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Parent-led Conferences as sites of Medical Work

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Abstract

Conferences are novel sites for understanding medical work. Through describing styles of presentation that take place at conferences attended by patients and parents, this article highlights how clinicians on stage present ordinary and extraordinary aspects of medicine. Attention is drawn to the reaction of the parents in the audience. The power of the presenter to direct proceedings highlights the potential vulnerability of the audience. The relationship between clinician on stage and parents in the audience reflects the clinical relationship between doctor and patient. But through identifying insiders and outsiders, the conference setting also enables new relationships and collective identities to be formed. Drawing on an ethnographic study of rare disease conferences, this article extends understanding of medical work by identifying how conferences offer new ways of witnessing the clinical gaze, the doctor-patient relationship and the formation and enactment of a conference community.

Key words: medical work; conference; ceremonial order, doctor-patient relationship, community

Introduction

The clinical consultation retains a symbolic presence within medical sociology, exemplifying the relationship between health professional and patient (Strong, 1979; Davis, 1982; Silverman, 1987; Nettleton, 1995; Latimer et al., 2006). However, there is increasing recognition of the diverse practices and locations contained under the rubric of ‘medical work’. In describing his approach to examining the work of clinicians, Atkinson (1995) identifies the extensive range of activities that construct, and are constructed by, medical work. :

“In paying detailed attention to the everyday work and talk of haematologists I seek to convey how they see and describe the medical phenomena that are their stock in trade; how they describe and narrate their cases to their medical colleagues; how they seek to persuade one another about diagnoses and clinical

management; how they justify and legitimate their knowledge and opinions”

Atkinson, 1995 p ix.

‘Hidden’ or ‘forgotten’ work includes record keeping (Berg, 1996; Haggarty et al., 2003; Prior, 2003, Rudge, 2003), medical teaching and professional socialisation (Atkinson, 1995), the interpretation of images (Shaw, 2003), the negotiation of diagnostic tools (Latimer et al., 2006, Featherstone et al., 2005; Somerville et al., 2008) and biographical and identity work to manage stigma and maintain relationships (Goffman, 1963; Featherstone et al. 2006). These kinds of work are rarely formalised, widely omitted from medical records and are frequently individualised, hidden and non accountable (Strauss et al., 1982 Nettleton, 1995; Featherstone et al., 2006). The significance of documenting these processes is that they provide insights into the production and construction of medical knowledge, identities and relationships by recognising the complex realities of intimate and locally managed productions (Lewis & Atkinson, 2011; Stephens et al., Glasner, 2011).

This article brings to attention the conference as a site where medical work is accomplished, skills are demonstrated, cases communicated, experiences shared and where identities and relationships are managed. Through these ordinary and

extraordinary achievements, conferences are revealed as a significant extension of everyday clinical work. This is a relatively novel claim.

The term ‘conference’ is widely used to describe meetings of various forms and functions. Within social work a ‘family conference’ has a specific meaning – a small group meeting to discuss palliative care, end of life decision making or within child protection. A case conference is similarly structured, a small number of people discussing a particular patient, whereas a ‘clinical teaching conference’ might describe the morning ward round between consultant and medical team. In contrast to these small focused meetings, many academic and professional organisations hold annual conferences, which can be attended by hundreds or even thousands of people. What all these kinds of events have in common is that they facilitate communication. The nature, content and media used to share or demonstrate expertise and knowledge is highly variable, depending on multiple factors including the purpose of the meeting, the expectations of organisers and attendees, the history of the event, numbers attending, the length of time attendees spend together, whether or not they were already acquainted and the space in which the event takes place.

However defined, the importance of conferences as occasions that bring people together is increasingly being recognised. The extensive activities that make up a ‘conference’

have attracted interested from disciplines including anthropology, sociology of medicine and science, business studies and linguistics, leading to a range of approaches and research methodologies. Whereas an analysis of language to establish claims to knowledge has traditionally focused on text books and journal articles (Myers, 1992), the ‘language of conferencing’ offers greater opportunities for understanding interaction and the presentation of knowledge. Most of those addressing linguistic aspects of the conference focus on the words of the presenter (McKinlay & Potter, 1987; Webber, 2005). Ethnographic or anthropological approaches generally examine how conferences contribute to the making of scientific disciplines and their communities through dissemination of knowledge, socialisation and ritual celebrations (Callon et al., 2001; Keating & Cambrosio, 2003; Collins, 2004; Richmond, 2006). In the context of scientific and professional conferences, interest has focused on the rites of passage that confirm membership of the community and reaffirm group cohesion (Lomnitz, 1983, Abir-Am, 1992). Within medical sociology, conferences appear as one of a number of key sites for examining how medical entities are constructed and for tracking biomedical processes (Heath, 1998; Taussig et al., 2003; Weiner, 2009; Featherstone & Atkinson, 2011). In the context of increased interest in citizenship and expertise, it is not surprising that conferences involving patients and professionals have become the focus for examining ‘bottom up’ activism (Taussig et al., 2003; Weiner, 2009).

This article specifically focuses on conferences organised by a patient group and attended by a patient or parent audience. I categorise these events as ‘parent conferences’ to distinguish them from ‘family conferences’ (which as highlighted previously can have a specific meaning) and from scientific conferences which are primarily attended by health professionals and scientists. However, all the ‘parent’ conferences described in this article also involved professional groups in a range of capacities. These configurations, in form and function, can usefully be understood as ‘hybrid forums’ involving diverse epistemic communities (Callon et al. 2001) and fulfilling both medical and social functions (Taussig et al.2003).

Conferences offer a platform for examining the presentation of knowledge. This article contributes to this literature by exploring how conferences extend the routine work of the clinic. Sociological understandings of the clinic have a long history, particularly in exploring the relationship between professional and parent or patient (Freidson, 1970; Nettleton, 1995; Dillard and Tiuczek, 2005). The ‘ceremonial order’ of the clinic (Strong, 1979) was identified to make sense of the different expectations of behaviour for both parties, and the changing political contexts within which the clinical encounter takes place has been noted (Gabe et al., 2004, Potter & McKinlay, 2005). However, how this relationship is enacted outside of the clinical or hospital, in addition to the potential for change or challenge, is only now being recognised as a central question.

First of all, this article describes the conference stage as a platform for the demonstration of medical work. Conferences enable the presenter to communicate detail of the process of work which is not always facilitated through alternative fora such as clinical consultations or medical text books. Secondly, this article explores the relationship between presenter and audience, one which echoes the doctor patient relationship. Conferences therefore provide an opportunity for understanding how 'public' performances of clinical work might be consumed by parents or patients in the audience, and for examining the possibilities for the formation of a 'conference collective'.

The Study

This article draws on observations of four one-day parent conferences which formed one strand of a multi-sited ethnography study, the aim of which was to document the social meanings of a rare genetic disorder. The study involved observation of conferences and clinical consultations, and interviews with clinicians and parents of children diagnosed with 22q11 deletion syndromeⁱ. In addition to the parent conferences, two scientific conferences (one three day event and one two day event)

were observed. Exploring the similarities and differences between parent and scientific conferences would prove interesting, although that is not the purpose of this article.

The parent conferences were organised by two UK and Ireland parent-led support groups, both of which were registered charities. The founders of each support group and most of the members of their committees were parents of children with 22q11 Deletion Syndrome. All the parent conferences observed for this study were national, annual meetings, attended by over one hundred parents. The events were held in a range of conference venues including a university building, hotel, sports stadium and a zoo. Children were invited to attend, and activities were organised away from the main hall, sometimes in a separate building. The conferences lasted one day each, often beginning with breakfast (for example, bacon rolls or Danish pastries) and involved seven or eight presentations followed by question and answer sessions. All of the presentations took place in the same room. Most of the presenters were professionals from various medical disciplines such as cleft surgery, dentistry, psychology or cardiology. Sometimes several members from a 22q11 deletion syndrome clinic presented as a panel, each talking about an aspect of the service they provide. On several occasions there were presentations on topics outside of medical care, including local support for families, education schemes or government benefits.

Observation of these events was opportune according to the conferences that were available at the time, all of which were recommended by participants (health professionals, parents and the organisers of the support groups) during the course of the study. Observations took place over a three year period between 2007 and 2010. All the conferences observed for this study required registration yet were open to the public and were publicised on the support groups' websites. The researcher's presence was agreed with the organisers of each conference and on occasion this was announced on the website prior to the event and at the welcome address. Leaflets explaining the research were made available to attendees. There are inherent tensions in utilizing conferences as a site of ethnographic research and these are discussed elsewhere (XXXX). The research was approved by the South Wales UK Research Ethics Committee and all names and places have been changed to ensure anonymity.

Ethnography involves the collection of many different types of data in an attempt to capture the detail, complexity and nuances of the research site (Hammersley and Atkinson, 2007). Extensive notes were taken during observation where possible, or immediately following the event in order to produce an "authentic picture" (Polgar and Thomas, 2000). These notes recorded the diverse dimensions of a complex social occasion, including rich descriptions of the physical space, the actors involved, the activities, timing and feelings expressed (Spradley, 1980).

Analysis was an ongoing process of observing, writing field notes, writing up fieldnotes, making notes and memos, and referring to current literature. This article does not present an exhaustive list of the themes that were generated through this analysis. Instead, the focal point of article is to use descriptions of presentations by health professionals to demonstrate why conferences are important sites for extending knowledge of medical work. In order to explore what happens at conferences I have purposefully provided descriptions of ordinary and extraordinary events. This serves to highlight the nature of these events as both routine and unpredictable. The extracts selected are based on my fieldnotes of the event, and are necessarily lengthy in order to preserve the context of the occasion.

Presenting medical work

Conferences facilitate a range of formal and informal activities for information exchange, discussion and networking. However, it is often formal presentations that form the structure of an event and this was the case for the parent conferences under discussion. Descriptions of some presentations provide examples of how the stage is used to communicate biomedical information and demonstrate skills and expertise. Each

extract has been selected because it provides a vivid account of both the process and outcome of medical work. The first example is taken from a presentation by a clinical geneticist in which he discussed the steps taken to correctly diagnosis one of his patients.

Dr Mellor is a consultant in clinical genetics. Using powerpoint, he showed a close up photograph of a girl's face, and alongside it a picture of her fingers. He said that she "didn't fit" with 22q and DiGeorge but he said she looked as though she had the 22q11 deletion. He introduced us to her as 'Sarah', said, "Sarah is a lovely lassee" then explained that the other image was of her "unusual fingers". He told us the story of Sarah, how she later became pregnant with daughter Shelley, and said that Sarah wanted a prenatal test to check for any heart problems. Dr Mellor said that Sarah tested negative using FISHⁱⁱ, and explained that they thought she might have a smaller deletion that hadn't been picked up. He said "eventually we found a duplication of the 'DiGeorge' region, so we had to go back to the literature". He put up a slide listing the features of 22q duplication syndromeⁱⁱⁱ, and said like the 22q deletion it was a highly variable syndrome. Included in the list were heart anomalies, learning disabilities, cleft palate, long fingers and hearing loss. He showed another picture of Sarah and this time alongside it, a picture of her baby who was also

diagnosed with 22q duplication. He said, “back to Sarah, I don’t think she looks that unusual”. Then he described the facial features of the baby, “wide-apart eyes, prominent septum, flat nose” and added, “she is now developing really nicely”.

[Parent conference B1]

Where conference presentations prove interesting, and can also be distinguished from textual media, is the flexibility in telling a story. Atkinson (1995) highlighted that when a clinician presents a case to colleagues, facts can be revealed slowly and carefully as a ‘mystery’ or ‘cliff-hanger’. Although in this example the clinician on stage is presenting to parents or patients and not medical colleagues, there are similarities in how Dr Mellor reveals the detail of his work.

Dr Mellor presents himself almost as a detective, working through a series of steps which can lead to a diagnosis. Each step reveals ‘clues’ such as ‘unusual’ fingers or genetic test results which need to be deciphered accurately in order to reach the correct conclusion. Comparing the diagnostic work of the health professional to a detective solving the mysteries of medicine is a common analogy. Aase (1990), a clinician with expertise in foetal alcohol syndrome^{iv}, identified strategies of how this detective work might be carried out. He suggested the Scotland Yard model, the Doctor Watson model

and the Sherlock Holmes model, each reflecting differences in style and pace of detection.

When talking about his patients or cases, this clinician on stage does not just present the identification and mapping of physical features. Detail is added. Important to the presenter's story was the inclusion of red herrings (the patient showed physical features which indicated 22q11 deletion syndrome), dead ends (negative test for a deletion) and alternative theories (a positive test for duplication necessitating a need to 'go back to the literature').

This presentation highlights an important difference between the conference and the clinic, and this is the extent to which the detail of medical work, in this case, the practice of dysmorphology, is revealed to the parents in the audience. Dysmorphology involves a process of identifying features that might be significant to a diagnosis and separating them from insignificant features that can be relegated to 'background' noise (Reardon and Donnai, 2007). Whereas the skills of ruling in or ruling out alternative diagnoses will often be revealed to colleagues, within the clinical consultation it is usual for the patient or parent to only be presented with the 'final' stage of diagnosis (Shaw, 2003).

In addition to describing his role in the diagnostic process, the clinician carefully weaved in clues about the person behind the patient image. Here the audience are told the history of the patient through hints of her moral character, she is described as 'lovely', but furthermore, she is pregnant and is making informed requests for further information. As an audience member I was drawn in by these details and wanted to hear what happened to Sarah and her daughter. Ultimately, I took up the invitation to invest in her story.

The following extract provides a different example of how process and outcome can be presented at conferences. On this occasion, a cleft surgeon^v describes a young patient with speech and language problems. During his talk the surgeon directed the audience to listen and observe the clinical signs of speech deficiency. When the final result following corrective surgery was revealed, the audience play a role in the performance by gasping in amazement and clapping spontaneously.

A cleft surgeon was on stage discussing the operations he has conducted on children with problems with verbal communication. We were played an audiotape of a girl's voice and were told that we were witnessing a seven year old girl before palate surgery. The cleft surgeon said, "listen to her voice". The girl's voice was high and squeaky. Two images appeared on screen. One was a

close up colour picture of the girl's face as she talked. The other was a black and white moving X-ray of the girl in profile. We were then invited to see images of the same girl after surgery. The girl was speaking, but this time she had a much deeper voice than before. Compared to the previous sound, the change was obvious. The cleft surgeon directed our attention to a section of the girl's palate on the X-ray, whereas before this piece was static, it now moved when the girl spoke. There were gasps in the audience and everyone spontaneously started clapping. The person next to me turned to the woman behind and said, "that's quite amazing", the woman responded with a beam "yes, it all makes sense now". At question time, although the cleft surgeon was on a panel with other members of the clinical team, most of the questions were directed to the cleft surgeon and all of these were about the video. One person asked what the time period was between the before and after video. The surgeon replied that the difference would normally be immediately noticeable after surgery but sometimes it would mean waiting till the swelling goes down. One woman a few rows in front said that her son had a cleft operation 5 years ago and that the improvement was nothing like that. The surgeon smiled and said, "yes, this is a good result". The surgeon, the panel and the audience laugh. [Parent conference A1]

Whereas the first extract focused on the steps leading to a diagnosis, the triumph of this presentation, and the focal point of the subsequent question and answer session, was the outcome, a successful operation with a visible and audible result. In describing the case of a girl with speech problems, the surgeon talked about the route from diagnosis to treatment. The audiotape of the girls speech and the Xray of the girls gullet were provided as evidence to persuade the audience not just to understand why surgery was necessary but to appreciate the difference surgery can make. Conference presentations provide a useful lens to examine the ways in which medical work and its associations can be represented. In celebrating a successful outcome, and presenting a mended broken body, the pain, suffering and recuperation of the patient experience does not feature. Thus this episode raises questions of what kinds of experiences are represented and which are obscured.

There is an important difference in my own presentation of these two extracts. The second is striking because the extract not only mentions the words and actions of the presenter, but also refers to the activities and reactions of the audience. The transformative properties of medicine have historically been both welcomed and feared. On stage, the girl's transformation from abnormal to normal becomes a spectacle, with members of the audience appearing visibly amazed and delighted by the result. The questions asked by parents following the presentation provide an insight into why the

‘good result’ provoked such a response. Audience members asked for clarification about the outcome, and specifically, how this might relate to their own circumstance. Overt comparisons were made between the ‘good result’ presented on stage and their child’s potentially less successful experience.

By including the reaction of others to the presentation, this extract confirms the importance and in many ways, uniqueness, of conferences as sites of medical work. Conferences not only enable the exploration of medical work as it is presented on stage, but it also offers an opportunity to examine the role and reaction of an audience.

The audience

The reaction of the parents in the audience, as described in the previous extract, is pivotal for the arguments presented here. First of all, the fact that presentations at conferences are co-constructed by presenter and audience within a ‘public’ arena highlight how these occasions offer new ways of understanding the production and circulation of biomedical knowledge and medical practice. Although many researchers attend conferences to understand the field, current sociological interests generally remain focused on the clinical consultation and not on these alternative forums.

Secondly, conferences where professionals are on stage and parents or patients are in the audience suggest a power imbalance which echoes that of the clinical relationship. The assertion that parent conferences facilitate a reflection and transformation of the doctor patient relationship is a novel assertion. Most importantly, this article is the first to identify that ‘hybrid’ conferences are both significant and potentially problematic *because* of the way they reconstruct the doctor patient relationship. In contrast to the previous example which suggested a collective celebration of the positive outcome, the following extract highlights how presentations can test the relationship between presenter and audience.

In this case the presenter used visual images to demonstrate the labour of medicine. Mr Simmons, a consultant plastic surgeon, talked about his role in paediatric cleft palate surgery. Although all of the presentations described in this article involve a dramatic element, in this case, it is the drama of the audience reaction that directs attention.

Mr Simmons, a consultant plastic surgeon, talked about the surgical procedures that children with palate problems might undergo. The first picture he showed was a patient who had been anaesthetised. We saw a child’s face, partially covered in a green surgical robe with eyes taped over. There were loud gasps from the audience. The surgeon said ‘oh dear, if you think that’s bad, I’ll skip

over the others' and proceeded to 'skip' through each of his slides until he found one that he felt *was* suitable for the audience. However, while 'skipping through' the audience saw every one of his slides. At each image the audience gasped and several people left the room. At one slide in particular the audience took a collective intake of breath. Simmons said 'that one was there to show there's lots of blood'.

[Parent conference B1]

As an audience member it was not the slides themselves that held meaning for me, but the reaction of the audience. During this surgeon's presentation, gasps could be heard and some parents got up from their seats and left the hall. I found the audible and visible signs of unease quite confronting. The response from members in the audience suggest that this presentation was extraordinary. However, this occasion remains important for discussion because it reveals how a 'hybrid' conference, where health professionals are invited to speak and parents invited to attend, has the potential to be problematic. The bloody world of a surgeon does not readily translate to the personal and emotional world of parenting a child with a complex medical condition. Mary Douglas (1966) in her eminent work on the classification of dirt as 'matter out of place', highlighted the way in which anomalous phenomena is reclassified as a device to preserve social order. It is important to note that this style of presentation might be considered unexceptional

if it were communicated to medical students as part of their medical teaching. On this occasion, it was the reaction of the audience that suggested that the images presented were ‘out of place’, providing a reminder of the importance of understanding the context within which information is presented.

Communication practices between health professional and patient or parent have been examined in many areas of health care (cf. McLaughlin, 2005) including the circulation of ‘horror’ stories when communication breaks down. When patients or families receive information during a consultation, in a manner that they consider inappropriate, this has the potential for a deleterious impact on the clinical relationship (Baird et al., 2000). Yet there remains a lack of knowledge about how parents consume images and stories within the context of the conference. I suggest that the ‘failure’ of this presenter to recognise the expectations and requirements of the audience, and the subsequent misalignment, left them vulnerable. In the conference setting, parents as audience members can be vulnerable to an unsolicited display. Biomedical information, including images, require interpretation. The clinician acts as mediator or gatekeeper within the clinic (Shaw, 2003). With the potential to prohibit certain speakers or topics from being discussed, conference organisers play potentially significant roles as gatekeepers or ‘boundary workers’. However it is important to note that parents or patients can also be

vulnerable when a 'good case' is presented. The 'good result' in the second extract left parents with questions about how their own child matched up to the example presented.

A conference community

Thus far I have highlighted how the presenter appears as director of the performance, celebrating clinical skill, highlighting successful cases and demonstrating the process of medical work. I have suggested that the conference produces a particular kind of setting for communication, one that can make audience members and one that has hitherto been little understood. However, the examples also highlight the engagement of the audience, emphasising that conferences are dynamic spaces because of the interaction they facilitate, involving significant roles for presenters and audience alike. Whereas the later extract suggested the potential for an antagonistic relationship between presenter and audience, this was not always the case. Here I describe how conferences can facilitate a relationship rooted in a shared sense of community.

Many of the presenters I observed during this study made overt attempts to foster a good relationship with his or her audience. One feature of parental conferences, which significantly, does not appear to be a feature of scientific conferences, is frequent

reference to the expertise of parents. For example, on one occasion, a speech therapist declared “I might be the expert on feeding, but you are the expert of your child” (B2).

The nature and frequency of the mantra of the ‘expert parent’ observed at parent conferences shows how lay expertise might be addressed within the conference setting. This appears to be a rhetorical device to communicate with the parental audience from the stage. On stage, the ‘expert parent’ can be used as a political tool, a deferral to parental expertise for purposes of public engagement. But in attending to parental identities, this usage is also an example of the moral and sentimental work that might normally be recognised within the clinic (Featherstone et al., 2006).

Conferences also provide an opportunity for the formation of a collective identity. The identification of ‘outsiders’ for example, appears in contrast to the celebration of clinical skill and expertise of parents and professionals. In the context of scientific meetings, when failure is mentioned on stage it is most often discussed within a framework of the failure of ‘others’ (McKinlay & Potter, 1987). Mention of failure also plays a significant role at conferences involving parents and health professionals. At these conferences, it was tales of GP incompetence that were frequently woven into presentations.

One woman in the audience announced herself as a parent of a child with 22q11 deletion syndrome and asked the clinical team on stage how to gain a referral to the specialist clinic. The paediatrician said that there were various routes to referral and the GP might be the first option. The mother replied ‘GP’s don’t know anything!’ and the audience, and those on stage, nod and laugh.

[Parent conference A1]

In these spaces, both presenter and audience can be celebrated as knowledgeable while ‘others’ are represented as ignorant. Here, one mother’s statement that ‘GP’s don’t know anything’ becomes a collectively sanctioned mantra. The GP appears as a court jester, lacking appropriate knowledge and experience. This was the case on other occasions. One time, a consultant in clinical genetics introduced herself and then added “I’ll bet most of you know more about this than your doctor” [Parent conference A1]. On another occasion, a speech and language therapist who was on stage advised the audience “ask for a cleft specialist, part of the specialist team, they have been trained, even if the GP is saying there’s nothing wrong” [Parent conference B2]. These stories of failure serve a dual purpose. Representing the GP as an outsider confirms the expertise and insider status of the speaker, but it also facilitates the formation of a united ‘conference’ community. The presenter colludes with the audience in the failure of the absent health professional enabling the celebration of collective expertise. This

collective action, uniting doctors and parents is significant for understanding the multiplicity of clinical relationships and highlights the conference as a complex space presenting opportunities for collusion and division.

Conclusion

The main thesis of this article is that conferences facilitate particular kinds of interaction which are constitutive of medical work. The conference offers a platform for understanding medicine as a local production (Bowker and Star, 2000) and how the 'clinical gaze' (Foucault, 1973) is presented. Mol (2002) identified how the healthy and unhealthy body is produced and enacted across multiple sites. The relationship between clinician and patient has consistently been mediated by technology; scans; X-rays, photographs and even the stethoscope represent the human body as well as disease. Conferences provide an alternative forum for presentation, with powerpoint yet another layer of mediation.

I have observed many occasions where a health professional presents a structured account of disease when talking about one of his or her patients. Accounts that are similar to those found in biomedical textbooks where close up images of affected body parts or a front facing picture of a child's face (sometimes with eyes obscured to protect

identity) are presented, accompanied by a list of symptoms and explanation of their impact. The three examples each described different approaches for presenting and talking about patients, including representation in different time frames and medical spaces.

Conferences enable flexibility in the presentation of the patient and their story, something that text books are unable to offer. The story behind the image can be told to the audience, entwining the patient's history with the presenters' version of discovery, diagnosis and outcome. The first example, which described the work of the geneticist, demonstrated how the disaggregation of body parts (prominence given to fingers or eyes for example) and the making up of the patient as a person (one who is able to make appropriate choices) can be performed simultaneously. Likewise, in the second extract, a patient with swallowing difficulties is reconstructed through audio recordings and X-Rays across two different time spans. Through digital technologies the patient body is inherently mobile, enabling the clinician to communicate aspects of disease to others (Heath, 1998). The selection of the 'good result' in the second example reminds us that for many, the conference is a workplace and whatever the style of presentation, images and stories perform work. Presentations are necessarily selective, an essential part of producing a 'glossy version' for public consumption (Fine, 2007).

Conferences facilitate a deeper understanding of not just how information is presented but also how they might be consumed by an audience. At all the conferences I observed, images of the child and patient attracted intense inspection from the audience. Thus the reaction of the parents in the audience to the ‘blood’ slides, as described in the second example, highlight a problem inherent in the ‘clinical gaze’. Representations of medical work at parent conferences can produce a tension between the medical identity of a patient and the normalisation and celebration of the child.

Parent or ‘hybrid’ conferences facilitate interaction between and across communities. They have been identified as sites for the expression of patient expertise and activism (Taussig et al., 2003; Weiner, 2009) but equally, they are recognised as significant sites because they enable patients and family members to access experts in the field (Zakrzewska et al., 2009). In this respect, the conference can be seen as an alternative site for performing the doctor patient relationship. The divergent roles and power differentials between presenter and audience are therefore important to note, particularly in the context of the status and legitimacy given to presenters (Lomnitz, 1983). The reenactment of the doctor patient relationship serves as a reminder that ‘hybrid’ events bring together individuals with different perspectives and vulnerabilities.

There is increasing recognition of the significance of place as the context through which science and medicine is produced (Wainright & Williams, 2008; Stephens et al., 2008).

The physical context of the conference is important for shaping what types of communication, and what kinds of interaction are made possible. As we have seen from the extracts provided, conferences are performative occasions which include the potential to inform, to entertain, to wow and to shock. From this analysis it is clear that there are differences between conferences attended by patients and parents, and those attended only by scientists or health professionals. Further research is needed to examine these differences and what are the implications for our understanding of medicine. Throughout I have drawn comparisons between conferences and clinical consultations. Conferences and consultations differ in our understanding of each occasion. Within the clinic, the ‘ceremonial order’ underlying the rules of behaviour is exposed when it is breached (Strong, 1979; Davis, 1982; Stokes et al., 2006). There is clearly a lot more to know about the ceremonial order of the conference. What are the expectations of behaviour and how are these constrained or encouraged within these spaces? How do these rules and sanctions differ for presenter, audience member, clinician, scientist, parent, patient or ‘lay public’? And how will we know when rules have been breached? The display of ‘blood slides’ in the third presentation extract raises an important question. If conferences facilitate a doctor/patient relationship, how can we conceptualise the responsibility a presenter has towards his audience?

The conference performs multiple roles. It is a site where knowledge is produced and communicated, identities are revealed and new collaborations fostered. The framing of parent conferences as dynamic sites of interaction, and recognition of power dynamics between presenters on stage and audiences, contributes to a deeper understanding of medical work. The ultimate aim of this article is to leave no doubt that conferences are socially significant occasions and worthy of further research.

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References

- Aase, J. M. (1990). *Diagnostic Dysmorphology*. New York: Plenum Medical Book Company.
- Atkinson, P. (1995). *Medical Talk and Medical Work: The Liturgy of the Clinic*, London: Sage Publications.

- Baird, G., McConachie, H. and Scrutton, D. (2000). Parent's perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood* 83, 475-480.
- Bassett AS, McDonald-McGinn DM, Devriendt K, et al. (2011). International 22q11.2 Deletion Syndrome Consortium. Practical guidelines for managing patients with 22q11.2 deletion syndrome. *J Pediatr*. 159,332–9.e1.
- Berg, M. (1992). The construction of medical disposals: Medical sociology and medical problem solving in clinical practice, *Sociology of Health & Illness*, 14, 2, 151-180.
- Bowker, G. C. and Star, S. L. (2000). *Sorting things out: Classification and its consequences*. Massachusetts Institute of Technology.
- Callon, M., Lascoumes, P., Yannick, B. (2001). *Acting in an uncertain world: An essay on Technical Democracy*. MIT Press, Cambridge, Massachusetts.
- Collins, H. (2004). *Gravity's Shadow: The Search for Gravitational Waves*. Chicago University Press.
- Courtens, W., Schramme, I. and Laridon, A. (2008). Microduplication 22q11.2: a benign polymorphism or a syndrome with a very large clinical variability and reduced penetrance?--Report of two families. *Am J Med Genet A* 146A(6) 758-763.
- Davis, A. G. (1982). *Children in Clinics: A Sociological Analysis of Medical Work with Children*. London: Tavistock Publications.

- Dillard, J. P. and Tiuczek, A. (2005). Information flow after a positive newborn screening for Cystic Fibrosis. *Journal of Pediatrics* 147(3 Supplement) S94-97.
- Douglas, M. (1966). *Purity and Danger: an analysis of concepts of pollution and taboo*. London: Routledge.
- Featherstone K, Gregory M, Atkinson P. (2006) The moral and sentimental work of the clinic: the case of dysmorphology. In Paul Atkinson, Peter Glasner and Helen Greenslade (eds), *New Genetics, New Identities*. London: Routledge.
- Featherstone, K. and Atkinson, P. (2011). *Creating Conditions: The Making and Remaking of a Genetic Syndrome*. Taylor & Francis.
- Featherstone, K., Latimer, J., Atkinson, P., Pilz, D. And Clarke, A. (2005). Dysmorphology and the spectacle of the clinic. *Sociology of Health and Illness* 27(5) 551-574.
- Fine, G. (2007). Ten lies of organisation ethnography. *Presentation to XXXX University*. May 2007.
- Foucault, M. (1973). *The Birth of the Clinic: An Archaeology of Medical Perception*. London: Tavistock Publications Limited.
- Freidson, E. (1970). *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. New York: Harper and Row.

- Gabe, J., Olumide, G. and Bury, M. (2004) 'It takes three to tango': A framework for understanding patient partnership in paediatric clinics. *Social Science & Medicine*. 59, 5, 1071-1079.
- Goffman, E. (1959). *The Presentation of Self in Everyday Life*. London: Penguin Books.
- Hammersley, M. and Atkinson, P. (2007). *Ethnography: Principles in Practice*. 3rd ed. Oxon: Routledge.
- Heath, D. (1998). Locating Genetic Knowledge: Picturing Marfan Syndrome and Its Travelling Constituencies. *Science, Technology & Human Values* 23 (1) 71-97.
- Keating, P., and Cambrosio, A. (2003). *Biomedical Platforms: Realigning the Normal and the Pathological in Late-twentieth-century Medicine*. Cambridge, Massachusetts: The MIT Press.
- Latimer, J., Featherstone, K., Atkinson, P., Clarke, A., Pilz, D.T. and Shaw, A. (2006). Re-birthing the clinic: The interaction of clinical judgment and genetic technology in the production of medical science, *Science, Technology & Human Values*, 31 (5) 599-630.
- Lewis, J. and Atkinson, P. (2011). 'The Surveillance of Cellular Scientists' Practice. *BioSocieties*, 6, 381-400.
- Lomnitz, L. (1983). The Scientific Meeting: An anthropologist's point of view. *4S Review*. 1 (2) 2-7.

- Loock, C., Conry, J., Cook, J. L., Chudley, A. E. and Rosales, T. (2005). Identifying fetal alcohol spectrum disorder in primary care. *The Canadian Medical Association Journal* 172(5) 628-630.
- Max Appeal, (2012). Consensus Document on 22q11 Deletion Syndrome (22q11DS). October 2012. <http://www.maxappeal.org.uk> accessed 20/10/2012.
- Mckinlay, A. and Potter, J. (1987). Model Discourse - Interpretative Repertoires in Scientists Conference Talk. *Social Studies of Science* 17(3) 443-463.
- McLaughlin, J. and Clavering, E.K. (2011). Questions of kinship and inheritance in pediatric genetics: substance and responsibility. *New Genetics and Society* 30(4) 399-413.
- Mol, A. (2002). *The Body Multiple: Ontology in Medical Practice*. Durham: Duke University Press.
- Murphy, K.C. and Scambler, P.J. (2005). *Velo-Cardio-Facial Syndrome: A Model for Understanding Microdeletion Disorders*. Cambridge University Press.
- Myers, G. (1992). Textbooks and the Sociology of Scientific Knowledge. *English for Specific Purposes* 11, 3-17.
- Nettleton, S. (1995). *The Sociology of Health and Illness*. Cambridge: Polity Press.
- Polgar, S. and Thomas, S. A. (2000). *Introduction to research in the Health Sciences*. 4th ed. London: Churchill Livingstone.
- Prior, L. (2003b). *Using Documents in Social Research*. Sage.

- Reardon, W. and Donnai, D. (2007). Dysmorphology demystified. *Archives of Disease in Childhood* 92(Fetal and Neonatal Edition) F225-F229.
- Robin, N. H. and Shprintzen, R. J. (2005). Defining the clinical spectrum of deletion 22q11.2. *Journal of Pediatrics* 147(1) 90-96.
- Rudge, T. (2003). Words are powerful tools: discourse analytic explanations of nursing practice. In: Latimer, J. ed. *Advanced Qualitative Research for Nursing*. Blackwell Science. pp. 155-182.
- Shaw, A. (2003). Interpreting images: diagnostic skill in the genetics clinic. *Journal of the Royal Anthropological Institute* 9, 39-55.
- Shprintzen, R. and Golding-Kushner, K. J. (2008). *Velo-cardio-facial syndrome* San Diego: Plural Publishing.
- Silverman, D. (1987). *Communication and Medical Practice*, London: Sage Publications.
- Somerville, C., Featherstone, K., Hemingway, H., Timmis, A. and Feder, G.S. (2008). Performing stable angina pectoris: an ethnographic study, *Social Science & Medicine*, 66, 7, 1497-508.
- Spradley, J. (1980). *Participant Observation*, Hold, Rinehart and Winstone.
- Stephens, N. Atkinson, P. and Glasner, P (2011). Documenting the Doable and Doing the Documented: Bridging Strategies at the UK Stem Cell Bank. *Social Studies of Science* 41 (6) 791-813 DOI: 10.1177/0306312711423306

- Stephens, N. Atkinson, P. and Glasner, P. (2008). The UK Stem Cell Bank as Performative Architecture *New Genetics and Society* 27, 87-99, DOI: 10.1080/14636770802076977
- Stokes, T. (2006). Breaking the ceremonial order: patients' and doctors' accounts of removal from a general practitioner's list. *Sociology of Health and Illness* 28(5): 611-636.
- Strauss, A., Fagerhaugh, S., Suczek, B. and Wiener, C. (1982). Sentimental work in the technologized hospital. *Sociology of Health and Illness* 4(3) 254-278.
- Strong, P.M. (1979). *The Ceremonial Order of the Clinic: Parents, Doctors and Medical Bureaucracies*, London: Routledge.
- Taussig, K.-S., Rapp, R. and Heath, D. (2003). Flexible Eugenics: Technologies of the Self in the Age of Genetics. In: Goodman, A.H. eds. *Genetic Nature/Culture: Anthropology and Science Beyond the Two-Culture Divide*. Berkeley, CA: University of California Press. pp. 58-76.
- Wainwright, SP. and Williams, C., (2008). Spaces of speech and places of performance: An outline of a geography of science approach to embryonic stem cell research and diabetes, *New Genetics and Society* 27 (2) 161- 173.
- Webber, P. (2005). Interactive features in medical conference monologue. *English for Specific Purposes* 24, 157-181.

Weiner, K. (2009). Lay Involvement and Legitimacy: The Construction of Expertise and Participation within HEART UK. *Journal of Contemporary Ethnography* 38(2) 254-273.

Zakrzewska, J. M., T. P. Jorns, and A. Spatz. (2009). Patient led conferences--who attends, are their expectations met and do they vary in three different countries? *European Journal of Pain* 13 (5) 486-91.

ⁱ 22q11 deletion syndrome is associated with an extensive and variable phenotype of more than 180 potential symptoms (Robin & Shprintzen, 2005). The most commonly reported symptoms include congenital heart defects, mild to moderate learning disabilities, cleft lip and palate and immune deficiency. National and international consensus guidelines have been produced to improve the complex and multidisciplinary management of patients (Basset et al., 2011; Max Appeal, 2012). The expansive range of symptoms has led to the development of various nomenclature, thus 22q11 deletion syndrome has also been described as Sedláčková syndrome, DiGeorge syndrome, conotruncal anomaly face syndrome, velo-cardio facial syndrome (VCFS), Shprintzen Syndrome and CATCH22 amongst others (Murphy & Scambler, 2005; Shprintzen & Golding-Kushner, 2008). To avoid confusion in this article I use the designation 22q or 22q11 deletion syndrome, although I acknowledge that this nomenclature can be contested (Author, unpublished thesis).

ii Fluorescence in situ hybridisation (FISH) is used to identify the 22q11 deletion (Murphy & Scambler, 2005; Shprintzen & Golding-Kushner, 2008). FISH involves firing replicated DNA probes containing a stain towards the chromosome. In unaffected cells, two stained probes will be identified, whereas in 22q11 deletion syndrome only one probe will be seen, therefore identifying the deletion.

iii 22q11 duplication syndrome is associated with a variable phenotype although most individuals have mild symptoms. The majority of cases are due to genetic inheritance and patients with the syndrome have a 50% chance of having a child who also has the syndrome (Courtens et al., 2008).

iv Foetal alcohol syndrome describes a range of physical and mental disorders due to alcohol exposure during gestation (Loock et al., 2005).

^v Difficulties with speech, voice, resonance and articulation are common features associated with 22q11 deletion syndrome (Shprintzen & Golding-Kushner, 2008) necessitating the involvement of speech therapists and cleft surgeons at specialist clinics.