Difficulties with employment: understanding the experiences of people with visible differences

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Since the 1980s, and in contrast to Japan, many researchers in the UK have revealed that facial disfigurement can disturb social interactions and have a great psychological impact upon the people affected. Despite the known psychological and social consequences associated with facial disfigurement, little is understood of the economic difficulties confronting people with visible differences. The aim of this paper is to explore the various difficulties that people with visible differences experience in terms of employment. Fourteen people with visible differences participated in this small qualitative study. This paper argues that research on the difficulties for people with visible differences people in terms of employment has to pay attention to the stage ‘before applying for a job’ and, in addition, focus on the significant effects arising from a person’s concealment of their visible difference.

Keywords: visible difference; facial disfigurement; difficulties with employment; qualitative research

Introduction

People have facial disfigurements due to disease or injury. The charity Changing Faces estimated that 542,000 (or one in 111) people in the UK have a significant facial disfigurement (Changing Faces). It is not easy to draw a boundary between what is and is not facial disfigurement, so several researchers define disfigurement as ‘a difference from a culturally defined norm which is visible to others’ (Rumsey & Harcourt, 2005). The causes of facial disfigurement include congenital malformations, such as birthmarks, cleft lips and/or palates and haemangiomas, and acquired conditions, such as burns, scars from traffic accidents and dermatological disease.

When one considers the high specificity of the face when compared with any other part of the body, it is not surprising to find that people with facial disfigurements encounter serious psychological and social problems. It is through the face that we recognize one another. The face is also the source of verbal communication and an important site of non-verbal communication. Moreover, the face is the main determinant in people’s perceptions of our individual attractiveness as related to appearance, and these perceptions make a difference to our self-esteem and life chances (Synnott, 1993). Because of the profound social significance of the face, facial disfigurement can drastically affect social interactions and have a great psychological impact upon the individual concerned.

In Japan, until very recently, people with facial disfigurements have received little attention. Since the establishment of a self-help group Unique Face in 1999 [1], a few researchers have

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become interested in the psychological and social consequences of facial disfigurement and in the coping strategies that people with facial disfigurements have developed to protect themselves and to live through stigmatizing situations (e.g. Matsumoto, 1999, 2005; Kondo & Yamazaki, 2005; Nishikura, 2008, 2009). However, as the problems connected to facial disfigurement are not widely understood, people who have facial disfigurements have not been provided with specialist services and psychological support, except through the cosmetic camouflage services of make-up specialists in several hospitals or cosmetics companies [2]. Thirty years ago, Macgregor (1979) suggested that people with facial disfigurements seemed to be ‘the forgotten people’, and this is still the case as far as Japan is concerned.

In contrast to Japan, many researchers in the UK from a variety of academic backgrounds, have, since the 1980s, studied the serious problems that people with facial disfigurements have to deal with. The problems most frequently reported are negative self-perceptions and difficulties with social interactions. First meetings with strangers are particularly problematic. Due to staring and other people’s rude comments, people who have facial disfigurements are subjected to a lack of anonymity in a crowd (Bull & Rumsey, 1988). They experience not only these invasions of their private space, but also rejection and avoidance by others. For example, many people attempt to avoid contact with those who have facial disfigurements in the street by quickening their pace, withdrawing their gaze and/or ignoring the person’s presence (Rumsey & Bull, 1986; Bull & Rumsey, 1988). Repeated exposure to these negative reactions by others can result in harmful effects on one’s self-perception, such as a low level of self-esteem and a negative self-image (Robinson, 1997). In addition to problems during first meetings with strangers, some people with facial disfigurements report negative effects of their appearance upon intimate relationships. Lanigan and Cotteril (1989) noted that about 10 per cent of their female patients with port wine stains did not see even their partners without cosmetic camouflage.

In the UK, specialist services have provided people with facial disfigurements with coping strategies to enable them to protect themselves and to maintain self-esteem (Rumsey & Harcourt, 2005). Social skills training has been found to be effective in reducing social anxiety and in acquiring coping strategies for managing social interactions (Robinson et al., 1996).

Studies to date in the UK are of significance to researchers in Japan where research on the problems related to facial disfigurement have only just started. Very little research, however, has focused on the difficulties that people with facial disfigurements encounter in the labour market, and nothing is known about the effects that the medical treatment or concealment of a facial disfigurement has on the working situation of those affected. Exceptions have been Bradbury (1997) and Stevenage and McKey (1999). Bradbury pointed out that people with facial disfigurements consciously tend to choose a low-profile career and are reluctant to seek advancement in their careers. Stevenage and McKey found that having a facial disfigurement had a markedly negative effect in the recruitment and selection process. In the US, Tartaglia et al. (2005) documented the experience of discrimination in the workplace for Americans with facial disfigurements. Using data from the Equal Employment Opportunity Commission, they showed that allegations from people with facial disfigurements were significantly higher for the retail and service industries and lower for the construction and manufacturing industries where employers could more easily ‘hide’ employees. Although research on employment to date has addressed the problems people with facial disfigurement confront both in the recruitment and selection process and in the workplace, these are not the only problems that people with visible differences in Japan have reported in the area of employment (Ishii et al., 2001; Alopecia Areata Foundation, 2005). This study, based on accounts given by the people
concerned, aims to explore the various difficulties that people with visible differences experience in the area of employment.

**Methods**

This qualitative study constitutes preliminary research to help create a draft questionnaire for quantitative data collection and analysis. Using qualitative methods, the focus of this study is an in-depth understanding of the lived experiences of those who have visible differences. These preliminary interviews were conducted in collaboration with Yasuo Yabuki, who was born with albinism and is a graduate student of sociology at Rikkyo University, and Masayuki Ishi, who published a book called *I am a journalist with a port-wine stain* in 1999, which charts his search for the answer to the question ‘What is the face for human beings?’ He also established the nation-wide self-help group, *Unique Face.*

The primary research questions were: ‘How has visible difference affected the participants’ work and occupation?’; ‘With what thoughts or attitudes have they sought employment?’; and ‘How has the medical treatment and concealment of a visible difference affected their work?’

**Participants**

The participants consisted of fourteen people who have lived with a visible difference in their face, hair or skin on almost every part of their body. One half of the participants were members of three self-help groups that support individuals who have a visible difference and their families in Japan [3]. The other half were recruited either from the community site of a social networking service in which people with visible differences exchanged medical information or talked about their troubles in everyday life with each other or through the private friendships that Yabuki formed in *Unique Face.*

Of the fourteen participants, there were six men and eight women, ten people who had congenital disfigurements (including cleft lips and/or palates, port-wine stains, cavernous haemangiomas, von Recklinghausen disease and albinism) and four people who had acquired conditions (caused by traffic accidents, burns and alopecia areata). At the time of the interviews, the participants ranged from 21 to 59 years of age. The educational level of three participants was high school, five had graduated from a vocational school or junior college and six had university degrees. Seven participants were permanent employees and three were employed as part-timers or as temporary staff. Four were unemployed. Apart from four women, all the participants had contact with a self-help group and, to varying degrees, were committed to social issues concerning visible difference. In addition, to gather as much information about people with visible differences in a clinical setting as possible, we interviewed a plastic surgeon who specializes in congenital disfigurements and a dermatologist who has assisted a patient support group for people with alopecia areata.

**Interviews and data analysis**

The collection and production of data occurred through fourteen interviews that took place over a three-month period. Each interview was approximately two hours in length. Influenced by Flick (1998), we used focused interviews with a semi-structured format to discover the difficulties that people with visible differences encounter with employment and the effects that the medical treatment and concealment of a visible difference have on their work. Flick explains that focused interviews enable us both to explore the ways of thinking that are specific to various social groups and to set up a hypothesis for subsequent quantitative research. Interviews were recorded and transcribed verbatim. The transcripts were
Findings
Although earlier studies on facial disfigurement and employment have focused entirely on the discrimination experienced by people with visible differences in the recruitment and selection process or in the workplace, it seems that the participants in this study encountered more diverse and complex difficulties when it came to their employment. These can be roughly classified into three types: (1) difficulties before applying for employment; (2) difficulties while applying for a job and during the recruitment and selection process; and (3) difficulties in the workplace. I shall consider these difficulties in turn and then deal with how the concealment of visible difference affects the participants’ employment because it appears that it is closely linked to all three types of difficulties.

Difficulties before applying for a job
Some participants reported that it is not easy to make up their mind to apply for work. As many researchers have revealed, people with visible differences feel that they are avoided and rejected by others. The fear of these negative reactions is so great that withdrawal from social situations involving an avoidance of occupational activities is frequently chosen as a way to deal with the difficulties and protect themselves. A man heading a parent support group for people with a cleft lip and/or palate indicated that there were not a few people with the condition who became preoccupied with their appearance and withdrew from the labour force. Furthermore, psychological problems such as feelings of isolation and low levels of self-esteem can result in a person avoiding employment. A 35-year-old man who had alopecia areata at the age of six months could not bring himself to find work when he was a university student:

I felt alone. There were no role models who showed me how to live with alopecia areata because I did not know anyone who had the same disease as me. While I only had to run on rails from elementary school to university, I could not have the confidence to start work after finishing university and withdrew into my own world when I was a senior.

He needed seven extra years to graduate from university and it was not until he took part in a self-help group that aimed to provide information and support to individuals with alopecia areata and got to know many people with the disease that he made up his mind to look for work.

A 31-year-old woman was involved in a serious car accident when she was a junior college student, which left her with a traumatic injury on the upper side of her face. She majored in childcare and was aspiring to become a nursery teacher at the time. However, for about six years after the injury, she had to receive continual treatment, which involved hospitalization and surgery, and she could not so much as try to find a job. Moreover, because of her doctor’s inappropriate attitude, she could not discover when she would be able to start looking for work. She complained of poor explanations concerning her treatment and expressed dissatisfaction with her doctor’s attitude:

At first, my doctor expected it to take me about three years to complete my treatment but, in the end, I required three more years. I continued to receive treatment without knowing how many times I had to undergo surgery. If my doctor had intelligibly explained his plans for my treatment, I could have made plans to look for a job. I think it is difficult for even a doctor to...
predict the outcome of surgery with accuracy but, from the standpoint of a patient, it is vital information.

Difficulties with applications and during the recruitment and selection process

Some participants said that they chose to seek work in industries with limited public interaction and exposure. The man with alopecia areata mentioned above remarked that people who lost their hair because of the disease and wore a wig consciously tended to choose a low-profile career. A 31-year-old woman who had congenital ichthyosiform erythroderma avoided looking for jobs in such industries as the retail and service sectors when she was a junior college student:

I knew it was completely impossible for me to get a job with customer contact. Even if I was employed in these industries, I would be exposed to negative reactions from customers, including invasive comments and staring. In addition, I thought I could never gain employment that involved the handling of foods because of my turned-up skin.

In addition, persons close to the participants also played an important role in preventing them from pursuing employment that made them more noticed by others. For example, a 21-year-old woman who had a port-wine stain and does not use cosmetic camouflage was told by a guidance counselor in her high school that it would be better to avoid seeking employment in situations involving extensive customer contact (for instance, as a sales person or a receptionist). The teacher counseled that she should choose a job with little or no customer contact so that her facial disfigurement would not cause anyone discomfort. A 37-year-old man with cavernous haemangioma on one side of his face was forced by his father to seek employment in industries with little or no customer contact. He was going to take a humanities course in college and wanted to become a businessman when he was a high school student. His father, however, told him that it was impossible for him to become a businessman because of the severe disfigurement of his face and advised him to take a science course in college to get employment in the construction or manufacturing industries, where there was limited public interaction and his condition would not be so visible:

Rejected without being given the chance to explain, I was reluctant to accept his advice, but I decided to take the science course. However, I felt seriously depressed and became discouraged about going to college. In the end, I went to a junior college because I continually failed my college-entrance exams.

Some participants tended to choose to look for work in industries with limited public interaction and exposure, as mentioned above, but others did not. Nevertheless, in the recruitment and selection process, they were rejected as ‘unqualified’ because of their appearance. One of the worst types of recruitment discrimination occurred when people with visible differences were denied employment because of the unjustified belief that customers would be offended simply by seeing them. A 24-year-old woman has very fair skin and light-colored hair as a result of albinism, which is quite different from the ‘normal’ appearance of Japanese. Since high school, she had tried to work part-time at a supermarket or store. One day, she made an appointment for a job interview by phone but as soon as the store manager saw her he told her that the store could not hire her because of her ‘unusual’ hair color. She remarked:

Few people know that there are those who live with albinism and have light-colored hair in
Japan. Consequently, employers fear the negative reactions of customers to my light-colored hair and I have been denied employment. They said, ‘Customers might get offended when they see you. Moreover, it is too much trouble for you to explain why your hair color is so unusual when you work as a cashier, isn’t it?’

A woman in her forties with a port-wine stain covering one side of her face was told at a job interview with a restaurant that she had to conceal her facial disfigurement by wearing a cotton mask for fear that co-workers as well as customers would feel uncomfortable when they saw her face.

**Difficulties in the workplace**

Even if people with visible differences are able to find work, some difficulties still lie ahead. Some participants described that they had been exposed to workplace harassment that was related to their visible difference. The harassment included teasing, ridiculing, bullying, verbal abuse, and arbitrary changes in their jobs or their assignments. A woman with a severe facial disfigurement as a result of von Recklinghausen disease got a clerical position in a small company after graduating from vocational school:

One day, I served tea to a client as usual but a co-worker said to me ‘How dare you do that? What would clients feel if they see your face?’ That was what I had to do at the office and the client didn’t look offended. I was deeply shocked to hear her say such a thing.

People with visible differences were targeted for harassment not only because of other people’s attitudes to the visible difference itself but also because the person with the visible difference concealed it. A member of a self-help group for people with alopecia areata said that those who had the disease and covered up their hair loss with a wig were frequently teased by their colleagues by being called, for instance, ‘baldie’ and ‘wiggy’. According to a dermatologist who assisted a patient support group for people with alopecia areata, those who developed the disease tended to be assigned against their wishes to positions with little or no customer contact because of the changes in their appearance. To make matters worse, people who were subjected to harassment in the workplace remarked that they had no one and nowhere to turn to for help or redress.

As several researchers have pointed out, some people with visible differences report that their appearance has negative effects not only during casual encounters with strangers but also in intimate and longer-term relationships. The woman with congenital ichthyosiform erythroderma mentioned above was reluctant to develop close relationships with co-workers when she was employed as a clerical worker in a small company:

Having been avoided and rejected frequently by classmates since childhood, I think everyone who sees me may not want to have close contact with me. Therefore I cannot get familiar with co-workers and have given up having close relationships in the workplace.

Those who work while receiving medical treatment that involves hospitalization and surgery confront the problem of having to balance their career and their medical treatment. The use of steroid injections is thought to be one of the most effective treatments for alopecia areata but it can cause such serious side-effects as a moon face, acne outbreaks, migraines, cataracts, and osteoporosis. According to a member of a self-help group for people with the disease, these side-effects make it difficult for some members to keep working. Additionally, a
dermatologist suggested that patients with alopecia areata who live in rural areas had to spend a lot of time in order to see a doctor regularly, so they tended to leave their work, because hospitals with dermatologists who specialize in the disease are only concentrated in large cities.

A lack of understanding of the difficulties experienced by people with visible differences prevents them from striking a balance between work and medical treatment. A woman in her thirties with a cleft lip and palate had regularly undergone corrective surgery involving hospitalization since she was a child and had got employment in a life assurance company after graduating from high school. She said:

I could not undergo corrective surgery after starting to work because my boss did not allow me to take paid vacations for it. For me, it was obvious that facial disfigurement affects not only my work but also every aspect of my life. But no one else thought so, and they could hardly understand why I required surgery. In the end, I had to give up working in the company.

Not all the difficulties people with visible differences encounter in a work setting, however, can be attributed to others. A woman with a port-wine stain thought that she could compensate for her facial disfigurement by hard work, and she tended to push herself to the limit. She got burned out, became depressed and damaged her relationships in her workplace. In this way, she could not stay in a job and she kept changing her work. She remarked:

Many people tend to regard people with disabilities as cheerful, honest and hardworking, don’t they? I have a psychological tendency to try to live up to other’s expectations but usually cannot meet them and end up seriously depressed.

**Effects of the concealment of visible difference**

The concealment of visible difference has a great impact at every stage of one’s employment, from applying for a job through to staying in one. A man who was a member of a self-help group for people with alopecia areata and wore a wig suggested that people with the disease had to choose a job from a limited number of options whether or not they wore a wig. It is almost always difficult for people living as ‘skinheads’ to find work in industries that involve a lot of contact with the public. Also, people with a wig feel the need to choose a job that minimizes the chance of exposure. They tend to work as part-timers, temporary staff or on short-term contracts, avoid developing close and long-term relationships in the workplace and change jobs frequently for fear that their visible difference may be noticed by colleagues. He remarked:

In particular, women are frightened of being told that their hairstyle does not change, because of the wig. I have heard some female members say that they abandon a job before their co-workers comment on their hairstyle. Although I do not know whether working as a temp or on a short-term contract is a means of avoiding close relationships in the workplace, there are several members in this support group who choose such a way to work.

He also pointed out that many members who wore a wig were interested in the question of whether or not to tell their colleagues about their alopecia areata and, if they did, when and how they could let their co-workers know.

Concealment could be used to reduce the risk that others might avoid them, to protect
themselves and to make themselves feel better, but it can also lead to psychological burdens like a sense of guilt, anxiety about exposure and a continual preoccupation with the possibility of exposure. It is likely that those who conceal their visible difference cannot open up and become close to co-workers as a result of these secondary effects of concealment.

**Discussion**

This study brings to light important implications about the difficulties with employment for people with visible differences and the effects of concealment on their work. Although research on this topic to date has mainly addressed the discrimination people with facial disfigurements experience in the recruitment and selection process (Stevenage and McKey, 1999) and in the workplace (Tartaglia et al., 2005), some participants in this study remarked that they had already encountered difficulties before ‘being an applicant’ and cannot make up their mind to look for work. Frequent exposure to such negative reactions as avoidance and rejection by others since childhood can result in withdrawal from social situations, avoidance of occupational activities and a reluctance to develop close relationships with others. Unfortunately, people with visible differences tend to be isolated because they do not have people with the same disease or medical condition around them. It is very hard for them to know how to live with a visible difference and thus have the confidence to enter the world of work. For some people, moreover, the work that they could try to get was largely limited by persons close to them, such as their family or teachers, to industries with little or no customer contact. Accordingly, it is necessary to pay attention not only to the recruitment and selection process or to workplace discrimination but also to the difficulties before someone applies for a job. Figuratively speaking, we need to expand our interest toward an ‘earlier’ point in time.

The difficulties people with visible difference confront with employment depend a lot on whether or not they conceal the difference. It is very hard for those who do not or cannot conceal their visible difference to get a job in industries with a high amount of customer contact. Even if they apply for or are employed in these industries, they are likely to be rejected at a job interview or are exposed to invasive comments and verbal abuse in the workplace. By contrast, those who usually use cosmetic camouflage or wear a wig tend to experience difficulty in keeping a job. They tend to change jobs frequently for fear that some day their visible difference may be discovered by their colleagues. Moreover, concealment involves a trade-off between preventing others from avoiding or rejecting them, on the one hand, and psychological burdens such as a sense of guilt and the giving up of developing close and long-term relationships with co-workers, on the other. Nevertheless, with one exception (Kent, 2000), very little attention has been paid to these secondary effects of concealment. It should be emphasized that concealment is significant, both positively and negatively, for people with visible differences when it comes to the issue of their employment and that research on this topic needs to explore how concealment influences the matter of work for those affected.

The results presented above offer an in-depth understanding of the experiences of people living with visible differences. Until recently, most research on visible difference has employed quantitative methods of data collection and analysis. The methodology used in these studies has enabled some meaningful comparisons to be made between studies that share the same quantitative measures, but little is known about the complexity of the psychological and social effects of visible difference. This qualitative study, based on accounts given by people with visible differences, is different from others in that it attempts to be an example of problem-finding research and to explore ways of thinking that are specific to these
people. However, this research has several limitations. First, as in many qualitative studies, the number of participants interviewed was relatively small. The descriptions given here may not be typical of the experiences of all people with visible differences. It may be that the participants (members of self-help groups and those interested in the social issues surrounding visible difference) and the types of question asked (about how visible difference has affected their employment) may have biased the responses toward a recounting of more negative experiences. Second, this study could not compare the difficulties for people who have a certain condition with people who have another condition, although we did interview people with a variety of conditions. It seems likely that there are significant differences between people with congenital visible differences and people with acquired differences, between people with concealable visible differences and people with non-concealable differences, between people with more severe visible differences and people with milder differences, and so on. I will explore the experiences of a larger sample of people who are living with visible differences using a questionnaire employing quantitative methods of data collection and analysis. As Rumsey & Harcourt (2004) suggest, it is important for researchers on visible difference to combine both qualitative and quantitative methods. In addition, I will examine the difficulties people with visible differences experience with employment by focusing on the type, severity and concealability of a visible difference as well as on demographic and social factors such as age, gender and socio-economic status.

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Notes
1. While this self-help group was run nationwide by people with facial disfigurements and their families until 2005, its activities are now practically suspended. *Unique Face* accepted applicants regardless of the medical condition that caused their facial disfigurement. Membership reached a total of approximately 300 people. This group regularly held voluntary meetings for peer counseling, published a quarterly newsletter and provided education about cosmetic camouflage for make-up specialists who had little experience in dealing with people with facial disfigurements.

2. In the UK, camouflage make-up that can be used on the face and body is available on the National Health Service via the British Red Cross (Rumsey & Harcourt 2005). Skin camouflage service of the British Red Cross teaches individuals how to cover visible skin conditions such as burns, scars and birthmarks on the face or body. The service is provided free of charge (British Red Cross).

3. The three groups are for people with a cleft lip and/or palate, alopecia areata and albinism. Each aims to provide information and support to the individuals concerned and their families.

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