Notes on Distributed Learning Seminar, 10/24/05
Notes by Doug Grimes and Barbara Edwards

Presentation on Use of Ephemeral Media in Study of Tourette Syndrome – Brian Goldfarb and Lisa Cartwright

Brian: Tourettes is a syndrome or spectrum disorder, ranging from mild to severe. It presents itself in many different ways, and has high co-presentation with other disorders, including obsessive-compulsive disorder.

Lisa: Why is Tourettes a significant project in education? Development of children with Tourette is the same as with other children. However, their behavior is different, e.g., 5-15% of Tourettes kids have coprolalia (uncontrolled obscenity), which is grounds for expulsion under the current no tolerance rule in schools. Tendency to touch others, which may be interpreted as hitting, also requires understanding.

Brian: One of the demands of Tourettes is that it requires different rules for different children. That runs against widespread preference for standard rules.

There is genetic component of Tourettes, but it also has cultural component, e.g., coprolalia is less in Latin America. There are psychological aspects, too, such as the way one explains tics.

Lisa: Typically Tourettes is handled in schools as an emotional disorder (ED). However, the motor problems of Tourettes are neurologically based, so it’s wrong to classify it as ED.

Brian: Medical researchers are interested in their use of ephemeral data in “natural” (non-clinical) setting.

Although tics appear as involuntary, they are better understood as non-voluntary, like breathing – you can control it, at least for a while. Children are encouraged to try not to blink and feel the urge to blink. His son, for example, has learned to modulate his facial tics so that they often go unnoticed. Some people suppress symptoms in public and let it go unrestrained at home.

Lisa: Why is this work important? Because it’s hard to get data on “normal” behavior with an observer present. Brain and Lisa are very concerned with language and gesture. Classroom approach is very concerned with control, but they’re looking at the disorder from perspective of what happens without control. They’re looking for positive side of Tourettes.

Brian: They’re also looking at Tourettes as a distributed, social disorder – behavior of rest of family changes in response to Tourettes.
Global Tourette initiative began last summer in Buenos Aires. It’s difficult for psychiatrists to share data with other researchers; B & L want to open up the data, share it. Their model is social, family oriented -- very different from drug model that prevails in U.S. Their projects involved fun, informal family self-help groups. Family uses animation and video, which becomes part of their data.

(Showed comical animations children prepared.) In one case, a boy who had dropped out of school made friends with another boy with Tourettes and took the initiative to go back to school, and has become regular student.

Lisa: It’s similar to Mike Cole’s work, where kids look forward to working on computer in after-school setting.

Brian: They try to use open source software so families can take it home. Easy learning curve is also important. (Displayed films of kids filming themselves and using software, including Apple’s GarageBand. Kids behaved naturally, as if not in front of video camera. Also used Playdough to make models.)

Lisa: Their research tradition has been applied to asthma and Navajo documentation.

Brian: They give study participants small $30 video cameras that are very simple to operate. They have a label saying the movies can only be retrieved by uploading to website. Families can use them to film Tourette or non-Tourette activity.

Lisa: Significance of the video technology cannot be over-emphasized. Video ethnography has been used for 35 years, but it was complicated and expensive for self-documentation.

Brian: The cameras they use have no street value. They were able to use these cameras in an intensely drug-infested area, giving them to drug addicts, who used them and returned them because they had no resale value.

(Showed video of an interview Tourettes boy made of his mother, who talked proudly of her affectionate, well-behaved boy.)

Lisa: “As you can see, self-esteem is a major issue for kids with Tourettes.”

(2nd video of same boy interviewing his sister, who talked candidly about the things about him that bothered her. “If you had to rate my tics on a scale of 1 to 10, how would you rate them?” Sister rated them at 5; their mother had given them an 8. Girl (around age 10, or 11, about a year older than her brother) said she accepted his tics, but they bothered her.

Brian: They developed software that allows families to upload videos, and write or draw on videos. They add keywords for cross-referencing, so that people in project can share
media. That's in a private section of Global Tourette website. They also have public area.

Work is distributed in many ways – social nature of Tourettes in family and school, Tourettes initiative, website, etc.

(Next video: 21 year-old biology student who is using holistic techniques like yoga and trying hard to drop is dependency on medical drugs to manage tics. Although his tics were very pronounced, he was also troubled by obsessions related to his father’s death from alcoholism and sleep apnea – related to throat. This young man complained that he could not write, drive, or appear in public, have a girlfriend. Hit or scratched people. Complained about the side effect of his medication -- impotence, sleepiness, drooling, irritability. At the health foundation he learned to breath deeply, relax his muscles. “I have a sick obsession with coughing,” was tempted to choke people (who coughed?). He’s easily irritated – bothered by dogs and motorcycles. In class he hits things, has trouble studying.)

(Next clip by the 7 year-old boy who decided to return to school – filmed his back yard and house. He filmed himself in bathroom mirror.)

(Next clip – 13 year-old boy recounts his problems.)

Brian: Also have interviews with families and medical professionals. They also visited insane asylum which has a radio/TV program produced by inmates. They did a program on how people think they’re insane, although they’re not. This is a major problem – Tourettes is mistaken for insanity.

B & L are starting programs in SD, LA, and TJ. Other projects starting in other countries.

Lisa: Due to science of brain research, understanding in public is shifting toward treating it as a neurological disorder, not a mental disease.

Sonja: This research raises many questions about how behaviors are socially created. Similar to digital story telling, letting children produce videos. Also uses performative documentation to educate problem. The videos we saw today show the power of media to help sufferers to gain social acceptance and audience. May have therapeutic effect, too.

Digital studies project at LCHC struggles with ephemerality. Videos are more performance-oriented than production-oriented. Tourettes films are similar to movies made by minority children, who struggle with social identity.

Kelly: Due to these interventions, do children exhibit fewer symptoms?
Brian: We can’t say, but there are some symptoms which increase and others decrease when Tourettes sufferers get together. They have a comfort zone around other assessors. Social stress of non-Tourettes gathering can produce symptoms.

Psychiatrists offer data they consider more scientific than ethnographic data. They are oriented toward changing patient, not his family or others around him. The point of B & L’s research is not to change the sufferer, but to help others understand Tourettes, e.g., fathers have said, “I beat my kid for years because I didn’t understand it. Now I understand it, and I don’t beat him.” Similarly, kids have said they understand why their parent beats them. That’s a powerful message.

Jenny: Similar pattern happens with other medical problems, such as diabetes. Transfer of knowledge to public is slow. Will be interesting to see how this work infiltrates medical profession and public.

Lisa: Buenos Aires has highest % of psychiatrists in the world. Psycho-analytic viewpoint has been very damaging to Tourettes sufferers, although the damage is mitigated in Argentina.

Brian: Lots of interest among medical profession.

Lisa: She presented it to a medical conference. Most Tourettes research has been focused on biology, not social side.

Stephanie: Definition of the disease is socially constructed. Also embedded in larger context of medical views.

The way of talking about it today is very affective, empathic. How would you position this work to other research at the center for distributed learning?

Brian: Both individual and group learning are going on, e.g., he’d link it to 5th Dimension project. Similar to the multi-user groups. B’s & L’s software is between visual wiki and visual MOO. They bring in multiple areas in people’s lives without creating boundaries.

Lisa: Responses of viewers to videos can vary. Can approach them as ethno documentation, or .... 5th Dimension project has similar problem with videography. In Buenos Aires the families and medical communities are very open to video.

Brian: Schools here are hard to work because of their worries about liabilities.

Lisa: Hutchins, Cole, and Warschauer can make claims about what to expect, based on their previous ethnography work. However, B & L don’t have that previous ethnography to refer to.
B & L: Tourettes syndrome especially hard to release because it’s so easy to confuse behavior and intention. Tourette person can be misunderstood if he starts to hit someone, even though he doesn’t want to.

Brian: There’s a strong social construction to meaning, and meaning changes when a person has little control over his/her impulses.

Lisa: Where does neurological disorder come together with social understanding? Need to develop this understanding into a model of teaching that tries to control children. Their approach is not to control the behavior per se, but social understanding of it and organizational response to it.

Joanne: Different communities of practice have their own ways of speaking about a problem. View used to be individual learning a body of knowledge, but no individual and no group has complete knowledge of any problem. Have to see it from distributed perspective.

Lisa: IDEA section 504 tries to level the playing field. It proposes a distributed model where accommodations to child’s needs are necessary.

Joanne: That assumes that if you could add up all our thoughts, you’d have sum total of them. However, there’s an interaction effect.

Lisa: Exactly. There’s multi-generational interaction in response to Tourettes.

Derek: Oliver Sachs work – flow states. Tics vary widely in different contexts.

Brian: Their interviews substantiate this variability over and over. e.g., one drummer says the only time his tics subside is when he drums.

Lisa: “Can you think of drumming itself as a tic behavior?” You can say that tics go away because he’s totally occupied, or you can say that drumming is an accommodation and incorporation of tic behavior.

Barbara: We’ve run over time, have to end the discussion.