I admire more people who are:
a. clever, but undependable,
b. in between,
c. average, but strong to resist temptations.
59. I make decisions:
a. faster than many people,
b. uncertain,
c. slower than most people.
60. I am more impressed by:
a. acts of skill and grace,
b. in between,
c. acts of strength and power.
61. I am considered a cooperative person.
a. yes, b. in between, c. no.
62. I enjoy talking more with polished, sophisticated people than with outspoken, down-to-earth individuals.
a. yes, b. in between, c. no.
63. I prefer to:
a. keep my problems to myself,
b. in between,
c. talk about them to my friends.

64. If a person doesn't answer when I make a suggestion, I feel I've said something silly.
a. true, b. in between, c. false.
65. I learned more in my school days by:
a. going to class,
b. in between,
c. reading books.
66. I avoid getting involved in social responsibilities and organizations.
a. true, b. sometimes, c. false.
67. When a problem gets hard and there is a lot to do, I try:
a. a different problem,
b. in between,
c. a different attack on the same problem.
68. I get strong emotional moods—anxiety, anger, laughter, etc.—that seem to arise without much actual cause.
a. yes, b. occasionally, c. no.
(End, column 4 on answer sheet.)
69. My mind doesn't work so clearly at some times as it does at others.
a. true, b. in between, c. false.
70. I am happy to oblige people by making appointments at times they prefer, even if it is a bit inconvenient to me.
a. yes, b. sometimes, c. no.
71. I think the proper number to continue the series 1, 2, 3, 6, 5, is:
a. 10, b. 5, c. 7.
72. I have occasionally had a brief touch of faintness, dizziness, or light-headedness for no apparent reason.
a. yes, b. uncertain, c. no.
73. I would rather do without something than put a waiter or waitress to a lot of extra trouble.
a. yes, b. occasionally, c. no.
74. I live for the "here and now" more than most people do.
a. true, b. uncertain, c. false.
75. At a party, I like:
a. to get into worthwhile conversation,
b. in between,
c. to see people relax and completely let go.
76. I speak my mind no matter how many people are around.
a. yes, b. sometimes, c. no.
77. If I could go back in time, I'd rather meet:
a. Columbus,
b. uncertain,
c. Shakespeare.
78. I have to stop myself from getting too involved in trying to straighten out other people's problems.
a. yes, b. sometimes, c. no.
79. In a store or market, I would prefer to:
a. design and do window displays,
b. uncertain,
c. be a cashier.
80. If people think poorly of me, I can still go on calmly in my own mind.
a. yes, b. in between, c. no.
81. If people seem cold and reserved to me, I usually:
a. just think they're in a bad mood,
b. uncertain,
c. worry about what I may have done wrong.
82. More trouble arises from people:
a. changing and meddling with ways that are already satisfactory,
b. uncertain,
c. turning down new, promising methods.
83. I greatly enjoy talking to people about local problems.
a. yes, b. sometimes, c. no.
84. Prim, strict people don't seem to get along well with me.
a. true, b. sometimes, c. false.

85. I guess I'm less irritable than most people.

a. true, b. uncertain, c. false.

(End, column 5 on answer sheet.)

86. I may be less considerate of other people than they are of me.

a. true, b. sometimes, c. false.

87. I would just as soon let someone else have all the worry of being in charge of an organization of which I am a member.

a. true, b. uncertain, c. false.

88. If the two hands on a watch come together exactly every 65 minutes (according to an accurate watch), the watch is running:

a. slow, b. on time, c. fast.

89. I am bored:

a. often, b. occasionally, c. seldom.

90. People say that I like to have things done my own way.

a. true, b. occasionally, c. false.

91. I find it wise to avoid too much excitement because it tends to wear me out.

a. yes, b. occasionally, c. no.

92. At home, with a bit of spare time, I:

a. use it chatting and relaxing,
b. in between,
c. arrange to fill it with special jobs.

93. I am shy, and careful, about making friendships with new people.

a. yes, b. occasionally, c. no.

94. I think that what people say in poetry could be put just as exactly in plain prose.

a. yes, b. sometimes, c. no.

95. I suspect that people who act friendly to me can be disloyal behind my back.

a. yes, generally,
b. occasionally,
c. no, rarely.

96. I think that even the most dramatic experiences during the year leave my personality much the same as it was.

a. yes, b. sometimes, c. no.

97. It would seem more interesting to be a:

a. naturalist and work with plants,
b. uncertain,
c. public accountant or insurance salesperson.

98. I get unreasonable fears or distastes for some things, for example, particular animals, places, and so on.

a. yes, b. sometimes, c. no.

99. I like to think out ways in which our world could be changed to improve it.

a. yes, b. in between, c. no.

100. I prefer games where:

a. you're on a team or have a partner,
b. uncertain,
c. people are on their own.

101. At night I have rather fantastic or ridiculous dreams.

a. yes, b. occasionally, c. no.

102. If left in a lonely house I tend, after a time, to feel a bit anxious or fearful.

a. yes, b. sometimes, c. no.

(End, column 6 on answer sheet.)

103. I may deceive people by being friendly when I really dislike them.

a. yes, b. sometimes, c. no.

104. Which word does not belong with the other two?

a. think, b. see, c. hear.

105. If Mary's mother is Fred's father's sister, what relation is Fred to Mary's father?

a. cousin, b. nephew, c. uncle.

(End of test.)

[illegible]

16 P.F. TEST PROFILE

FACTOR	Raw Score			Standard Score	Low Score Description	Standard Ten Score (STEN)										High Score Description
	Form	Form	Total			1	2	3	4	5	6	7	8	9	10	
A					RESERVED, DETACHED, CRITICAL, COOL (Sizothymia)	.	.	.	.	.	.	.	.	.	.	OUTGOING, WARMHEARTED, EASY-GOING, PARTICIPATING (Affectiohymia, formerly cyclothymia)
B					LESS INTELLIGENT, CONCRETE-THINKING (Lower scholastic mental capacity)	.	.	.	.	.	.	.	.	.	.	MORE INTELLIGENT, ABSTRACT-THINKING BRIGHT (Higher scholastic mental capacity)
C					AFFECTED BY FEELINGS, EMOTIONALLY LESS STABLE, EASILY UPSET (Lower ego strength)	.	.	.	.	.	.	.	.	.	.	EMOTIONALLY STABLE, FACES REALITY, CALM, MATURE (Higher ego strength)
E					HUMBLE, MILD, ACCOMMODATING, CONFORMING (Submissiveness)	.	.	.	.	.	.	.	.	.	.	ASSERTIVE, INDEPENDENT, AGGRESSIVE, STUBBORN (Dominance)
F					SOBER, PRUDENT, SERIOUS, TACITURN (Desurgency)	.	.	.	.	.	.	.	.	.	.	HAPPY-GO-LUCKY, IMPULSIVELY LIVELY, GAY, ENTHUSIASTIC (Surgency)
G					EXPEDIENT, EVADES RULES, FEELS FEW OBLIGATIONS (Weaker superego strength)	.	.	.	.	.	.	.	.	.	.	CONSCIENTIOUS, PERSEVERING, STAIID, RULE-BOUND (Stronger superego strength)
H					SHY, RESTRAINED, DIFFIDENT, TIMID (Threctia)	.	.	.	.	.	.	.	.	.	.	VENTURESOME, SOCIALLY BOLD, UNINHIBITED, SPONTANEOUS (Parnia)
I					TOUGH-MINDED, SELF-RELIANT, REALISTIC, NO-NONSENSE (Harrla)	.	.	.	.	.	.	.	.	.	.	TENDER-MINDED, DEPENDENT, OVER-PROTECTED, SENSITIVE (Premia)
L					TRUSTING, ADAPTABLE, FREE OF JEALOUSY, EASY TO GET ON WITH (Alaxia)	.	.	.	.	.	.	.	.	.	.	SUSPICIOUS, SELF-OPINIONATED, HARD TO FOOL (Protension)
M					PRACTICAL, CAREFUL, CONVENTIONAL, REGULATED BY EXTERNAL REALITIES, PROPER (Praxemia)	.	.	.	.	.	.	.	.	.	.	IMAGINATIVE, WRAPPED UP IN INNER URGENCIES, CARELESS OF PRACTICAL MATTERS, BOHEMIAN (Autia)
N					FORTHRIGHT, NATURAL, ARTLESS, SENTIMENTAL (Artlessness)	.	.	.	.	.	.	.	.	.	.	SHREW'D, CALCULATING, WORLDLY, PENETRATING (Shrewdness)
O					PLACID, SELF-ASSURED, CONFIDENT, SERENE (Untroubled adequacy)	.	.	.	.	.	.	.	.	.	.	APPREHENSIVE, WORRYING, DEPRESSED, TROUBLED (Guilt proneness)
Q ₁					CONSERVATIVE, RESPECTING ESTABLISHED IDEAS, TOLERANT OF TRADITIONAL DIFFICULTIES (Conservatism)	.	.	.	.	.	.	.	.	.	.	EXPERIMENTING, CRITICAL, LIBERAL, ANALYTICAL, FREE-THINKING (Radicalism)
Q ₂					GROUP-DEPENDENT, A "JOINER" AND SOUND FOLLOWER (Group adherence)	.	.	.	.	.	.	.	.	.	.	SELF-SUFFICIENT, PREFERS OWN DECISIONS, RESOURCEFUL (Self-sufficiency)
Q ₃					UNDISCIPLINED SELF-CONFLICT, FOLLOWS OWN URGES, CARELESS OF PROTOCOL (Low integration)	.	.	.	.	.	.	.	.	.	.	CONTROLLED, SOCIALLY-PRECISE, FOLLOWING SELF-IMAGE (High self-concept control)
Q ₄					RELAXED, TRANQUIL, TORPID, UNFRUSTRATED (Low ergic tension)	.	.	.	.	.	.	.	.	.	.	TENSE, FRUSTRATED, DRIVEN, OVERWROUGHT (High ergic tension)

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DP. 15M 11/75

Comments:

APPENDIX 6

LETTER REQUESTING PARTICIPATION IN THE STUDY



THE UNIVERSITY OF SYDNEY

DEPARTMENT OF PROSTHETIC DENTISTRY

2 CHALMERS STREET
SYDNEY 2010
NEW SOUTH WALES
AUSTRALIA
TELEPHONE
(02) 211 4322

Dear

You will remember me from your visits to the Dental Hospital in Sydney when we made your facial prosthesis.

At present I am carrying out research into the experiences of people who are using, or have used facial prostheses, to find out both the good and bad aspects, so that even better care can be provided in the future for those needing prostheses.

This research is being carried out at the University of Sydney under the supervision of Associate Professor Wendy-Louise Walker of the Department of Behavioural Sciences in Medicine and Professor Iven Klineberg of the Department of Prosthetic Dentistry.

If you were willing, I would like to meet you and conduct an interview for about an hour and have you complete a questionnaire about your experiences of having the prosthesis. We could meet either at your home or at the University, whichever would be more suitable and convenient for you.

Your identity would be confidential and would be known only to Professor Walker, Professor Klineberg and myself. If you decide to participate, would you also be willing for me to see the hospital records relating to your medical treatment as well as to the prosthesis?

Your help with the study would be greatly appreciated and would contribute to the development of an improved patients in the future. I will telephone you in the next two weeks to find out if it is possible for you to participate. Alternatively, you are welcome to telephone me on (02) 282 0258 or 282 0200.

Yours sincerely,

James R Fisher, BDS

APPENDIX 7

CONSENT FORM



THE UNIVERSITY OF SYDNEY

DEPARTMENT OF PROSTHETIC DENTISTRY

2 CHALMERS STREET
SYDNEY 2010
NEW SOUTH WALES
AUSTRALIA
TELEPHONE
(02) 211 4322

INFORMED CONSENT FORM FOR STUDY OF FACIAL PROSTHESES

In this study, you will take part in an interview, where you will be asked about the condition that led to needing your prosthesis, about your experiences of treatment and, later, of the prosthesis. Your responses to the interview will be tape-recorded but will be confidential to Dr Fisher and Associate Professor Walker. You will be also asked to complete two questionnaires, which will also be confidential. In the final report, no person will be identified.

You will also be asked to allow Dr Fisher to read the medical records in the hospital, but he will be the only person to read these.

CONSENT :

I, ... give consent to an interview with Dr J Fisher, to completing questionnaires relating to my prosthesis and give consent for Dr Fisher to read the medical records in the hospital.

Signature :

Date :

APPENDIX 8

DEMOGRAPHIC DATA

SUBJ. NO.	SEX	AGE (YRS)	MARITAL STATUS ¹	CAUSE OF DISFIGUREMENT, TREATMENT	DEFECT
1	F	55	M	BCC nose, multiple operations, radiotherapy. Later reconstructed.	Cheek defect about 2.5cm diameter adjacent to nose.
2	M	72	M	BCC nose, single operation	Most of nose absent, not including bridge.
3	M	72	M	Carcinoma ear, 2 operations, radiotherapy	Ear, adjacent bone of skull absent, radical neck dissection with shoulder drop.
4	M	87	W	Carcinoma ear, single operation	Ear and adjacent bone of skull absent.
5	M	66	M	BCC ear, surgery.	Upper $\frac{2}{3}$ rds of ear absent.
6	M	26	S	Microtia (congenital).	Rudiments of ear tissue only present.
7	M	68	M	Carcinoma ear, radiotherapy, single operation.	Ear absent.
8	F	78	W	Carcinoma nose, radiotherapy, surgery.	Alar and side of tip of nose absent.
9	F	89	W	Carcinoma nose, radiotherapy, surgery.	Whole nose absent.
10	M	72	M	Carcinoma nose, radiotherapy, surgery.	Lower $\frac{1}{2}$ of nose absent.
11	M	62	M	Carcinoma nose, surgery.	Lower $\frac{1}{2}$ of nose absent.
12	M	45	M	Sarcoma left maxilla. Seven operations, radio- and chemotherapy.	Large orbit, cheek, sinus, palate defect. Mass of soft tissue over jaw angle due to surgery.
13	M	70	M	Carcinoma nose, radiotherapy, radical and reconstructive operations.	Whole nose absent. Mass on scalp due to tissue expander. For reconstructive surgery.
14	M	55	M	Carcinoma antrum. Radiotherapy, 1 operation.	Defect of orbit and palate.
15	M	75	M	SCC ear. Radiotherapy and 2 operations including radical neck dissection.	Ear, adjacent skull bone absent. Large, pale, thick flap repair of defect and neck.
16	M	60	M	Melanoma ear. Two operations for removal and radical neck dissection.	Upper $\frac{2}{3}$ rds of ear absent, radical neck dissection. Largely hidden by hair.
17	M	62	M	Carcinoma ear. One operation.	Upper $\frac{2}{3}$ rds of ear absent.
18	M	81	M	BCC nose. Several operations.	Alar of nose absent.
19	M	54	M	Metastatic SCC eyelid. Operation. Palliative radiotherapy and chemotherapy.	Defect of orbit, deep paranasal sinuses.
20	F	73	M	BCC nose. Numerous different treatments before one surgical resection.	Alar and side of tip of nose absent.
21	F	85	W	BCC ear. One operation.	Ear absent. Defect well hidden by hair.
22	F	81	W	BCC nose. Surgery and later reconstructed.	Lower $\frac{1}{2}$ of nose absent, now reconstructed.

SUBJ. NO.	SEX	AGE (YRS)	MARITAL STATUS ¹	CAUSE OF DISFIGUREMENT, TREATMENT	DEFECT
23	M	69	M	Carcinoma nose. Two operations, later surgical reconstruction.	Defect of side of bridge of nose 2cm diameter.
24	M	21	S	Microtia (congenital).	Rudiments of ear tissue.
25	F	43	M	Carcinoma of eyebrow. Several operations, radio- and chemotherapy.	Loss of eyeball, collapse of eyelids.
26	F	74	W	SCC orbit. One major operation.	Loss of right orbital tissues and adjacent bone of forehead and temple back to hairline.
27	M	79	M	SCC ear. One surgery, with neck dissection.	Lower $\frac{1}{2}$ of ear absent, shoulder drop.
28	F	78	W	BCC nose. Various treatments including finally surgical resection.	Alar of nose absent.
29	M	81	M	Carcinoma ear. Radiotherapy and surgery.	Ear absent. Thick flap on side of head/neck.
30	M	68	W	Melanoma near eye. One major operation.	Large defect including orbit, cheek, temple.
31	M	54	M	Traumatic eye injury, gas gangrene nearly fatal, surgery, prolonged hospital treatment.	Defect of orbit, closed with skin.
32	F	74	M	Terminal BCC nasal cavity. Surgery, palliative chemo- and radiotherapy.	One side of nose absent, inflammation, swelling of surrounding tissues.
33	M	74	M	Recurrent carcinoma ear. Number of major operations, radio- and chemotherapy.	Ear, adjacent skull-, jawbone absent. Large grafts, cheek fistula, gross disfigurement.
34	F	81	W	Carcinoma nose. Radiotherapy, 2 operations.	Lower $\frac{2}{3}$ of nose absent.
35	M	64	M	Carcinoma eyebrow. Several operations. Radiotherapy.	Loss of contents of orbit and disfigurement due to use of scalp flap for repair.
36	M	66	M	Tumour ethmoid sinus. One operation.	Defect of bridge of nose 2cm diameter.
37	M	75	D	SCC nose. Cryotherapy, several operations.	One side of nose absent.
38	M	68	W	SCC nose. Two operations.	Alar of nose absent.
39	F	66	M	SCC cheek. Radiotherapy, surgery.	Large defect of orbit and cheek.
40	M	56	M	Tumour orbital tissues. Two operations, radiotherapy.	Contents of orbit absent, puckering of adjacent cheek.
41	M	37	M	Amelanotic melanoma ear. One operation including radical neck dissection.	Ear absent, defect partly hidden by hair. Shoulder drop.

¹ S - Single; M - Married; D - Divorced; W - Widowed.

APPENDIX 9

INTERVIEW DATA TABLES 9.1 TO 9.8

SUBJ. NO.	SEX	HISTORY	SUBJECT REACTION TO MANNER OF DOCTORS PRESENTATION OF DIAGNOSIS		OBJECTIVE RATING OF SUBJECT COPING WITH DIAGNOSIS AND PROSPECT OF TREATMENT		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT INDICATION OF WHETHER ADEQUATE PRIOR NOTICE OF OPERATION GIVEN		SUBJECT INDICATION OF HOW WELL INFORMED ABOUT NATURE OF OPERATION PREOPERATIVELY		SUBJECT INDICATION OF HOW WELL INFORMED ABOUT POST-OP. APPEARANCE, FUNCTION		DOCTORS' MANAGEMENT DURING PREOPERATIVE PERIOD - SUBJECT REACTION	
5	M	Numerous treatments since 1950's for skin cancers all over body. In 1987 partial left ear resection op. delayed - resented. Prosthesis made. Adhesive a problem.	Had been happy with this phase of treatment over the years.	+	Seems to have coped with it over the years.	+	Good support from wife and friends.	+	Yes	+	Well-enough informed.	+	Surgeon said he would only lose small amount top of ear. Due to hospital bed delay, lost upper half of ear - surgeon not held responsible for the misconception.	-	Patient seems happy enough.	+
6	M	Congenitally malformed right ear. Used prosthesis from age 7. Keeps ear covered with long hair. Apparently normal life and development.	Not relevant.		Not relevant		Good support from family.	+	Not relevant		Not relevant		Not relevant		Not relevant	
7	M	Lesion left ear 1984, inadequately treated. Resented mismanagement, and unhelpful 2nd opinion. Finally saw different specialist, ear removed, prosthesis made and used successfully.	Unclear about manner of first 2 specialists. Third specialist diagnosed accurately and immediately. Clear about need for urgent surgery - appreciated.	-+	Coped well with news of seriousness of condition and need for immediate removal of ear. Acceptance of it made easier by need for relief from pain.	+	Good family support	+	Yes	+	Well informed, that would lose ear and perhaps more tissue.	+	As well informed as he could be.	+	Resented misdiagnosis by specialist and one who gave 2nd opinion - seemed to be protecting 1st one. Third specialist diagnosed accurately and immediately. Clear about need for urgent surgery - appreciated.	- +
8	F	Former photographic model. BCC left nostril 1987. Misdiagnosis and wrong treatment for about 1 year. Then radiotherapy, several operations, then resection of left alar of nose. Prosthesis not very successful - few outings now.	Doctor told her loudly that she had cancer in front of other patients. Other surgeon direct and to the point - appreciated.	-+	"I didn't believe it". "Couldn't quite believe it because I have always been a very strong, healthy, energetic person."	-	Very close to her son - good support from him.	+	Yes	+	She accepts that she was as well informed as she could have been.	+	Had not expected her appearance would be affected (but accepts that surgeon could not have predicted it would be necessary).	-	Resents 1st doctor's mismanagement. Hurt by second doctor's public and blunt news of cancer. Very happy with plastic surgeon who did surgery.	- +

SUBJ. NO.	SEX	HISTORY	SUBJECT REACTION TO MANNER OF DOCTORS PRESENTATION OF DIAGNOSIS		OBJECTIVE RATING OF SUBJECT COPING WITH DIAGNOSIS AND PROSPECT OF TREATMENT		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT INDICATION OF WHETHER ADEQUATE PRIOR NOTICE OF OPERATION GIVEN		SUBJECT INDICATION OF HOW WELL INFORMED ABOUT NATURE OF OPERATION PREOPERATIVELY		SUBJECT INDICATION OF HOW WELL INFORMED ABOUT POST-OP. APPEARANCE, FUNCTION		DOCTORS' MANAGEMENT DURING PREOPERATIVE PERIOD - SUBJECT REACTION	
9	F	Former opera singer. Skin cancer on nose treated with heavy dosage radiotherapy in 1940's. Over years several surgeries, each reduced size of nose; in 1988 complete resection and prosthesis. Former social activity etc regained with prosth.	Happy with care of all doctors other than the first. Not clear about how they presented diagnosis except with doctor who explained need for total removal of nose - he was very gentle.	+	"I felt as though the roof had fallen in" - but this does not necessarily mean she coped badly - unclear.	0	Good support from close friends, niece, and surgeon.	+	No specific mention		Well enough informed	+	Well enough informed	+	Does not appreciate first doctor who gave heavy radiotherapy - this thought to have caused cancer. Management by all doctors appreciated except that of the first.	- +
10	M	1978 small lesion next to side of nose - diathermy, cobalt ray then numerous operations, small opening and prosthesis made. 1987 small spot at tip of nose, surgery resulted in much greater loss than expected by patient - very angry. Prosthesis made but not used.	Not mentioned.		Was angry that first specialist hadn't taken a biopsy and eradicated cancer early - but otherwise accepting of this period.	+	Support from family.	+	Not mentioned		Main cause of resentment. One of last operations - surgeon removed much more tissue than patient had expected - very angry about it.	-	Only discovered actual amount of tissue lost when shown by ward sister - much more than he had expected - very angry.	-	Minor complaint about initial specialist - subj. says he should have taken a biopsy, found exact nature of tumour and eradicated it, so he could have avoided "20-odd operations".	- +
11	M	1978 BCC on tip of nose, total of 7 operations in 9 years due to recurrences, initially reconstructed surgically, later not. Prosthesis made - used with some problems.	Not clear		Coped well. "Naturally I was concerned but I wasn't unduly upset over it".	+	Good support from family	+	Not mentioned		Not mentioned		In retrospect subj. feels that it would be good if surgeon could be as clear as possible about amount of tissue to be removed. He didn't have a clear idea of amount of this.	0	No specific problems	+

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12	M	1986 rapidly-growing sarcoma left maxilla. Radio- and chemotherapy, 7 operations. Massive defect. Loss of left palate, eye, cheek tissue. Large opening from mouth to cheek. Major disfigurement, disability, psychosocial disruption. Large complex prosthesis in 3 parts.	Not clear		A crisis for him, prospect of death, received psychological support at hospital. Not clear how well he coped emotionally. Said to wife "If you want to go, go now".	-	Crisis for family as they didn't know how long he would survive. Married (2nd time) 7 months at time of diagnosis (wife pregnant). Said to his wife "If you want to go, go now". At first his wife couldn't believe diagnosis. Later was supportive. Also support from family.	+	Yes	+	After tumour growth controlled by chemo- and radiotherapy. Given time to think, discuss with family about whether to have surgery which would be mutilating. They decided to go ahead. Well-enough informed.	+	Knew that the surgery would be major and mutilating. Now says if he had known then how the aftermath would actually be he probably would not have had it done. Not clear how well he felt informed.		Anxiety and anger at the time about the doctors' inability to explain his condition for 4 to 5 weeks during which he had antibiotics, X ray, CT scan, many consultations, 2 weeks hospitalisation. They could probably have been more informative than they were about the progress of their investigations. In retrospect he says is happy with the way they handled it.	- +
13	M	Late 1970's, radiotherapy for skin cancer on nose. Three recurrences since. First 2 with surgical reconstruction, second involving whole nose. After last recurrence and excision, reconstruction delayed 1 year, interim nose prosthesis made.	Happy with this	+	Seems to have coped well	+	Wife, family and friends very supportive.	+	Not clear		Felt as well informed as he could have been.	+	Felt as well informed as he could have been.	+	Happy with the surgeons and how they dealt with him. Very much appreciated one anaesthetist who "took a personal interest" but not the others with whom "it was as if you were on a production tray."	- +
14	M	1981 carcinoma left maxilla. Radical maxillectomy and orbital exenteration and radiotherapy. Depressive condition resulted. Obturator prosthesis and facial prosthesis made and used.	Surgeon said it was "very bad". He feels surgeon was "too forward" when he gave diagnosis, that he could have given the news "in a much better way".	-	Coped adequately.	+	The night he received the news his close friends gathered at his home to discuss the situation. Good support from wife and close friends.	+	Not specifically mentioned.		Patient later realised that he had not been told he would lose the left side of his upper jaw and his left eye but says this did not trouble him.	+	Felt well enough informed	+	Says surgeon could have presented diagnosis better, but appreciated speaking to another man who had similar operation previously (organised by surgeon). Otherwise happy with management.	- +

SUBJ. NO.	SEX	HISTORY	SUBJECT REACTION TO MANNER OF DOCTORS PRESENTATION OF DIAGNOSIS		OBJECTIVE RATING OF SUBJECT COPING WITH DIAGNOSIS AND PROSPECT OF TREATMENT		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT INDICATION OF WHETHER ADEQUATE PRIOR NOTICE OF OPERATION GIVEN		SUBJECT INDICATION OF HOW WELL INFORMED ABOUT NATURE OF OPERATION PREOPERATIVELY		SUBJECT INDICATION OF HOW WELL INFORMED ABOUT POST-OP. APPEARANCE, FUNCTION		DOCTORS' MANAGEMENT DURING PREOPERATIVE PERIOD - SUBJECT REACTION	
15	M	1982 SCC right ear. Doctors discussed options with patient - surgery or radiotherapy. Radiother. given but failed. Lesion now much larger than before needing wide resection of ear, adjacent bone, radical neck dissection, large flap reconstruction. Ear prosthesis made and used.	Happy with presentation of diagnosis.	+	At news of recurrence indicating failure of radiotherapy and big operation to come - "Naturally"... "It was really traumatic - even for me". "I'm very even-tempered"... "I'm a person that lives from day to day". "Initially I broke down". These reactions are to be expected - coped well.	+	Good support from family and friends. "Naturally everybody was upset...it was really traumatic".	+	Yes	+	Surgeons gave some indication, he would lose ear, some bone, soft tissue and jaw joint. He felt well-enough informed.	+	Subject felt well enough informed	+	Good. Doctors acted quickly to diagnose and treat - but concerns about radiotherapy (see table on this)	- +
16	M	1987 melanoma left ear. Partial ear resection, prosthesis made and used. 1988 radical neck dissection.	Patient appreciated the surgeon's presentation of diagnosis. He said it was "pretty grave" and advised that the ear should be removed.	+	He spent some time with the surgeon discussing it "at reasonable length because I had to get it straight in my mind". "I think I was adjusted to having the ear amputated when I left his surgery".	+	Good support from wife and family. "You wonder how you could cope if you hadn't a wife to be there to talk. I wanted to talk to somebody about it."	+	Four days notice was given but patient felt he was prepared and that the minimum delay was good.	+	"The specialist told me exactly what he was going to do. He left no doubt in my mind as to what was to happen."	+	Patient well informed	+	Patient very happy with doctors management	+
17	M	1988 skin cancer right ear, partial resection of ear then radiotherapy. Prosthesis made and used.	Patient was happy with doctor's handling of diagnosis.	+	Diagnosis a blow to the patient, worrying about possible malignancy was "quite a burden". Put all his financial affairs in order and explained everything to his wife. Tried to be positive with the attitude "there's always someone worse off than yourself". "I reckon that helped me quite a bit".	0	Good family support	+	Yes, 3 days notice, appreciated having no delay, no time to worry.	+	Not specifically mentioned		Not specifically mentioned		Happy with doctor's management	+

SUBJ. NO.	SEX	HISTORY	SUBJECT REACTION TO MANNER OF DOCTORS PRESENTATION OF DIAGNOSIS	OBJECTIVE RATING OF SUBJECT COPING WITH DIAGNOSIS AND PROSPECT OF TREATMENT	SUPPORT FOR SUBJECT BY SUPPORT GROUP	SUBJECT INDICATION OF WHETHER ADEQUATE PRIOR NOTICE OF OPERATION GIVEN	SUBJECT INDICATION OF HOW WELL INFORMED ABOUT NATURE OF OPERATION PREOPERATIVELY	SUBJECT INDICATION OF HOW WELL INFORMED ABOUT POST-OP. APPEARANCE, FUNCTION	DOCTORS' MANAGEMENT DURING PREOPERATIVE PERIOD - SUBJECT REACTION
18	M	Early 1970's, small BCC on nose. Two small local excisions, then more radical operation - removal of alar of nose. Prostheses made and used. Normal pattern of daily life unaltered.	Not mentioned	No problem coping at all +	Support from wife. +	Yes +	Just before going into theatre for the last operation the surgeon told him "I'm afraid we're going to have to be a bit more drastic than we first thought". Resulted in disfigurement. Patient happy with his management. +	Patient only informed about more radical nature of last operation, and ?possibility of disfigurement, just before entering theatre - not cause for concern by patient. +	Happy with doctor's management +
19	M	1987 developed double vision, misdiagnosis by GP of blocked tear duct. Eventually found to be SCC. Left orbital exenteration and deeper tissues, radiotherapy. Prosthesis made but little used. Now terminal with metastases in the spine. Intermittent palliative radiotherapy.	Not specifically mentioned	Seems to have coped well +	Good family support. "The family has been really good". "My wife has been an absolute brick...solid as a rock...magnificent". +	Yes +	Told he would "more than likely lose the eye". +	Had not expected resection would be as extensive as he discovered it was after operation. No particular reaction by patient. 0	Says he "was a little bit upset about the local doctor" who could have been more thorough in examining and palpating the eye and detected the "massive SCC" that was growing there. "Perhaps treatment may have been a little bit quicker". -
20	F	Numerous treatments for recurrent BCC on her nose since 1945. In 1987 was too busy looking after a sick daughter to go for treatment of another recurrence. Eventually needed resection of alar and tip of nose. Prosthesis made but not used. Daily life unaffected.	Diagnosis of recurrent skin cancer after many recurrences had occurred previously would have been no surprise. No specific mention.	No problem coping with anything. +	Good family support. +	Not mentioned. Patient generally happy with doctor's management. Unclear.	As well informed as surgeon was able to. +	Knew her appearance would be affected, but understood surgeon could not predict extent of resection that would be necessary. +	Regards the treatment she has received as "very satisfactory". +
21	F	Small lesion on left ear intermittently present for about 10 years. In 1987/88 suddenly flared up, ear amputated. Prosthesis made but not used. Daily life not altered.	Not clear	"It didn't worry me, I'm like this - what has to be will be". +	Patient has good support from neighbours and relatives. +	Yes +	Patient knew what would be done +	She knew she would lose either most or all of her ear +	No specific comment

SUBJ. NO.	SEX	HISTORY	SUBJECT REACTION TO MANNER OF DOCTORS PRESENTATION OF DIAGNOSIS	OBJECTIVE RATING OF SUBJECT COPING WITH DIAGNOSIS AND PROSPECT OF TREATMENT	SUPPORT FOR SUBJECT BY SUPPORT GROUP	SUBJECT INDICATION OF WHETHER ADEQUATE PRIOR NOTICE OF OPERATION GIVEN	SUBJECT INDICATION OF HOW WELL INFORMED ABOUT NATURE OF OPERATION PREOPERATIVELY	SUBJECT INDICATION OF HOW WELL INFORMED ABOUT POST-OP. APPEARANCE, FUNCTION	DOCTORS' MANAGEMENT DURING PREOPERATIVE PERIOD - SUBJECT REACTION
22	F	1987 small lesion on the side of her nose declared "cancerous" and at operation lower half of nose resected. Prosthesis made and used. Surgical reconstruction of nose more recently. Little or no effect on daily life or life satisfaction.	Not clear	No difficulty coping +	Good family support - neither they nor the patient seem to have been concerned. +	Yes +	Patient did not know how much tissue would be removed. No concern expressed by patient +	Did not know she would lose at least half of her nose. Patient expressed no concern. +	No specific comment - patient and family do not seem to have been upset about it.
23	M	1986 surgery to small, growing lesion on nose mismanaged by local specialist. Growth accelerated, second operation by another specialist left open defect in right side of nose. Two prostheses made, used successfully. Finally excellent surgical reconstruction.	Not mentioned	"It's a bit of a shock". "You've got to accept it, you've got to live with it". +	Family support +	With both surgeons, yes. +	Well enough informed +	Not clear with first operation. With second operation surgeon said he did not know how much would need to be removed but that he would "keep going until I get what I think is the whole lot". +	No specific comment on the preoperative management of the first surgeon. Appreciated the preoperative management of the second surgeon. +
24	M	Born with abnormality of left side of face and no left ear. The missing ear kept covered with long hair, which was the fashion then. Grew up without any psych. or social problems, was vice captain at primary school and prefect at high school. Now in family business. Ear prosthesis made when the patient was 21 (1988), used constantly.	Not applicable	Not applicable	Good family support. +	Not applicable	Not applicable	Not applicable	Not applicable

SUBJ. NO.	SEX	HISTORY	SUBJECT REACTION TO MANNER OF DOCTORS PRESENTATION OF DIAGNOSIS	OBJECTIVE RATING OF SUBJECT COPING WITH DIAGNOSIS AND PROSPECT OF TREATMENT	SUPPORT FOR SUBJECT BY SUPPORT GROUP	SUBJECT INDICATION OF WHETHER ADEQUATE PRIOR NOTICE OF OPERATION GIVEN	SUBJECT INDICATION OF HOW WELL INFORMED ABOUT NATURE OF OPERATION PREOPERATIVELY	SUBJECT INDICATION OF HOW WELL INFORMED ABOUT POST-OP. APPEARANCE, FUNCTION	DOCTORS' MANAGEMENT DURING PREOPERATIVE PERIOD - SUBJECT REACTION
25	F	1980 malignant skin cancer right eyebrow. Chemotherapy, surgical excision and 2 more operations to complete the reconstruction. Then recurrent disease requiring enucleation of right eyeball. Prosthesis made and used. Some coping problems. Daily life virtually normal.	Not specifically mentioned	When told of the first biopsy result she was in tears, but coped well	Good family support from husband and daughters	Not specifically mentioned but subject made a point of how good the surgeon was in keeping them fully informed.	"He's never pulled any punches, he always told us straight out". At the last operation, he said "We don't know how big it is". Patient seems to have accepted this.	Before the last operation the surgeons did not know that the eyeball would be lost and that her appearance would be affected. She seems to have accepted this.	"Marvelous". "I was lucky I had the best". "He treated me like a person from the very first time I walked into his office".
26	F	In early 1980's had radical surgery for cancer involving loss of right eye and wide excision of bone of right forehead, and temple about the hairline. Prosthesis made and used. Life little changed from before.	Surgeon told her she had "an uphill battle". Patient does not seem to mention at any time that the problem she had was cancer. She seems to relate it to an infection she had in her hand requiring it to be amputated just before the cancer operation. Does not seem to know about the cancer or this may be denial. Reaction at diagnosis not clear.	Very good copier. Was popular with hospital staff and doctors because of her positive and lively disposition.	Support from son and husband. Does not seem to have been remarkably strong support.	Patient described the amount of notice without saying that it was not enough. Unclear.	Subject did not know exactly what would be done because she thinks that the surgeon did not know how much removal would be necessary - she accepts this.	Did not know prior to operation that she would lose her eye, but this is not resented because she thinks that the surgeon did not know how much resection would be needed either.	She was delighted with her treatment by the surgeons.
27	M	1987 skin cancer on ear began to bleed. Biopsy taken, but result very slow in being returned - positive. Referred to surgeon, lower half of ear resected and radical neck dissection. Prosthesis made and used. Life significantly changed due to limitation of right arm mobility	Not specifically mentioned	Subject and his wife were "rather stunned" when told of the extent of surgery needed and hence the seriousness of the condition.	Support from wife and family	Very short notice - 1 day. "Quite a shock". They seemed to understand. The surgeon said if they had waited 2 - 3 weeks for a hospital bed "it may have been too late" to save his life.	Well informed by the surgeon about the nature of the operation - patient and his wife "quite shocked" about the extent of surgery necessary.	Seems to have been quite well informed about this.	The local GP "handled it well" and the surgeon was "good".

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28	F	Having skin cancer on nose treated many times for many years with radiotherapy, surgery and reconstruction. Neglected it while husband ill in 1986. Right alar of nose resected, prosthesis made - not completely satisfactory. Copes well, no social problem.	Not appropriate - patient knew she had skin cancer many years ago.	Subject coped very well with knowledge that she would be disfigured. +	Support from relatives and friends +	Not clear	Patient was expecting that resection would be much bigger than it was - was afraid that it might be near the brain. -	Thought much more might be lost than actually was. 0	Not clear
29	M	Has fair skin. Many years of treatment for skin cancer. In early 1980's had radiotherapy then 3 operations ending in resection of right ear and wide area around it, radical neck dissection and repair with large tissue flap from chest. Prosthesis made and used.	Not specifically mentioned	Not specifically mentioned	Support given by wife +	Not specifically mentioned	Knew that tissue would be lost. +	Knew that appearance would be affected but had no idea how it would look. "...but I was getting on in age and I didn't worry too much". +	Patient positive about this. +
30	M	Malignant melanoma adjacent to left eye. In 1985-6 had major resection of left eye, cheek and temple. Prosthesis made and used. Remarkably unaffected psychosocially. Came from broken home and had hard life - good copier.	Seems to have been happy with the way the diagnosis was presented, but didn't specifically mention how he found it.	When told he would have to lose his eye, thought "If it's got to come out, it's got to come out, that's all there is to it". Seems to have faced the idea and accepted it with a minimum of anxiety and depression. +	Friends gave good support. +	Yes. Waited 6 weeks for hospital bed. Not resentful about this. +	"He did tell me. I wouldn't remember those things." +	"All they told me as far as I'm concerned was they had to remove the eye, (and) that part of the face." +	"Fantastic". "Lovely. I had no problems, never had a care, never worried". +

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31	M	October 1986 struck in eye by machine at work. Subject and wife very unhappy about early treatment. Developed acute infection, gas gangrene close to brain. Operation to remove eye, long recovery in hospital with intensive treatment. Off work 12 months after returning home. Two eye prostheses made, second preferred. Never regained former strength, placed on light duties at work, significant disability due to loss of eye. Some depressive tendency since accident, but good family support.	Not applicable.	Subject and particularly his wife were naturally worried about the condition of his eye. 0	Good support from wife and family. +	Emergency surgery to remove eye and treat life threatening infection. Wife's consent asked over telephone. Could not have been any more notice. Difficult to rate.	Not applicable.	No opportunity.	Subject and particularly his wife were very unhappy with the way the treatment was managed by the eye specialist they first saw due to - . very little treatment given in first 48 hours after the accident; . delay in sending him to Sydney for hospital treatment; . the manner of the doctor. -
32	F	"About 4 years ago" developed lesion on side of nose - local excision. Two recurrences each followed by surgery, then referred to hospital and larger operation removing side of nose. Tumour inoperable, given palliative chemo- and radiotherapy. Tumour gradually invading deep tissues of face, copes v. well. Nose prosthesis made and used. Assists other terminal cancer patients to cope.	Not described.	Not specifically described	Support from family, but problem with one (adult) son who could not accept the radical surgery and disfigurement of his mother's face and reacted with anger and aggression to the surgeons.	Not specifically mentioned 0	Seems to have understood what was involved - not specifically mentioned.	Not specifically mentioned.	"I was quite happy with it". "I knew they were doing the best they could". +

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33	M	Skin cancer 1972 right temple, 1981 right side neck and recurrences over the years since affecting ear, neck and jaw. Had radio- and chemotherapy, a number of radical surgeries and reconstructions resulting in loss of right ear; small fistula from mouth to cheek; gross disfigurement; marked disability of jaw, neck and eye; chronic pain. Uses ear prosthesis, rubber plug for fistula, analgesics for pain. Some limitation of activity but copes very well, very good support.	Not specifically mentioned but has highest praise for doctors.		Acknowledges some upset for himself and the family when they knew he had cancer in neck, but says this was only transient. Also had some trouble accepting that his ear had to be removed but soon accepted it when faced with no alternative.	0	"Well, I don't know". "It was a lot on the wife - but she coped with it". "I got a good wife, a good son and daughter and 2 good grand kiddies". "They couldn't be any better, they're perfect"... "do anything for me".	+	Not clear	0	Not specifically mentioned		Not specifically mentioned		Has highest praise for his doctors	+
34	F	Early 1970's had radiotherapy and minor surgery for skin cancer on nose. At later op. for cosmetic improvement of nose, cancer found under skin, resection of half of nose done instead of cosmetic reconstruction. After op. this news badly presented to patient by surgeon - a great shock. Lasting emotional effects on subject and grandson. Prosthesis made, used.	Not mentioned		Good coping because was expecting reconstructive surgery.	+	Good support from daughter and family.	+	No specific mention		Knew about intended nature of operation, but this changed from reconstruction of nose to resection and disfigurement during operation.	+	Informed about expected improvement in appearance according to surgeon's knowledge before operation. (This was changed during operation due to discovery of cancer).	+	No specific comment	

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35	M	Late 1970's had lesion on right eyebrow. Treated unsuccessfully by skin specialist - resented by patient. Went to eye specialist, referred to surgeon. Right eyeball and contents of orbit removed and radiotherapy. Prosthesis made and used. Good family support returned to normal daily life.	Surgeon very direct. Appreciated.	+	"I wasn't very happy".	-	Good	+	Yes	+	Told	+	Not told. Initially more disfigurement than expected - patient got a surprise. A week or 2 later another operation done to improve it. Patient does not resent it.	0	Happy with doctors except the first - the skin specialist who was giving wrong treatment. "He should have picked it. I don't like him."	+ -
36	M	1986 surgery to remove tumour on right side of bridge of nose leaving opening. Coped well, had good family support and from friends and acquaintances. Prosthesis made and used. Returned to normal life.	"Blunt and to the point." Appreciated.	+	Coped well. "I wasn't worried at all".	+	Good.	+	Yes. "The sooner the better".	+	Not mentioned		Not mentioned		Patient very happy.	+
37	M	Skin cancer left side of nose 1970's. Primary treated with cryotherapy, then 3 recurrences, first treated with surgical removal/repair, others by removal only leaving defect left side of nose. Resents first doctor (wrong treatment). Not sent for prosthesis for ?1-2 years. Marriage breakdown attributed to this. Prosthesis made and used. Says disfigurement has ruined his life. Now socially isolated, depressed, drinks, has attempted suicide.	Not specifically mentioned.		Seems to have coped fairly well over all despite mismanagement by one doctor, delay in correct treatment and growth of tumour.	+	Not specifically mentioned		No problem mentioned		Well enough informed	+	Felt that he was as well informed as he could have been	+	Very happy with most of his doctors except by the first (Repat. Dept.). "Very unhappy" with him. Kept treating initial lesion with cryotherapy in spite of repeated failure to eradicate lesion and the opinion of patient's GP that it needed surgery. This delayed subsequent surgery. "If they'd have done it 12 months earlier I'd have had a little mark on me nose and nothin'" ... "not a bloody great hole".	+ -

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38	M	Late 1984, developed skin cancer on side of nose. Resected by plastic surgeon leaving defect. Prosthesis made and used. Wrong assumption by well-meaning family insisting that area would be surgically repaired. This led to shock when found to be wrong. Also shock, depression at first seeing defect, worry about possible reaction of grandchildren. Returned to normal life.	Not specifically mentioned		Wasn't happy but coped well	+	Good, but misguided. Family advice to patient that area would be surgically repaired (in spite of contrary advice from the surgeon), caused shock when this found to be wrong.	0	Yes	+	Yes	+	Was explained that there was an opening, if not before op. then certainly immediately after and before dressing removed. But wrongly understood by well-meaning relatives who insisted that area would have been surgically repaired. Created false expectation.	+	Patient was happy with his doctor.	+
39	F	1981 small SCC right cheek cauterised twice by dermatologist, then ref'd to plastic surgeon. At operation found extensive spread to deep tissues, ref'd to head/neck surgeon. Heavy radiotherapy, then radical surgery, loss of right eye and part of right cheek - large cavity. Prosthesis made and used. Returned to normal life. Good family support, good copier herself.	Not specifically mentioned		Shock to be told about deep spread of cancer. Coped well. Helped other family members to cope.	+	Good support generally from family although more from some than others. Patient supported them a lot too.	+	Not mentioned		Well informed	+	As well informed as she could have been.	+	Happy with doctors' management.	+

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40	M	1984-85 lump in left eyelid misdiagnosed as infection and wrongly treated for 18 months. Second opinion - rare malignant tumour. Ref'd to very good surgeon, had left eye removed. Radiotherapy after - hated it. Didn't want prosthesis but sent for it because others wanted him to have it - used it very little. Returned to normal daily life. Resented first specialist.	Not specifically mentioned.		Was a shock but he coped.	+	A shock to family but they coped. Good support.	+	Yes. Happy to get it over with	+	Well informed	+	Well informed.	+	Unhappy with first specialist. Appreciated thorough preparation by surgeon who did operation.	- +
41	M	1985 developed amelanoma on left ear. Operation to remove ear and adjacent neck tissues. Coped with good family support, and with help of Christian faith. Prosthesis made and appreciated but not used much - doesn't think he needs it. Returned to normal daily life and work.	Good	+	Was a shock but he coped with support from family, surgeon and church.	+	Good support.	+	Yes	+	Well informed.	+	As well as possible.	+	Happy with this.	+

TABLE 9.2 AFTER OPERATION IN HOSPITAL

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
1	F	Doctors never prepared her for the appearance change after each operation. Was "pretty traumatic" having to look each time. Shock after 3rd op. that facial defect would remain for 12 months. Scared to look in mirror, it was "horrendous", "gruesome".	-	Trauma of seeing postoperative result. At 3rd operation, shock of news about facial defect for 12 months - counsel would have helped. Gruelling 4th operation which when complete and patient conscious, operation had to be repeated immediately due to failure of flap graft. Coped remarkably.	+	Family, husband good support	+	No particular comment	
2	M	When dressing was removed and he looked in mirror he thought "that's not too bad"	+	Well	+	"No trouble" for family with appearance. Good support.	+	"Everybody was great, right down to the nurses".	+
3	M	Surgeon showed him "exactly what he was doing and what he found", the surgery areas, incisions and how they came to be there. He appreciated the surgeon's explanation.	+	"I couldn't have got better treatment".	+	Very good. Wife and daughter were at hosp. during op.	+	"I got the feeling all the time they were acting in my best interests".	+
4	M	Patient didn't look - area was covered with dressing. It "didn't interest me". "I don't know what it looked like".		"I just went about things as usual"	+	Unclear		No problem	+
5	M	Shocked to find that instead of the top part of the ear, the upper 2/3rds had been taken (due to delayed surgery due to lack of hospital beds).	-	Was happy with treatment.	+	Good support from wife.	+	No complaints	+
6	M	Not applicable		Not applicable		Not applicable		Not applicable	

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
7	M	Can't remember clearly. Didn't get clear view until going home. Found it unpleasant. "A pretty nasty sight".	-	Got on his feet pretty quickly.	+	Good. Son came from interstate to be with wife. "They were worried about possible future consequences"	+	No complaints. "If you appear to be in reasonable shape they don't worry about you too much".	+
8	F	After surgery surgeon explained how amputation had been necessary. Even so when she saw it she "was horrified". "It made me very disappointed". "It's quite a blow to one's ego".	-	Seems to have coped well enough except for being horrified when she saw the defect.	0	"My son talked to me". She is very close to her son.	+	Not mentioned.	
9	F	Avoided looking at it while in hospital and until 9 weeks after operation (ie at home). "I dreaded seeing it". Eventually urged to look at it by district nurse. She was horrified "(I) nearly fainted with how awful I looked". "An enormous hole". This reduced in size in succeeding time.	-	Coped well in hospital but didn't deal with defect, used denial.	0	No mention		"Wonderful treatment"	+
10	M	Ward sister offered to show him saying "It's not exactly beautiful". Not concerned about how this was done (but was very angry about not having been warned that he would lose half of his nose).	-	Coped very well but was angry that not informed properly about amount of tissue to be removed.	+	Good family support.	+	Encountered one officious sister, but otherwise staff were "A1".	+ -
11	M	Not mentioned		Not mentioned		Good	+	No problem	+
12	M	Not mentioned		Spent 6 months in hospital. Was not happy, hadn't realised he would lose so much of his face.	-	Had support from wife and some family members. Also saw hospital doctors and counsellors.	+	Seems to have been all right	+

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
13	M	Doctor did not explain or show him but this not a problem to patient.	+	Not mentioned		Good	+	Inefficiency in changing dressings and cleaning wound due to frequent staff changes.	-
14	M	Can't remember		Didn't cope well. Had disorientation for 10 days, then couldn't see properly because his good eye had been removed and nothing was done to improve the sight of the weak eye - couldn't read, watch TV etc. Resents this.	-	Good support from wife, family and friends.	+	Good.	+
15	M	Not specifically mentioned.		Initially was depressed. Surgeon remonstrated "Don't let yourself go, be glad we got you through". That put him right - "My mental attitude changed". "They (the surgeons) were terrific"	+	Not specifically mentioned. Support by doctors very good.		Nurses forgot to give medicines at correct times. Anger at one nurse who took his pulse every half hour day and night. Beeping monitors in intensive care unbearable.	-
16	M	Done after leaving hospital, in surgeon's rooms. Was wondering "What am I going to see when this (bandage) comes off?". Patient appreciated considerate manner of surgeon - "He did that very well"	+	Good. Felt "a bit sorry for myself" at first - soon got over this with help of support group	+	Good support from family and friends. A friend said "You're pretty lucky really, it could have been your arm or your leg" - "That really put me back on my tracks".	+	"They were excellent"	+
17	M	First saw the area after returning home, in the mirror - shock. Thought "My heavens I won't go outside again."	-	Good.	+	Good support from family.	+	"Very good...top"	+

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
18	M	No impact. "None at all, not in the least". "I suppose if I was a lot younger it might have but at my age (then in 60's) you're not really greatly concerned about what people think on anything."	+	Good.	+	Not mentioned. Had good support from medical people.	+	"Excellent"	+
19	M	Ward sister helped him. "You are going to eventually have to see this" and asked whether he felt he could do it then. He did, it was a shock. More extensive than he had expected.	-	Seems to have coped well with postoperative period in hospital - very much appreciated the staff.	+	Good family support from wife and children.	+	"Fantastic, tremendous. You couldn't wish for better attention."	+
20	M	Not mentioned		Coped very well.	+	Good support from family	+	Not mentioned	
21	F	Not mentioned.		Coped well.	+	Good support from medical staff, friends	+	"They were kindness itself".	+
22	F	After the operation her sister gave her a mirror and told her she had her nose removed. "When I woke up I had no nose". Patient and family not in least concerned. Even joked about it, "Well it certainly doesn't improve my looks any!"	+	Coped well. "What can't be cured has got to be endured. There's nothing I can do about it".	+	Good family support	+	"Very nice"	+
23	M	Not mentioned.		Seems to have coped well.	+	Good support from hospital staff and family. Surgeon "was a marvelous man" - gave sound advice about not letting the disfigurement interfere with normal way of life. Very much appreciated.	+	Good.	+
24	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
25	F	She was given a mirror to look at the defect. "It didn't worry me".	+	Coped well with seeing the defect and with being in hospital.	+	Good family support.	+	Good, except for when a nursing sister put dry gauze instead of liquid dressing on raw graft donor site. Took 6 hours to remove the gauze - agonising.	+ -
26	F	They "just came and told me quietly... about the eye being removed and...you know". Not clear.		Coped very well.	+	Good support from hospital staff. Some support from family.	+	"Lovely".	+
27	M	Not clear		Doesn't seem to have particularly enjoyed his time in hospital but doesn't mention any problems when asked. Not clear how he coped.		Support from family	+	"Fair enough... I won't say more". "Quite good"	+
28	F	Did not want to see the area. Sister said "You've got a gaping hole there, haven't you. How do you feel?" Patient thought "Well I'm lucky to be alive. I don't go out a lot. I took it in my stride"... "But you do feel sensitive". The comment made her think the defect was bigger than it actually was. She does not seem to be resentful about the comment.	-	Coped very well in spite of the unhelpful remark by the nursing sister.	+	"Oh, they get upset". She has always been the one who helped to support others in the family.	-	Good apart from unhelpful comment by nursing sister about the defect.	+
29	M	Saw the area when he looked in a mirror. "I thought it was terrible but it didn't worry me much." Coped well.	+	Coped quite well.	+	Not mentioned.		Good	+
30	M	Not mentioned.		Coped very well. Didn't let it affect him.	+	Support from hospital staff and friends.	+	"I was looked after like a king."	+

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
31	M	"It upset me quite a bit but I wasn't really game to face up to it" at first. Ward sisters asked him if he wanted to see it but "They didn't push it". One day he had courage to look, thought it wasn't too bad.	0	Was upset at idea of change in appearance at first but eventually faced this and looked at himself in the mirror.	+	Good support from wife, family, friends.	+	Not mentioned	
32	F	Not mentioned.		"Well"...I just took it all in my stride I suppose". "It's no use complaining. I'd seen others die with cancer". Subject endures her terminal disease with great courage and minimum fuss.	+	Had some support from one son and ?husband. Other son was angry about it, "went berserk when he knew I had to have it done", and "went and abused" the doctors who did the surgery. Patient "didn't want to bother" her own siblings, some of whom were interstate.	+-	"Very good, very attentive."	+
33	M	"It didn't worry me how it looked as long as I felt all right".	+	Coped very well.	+	Good support from family	+	Very happy.	+
34	F	"It was a terrible shock. I will never forget". "I had no idea what I was going to see". The defect was uncovered for the first time in front of a room full of students. They held a large mirror at the foot of the bed for her to see. "Oh, (I) never forget it".	-	Coped very badly with the disfigurement after the shock of how it was presented to her. "I was just quite ... gave up. I wouldn't have tried to fight or done anything" until the prosthesis maker came. He "was really wonderful", gave her hope.	-	Elder daughter was prepared for the disfigurement, but when her eldest grandson (about 12) - who was very close to her - saw her he "just screamed 'What have they done to my grandma' and almost passed out".	+-	Good	+

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
35	M	Saw it as soon as he woke up, family was there. It gave him "a bit of a surprise". "I looked like a Mohawk indian". Thought "...what a bloody mess". Appearance would improve with healing, surgeon explained next day.	0	"It wasn't as bad as I thought it was going to be".	+	Good family support.	+	"Unbelievable". "They do all they can for you"	+
36	M	Not concerned about effect on his appearance	+	Coped very well.	+	Support from wife, family and medical staff. Wife fainted when she saw the defect.	+	Good	+
37	M	"They showed me the bloody mirror" and then told him surgical reconstruction was too risky. Doesn't blame surgeons but very unhappy about his appearance.	-	Coped well after first 2 operations when he had reconstruction. After 3rd operation, when left with defect, was very unhappy. Surgeon suggested he use plastic sun shield (from chemist) that hung down from his glasses over defect, and didn't try to refer him for a proper prosthesis. Shield didn't hide defect properly, would flick up if he sneezed, and looked silly. Knew others in the ward "passed remarks" about him, didn't like it. Subject v. unhappy.	-	Subject attributes his marriage breakup to the facial defect. His wife saying "nothing against you but I just can't stand seeing that every time I wake up in bed". Daughters were supportive. Son said nothing.	+-	Good	+

SUBJ. NO.	SEX	REACTION ON FIRST SIGHT OF DEFECT		SUBJECT COPING OVERALL IN HOSPITAL		SUPPORT FOR SUBJECT BY SUPPORT GROUP		SUBJECT'S COMMENTS ON NURSING STAFF	
38	M	Surgeon v. gentle - explained about the defect and offered to remove the dressing and show him. But subject chose to see himself alone in mirror - nasty shock.	-	Everybody helpful. Other patients good. Keen to be up and about.	+	Doctor, nursing staff and family very supportive. But "felt like jumping out the window" - due to false expectations fostered by well-meaning family/friends who assured him, contrary to advice from surgeon, that he would not "have a hole".	+ +	Very supportive	+
39	F	Not mentioned.		Coped well	+	Good family support. Patient did a lot to support family too.	+	Not mentioned.	
40	M	Took dressing off and looked at it himself in the mirror the night after the operation. It "didn't look very nice" but didn't get emotionally upset by it.	+	Thought it "Didn't look very nice", but didn't get emotionally upset by it.	+	Good family support.	+	Very good	+
41	M	After 4 to 5 days dressing was removed. Wasn't afraid, "the sister got a mirror one time and showed me" - was quite happy about it.	+	Coped well	+	Good support from wife and daughter, but not so clear about his own family. "Camaraderie" among ward patients (all with cancer) and staff, one sister particularly kind and supportive. Visitors - often found himself having to comfort them, helped him to cope. Cancer care counsellors good. One minister who came was "a wreck", "useless".	+	Some "excellent", some were "pigs" ie insensitive, uncaring, bullying. One very kind, supportive.	- +

TABLE 9.3 RETURN TO HOME, COMMUNITY AND JOB

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
1	F	Most difficult after 3rd op., with facial defect. Husband cleaned it - upsetting for patient. If she had to do it - "frightening". Took Amytal. Used dressing. Back to normal home life with some difficulties.	+	Went back when prosth. complete. "Had to get back as soon as possible or wouldn't go back". Felt it would be easier to cope with reactions of workmates to prosth. than public reaction	During first 4 months after 3rd operation went shopping and to see friends with dressing on. People noticed it but didn't treat her differently.	+	Had difficulty coping emotionally with cleaning defect, wearing dressing in public - but made the best of it.	+	They asked to see and accepted defect.	+
2	M	"No worries". "It didn't affect me in any way, you've got to have the right attitude".	+	Back to work with dressing on nose while prosth. being made. "Job wasn't affected in any way"	No problem. People in public "wouldn't say nothing".	+	Very well.	+	Good support from wife, family.	+
3	M	Doesn't seem to have been any problem.	+	No specific mention.	At first thought people might look. Later thought "Oh well, so what?"	+	He thought "Well I can't help this, I'm not going to worry about this"... if he saw someone take a second look.	+	Family accepted his altered appearance "pretty well".	+
4	M	Not mentioned		Not applicable.	"Same as before"	+	No apparent problem	+	"They took it". No apparent probs. with support.	+
5	M	Not mentioned		Not applicable	Went out less than before. Embarrassed.	-	Did not cope well with people staring. Would sometimes challenge with "Do I owe you something?"	-	Wife and friends shocked at unexpectedly large resection, but supportive.	+

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
6	M	No problem growing up at home with congenitally absent ear.	+	School years some embarrassing incidents. Progressed through school and university, no indication of any social or psych. effects.	No specific indication of social activities.		Seems to have coped well - some embarrassing times at school.	0	Good family support always.	+
7	M	Initially depressed. Soon returned to normal	+-	Returned to work but eventually forced to retire by health.	Resumed golf, charity work as soon as possible.	+	Depressed at first but soon overcame this and returned to normal activities.	+	Family coped "pretty well".	+
8	F	Lived alone, no specific problem mentioned.		Not applicable	Could not cope with going out in public. Became isolated at home. Often visited by friends and family.	-	Was depressed for a period. Could not cope with going out in public with a dressing on.	-	Son supportive.	+
9	F	Prior to receiving prosthesis, was at home several months. Isolated herself due to shame about disfigurement.	-	Not applicable	For several months after returning home before receiving prosthesis, avoided social contact - felt like "a monstrosity".	-	Coped badly with the disfigurement. Could not bring herself to look at it for 9 weeks and then was so shocked and ashamed of the disfigurement that she hid herself away from people.	-	No indication	
10	M	Returned to normal life at home.	+	Not applicable.	Returned to normal social activities, friends etc.	+	Coped well - returned to normal. Took the view "Why should I let it worry me?"	+	Seems to have been same as his reaction - no concern.	+
11	M	No problem fitting in at home.	+	Not applicable	Went out, saw friends with dressing on	+	Seems to have coped well	+	"Underneath, were a bit shocked to see it,...but they accepted it".	+

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
12	M	Very difficult. Multiple disabilities, chronic pain. Needed constant by care wife. Unable to walk unassisted for 2 years. Gradual improvement with time.	-	Severe disabilities prevented return to work.	Difficulty with outings due to disabilities and disfigurement. Family and friends would visit him, others have neglected him.	-	Coped with the extreme difficulties with the support of his wife and friends.	+	Not mentioned	
13	M	Not mentioned		Not applicable	Not indicated		Seems to have coped well	+	Very positive	+
14	M	No particular problem mentioned. Was at home 2 months before going back to work.	+	Problem. Former good friend who had filled in for him at work didn't want to give back the job. Patient v. depressed over this - spent 4 weeks in psych. ward - has continuing depression.	Initially didn't go out as much after operation as he had. Gradually returned to normal, social life not affected by disfigurement.	+	Didn't cope well with return to work. Going out in public did not seem to be much of a problem - used a patch.	0	Wife remained as constant as ever. No indication of reaction of other family or friends to appearance.	+
15	M	Not mentioned.		Forced to retire due to physical probs. after operation	Resumed social activity after recovery.	+	Not specifically mentioned		Family coped "no trouble at all". Good support from family, friends.	+
16	M	Home life soon got back to normal.	+	Returned to work after had prosthesis. No problem at work with prosthesis.	Went back to shopping, Rotary etc. "the fellows were wonderful"	+	Coped well after initial concern before dressing removed.	+	Positive reaction. Had good support from family and friends.	+

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
17	M	Not mentioned.		Not applicable.	At first embarrassed going out - but accepted this. After "quite a few weeks" went to tennis. "It never altered me life from then on".	+	After return home was told lesion not malignant. "I just started to live then". (NB: Inconsistency here. Later sent for 25 sessions of radiotherapy).	+	Not mentioned	
18	M	No problem	+	Not applicable	Returned to normal.	+	Didn't prevent normal social activities.	+	Not mentioned	
19	M	Not mentioned. Altered role from bread-winner to dying invalid.		Couldn't return to work	Not clear		Coped. Was offered counselling but didn't feel he needed it. "It sort of hasn't got to me in any way".	+	No less support given due to appearance.	+
20	F	"Exactly the same".	+	Not applicable.	Continued as normal.	+	Coped very well, life continued as normal.	+	Coped "quite well". They all accept it.	+
21	F	Returned to normal as soon as possible. Friends and neighbours very supportive while recovering.	+	Not applicable.	Went out shopping, saw friends.	+	Coped very well. "I didn't make an invalid of myself." Went out without the prosthesis. At first selfconscious, then realised there was nothing to worry about.	+	Positive. When she went out without prosthesis her friends "didn't worry about it".	+
22	F	Daily life unchanged from normal. Used dressing when going out.	+	Not applicable.	As normal.	+	Coped very well. Not concerned about it - just continued on as normal.	+	Not concerned.	+
23	M	Followed surgeon's advice. Returned to normal activities.	+	Not applicable.	Went back to normal activities.	+	Coped well. Dressed the wound himself each day.	+	"Coped well".	+

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
24	M	No problem growing up with congenitally absent ear.	+	Was popular at school. Vice captain in primary school and prefect at high school. Spent 2 years in tertiary course then entered family conveyancing business.	Seems to have been normal, outgoing, popular, plenty of friends.	+	Coped very well. Merely wore hair long to cover the missing ear.	+	Mother was concerned when newborn son found to have abnormal ear, but otherwise no problem.	+
25	F	Not mentioned.		Returned immediately to the family fencing business.	Returned to social activities.	+	Was "very nervous", was advised to keep it uncovered to assist healing. Had some distressing incidents with curious people.	-	Her husband "could never handle it. He still can't handle it". "He still hasn't accepted it". "It doesn't worry the girls".	- +
26	F	No particular problems. Did remarkably well looking after herself and husband without right hand and right eye.	+	Not applicable.	Returned to normal daily activities including shopping. Wore scarf over defect.	+	Coped well.	+	Not mentioned.	
27	M	Stayed at home at first to regain strength. Never regained full function of his right arm he had previously.	0	Not applicable.	Did start to go out again after time resting at home, but not to extent that he had prior to operation. Due to disability not disfigurement.	-	Some difficulty coping at home physically and went out less because less strong.	0	Not mentioned.	

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
28	F	Life at home unaffected (lives alone).	+	Not applicable.	Went out shopping as normal. "You have to".	+	Coped well. "Oh you've got to take things in your stride. Look, you're glad that you're alive". Turns comments by strangers in public into a joke. "Years ago... cancer was something you didn't talk about". "Now, cancer people speak about it".	+	Not mentioned.	
29	M	"Everything went well, very well."	+	Not applicable.	Went out. "I wasn't embarrassed."	+	Coped fairly well.	+	Not mentioned.	
30	M	Went on a holiday to Queensland. No apparent difficulties returning home.	+	Not applicable.	Returned to normal social activities eg seeing friends at the pub, bowls etc	+	Coped well.	+	Positive	+
31	M	Took a long time to regain strength.	0	Did not return to work for 12 months. Light duties only.	Did not go out much at first, still unwell. Eventually back to normal.	→	Made slow recovery at home.	0	Patient and wife were expecting an enucleation of eyeball and replacement with ocular prosthesis. Other family members "a bit shocked at first".	- +

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
32	F	Not mentioned.		Not applicable.	"(It) may not have been so much, but around the same". Used a cardboard patch over the front of her face.	+	Coped remarkably well.	+	One son quiet and supportive. Other son very angry, abused the doctors "for cutting my face ...and scarring it". Husbands reaction not clear.	+ -
33	M	Returned to normal life at home except that can't drive and there are limitations in eating.	+	Not clear.	Returned to normal social activities. Wasn't prevented from going out by concern about how others would react to his disfigurement.	+	Coped very well.	+	Seems to have been very positive.	+
34	F	Spent much time with daughter's family. This helped	+	Started voluntary work at hospital cafe. "They were marvelous in there the way they accepted me".	Resumed going out etc. Effect on social activities not clear.	+	With family support got over the initial shock and depression about her appearance. Coped with help.	+	Eldest grandson very upset about it. Otherwise support group seem to have accepted it.	- +
35	M	Returned to normal social and home activities	+	After 1st op. returned to work. After 2nd op. retired.	Says he resumed normal social activities.	+	Good family support	+	Negative at first (agreeing with subject). Later accepted it.	- +
36	M	The area was dressed by his daughter at home. No problems readjusting to home life	+	Returned to work	Returned to normal social activities.	+	Coped very well	+	Wife passed out when she saw the defect at first.	+ -

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
37	M	Bad. Subject and wife living in caravan. Wife left him, marriage broke up. She said "nothing against you but I just can't stand seeing that every time I wake up in bed". Subject attributes this to defect, and the plastic sun shield the surgeons gave him to use. (Not referred for a prosthesis).	-	Not applicable.	Became socially isolated after his wife left him. "I've been left on my own more or less ever since". Went out freely enough but had problems forming relationships with women.	-	Coped badly with the disfigurement, the inadequate shield, the marriage breakup, the loneliness, the reactions of people in public.	-	Bad. Wife left him, marriage broke up. Daughters both supportive throughout. Little support shown by surgeons who hadn't referred him for a prosthesis.	-
38	M	No problem returning to normal life at home.	+	Not applicable.	Resumed social activities as normal. Covered defect with white pad. No significant problem in public.	+	Very worried about seeing his grandchildren. Once they had seen it and accepted it, had no trouble coping.	+	Delayed return home 2 or 3 weeks - afraid to face grandchildren. They watched him take off dressing and were OK. "I started to live again".	+

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
39	F	Resumed normal role at home as supportive wife and mother.	+	Not applicable.	Returned to going out seeing friends.	+	Coped well.	+	Varied. Husband and elder daughter coped well. Son seems to deny to himself that anything has happened. Younger daughter unable to look at defect. Grandchildren have seen it and accept it. Some friends can talk about it, others don't.	+ -
40	M	Home life has never got right back to normal. Can't work in garden as before. Relationships within the family were normal.	0	Returned to job.	Going out socially was impeded by the need to pack the defect to prevent a sudden outflow of mucus. Then the irradiated skin gets overheated and irritated. Still has friends and goes out.	+	Coped without apparent emotional trauma.	+	Eldest daughter is nursing sister - dresses area for him, no problem. Subject doesn't like other family members to see it because it's not nice to look at.	+

SUBJ. NO.	SEX	READJUSTMENT TO HOME LIFE		WHETHER RETURNED TO JOB	WHETHER NORMAL SOCIAL ACTIVITIES, OUTINGS RESUMED		OVERALL SUBJECT COPING		SUPPORT GROUP REACTION TO APPEARANCE	
41	M	Got back to normal family life quickly. Spent 2½ months at home before returning to work.	+	Returned to desk job (in sales). Edged out after op. because "un-presentable". Went through difficult couple of years trying to find steady job. Seemed to cope well, with wife's support.	Did return to social activities, not clear how soon.	+	Coped well with support from wife, cancer care counsellors at hospital, Christian faith and a particular church service that helped alleviate guilt of cancer.	+	Wife accepted it quickly. Subject's brothers and mother could not accept it so easily, seem to have felt left facial palsy (due to nerve damage) could have been foreseen by doctors; also that treatment was too radical, could have been more conservative.	+ -

TABLE 9.4 RADIOTHERAPY AND CHEMOTHERAPY

SUBJ. NO.	SEX	RADIOTHERAPY - EXPERIENCE OF HAVING THE TREATMENT. THE STAFF.		RADIOTHERAPY - HOW WELL INFORMED ABOUT TREATMENT SIDE-EFFECTS		RADIOTHERAPY - IMPACT OF SIDE EFFECTS, LONG TERM EFFECTS		RADIOTHERAPY - RATING OF EMOTIONAL AND SOCIAL COPING OVERALL		RADIOTHERAPY - SUPPORT FOR SUBJECT BY SUPPORT GROUP		CHEMOTHERAPY - HAVING THE TREATMENT.		CHEMOTHERAPY - PATIENT COPING
1	F	"The treatment itself was nothing". Staff were "great". "You'd see people worse off than yourself."	+	Not mentioned		Afterwards felt "tired". After 2 weeks mouth ulcers, raw throat, some hair fell out, double vision.	-	Seemed to cope well	+	No specific comment-seems to have been good		Not applicable		Not applicable
2	M	Not mentioned.		Not mentioned		Small dose. No side effects.	+	No problem	+	Not mentioned		Not applicable		Not applicable
3	M	No problem. Staff "good". Clanging sound when machine turns on - no problem.	+	Not mentioned		Felt "bone weary" for 6 months after, had to urinate every 2 hours day and night.	-	Found the side effects unpleasant, but coped well	+	Good	+	Not applicable		Not applicable
4	M	Not applicable		Not applicable		Not applicable		Not applicable		Not applicable		Not applicable.		Not applicable
5	M	No problem, "boring". Staff "very good".	+	Not mentioned		"Knocks you around quite a bit". Dry throat, dysphagia, difficulty eating, listlessness, fatigue.	-	Coped quite well	+	Good	+	Not applicable		Not applicable
6	M	Not applicable		Not applicable.		Not applicable		Not applicable		Not applicable		Not applicable		Not applicable
7	M	Had small dosage. No problem with staff.	+	Not mentioned.		Some pain, but ear was painful anyway. No significant problem.	0	No problem	+	Good	+	Not applicable.		Not applicable.
8	F	"Was quite happy about" having it done. Staff were "beaut"	+	Not mentioned		Had loss of memory for about 1 year afterwards. eg couldn't remember how to make her bed.	-	No clear response		Good support from son	+	Not applicable.		Not applicable.
9	F	Not mentioned		Not mentioned		Gathers from doctors that heavy dosage of radiotherapy given many years ago has contributed to constant recurrences of cancer in her nose.	-	No indication		Not indicated		Not applicable.		Not applicable.
10	M	No problem	+	Not mentioned		Hair fell out and later grew back. No concern	0	Seems to have coped well	+	Not indicated		Not applicable.		Not applicable.
11	M	Not applicable		Not applicable		Not applicable		Not applicable		Not applicable		Not applicable		Not applicable

SUBJ. NO.	SEX	RADIOTHERAPY - EXPERIENCE OF HAVING THE TREATMENT. THE STAFF.		RADIOTHERAPY - HOW WELL INFORMED ABOUT TREATMENT SIDE-EFFECTS		RADIOTHERAPY - IMPACT OF SIDE EFFECTS, LONG TERM EFFECTS		RADIOTHERAPY - RATING OF EMOTIONAL AND SOCIAL COPING OVERALL		RADIOTHERAPY - SUPPORT FOR SUBJECT BY SUPPORT GROUP		CHEMOTHERAPY - HAVING THE TREATMENT.		CHEMOTHERAPY - PATIENT COPING	
12	M	Not mentioned		Not mentioned		Not mentioned		Not mentioned		Not mentioned		"Horrible", "painful", nausea, drowsy, "lazy", hungry, thirsty, thinking affected. Had to force himself to accept it.	-	Found it very hard to cope until noticed swelling of the tumour going down. Then he felt happier, more hopeful.	+
13	M	Not mentioned		Not mentioned		Very little problem	+	Not mentioned		Good	+	Not applicable		Not applicable	
14	M	No problem	+	Not mentioned		Little effect, loss of some hair in beard area - not a problem.	0	Resented inconvenience of getting to treatment rooms in the city for 20 visits. Sees this as lack of consideration for patient by the medical profession.	-	Good support from wife.	+	Not applicable		Not applicable	
15	M	Treatment "no problem" Staff "very good".	+	Inadequate. Not told of effects on skin, teeth and jawbone due to radiotherapy. Says he would not have wanted it had he known. Surgery would then have been earlier and less extensive.	-	Burns of irradiated skin were "sheer agony". Jawbone has poor resistance to infection.	-	Not specifically mentioned - seemed OK.		Not specifically mentioned		Not applicable		Not applicable	
16	M	Not applicable		Not applicable		Not applicable		Not applicable		Not applicable		Not applicable		Not applicable	
17	M	"Not too bad"	+	Not mentioned		During the treatment - "makes your throat a bit dry", "can't drink alcohol", had to avoid certain foods. After would have to lie down for about an hour. No after effects, only a little "burning of the skin".	0	Coped well	+	Good support from family.	+	Not applicable		Not applicable	
18	M	Not applicable		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.	

SUBJ. NO.	SEX	RADIOTHERAPY - EXPERIENCE OF HAVING THE TREATMENT. THE STAFF.		RADIOTHERAPY - HOW WELL INFORMED ABOUT TREATMENT SIDE-EFFECTS		RADIOTHERAPY - IMPACT OF SIDE EFFECTS, LONG TERM EFFECTS		RADIOTHERAPY - RATING OF EMOTIONAL AND SOCIAL COPING OVERALL		RADIOTHERAPY - SUPPORT FOR SUBJECT BY SUPPORT GROUP		CHEMOTHERAPY - HAVING THE TREATMENT.		CHEMOTHERAPY - PATIENT COPING
19	M	Treatment no particular problem, staff "tremendous, they can't do enough for you".	+	Not mentioned.		"Depleting". "felt like something the cat had been playing with". "Worn out, just fagged right out". It burned, "like sunburn". Nausea, vomiting "it's just been knocking my system around completely".	-	Coped well in spite of the severe side effects.	+	Good support.	+	Not applicable.		Not applicable.
20	F	Not mentioned.		Not mentioned.		Made nose sore. Went in about 6 weeks.	-	Coped well.	+	Good	+	Not applicable.		Not applicable.
21	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
22	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
23	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
24	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
25	F	First time got frightened by the machine. "They didn't realise I hadn't had anything explained to me." After the explanation it didn't worry her.	-	Not mentioned.		"Very tiring". Had to be stopped for a week "because it was burning all the skin and the surroundings". Some hair loss also.	-	Coped well overall.	+	Good.	+	"That knocked me - I was so sick". "My head and body wanted to go one way and my legs and arms wanted to go another way".	-	Could not cope with it physically. Emotional coping not mentioned.
26	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
27	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
28	F	Not mentioned.		Not mentioned.		Not mentioned.		Not mentioned.		Not mentioned.		Not mentioned.		Not mentioned.
29	M	"No trouble"	+	Not mentioned.		No side effects	+	Seemed to cope well.	+	Not mentioned.		Not applicable.		Not applicable.
30	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
31	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.
32	F	Not mentioned.		Not mentioned.		No side effects	+	Seems to have coped well. Appreciated the hospice accommodation. "Everybody's so good to you that you don't notice the time going". "We had a good crew".	+	Not mentioned.		First week all right. Second week "I was sick everywhere"... "they stopped giving it to me". "(At) one stage they thought they'd lost me" ... "after I'd been that sick".	-	Emotional coping not mentioned

SUBJ. NO.	SEX	RADIOTHERAPY - EXPERIENCE OF HAVING THE TREATMENT, THE STAFF.		RADIOTHERAPY - HOW WELL INFORMED ABOUT TREATMENT SIDE-EFFECTS		RADIOTHERAPY - IMPACT OF SIDE EFFECTS, LONG TERM EFFECTS		RADIOTHERAPY - RATING OF EMOTIONAL AND SOCIAL COPING OVERALL		RADIOTHERAPY - SUPPORT FOR SUBJECT BY SUPPORT GROUP		CHEMOTHERAPY - HAVING THE TREATMENT.		CHEMOTHERAPY - PATIENT COPING	
33	M	No problem	+	Not mentioned.		Unpleasant. Mouth ulcers, difficulty eating, loss of taste, soft diet.	-	Not mentioned.		Good support at all times	+	Made him very ill. Had to be discontinued.	-	Not mentioned.	
34	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.	
35	M	"Good"	+	Not mentioned.		"Knocks you about". After about a week became nauseated and off his food.	-	Any problems? "No not really". Coped well.	+	Good support from family.	+	Not applicable.		Not applicable.	
36	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.	
37	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.	
38	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.	
39	F	Not mentioned.		Well informed	+	Very bad. "Was more or less a vegetable for 6 months." Tiredness, sickness, slowed mental processes. Husband "kept me alive" then "because I couldn't have cared less".	-	Did not cope well. Found after effects extremely distressing. Even now finds it upsetting to discuss.	-	Very good. Particularly from husband.	+	Not applicable.		Not applicable.	
40	M	Very bad. Having treatment "disgusting", frightening, dehumanising, debilitating. One inexperienced person (in training) left on her own for several days to give the treatment. Seemed unreliable, frivolous - worry about this person operating potentially dangerous radiotherapy machine. Patients not supported enough, not cared for enough in waiting room. Had to help each other if sick.	-	Hair loss, fatigue and nausea explained to him "but you couldn't imagine the extent to which it goes". ie much worse for him than was explained. Inadequately informed.	-	Both short and longterm effects had big physical and emotional impact on subject. Mucositis in mouth, nose became dry, spontaneous bleeding from nose, mouth or defect, nausea, vomiting, extreme exhaustion on long trip home daily on the train. Longterm, sensory loss in area of radiotherapy, markedly slowed thought processes.	-	Found the whole experience extremely unpleasant both physically and emotionally.	-	Very good.	+	Not applicable.		Not applicable.	
41	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.		Not applicable.	

TABLE 9.5 PROSTHESES

SUBJ. NO.	SEX	TYPE	MAT-ERIAL	HAVING THE TREATMENT		RETENTION		SHAPE		COLOUR		COMFORT		PUTTING IT ON		PROTECT FROM DAMAGE		CLEANING		FAMILY, FRIENDS REACTION		ESCAPING NOTICE IN PUBLIC		BENEFIT TO SUBJECT OVERALL		PREFERENCE PROSTH OR OTHER		PROSTH COPING RATING	
1	F	Cheek	Acrylic resin	Staff "great"	+	Fixed to glasses with headband. Problems with slipping. Showed defect edge. Glue hurt skin on removal.	-	"Wasn't too bad".	+	"A bit off". People kept looking to see what it was.	-	"Not very comfortable but didn't worry me unduly". Moderately bad.	-	No problem	+	No problem	+	Without glue a nuisance. With glue terrible	-	Husband didn't like it and preferred dressing. Others said not too bad and good as cover	-	People seemed to notice it very readily and look to see what it was.	-	Not much benefit. "Appearance is very important, especially for a woman". Was not used much.	-	Dressing preferred. Seemed to attract less attention than prosthesis	-		
2	M	Nose	Silic. rubber	No prob.	+	"Good". Never any trouble	+	No complaint	+	Uses make up to fix it. Moderately good.	+	No problem	+	No prob	+	No prob	+	No prob	+	Grand children are delighted to see him. "What more do you want?"	+	"public don't hinder me". They look but don't say anything. Moderately good.	+	Good	+	Prosthesis preferred.	+		
3	M	Ear	Silic. rubber	No prob.	+	Good	+	Happy	+	Happy	+	Good	+	"A bit difficult"	-	Good	+	No prob	+	Family happy. Friends laugh. No prob.	+	Acceptable	+	Good	+	Prosthesis preferred.	+		
4	M	Ear	Silic. rubber	No prob.	+	"Stays well"	+	"OK"	+	"Quite happy"	+	"Comfortable"	+	By staff at hostel.		Not mentioned		No problem	+	"They're quite used to it"	+	"Nobody notices it"	+	"Yes"	+	Not asked.	+		
5	M	Part. ear	Silic. rubber	Happy	+	Problem. One adhesive ineffective. Other caused adverse skin reaction.	-	Happy	+	Happy	+	Happy	+	Wife, happy with this	+	Not mentioned		Neutral	0	"They thought it was natural".	+	Happy	+	Good	+	Prosthesis preferred.	+		
6	M	Ear	Silic. rubber	"Cumb-ersome, old-fashion-ed"	-	Not mentioned		Not mentioned		Not mentioned		Heavier than he is used to	-	Not mentioned		Not mentioned		Not mentioned		Not mentioned		Not mentioned		Did not seem to like it. Not clear.		Not mentioned.	-		

SUBJ. NO.	SEX	TYPE	MAT-BRIAL	HAVING THE TRTAMENT		RETENTION		SHAPE		COLOUR		COMFORT		PUTTING IT ON		PROTECT FROM DAMAGE		CLEANING		FAMILY, FRIENDS REACTION		ESCAPING NOTICE IN PUBLIC		BENEFIT TO SUBJECT OVERALL		PREPERENCE PROSTH OR OTHER	PROSTH COPING RATING
7	M	Ear	Acrylic resin	No prob-lem	+	Good	+	Not a good fit at the back. Doesn't worry him. Moderately good.	+	Good	+	Good	+	Wife helps some-times	+	Slight reserva-tion. Moder-ately good.	+	Good	+	"I'm at peace" with support group.	+	Not a problem	+	Good	+	Prosthesis preferred.	+
8	F	Part. nose	Silic. rubber	No prob.	+	Problem	-	Good	+	Neutral	0	Good	+	Problem	-	Good	+	Diffi-cult	-	Good	+	Bad	-	Not clear		Not clear.	-
9	F	Nose	Acrylic resin	No prob.	+	Slight slipping	0	Good	+	Good	+	Good	+	Good	+	No prob.	+	No prob.	+	Good	+	Good	+	Good	+	Prosthesis preferred.	+
10	M	Part. nose	Acrylic resin	No prob-lem	+	Problem	-	Good	+	Good	+	Good	+	Prob-lem	-	No prob.	+	Problem	-	Variable and equivocal.	+-	No prob.	+	Cannot use it	-	Dressing preferred.	0
11	M	Part. nose	Silic. rubber	No prob.	+	Problem. Glue not reliable.	-	Good	+	Neutral	0	Good	+	Neutral	0	Good	+	Bad	-	Good	+	Good	+	Good	+	Prosthesis preferred.	+
12	M	Eye-cheek palate	Acrylic resin	Felt it took too long.	-	Moderately good	+	Moderately good but (Not good fit at edges).	+	Moderately good	+	Moderately good	+	Good	+	Moder-ately good	+	Moder-ately good	+	Good	+	Moderately good	+	Moderately good	+	Prosthesis preferred.	+
13	M	Nose	Acrylic resin	No prob.	+	Problem	-	Moderately good	+	Good	+	Neutral	0	Good	+	Good	+	Good	+	Good	+	Good	+	Neutral	0	Not clear	+
14	M	Eye	Acrylic resin	Too many visits	-	Moderately good.	+	Slight re-servation due to skin contact	+	Good	+	Moderate problem	-	Good	+	Neutral	0	Moder-ately good.	+	Good	+	Good	+	Neutral	0	Prosthesis preferred when out	+
15	M	Ear	Sil. rubber	Good	+	Good	+	Good. (Fit at edges neutral).	+	Good	+	Good	+	Wife does it. Adhes-ive	0	No problem	+	No problem	+	Good	+	Very good	+	Good	+	Prosthesis preferred.	+
16	M	Ear	Sil. rubber	Good	+	Good	+	Good. (Fit at edges neutral).	+	Moderately good	+	Moderately good	+	Wife has to do it. Problem	-	Good	+	Neutral	0	Good	+	Moderately good	+	Good	+	Prosthesis preferred.	+

SUBJ. NO.	SEX	TYPE	MAT-ERIAL	HAVING THE TREATMENT		RETENTION		SHAPE		COLOUR		COMFORT		PUTTING IT ON		PROTECT FROM DAMAGE		CLEANING		FAMILY, FRIENDS REACTION		ESCAPING NOTICE IN PUBLIC		BENEFIT TO SUBJECT OVERALL		PREFERENCE PROSTH OR OTHER	PROSTH COPING RATING
17	M	Bar	Sil. rubber	Good	+	Moderately good. Skin gets a bit sore with adhesive.	+	Good	+	Moderately good	+	Moderately good. Gets sore sometimes with adhesive.	+	Wife or daughter does it. Good	+	No mention		Good	+	Good	+	Good	+	Good	+	Prosthesis preferred.	+
18	M	Nose	Acrylic resin	Prob with impression material.	0	Tends to fall off when he bends forward. Neutral.	0	Better than before.	+	Neutral.	0	"I'm not conscious of it".	+	Does it himself. Moderately good.	+	Moderately good.	+	Moderately good	+	Good	+	Good	+	Neutral	0	Prosthesis preferred.	+
19	M	Eye	Sil. rubber /acryl. resin	Not mentioned		Moderately good. Adhesive lost grip with sweat.	+	Moderately good.	+	Moderately good	+	Problem. Was bearing on unhealed tissues.	-	Did it himself. Moderately good.	+	No mention		Neutral	0	Wife didn't like it but others did. Equivocal.	+	Good	+	Little used. Inconsistent response.		Patch preferred.	-
20	F	Part. nose	Sil. rubber	No problem	+	Good.	+	Good.	+	Good.	+	Problem. Moderately bad.	-	Herself. Took too much time.	-	Good	+	Moderately bad.	-	Good	+	Good	+	Moderately bad	-	No cover preferred.	0
21	F	Bar	Sil. rubber	Good	+	Problem. Tissue changes.	-	Outside OK, fitting side "no good"	-	Good	+	Good	+	Problem Glue in hair.	-	Moderately good	+	Problem glue in hair	-	Good	+	Never used in public		No benefit, not used	-	No cover preferred.	0
22	F	Part. nose	Acrylic resin	No problem	+	Would slip. Funny or minor problem.	-	"Too thick on the end" ... "I didn't expect it to be perfect".	0	"I just accepted it as it was". Would put powder on it.	0	"Not a very comfortable type of thing"	-	No problem	+	Not mentioned		Difficult	-	Accepted it	+	Doesn't know		"It was benefit more or less I suppose".	0	Prosthesis used.	+
23	M	Part. nose.	1.Acrylic resin 2.Sil. rubber	1. Good	+	1. Good	+	1. Good	+	1. Good	+	1. Good	+	1. Good	+	1. Good	+	1. Moderately good.	+	1. Good	+	1. Good	+	1. Good	+	Prosthesis preferred.	+
				2. Good	+	2. Good	+	2. Good	+	2. Good	+	2. Good	+	2. Good	+	2. Good	+	2. Good	+	2. Good	+	2. Moderately good.	+	2. Good	+		
24	M	Bar	Sil. rubber	Good. Some minor discomforts.	+	"Perfect"	+	Good.	+	Good.	+	Good.	+	Neutral. Glue sticks in hair	0	Good.	+	Moderately good.	+	Good.	+	Good.	+	Good.	+	Prosthesis preferred.	+

SUBJ. NO.	SEX	TYPE	MAT- BRIAL	HAVING THE TREATMENT	RETENTION	SHAPE	COLOUR	COMFORT	PUTTING IT ON	PROTECT FROM DAMAGE	CLEANING	FAMILY, FRIENDS REACTION	ESCAPING NOTICE IN PUBLIC	BENEFIT TO SUBJECT OVERALL	PREFERENCE PROSTH OR OTHER	PROSTH COPING RATING
25	F	Eye	Acrylic resin	Not mention ed.	Good +	Good +	Moderately good +	Good +	Good. +	Good +	Good +	Good +	Good +	Good +	Prosthesis preferred.	+
26	F	Eye/ fore- head/ temple	1.Acryl resin 2.Acryl resin	1. Good + 2. Good +	1. Good + 2. Good +	1. Good + 2. Moder- ately bad. - Upper edge of prosth. is too high.	1. Good al- though faded. + 2. Good +	1. Good + 2. Good +	1. Good + 2. Good +	1. Good + 2. Good +	1. Good + 2. Good +	1. Good + 2. Good +	1. Good + 2. Moder- ately bad -	1. Good + 2. "No benefit at all really". - Not used.	Prosthesis preferred.	+
27	M	Part. ear	Sil. rubber	Good +	Good +	Moderately good +	Moderately good +	Moderately good +	Wife does it. +	Not mention ed.	Neutral 0	Good +	Moderately good +	Good +	Prosthesis preferred.	+
28	F	Part. nose	Sil. rubber	Impress ion unpleas- -ant. -	Problem. - Front part comes out. Whole thing comes out when sneezes.	Good +	"Not too bad" 0	Feels as though nose is blocked. -	Needs a mirror +	Good +	Good +	Good +	Good +	Good +	Prosthesis preferred.	+
29	M	Ear	Sil. rubber	Good +	Good +	"Rather large" 0	Good +	Good +	Put on by another person. Some prob- lems. -	Not mention ed.	Not mention- ed.	Most had "no comment". Brother "disgust- ed" that it was too big -	Good +	Good +	Not mentioned.	+
30	M	Eye/ cheek/ temple	Acrylic resin	Good +	Good +	Good +	Good +	Good +	Good +	Good +	Good +	Good +	Moderately good +	Good +	Prosthesis preferred.	+
31	M	Eye	Sil. rubber /acryl. resin	OK +	Problem -	"Fairly good" +	"Very good" +	"Very un- comfortable" -	Moder- ately bad -	Moder- ately good +	Good +	Good +	Conflicting responses. Unclear.	Moderately bad -	Darkened glasses preferred to prosth.	+
32	F	Nose	Acrylic resin	"Didn't worry me". +	Problem - slips down.	Not big enough to cover defect. -	"Could be lighter". "Doesn't worry me". 0	"...not real - comfortable". -	No prob +	Not mention ed.	No problem +	No reaction, except one son "doesn't like it at all". -	People stop and look. "Children are the worst". -	"I guess it is (of benefit) when I go out shopping and that" 0	Prosthesis preferred.	+

SUBJ. NO.	SEX	TYPE	MAT-BRIAL	HAVING THE TREATMENT		RETENTION		SHAPE		COLOUR		COMFORT		PUTTING IT ON		PROTECT FROM DAMAGE		CLEANING		FAMILY, FRIENDS REACTION		ESCAPING NOTICE IN PUBLIC		BENEFIT TO SUBJECT OVERALL		PREPERENCE PROSTH OR OTHER	PROSTH COPING RATING
33	M	Bar, facial plug.	Sil. rubber	No prob.	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Prosthesis preferred.	+
34	F	Nose	Acrylic resin	Not ment-ioned.		Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Prosthesis preferred.	+
35	M	Eye	Acrylic resin	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Prosthesis preferred.	+
36	M	Part. nose	Sil. rubber	Not ment-ioned.		Moderately good	+	Moderately good	+	Moderately good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Good	+	Prosthesis preferred	+
37	M	Part. nose	Acrylic resin	"Mar-vel-ous"	+	Good	+	Good	+	Good	+	Good	+	Moder-ately bad	-	Bad	-	Moder-ately bad	-	Not mention-ed.		Good	+	Good	+	Prosthesis preferred.	+
38	M	Part. nose	Sil. rubber	Not ment-ioned.		(Old) Good	+	(Old) Bad	-	(Old) Bad	-	(Old) Good	+	(Old) - Bad	-	(Old) Good	+	(Old) Good	+	(Old) Good	+	(Old) Moderately bad.	-	(Old) Moderately good.	+	Prosthesis preferred.	+
						(New) Good	+	(New) Good	+	(New) Good	+	(New) Good	+	(New) - Good	+	(New) Good	+	(New) Good	+	(New) Good	+	(New)Good	+	(New)Good	+		
39	F	Eye/cheek	Acrylic resin	Not ment-ioned.		Very good	+	Very good	+	Moderately good	+	Very good	+	V.good	+	Moder-ately bad	-	Very good	+	Variable	+-	Variable	+-	Very good	+	Prosthesis preferred.	+
40	M	Eye	Acrylic resin	Not ment-ioned.		Very good	+	"It was me". Good.	+	"Perfect"	+	Good	+	Good	+	Bad	-	Good	+	Bad	-	Bad	-	None. "I didn't want it".	-	Patch preferred.	0
41	M	Bar	Sil. rubber	"No prob-lem"	+	Moderately good	+	Very good	+	Very good	+	Neutral	0	Moder-ately bad	-	Very good	+	Very good	+	Very good	+	Very good	+	Moderately good	+	Mostly prefers to use no cover.	0

TABLE 9.6 COUNSELLING

SUBJ. NO.	SEX	OFFERED BY WHOM, AT WHAT STAGE	WHETHER SUBJECT WANTED COUNSELLING		VALUE OF COUNSELLING RECEIVED		SUBJECT SUGGESTIONS
1	F	Given after last operation in 1988 by social worker. Not offered before that.	She had it once, would have liked more	+	"Excellent, couldn't praise her enough".... "told me exactly what would happen to me".	+	Would have helped to have counselling about.... . cleaning and dressing the facial defect at home - emotionally upsetting . coping with the disfigurement. "If you could talk to people who have had it done"... "you'd feel a lot better".
2	M	Not mentioned	Didn't have it or want it.	-	He sees that it is helpful to people.	+	Offers to help others going through same experience.
3	M	Given by social workers at hospital, 3 or 4 times while he was there. Saw his wife "nearly every day". "To make sure you had someone visiting"	Patient didn't think he needed counselling. "I can resolve most of my own difficulties".	-	Patient seems to have appreciated the support offered by the social workers.	+	Nil
4	M	None mentioned	Not mentioned		Not mentioned		Nil
5	M	None mentioned	Didn't think it would have made any difference.	-	Not applicable		Nil
6	M	Not mentioned	Not mentioned		Not mentioned		Nil
7	M	Not mentioned	Doesn't seem to think he needed it.	-	Not mentioned		Nil
8	F	Not mentioned	"No definitely not. I'm the sort of person who can cope alone".	-	Not mentioned		Nil
9	F	Not mentioned	Never thought of it, just wanted to cope, doesn't think it would have helped.	-	Not applicable		Nil

SUBJ. NO.	SEX	OFFERED BY WHOM, AT WHAT STAGE	WHETHER SUBJECT WANTED COUNSELLING		VALUE OF COUNSELLING RECEIVED		SUBJECT SUGGESTIONS
10	M	Not mentioned	None offered or wanted. "If you can't get through what's the good of living"? "I've got a life to live, that's all about it". "(I) can't have a bloke sitting on the side of my bed telling me what to do all day". "You've got to take things as they come."	-	Not applicable		Nil
11	M	Not mentioned	Not clear.		Not applicable		Thinks that people who are going to have possibly disfiguring surgery should be warned that it might need to be more extensive than they expect.
12	M	Offered while in hospital by psychologist and/or psychiatrist to help him cope emotionally.	Not indicated		Helped him to cope emotionally while in hospital	+	Nil
13	M	Not offered	"No way" it would have been helpful.	-	Not applicable		Says his years in the Army in WWII helped him to cope.
14	M	Preoperatively surgeon had him speak to a man who had had a similar operation - was helpful. Needed psychiatric treatment for 10 days postoperatively and subsequently for chronic depression.	Had psychiatric counselling after surgery	+	Beneficial	+	Would like to help another person who is facing the same type of operation by talking to them beforehand
15	M	Not offered	"I don't think that would have made any difference".	-	Not applicable		Nil

SUBJ. NO.	SEX	OFFERED BY WHOM, AT WHAT STAGE	WHETHER SUBJECT WANTED COUNSELLING		VALUE OF COUNSELLING RECEIVED		SUBJECT SUGGESTIONS
16	M	During second surgery for radical neck dissection, offered by social workers	Doctor was very helpful in counselling. "It would be hard if you didn't have someone to lean on. It would be difficult to do it yourself".	+	Didn't have much because he felt well supported by the family and both surgeons. What he did have was "very good".	+	Would be of value to speak to someone else who had been through the same experience "provided the right kind of person was chosen".
17	M	Both doctors offered to help if he had any concerns. Also good support from family.	"I didn't need nothing like that".	-	Not applicable		Nil
18	M	Not mentioned	"I think I can handle my own problems".	-	Not applicable.		Nil
19	M	Offered by counsellor at local hospital after he returned home after operation.	"I've never had any need of it". (Had very good support from wife and family).	-	Not applicable.		Nil
20	F	Never offered.	"Do you think I needed it?" (Spends much of her time counselling others about their problems).	-	Not applicable.		Nil
21	F	Not mentioned.	Says she never needed it.	-	Not applicable.		Nil
22	F	Not mentioned.	Any need? "No"	-	Not applicable.		Nil
23	M	Surgeon gave counselling after operation.	Patient very grateful for surgeon's advice, but didn't think he needed to see special counsellor.	+	Surgeon advised him "don't let this interfere with your normal life in any way. This is one of the main things. If you start locking yourself...in home, not getting out and about, you're going to start brooding over it. Just lead your normal life, do your normal things."	+	Thinks it would be a "big help" to talk to another person who has already been through the same experience. Was asked to do this for another patient himself. "In my opinion he's more inclined now to go along and have them (the prosthesis) done".
24	M	Not mentioned.	Not mentioned.		Not mentioned.		Not mentioned.

SUBJ. NO.	SEX	OFFERED BY WHOM, AT WHAT STAGE	WHETHER SUBJECT WANTED COUNSELLING		VALUE OF COUNSELLING RECEIVED		SUBJECT SUGGESTIONS
25	F	Was offered (when and by whom not mentioned)	Not accepted. "I fought it myself". Thought "It's not going to get me" - her daughters were only young. "It was hard"...and (is) even now".	-	Not applicable.		Thinks that it would be helpful to talk to a person who had previously been through the same experience. She would do it for another person.
26	F	Not mentioned.	"No, no." "A lot of them people, I've met them, they've got no will power with them".	-	Not applicable.		Nil.
27	M	Not mentioned.	"No. I don't think so. It's never been a worry that there has ever been any need for counselling".	-	Not applicable.		Nil.
28	F	Not offered.	"No, I don't think they can do anything for you". Thinks the person can only learn what it's like and how to cope by experiencing the problem first hand.	-	Not applicable.		"I think myself it's how you take it, and you work it out yourself." Nevertheless ... "Some people might want it".
29	M	Not understood	Not understood		Not applicable.		Nil.
30	M	Not mentioned.	Did not think he needed to speak to a counsellor.	-	Not applicable.		Nil.
31	M	Offered to wife at the hospital in Sydney, not taken up. Given to patient by eye surgeon, at checkup appointment, about not getting "down in the dumps" and making the most "of what you've got now".	Says he had never really thought about it. Had plenty of support from family and friends. "That would be as good as any".	-	Wife says that counselling of eye surgeon was very good - "Coming from him"... "and with us"... "he's coped".	+	Nil.

SUBJ. NO.	SEX	OFFERED BY WHOM, AT WHAT STAGE	WHETHER SUBJECT WANTED COUNSELLING		VALUE OF COUNSELLING RECEIVED		SUBJECT SUGGESTIONS
32	F	In hospice, when she goes there.	Subject had strength to cope herself, and counselled others. Not clear.		Subject recounts how she has cheered up others in the hospice who have terminal cancer and are depressed.		Subject recounts how she has cheered up others in the hospice who have terminal cancer and are depressed. Also how this is appreciated by the matron.
33	M	Not applicable.	"No". "I never worried about it".	-	Not mentioned.		Nil.
34	F	Not mentioned.	Thinks that without family support would have needed counselling. Could have done with it after the shock of the presentation of the disfigurement.	+	Not applicable.		Nil.
35	M	At hospital, spoken to by social worker.	Says he thinks "it would be nice" to have the chance to talk to someone else who has been through the same experience.	+	Social worker "was good to talk to"	+	Nil.
36	M	Not applicable.	"No". Says he didn't worry about the cancer or the treatment.	-	Not applicable.		Nil.

SUBJ. NO.	SEX	OFFERED BY WHOM, AT WHAT STAGE	WHETHER SUBJECT WANTED COUNSELLING		VALUE OF COUNSELLING RECEIVED	SUBJECT SUGGESTIONS
37	M	Not mentioned.	Didn't have it himself but approves of it, didn't say whether he actually wanted it. Not clear.		Not mentioned.	Advises people with that problem to get a prosthesis because it makes a big difference to how you feel to have your face covered. "Gives you confidence that you can look people in the eye without them feeling sorry for you". Thinks facial prosthesis patients should have counselling to help them cope with the curiosity and comments of others.
38	M	Not mentioned.	Doesn't think so.	-	Not applicable.	Says of coping successfully - "It all depends on your disposition. As long as you don't let it get you down you're right".
39	F	Not mentioned.	Says it would have helped during radiotherapy.	+	Not applicable.	Says she was very lucky because she had the backup from the family and from her doctor who had been a friend from childhood.
40	M	Not mentioned.	"...would have been no good to me". "I'm not that sort of person".	-	Not applicable.	"Counselling for certain people is good". People who have worries about cancer come to him or ring him for advice..."They need it, they need it desperately".

SUBJ. NO.	SEX	OFFERED BY WHOM, AT WHAT STAGE	WHETHER SUBJECT WANTED COUNSELLING	VALUE OF COUNSELLING RECEIVED	SUBJECT SUGGESTIONS
41	M	At diagnosis, by surgeon. After operation in hospital - by minister. After returning home - by cancer care counsellors group - religious "healing" service.	Found it beneficial. Surgeon was very helpful before operation. One religious "healing service" he found helped to alleviate guilt feelings of cancer. Thinks that it would be very good to talk to a person who had already been through the same experience.	Preop. surgeon - very good. Postop. minister - inexperienced, useless. After returning home - Cancer care counsellors and "healing service" good.	NIL

TABLE 9.7 CURRENT CONCERNS, SOCIAL ACTIVITY AND LIFE SATISFACTION

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
1	F	Concern about possible recurrence of cancer at skull base. Copes well.	+	Not specifically mentioned.		Goes out as normal. She and her husband are one of 4 close couples.	+	Much worse. Still the worry about cancer.	-
2	M	Copes well. Aware that attitude to life important. Others are worse off.	+	Calls child over and explains he had an op. and now has a new nose.	+	Normal. Sees family, grandchildren, goes out as normal.	+	Basically as it was.	+
3	M	No particular problems related to operation or prosthesis. "I go for days when I don't even think about it".	+	Hasn't happened to him except once when a small child visiting the house noticed it. Subject was amused.	+	No different from normal	+	"I enjoy life just as much as I did before. I go around as much as I did. I don't hide from the public. If my ear is off I go shopping without it."	+
4	M	Lives in retirement hostel. Has friends, seems cheerful. Some limited mobility of arm and head since op. Life no different from before operation.	+	Happened once. He was amused and just explained to the child that "We don't know what's around the corner at any time".	+	Sees other residents of the hostel as normal.	+	No difference from before to after operation except that he elected to retire after operation (many years before entering hostel)	+
5	M	Lives at home with wife. Maintains some social activity. Wears head bandage over ear if going out (can't use prosthesis due to further surgery since prosth. made). Facing loss of eye and possibly life in operation 2 weeks after interview.	-	Children didn't comment - unclear		Reduced compared with before original disfiguring operation.	-	Had been getting back to normal with the prosthesis but then needed more surgery and could not use it any more - still under treatment.	-

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
6	M	Is an accountant, covers his congenitally missing ear by having his hair long. Slight problem that other people at work don't wear their hair as long as he does... "that doesn't bother me".	+	No problem	+	Not mentioned		Not applicable	
7	M	Coping well, life back to normal. No specific concerns.	+	No problem	+	Golf with friends, charity activities.	+	Back to normal	+
8	F	Not coping well. Won't go out. Friends and family visit her at home. Misses social activities. Prosthesis is a problem. With many illnesses the problem is transient. But "this (the disfigurement) I have for the rest of my days - and that upsets me".	-	Doesn't mind children because they are "curious".	+	Inactive. Does not like to go out due to public reaction to prosthesis. Misses going to exhibitions etc. Sees her friends at home. Son is in daily telephone contact.	-	Worse because she doesn't go out.	-
9	F	Lives in retirement village where others only recently have become aware that she has a nose prosthesis. Has normal level of social activity, apparently acceptable level of life satisfaction.	+	No particular problems. doesn't see children - unclear.		Back to normal	+	Now much same as it was before the loss of her nose.	+
10	M	Says his daily life has "never altered" since he first had the skin cancer. Not concerned about reactions of public to his face - "I've got pretty thick skin". Copes very well.	+	There has been some episode with children reacting to his disfigurement "but if you let things like that worry you, you won't get very far at all" ie copes well.	+	Normal. Active in the golf club, gives speeches etc, no interference with social life at all.	+	Patient says it has "never altered"	+

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
11	M	Seems to cope well, and lead normal life. Good family support, they say "Well Dad, you look alright whether you wear it or you don't".	+	"(It) doesn't worry me". One was "pretty persistent" so he made up a funny story to explain.	+	Goes out shopping and to see friends etc. Uses prosth. when seeing friends, problem with slipping. When shopping uses dressing. Most people take no notice. Doesn't get "unduly upset" if they do, although it "makes you realise you look a bit different from most people".	+	"I don't think it's altered a great deal".	+
12	M	Takes a positive attitude. Every year improves in physical capabilities, range of activities.	+	Sometimes encounters inquisitive children in public. Doesn't worry him, just ignores it.	+	Doesn't go out much except to hospital for checkup, shopping, but not often because "some people don't give you a chance". Some friends and relatives have "disappeared" since he had his illness - makes him feel "Now I just don't feel I want to see anyone any more". But does go to evening computer classes and gets positive responses from some people there - that is helpful	-	Daily life now very different from before the illness... due to disabilities, facial disfigurement (not completely hidden by prosthesis), inability to work.	-
13	M	Copes very well. Has normal home life, with wife. Regularly sees his family, and goes out for a walk and shopping.	+	Doesn't cope well with inquisitive children, avoids them.	-	Doesn't have any particularly close friends, but knows many people in the home units where he lives and in the shopping centre. Contact with family and friends is not diminished.	+	Compared with before he had the problem with his nose, family life would be much the same, but he goes out "nowhere near" as freely as he used to.	-

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
14	M	Similar to before the operation.	+	Children don't notice the prosthesis. If he wears black patch they notice, stare and may ask questions. This is not problem.	+	Social activity same as before the operation.	+	Much the same.	+
15	M	Jaw resection - makes eating v. difficult. Loss of hearing on right side. Hearing aid "troublesome". Can't see well. "But you get used to everything... if you have the right attitude"	+	Not well. Finds it embarrassing if they draw attention to his ear. Sees friends children, grandchildren.	-	Sees his children, grandchildren and friends, and plays in bridge tournaments.	+	"Quality of my life is now way below what it was" due to jaw resection and loss of hearing right side. Too disabled to work now, which he did before surgery.	-
16	M	Copes well, lives at home with wife.	+	No problem. Was principal at a primary school - there was never any comment by the children. "Part of that might be how I react too...normality (sic)"	+	Rotary, church, and has close friends	+	Life much the same as it was before the operation.	+
17	M	Lives at home with family, has close friends. No problems mentioned.	+	Doesn't seem to have a problem.	+	Goes out to tennis and to the club, "no worries". Notices people staring at him at times, "you know they're doing it but they never say anything". Perhaps some aggressive feeling towards this but didn't mention any incident.	+	"Yes...I'm relaxed, quite contented...no worries". Seems to mean that the worry about the cancer is over and life is back to normal.	+
18	M	Leads full and active life. Interests in fitting and turning, photography, home computer and animal psychology. Intensely practical person.	+	Has never been concerned about reactions of others to disfigurement. "I haven't had any psychological problems that I'm aware of".	+	Has many close friends.	+	Disfigurement and prosthesis have made no significant impact on his daily life.	+

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
19	M	Has terminal cancer. Stays home, is taken for palliative radiotherapy by wife. Leaves him very weak and ill. Can't do any work "No strength at all in my back." Uses eye patch. Copes as well as could be expected.	+	Not mentioned.		Still goes out shopping, has close friends.	+	Very much more restricted, waiting to die.	-
20	F	Leads very full and active life at home with her husband as she has always. Others come to her for help, advice and emotional support. She is far too busy to worry about the disfigurement or using the prosthesis.	+	Not mentioned.		Has many friends and acquaintances, wants to study at night classes. Far too busy to let the disfigurement interfere with her schedule.	+	"Exactly the same"	+
21	F	Copes very well. "I think I'm richly blessed" as to the outcome of the operation.	+	No problem. Any that notice, she just shows the prosthesis and explain in simple terms to satisfy their curiosity.	+	She is popular with neighbours and friends. "Down at the pensioners (club) where I go"... "they're all very supportive."	+	"Not at all (different), no, in fact it's richer. I'm still the same person."	+
22	F	Normal daily life. Wasn't troubled at any stage by the disfigurement. Took problems with prosthesis with a grain of salt. Has now had surgical reconstruction.	+	"I don't think so". Doesn't seem to have had problems.	+	Bowls and the club. Has friends.	+	"Same difference." Made it clear that her life was back to normal.	+
23	M	Life is back to normal. Patient had surgical reconstruction after using the prostheses for about a year.	+	No problem now. (With the prosthesis "You would always think of some answer to give").	+	Sees friends regularly, goes fishing, does part-time greenkeeping etc.	+	Same as before illness.	+

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
24	M	Copes very well. "I just live as normally as possible - that's the only way to do it."	+	Not mentioned.		Normal, has plenty of friends. "If people can't accept you like that, I mean, they're not worth knowing anyway".	+	Not applicable.	
25	F	Daily life now much as it was before she became ill. "I will admit I get more cranky and irritable than what I used to get". "I still get very tired...it knocks you a bit. I don't think I ever get over it.. Little things that didn't worry me, now do worry me".	0	Says they don't worry her "any more" ie may have bothered her at first.	+	Normal. Attention of acquaintances is sometimes offensive and sometimes reassuring. Equivocal.	+	Much same as before illness except that she is now more irritable. Her husband is still unable to accept the disfigurement and/or cancer - the daughters can accept. Not clear.	
26	F	Life at home is normal. She lives alone, is very active and in good spirits.	+	No problem. She understands that they notice.	+	Has many friends and acquaintances, goes shopping etc.	+	No different from before.	+
27	M	The disfigured ear causes little problem at present and prosth. is helpful. Main problem is disability of right arm since operation, limits his activities at home.	-	"Very rarely" any incident with children. Didn't mention how he copes.		Goes out but not as much as he did before the operation due to lower strength, not due to disfigurement or prosthesis. Has friends but not very close.	0	The operation made a big difference to his life because of the disabled right arm that resulted. This has restricted his activities at home significantly.	-
28	F	Lives alone, copes very well in spite of problems with the prosthesis coming partially dislodged at the front. Has a great fund of common sense and wisdom about coping with life.	+	"Children always look twice" and then touch that part of their faces. Ever a problem? - "Oh no. Children are wonderful".	+	Goes shopping etc normally. Has contact with many acquaintances, friends and neighbours.	+	Says it's better than before because then her nose was always bleeding and sore "and everyone would look at you". "It's made a great difference".	+

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
29	M	Says life at home is unchanged since before the major operation on his ear.	+	Not aware of a problem	+	"My periods in hospital"... "removed all my social activities". "I used to go to the Club every day"... "seeing friends, getting their views". "After a period in hospital of 4 or 5 months, you forget all that, and the alcohol". "You think 'Well, if I can go without it that long, why can't I go without it all together and save money?'"	0	Less active at home and socially. At present prosthesis cannot be used because the tissue shape of the prosthesis site has changed and the prosthesis will no longer stay in position.	-
30	M	Daily life now is as it was before the operation. It "never changed".	+	(With amusement) "Oh they'd have a little pick" ... "They'd say 'What's that mister?' There are no problems, no worries".	+	Plays bowls, drinks with friends, watches TV with a friend, drives a taxi from time to time. Same activities as before surgery.	+	"Never changed. I do the same things".	+
31	M	Copes well with good support from family and friends. Thinks his mental processes are slowed since the illness, and memory now poor. Tires much more quickly than before illness. Sometimes doesn't judge distance properly having only one eye. Has "a down day" occasionally, but talks himself out of it by thinking "Well, there's always somebody worse off than I'll ever be".	+	Strange children in the park (where he works) sometimes comment to their parents "That man's only got one eye". It doesn't worry him - "I'm used to it".	+	Goes to the bar and the club. His friends call him "one-eyed bastard". He says "(it has) done me a lot of good". "My friends have helped me a lot".	+	Patient feels that physically he is not as strong and less capable than he used to be, and that his thought processes are slower. His activities have not been affected by the change in appearance.	-

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
32	F	Has inoperable progressive BCC of mid-face. Has radiotherapy in 5 week session intermittently for palliation. Very matter-of-fact and brave in carrying on as normal, without fuss, and not wanting to bother others because she says there is nothing they can do. Doctor said "I've never seen anybody so determined not to give in". She replied "Well why give in - you've still got life haven't you? And"... "you can still get about".	+	"Children are the worst". "...kids will try to get under your nose"... "and look (up) like that". "One girl on the train the other day - about 10 or 11 - she got the giggles over it". "She thought I was being funny with a funny nose". "I've got that way now that it doesn't worry me".	0	Goes shopping. Goes out "quite a bit". "Go for a day out, have lunch out". Don't go with others, usually just for a drive. Not many friends. Mentioned at one stage about other terminally ill cancer patients whose cancer is not on the face. "I can't walk down the street like they can - nobody could tell that they ever had it".	+	Not mentioned.	
33	M	Patient copes very well, enjoys living at home with his wife and seeing his children, grandchildren and other relatives and friends. "...as I say - we've got something to live for" (because the doctors have been so good). Can't drive and is limited in ability to eat and swallow, and can't eat out because of leakage of food through orofacial fistula, but has accepted these limitations. "(I) just accepted it"... "it doesn't worry me". "I'm here and I can get around".	+	Relates 2 incidents with delight about small boys who noticed his face or his artificial ear in public, and how he answered the question.	+	Having the disfigurement and the prosthesis have not prevented him from going out. Is happy to ask acquaintances what they think of his new ear. Doesn't notice whether people are looking and doesn't care if they are.	+	Very similar to how it used to be. "I've made it that way". He misses the car which he can no longer drive due to vision problems but he has adapted to this. "It doesn't really make that much difference". "I'm here and I can still get around".	+

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
34	F	Currently life is normal. Lives alone in unit, but with regular daily/weekly contact with daughter who lives in Sydney.	+	Finds situations with inquisitive children very difficult.	-	Has friends among local residents.	+	"More or less the same"	+
35	M	After operations and prosthesis, life at home returned to normal. (Now, having more radiotherapy for recurrent disease - is quite ill.)	+	Says he doesn't worry about it now, but in the beginning it did. "They just stand there and stare at you"... "at the start it used to worry me a bit".	0	After the operations and prosthesis life returned to normal. Not well at present, has friends in local area who visit. He doesn't go out much.	+	Daily life returned to normal after operations and prosthesis.	+
36	M	Home life is normal. Has no concerns about the defect or the prosthesis.	+	"Never struck it" - unclear.		Goes to the club, golf and sees friends.	+	"...except that I've retired, nothing's changed at all".	+
37	M	Cites disfigurement as primary cause of his problems. "It has really bugged my life". "It has ruined my sex life". Socially isolated in caravan 14km from country town. Lonely, depressed, wants to die, fears becoming ill and being a burden to others. "Afternoons are the worst". Often drinks, watches TV. Fortnight before interview took overdose of sleeping pills - found and saved by chance visitor.	-	Copes badly. "Kids used to upset me more than anything". Now, says he's used to it, just "doesn't hear it". Ignores it. Says you can't blame them for being curious.	-	Has few visitors to caravan, except his daughter (sees her each week), "no actual friends". Prosthesis has enabled him to go to clubs etc. New lady friends are usually supportive when he tells them he's disfigured, but they're put off when he takes his glasses/prosthesis off - "You see a different look come in their eyes straight away"... "it doesn't do terrible much for the romance does it?" Has resisted both daughters repeated offers to live with them. Doesn't want to intrude.	-	Much different. Before was a married man with his own house, car and job. Now is divorced, socially isolated, desperately lonely, depressed, even suicidal.	-

SUBJ. NO.	SEX	SUBJECT COPING, CURRENT CONCERNS OVERALL		COPING WITH INQUISITIVE CHILDREN		SOCIAL ACTIVITY		DAILY LIFE COMPARED WITH BEFORE ILLNESS	
38	M	Lives in country town with daughter and family. Keeps busy gardening, mowing, fencing, ploughing. People treat him as they always did.	+	No problem. Simply explains what happened and warns them to keep out of the sun.	+	Goes to RSL and golf club regularly. Meets his brother and friends regularly.	+	Same as before.	+
39	F	Lives normal life with husband, sees family frequently, regularly. Concerns about somewhat harsh attitude of husband now that things have returned to normal.	+	Not mentioned.		Normal social activity.	+	Not mentioned.	
40	M	Subject seems to live relatively normal daily life at home, with family and sees friends as often as he feels like it.	+	Enjoys explaining to them and showing them if they ask for a look. Sees it as a means of establishing contact with them.	+	Less socially active now than he used to be, mainly because he doesn't accept all offers. Not to extent of social isolation. Still goes to club with friends. Says he had to reevaluate his friends after operation, some were genuine friends, others were not.	+	Life has never returned to being "normal" as it was before the operation. There are certain things he cannot do (and will never be able to do) exactly as he could before the operation eg gardening, interacting socially, due to the presence of the defect, leakage of mucus, loss of sight, irritability of irradiated skin.	-
41	M	Lives normal life at home with his family. Had a difficult couple of years due to operation, mother-in-law's death overseas and with unemployment. Getting over that now.	+	Enjoys explaining to them about it, no problem.	+	Normal social activity. Mostly doesn't use prosthesis, area hidden by hair.	+	Much the same.	+

TABLE 9.8 SURGICAL RECONSTRUCTION

SUBJ. NO.	SEX	SUBJECT RESPONSE		SUPPORT GROUP RESPONSE		FEELING IN PUBLIC COMPARED WITH WHEN USING PROSTHESIS		SOCIAL ACTIVITY COMPARED WITH WHEN USING PROSTHESIS	
1	F	Much happier with this than prosthesis. But was once told before op. that she was having "plastic surgery". Assumed this meant "cosmetic surgery", and that she would look better than ever - wrong. It was reconstruction of defect area.	+	Not specifically mentioned.		Much more relaxed.	+	Much much easier than with prosthesis	+
2	M	Not applicable		Not applicable		Not applicable		Not applicable	
3	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
4	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
5	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
6	M	Not considered		Not applicable.		Not applicable.		Not applicable.	
7	M	Not applicable		Not applicable.		Not applicable.		Not applicable.	
8	F	Not done		Not applicable.		Not applicable.		Not applicable.	
9	F	Not applicable		Not applicable.		Not applicable.		Not applicable.	
10	M	Not applicable		Not applicable.		Not applicable.		Not applicable.	
11	M	Not applicable		Not applicable.		Not applicable.		Not applicable.	
12	M	Not applicable		Not applicable.		Not applicable.		Not applicable.	
13	M	Has had surgical reconstruction in the past and prefers it to prosthesis, but at present reconstruction is only partly completed. Therefore he is still disfigured, but cannot use the prosth.	+	Not specified.		When completed patient feels better with the reconstruction.	+	Not made clear	
14	M	Not applicable		Not applicable		Not applicable		Not applicable	
15	M	Not applicable		Not applicable		Not applicable		Not applicable	

SUBJ. NO.	SEX	SUBJECT RESPONSE		SUPPORT GROUP RESPONSE		FEELING IN PUBLIC COMPARED WITH WHEN USING PROSTHESIS		SOCIAL ACTIVITY COMPARED WITH WHEN USING PROSTHESIS	
16	M	Not applicable		Not applicable		Not applicable		Not applicable	
17	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
18	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
19	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
20	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
21	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
22	F	"Well if it could be better it could be a Hell of a lot worse". There are still some surgical refinements to made "otherwise I'm satisfied the way it is".	+	Not mentioned.		"Oh, definitely (better)"	+	"Same difference". No significant difference because social activity was not affected by disfigurement any-way.	0
23	M	Patient prefers it. "You're back to normal".	+	Not mentioned.		Back to normal ie as good or better than prosthesis.	+	The same, social activity not diminished with prosthesis.	0
24	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
25	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
26	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
27	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
28	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
29	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
30	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
31	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
32	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
33	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
34	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
35	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
36	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	

SUBJ. NO.	SEX	SUBJECT RESPONSE		SUPPORT GROUP RESPONSE		FEELING IN PUBLIC COMPARED WITH WHEN USING PROSTHESIS		SOCIAL ACTIVITY COMPARED WITH WHEN USING PROSTHESIS	
37	M	Had it after first 2 operations, returned to normal social/daily activities. (Couldn't have it after last operation due to heart condition - social problems ensued.)	+	Good - to surgical reconstruction.	+	No adverse effects reported when had surgical reconstruction. (With prosthesis, people sometimes stare or comment. Bars him from close relationships with women).	+	With reconstruction, no adverse effect on social activity reported. With prosthesis, problems with forming close relationships with women.	+
38	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
39	F	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
40	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	
41	M	Not applicable.		Not applicable.		Not applicable.		Not applicable.	

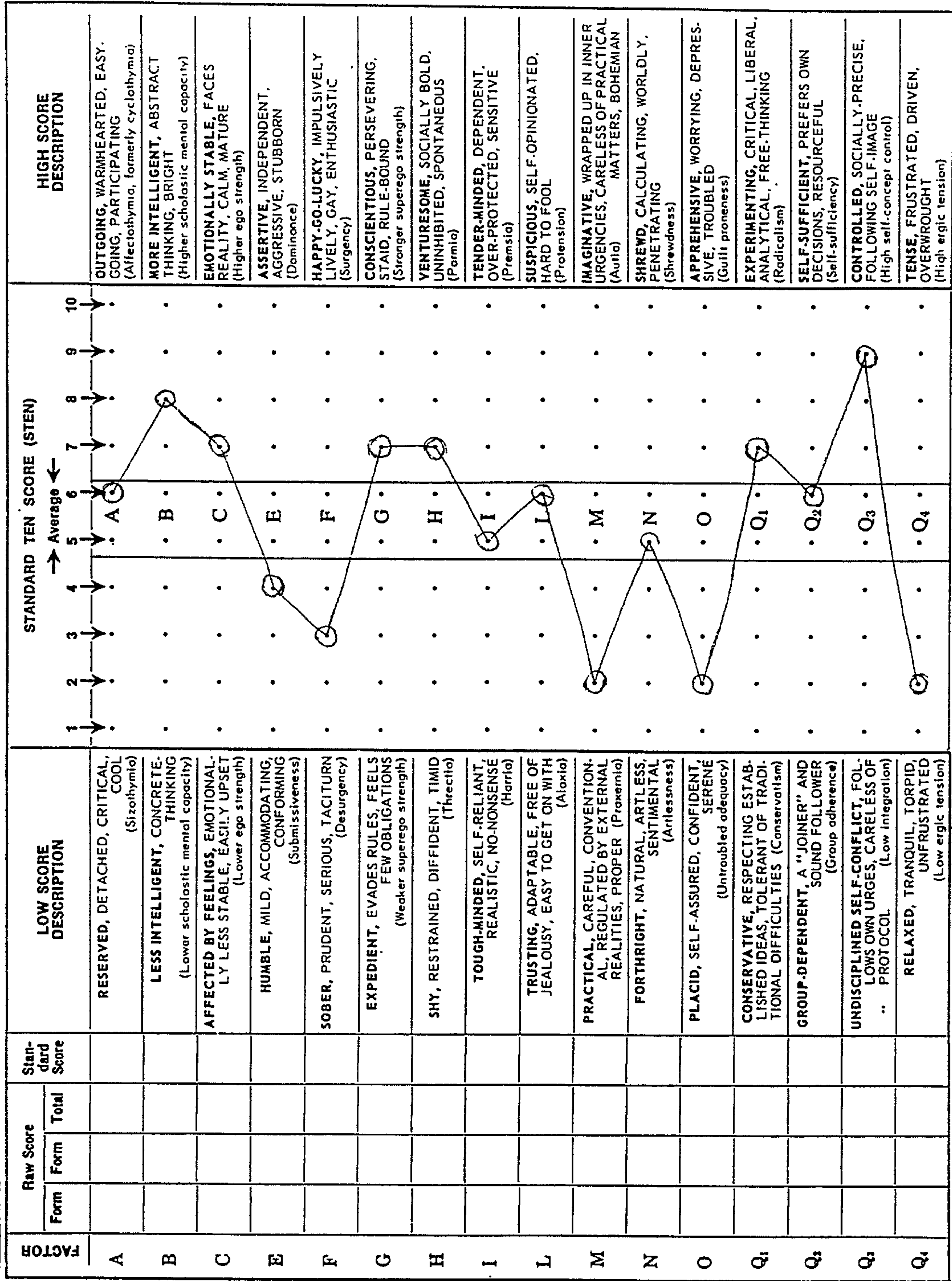
APPENDIX 10

16 PERSONALITY FACTOR TEST PROFILES OF SUBJECTS¹

¹ 16 PF Test not done by subjects 4, 9, 11, 22, 29, 32 and 33.



16 P.F. TEST PROFILE



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A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

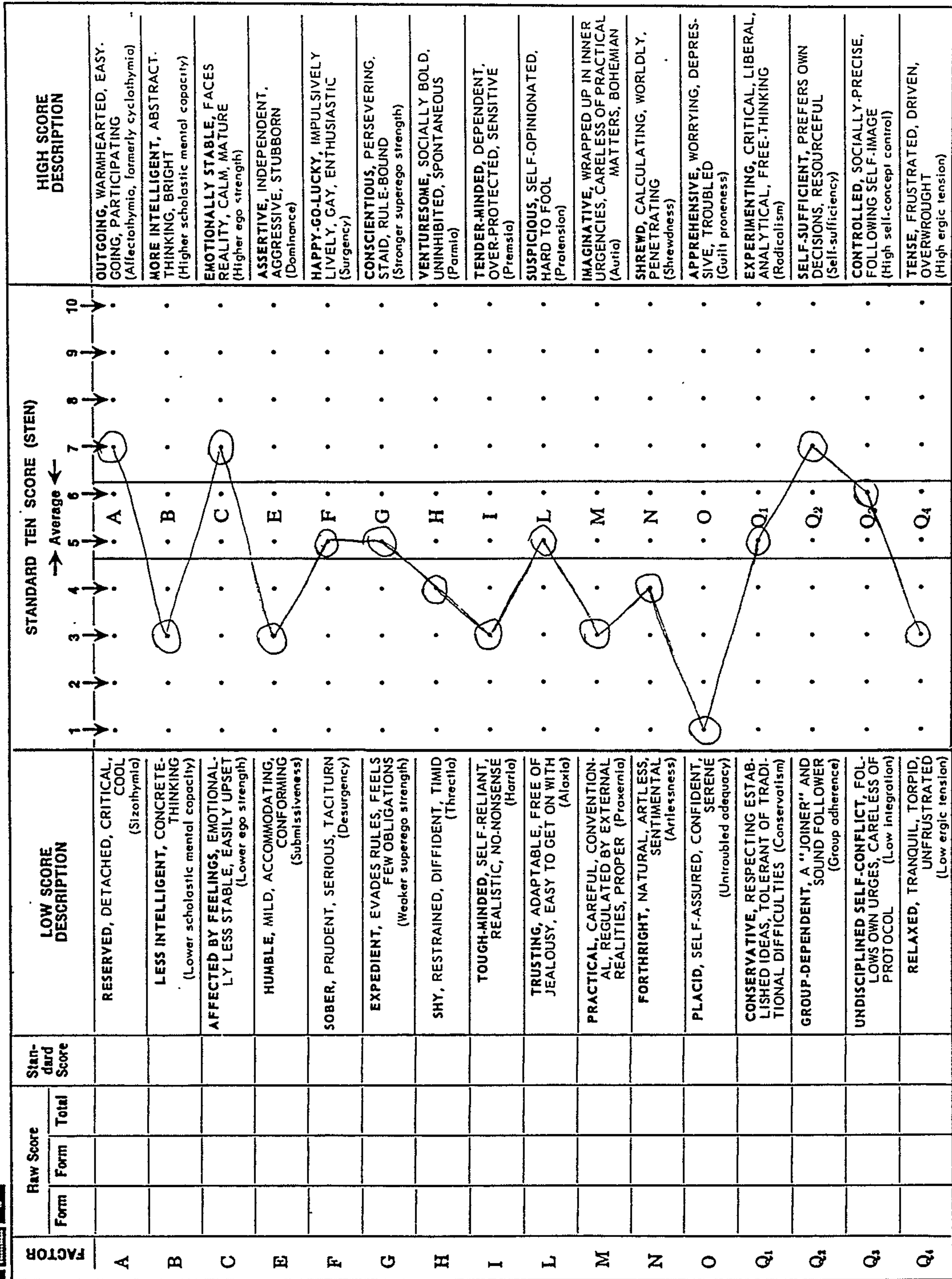
DP. 15M 11/75

Motivational distortion sten score (IPAT Staff, 1979).

Comments:



16 P.F. TEST PROFILE



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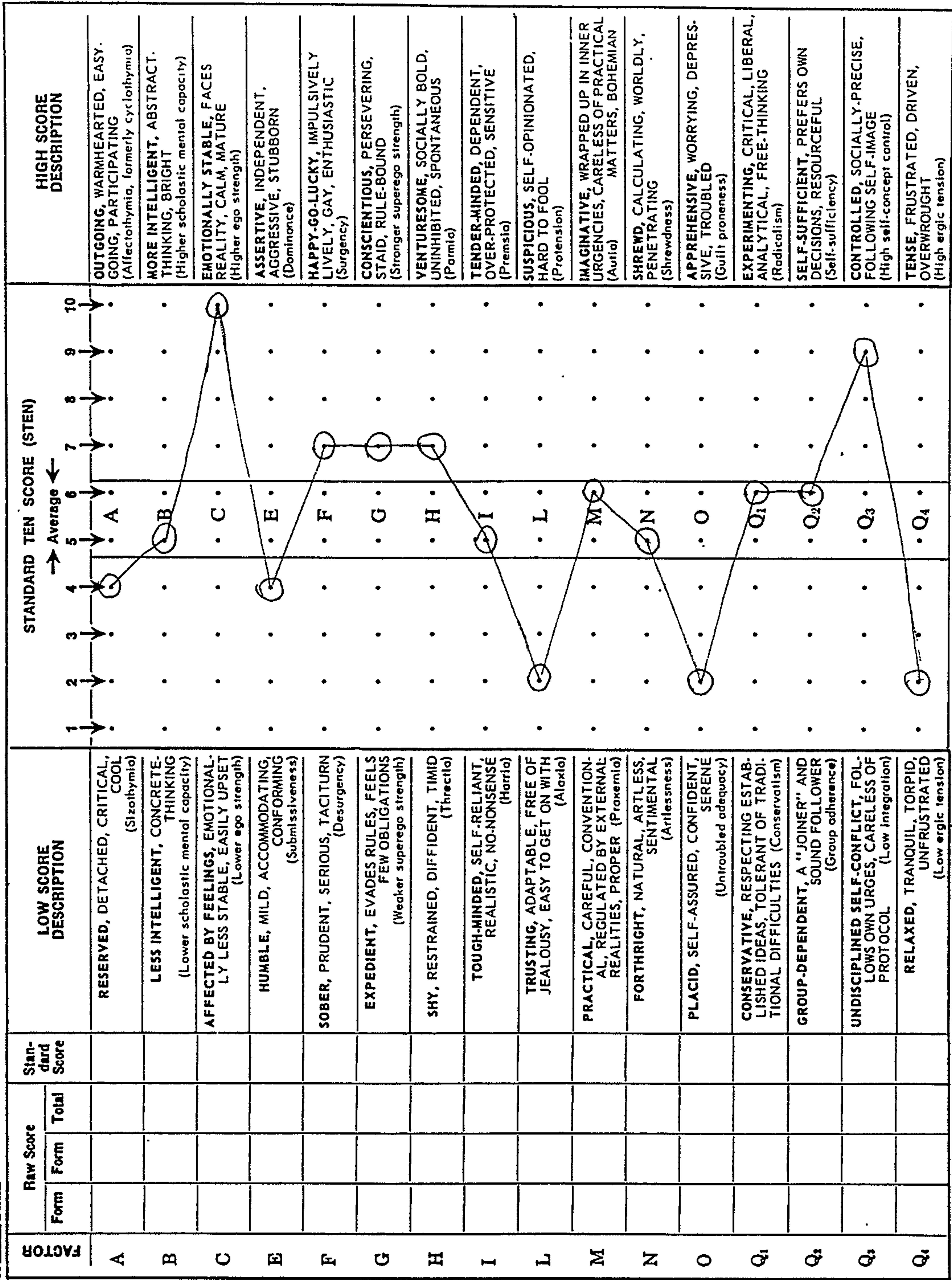
A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE



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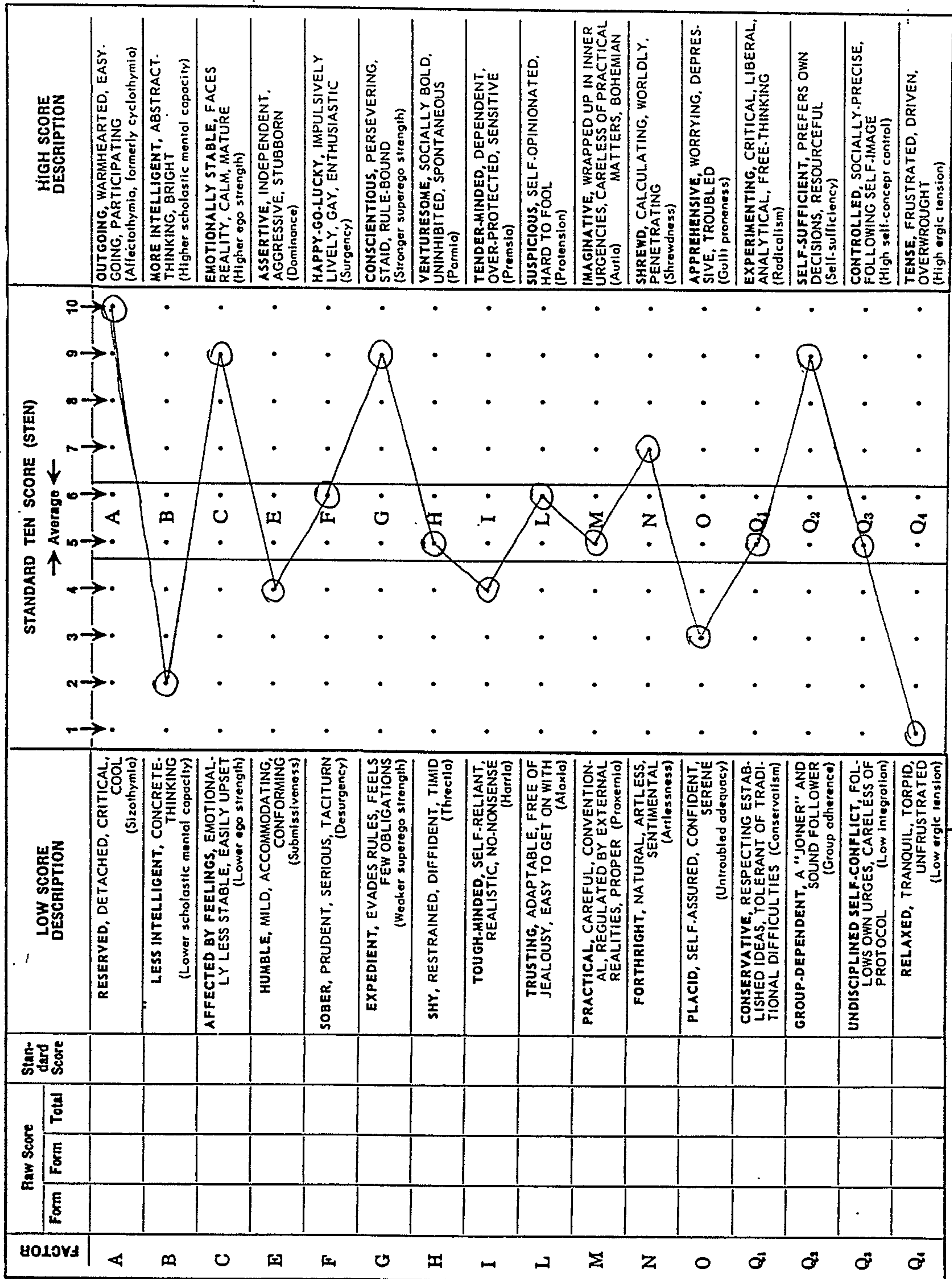
A sten of 10 is obtained by about 2.3% of adults

DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE



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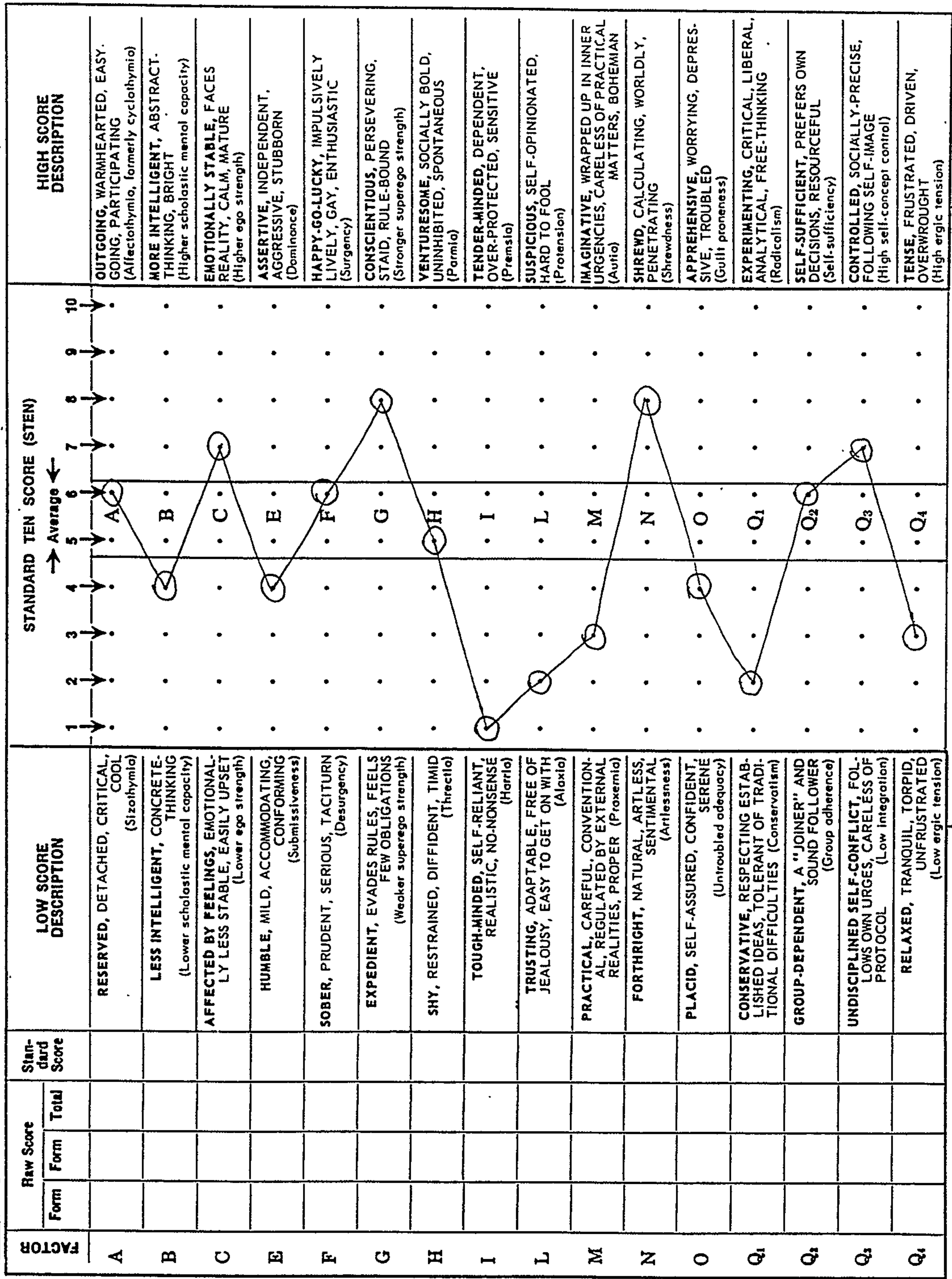
A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP: 15M 11/75

Comments:



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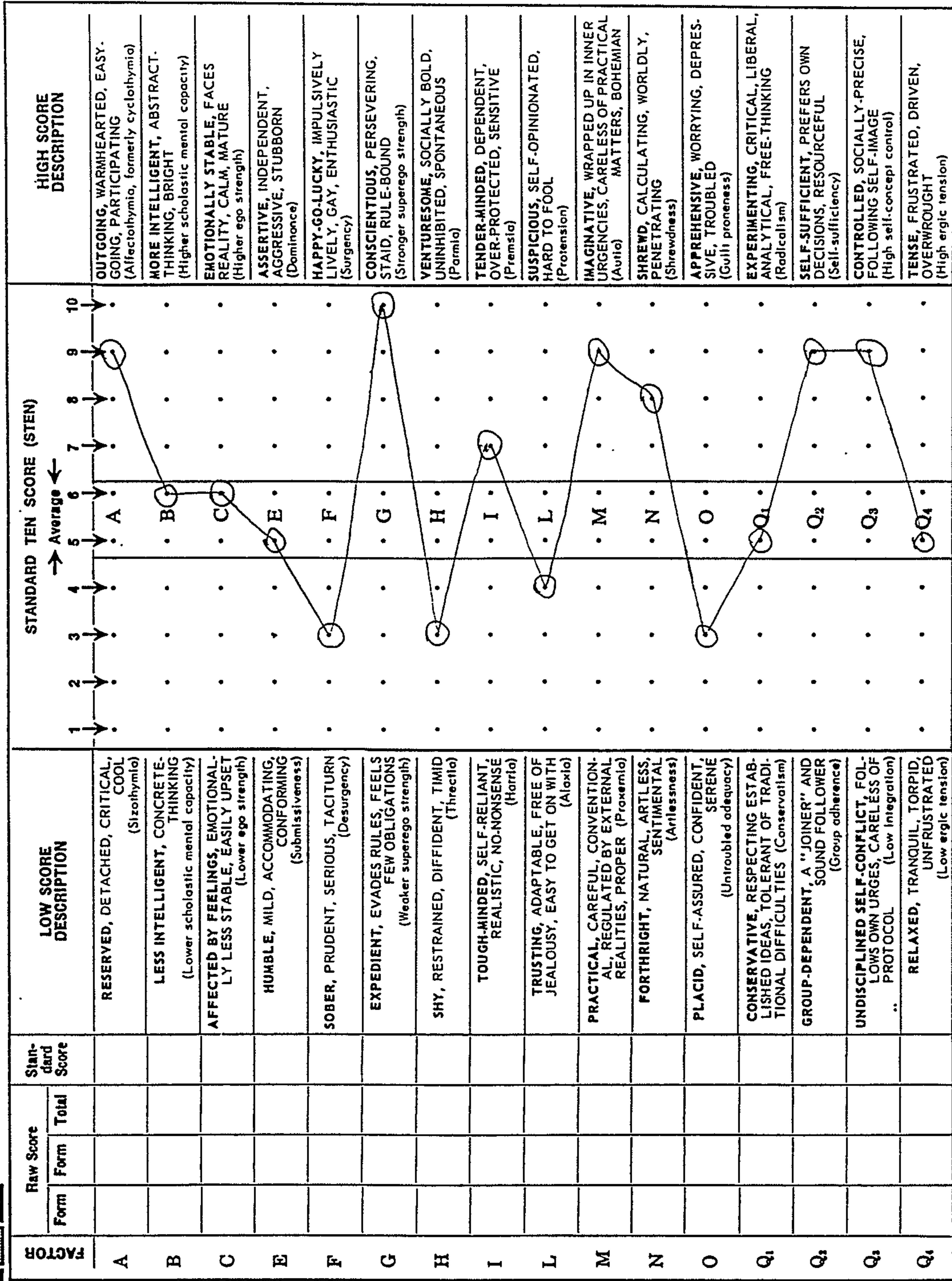
Comments:

A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP. 15M 11/75



16 P.F. TEST PROFILE



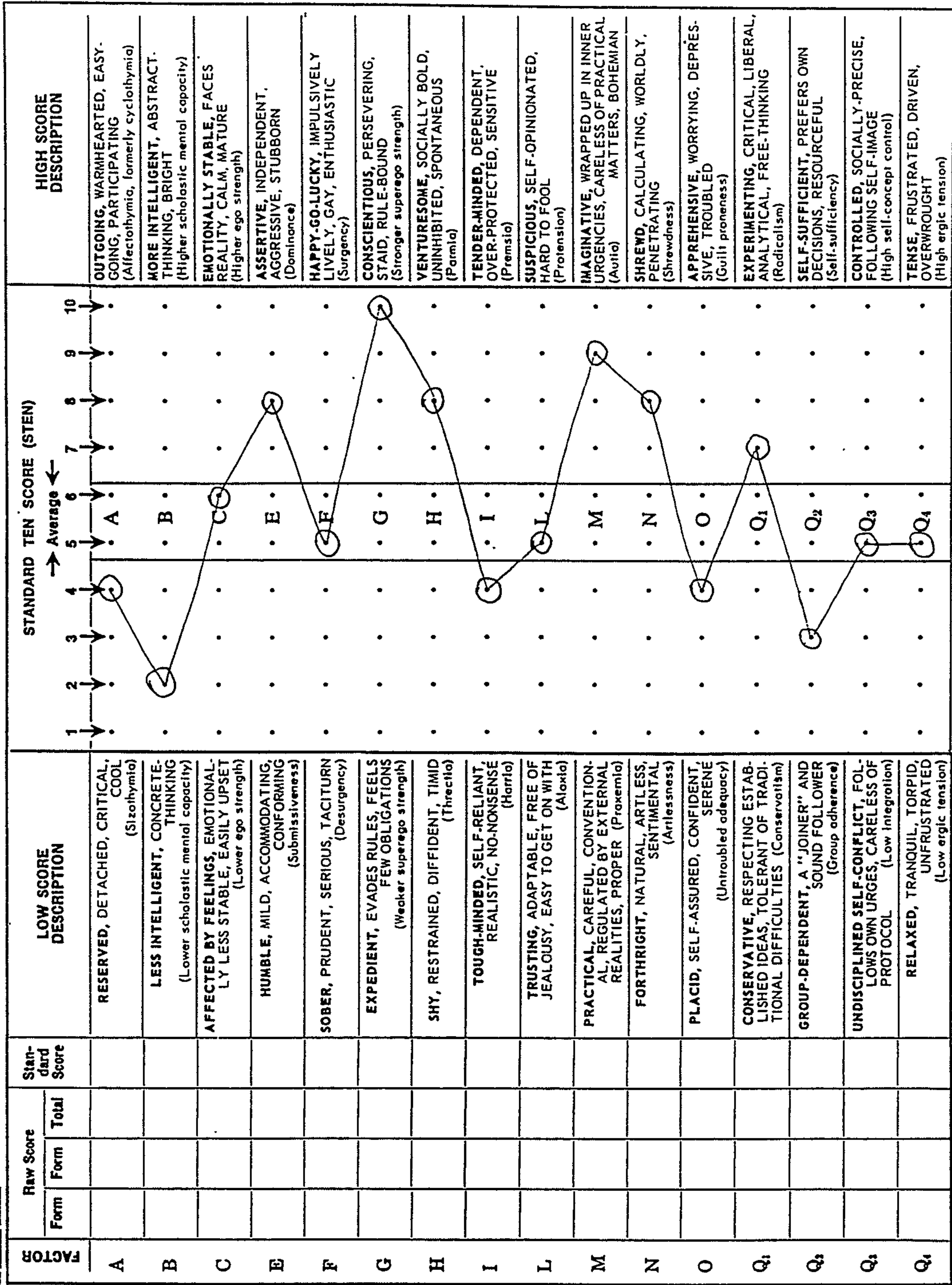
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DP. 15M 11/75

Comments:



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Comments:

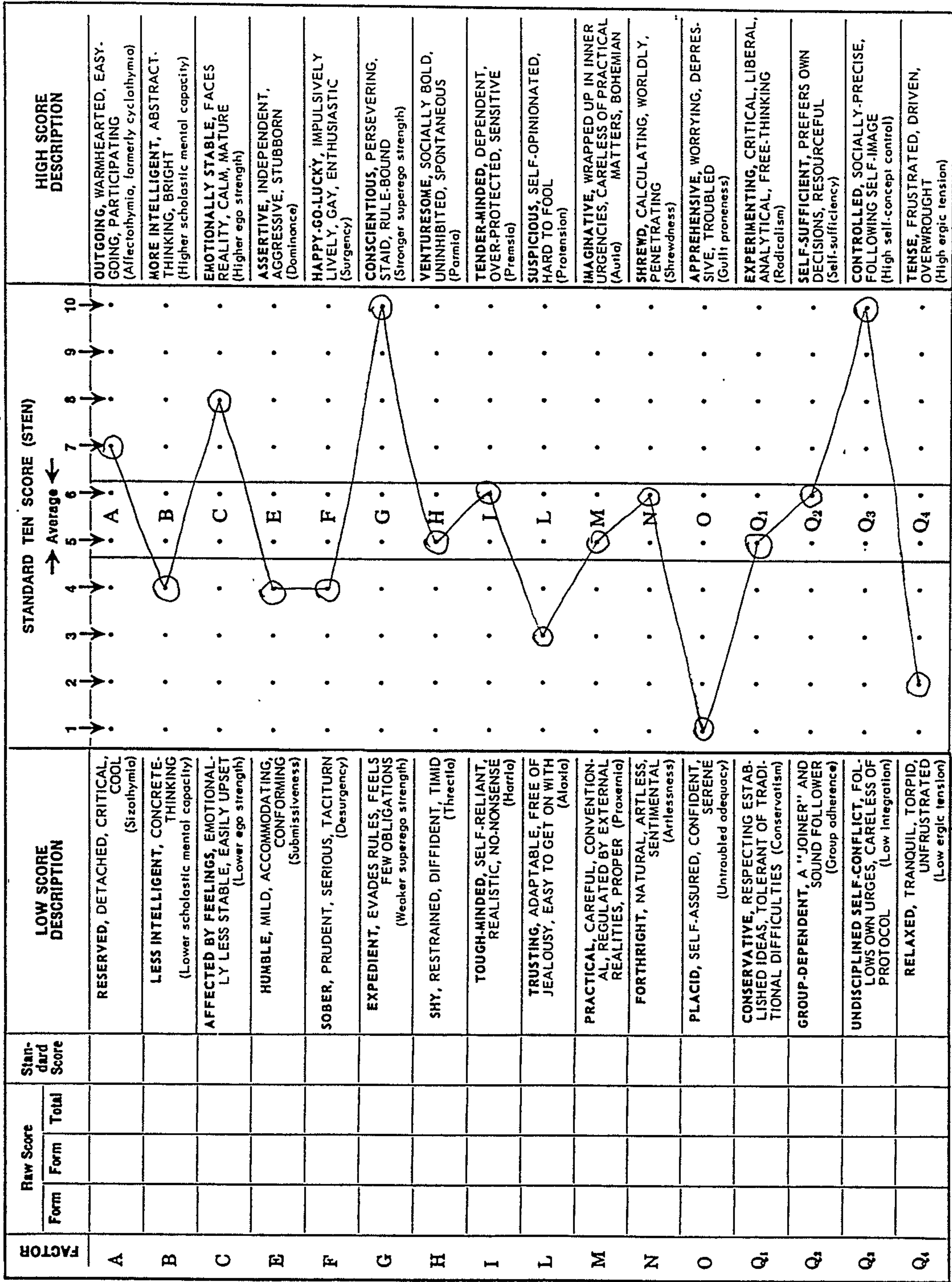
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A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP. 15M 11/75



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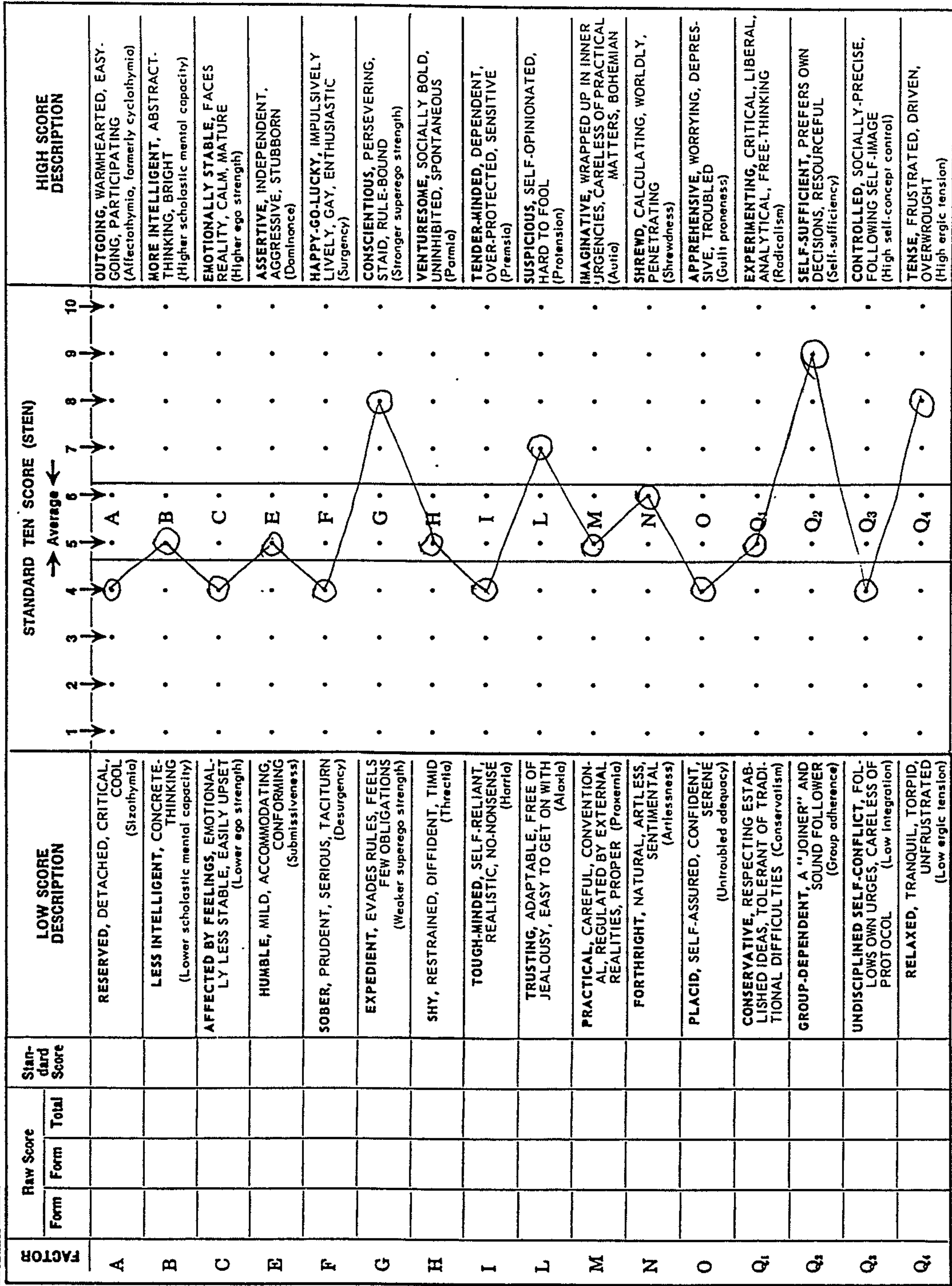
Comments:

DP. 15M 11/75

A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults



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DP. 15M 11/75

Comments:

16 P.F. TEST PROFILE

SUBJECT 13

Age-corrected scores. MD= 6

FACTOR	Raw Score			Standard Score	LOW SCORE DESCRIPTION	STANDARD TEN SCORE (STEN)											HIGH SCORE DESCRIPTION
	Form	Form	Total			1	2	3	4	5	6	7	8	9	10		
A					RESERVED, DETACHED, CRITICAL, COOL (Sizothymia)	.	.	.	.	.	A	.	.	.	.	.	OUTGOING, WARMHEARTED, EASY-GOING, PARTICIPATING (Affectothymia, formerly cyclothymia)
B					LESS INTELLIGENT, CONCRETE-THINKING (Lower scholastic mental capacity)	.	.	.	.	.	B	.	.	.	.	.	MORE INTELLIGENT, ABSTRACT-THINKING, BRIGHT (Higher scholastic mental capacity)
C					AFFECTED BY FEELINGS, EMOTIONALLY LESS STABLE, EASILY UPSET (Lower ego strength)	.	.	.	.	.	.	.	.	.	C	.	EMOTIONALLY STABLE, FACES REALITY, CALM, MATURE (Higher ego strength)
E					HUMBLE, MILD, ACCOMMODATING, CONFORMING (Submissiveness)	.	.	.	.	.	E	.	.	.	.	.	ASSERTIVE, INDEPENDENT, AGGRESSIVE, STUBBORN (Dominance)
F					SOBER, PRUDENT, SERIOUS, TACITURN (Desurgency)	.	.	.	.	.	.	.	.	.	F	.	HAPPY-GO-LUCKY, IMPULSIVELY LIVELY, GAY, ENTHUSIASTIC (Surgency)
G					EXPEDIENT, EVADES RULES, FEELS FEW OBLIGATIONS (Weaker superego strength)	.	.	.	.	.	.	.	.	.	G	.	CONSCIENTIOUS, PERSEVERING, STABLE, RULE-BOUND (Stronger superego strength)
H					SHY, RESTRAINED, DIFFIDENT, TIMID (Threptic)	.	.	.	.	.	.	.	.	.	H	.	VENTURESOME, SOCIALLY BOLD, UNINHIBITED, SPONTANEOUS (Parric)
I					TOUGH-MINDED, SELF-RELIANT, REALISTIC, NO-NONSENSE (Harric)	.	.	.	.	.	.	.	.	I	.	TENDER-MINDED, DEPENDENT, OVER-PROTECTED, SENSITIVE (Premia)	
L					TRUSTING, ADAPTABLE, FREE OF JEALOUSY, EASY TO GET ON WITH (Alaxia)	.	.	.	.	.	.	.	.	L	.	SUSPICIOUS, SELF-OPINIONATED, HARD TO FOOL (Protension)	
M					PRACTICAL, CAREFUL, CONVENTIONAL, REGULATED BY EXTERNAL REALITIES, PROPER (Proxemia)	.	.	.	.	.	.	.	.	M	.	IMAGINATIVE, WRAPPED UP IN INNER URGENCIES, CARELESS OF PRACTICAL MATTERS, BOHEMIAN (Auric)	
N					FORTHRIGHT, NATURAL, ARTLESS, SENTIMENTAL (Artlessness)	.	.	.	.	.	.	.	.	N	.	SHREW, CALCULATING, WORLDLY, PENETRATING (Shrewdness)	
O					PLACID, SELF-ASSURED, CONFIDENT, SERENE (Untroubled adequacy)	.	.	.	.	.	.	.	.	O	.	APPREHENSIVE, WORRYING, DEPRESSED, TROUBLED (Guilt proneness)	
Q ₁					CONSERVATIVE, RESPECTING ESTABLISHED IDEAS, TOLERANT OF TRADITIONAL DIFFICULTIES (Conservatism)	.	.	.	.	.	.	.	.	Q ₁	.	EXPERIMENTING, CRITICAL, LIBERAL, ANALYTICAL, FREE-THINKING (Radicalism)	
Q ₂					GROUP-DEPENDENT, A "JOINER" AND SOUND FOLLOWER (Group adherence)	.	.	.	.	.	.	.	.	Q ₂	.	SELF-SUFFICIENT, PREFERS OWN DECISIONS, RESOURCEFUL (Self-sufficiency)	
Q ₃					UNDISCIPLINED SELF-CONFLICT, FOLLOWS OWN URGES, CARELESS OF PROTOCOL (Low integration)	.	.	.	.	.	.	.	.	Q ₃	.	CONTROLLED, SOCIALLY-PRECISE, FOLLOWING SELF-IMAGE (High self-concept control)	
Q ₄					RELAXED, TRANQUIL, TORPID, UNFRUSTRATED (Low ergic tension)	.	.	.	.	.	.	.	.	Q ₄	.	TENSE, FRUSTRATED, DRIVEN, OVERWROUGHT (High ergic tension)	

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A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP. 15M 11/75

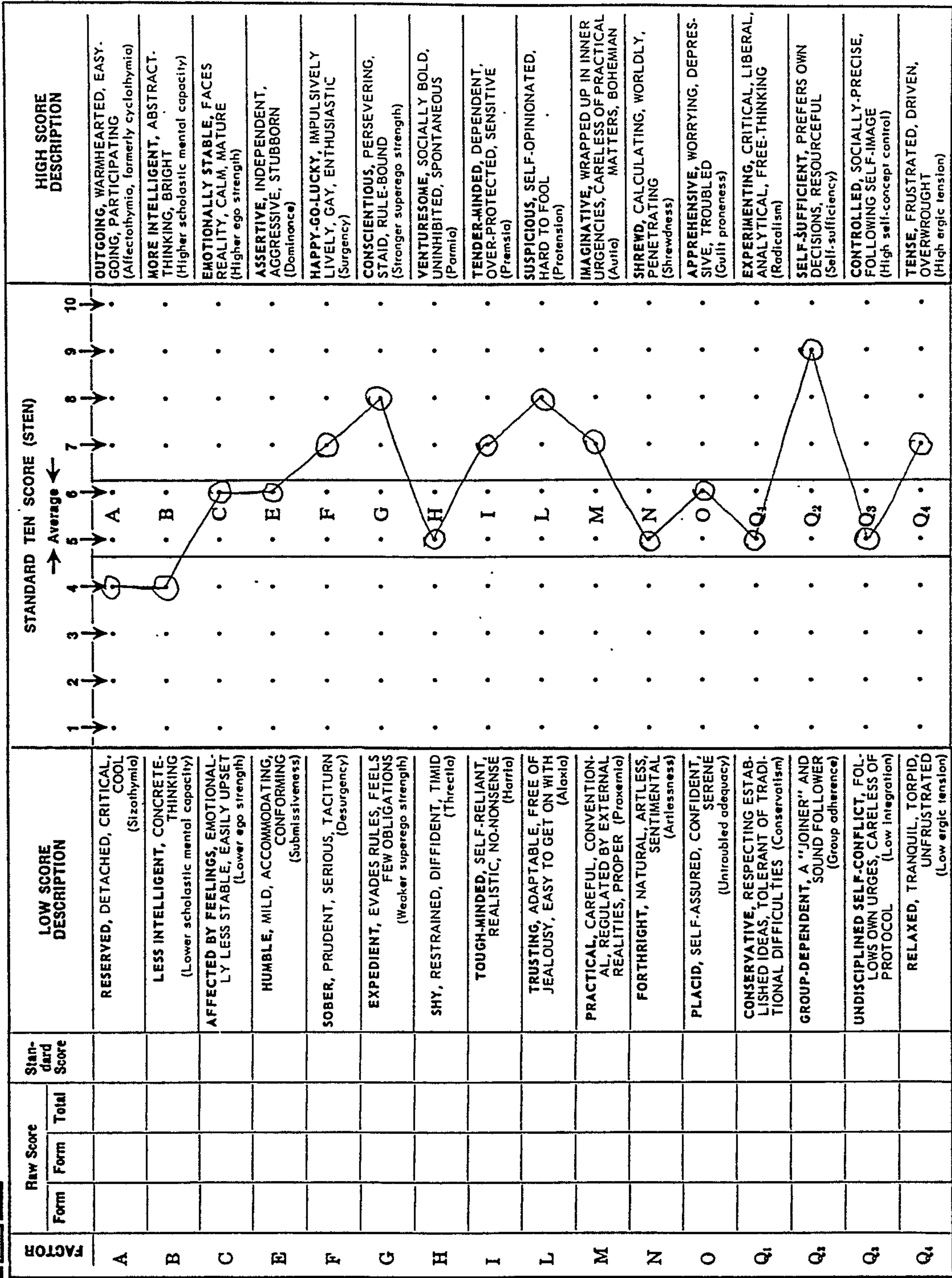
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Comments:

SECRET



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A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

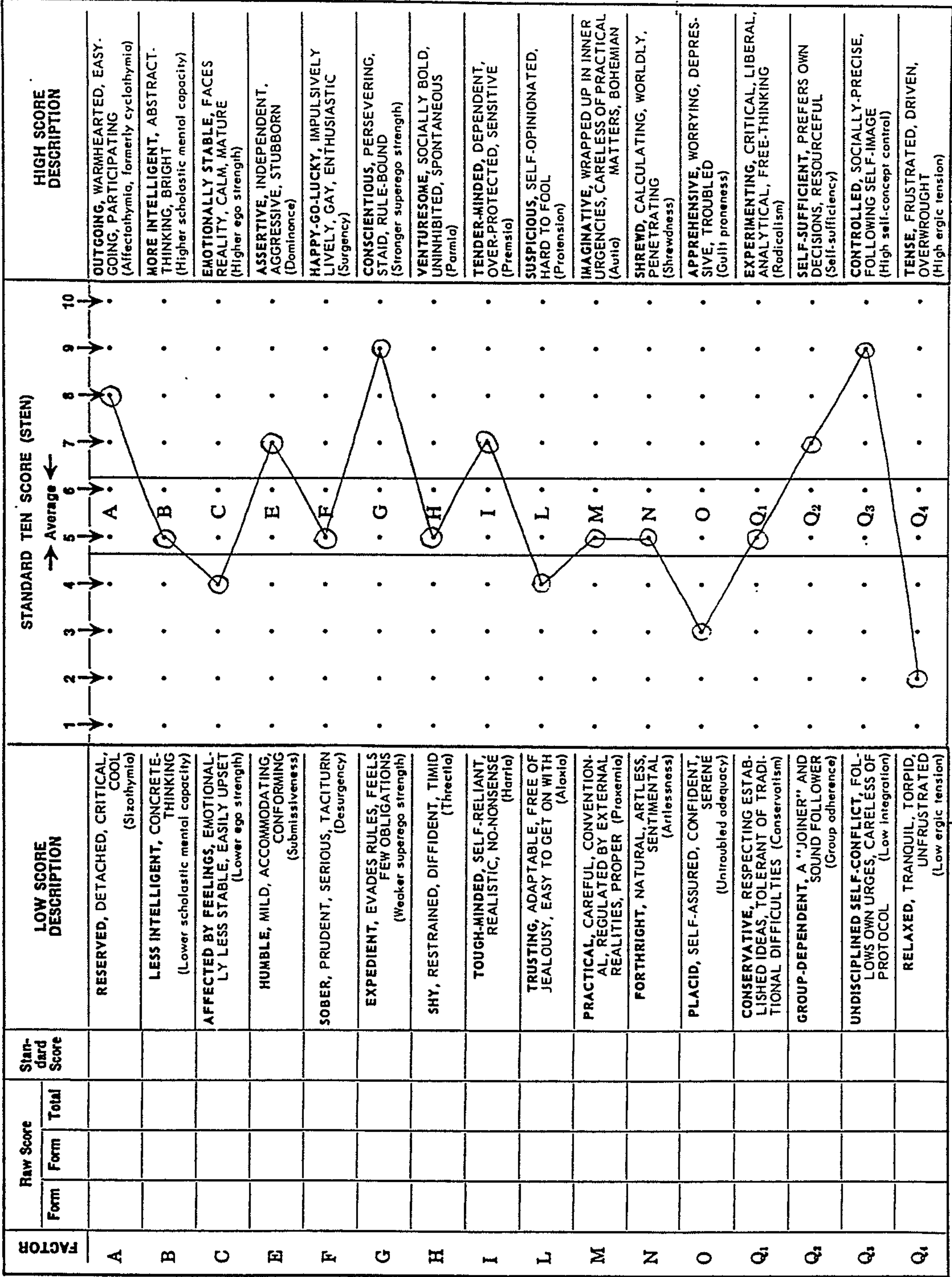
DP, 15M 11/75

Comments:

SUBJECT 15

Age-corrected scores. MD= 7

16 P.F. TEST PROFILE

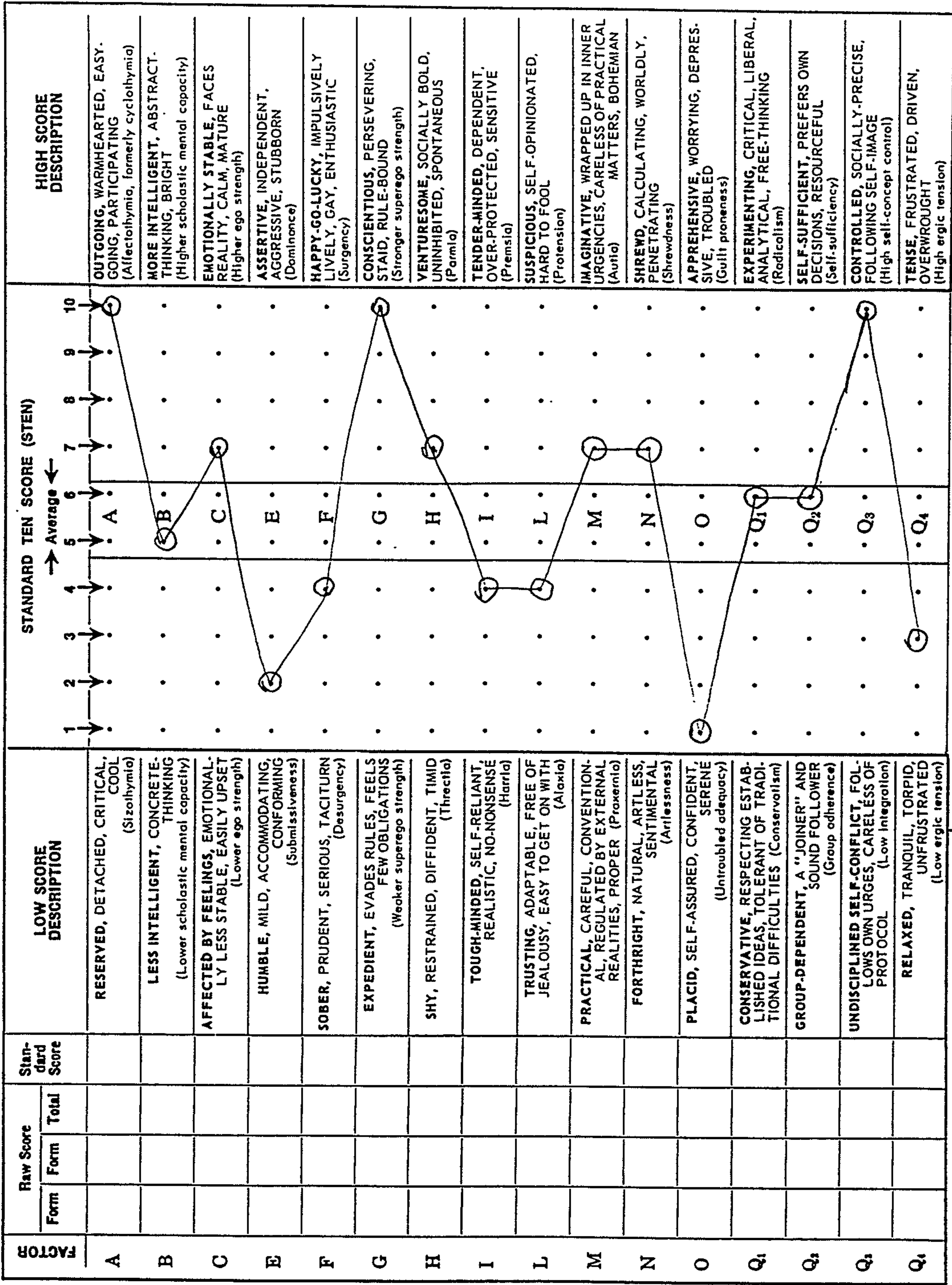


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Comments:



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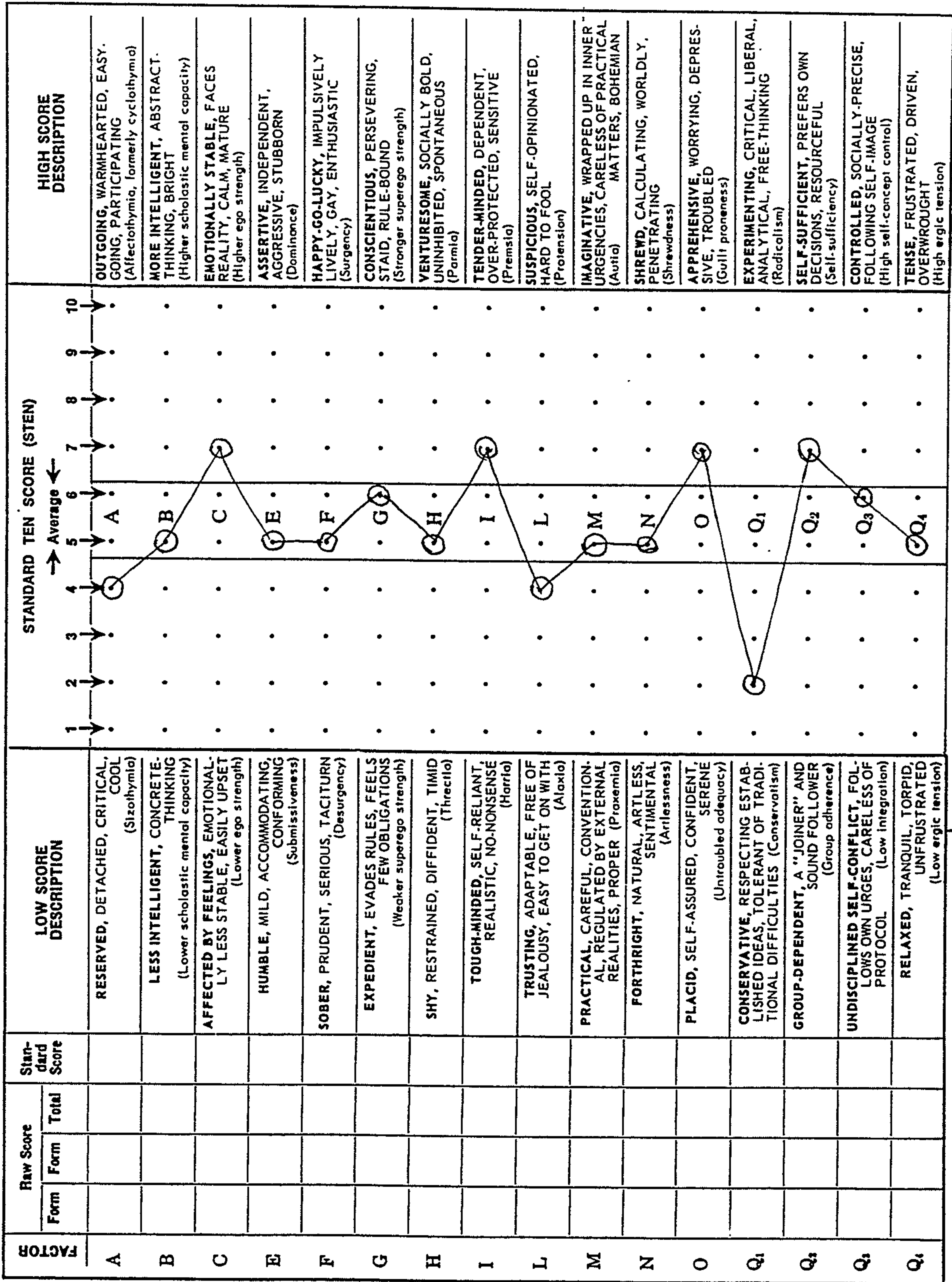
Comments:

A sten of 10 is obtained by about 2.3% of adults

DP. 15M 11/75



16 P.F. TEST PROFILE



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Comments:

DP. 15M 11/75

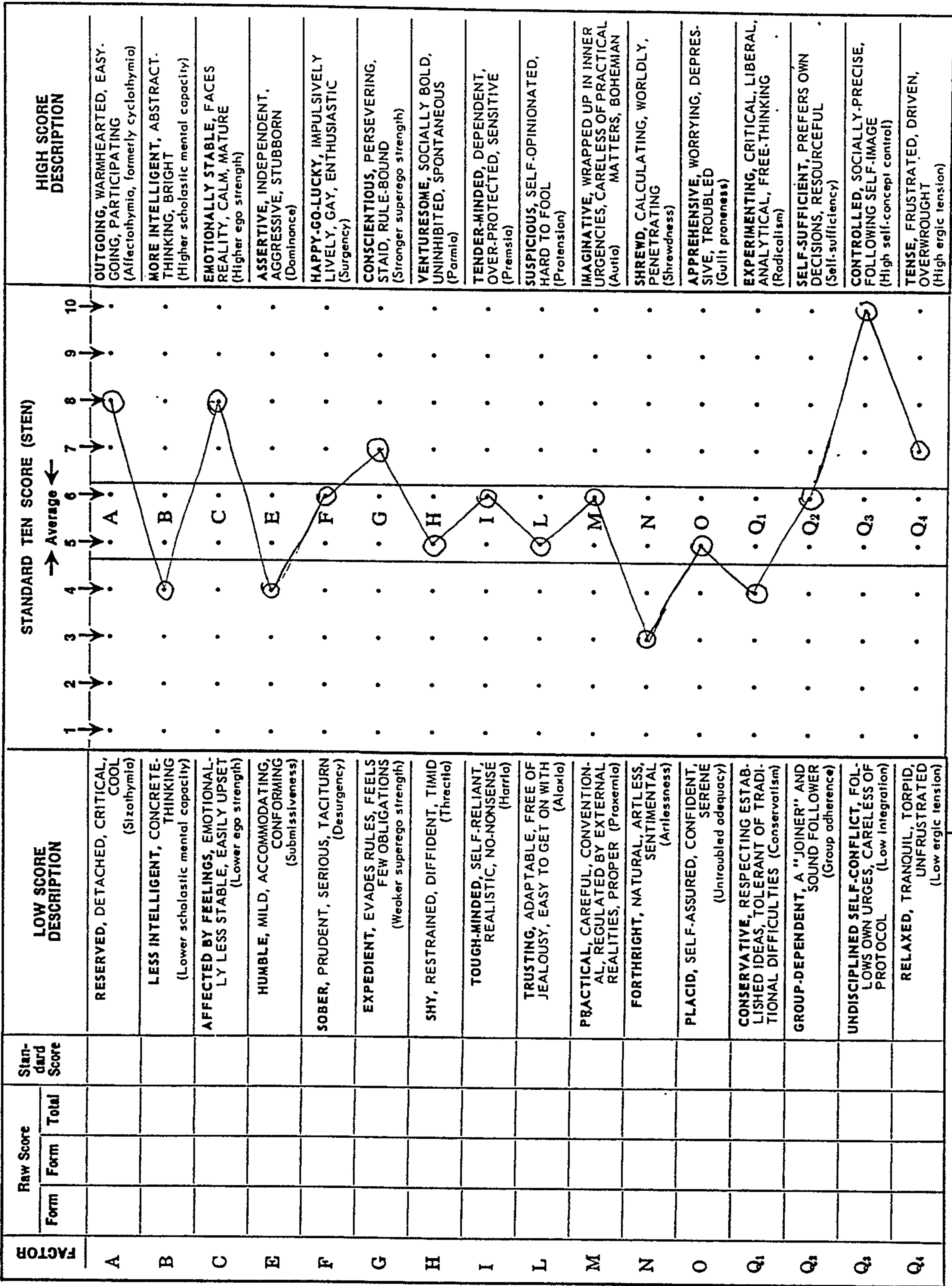
A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

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Comments:



16 P.F. TEST PROFILE



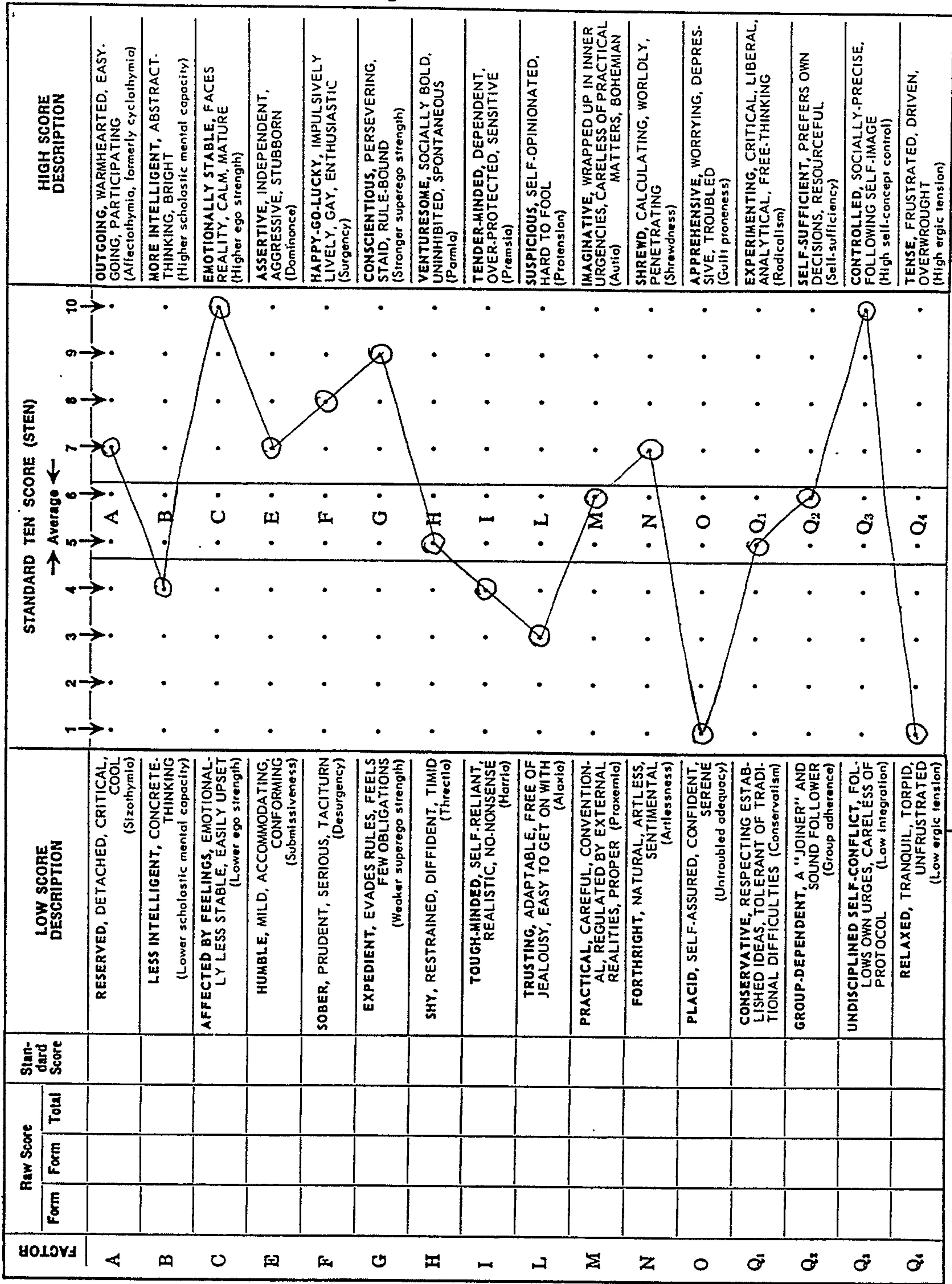
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DP, 15M 11/75

Comments:



16 P.F. TEST PROFILE

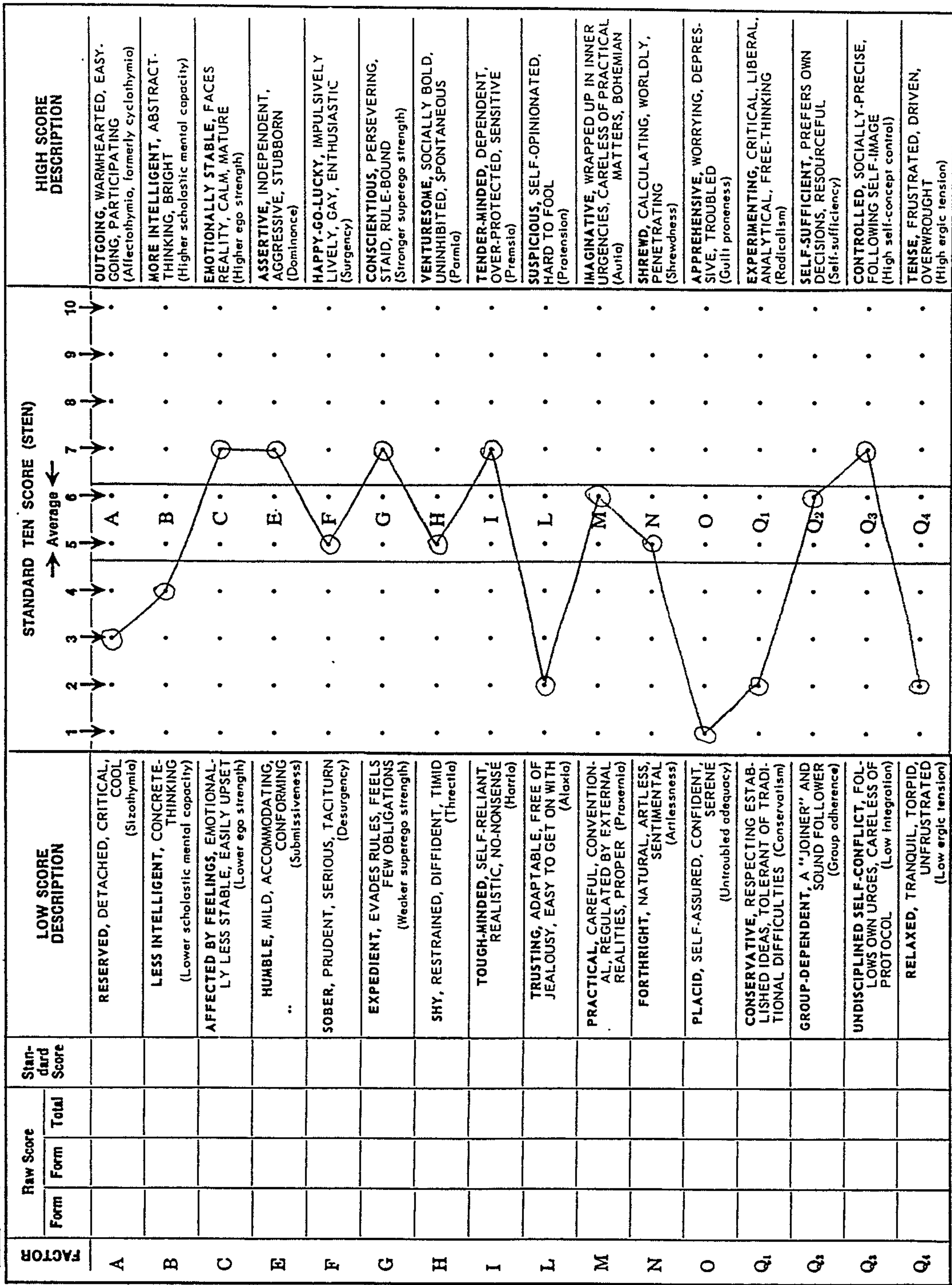


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Comments:



16 P.F. TEST PROFILE



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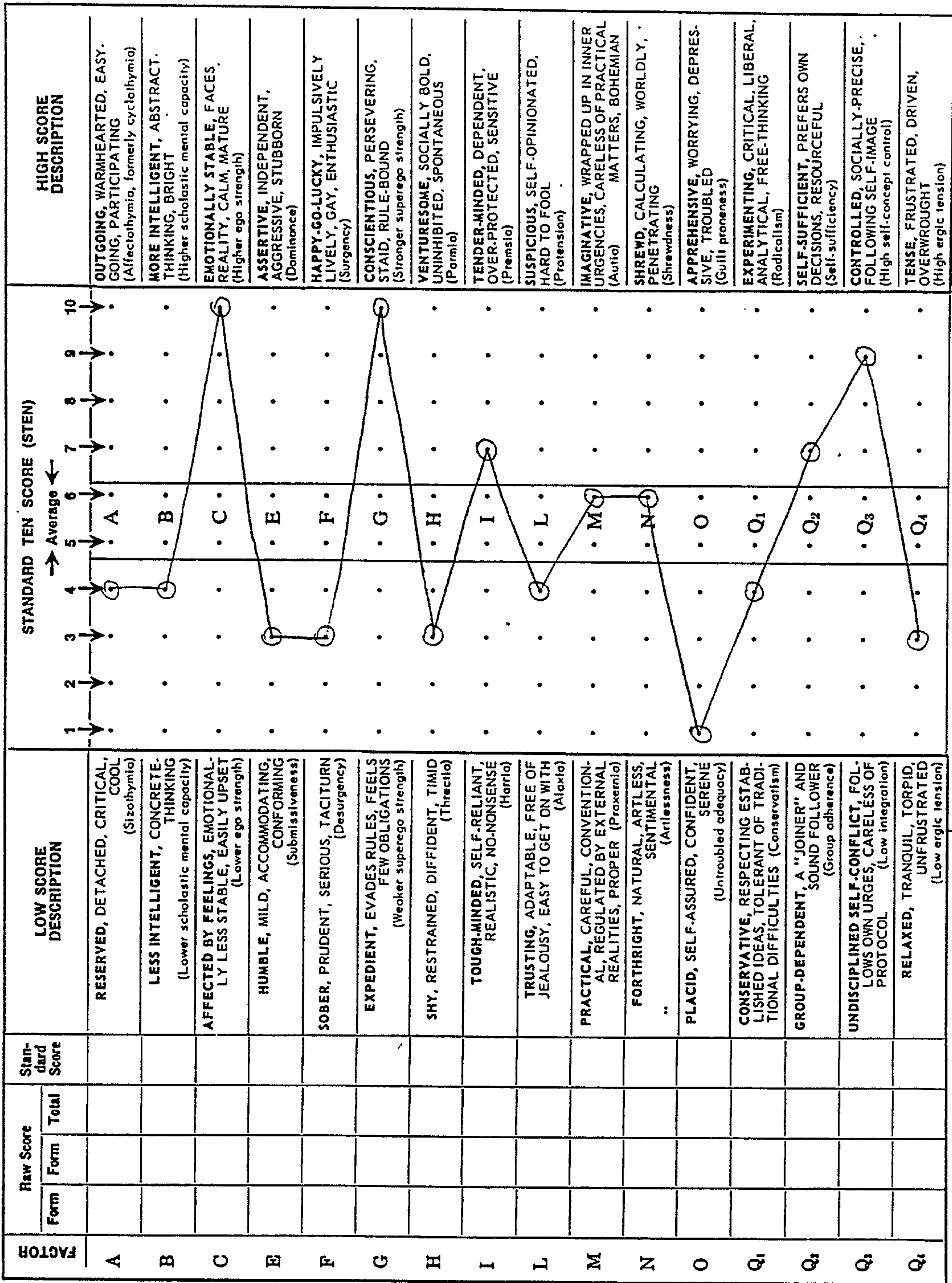
A sten of 5 is obtained by about 2.3% of adults

DP, 15M 11/75

Comments:



16 P.F. TEST PROFILE



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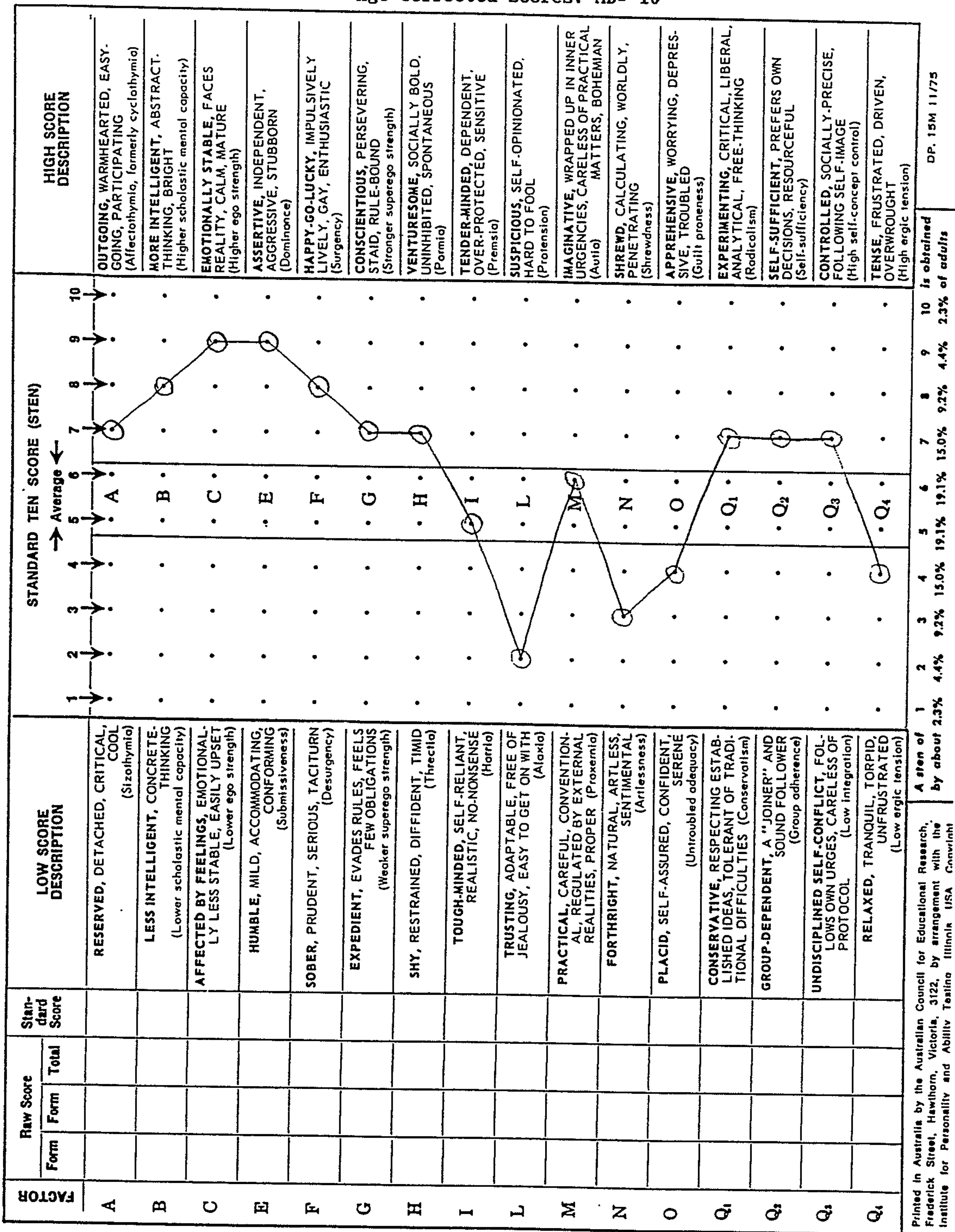
A sten of 1 is obtained by about 2.3% of adults

DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE

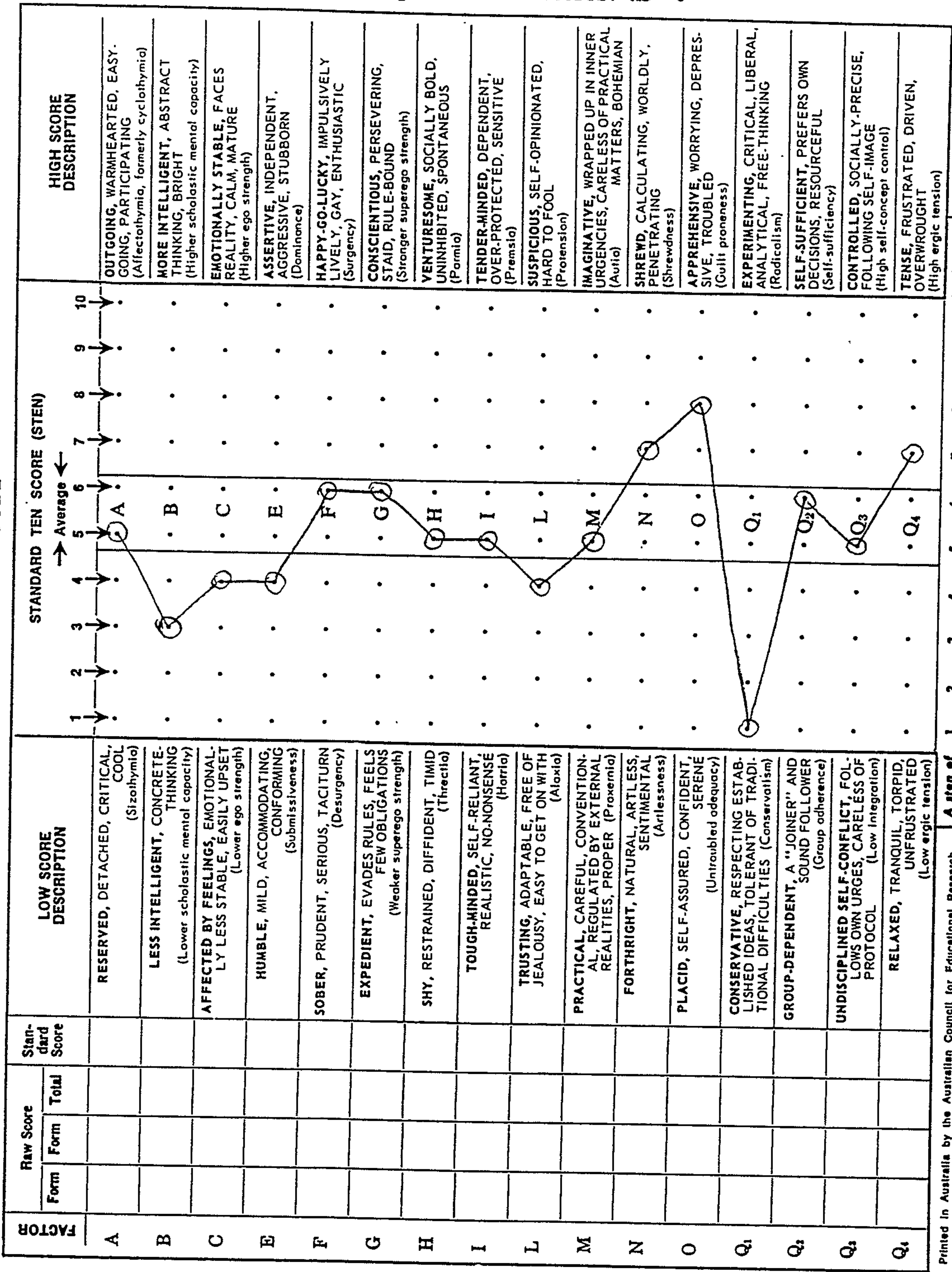


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DP. 15M 11/75



16 P.F. TEST PROFILE



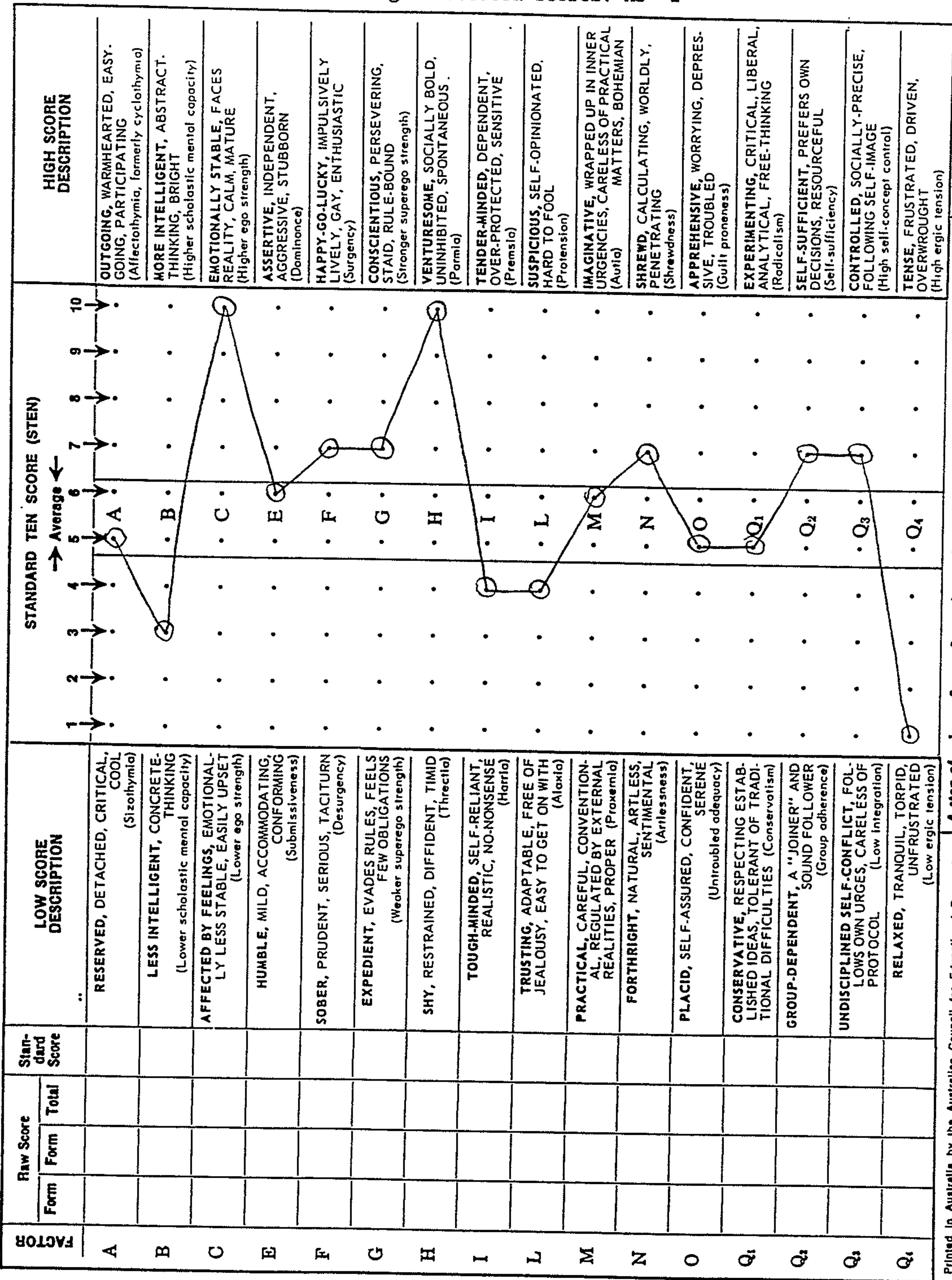
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A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE



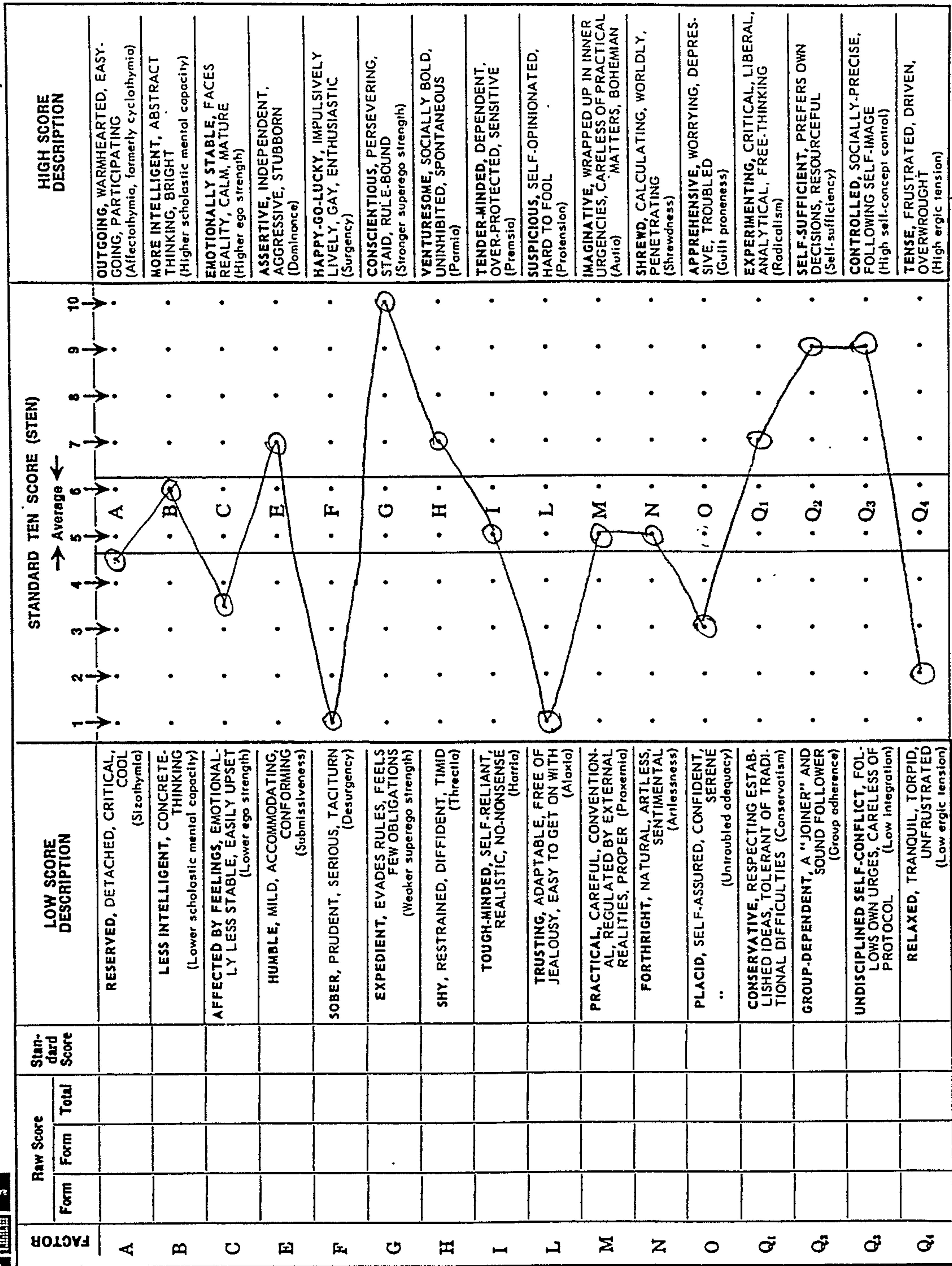
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DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE

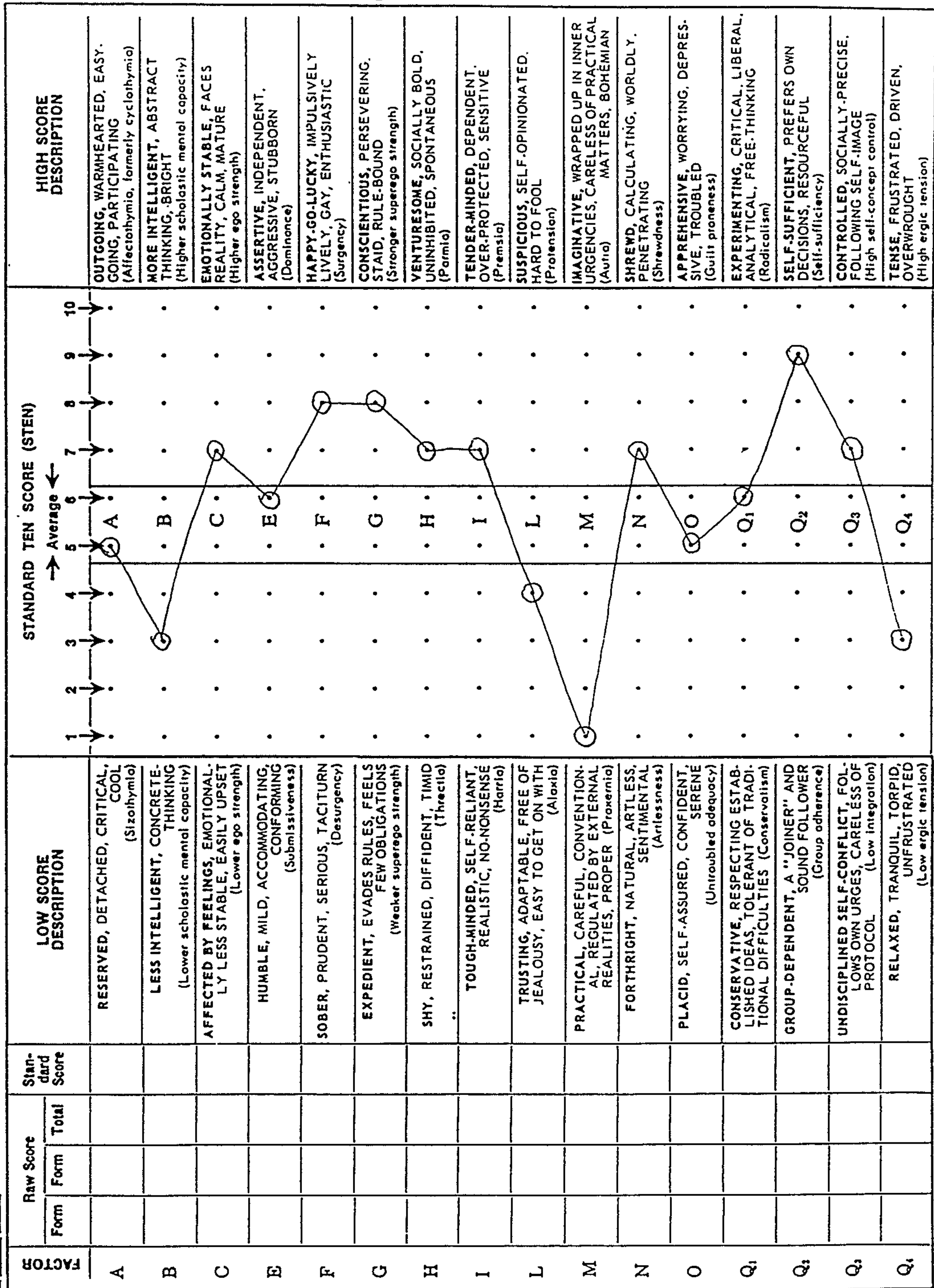


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Comments:



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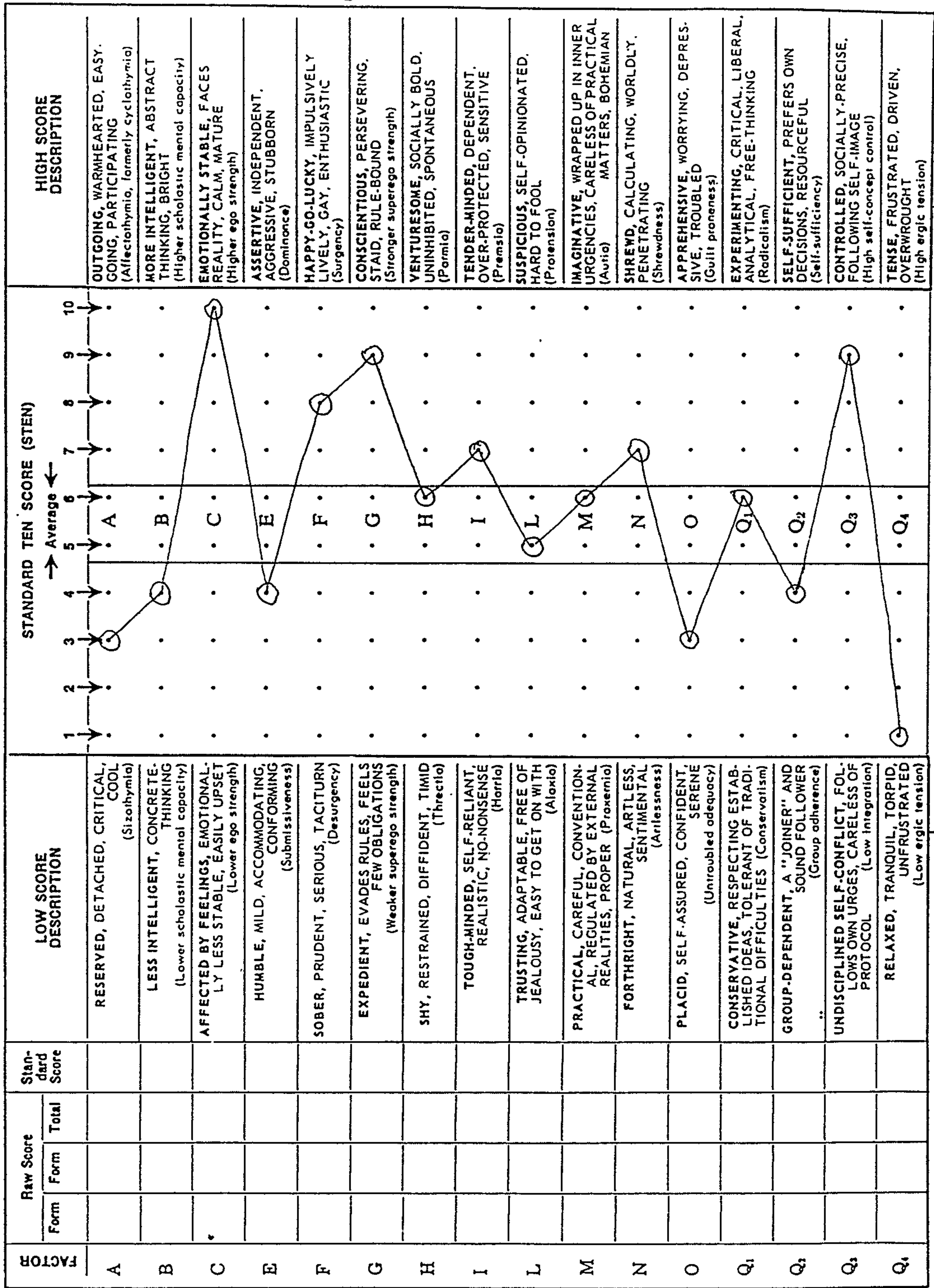
Comments:

DP. 15M 11/75

A sten of 10 is obtained by about 2.3% of adults



16 P.F. TEST PROFILE



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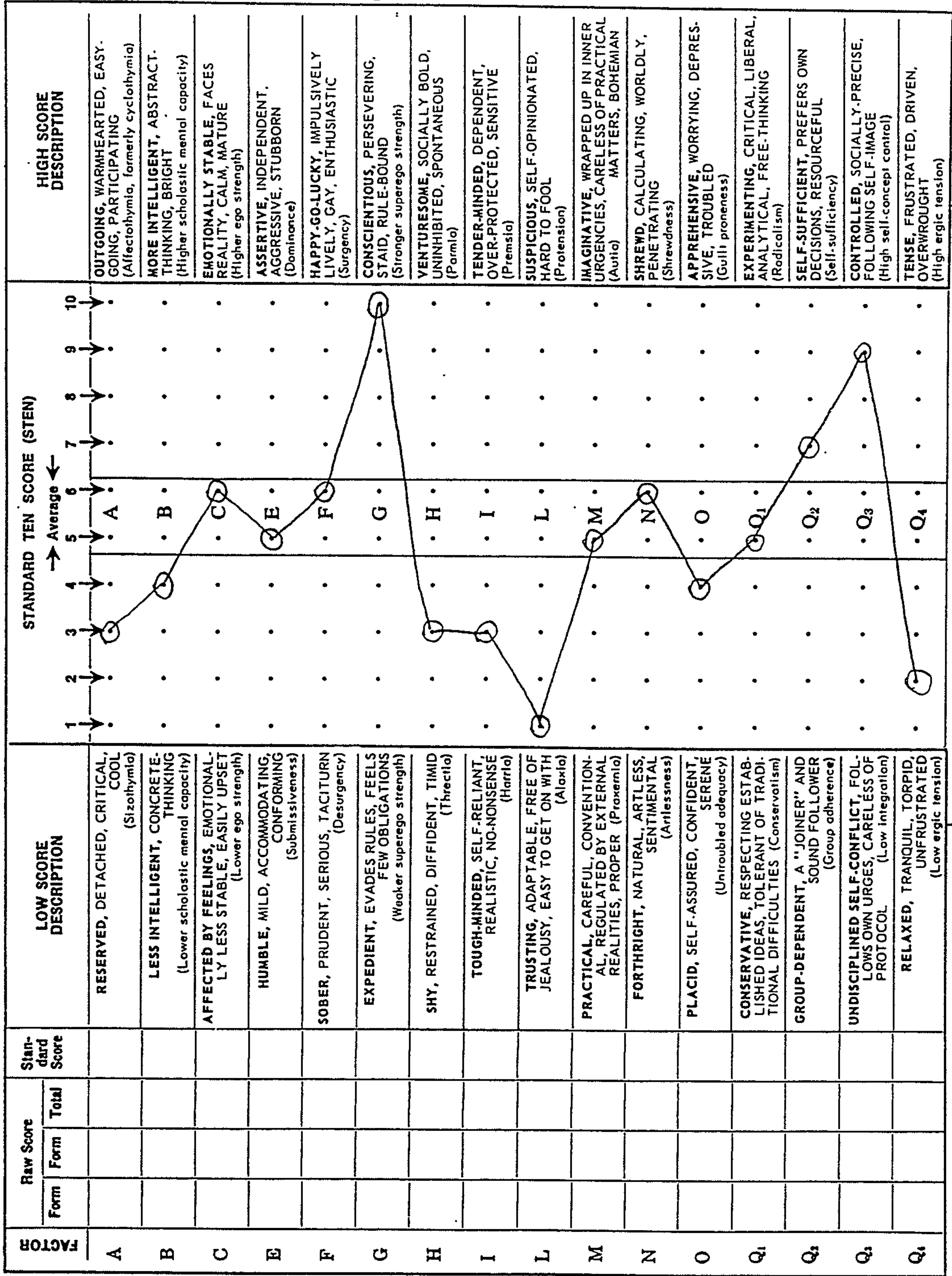
DP, 15M 11/75

Comments:

Comments:

Age-corrected scores. MD= 8

16 P.F. TEST PROFILE



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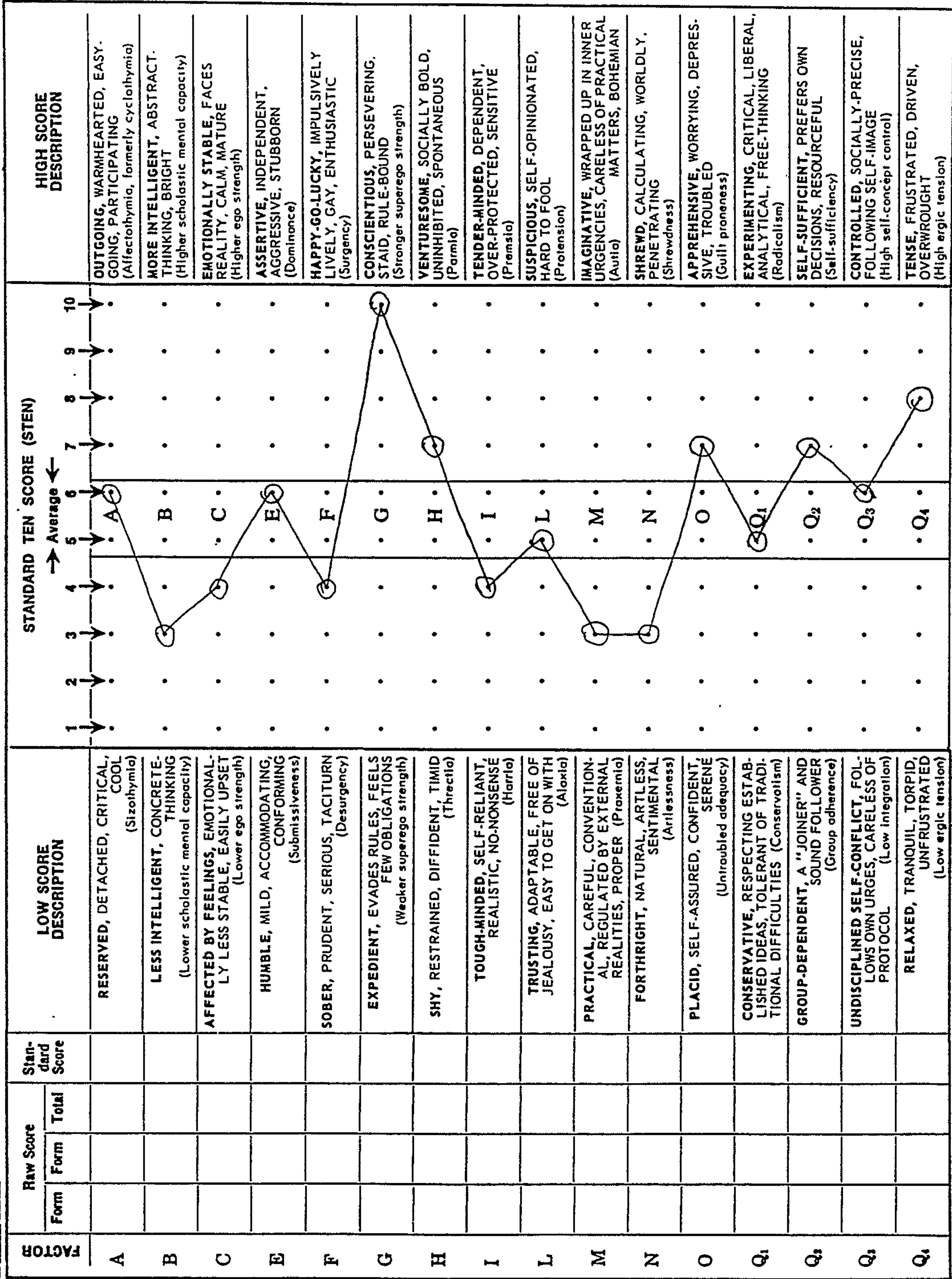
A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE



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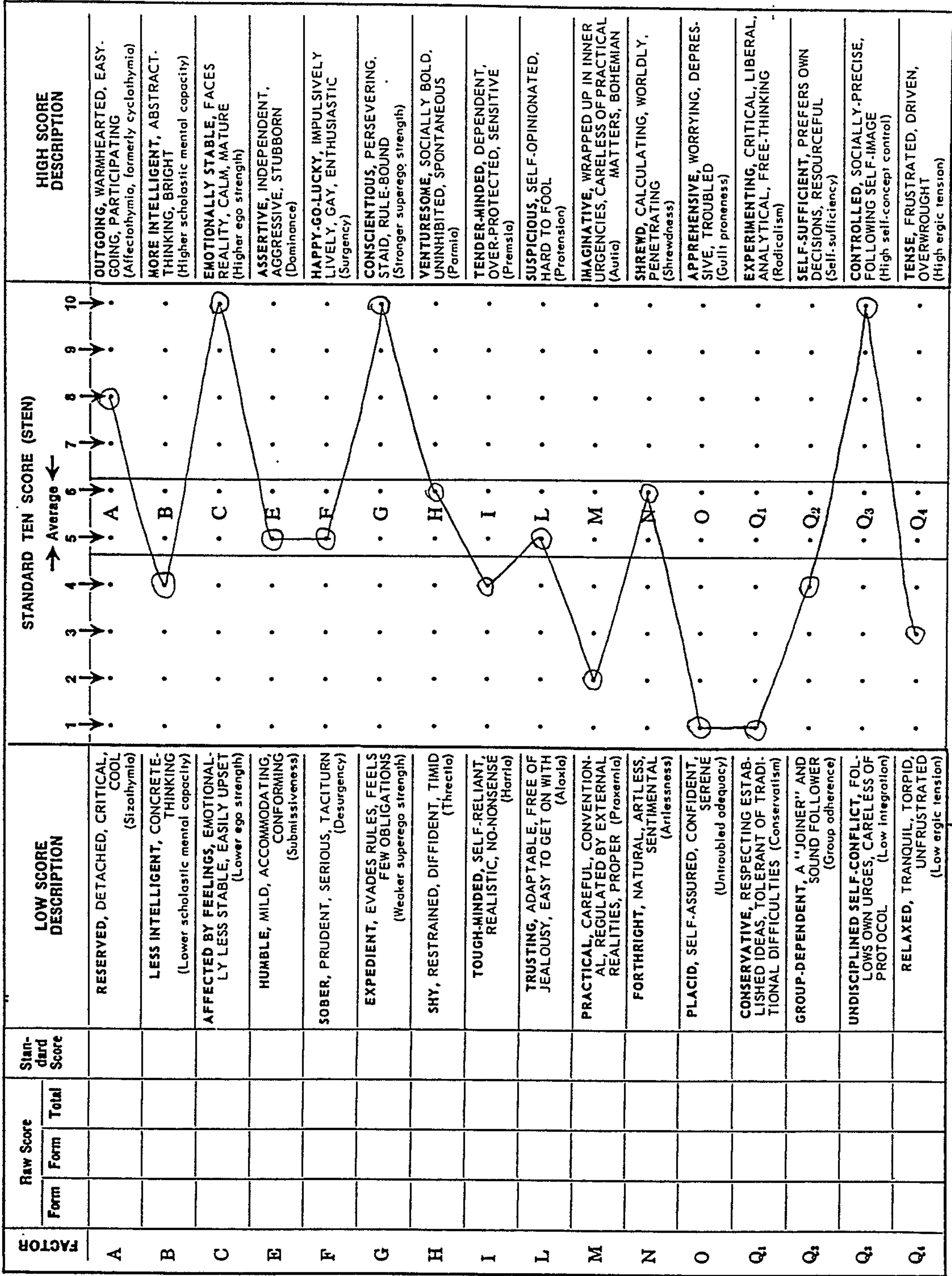
A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults DP. 15M 11/75

Comments:

SUBJECT 36

Age-corrected scores. MD= 6

16 P.F. TEST PROFILE



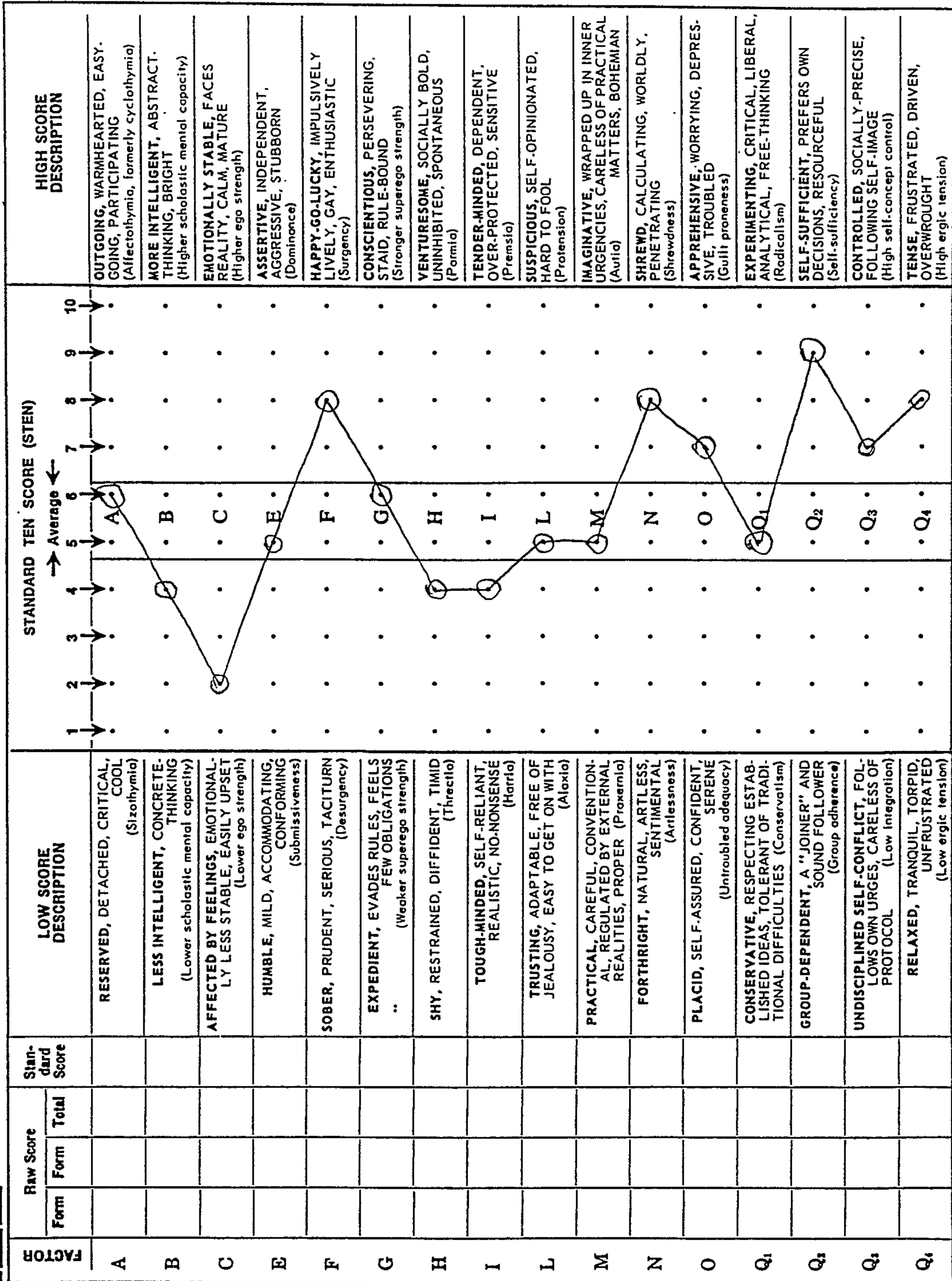
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DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE



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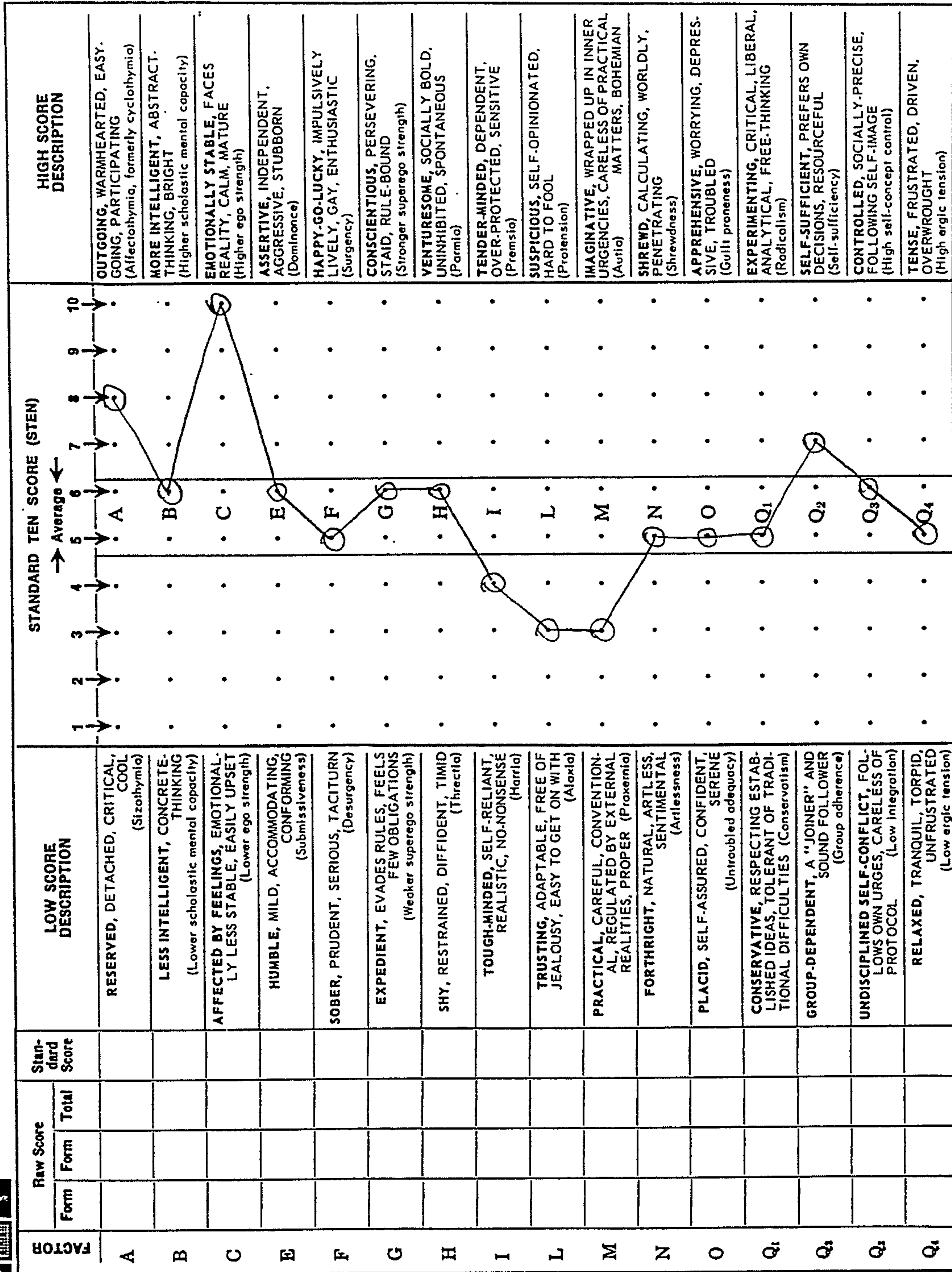
DP. 15M 11/75

A sten of 1 2 3 4 5 6 7 8 9 10 Is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

Comments:



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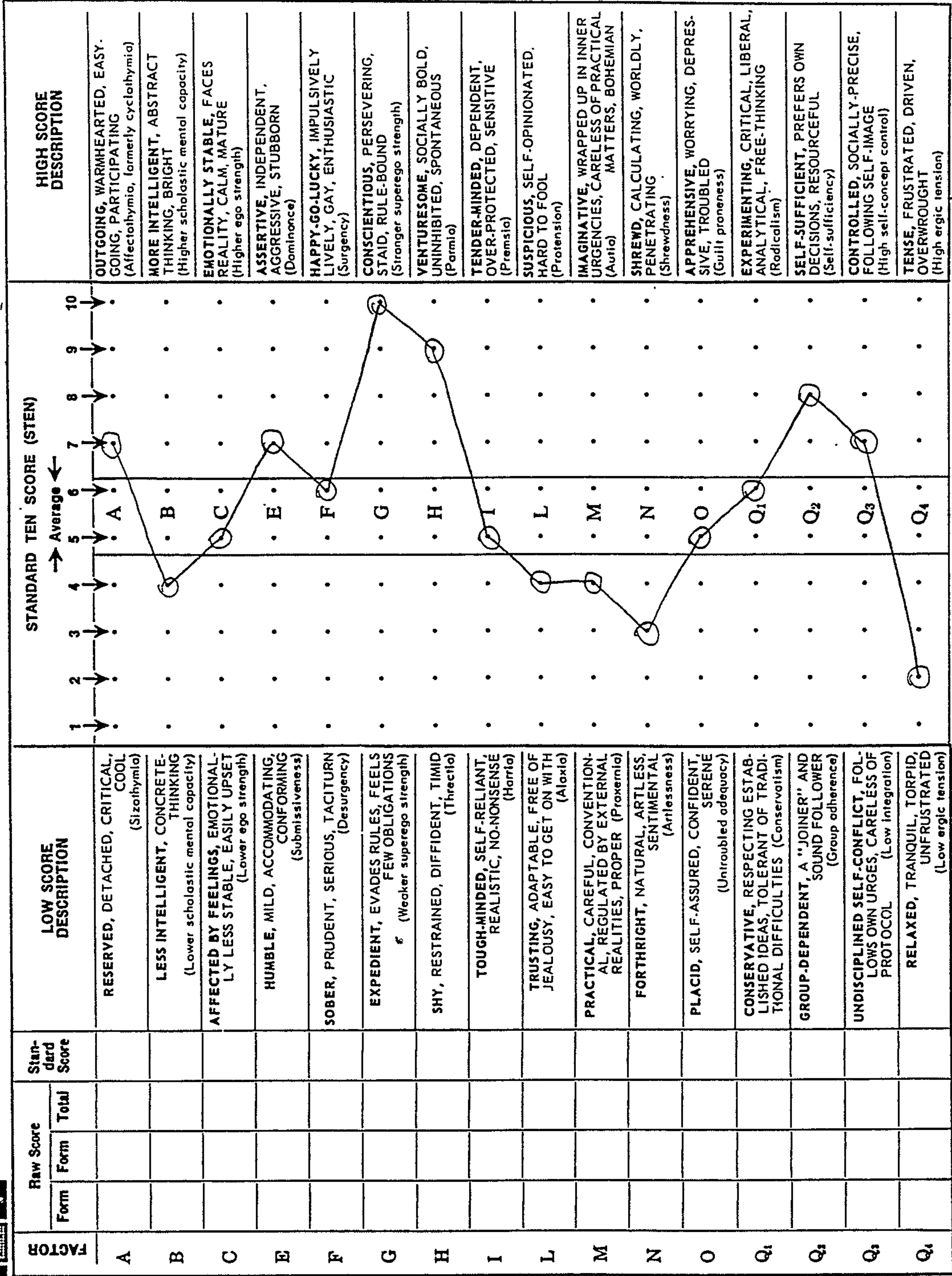
Comments: _____

DP. 15M 11/75

SUBJECT 39

Age-corrected scores. MD= 7

16 P.F. TEST PROFILE



DP. 15M 11/75

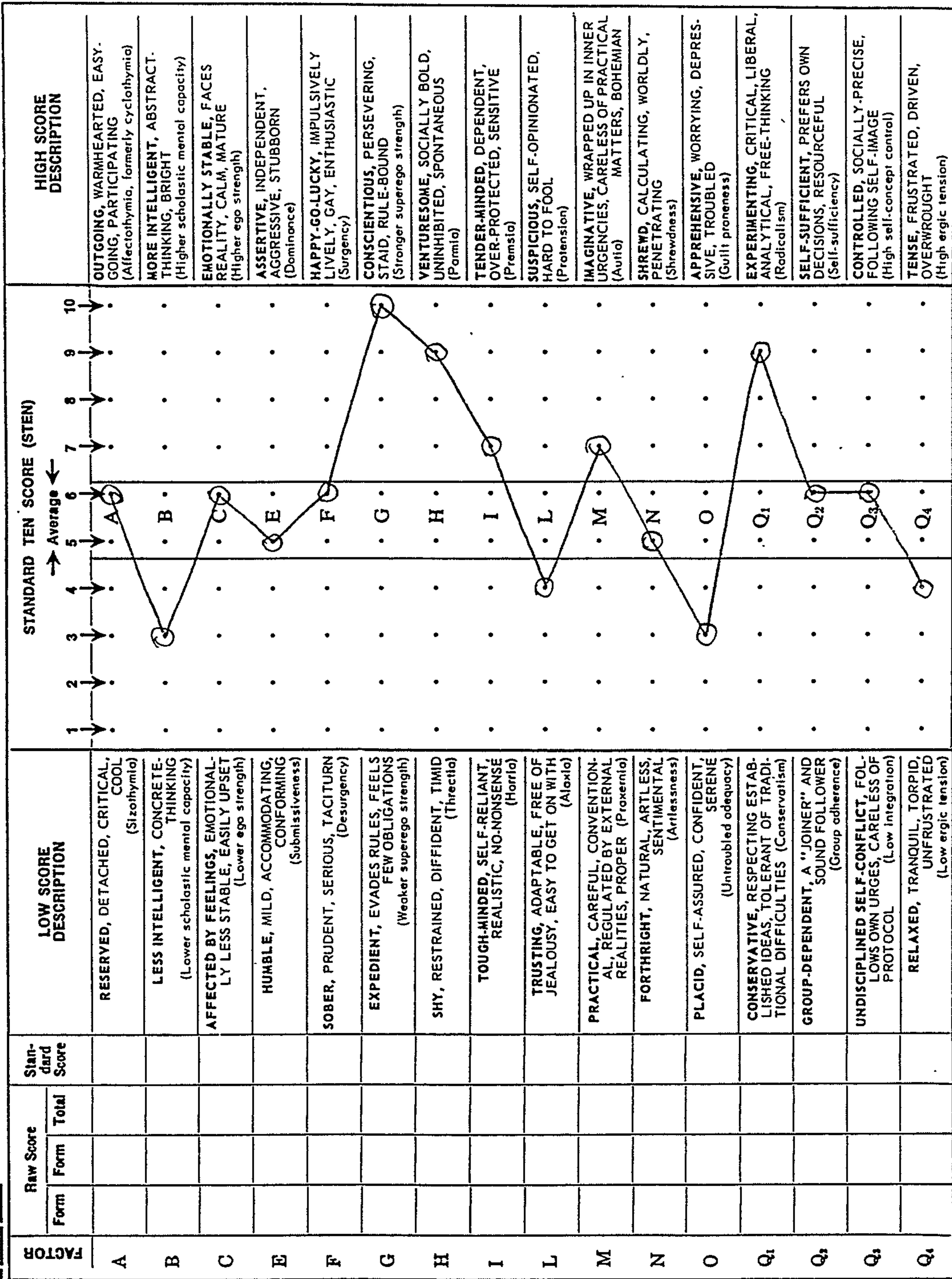
A sten of 10 is obtained by about 2.3% of adults

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Comments:



16 P.F. TEST PROFILE



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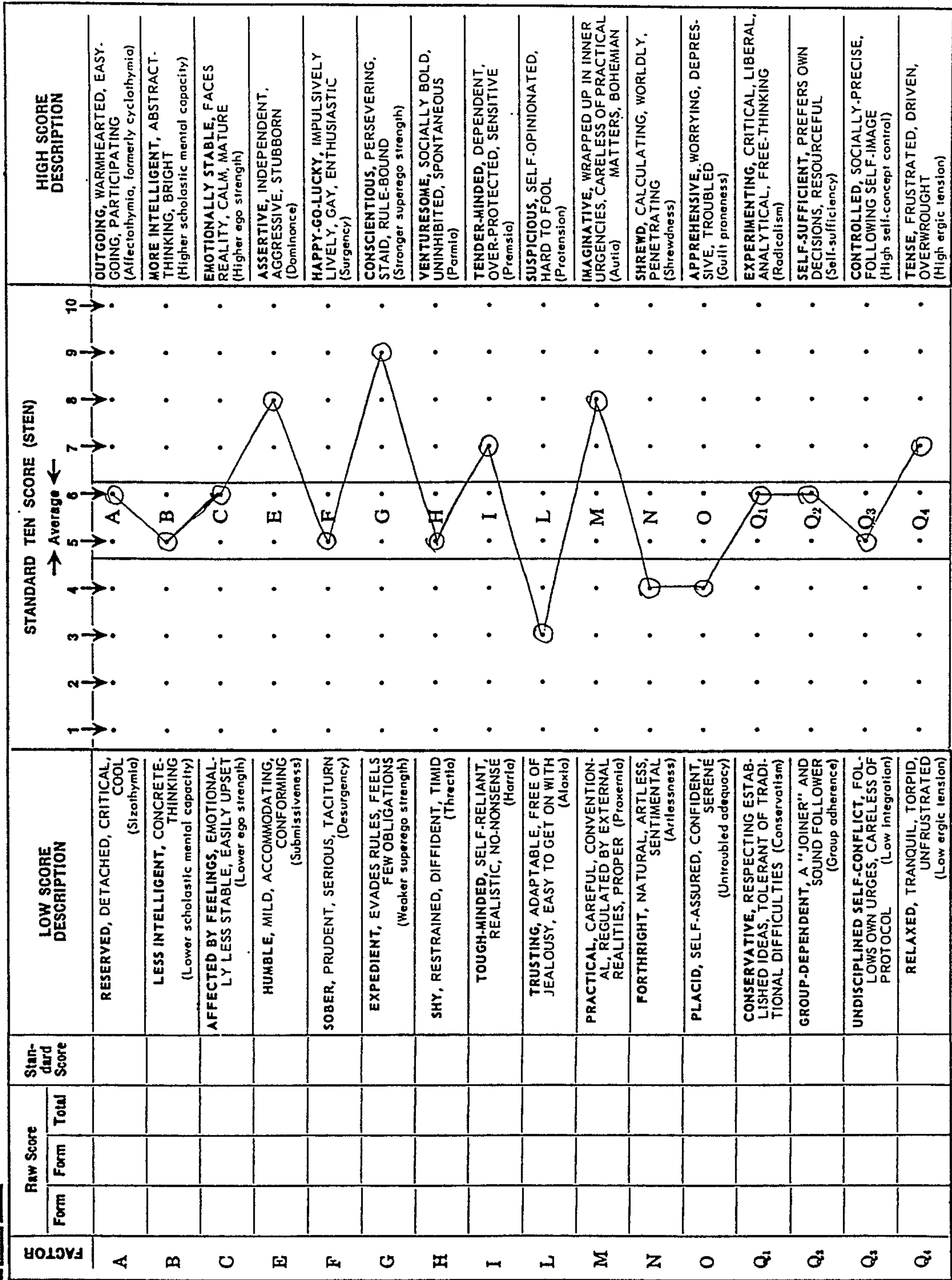
A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP. 15M 11/75

Comments:



16 P.F. TEST PROFILE



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Comments:

A sten of 1 2 3 4 5 6 7 8 9 10 is obtained by about 2.3% 4.4% 9.2% 15.0% 19.1% 19.1% 15.0% 9.2% 4.4% 2.3% of adults

DP. 15M 11/75

APPENDIX 11

ANALYSIS OF COPING USING 16PF TEST FACTORS

Factors C, O, Q₃ and Q₄ were postulated to be associated with the subjects' capacity to cope emotionally. Age-corrected sten scores for these factors for each subject were assigned to the categories "+" (high), "0" (average), or "-" (low)¹.

SUBJ. NO.	ASSIGNED VALUES FOR STEN SCORES OF 16PF FACTORS ASSOCIATED WITH COPING			
	C Emotional stability	O Confidence, serenity	Q ₃ Controlled, socially precise	Q ₄ Relaxed, unfrustrated
1	+	+	+	+
2	+	+	0	+
3	+	+	+	+
4	16PF not done.			
5	+	+	0	+
6	+	+	+	+
7	0	+	+	0
8	0	+	0	0
9	16PF not done.			
10	+	+	+	+
11	16PF not done.			
12	-	+	-	-
13	+	+	+	-

¹ Sten scores were assigned to categories in the following way -

	Sten Score	Category
For factors C and Q ₃ -	1 - 4	- (low)
	5 - 6	0 (average)
	7 - 10	+ (high)
For factors O and Q ₄ -	7 - 10	- (low)
	5 - 6	0 (average)
	1 - 4	+ (high)

SUBJ. NO.	ASSIGNED VALUES FOR STEN SCORES OF 16PF FACTORS ASSOCIATED WITH COPING			
	C Emotional stability	Q Confidence, serenity	Q ₃ Controlled, socially precise	Q ₄ Relaxed, unfrustrated
14	0	0	0	-
15	-	+	+	+
16	+	+	+	+
17	+	-	0	0
18	+	+	+	+
19	+	0	+	-
20	+	+	+	+
21	+	+	+	+
22	16PF not done.			
23	+	+	+	+
24	+	+	+	+
25	-	-	0	-
26	+	0	+	+
27	-	+	+	+
28	+	0	+	+
29	16PF not done.			
30	+	+	+	+
31	0	-	+	0
32	16PF not done.			
33	16PF not done.			
34	0	+	+	+
35	-	-	0	-
36	+	+	+	+
37	-	-	+	-

SUBJ. NO.	ASSIGNED VALUES FOR STEN SCORES OF 16PF FACTORS ASSOCIATED WITH COPING			
	C Emotional stability	O Confidence, serenity	Q ₃ Controlled, socially precise	Q ₄ Relaxed, unfrustrated
38	+	0	0	0
39	0	0	+	+
40	0	+	0	+
41	0	+	0	-

APPENDIX 12

ANALYSIS OF COPING USING INTERVIEW DATA

Objective ratings of the psychosocial coping of each subject from interview data tables 1, 2, 3, 5 and 7.

SUBJECT NUMBER	TABLE 1 PREOP. PERIOD	TABLE 2 AFTER OPERATION	TABLE 3 RETURN HOME	TABLE 5 PROSTHESIS	TABLE 7 PRESENT
1	+	+	+	-	+
2	+	+	+	+	+
3	+	+	+	+	+
4	0	+	+	+	+
5	+	+	-	+	-
6	1	1	0	-	+
7	+	+	+	+	+
8	-	0	-	-	-
9	0	0	-	+	+
10	+	+	+	0	+
11	+	(+) ²	+	+	+
12	-	-	+	+	+
13	+	(+) ³	+	+	+
14	+	-	0	+	+
15	+	+	(+) ⁴	+	+
16	+	+	+	+	+
17	0	+	+	+	+
18	+	+	+	+	+

¹ Not applicable as subject had congenital disfigurement.

² Estimated score. Of 14 other subjects with an identical pattern of coping scores in other aspects, 13 scored "+" in this aspect and 1 scored "-".

³ As for Footnote 2.

⁴ Estimated score. Of 13 other subjects with an identical pattern of scores in other aspects, all scored "+" in this aspect.

SUBJECT NUMBER	TABLE 1 PREOP. PERIOD	TABLE 2 AFTER OPERATION	TABLE 3 RETURN HOME	TABLE 5 PROSTHESIS	TABLE 7 PRESENT
19	+	+	+	-	+
20	+	+	+	0	+
21	+	+	+	0	+
22	+	+	+	+	+
23	+	+	+	+	+
24	1	1	+	+	+
25	+	+	-	+	0
26	+	+	+	+	+
27	0	5	0	+	-
28	+	+	+	+	+
29	(+) ⁶	+	+	+	+
30	+	+	+	+	+
31	0	+	0	+	+
32	(+) ⁷	+	+	+	+
33	0	+	+	+	+
34	+	-	+	+	+
35	-	+	+	+	+
36	+	+	+	+	+
37	+	-	-	+	-
38	+	+	+	+	+
39	+	+	+	+	+
40	+	+	+	0	+
41	+	+	+	0	+

⁵ Subject's response unclear.

⁶ Estimated score. Of 17 other subjects with an identical pattern of coping scores in the other aspects, 13 scored "+" in this aspect, 3 scored "0" and 1 scored "-".

⁷ As for Footnote 6.

APPENDIX 13

STATISTICAL ANALYSIS OF FACTORS AFFECTING COPING - GRAPHS 13.1 TO 13.9

Notes on the interpretation of graphs. (These comments are based on advice from a statistician). This form of correspondence analysis has been described as "essentially geometric, and consists of looking for directions of maximum inertia for a cloud of points in a metric space" (Hill MO, 1982, p.206)[†].

On each graph the legend shows the abbreviations used for the personality test factors and coping periods. For example in Graph 13.1, "PP" means preoperation period. For each factor or coping period there are 3 points on the graph, 1 each for the low, average and high scores, indicated by the letters "L", "A" and "H" respectively after the abbreviation for that factor. For example in Graph 13.1 the points representing the low, average and high scores for the preoperation period points are labelled "PPL", "PPA" and "PPH".

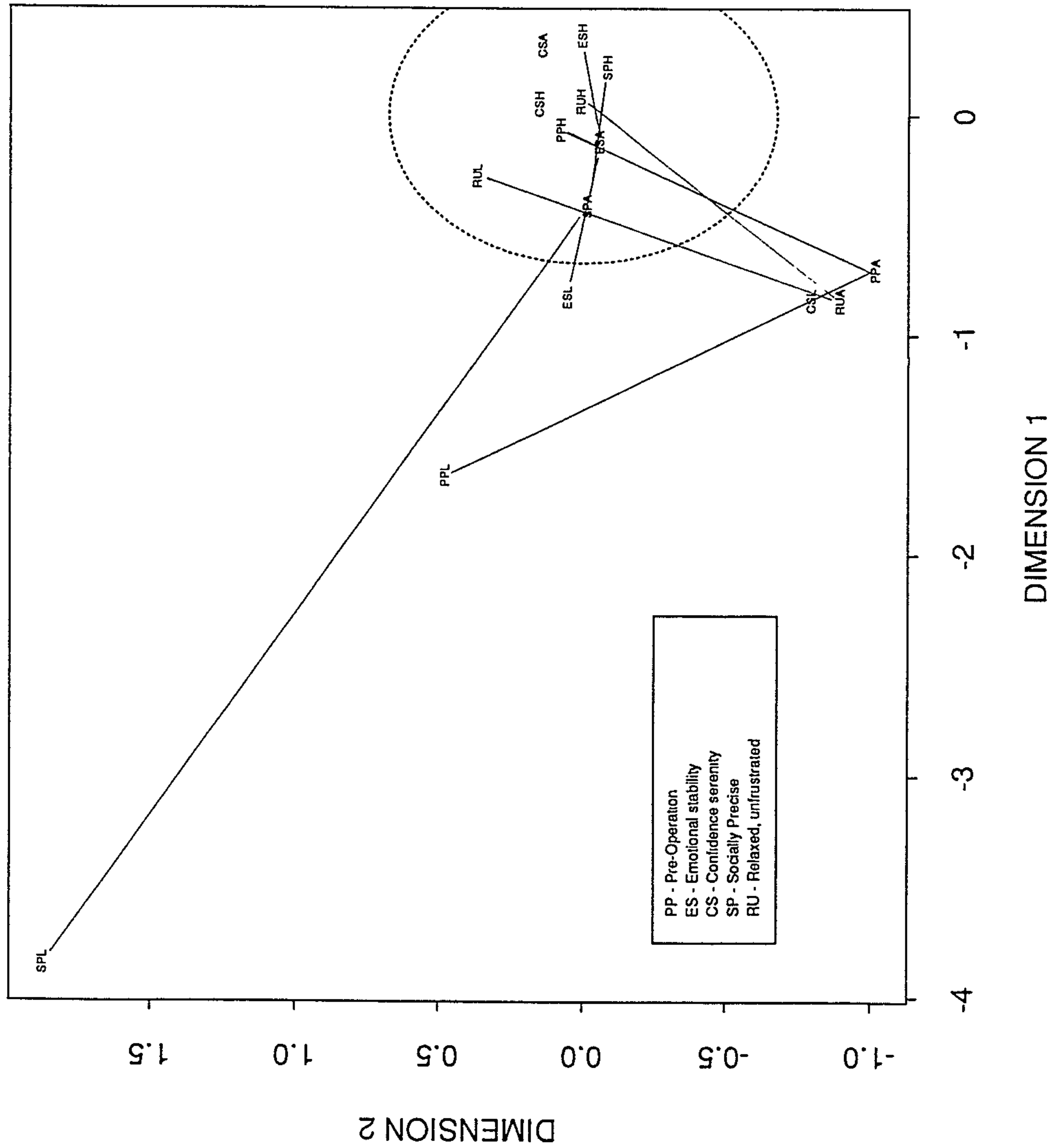
The elliptical zone indicated by a dotted line on each graph contains points between which there is no statistically significant association ($p > 0.05$). The dotted line represents a level of statistical significance of $p = 0.05$. Points located outside the elliptical zone are associated at a higher level of statistical significance ($p < 0.05$), the level of significance increases with increasing distance of the point from the elliptical zone.

Points that are significantly associated with each other are outside the elliptical zone and in close proximity to each other, or if not in close proximity, lie in an approximately linear relationship directed radially from the elliptical zone. For example in Graph 13.1, points SPL, PPL and ESL lie in an approximately linear relationship radiating from the elliptical zone. The association between PPL and SPL is more significant than that between PPL and ESL, since SPL is much further away from the elliptical zone than ESL. The points CSL, RUA and PPA are significantly associated with each other because they are grouped closely together. However none of the points SPL, PPL and ESL are significantly associated with any of the points CSL, RUA and PPA because these two groups of points are not close to each other and do not lie in a radial relationship with respect to the elliptical zone.

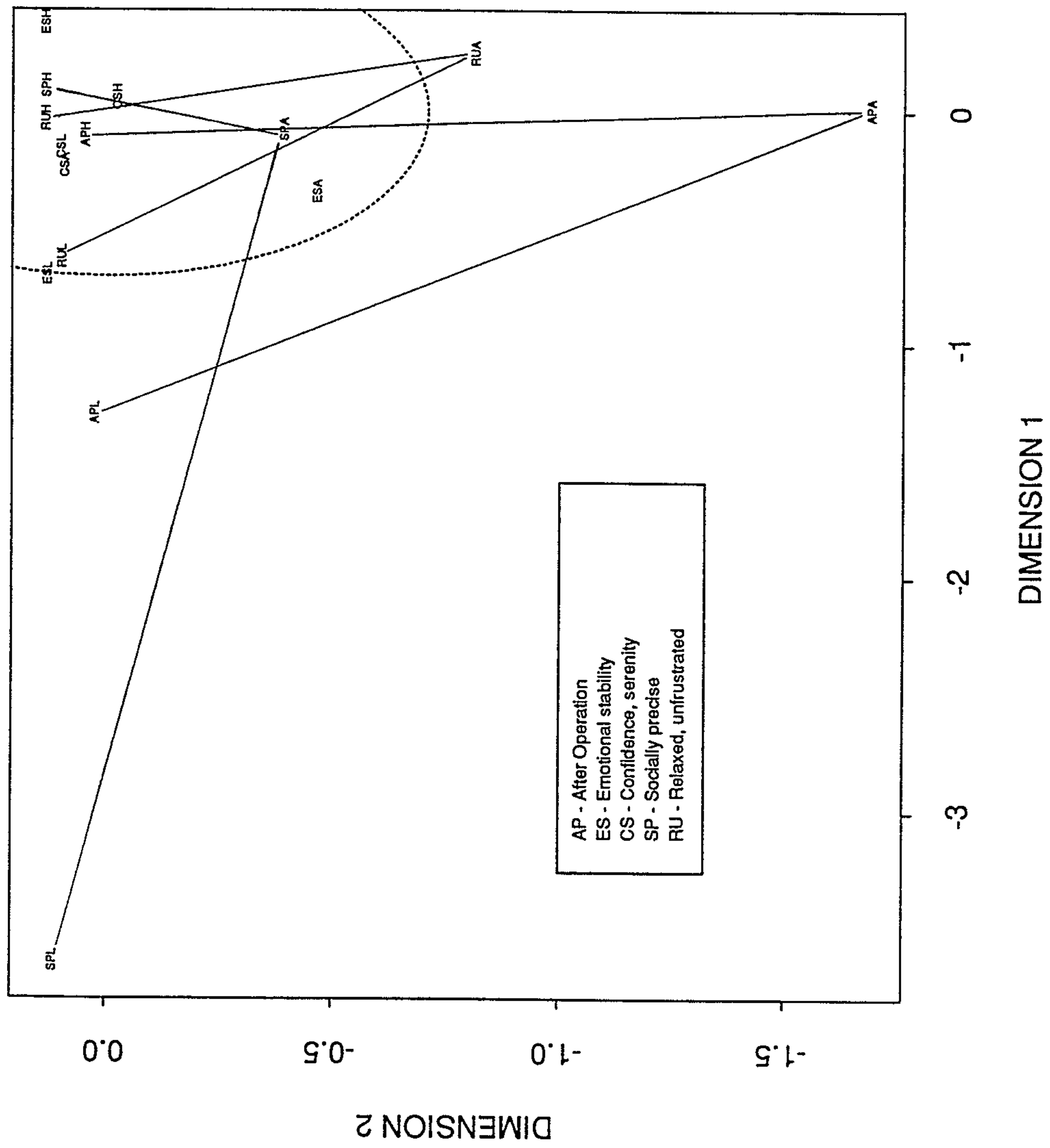
Another situation in which points are significantly associated occurs when for a particular factor and a particular coping period the points for low scores are close together, as are the points for average scores and for high scores. In these cases the factor and coping period are significantly associated throughout the range of low, average and high scores even though some of the points may lie within the elliptical zone. An example occurs in Graph 13.6 where significant associations exist between points ESL and PPL, ESA and PPA, and ESH and PPH.

[†] Hill MO: Correspondence analysis. In: Kotz S, Johnson NL, Read CB eds. Encyclopedia of Statistical Sciences. Vol 2. New York, John Wiley and Sons, 1982:204-210.

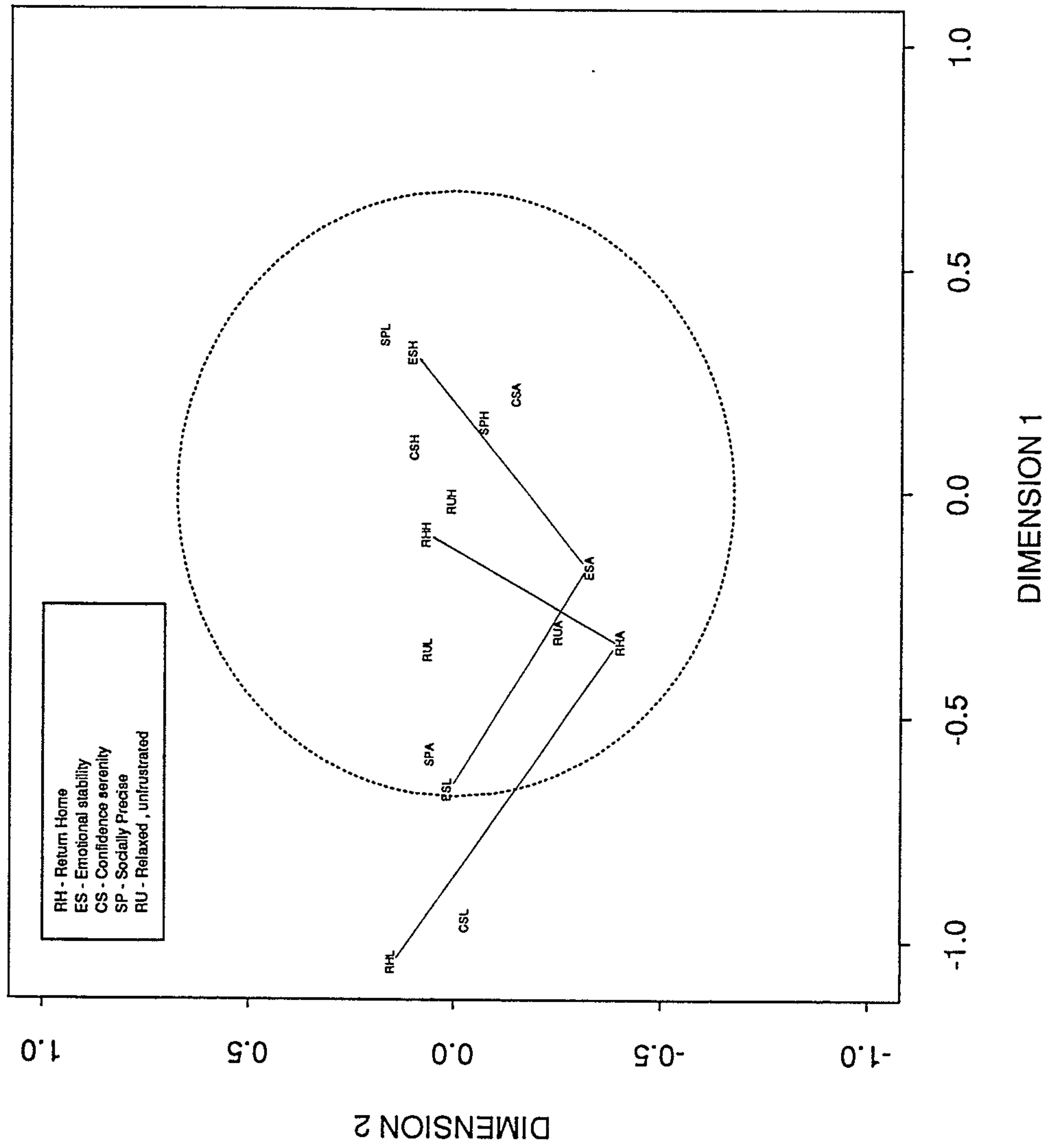
Correspondence Analysis: Association between Pre-Operation and Test Factors



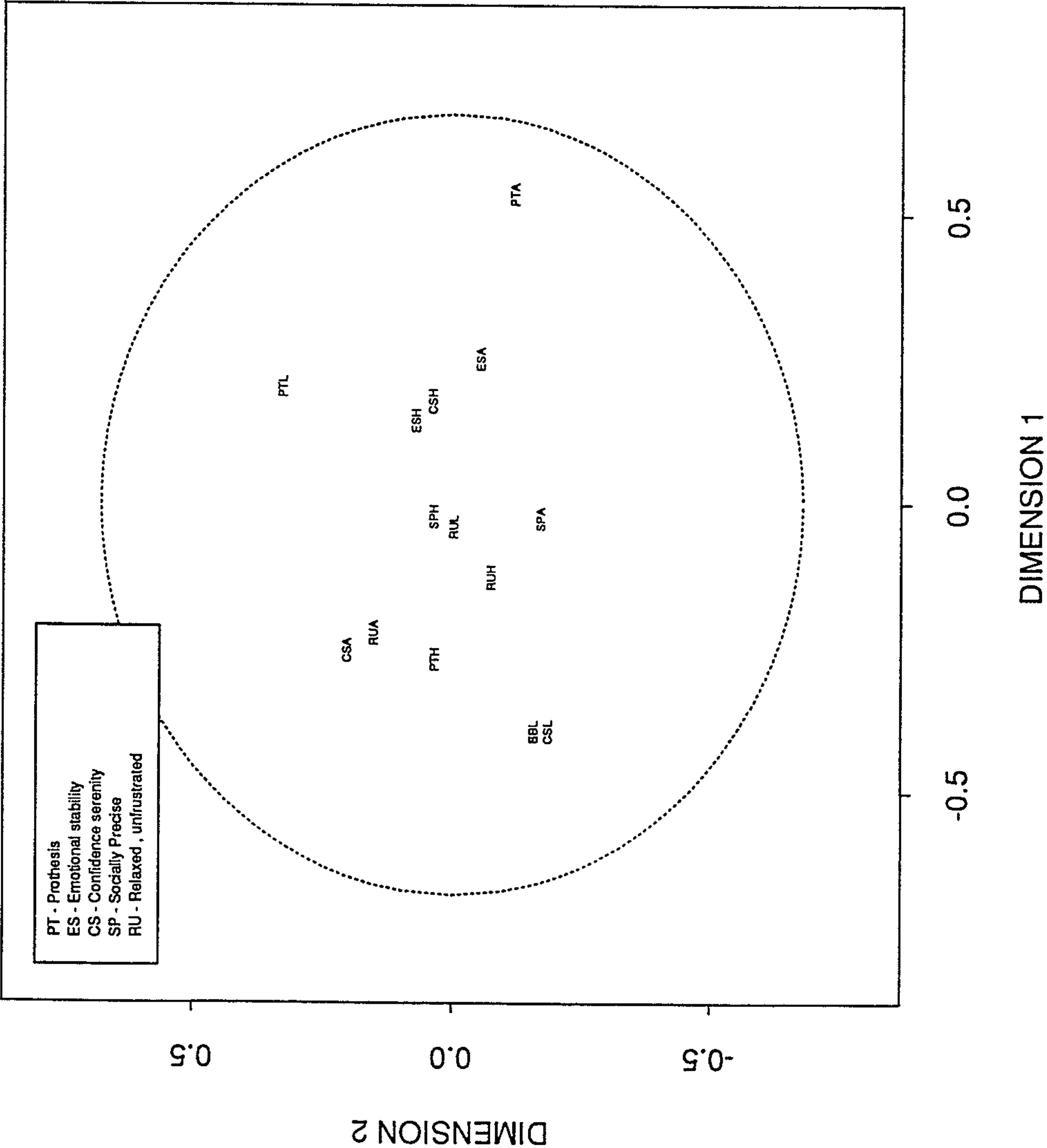
Correspondence Analysis: Associations between After Operation and Test Factors



Correspondence Analysis: Associations between Return Home and Test Factors

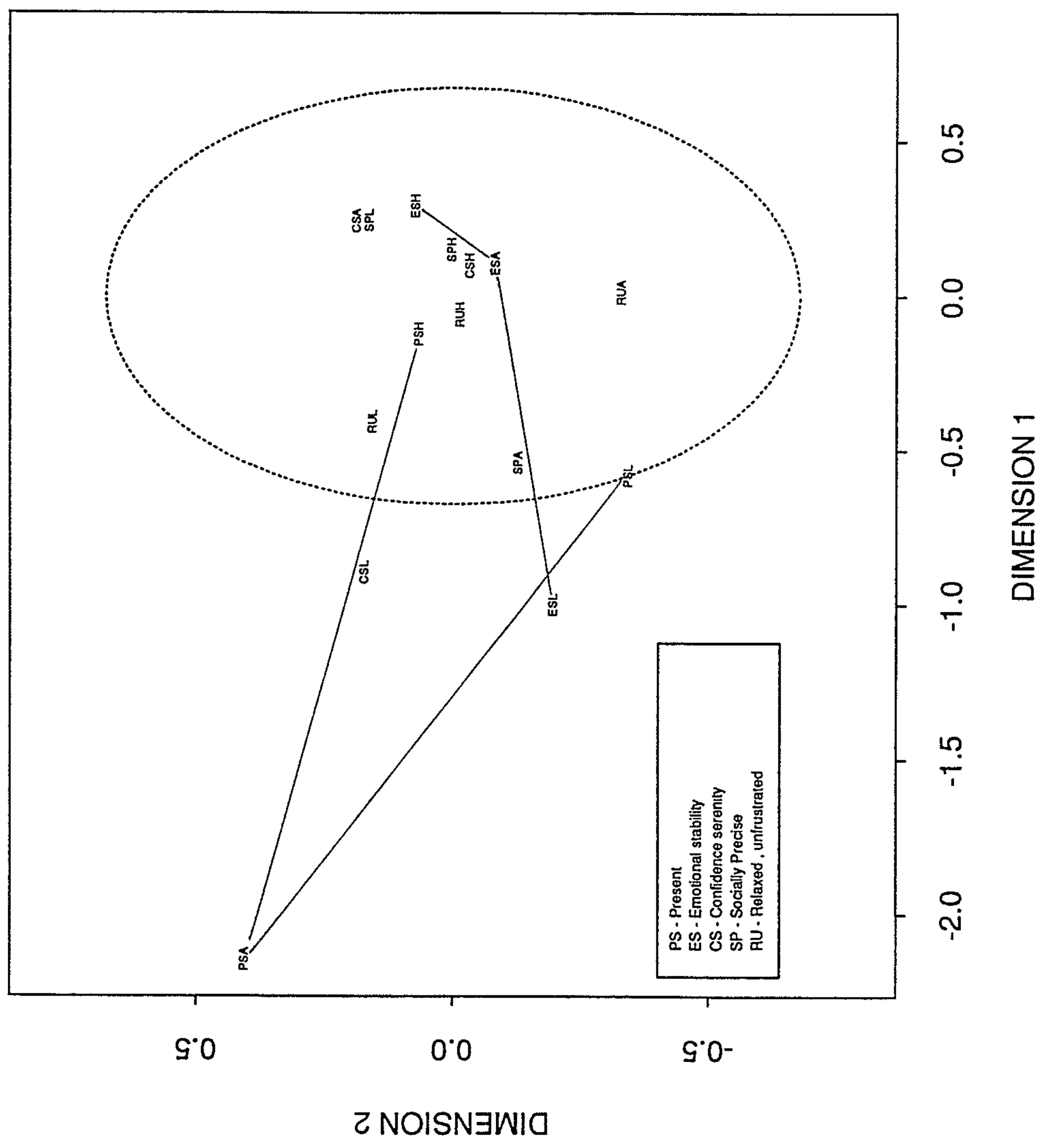


Correspondence Analysis: Associations between
Prosthesis and Test Factors



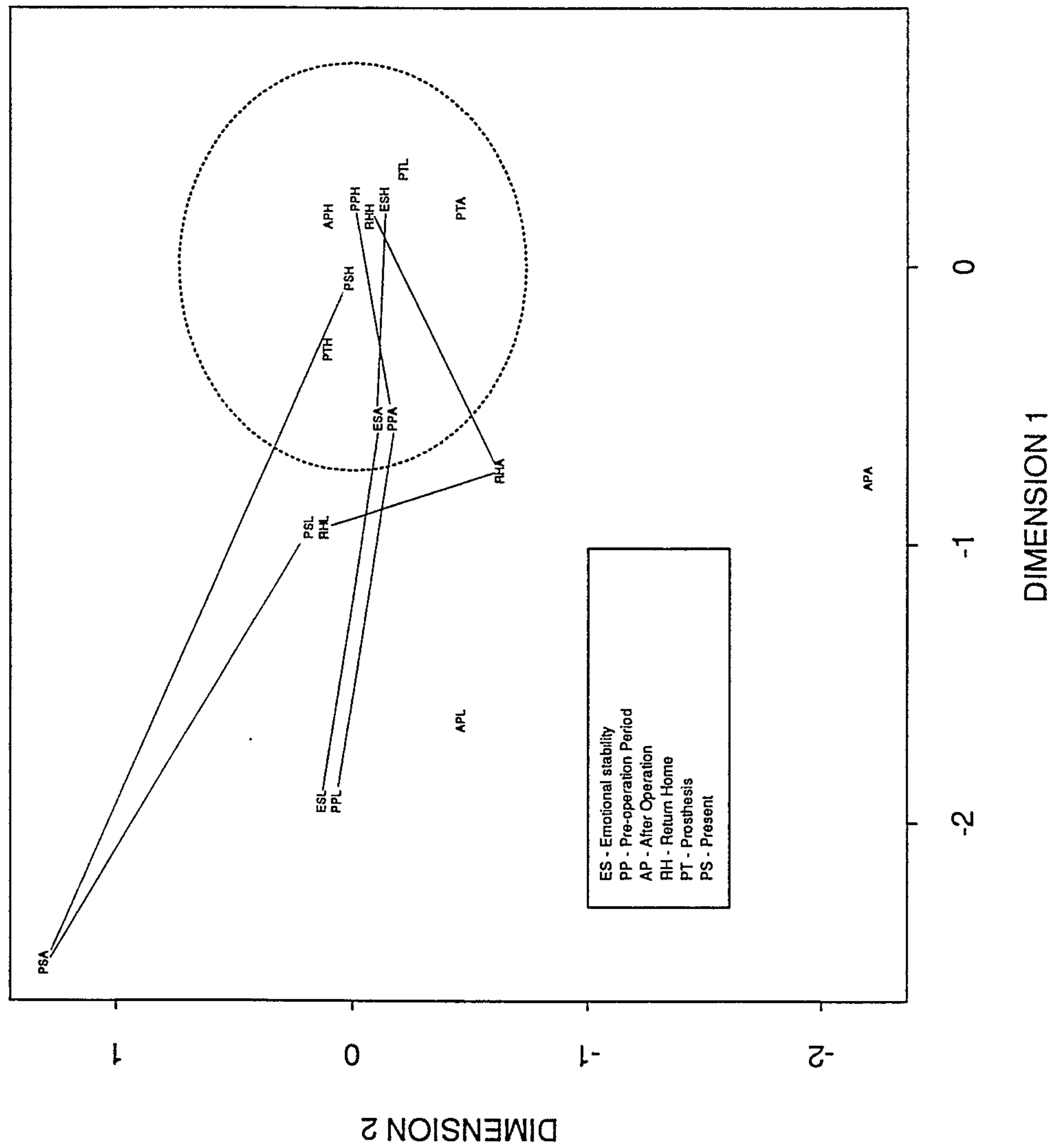
GRAPH 13.4

Correspondence Analysis: Associations between
Present and Test Factors

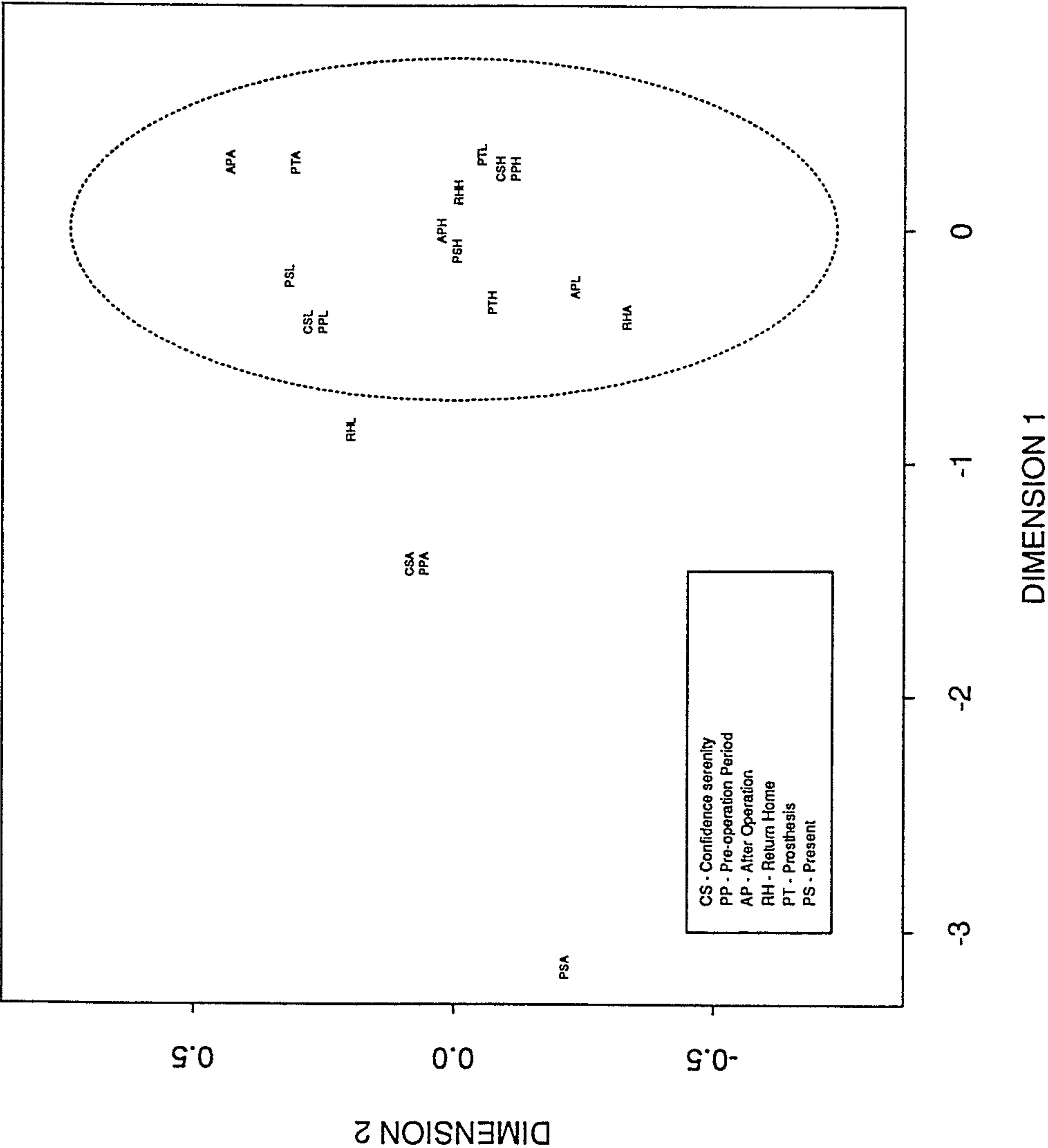


GRAPH 13.5

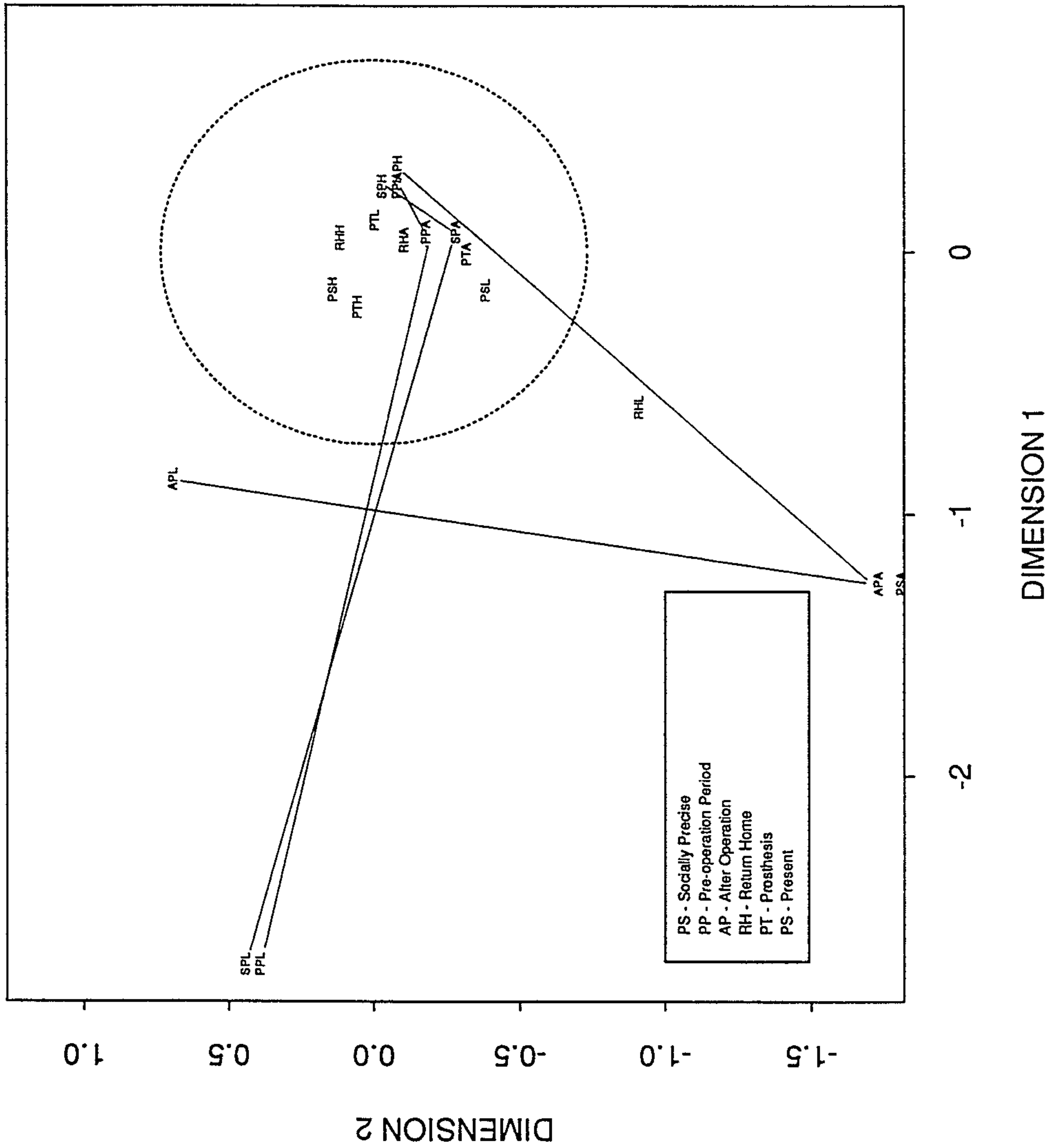
Correspondence Analysis: Associations between Emotional stability and Coping Period



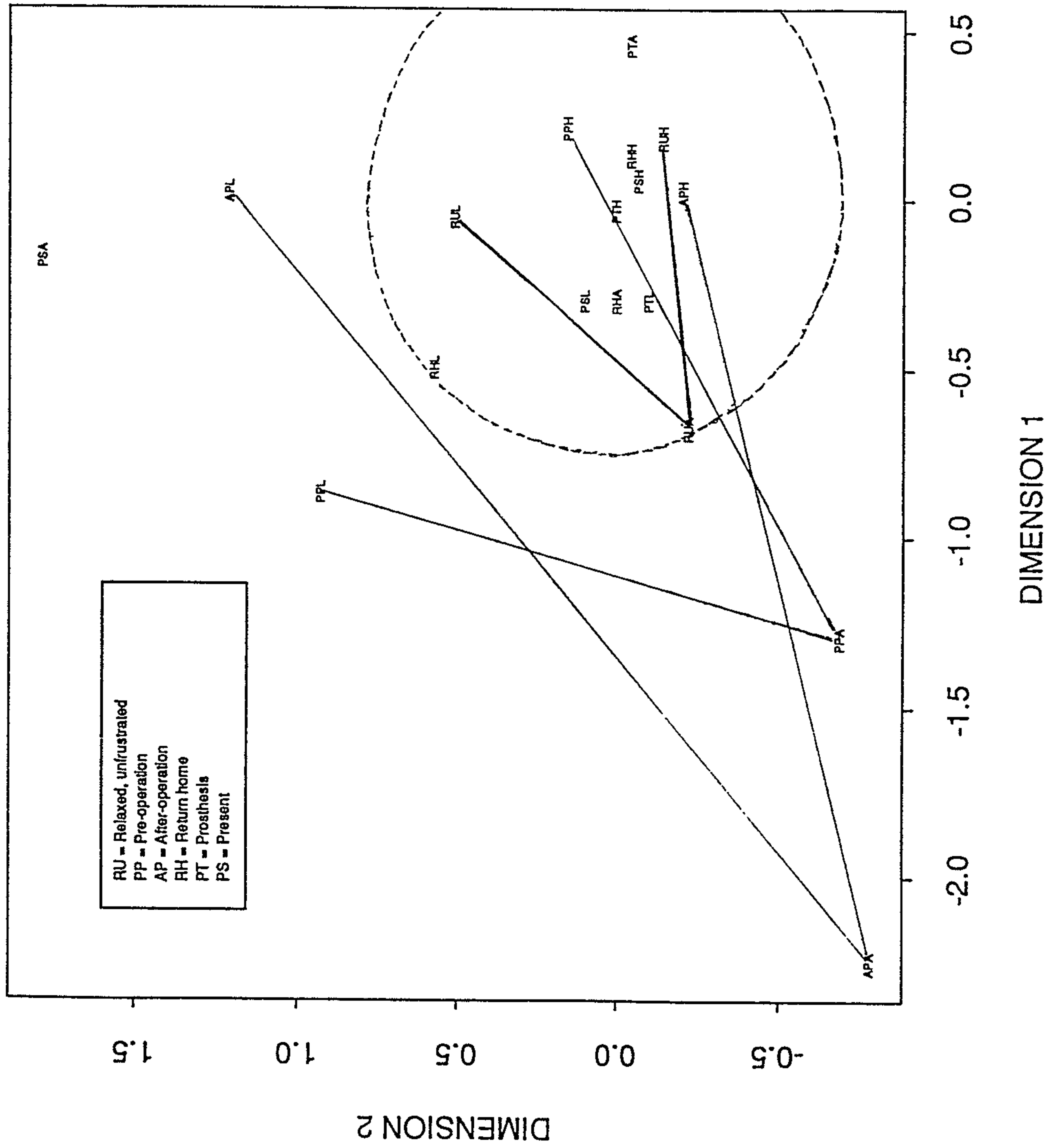
Correspondence Analysis: Associations between
Confidence serenity and Coping Period



Correspondence Analysis: Associations between Socially Precise and Coping Period



Correspondence Analysis: association between Relaxed, unfrustrated and Coping Period



APPENDIX 14

PROSTHESIS MATERIAL AND LOCATION¹

	MATERIAL			
	<i>Acrylic resin</i>	<i>Silicone rubber</i>	<i>Combination</i>	<i>Total</i>
<i>Nose</i>	10	9	-	19
<i>Ear</i>	1	13	-	14
<i>Eye</i>	9	-	2	11
<i>Total</i>	20	22	2	44

¹ There was a total of 41 subjects of whom 3 (subjects 23, 26 and 38) had 2 prostheses each, making a total of 44 prostheses.

APPENDIX 15

DAILY USAGE OF PROSTHESES^{1 2}

TABLE 15.1 NOSE PROSTHESIS USAGE

SUBJ. NO.	TYPE	MAT-ERIAL	RETENTION	WHEN USED	PROTECTION FROM DAMAGE WHEN NOT IN USE
10	Partial	Acrylic resin	Adhesive	Not used	Not used
18	Partial	Acrylic resin	Adhesive	Breakfast to bedtime daily	No problem
22	Partial	Acrylic resin	Adhesive	Was used, not clear when. No longer used	Not mentioned
23 (A)	Partial	Acrylic resin	Fixed to glasses	In public and for reading	No problem
37	Partial	Acrylic resin	Fixed to glasses	During waking hours	Problem. Easily broken, difficult to store safely
8	Partial	Silicone rubber	Adhesive	Daily 8am to 6pm	No problem
11	Partial	Silicone rubber	Adhesive	When going out only	No problem
20	Partial	Silicone rubber	Adhesive	Not used	Not used
38 (A)	Partial	Silicone rubber	Adhesive	Two days continuously then leaves off overnight. No longer used	No problem
38 (B)	Partial	Silicone rubber	Adhesive	Not mentioned	Not mentioned
23 (B)	Partial	Silicone rubber	Tissue undercuts	During heavy exertion and during waking hours when at home	No problem
28	Partial	Silicone rubber	Tissue undercuts	When going out or in presence of visitors	No problem

¹ Prostheses are listed by location, type and material, rather than by subject number.

² Subjects who used their prostheses for a period of time, for example months, and then stopped using them appear both in the tables recording prosthesis usage and in Appendix 18, recording prostheses not in use.

TABLE 15.1 NOSE PROSTHESIS USAGE

SUBJ. NO.	TYPE	MAT- ERIAL	RETENTION	WHEN USED	PROTECTION FROM DAMAGE WHEN NOT IN USE
36	Partial	Silicone rubber	Tissue undercuts/ weight of glasses	During waking hours	No problem
1	Partial nose/ cheek	Acrylic resin	Fixed to glasses/ Adhesive	At home, when someone came unexpectedly to the front door. No longer used	Not mentioned
2	Complete	Silicone rubber	Adhesive	3 days continuously	No problem
9	Complete	Acrylic resin	Fixed to glasses	In presence of others	No problem
13	Complete	Acrylic resin	Fixed to glasses	During waking hours except when going for a walk. No longer used	Not mentioned
32	Complete	Acrylic resin	Fixed to glasses	When out, not specific	Not mentioned
34	Complete	Acrylic resin	Fixed to glasses	During waking hours except when showering	No problem

TABLE 15.2 EAR PROSTHESIS USAGE ³

SUBJ. NO.	TYPE	MAT-ERIAL	RETENTION	WHEN USED	PROTECTION FROM DAMAGE WHEN NOT IN USE
5	Partial	Silicone rubber	Adhesive	Not mentioned. Not in use	Not mentioned
17	Partial	Silicone rubber	Adhesive	During day, length of time not mentioned	Not mentioned
27	Partial	Silicone rubber	Adhesive	Seven days continuously	Not mentioned
3	Complete	Silicone rubber	Adhesive	Up to 14 days continuously with 2 days rest.	No problem
4	Complete	Silicone rubber	Adhesive	14 to 21 days continuously	Not mentioned
6	Complete	Silicone rubber	Adhesive	Not used because heavier than old prosth.	Not used
15	Complete	Silicone rubber	Adhesive	Continuously for 2 week period	No problem
16	Complete	Silicone rubber	Adhesive	7 days continuously	No problem
21	Complete	Silicone rubber	Adhesive	Not used	Not used
24	Complete	Silicone rubber	Adhesive	5 to 6 days continuously	No problem
29	Complete	Silicone rubber	Adhesive	8 - 10 days continuously. Not in use	Not mentioned.
33	Complete	Silicone rubber	Adhesive	7 days continuously	No need
41	Complete	Silicone rubber	Adhesive	Occasionally when going out. Rarely used	No problem
7	Complete	Acrylic resin	Adhesive	Waking hours each day	No problem

³ Prostheses are ordered by location, type and material, rather than subject number.

TABLE 15.3 EYE PROSTHESIS USAGE ⁴

SUBJ. NO.	LOCATION	MATERIAL	RETENTION	WHEN USED	PROTECTION FROM DAMAGE WHEN NOT IN USE
14	Orbit	Acrylic resin	Fixed to glasses	When out of house	Slight problem due to fragility
40	Orbit	Acrylic resin	Fixed to glasses	Not used	A problem due to fragility
25	Orbit	Acrylic resin	Adhesive	When out of house or with visitors. Three days on, 1-2 days off	No problem
35	Orbit	Acrylic resin	Tissue undercuts/ adhesive	Daily for most waking hours	No problem
19	Orbit	Silicone rubber/ acrylic resin	Supported by glasses/ Adhesive	Tried for short time, did not fit due to tissue changes, wife disliked it. Not used	Not mentioned
31	Orbit	Silicone rubber	Adhesive	In presence of people other than family, not at work. Not used now	No problem
12	Orbit/ cheek/ palate	Acrylic resin	Fixed to glasses	During waking hours	No problem
26 (A)	Orbit- temple- forehead	Acrylic resin	Fixed to glasses	After morning shower until bed at night.	No problem
26 (B)	Orbit- temple- forehead	Acrylic resin	Fixed to glasses	Not used	Not used
30	Eye- cheek	Acrylic resin	Fixed to glasses	During waking hours	No problem
39	Eye- cheek	Acrylic resin	Fixed to glasses	In the presence of others or when going out	Fragile. Problem storing at home and while travelling.

⁴ Prostheses are listed by location, type and material, rather than subject number.

APPENDIX 16

PROSTHESIS RETENTION

TABLE 16.1 FORMS OF RETENTION AND PROSTHESIS LOCATION¹

FORMS OF RETENTION	NOSE	EAR	EYE	TOTAL
ATTACHMENT TO GLASSES	6		7	13
SKIN ADHESIVE	9	14	2	25
ENGAGEMENT OF TISSUE UNDERCUTS	3			3
COMBINATION OF METHODS	1 adh/glasses		2 adh/glasses adh/tiss	3

TABLE 16.2 NOSE PROSTHESES - EFFECTIVENESS OF RETENTION²

FORMS OF RETENTION	EFFECTIVENESS	ACRYLIC RESIN	SILICONE RUBBER	TOTAL
ATTACHMENT TO GLASSES	EFFECTIVE	S23 A, S34, S37		3
	EQUIVOCAL	S9		1
	PROBLEM	S13, S32		2
SKIN ADHESIVE	EFFECTIVE		S2, S20, S38 A, S38 B	4
	EQUIVOCAL	S18		1
	PROBLEM	S10, S22	S8, S11	4
ENGAGING TISSUE UNDERCUTS	EFFECTIVE		S23 B, S36	2
	PROBLEM		S28	1
COMBINATION OF METHODS	EFFECTIVE			
	PROBLEM	S1		1

¹ Figures given in this table are aggregate numbers of prostheses only. Prostheses belonging to specific subjects are not identified.

² Prostheses of individual subjects, identified by the subject number (prefixed with "S") are tabulated, and the aggregate number of prostheses in each row is shown under "Total".

TABLE 16.3 EAR PROSTHESES - EFFECTIVENESS OF RETENTION²

FORM OF RETENTION	EFFECTIVENESS	ACRYLIC RESIN	SILICONE RUBBER	TOTAL
SKIN ADHESIVE	EFFECTIVE	S7	S3, S4, S15, S16, S17, S24, S27, S29, S33, S41	11
	PROBLEM		S5, S21	2
	UNKNOWN		S6	1

TABLE 16.4 EYE PROSTHESES - EFFECTIVENESS OF RETENTION²

FORMS OF RETENTION	EFFECTIVENESS	ACRYLIC RESIN	ACRYLIC/SILICONE	TOTAL
ATTACHMENT TO GLASSES	EFFECTIVE	S12, S14, S26 A, S26 B, S30, S39, S40		7
	PROBLEM			
SKIN ADHESIVE	EFFECTIVE	S25		1
	PROBLEM		S31	1
COMBINATION OF METHODS	EFFECTIVE	S35	S19	2
	PROBLEM			

APPENDIX 17

PROSTHESIS RETENTION USING SKIN ADHESIVES¹

TABLE 17.1 NOSE PROSTHESES

USE OF SKIN ADHESIVE AND SUBJECT RESPONSE		ACRYLIC RESIN PROSTHESIS			SILICONE RUBBER PROSTHESIS		TOTAL
		ADHESIVE TYPE			ADHESIVE TYPE		
		SKIN- BOND ²	MED AD B ³	UNKNOWN	URO-BOND ⁴	MED AD B	
PROSTHESIS POSITIONED BY SUBJECT	NO PROBLEM	S18		S22	S38B	S2	4
	EQUIVOCAL				S11		1
	PROBLEM		S10		S8, S20, S38A		4
	UNKNOWN			S1			1
PROSTHESIS REMOVAL	NO PROBLEM	S18			S8, S11, S38A, S38B	S2	6
	PROBLEM		S10	S1			2
	UNKNOWN			S22	S20		2
ADHESIVE REMOVAL	NO PROBLEM	S18			S38A, S38B	S2	4
	PROBLEM		S10	S1, S22	S8, S11, S20		6

¹ Prostheses of individual subjects, identified by the subject number (prefixed with "S") are tabulated, and the aggregate number of prostheses in each row is shown under "Total".

² Skin-bond Cement, Smith and Nephew United, Inc. Largo, Florida, USA.

³ Medical Adhesive "B", Dow Corning Corporation, Midland, Michigan, USA.

⁴ Urobond 5000, Stanimed Pty Ltd, Northbridge, NSW, Australia.

TABLE 17.2 EYE PROSTHESES

USE OF SKIN ADHESIVE AND SUBJECT RESPONSE		ACRYLIC PROSTHESIS		ACRYLIC/SILICONE PROSTHESIS	TOTAL
		ADHESIVE TYPE		ADHESIVE TYPE	
		SKIN-BOND	MED AD B	SKIN-BOND	
PROSTHESIS POSITIONED BY	SUBJECT, NO PROBLEM	S35	S25	S19	3
	OTHER PERSON, IS A PROBLEM			S31	1
PROSTHESIS REMOVAL	NO PROBLEM		S25	S31	2
	PROBLEM	S35			1
	UNKNOWN			S19	1
ADHESIVE REMOVAL	NO PROBLEM	S35	S25	S31	3
	EQUIVOCAL			S19	1

TABLE 17.3 EAR PROSTHESES

USE OF SKIN ADHESIVE AND SUBJECT RESPONSE		ACRYLIC PROSTHESIS	SILICONE RUBBER PROSTHESIS			TOTAL
		ADHESIVE TYPE	ADHESIVE TYPE			
		SKIN-BOND	SKIN-BOND	URO-BOND	MED AD B	
PROSTHESIS POSITIONED BY	SUBJECT	EQUIVOCAL		S24		1
		PROBLEM		S3		1
		UNKNOWN			S6	1
	OTHER PERSON	NO PROBLEM	S7	S17, S27, S33	S5	5
		EQUIVOCAL		S15		1
		PROBLEM		S16, S21, S29	S41	4
		UNKNOWN		S4		1
PROSTHESIS REMOVAL	NO PROBLEM	S7	S3, S4, S15, S16, S21, S33	S5, S41	9	
	PROBLEM		S24		S6	2
	UNKNOWN		S17, S27, S29			3
ADHESIVE REMOVAL	NO PROBLEM	S7	S3, S4, S15, S17, S24, S33	S41		8
	EQUIVOCAL		S16, S27	S5		3
	PROBLEM		S21		S6	2
	UNKNOWN		S29			1

APPENDIX 18

PROSTHESES THAT WERE NOT IN USE^{1 2}

SUBJ. PROSTH. NO.	TYPE	MAT- ERIAL	RETEN- TION	PROBLEMS WITH PROSTHESES NOT IN USE - "M" DENOTES MAIN REASON										PROSTH NOT NEEDED WANTED
				DISCOM- FORT, SKIN INJURY	POOR RETENT- ION	APPEAR- ANCE PROB.	PROB. WITH ADHES- IVE	CLEAN- ING PROB.	SUBJECT PREFER- ENCE	BAD FAMILY REACT- ION	BAD PUBLIC REACT- ION	MORE SURGERY /TISSUE CHANGES	MATER- IAL BREAK- DOWN	
1	Cheek/ nose	Acrylic resin	Fixed glasses/ adhesive	*	*	*	*	*		*	*	* M		
10	Nose	Acrylic resin	Adhesive	*	*		* M	*						
13	Nose	Acrylic resin	Fixed to glasses	*	*							* M		
22	Nose	Acrylic resin	Adhesive	*	*		*	*				* M		
23A	Partial nose	Acrylic resin	Fixed to glasses									* M		
23B	Partial nose	Silicone rubber	Tissue undercut									* M		
20	Partial nose	Silicone rubber	Adhesive	*			* M	*						
38A	Partial nose	Silicone rubber	Adhesive			*	*				*		* M	
5	Partial ear	Silicone rubber	Adhesive	*	*		* M					*		
6	Ear	Silicone rubber	Adhesive	*			*	*	* M					
21	Ear	Silicone rubber	Adhesive		*		*	*						* M

¹ Prostheses are listed by type, material and retention, not by subject number.

² Eight of these prostheses (S1, S13, S22, S23A, S23B, S38A, S5 and S29) had been in more or less regular use but had ceased to be used prior to the time of interview. The remaining prostheses had never been in regular use.

SUBJ. PROSTH. NO.	TYPE	MAT- ERIAL	RETEN- TION	PROBLEMS WITH PROSTHESES NOT IN USE - "M" DENOTES MAIN REASON										PROSTH NOT NEEDED WANTED
				DISCOM- FORT, SKIN INJURY	POOR RETENT- ION	APPEAR- ANCE PROB.	PROB. WITH ADHES- IVE	CLEAN- ING PROB.	SUBJECT PREFER- ENCE	BAD FAMILY REACT- ION	BAD PUBLIC REACT- ION	MORE SURGERY /TISSUE CHANGES	MATER- IAL BREAK- DOWN	
29	Bar	Silicone rubber	Adhesive		*							* M	*	
41	Bar	Silicone rubber	Adhesive			*	* M				*			
19	Eye	Acrylic/ silicone rubber	Adhesive	*						*		* M		
26B	Eye/ temple/ forehead	Acrylic resin	Fixed to glasses			* M					*			
31	Eye	Acrylic/ silicone rubber	Adhesive	*	*		* M							
40	Eye	Acrylic resin	Fixed to glasses							*	*			* M
TOTAL				9	8	4	10	6	1	3	5	8	2	2
TOTAL "MAIN REASONS"				0	0	1	5	0	1	0	0	7	1	2