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# What Binds Biosociality? The Collective Effervescence of the Parent Conference

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## **Abstract**

Questions of community are central to many research sites in the social sciences. Rabinow argued that, in the wake of the Human Genome Project, an increasingly important form of collectivity would be *biosociality*. Biosociality highlights the central role of biomedical knowledge in constructing genetic identities and producing and reproducing social relationships. Accordingly, it is often imagined as a *new* form of social interaction. We draw on observations of parent-led conferences organised around a particular genetic syndrome – 22q11 deletion syndrome – to empirically explore the mechanism through which biosociality is enacted. The conferences took place within the UK between 2007 and 2010 and were observed as part of a multi-sited ethnography. What binds individuals and creates a sense of community is a social process, and conferences are significant occasions where such biosociality ‘happens’. Furthermore, we suggest that the creation of bonds between members of a community is facilitated by the expression of a traditional theoretical social process – *collective effervescence*. This paper therefore demonstrates a commonality between established sociological understanding of collective effervescence and more recent theories of biosociality. We argue that in the case of the 22q11 deletion syndrome groups examined in this paper, parent conferences brings individuals together physically, and it is the shared emotional experience of the conference – the collective effervescence – that consolidates and renews the connection between members of the community.

## **Introduction**

How do people connect with one another in the 21<sup>st</sup> Century? In what ways are communities formed? These questions are central to many research sites in the social sciences. From research on families and kinship (Featherstone *et al.* 2006; Young and Willmott, 1957), to studies of work and organisations (Salamon, 1974; Lave and Wenger, 1991), through to more

modern contemporary projects exploring the rise of the Internet and the digital age (Castells, 2009; Zhang and Watts, 2008) and studies examining biomedicine, genetics and biosociality (Rabinow, 1996; Rose and Novas, 2005), the focus of much social science has been on the new social structures that support late-modern society. Increasingly, sociologists are identifying geographically dispersed communities as the source of belonging. Where once we connected through our relationships built on the basis of our immediate physical location – our neighbourhood, our workplace, our communal pastimes – the formation of 21<sup>st</sup> century communities is less dependent on co-location. Greater physical mobility and developments in communication technologies makes it easier for individuals to seek and form relationships based on shared interests. People connect through their occupations, their passions - fans of sports and music, for instance - and their political and philosophical belief systems. “[I]n the ‘advanced liberal’ societies of the West, we observe new collective formations emergent everywhere” (Rabinow and Rose, 2006, p204). These are often dispersed associations of people.

Rabinow (1996) argued that, in the wake of the Human Genome Project, an increasingly important form of collectivity would be *biosociality*. He wrote, “it is not hard to imagine groups formed around the chromosome 17, locus 16, 256, site 654, 376 allele variant with a guanine substitution. Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and ‘understand’ their fate” (1996, p102). The question Rabinow addressed in thinking about biosociality was ‘how had sociality changed given the rise of the new understanding of genetics?’ (Rabinow, 2008, p188). Although originally intended to be a peripheral concept, it has since been taken up enthusiastically by subsequent authors. Biosociality is widely imagined as a *new* form of social interaction, which can help us to understand aspects of contemporary (and possible future) societies (Rose and Novas, 2005). The role of patient communities in civic society have been well documented in raising awareness of little known medical conditions and campaigning for access to research funding and healthcare resources (Allsop, Jones and Baggot, 2004). Biosociality is particularly prominent in attempts to explain the role of patients and patient groups (see Gibbon and Novas, 2008). It provides a way of understanding why individuals choose to seek connections with others, particularly in relation to genetic classifications. For example, Rapp et al. (2001) identified how members of patient communities shared a collective sense of identity, which were ‘anchored in a genetically marked category’ (p393). Furthermore, they suggest that individuals are empowered through the formation of an ‘imagined community’, engendering a sense of

kinship, where protection and support are offered, differences normalised and values reproduced.

This paper argues that, if a community is formed when individuals are bound together on the basis of shared biology, then there must be a mechanism through which this sense of community is produced and expressed. We focus on the fundamentals of groups as *communities*, a topic that is less frequently the subject of sociological investigation. In doing so we address the question of how sociality is performed. We argue that what binds individuals together is a social process, independent of the ‘shared allele variant’ or other biological factor. In order to explore these social processes, we examine conferences organised around a particular genetic syndrome – 22q11 deletion syndrome. Despite being a standard site of biomedical consultation and discussion, the conference is a surprisingly under researched and under theorised space. Indeed, this oversight is particularly striking when compared to the attention given to the hospital (Featherstone et al., 2005; Strong, 1979) and laboratory (Knorr-Cetina, 1999; Latour and Woolgar 1979). However, conferences that involve the meeting of patients and professionals are increasingly attracting attention as sites to explore emerging citizenship, patient activism and the mobilization of ‘lay’ expertise. By tracking the activities of support groups and by examining how rights and responsibilities are enacted and how claims to knowledge are contested, researchers have developed an empirical understanding of biosociality, expertise and participation (Rabeharisoa, 2006; Weiner, 2009).

Conferences enable those with a biological factor in common (in this case, the parents of children with 22q11 deletion syndrome) to come into contact with each other, and with their shared ‘panoply of pastoral keepers’. We suggest that it is at these occasions where biosociality ‘happens’, where the bonds between the members of the biosociality can be made and renewed. This, we argue, is facilitated by the expression of *collective effervescence*. ‘Collective effervescence’ was coined by Emile Durkheim (1912) to describe the evocation of mutually shared emotional stimulation - an unusual state of shared excitement involving exceptionally intense feelings. His analysis was based, for the most part, on the religious practices of Australian Aborigines in which he sought to discover the basic principles of religious experience (Cariton-Ford, 1993). Durkheim argued that a grounding of the religious beliefs in practical and phenomenal experience was required to create a sense of mutual community. The central feature of these gatherings is that they are *effervescent assemblies* generating intense mutual emotional connection and arousal (Pickering, 1984). As well as helping sociologists analyse religion, the concept has been used to understand the collective

emotions experienced in secular contexts, such as at sporting events (Fox, 2006), nightclubs (Tutenges, 2013) and therapeutic clinics (Scott, 2011). Durkheim argued that when people express similar types of emotions, these become reinforced and develop into a collective passion (Tang, 2009).

In the case of the conferences examined in this paper, members of the 22q11 deletion syndrome support group are brought together physically. It is the shared emotional experience of the conference – the collective effervescence – that consolidates and renews the connection between the members of the community. This paper therefore demonstrates a commonality between recent theories of biosociality and more established sociological understanding of collective effervescence.

### **The research site: the 22q11 conference**

22q11 deletion syndrome is caused by a small deletion of genetic material on chromosome 22. The syndrome is characterised by a wide range of potential symptoms including congenital heart defects, mild to moderate learning disabilities, cleft lip and palate and immune deficiency (Shprintzen and Golding-Kushner 2008). We draw on observations of four one-day 22q11 deletion syndrome parent conferences and one three-day scientific conference to explore the link between biosociality and collective effervescence. The parent conferences were organised by UK and Ireland support groups established and led by parents of children with 22q11 deletion syndrome. These were annual meetings lasting all day and attended by over one hundred people, most of whom were parents and family members. They were open to the public, publicised on the support group website and took place in a range of venues including university buildings and conference facilities within a sports stadium. The scientific conference was organised by a national 22q11 deletion syndrome scientific and medical organisation, but was hosted by a parent-led support group. It was attended by a large scientific/medical contingent as well as a significant body of parents and families. This conference took place in a large hotel on the outskirts of a European city centre. One important similarity between all the conferences observed (and a difference between these and the many academic conferences the authors have attended) was that children (whether patients or siblings) were invited. During the events, some children remained with their parents in the main hall, although the majority took part in separate activities that were organised. The conferences took place over a three-year period between 2007 and 2010 and

were attended by Author One. The descriptions of the conferences and the extracts included are taken from Author One's observation fieldnotes. Her attendance was agreed beforehand with the organisers of each event and all names and places have been changed to ensure anonymity. The research was approved by the South East Wales Research Ethics Committee.

Although organised by different groups, on different occasions and at different locations, all the conferences which were observed had a recognisable internal structure which informed a particular set of behaviours and expectations. We suggest this can be usefully theorised as relating to a 'ceremonial order' (Strong 1979). In his work on doctor/parent interactions within paediatric clinics, Strong identified an enduring structure to the clinical encounter where doctors were perceived as clinically competent and parents gratefully respectful and accepting of the doctor's expertise (Stokes, Dixon-Woods and Williams, 2006). Strong focused on the ritual elements of social interaction. He recognised that the power of the health professional was maintained through the ritualistic ceremonial order of parent interactions and the restrictions on the parental role within these encounters. The conferences shared many of the rituals that might be associated with academic or professional conferences. Attendees would stay on site for the duration of the event and meals were provided. Each day began with the organiser providing a welcome from the stage, and questions were invited from the audience, usually at the end of each presentation. Although all the conferences were hosted by parent-led support groups and were attended by parents, there were some significant differences. The parent conferences involved six or seven presentations across the course of the day. Most of the presenters were health professionals from various specialisms such as cleft surgery, dentistry, psychology or cardiology. Sometimes several members of a 22q11 deletion syndrome clinic would sit on stage together, each talking about an aspect of the services provided. There were also presentations on topics outside of medical care, including local support for families, education schemes or government benefits. While the scientific conference followed a similar structure, there were many more presentations during the day with the majority focusing on scientific or medical aspects of 22q deletion syndrome.

The features that form the structure of a conference - including the welcome address, the programme of talks and the question and answer format following a presentation - are simultaneously functional and symbolic. An elevated stage for example not only allows better amplification but marks out the speaker as someone with authority. The question and answer session where audience members are given the opportunity to address the speaker further

marks him or her out as ‘expert’. These practical structures are ritualised, specifying and regimenting specific roles for each actor and the relationship between stage and audience. Most of the extracts used in this article reflect this structure, the ‘expert’ on stage speaking to the attentive audience, thereby demonstrating the ceremonial order of a conference. However, by describing how some presentations were punctuated by extraordinary moments of collective emotion within the audience, we comment on how this order can be challenged. It is both the ceremonial order of the conference and the breaking of this order, which creates the conditions for the collective effervescence. The ability of these conferences to produce heightened emotion was clear from the first moments of Author One’s fieldwork:

After arriving at the conference and collecting my conference pack, I shared the lift to the first floor with a man and woman. The woman was crying in large sobs, hiding her tears with a tissue as the man tried to console her. I felt I should say something but this was my first conference and I was nervous. I didn’t know what to say or what would have been appropriate. As I left the lift and walked towards the conference hall, I saw several more women and men with tears in their eyes, I realised that this day was already difficult for many parents.

[Parent conference I1]

This example highlights how conferences blur the boundary between the personal and the public. On arrival at the conference venue the researcher was confronted by the expression of emotion within what she considered to be a public space. It was because this experience was not anticipated that the researcher realised its importance as extraordinary. In this article we examine the role of presentations, presenters and audiences, in producing moments of collective, emotional effervescence. These moments are when the ties that bind members of a biosocial community are made visible. The researcher was not immune to this emotional reaction and the academic distance provided by discussion with Authors Two and Three has therefore been invaluable in the production of this article.

### **Expressions of shared understandings**

The authors have witnessed many presenters addressing and producing a biomedical account of health and illness. Although interesting in themselves, for the purposes of this article, the majority of these are unremarkable. However, the following account provides a striking

departure. The extract describes a presentation by a speech therapist, and it is the reaction of the audience that demands our attention.

The speech and language therapist then showed a film montage (of the type you might see on *You've Been Framed* or *YouTube clips*) of babies and children projectile vomiting. The audience seemed to really enjoy these, laughing out loud for example, when a baby was sick in her father's face as she was being lifted into the air. I didn't enjoy these clips at all – to me they seemed entirely inappropriate. But the audience were practically rolling around laughing. At the end of the montage, the presenter said “reflux doesn't have to be through vomiting. I need to get this through to parents” and explained that there are different, sometimes difficult to notice, ways of a child having reflux. She stated “it can really effect feeding”. She then showed several X-rays of children with 22q11 [deletion syndrome] swallowing.

One X-ray showed the child swallow, then a lump (the food) stayed in the throat a bit and remained there until the next swallow. The presenter said “it just doesn't look clean”. The audience “aww” and “ahh” when they saw the swallowing and the food staying in the front, in sympathy with the child who was experiencing the difficulty. After each X-ray, before the presenter moves on to the next X-ray (of another child) she mentioned what help she gave that child. [Parent conference I2]

The language and style of presentation used at conferences differ significantly from other types of communication, particularly the written word (McKinlay and Potter, 1987; Webber, 2005). The use of humour, as used on this occasion, is an example of how conferences facilitate interaction. What the use of humour, and its reaction, also demonstrates is the importance of shared understanding for building or sustaining community. When the speech therapist showed the video montage of babies being sick, the audience reacted in a different way to the researcher (Author One). The researcher initially felt this part of the presentation was remarkable because it was inappropriate, but the audience clearly did not share her view. It soon became evident that what was actually remarkable was the reaction of the audience. By laughing at each clip, the audience demonstrated that they were not just tolerating these images but were enjoying the display. This occasion reveals how biosociality is enacted, and how conferences, in this case those involving parents of children with 22q11 deletion syndrome, facilitate its expression. By being members of the 22q11 biosociality and sharing the implicit rules and understandings of what that involves, it was acceptable to find humour



in these videos. In contrast, the same clips prompted a different emotional response from the researcher. To the researcher, the ‘humorous’ clips seemed inappropriate and the X-rays were illustrations of a mechanical process rather than images that would elicit empathy.

Conferences are increasingly recognised as important for disseminating information and building bonds. Patient conferences have been identified as important for facilitating dialogue and engendering a sense of trust between lay and professional groups of ‘experts’ (Creighton et al. 2004; Huyard, 2009; Zakrzewska et al. 2009). Some events might involve medical practitioners, laboratory scientists, research administrators, other allied professionals, patients and families to specifically develop relationships across disciplines in order to advance developments in the field (Weiner, 2009). One way in which parents and families can contribute to these discussions is by drawing on their embodied experience of living with the syndrome. It is the implications of this experience which are highlighted here. The audience “awwed” and “ahhed” in unison, and laughed in concert, suggestive of a shared experience and acknowledgment. It is significant that it was the health professional who presented these clips, demonstrating her awareness that they would be found humorous rather than offensive. Who is, or feels part of a community is fluid and highly context dependent. Thus while health professionals can also be members of the 22q community, in the following section we attribute particular significance to experiential knowledge as the foundation for the expression of shared understanding.

## **Sharing experiences**

Whereas the majority of presenters who spoke at the 22q11 conferences were professionals from medicine or allied fields, here we note that alternative voices can also be heard. At these events, patients and family members are given sanction to address the audience. One of the features of the parent conferences was that each event included one presentation by someone with personal experience of 22q11. On one occasion this was a parent, another involved a child patient and on two occasions the audiences were addressed by young adult patients. These speakers would be invited to tell the audience about the experience of living with the syndrome. The audience reactions to, and emotional engagement with, these presentations created a powerful and emotionally charged environment. The following extract describes an occasion when the audience was addressed by a patient with 22q11 deletion syndrome:

Jake was a boy of 12, dressed in a suit, who spoke slowly and clearly. He used PowerPoint, telling his father, who was on the other side of the stage, when to press the button for the next slide. A copy of these slides was included in the conference pack. He said he has hobbies. He likes cars and trains and showed a picture of himself standing by an engine at a train museum. He described what he said were his 'problems' including constipation and difficulties sleeping. Many people had tears in their eyes throughout this talk, several were holding tissues to their eyes and sniffs and sobs could be heard.

Apart from these sounds, there was silence as if every person in the room was hanging on his every word. When he was finished, there was an amazing round of applause and a lot of people stood up and shouted out. I had goosebumps; it was a really emotional moment. When the applause quietened, the support group representative who was standing at the side of the stage said "isn't he brilliant?" and there was a warm and loud "yes" from the audience. After the conference I spoke about the presentation to a member of the local 22q11 deletion syndrome clinical team who said she thought the audience were unsure about the boy's speech at the beginning, "they thought he was there just 'because', but then people realised he did have something to say". [Parent conference M2]

A 12 year old boy, commanding the audience from the stage might be an unusual sight at an academic or scientific conference. The potential for this to be cast as an extraordinary event was recognised by the health professional attending as part of the local clinic. The health professional expressed her concern about the boy's presence on stage and how the child might be positioned. However, the boy's words and the reaction of the audience provided her with reassurance. The child onstage was not treated as an object of medical science. Instead, his personal presentation about life with 22q11 deletion syndrome was celebrated. The way in which the patient body is transformed through the 'medical gaze' has been extensively documented within sociological literature (Atkinson, 2002; Foucault, 1973; Mol, 2002). In this case, however, the patient was accounting for his own body, and was doing so from a platform usually accorded to medical experts. The emotional effect of this switch upon the audience was clear by the call - 'isn't he brilliant?' with the response 'a warm and loud 'yes''.

In some cases, in cults for example, it is often the power of a charismatic leader to command an audience that attracts media attention (Scott, 2011). What is remarkable about the child speaker is the emotional power he wielded over his audience. This is created by the shared experiences and understandings associated with 22q11, and the context of the conference which enables such biosociality to be expressed. The power of the speaker to provoke an emotional response from his or her audience is also evident in the following extract, which highlights an occasion when a parent took the stage. By taking the stage, patients and parents are *symbolically* afforded the status of expert, alongside professionals in the field. However, the reaction of the audience on this occasion, where one particular parent was invited to take the stage, reveals that once again this was no ordinary presentation.

A woman walked on stage and addressed the audience. She began with “I will tell you my story”. She told the audience that when she was 38 she had “an exemplary pregnancy”. When her child was born, a heart problem was picked up but she said she wasn’t too worried because “lots of children have heart murmurs”. The audience nod and some said “yes!” Her child was five when she was diagnosed with 22q11 deletion syndrome. She said when they received the diagnosis the paediatrician had “googled” and “read out every single symptom...I was told ‘she will be a very special child’”. There was an audible “Ah” from the audience. She talked about how in the early stages she didn’t want the child to leave the house, how she always wanted to check on her, she says, “it’s what diagnosis does to you”. At this, a woman on my right shouted out, appearing to recognise this story, “hmm, hmm, hmm”. The presenter said that at school her daughter is bright, happy and has lots of friends “and these are the things I wanted to hear at her diagnosis...I forget she has it, there’s so much right with her”. There were lots of nods and a collective ‘yes’ from the audience.

[Parent conference M2]

It is important to note that not every parent is, or would be, invited to take the stage. Only some people are invited to become the public story-teller. The organisers of each event, who were parents themselves, often hosted the events, providing the welcome address and introduced speakers, whereas this presenter was specifically invited to present because she was a well-known journalist. She was therefore qualified to take the stage not only by virtue of the fact that she is a parent of a child with 22q11 deletion syndrome but also by her standing (and skills) as a professional writer and communicator. She was not a medical expert and her role was not to provide celebrity endorsement. As with the previous extract,

important for our argument is the way in which the audience acknowledge what this presenter was saying. Members of the audience shouted yes and voiced their accord. This is a collective demonstration of shared understanding and mirrors the two previous extracts where there were also audible rejoices of agreement. The audience's positive, vocal response to the story told by a mother of a child with 22q11 deletion syndrome was one of identification. The parents were moved by the collective similarity of their experiences. Audience reactions at conferences such as these are rarely documented in the literature. Apart from a few notable exceptions (including Rapp *et al* 2001; Weiner 2009), previous research on conferences has primarily focused on linguistic aspects (see for example McKinlay and Potter, 1987; Webber, 2005). The collective emotional response from the audience, the compulsion to stand, shout out and applaud, has some resemblance to religious ceremonies, or sports and music events. The shared emotional reaction to the stories told from the stage point to one of the ways in which bonds between members of the group are formed. Sentimental affinities are intensified by the fact that members have shared the same exceptional experience (Durkheim, 1912).

One way of understanding the context of this expression of collective emotion is to suggest that both the child presenter and the parent presenter reveal a particular representation of health and illness. This representation has resonance with the parents in the audience. The child's narration of his own body provided an embodied account of health and illness and provided an alternative route of knowledge transmission to that given by medical experts. It is a model through which the parents in the audience can 'see' and 'feel' the syndrome, potentially becoming a resource that parents draw upon to inform their expectations and hopes for their own child and future. In a similar way, the journalist's reclaiming of the positive aspects of her daughter's life with 22q11 deletion syndrome was welcomed as an opportunity to celebrate the child and her achievements. The difference between communities is that in our examples, the value of this knowledge rests in the expression and acknowledgment of shared understanding associated with embodied experience. Indeed, through Author One's discussions – both formal interviews and informal discussions over coffee – with parents at conferences and clinics, parents have highlighted the fact that medical experts often focus on what is *wrong* with the child. Child and parent speakers enable the syndrome to be projected with a new vision, an alternative to the medical lens that focusses on illness. Here there are resemblances as to how communities of promise (Martin, Brown and Kraft, 2008) are formed around technical developments which contribute to the political economy of hope (Novas, 2006). During the patient conferences, parents are able to

redress the balance and provide a collective sense of optimism and hope by focusing on abilities rather than deficiencies (see Huyard, 2009).

## **Spaces of Support**

Although parents might also be professionals in their own fields, it is an alternative identity that is important in producing the kinds of collective effervescence we see here. It is the experience of being a parent of a child with 22q11 deletion syndrome, or having that embodied experience, which enables individuals to express collective emotion. Patient conferences allow the sharing of experiences and the expression of support and empathy. The following extract describes such an occasion, providing further evidence of how biosociality can be expressed as collective emotion.

During a break-out session on psychiatric issues, one woman stood up and began her story by explaining that she did not want to go into personal details about her child. She then gave the audience a brief outline of the problems her eight year old son was facing; he was struggling in school and beginning to misbehave. Very soon she began talking freely about her son, mentioning his name, the names of his teachers and the school he attended. She talked about the difficulties she had in gaining a diagnosis and referred to intimate medical and personal details.

[Scientific conference also attended by parents R1]

In contrast to the previous extracts, the focus here is on the words of an audience member. On this occasion, the mother was given time and space to talk about the difficulties her son was experiencing. While remaining positioned in the audience, the mother was allowed to ‘take the stage’ to talk about her own experiences. This exchange reflects the creation of a ‘confessional space’. The personal is made public and the ‘audience’ respond to these ‘confessions’ within a supportive environment (Denzin, 1987; Scott, 2011). This extract is remarkable because of the context within which this discussion occurred. Whereas the extracts that have previously been discussed in this article represent occasions that took place at parent conferences, this extract refers to a discussion that took place at an international scientific conference. We have previously described the ‘hybrid’ nature of this conference, which was attended by scientists, clinicians, patients, parents and families. Significantly, this encounter was held in the ‘backrooms’ of the conference, in a small side room away from the main stage and the main events and at lunchtime, during a natural ‘break’ in the scientific

programme. Thus, although a team of psychiatrists sat at the front of the room, the discussion amongst the twenty five attending parents was informal.

We have highlighted how presenters can evoke emotional reactions from his or her audience. In contrast, this event was not punctuated by these moments of overt reaction – the ‘collective effervescence’. Instead, another type of emotional connection is evident, one of empathy, allowing the mother the freedom to speak. The communal aspects of these conferences, and the way in which a space can be created provides attendees the opportunity to share their experiences. The room was transformed into a space of mutual support in which parents talk freely amongst ‘friends’ or ‘confidants’. These ‘confessional’ spaces enable the merging of the social with the medical. Children with 22q11 deletion syndrome (and stories of the child) become normalised. The spaces offer a moment to celebrate the child; parents describe their son or daughter learning to play the piano, forging friendships and settling in at school, and the pride that they feel in their child's achievements in overcoming the difficulties posed by their body. Other than when parents or patients were invited as speakers, these were the only timetabled sessions that Author One heard parents talk freely and at length about their children. Symbolic boundaries were constructed to produce a place of ‘public privacy’. These factors that inform the ceremonial order – being located away from the main stage and time allocated for parent discussion - facilitated this ‘confessional space’ within a scientific conference.

### **Breaking the ceremonial order - an effervescent revolution at the conference**

Primarily, the parents in the audience followed the implicit rules of conference behaviour. This is, as we have previously highlighted, associated with the internal structure of the conference. The ‘informal’ break-out sessions were recognised as spaces which facilitated an alternative order, where the rules on turn-taking, including who can speak and about what, were relaxed. However, in the main hall, the order was usually (but not always) maintained. Presenters spoke from the stage and the audience reacted from the floor. The following extract describes an occasion during which this order was overturned. While this refers to an unusual incident, it is important because it reveals the implicit expectations and assumptions we hold about the relationship between presenter and audience.

One man from a local advice centre took the stage to talk about benefits. He spoke quietly and slowly, talking in general terms about the help that parents might need, but did not talk about specific benefits or how to access them. The audience appeared to get more and more restless, and some started talking over the man so it was difficult to hear him. One woman in the audience said that she had tried for two years to claim a mobility benefit for her child. In response, another woman who was sitting a few rows behind said her doctor had helped her. She asked the woman where she lived and offered to pass on his details. One man in the audience shouted out that if every family who needed a benefit wrote in after the conference, then the benefits office would be obliged to find out more about the syndrome. Another man calls out “parent power!” There were nods in agreement and many in the audience shout “yes!” [Parent conference I1]

The reactions of the parents as described in this extract are striking as the person talking on stage is usually treated with respect, as if they are, for that moment at least, the expert. The time provided by the expert might normally be protected until completing their turn. Of course, rules of etiquette are dependent on context. Comedians for example might expect to be ‘heckled’ by the audience, whereby a timely retort becomes part of the show. At scientific or academic conferences the speaker might also expect to be challenged. Yet the nature of that challenge is often structured and is more often than not an individual pitting themselves against the individual on stage. Here, the response from audience members suggests something different is happening. This is not an individual response, but a demonstration of collective action. On this occasion, the conference was transformed from one that accords a platform to an ‘expert’ speaker to a participatory debate. Attention was shifted away from the speaker as the audience denied the expertise of the speaker whose description of the world did not match that of their shared experiences. With the talk moving from the stage – although the presenter remained at the front – to the audience, it is the audience that took over the conference space and directed proceedings. In this unusual example we can see the biosocial collective at work. Those involved in this exchange share far more than biology. They share experiences, perspectives, passions and frustrations. It is these, not a deletion at 22q11, which produced the effervescent exclamations of ‘parent power!’

## **Discussion**

The main thesis of this article is that there is equivalence between established sociological expression of 'collective effervescence' (Durkheim, 1912) and more recent theories of biosociality (Rabinow, 1996). This is an important union because the latter theory was designed to reflect new social configurations emerging through developments in biomedical technology. Biosociality as a concept has been applied to numerous different settings and developed in directions, which Rabinow (1996; 2008) had not envisaged. We also note that the concept of biosociality has limitations, including ambiguity and the reduction of complex social relations to technoscientific explanation (Plows and Boddington, 2006; Wehling, 2011). Instead of exploring the nature of biosociality and the contexts in which it is, or is not, played out, we have used biosociality as a contemporary tool to explore links between different ways of understanding collectives. Our focus is therefore on community, and specifically the role of emotion in creating bonds between its members.

This article offers empirical support for the claim that communities can form around biomedical categories, and that this process is facilitated by shared experiences and collective emotions. While emotion in medical practice has received attention, for example in the emotional labour performed by medical professionals (Theodosius, 2008; Smith, 2012), less has been said about the role of emotion within the collectivities that have emerged through contemporary biomedicine. We assert that all communities, in whatever context they are formed, require some method of binding their members into a collective. The site of our research and the context in which we examine emotion are conferences attended by parents of children with 22q11 deletion syndrome. As conferences bring individuals together within the same physical location, they offer an ideal platform to examine how community ties are produced and expressed. Identification and participation are suggestive of biosociality. Conferences bring together individuals who are connected through biology, in this case 22q11 deletion syndrome. Attending such occasions demonstrates identification with the 'genetically marked category' of 22q11 deletion syndrome, and engagement with its community. These are national events, attracting patients and their families from across the country, potentially requiring attendees to travel a considerable distance. The extracts provided to support our claims highlight that at these events, collective passions are displayed. We highlight how these heightened emotions are produced within particular contexts. Although the presenter is prominent in most of the accounts, we do not always focus on their words but instead, highlight the reactions of the audience. We demonstrate that conferences are not simply sites of information transfer, but can be emotionally charged events.



A distinctive aspect of the conferences described in this paper is the degree to which these events produce moments of effervescence. Tears, loud and warm acclamations, and shouts of agreement are evidence of collective effervescence that Durkheim (1912) identified more than a century ago. This theory of human emotion that was established to understand what binds pre-modern societies is also relevant in the decidedly late-modern biosociality of 22q11 deletion syndrome. Furthermore, Durkheim proposed that heightened emotion would diminish over time, and that communal occasions would be required to re-stimulate the sense of the collective. Group events such as conferences, are therefore important in the life of the community, for generating and maintaining a sense of social cohesion. Conferences serve to create “periods of creation and renewal”, during which people “are brought into more intimate relations with one another, when meetings and assemblies are more frequent, relations more solid and the exchange of ideas more active”. These meetings bring people “together and [make] them communicate in the same intellectual and moral life” (Lukes, 1973, p.422 quoting Durkheim). While some ‘communities’ might be mere administrative collections of people (a mailing list for example), this paper demonstrates that the 22q11 deletion syndrome conferences facilitate the development of emotional bonds on which communities are built. In describing the ways in which conferences work to build and deepen biosociality, this paper demonstrates that the most important part of a biosociality is its sociality. The biosocialities that have been identified since Rabinow (1996) have often been imagined as a novel form of social organisation. We agree that many of these communities are initiated on the basis of a biomedical category, many of which have only come into existence because of developments in genetic technologies. However, as communities, they share commonalities with other forms of association that can be usefully understood with reference to classical social theory. It is not the genetic variation itself that binds members, but rather what individuals and collectives do with that knowledge.

Communities are not always forged on the basis of locality (see Salaman, 1974; Tonnies, 1957; Wilmott, 1986) and this is even more evident in the context of the digital age, facilitating networking across national and international borders. For those affected by rare disease, support groups can play an important role by creating a network of individuals with shared experiences. Although the 22q11 parent associations were established and directed by parents of children with 22q11 deletion syndrome, the groups have developed strong ties with health professionals in the field. This might be evidence that in the biosocial age, activities of patient groups are increasingly directed towards influencing the scientific agenda, and doing

so in collaboration or partnership with scientists and researchers (Epstein, 1996; Rapp et al., 2001; Rabeharisoa and Callon, 2004; Landzelius, 2006). Yet despite the visibility of some health professionals at the conferences observed as part of this study, the focus in this article remains on the parents. As a result, this article leaves unexplored the role of health professionals in building a biosocial collective, and their place within or without. Professionals have a number of different interests in the existence of biosocial collectives; as supportive campaign or lobby groups, as biomedical organisations who have the resources to pursue the research agenda and as associations that aid the distribution of health and social care information. Within new social movements, the nature of the role of the ‘panoply of pastoral keepers’ and their relationship to the biosociality becomes an important question. Are those who are counted among the ‘panoply of associated professionals’ members of the 22q11 deletion syndrome biosociality? And to what degree do the associated professionals share the meanings and understandings of the parent/patient communities that are normally taken as the archetypal forms of biosociality?

It is important to note that not every biosocial community will involve these kinds of conferences, nor involve events that move the collective emotions of the members in such a way. We do not therefore claim that collective effervescence in particular, nor patient/parent conferences in general, are the only ways by which a biosocial collective may be bound together. But all biosocialities must have a means of generating shared meanings and collective understandings that bind them together, distinguishing members from non-members. Further empirical examples are needed to examine the diverse contexts within which biosociality might be expressed. Future studies of biosociality should concentrate on the socialness of collectivities, examining the continuities and similarities with other, non-biologically based, forms of sociality. We need to know more about how the rules of behaviour, that is the ‘ceremonial order’, changes between communities, and how the boundaries of membership are expressed. Ultimately, this article has contributed to our knowledge of biosociality by drawing on established ideas of effervescent assemblies and the formation of communities.

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