

16 The Role of the Face in Intersubjectivity, Emotional Communication and Emotional Experience; Lessons from Moebius Syndrome

Jonathan COLE

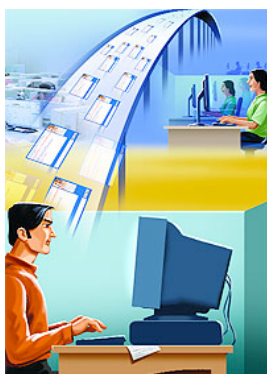
Abstract. The importance of the face and facial expression in enactive intersubjectivity is explored by reference to the experience of those with Moebius Syndrome. This rare, congenital condition affects the brain stem, leading to a variety of impairments of which the cardinal ones are an absence of movement of the muscles of facial expression and an absence of movement of the eyes laterally. Those with Moebius have no facial expression and have difficulty with changing the direction of eye gaze. Narratives from several people with Moebius are given. For some their impairments in facial expression lead to problems in interpersonal relatedness and in both emotional communication and in emotional experience itself. Embodied, facial expressions seem to have a large role in interpersonal communication of emotion; without such exchanges the development of emotional experience itself may be difficult.

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16.1 Introduction

Two necessary conditions for the development of intersubjectivity seem to be individual, unique embodied identifiers and interaction between individuals - movement. In humans the most obvious unique identifier is the face. Movement, in turn, is often described in terms of instrumental or locomotor action which may - or may not - be designed to be intersubjective. However there are other embodied actions, many of which are often not attended to, which nevertheless are designed primarily for, and have profound effects on, intersubjectivity and on the perception of self; gesture and facial expression. The face and facial expression are so central to intersubjectivity, embodiment and emotional communication that their roles are difficult to understand unless one considers those who live without them. In this review, some of the experiences of those with a specific congenital impairment, Moebius Syndrome, which leaves subjects without the ability to move the muscles of facial expression from birth, are given. The narratives reveal something of the link between embodied enactive facial expression and intersubjectivity, and between that expression and emotional experience itself.

In a recent book I explored the relationship between the face and the self through the extended narratives of those who have a fractured relation between these two; those whose faces have been called into question [1]. One man who went blind progressively as an adult tried to remember his loved ones by remembering their faces, as though photographs on a wall. He became most depressed not when he was finally blind but when these visual memories faded and he had no way of representing others. He was saved by a progressive shift in this from the visual to the auditory sense. The painfulness of this loss, however, was emphasised by another who had gone blind in his 20's; he thought that the lucky ones were blind from birth. Another man, blind from birth and who had never seen faces, said that for him others always were their voices. His selfhood, he said, 'resided in voice.'

The importance of the social dimension of faces was shown again and again in those with facial disfigurement¹. Often people with a facial disfigurement would have no problem in their use of the face, in their eyesight, in facial movement and expression, or in eating or speech, but their lives were made miserable and incomplete by the responses of some people they met. Some felt stigmatised to such an extent that they would lose confidence so much that buying food, or a bus ticket, or going to the cinema, was beyond them and they retreated to an almost asocial existence. They showed the fundamental nature of face for self - other relationship. As Merleau-Ponty wrote, 'I exist in the facial expression of the other.' [2] I gauge my success by the feedback of those around me, and if those people, particular new people, look away from me, and my appearance, then my self-perception and self-hood suffers.

Within these groups of people there was main one division; between those born with the condition, like some with blindness, and those who have a change in their embodiment, say a disfigurement. The latter seemed more able to describe their

¹ Here the use of the term disfigurement for a visible difference follows the use adopted by the UK organization which supports those with facial problems, Changing Faces (www.changingfaces.com). It is a compromise between current usage and the need to de-stigmatise, and remove the dysfunction, abnormal and pathological attitude to the way others live.

journeys compensating for, and coming to terms with, their altered selves. Those with congenital conditions, and who had known no other existence, seemed less able to unpick the seamless relationships between self and face, and between self and others.

Two chapters within the book focussed on a rare and fascinating condition, Moebius Syndrome. This is usually a developmental, sporadic genetic condition of a part of the brain between the spinal cord and the brain called the rhomboencephalon. Though sometimes, more correctly, called a sequence rather than a syndrome, because all with it do not have exactly the same problems, the cardinal features are lack of functioning of cranial nerves VI and VII, which control abduction or outward movement of the eyes and movement of the muscles of facial expression. Other variable features include conjugate gaze disturbances, tongue malformation, hand and feet disorders, difficulties in swallowing and speech, dental problems and a small lower jaw, as well as clumsiness and poor coordination [3]. Some suggest an excess incidence of learning difficulties and or autism too, though this remains uncertain. The most obvious aspect of the condition however, is that people with Moebius have no movement, or very little movement, in their faces, meaning that facial expression is absent.

In *About Face* I spoke with several adults with Moebius who described their lives and their problems in some detail. They seemed to suggest that one large deficit was in emotional expression and experience. This seemed to take two, polar opposite, forms; absence or reduced emotion and, when emotion 'broke through,' an inability to control it or express it appropriately. The people I spoke with are called James, Clare and Duncan in the book.

16.2 Thinking happy

James, in his 50's, does not remember any awareness of being different until he moved out of the family circle aged eight to go to the village school. He was very late going because of Moebius.

"I don't think it had occurred to me inside the family environment that there was anything particularly unusual about me. What made me realise I was different was the questioning about my funny face. At the age of eleven, when I went to the grammar school, I used to be asked why do I cry when I eat? I still do and have to wipe my face. I did, however, begin to become aware of difficulties in communicating with people. For instance in those early years at grammar school some people didn't understand me. If I put my hand up in class because I knew the answer the teacher wouldn't ask me. I felt neglected."

He had speech therapy and was bright enough to go to Cambridge, where he read religion, having wanted to become an ordained vicar for sometime. I asked him how he viewed his face and his self in those days. He answered tangentially.

"I have a notion which has stayed with me over much of my life - that it is possible to live in your head, entirely in my head. Whether that came out of my facial problem I don't know. I was very introspective. I divided people into two

categories: those who didn't want to have anything to do with me for various reasons and those who did.

I think I had a low idea of self worth. I haven't related these things to my face particularly and that's why I haven't been speaking about it. I just haven't focused anything on the face. I had feelings of low self-esteem and loneliness and isolation in company, where I wasn't with anyone particularly, and I had the feeling, say, at a long table during a meal, say in my Cambridge College, that the conversation divided around me and I was left on my own to eat my food and I was happy to do that - but not really happy. These feelings I have lived with, in my head. I always found it difficult to break in.

It is only very recently that the whole area of non-verbal communication has even come to my attention. I know now that since I put out a reduced range of signals I receive back a similarly reduced range. Is he going to know me today, is he going to speak to me today, as I approach someone? As I go about in the street I see people coming towards me and I can tell if they're going to get ready to speak to me if I speak to them, but it's taken me a long time to latch onto that fact."

He was a very good and placid child, which reflected his reduced emotional range. When he met the wife, he told me:

'I think initially I was thinking I was in love with her. It was some time later when I realised that I really felt in love.'

He became a parish priest and for many years hid behind his vestments which gave him a social role. In his 40's, however, his mother died and this triggered a period of depression and self-doubt. He approached people in the Church and tried to make them understand but it was difficult.

"I had never previously talked to anyone very much. I love the Church of England and there are fine men amongst its leaders but they don't really want to know. They may ask you how you are and it's OK if you say, "Very well," but if you say, "I'm about to drop this tea tray," they don't know what to do. Or they give you the impression that they'd say, "Well drop it and then we can do something. But before then we're powerless."

I did go through a period in the late '80's when I was quite desperate and I would describe it in terms of "I am going to drop this tea tray". Perhaps to get attention but I didn't really want to drop it I just wanted someone to listen and do something. Those problems I didn't explicitly relate to the problems of the Moebius Syndrome. But they do relate to the more general need to find myself, which in turn relates to the Moebius. Perhaps I did turn my back on self expression. Perhaps self expression was beyond me. It was just quite enough to get by day to day.

I think there's a lot of dissociation. But I think I get trapped in my mind or my head. I sort of think happy or I think sad, not really saying or recognising actually feeling happy or feeling sad. Perhaps I have had a difficulty in recognising that which I'm putting a name to is not a thought at all but it is a feeling, maybe I have to intellectualise mood. I have to say this thought is a happy thought and therefore I am happy.

I think also that I have a fear of being out of control with emotions, feeling

something that I can't manage. I have also found it very difficult to communicate feelings throughout my life, whether as a child or with my wife, though I think I am getting better at it now. I don't really know how I communicate happiness or sadness. That's a very hard question. Some people cry when they're sad. I don't. I sometimes felt that I would like to be able to cry but you see I am not really able to cry, my tears can come but there's nothing else. My tears only flow when I eat. I am afraid of such feelings. I try and shut them off."

Recently, in his 50's, he began to explore his feelings more. Whereas before he had almost repressed the idea that his problems reflected the Moebius, now he is coming to terms with it.

"I now realize that some things which may have been due to the condition I felt were just down to me. Rather than saying that the condition has made life difficult I have been saying I have made life difficult. It was my fault. I have failed. One of the things I think that's happening now is that I have a sense of becoming freer; freer in the sense of becoming more myself, not playing a role. I certainly wanted to try and explore me behind the mask of the priesthood. If you say where does 'me' now reside, I think I am slowly coming out of my head. I am not sure I can locate where I am but I don't think I am entirely in my head or even my mind. I have an expression of living 'a life of the mind,' but I do accept that the mind is not easily able to communicate its thoughts or even its feelings. I think I was out of touch with my feelings, or I suppressed a lot of them."

16.3 Losing control

Clare was in her 30's² when we met. Though I had arranged to talk with her, her parents were there and it was her mother who answered most.

"She's always been very highly strung. If she was sitting down or in a pram and I'd walk out of the room she'd scream. She screamed a lot. If I didn't take her with me everywhere she'd scream; if I went upstairs she had to come with me – she went everywhere with me.

We didn't have a night's sleep for four years; she used to scream and wake us up. Thinking back, I realise it was because she couldn't shut her eyes [people with Moebius cannot move their eyelids much and so cannot shut their eyes]³. She may have woken up and been frightened of the dark. Maybe if we'd had a small light in her room it may have been better. To wake up in the pitch black and be unable to see anything must have been terrifying.

If she did not talk until she was five or so I wondered what was going on in her mind. I imagine she thought a lot, I don't know. When I was in the room she

² People with Moebius tend not to have many wrinkles and so their ages are difficult to judge.

³ Clare told me that, 'My first childhood memory is of having my teeth out at 3, a big black mask came over my face. Even now if somebody goes towards me I can't bear it.' Unable to close her eyes she must have just lain there till she passed out, seeing everything.

followed me with her eyes, and her head of course⁴, but as soon as I left the room she'd yell.

In really stressed situations she'd lose control. She couldn't cope any more and fall down, kicking out, spluttering and shouting. Once she ended up in Casualty. She's had two EEG's to see whether these episodes are epileptic.'

Earlier that year she had a severe episode, whilst her mother was in hospital. Previously she had been seen by a psychiatrist about her emotional outbursts. This time she walked round to the GP, apparently calmly, and asked to go to the local psychiatric hospital. Clare said:

"I remember, though I try and block it out of my mind. I know what's going on. I can't cope with assertive situations."

She stopped, so I tried to help her out, suggesting that whereas some people might say something's awful, or even bloody awful, and then get angry, she might find it difficult to express emotions until they boil over, that she might go from nothing to a meltdown? She agreed:

"I've always felt it difficult to express how I feel. I know it's only in the last couple of years that, say, at church, when I meet someone, I just say "I can't smile" and then it becomes easier. For 30 years or so I used to put it to the back of my mind. Now I'm beginning to be aware more of it."

I wondered if she felt that the 'up and down' parts of her emotions were different to others. I asked if she remembered getting excited at Christmas or birthdays.

"Not really."

It was a similar story from the mother of a small boy with Moebius that I saw, Duncan. The highlights of a normal childhood seemed to pass him by. His mother said:

"I remember his fifth birthday party, he was sat in his high chair and went to sleep; it was just like another day for him. He didn't want to know, he didn't want to play. He doesn't really get excited on birthdays, even his own. It is difficult to know when he's having fun. When he comes home from school we don't know how he's feeling, we have to ask him. Everything is questions and answers. He has always been a very placid child. He never really gets angry, never really appears upset.

I wish I had taken more photographs. Because he never did anything and you usually take milestones, I never took them. He always sits back and listens and stores things for later, much more reflective. We always cuddle him but it's true that probably because he's so thoughtful and reflective our approach to him is less spontaneous. I used to cuddle him but he never really cuddled back. Now I

⁴ Those with Moebius have to move their heads to look around since they cannot move their eyes much.

still cuddle him because he's my baby but he just sits there saying "I'm too old for this now Mum".

All these experiences I had gathered for *About Face*. In that I tried to weave a thesis about the face as evolving to express more complex emotional states as we became increasingly social and needed to look at others more closely. The face, I suggested, was crucial in the development of the individual, as a unique identifier, but also in the way on which emotions were communicated and indeed developed.

But I was always concerned whether the experiences of those with Moebius that I had seen were typical though, of course, even if not they would still be important. So with a friend and colleague who actually lives with Moebius, Henrietta Spalding, we have been seeking the experiences in others who live with Moebius [4].

16.4 Collection of bits

The next interviews with people with Moebius are of interest not only for their memories of childhood, but because they can reflect on how they have changed over the years. Though Moebius is congenital and so people know no other condition, these individuals are able to look back with some insight. Celia is a woman who remembers her time as a young girl, both before school and during those first few years of education.

"I did not do ballet, horse riding etc, I did hospitals and operations. I had the eye doctor and the foot doctor and a speech therapist, who I don't remember, and a face doctor."

She was never aware of not seeing before these ops but then, as she says, she cannot see well even now.

"My limitations were a fact of life. Not being able to see the blackboard, or not being able to see someone over there. I have, or had, a squint and astigmatism. The shape of the Moebius eye is also different and I cannot move the eyes or move the head so easily, my muscle being not so well developed. Crossing a road is still difficult. I cannot judge when a car over there is going to get to me. I cannot measure distance and moving, the velocity or whatever is out. As a child I could never catch a ball."

As well as having the talipes, her feet were also painful; she never told anyone.

"No one asked. When I was 7 I stopped walking because the feet were so bad and I had to go to school in a wheelchair. I don't remember learning to walk. After some surgery I could walk but I never told anyone I was in pain. People don't ask little children. I always remember that as an adult I have had pain, but I don't remember pain as a child."

The myriad of conditions - feet, mouth, eyes, skin (and other ailments too) - and the countless visits to doctors and therapists had an unusual effect on the way Celia viewed herself.

"I never thought I was a person; I used to think I was a collection of bits. I thought I had all these different doctors to look after all the different bits. At half term other children would go off camping or swimming courses, I would see the doctors, this one, then that one. 'Celia' was not there; that was a name people called the collection of bits.

I did not like my feet; I liked my spirit because I was strong as a child. I liked my brain; I knew I had a brain. I loved reading and read very early on. I liked that bit. I could think and dream and imagine. I had an IQ test which was very high. I was bright, so I didn't worry about the rest. Even though I was a collection of bits I always knew there was something strong inside that I had a mental dialogue with, but it was not the physical body; it was very separate from the physical."

In his famous Meditations, Descartes, exploring certainty and the nature of identity, doubted his embodiment but could not conceive of existence without mind; this was where his famous dictum, 'I think therefore I am,' originated. Celia here seems to be making a similar disjunction between herself as whole, thinking being and her imperfect body; Celia was a Cartesian child. She would have an internal dialogue with herself in her thoughts and imagination. In contrast her speech with others was about matters of fact.

"At 5 the only talking I could do was big, about operations, say to doctors; I could only talk to adults, about my bits, not about me. I could also talk about books. Adults were my friends, not children. I just could not do playing with the other kids."

School wasn't bad in the early years though. She loved learning and liked to lose herself in the routine. Learning fed Celia like nothing else.

"I did not express emotion. I am not sure that I felt emotion, as a defined concept. At my birthday parties I did not get excited. There were people around excited, but I followed what they did.

I don't think I was happy, or even had the concept of, happiness as a child. I was saddened by being in pain or having horrid things like a blood test. Sometimes I would cry but even that would almost be a delayed reaction. I would have been sad so long the tears would come as I did not know what to do."

Tears would come when she could not deal with a situation. Once, a mum at a birthday party told her to close her mouth when eating. She did not know what to say, so she cried so she could leave the party.

"I did not know about an emotional world. I thought it might be related to my legs. I knew that being happy was something I couldn't do. Everyone told me I couldn't smile. I never got excited at Christmas. I watched others being excited. I verbalised it but not in an emotional way. I knew things were not as they should have been, even though I did know how they could have been different. I was the

eternal happy ending girl. Even though things were pretty grim, as a child you don't have a choice, you cannot just stop. I did not realise I was unhappy, I just was.

Now, as an adult, I will say, "This is nice!" when I see something I like, just as you smile. Then, with adults, I would have a conversation but with children I was a bystander. Children had another language, a word language, a body language, a facial language. They run around and jump up and down and I could not do that because my legs did not work and because of my lack of balance."

16.5 Emotion and music

Interestingly, for two other young women with Moebius music was an important way to explore emotions. Music, uniquely perhaps, captures and imposes emotional experience. Though it presumably evolved to be social, accompanying dance etc., it has also an abstract, almost asocial canon, usually classical music, which allowed these two to explore emotion, through it, on their own and without outward sign.

Eleanor is now in her 30's, but she too remembers her time as a child with Moebius, and mentioned two things, her playing and experiencing of music and a novel experience she had with a friend.

"Sometimes, if you are in one state of mind, you need others to know. Emotion came for me when I played the piano. We always had a piano and I had lessons from aged 6. By 13 I was quite competent and I found that my fingers unleashed emotion and expression in me, even though I did not know what they were. I would play one piece again and again in various ways; happy, sad, cheeky, all jumbled up inside.

Musical notes and pattern imposed a mood... though not always the mood I felt. I might have been in one mood, but another would come out through my fingers, there were channels of all sorts of different things inside me. There were some sounds, often chords, which did give a feeling of pathos or tragedy; some seemed to sum up my pain."

She seemed to be expressing and exploring moods through music even before she knew what these moods were. An artist might start with a palette with just grey and then, suddenly, red, blue, green are there to play with. As she played with them so she began to experience them too. Then, by playing with the colours, she understood what they meant. Eleanor agreed:

"Yes, I had to learn the palette without the feeling initially and then map feeling on. I grew up with music and heard different tones, even though I was not fully aware of emotions. Since I did not have the language, or the words, for feelings, the music and my fingers would convey them. Often what was conveyed was real pain. They could really say it. At that time, everything was in the fingers. I had no body language."

She went on to talk about an old family friend and the simple yet profound effects of physical contact where previously it had been sparse.

“Peggy loved me as a child. I always had the adult thing with her and we would talk about how her young daughter behaved and, since I was only 14 myself, it was strange. Once I was with her during holidays and I was near the edge, being so unhappy with myself, I tried to speak with her. But, in the end, I told a cousin instead. She obviously told this friend and there was a real shift in our relationship. Peggy just gave me a hug; no one had given me a hug before.

We would spend hours talking. I found a way to articulate things to her – being different, being excluded – and when she gave me the hug I was so shocked to know what physical warmth was, to be approached through the body not through the intellect. This embodied experience was extraordinary, and the next day it startled me out of my wits. There is a whole new something out there I knew nothing about.”

Music might have awakened emotional experience but there was something about the social and about an embodied experience which was essential too. Later she went to university, where she learnt far more than academic matters.

“I learnt in the first year to mix with people. I learnt about experiences, interests and cultures I had not met. I heard of abortions, single parent families and of poorer families. I just started talking to people. For the first time I had the choice of friends. I would go to a group, look around and talk to someone with the same interests and you’d have common experience and could start to talk. For the first time my identity was not Moebius, though I did not know what it was – that had not yet become defined. For a long time all my efforts had been to get to university. Now I was there, all the others were with their hair, make-up clothes, interests; I was not sure what I was.

I did not really have anything to wear, but it didn’t matter. Over the months I bought clothes like everyone else to wear, hippie clothes, and I started to develop a character. It was maybe artificial, but I could design my own. Most people’s evolve as they grow up; mine I picked. I wanted to be someone who people would like. Before people had not liked me, so I wanted to be sweet, gentle and likeable. I did not want to be radical – at the time there were lots like that. I did not want to stand out. I just wanted to be non offensive, reliable and so that is what I became. That sort of person meant that I did attract people towards me. By the time I left university I was renowned for knowing everyone and everyone knowing me. How did I go from that first night, not knowing how to interact, to that?

I learnt body language, interaction, to be comfortable with myself. I think I developed a broad circle of friends, because I found I could express different things with different people. I did not find a single, really intimate friend to whom I could tell everything but my series of friends fulfilled different needs.”

Eleanor learnt to become a character not as a child, naturally, but as a student through trial and error, acute observation and a formidable will to escape from the straightjacket of Moebius. But still it was not entirely clear that she was capable of taking into herself and feeling what she saw in those around her and aped. This is certainly the experience of another with Moebius, called Lydia.

16.6 Learning to feel

Lydia is in her 50's. It was at university in the 60's that she first found she was a social success very like Eleanor. People seemed not to care about Moebius and she learnt, from watching people, for the first time, how to be social. But, looking back, she realises that at this time she was not actually feeling much. She could gesture and sympathise but, to an extent, she was mimicking. It was later, when she moved to Spain and to another culture that she really began her emotional catch up.

“I do not think I had emotion when I was a child but now I have it. How did I get it? It was in Spain. I learnt Spanish in two months but – more – they are so theatrical in their emotional expression. The body language I had learnt and used at university could be exaggerated in Spain, using the whole body to express one's feelings. Over here in England it would be over the top, but there it was fine and because of this I learnt to feel within me.

At Oxford I had learnt a lot of imitating and mirroring and copying but had not, to a very profound depth, had the feeling. I had been using it to conform and because if I did it I got the response, but I, myself, wasn't feeling. But in Spain everyone is so dramatic. If something awful happens then the world is coming to the end, and if fine you party all night. If sad you burst into tears and then go off to the pub. I had gathered all these skills in language and gesture and then in Spain I could just be me.

Because of the cultural up regulation of feeling in gesture I learnt to feel. I am not sure how I mapped gesture and feeling onto my body, but I was starting to feel then. I could feel really ecstatic, happy, for the first time ever. Before, without the expression, I had found feeling difficult. Once in Spain I certainly had the means, the channel and the vehicle, and the feeling. Before, my thought was frigid or cold. I needed the continuation of a thought into real time expression within the body.”

Darwin said that an emotional feeling can either be expressed, continued and become exaggerated or, if not expressed, reduced and lost. It is as though it has to be in the continual present, continually expressed to be continually experienced.

“That was how it was for me. I was an intellectual at university. In Spain I experienced emotion. As a child I used to play a musical instrument with emotional expression, but the emotion did not really come from within. I could not let it out. Now, once I could express there was no stopping me.”

Lydia's new experiences were not of course within her or about her alone. They emerged within a rich social, cultural world. In a place where emotions were communicated publicly more than in the UK she learnt, somehow, to experience and as well as imitate feelings.

“When you live and share emotion together then you all experience it together. I met a man with Moebius who lived in Sweden and he was one of the saddest people. He was completely wooden, with no body language, like a puppet. I met him in Italy; I hope he learnt something from them. If I had not lived in Spain I don't know how I would have turned out.

In Spain, ironically, though they use gesture a lot, they talk in a much more monosyllabic way than here. They are not as musical in speech. My voice is melodious and I had begun to use it to control people's response. So, in Spain, they all talked about my voice and loved it. That was a Eureka moment. My voice could be my thing, my tool, my vehicle of expression. The voice was the link from me to other people for feeling and for emotion. The language and words don't do it. I had those in Oxford. It was the voice, the melody going with the embodied gesture that completed the circle."

16.7 Conclusions

These narratives are individual and from a small number of people, but do suggest that some with Moebius experience profound impairments with emotional experience. Until such experiences are quantified in larger groups it is not possible to know precisely how common they are. But even seen in a few, one must consider the possible explanations.

It is possible that associated with Moebius there is a constitutional impairment of emotional experience, say a defect in amygdala/insula emotional resonance. However, the fact that people with the condition learn to feel later suggests that this is unlikely.

One small boy with Moebius once looked up at his father and asked, '*Why can't I be happy?*' clearly associating facial movement with the emotional experience. We do receive internal feedback of muscle and skin movement in the face; might this contribute to our own mood and emotion? William James developed what has come to be known as the James-Lange Theory of Emotion, that we are happy because we smile rather than the reverse [5].

More recently Fridlund reviewed the evidence for this 'facial feedback hypothesis' and found none of it convincing [6]. He used examples which were necessarily limited; Bell's palsy, in which one side of the face is paralysed and drug induced temporary muscular paralysis. Neither provided evidence for changed mood and emotion following reduced facial movements, but both were unusual situations and unlikely to reflect natural functioning. Adelman and Zajonc were much more convinced, and quoted experiments in which subjects posed emotion whilst looking at a scene or film and rating it as sad or happy [7]. Those posing a smile rated the film funnier than those posing a grimace. In one ingenious paper the subjects viewed a cartoon with a pen in their mouth, either between the lips, (so preventing smiling), or between the teeth, (so enabling, even facilitating, smiling). The latter group found the film funnier. All such studies have many drawbacks, not least that a posed smile is hardly natural, but this is not to say that there may be some contribution from feedback from the body to mood and emotion. When making a posed smile we are aware of the facial expression changing; when we do so naturally we are not aware of facial movement explicitly though it still may have an implicit effect. This of course would be missing in those with Moebius.

Another important contribution may come from social and developmental factors. As a child we learn to express emotions which are usually larger and more labile than in adults. One of the things we do in childhood is to observe the effects of emotional outbursts and expressions from the response of those around us,

particularly our parents. If we cannot express, in the body and on the face, then maybe our capacity to experience these emotions does not develop either. Certainly Clare and, to an extent, James were not able to express smaller, more subtle emotions and found these difficult to experience. For others emotional experience itself seems to have either not developed, or atrophied, or lain dormant for years. Interpersonal relationships may be more difficult to make and develop due to the somatic effects of Moebius. Without gaze control or facial expression and often with delayed language, drooling, and poor motor control it must be more difficult to engage with others and so develop a social existence.

In the end the precise reasons for this emotional impairment may be multifactorial, with the somatic absence of facial expression and the effects this has on development and socialization being of most relevance. But from the narratives above what is clear is that for a range of emotion to be experienced it has to be expressed and communicated, and that these have to be through embodied action. Those with Moebius who learn to express do so through voice and prosody, through words and through gesture, to circumvent their facial immobility. Emotional experience appears to be linked to emotional communication via conversations between people. The development of intersubjectivity may therefore require both unique means of identifying individuals and means for these individuals to communicate their feelings. The roles of the face and of embodied action through facial expression in these become apparent in the narratives of those who live without facial mobility.

16.8 References

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