

Identifying the psychosocial factors and processes contributing to successful adjustment to disfiguring conditions

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THE HEALING FOUNDATION

Rebuilding the bodies, minds and lives of people with disfigurements

This research explores the psychological factors that influence adjustment to a visible difference. The project was generously supported by the Welton Foundation and The Worshipful Company of Tin Plate Workers.



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Introduction

In excess of 1 million people in the UK have a significant disfigurement to the face or body. The difficulties experienced can be pervasive and debilitating, and include negative experiences related to social encounters with others and adverse effects on self-esteem and quality of life.

Not all people are equally affected and a proportion adapt positively to the demands upon them, in some cases perceiving their visible difference as a positive advantage.

This collaboration of experts in the field of psychosocial distress research examined the processes that influence the extent to which individuals adjust positively to the challenges of living with a visible difference.

Aims

1. To clarify the psychosocial factors and processes which contribute to variation in adjustment in people with visible disfigurement
2. To use the results to inform the development of packages of support and intervention

Research methods

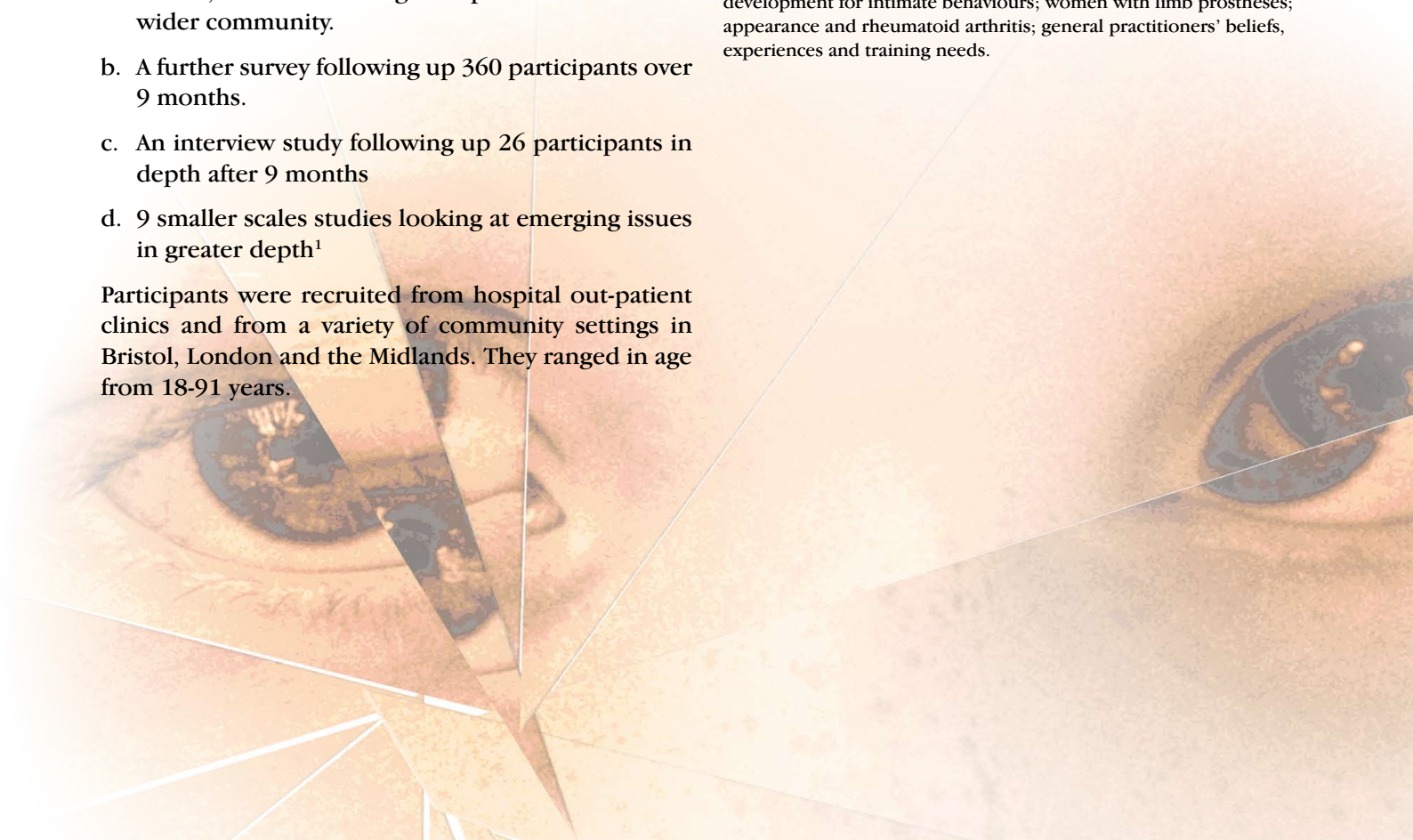
- a. A large, cross-sectional survey of 1,265 participants with visible differences resulting from a variety of causes, recruited through hospital clinics and the wider community.
- b. A further survey following up 360 participants over 9 months.
- c. An interview study following up 26 participants in depth after 9 months
- d. 9 smaller scales studies looking at emerging issues in greater depth¹

Participants were recruited from hospital out-patient clinics and from a variety of community settings in Bristol, London and the Midlands. They ranged in age from 18-91 years.

Key findings

1. Adjustment to disfigurement is very variable, and, whilst many adjust well, others experience high levels of distress.
2. Relationships between adjustment, age, gender and other demographic features are equivocal.
3. The important role of thought processes and interactions in mediating adjustment is clear.
4. The media, society and culture contribute to distress experienced by those vulnerable to appearance concerns.
5. Support and intervention of varying levels of intensity should be readily available to ameliorate distress and promote positive coping.
6. Findings of the research programme have informed the development of a model of adjustment to disfigurement and support the need for interventions which seek to address unhelpful appearance related thoughts and social behaviour.

¹ Studies examined positive adjustment; black & minority ethnic community views; South Asians with vitiligo; social comparison processes; appearance concern, hostility and social situations; scale development for intimate behaviours; women with limb prostheses; appearance and rheumatoid arthritis; general practitioners' beliefs, experiences and training needs.



Main findings

1. Profiles of Adjustment and Distress

- a. Participants demonstrated very variable profiles of adjustment and distress. Difficulties and distress were often considerable, indicating unmet need. Distress was evident in those seeking treatment at the time of the study and also in those not undergoing any form of intervention.
- b. Adjustment is multi-factorial. Contributory factors include dispositional style (optimism/pessimism) and cognitive (thought) processes (such as fear of negative evaluation by others, perceived social acceptance), appearance specific cognitions, including salience, valence (the personal value attached to physical appearance) and appearance-related self discrepancies (differences between how an individual thinks they look, how they would like to look and how they feel they should look).
- c. The role of some factors in adjustment to disfigurement, hitherto neglected in research, have also been highlighted, including aggression in response to appearance-related threats, and the added burden of functional disability for those who wish to function independently.
- d. Additional factors and processes produced contradictory findings within this programme and are in need of further research, including the issue of the visibility of a disfigurement to others and the role of social comparison processes in adjustment.

2. Positive Adjustment and Resilience

- a. People who self reported as positive adjusters described the experience of disfigurement as one of personal growth and reported a number of strategies that appeared to work well, including pragmatism and 'getting on with it' in the face of challenges, acceptance, determination and engaging with problems and difficulties rather than avoiding them.

3. The Impact of Appearance-Related Distress

- a. Appearance-related distress impacted on a wide range of daily activities and thoughts about the self, social functioning and intimate relationships.

4. The Multiple Nature of Appearance Concerns

- a. Distress relating to appearance can relate to many different aspects of the body and can include an exclusive focus on disfigurement. However distress may result from concerns about weight, shape, and the effects of ageing on appearance.
- b. In some cases these latter concerns caused more distress than the disfigurement. The consequences for the individual of concerns about aspects of appearance which are not normally considered to be disfigurements (such as body shape and size and the effects of ageing) were strikingly similar to the distress caused by disfigurement.

5. The Dynamic Nature of Adjustment

- a. Fluctuations in the salience and impact of appearance concerns are triggered by a variety of events and changes, including life events, developmental milestones, signs of ageing, and the cumulative impact of daily stressors such as the reactions of others.
- b. Even when adjustment is positive over long periods of time, coping with a visible difference can be an ongoing strain on a person's psychological resources.

6. The Impact of Age, Gender and Ethnicity

The focus of this research programme has been on those psychological factors and processes which are amenable to change, yet these issues are also contextualised by characteristics which cannot be altered through intervention.

- a. There were overall decreases in levels of distress with age, but individual variation was considerable, and large numbers of older people were distressed about their appearance.
- b. Appearance related distress was higher in women, but differences between men and women were small, and many men had significant and, in some cases, debilitating concerns about their appearance.
- c. Within the ethnic groupings examined in two of the smaller studies, there was evidence of the strong influence of cultural and religious beliefs on the beliefs and attitudes about disfigurement and on the experiences of those who are personally affected.

Conclusion

This has been the largest programme of research to date into psychosocial aspects of disfigurement. It has made a significant contribution to knowledge concerning adjustment to a visible difference by providing evidence to support a model of adjustment that will inform both further research and provision of care.

Average scores on all measures did not reflect high levels of distress. This is an important finding which demonstrates that many people with visible difference adjust well. However, the variation in levels of adjustment was considerable, with substantial numbers of participants reporting high levels of distress, highlighting widespread unmet need. Contrary to expectations, levels of adjustment and distress in the cross sectional study were similar in the samples recruited from hospital clinics and from the community. In the clinic sample, levels of distress were not explained by the type of clinic attended.

Adjustment and distress are multi-factorial. A synthesis of findings from all the studies indicates that the psychological characteristics of those who were positively adjusted included higher levels of optimism, greater feelings of social acceptance and satisfaction with social support, a lack of concern about negative evaluations by others, and a self-system with lower levels of salience and valence afforded to appearance related information. Levels of social anxiety and social avoidance were low, as were levels of negative affect, general anxiety and depression. These people felt their disfigurement was reasonably easy to disguise, and tended to be older than people with higher levels of distress.

In contrast, those experiencing high levels of distress were characterised by a more pessimistic outlook on life, higher levels of fear about negative evaluations by others and lower levels of satisfaction with levels of social support. The discrepancy between how they perceived their appearance to be, and how they thought it should be was considerable. They believed their disfigurement was visible to others, and hard to disguise. Appearance concerns occupied a more central position in their cognitive architecture and in the way they process information from their social environment.

These findings have consequences for the wellbeing of people with visible difference, as many of the characteristics of those with higher levels of distress are amenable to intervention. Accordingly, the results of this programme of research have been used to inform the development of an intervention manual which is being evaluated in further research.



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