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A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference

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Abstract

Individual and group interviews explored experiences of positive adjustment among 12 people with a range of visible differences. Thematic analysis identified four main themes: importance of appearance; personal growth; relationships with others; and coping (factors in the coping theme considered to be paramount to positive adjustment were inner strength and positivity, active coping techniques, downward social comparisons, taking things day-by-day, spirituality and humour). The findings provide insight into behaviours and personal outlooks that may contribute to adaptive coping and have implications for future research and interventions aimed at those who exhibit poor adjustment to visible difference. The article reflects on the use of both individual and group interviews for research in this field.

Keywords

appearance, coping, disfigurement, positive adjustment, qualitative methods, visible difference

Introduction

It is estimated that a minimum of one million people in the UK have a visible difference (disfigurement) of some kind (Changing Faces, no date). To date, the majority of research exploring the psychosocial impact of visible difference has focused on the experiences of people who report having problems such as difficulties in social situations, and on negative outcomes, such as anxiety and depression (see Rumsey and Harcourt, 2004). Yet, despite the challenges presented by an appearance that differs in any way from ‘the norm’, many people living with a visible difference do not report such problems. For example, while more than 30 per cent of participants in a study of 650 people with a range of visible differences reported significant levels of distress (Rumsey et al., 2004), the majority did not. Furthermore, more than 70 per cent of respondents to a survey by the UK Cleft Lip and Palate Association reported positive consequences of having their cleft (Cochrane and Slade, 1999). James Partridge (1990: x–xi), who acquired burn injuries at the age of 18, has talked of how his visible difference brought about new outlooks and opportunities: ‘Above all, my face has opened new doors in my understanding of life and people.’

Eiserman (2001) has suggested it is unethical to focus solely on pathology and not to consider positive aspects and outcomes of visible difference. Studying positive functioning can be beneficial in terms of promoting well-being (e.g. Cicchetti et al., 2000). Yet, while some research has examined positive aspects of chronic illness including benefit finding and adversarial growth (e.g. Katz et al., 2001; Sodergren and Hyland, 2000; Sodergren et al., 2004), there is currently little research focusing on positive outcomes and experiences associated with a visible difference. That which has been conducted has shown that humour, a good sense of self, family support and faith all contributed to resilience and success among individuals with Moebius syndrome (a congenital condition characterized by lack of facial movement) (Meyerson, 2001), while inner strength and a valued social circle have been identified in those with a craniofacial difference (Eiserman, 2001). These studies, and others (e.g. Fortune et al., 2005) have focused on specific conditions as opposed to visible difference more generally. More recently, Thompson and Broom (2009) conducted interviews with participants with a variety of appearance-altering conditions looking at how they positively manage intrusive reactions to their disfigurement. Factors such as social inclusion and acceptance were identified as being significant.

Since the issues and challenges typically faced by people with a visible difference are similar, like Thompson and Broom’s (2009) study, the current study was conducted with people living with a variety of visible differences. Therefore, the aims of the current study were:

- To investigate positive experiences and adjustment to living with a visible difference. Specifically:
 - What are the positive consequences of living with a visible difference?
 - Why are these considered positive?
 - What facilitates these positive experiences?

Method

Methodological rationale and design

A review of available quantitative measures that assess positive outcomes associated with health and illness (e.g. Silver Linings Questionnaire; Sodergren and Hyland, 1997) failed to identify any that would give a sufficiently in-depth understanding of the specific issues

relevant to people with a visible difference. In addition, measures widely used within appearance research (e.g. Derriford Appearance Scale; Carr et al., 2000) do not give insight into why some people with an altered appearance are able to interpret appearance-related situations in a positive way. A qualitative methodology therefore, felt more appropriate to capture rich, personal accounts of participants' positive experiences and perceptions of living with a visible difference.

Data collection was approached pragmatically. Focus group interviews were chosen as the primary means of data collection since they encourage participants to evoke memories and attitudes from each other, thereby providing a richness of data (Frith, 2000). It was hoped that data collection could be via group interviews alone; however due to a small number of participants and logistical difficulties with arranging group interviews, additional, more accessible forms of qualitative data collection were adopted (i.e. face-to-face interviews and telephone interviews). Consequently, a mixture of qualitative methods was adopted to facilitate the inclusion of a greater number and breadth of participants.

Participant characteristics and recruitment

All necessary NHS and university approvals were obtained prior to recruitment. All participants were over the age of 18, had a self-reported visible difference of some kind and had previously taken part in an appearance-related study in which they had self-reported that they considered that they 'coped well with their visible difference'. They had also provided consent to be contacted again about possible participation in further research. Hence, there was a targeted approach to the recruitment strategy in the current study. Thirty-eight potential participants who met the criteria were sent details of the study which clearly stated that this research was focusing on positive adjustment and coping. Potential participants were invited to take part in a small focus group. If it was not possible for those who agreed to participate to attend a focus group interview, they were offered a face-to-face or telephone interview as an alternative. A few people did contact the first author to explain that they did not feel eligible to take part in this research at this point in time (i.e. did not feel they were currently coping well). Two participants failed to attend a planned focus group interview. One individual explained that this was because they decided at the last minute that they did not want to reflect on the past in case it would impact negatively on their current positive state. Twelve people (nine female) aged between 31 and 80 years (mean age 56.7 years) chose to take part. Self-reported visible differences were: psoriasis, port wine stain, scarring, amputations, burn injuries, impact of thyroid eye disease, mastectomy, alopecia and altered appearance of their hands or nose. Details of study participants are provided in Table 1.

Data collection

Three group interviews and four one-to-one interviews (one face-to-face and three telephone interviews) were conducted by the first author using an open-ended interview schedule based on previous literature on positive adjustment (e.g. Sodergren and Hyland, 2000), and examined how the participants' visible differences had impacted on their lives and how they had come to consider this a positive experience. Interview questions included, 'What, if anything, has your visible difference taught you?' and 'How did you/do you deal with the difficult times?' Although research indicates focus groups should ideally contain four to eight participants (Wilkinson, 2003), it was felt that smaller groups would be preferable since participants would be discussing a highly personal and complex topic; thus it was probable that they would have plenty to discuss on the matter and this would allow for the development of rich data. A smaller group may also facilitate involvement in discussions around sensitive

topics (Frith 2000). All group and face-to-face interviews were conducted by the first author who did not have a visible difference, and took place in a university setting or the participant's home. Each lasted approximately one hour and was audio-recorded with each participant's permission. The audio recordings were then transcribed verbatim. Participants in the group interviews were not known to one another prior to this study.

Analysis

Transcripts were analysed using an inductive thematic analysis (Braun and Clarke, 2006). This method of analysis was selected because it was felt that its flexibility and potential to yield rich data was most appropriate to reflect the reality of participants' experiences. Group and one-to-one interview transcripts were initially analysed individually to allow for any differences resulting from the type of methodology to emerge. The transcripts were read repeatedly and initial ideas were noted down. Data were then coded and data with the same codes were collated. Codes were then sorted into identifiable themes which were then refined (i.e. some were combined) and some were re-named to suit the data accordingly. As the extent of the similarities between the focus group and interview themes and codes became evident, the whole data set was then analysed collectively. The analysis was then re-checked by the first author and amended as necessary to ensure that the themes, sub-themes and codes were an accurate reflection of the data set. The analysis and themes were verified by the second author to check the credibility of the analysis and a summary of findings was sent to participants who were invited to feed back any comments as a further check of the analysis. Four participants responded. They all supported the analysis and no amendments were necessary as a result of their feedback.

Results

Four main themes emerged from the analysis: importance of appearance; personal growth; relationships with others; and coping (which consisted of six sub-themes). It was not necessary to exclude any themes on account of them not being appropriate for the research aims. The themes are described below and presented with supporting quotes from participants. Pseudonyms are used throughout this article.

Importance of appearance – participants' and others' views on appearance

Participants described how they place little significance on appearance and value other characteristics and qualities more highly. Many participants made reference to the over-importance attached to appearance in society and made specific reference to the media and cosmetic surgery. They also discussed trying to overcome the stigma associated with being visibly different by talking about it openly and not camouflaging or covering up their disfigurement: 'if you are just yourself with it, you are not kind of hiding away or being embarrassed by it, if you can just be confident in yourself ... then maybe it's showing something' (Jane).

Some participants did not perceive others' reactions to their visible difference to be consistently negative and this interpretation of other people's behaviour helped them to be more confident with their visible difference: 'people don't necessarily mock you ... people do rate you for what you are and not necessarily for what you look like' (Edna).

Personal growth – processes of growth in terms of personal outcomes

Participants felt they had changed in numerous positive ways as a result of living with a visible difference, including becoming more resourceful, more resilient, having a calmer approach to the hassles of daily life and taking up new interests and opportunities (e.g. choosing career paths which centred around helping others, meeting inspiring people and finding new religious beliefs):

it has made me more resilient. (Jackie)

my life has been enriched by other people, inspired by others that I never would have met otherwise. (Claire)

Personal growth extended to improved relationships with, and understanding of, other people. Some participants also spoke of how they hoped they had helped other people with a visible difference by sharing their experiences of how they had coped well: 'I've been able to say [to people with similar problems] "well yeah I know exactly what you are going through but it does alter [i.e. does improve]." And I think it helps for people to know' (Anne).

Relationships with others – impact on positive adjustment

Many participants had had a visible difference since childhood and talked about the significance of their families in influencing their attitude towards it. They also described how being treated 'no differently' had been particularly helpful. Some discussed how a lack of family support at a young age was now interpreted as a positive experience since it had increased their sense of independence: 'I learnt to kind of deal with stuff myself. I didn't really tell my family when I was growing up ... I was quite independent' (Jane). Participants gave examples of the honesty of relatives alongside examples of situations where friends had withheld their true opinions in an attempt to protect the participant's feelings:

he [cousin] said 'you've done very well for somebody not having much ... going for them.' [laughter] And I thought, that's honest and it's true. (Sarah)

[friends] tried to convince me it didn't look bad but it's only now I look better that they are telling me how awful I did look. (Edna)

In addition to family relationships and friends, participants were particularly appreciative of the consideration, support and acceptance they had received from significant partners.

A few participants talked about how others admired them for coping so well with their visible difference. This admiration can boost self-esteem and thus aid the maintenance of successful or positive adjustment:

[others] admire your strength and your resilience and just feel how lucky they are, not having that [visible difference] to deal with. (Mike)

I wouldn't have said I was a very brave person but it has been said to me over and over by friends and acquaintances umm, self-praise is no recommendation really, but they have said to me over and over 'you have been so brave. I hope if anything like that ever happened to me I could cope as you have.' (Veronica)

Coping

Participants spoke of personal coping strategies and attributes which had contributed to enhanced adjustment to living with a visible difference.

Inner strength and a positive outlook. When asked ‘How did you deal with difficult times?’ participants explained how they had chosen to confront and embrace the difficulties presented to them in life and to make the best of any situation: ‘I’ve just learned to accept that, you know, I can’t change it, there’s no surgery to get rid of it ... don’t hide it, just get out there and enjoy your life and basically be positive’ (Mike).

A common thread through both the individual and group interviews was dealing with things on a daily basis. Many participants talked of the importance of allowing themselves time to be upset and having ‘bad days’ but emphasized that these are temporary emotional states: ‘If I am having a bad day ... all I need to is keep reminding myself that ... it’s just a bad day and know that it is going to change’ (Jane). Participants had a very positive outlook on life – they were optimistic and forward thinking, and reflected that those who have difficulties in adjusting to their difference may not share this outlook:

my blood group is B+ so that has always sort of always been my motto, you know to be positive about things, try and find the positive. (Sarah)

perhaps some people want to throw them [cards dealt by life] down and walk away. (Veronica)

Several participants referred to humour. What was interesting is that some used humour in a defensive way to avoid teasing or to distract people from their visible difference:

I think my sense of humour kept me going ... I tried very hard, you know, and however I felt, when someone rang up, I tried to joke about it. (Veronica)

Sometimes you sort of make a joke because you’re, I think you’re trying to make people laugh so that they won’t notice. (Sarah)

Cognitive re-framing. Participants also described putting their visible difference in context by placing greater significance on other aspects of their lives and not seeing it as the cause of other difficulties they may have: ‘It would be easy to hang every bad day on your disfigurement ... Whereas actually it could be a multitude of other things that are causing it’ (Eleanor). They frequently reported making downward social comparisons as a means of increasing their sense of well-being and bolstering their self-esteem: ‘I’m actually quite lucky because I’ve got something [psoriasis] that can be quite awful in some people, so I actually feel quite fortunate’ (Nick).

Active coping. Other coping strategies included distraction, practical solutions, treating themselves well and focusing on aspects of their appearance (other than their visible difference) that they felt they did have some control over:

it’s encouraged me to put a bit of a higher priority on trying to take care of whatever physical assets I’ve got ..., I try and keep fit and everything, I run a lot. I think I probably ... having kept all my hair ... probably err try and look after the things that are all right, you know. (Nick)

Managing other difficulties. Some explained that their ability to cope with their visible difference had enabled them to develop effective coping strategies they could apply to other situations and difficulties encountered in other aspects of their lives: ‘Could I have coped with it [chronic pain] if I hadn’t had this [burns] already, I don’t know? You’re able to deal with problems better’ (Mike).

Spirituality. Some participants identified how having, or finding, a sense of spirituality and faith had been important: ‘I am Buddhist now ... through being different and questioning life and finding it difficult ... made me look for answers and try and understand. So it [visible difference] did have a big impact on my spiritual life’ (Jane). Meanwhile several referred to not questioning why they had their visible difference: ‘To my recollection I’ve never said “why me?” Never, you know. “Why not me?” more the case’ (Eleanor).

Support. Finally, participants spoke very positively about the benefits of support, in particular being able to talk to someone who had shared similar experiences. Finding this support beneficial had prompted them to share their own, positive experiences with others (see ‘personal growth’ theme). Generally there was a sense that health professionals needed more training in how to provide support in relation to appearance issues, and that a pathologizing approach to care (i.e. focusing on difficulties) was typical, but not always helpful. Many participants were not aware of any existing support groups for people with a visible difference and felt that there should be a greater awareness of the support that is currently available (e.g. through charitable organizations).

Discussion

Little research to date has focused on the concept of resilience and positive outcomes among people with a visible difference. Other than a recent study by Thompson and Broom (2009), previous research has tended to be limited to individual disfiguring conditions. Since the challenges facing people who have a visible difference are typically similar, regardless of the type or cause of disfigurement, this qualitative study has explored the issues of resilience and positive outcomes among a group of individuals with a range of visible differences.

The current findings support Tugade and Fredrickson’s (2004) assertion that individuals with high levels of resilience tend to use positive emotions. One could speculate, therefore, that individuals who display poor adaptation to their visible difference are low in resilience and display more negative emotions. Participants valued the benefits of supportive friends and family. This is in line with previous research findings that positive perceptions of social support are related to a reduced impact of appearance concerns on lifestyle (Rumsey et al., 2004) and that social support may increase acceptance through maintenance of self-esteem (King et al., 2006; Thompson and Kent, 2001). Furthermore, Rosenbach and Renneberg (2008) demonstrated that social support was a strong predictor of post-traumatic growth among people with burn injuries and Thompson and Broom (2009) found that social support helped participants cope with other people’s reactions to their visible difference.

Several participants referred to ‘taking each day as it comes’. This strategy has also emerged in the cancer literature (e.g. Walton and Sullivan, 2004). Participants in the current study allowed themselves to be upset at times, accepting that everybody has ‘bad days’ and spoke of not dwelling in self-pity – having, instead, the strength to move on. One could speculate that those who do not cope so effectively might not allow themselves to be openly upset, resulting in a build-up of negative emotions which could manifest in the form of depression, anger, low self-esteem or anxiety (outcomes that have been identified in the visible difference literature, see Thompson and Kent (2001)).

Humour was identified as an effective coping strategy by many participants. It was used in various forms, such as a distraction technique and as a way to respond to difficult remarks relating to their appearance. Thompson and Broom (2009) also refer to specific types of humour used in relation to coping with a visible difference, namely sarcasm, understatement

and self-deprecation. Other disfigurement research has identified humour as a source of resilience and strength (Meyerson, 2001). More generally, ‘coping humour’ has been described as the use of humour to manage a situation that threatens one’s usual pattern of living (Martin, 1996) and it is thought to help diffuse emotions in adverse circumstances.

Participants’ determination was prevalent throughout the transcripts and emerged as a strength exhibited by them all. Determination has previously been related to better adjustment to chronic illness (e.g. Lo and MacLean, 2001) and, in the disfigurement literature, Meyerson (2001) identified it as a way of bolstering resilience.

Several health-related studies have shown that participants’ reports of the extent to which they engage in downward comparison are positively correlated with their reports of positive affect or well-being (e.g. Buunk and Ybema, 1995) and the current findings also support this theory that downward comparisons produce positive consequences (Festinger, 1954). It is likely that participants found these downward comparisons helpful as they protected their self-esteem and put their visible difference into context, that is, made them aware that things could be worse.

The tendencies to question and search for meaning were commonly reported by participants. Finding meaning is often cited as part of the process of positive adaptation to threatening events (Taylor, 1983). What was particularly interesting was that many participants said that they never questioned why they had their visible difference. Their responses implied a belief that everyone is susceptible to adversity and they did not feel that they should be any different. Some participants asserted that continuous questioning could be upsetting and maladaptive. One participant described how her questioning and searching for meaning had led her to become a Buddhist, which had offered a framework within which to understand her experience. Similarly, Sodergren and Hyland (2000) found that some people became more open to other religions as a result of illness. Evidence to support these findings on the role of spirituality is limited in the disfigurement literature, although individuals with Moebius syndrome have identified faith as contributing to their resilience (Meyerson, 2001).

Several participants discussed how they had spoken to other people with similar disfigurements and how they felt that this was beneficial for both parties. Roberts et al. (1999: 843) suggested that the act of helping others can benefit the ‘helper’ by improving his or her sense of well-being through fostering ‘increased feelings of competence, equality, social usefulness, independence, and social value’.

While all participants in this study felt that they now accepted their visible difference, this had not always been the case. Their accounts demonstrate how experiences of a visible difference can change over time and have illustrated a variety of cognitions and behaviours that they perceive to have played a part in the process of positive adjustment.

Reflections on methods

Participants in the focus group interviews talked openly both to the interviewer and to each other about their experiences. They were responding to points that others had made and the interaction was clearly beneficial in terms of the amount of data generated. Small groups allowed participants to build a good rapport with others and gave them confidence to ask each other personal questions, which they may not have felt comfortable doing in a larger group. The current study supports Frith’s (2000) assertion that focus groups are ideal for gaining knowledge on issues that are under-researched, including sensitive topics. Additionally, this

study supports Frith's point that researchers are able to get an awareness of the strength with which particular views are held and to understand the ways in which participants defend and rationalize these views. Although one could argue that the study included a motivated sample, as the participants had previously taken part in appearance-related research, none of the participants in the group interviews had attended one before, and they gave a large amount of positive feedback to the researcher, for example by expressing that it had been 'useful for them', they were 'happy to help', and 'glad they had come'. This suggests that focus groups are not only beneficial in terms of data collection but that they can also be a valuable experience for those who take part.

Telephone interviews have previously been criticized, first for the participants becoming distracted when in their own environment (McCoyd and Kerson, 2006) and second, as telephone conversations lack the non-verbal communication which contributes to the richness of data (Burnard, 1994; Chapple, 1999; Fontana and Frey, 2005). It was anticipated that because of the differences in methods used, the information obtained from participants who took part in telephone interviews might be noticeably different from that gained from face-to-face or group interviews. However, this was not the case and telephone interviews actually exceeded expectations and produced rich data which were consistent with findings from other studies (e.g. Chapple, 1999; Kavanaugh and Ayres, 1998; Sturges and Hanrahan, 2004). Although information portrayed in gestures and actions were not visible to the interviewer, other forms of communication such as intonation, pauses and sighs helped interpretation of the data. This supports views that lack of non-verbal data is not always a problem (Burnard, 1994; Chapple, 1999; Sturges and Hanrahan, 2004) and that there are alternative ways of compensating for the absence of non-verbal responses (Opdenakker, 2006). Studies which have been less critical of telephone interviews suggest that respondents can be relaxed using this medium and therefore are willing to talk freely (Hopper, 1992); the current study supports this view. It is possible that participants were so open because this was a topic that they were keen to discuss through any means offered. The results demonstrate there were clear similarities between the dialogue obtained from all sources of data collection, which enabled the data to be analysed as a whole. It is likely that this was because the same semi-structured interview schedule was used for all means of data collection and since all interviews and focus groups were conducted by the same author, there was a degree of consistency in both the interviews and focus groups. Hence the research has shown that, in this context, telephone interviews are a convenient method to access potentially hard-to-reach participants and can produce data equal to that obtained from face-to-face interviews. Furthermore, the research has demonstrated that a mixture of methods of data collection can be an effective way to increase sample size without necessarily compromising on the quality of data.

Implications for provision of care

This study has shown that having a visible difference is not necessarily a solely negative experience and supports calls (Rumsey and Harcourt, 2004) for the need to move away from assumptions that this is the case. Additionally, the findings suggest some health professionals need greater awareness of existing sources of support available for people who have a visible difference, and to inform those who may benefit from such resources.

A review by Bessell and Moss (2007) highlighted a need for the development of high quality psychosocial interventions to support people who are experiencing difficulties as a result of a visible difference. By providing an insight into the experiences of people who consider themselves to have adjusted positively to a visible difference, the current study can usefully inform

the development of such interventions. For example, cognitive-behavioural therapy (CBT) interventions could use examples from this study to encourage individuals to identify positive consequences and not to attribute other problems to their visible difference, while online discussion forums might offer access to support from others who report positive experiences as a result of a disfigurement.

Implications for research

This study has contributed to a small but growing body of literature focusing on positive aspects of visible differences and it challenges research findings which convey that being born with or acquiring a visible difference is primarily a negative experience. As shown, people who perceive themselves to have adjusted positively to their visible difference can make a significant contribution to research in this area. Further work is needed to substantiate these findings and should include participants from a range of ethnic backgrounds and geographical locations. Future quantitative research could also explore the extent of positive outcomes, and the factors that facilitate them, among a larger sample.

Participants in this study have demonstrated their resilience to the potential challenges presented by having a visible difference. Discussion is ongoing regarding the extent to which resilience is a stable personality trait or whether it can be taught (see Olsson et al., 2003). More work is needed to define the components of resilience among people living with a visible difference and to continue to determine its potential to inform interventions aimed at promoting positive adjustment.

Group interviews produced rich data which benefited from participants' interaction with one another but it is important to acknowledge the logistical difficulties of providing a time and location suitable for all participants, which necessitated some individual interviews being carried out. The research demonstrated that telephone interviews are a convenient method to access hard-to-reach participants and can produce high quality, rich data.

Conclusions

Whereas a small amount of existing research in this field has examined positive aspects of disfigurement among individuals with specific conditions, the current study explored the experiences of individuals with a variety of visible differences and highlighted similarities in positive consequences, effective coping and adjustment across this group. It demonstrated the effective use of both group and individual interviews in this area and the utility of taking a positive as opposed to problem-focused approach when considering the psychosocial impact of visible difference. This research has provided insight into a broad range of mechanisms developed and utilized as part of positive adjustment to visible difference. These findings can inform both the provision of care, including the development of interventions to promote positive adjustment, and further research aiming to help individuals who experience difficulty adjusting to a visible difference.

Competing Interests

None declared.

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Table 1. Participant details

Pseudonym	Age	Gender	Visible difference	Method of data collection
Amelia	58	Female	Disfigurement of hand from childhood injury	Group interview 1
Anne	73	Female	Single mastectomy and current hair loss following cancer treatment	Group interview 3
Claire	31	Female	Lower limb amputation and scarring	Telephone interview
Dave	61	Male	Alopecia since childhood	Group interview 2
Edna	80	Female	Appearance of eyes (associated with thyroid eye disease)	Telephone interview
Eleanor	59	Female	Scarring on lower limbs since childhood injury. Current alopecia following cancer treatment	Group interview 1
Jackie	54	Female	Skin condition (psoriasis)	Telephone interview
Jane	31	Female	Disfigurement of nose (associated with the disorder chondrodysplasia punctata)	Group interview 1
Mike	51	Male	Burn scarring	Group interview 2
Nick	45	Male	Skin condition (psoriasis)	Face-to-face interview
Sarah	59	Female	Facial port wine stain (associated with Sturge-Weber syndrome)	Group interview 2
Veronica	73	Female	Appearance of eyes (associated with thyroid eye disease)	Group interview 3