Virtual Disability: Sameness and Difference in an Electronic Support Group
Gerald L. Gold
- MSN-L is "a community focused on persons with multiple sclerosis"
- "Facilitate a frequent, often frenetic exchange of information and on more infrequent occasions, exchanges of personal assistance" (tag Garnovetter 1981)
- "Enhancing this access, virtual support groups are not limited by scheduled meetings and fixed gathering places. Like face-to-face groups often include persons with "experiential authority" (Borkman 1990:20) who become foci of knowledgeable information and of resistance to the negative gaze of outsiders."
- Visits and notes became the equivalence of anthropological research
  - Cyberspace as a "place" for anthropological, geographical and sociological inquiry
- *In face to face encounters, not everyone is aware of conversations that take place in public, but on something like a thread on a social website, it's the center of attention and everyone will respond/add to it
- On private conversations it is almost as if the other person is invisible because you have no real knowledge of them or what they look like, or if it is actually their caregiver corresponding. "Imagined community"
  - "Experiential and professional authority become blurred"
- Benefits of direct contact support groups: provide nonmedical and nonclinical "milieu" to talk about things such as alternate doctors or medicines
- Faults: They are small, only have specific times where members can meet and discuss, also there is only really a set geographic range
- Easy access/community for disabled and their caregivers when they cant actually get to groups because of their disabilities
- "strength of weak ties" (Garnovetter 1982) meant for urban networks but applicable to global support communities
- What members of virtual communities want: social support of others and information on treatments, things like medications, side effects, and numbers to doctors, etc.
- "Virtual communities can be dispersed over broad distances, an international borders, not leading to direct social interaction. These extensive weak networks are related to strength of virtual disability where computer mediated communication bridges physical barriers to accessibility."
- Effectiveness: Gold did several case studies
- Imagined communities 'without apparent special boundaries'

Support Groups: conventional and virtual
- Commonalities:
  - Public and private networks of communication
  - Reported and imagined similarities which create and reinforce communities

- o Nothing to due with occupation or expertise, purely based on experience
- Virtual
  - o As broader number of people learn 'computer assisted' communication, the more widely accessible this is
  - o "Computer users often do not create sharp boundaries between everyday and virtual or "on the screen" worlds were movement from one to the other may be fluid and imperceptible" ****Not sure what this means
  - o Participants in a virtual group are invisible to each other, which is hugely different from the 'isolation' of something like a doctors office or assisted living
  - o "Experiential authority" is the disabled and their caregivers that have lived through treatments, etc. and can speak freely with an understanding authority different from the way doctors command their own knowledge of a certain treatment (seems to be more welcoming/less intimidating)
  - o Medical presence is largely absent
- Problems with interaction based support groups: scheduled and regularly timed intervals, but are also under the supervision of charitable or public service organizations or medical staff

The Virtual Support Group
- There are emails sent out by a group moderator to provide things like guidelines for correspondence or things like "netiquette" of how to deal with something should there be a problem (ex. Personal attacks, etc.)
- Several members are usually members of various other virtual communities
- Agenda often includes "time-specific" urgency about things like medications/treatments
  - o It is because of this that virtual support "encourages face-paced intra-community communitcation" and a lot of the correspondence or 'narratives' are time-bond that cannot be replayed (this could also be a privacy measure)

Fieldwork in a virtual support community
- Relatively informal as Gold;s role was primarily as a participant and secondly as an observer
- No interviews or questionaires, met with a few people but also had access to all public feeds
- "Underscores the effectiveness and limitations of a virtual support group for what is both a disability and chronic illness"
- 225 self identified members (1/5th or 45 of whom actually post/correspond a lot or seen as "influential participants")
- Because the group is public, messages could be read by hundreds if not thousands or times/people

- Members may attempt to control its public identity, however many members also make use of private messaging features
  - QUESTION: Do you think private messaging features allow a more intimate correspondence than group postings or chats despite that both of these have no physical contact involved? Or is it maybe the act of someone directly reaching out to you that makes it more intimate? Why would this be?
    - Technically could it not even be this person responding but their caregiver? Is this vastly different from either meeting with some of the correspondents in person or past anthropological fieldwork interviews?

MSN-L: Virtual Support for Multiple Sclerosis
- Posts on the site come at about 35 posts per day at varying rates
- Gold sends about three messages weekly to the entire list and an average of about 6 to private message yearly to the list manager and another 30 to members who had posted something privately or publicly
  - QUESTION: What does the list manager do? Does someone "facilitate" discussions, i.e. post questions or topics of discussions that group members then communally respond and expand on?
- Included several face-to-face conversations as well as telephone convos
- Internet correspondence from a research perspective was always much more detailed and thought out than the occasional fac-to-face or personal encounter
  - QUESTION: Do you think this was more due to the idea that when people sit down to write something it is usually much more thought out and more of a reflective process, or do you think it was mainly due to the open-ness and community support that the virtual support site tried to foster?
  - Could be due to the "rapid cure" agenda that you talked about??
- Constantly changing dynamic where new members are always going and coming and old members leave the community all together
  - QUESTION: I guess this is more related to what we are currently learning about in class involving fieldwork and the expectations the anthropology community has about fieldwork, but do you think it is more or less difficult to form close bonds with the members of a virtual community. For example, you aren't necessarily living alongside them, but at the same time you both encounter similar struggles and day to day activities living with MS.
- Topics are clearly labeled in the header of each message to allow for meber "cruising" or else reading specific messages and all of their repsonses could take hours
- In 2 years, at least 50 members sent messages weekly
  - QUESTION: Are most of the people you encountered working jobs or do you think people's work schedule/other commitments interfere

with consistently posting or posting frequency or the "immediacy" or the community atmosphere you mentioned?

Threads and a MS Agenda

- This intricate and building network usually centers around
  - New drugs
  - Pioneering Physicians
  - Means of dealing with the symptoms (often controversial)
  - Personal thread (the symptoms or life of one person becomes public)
- Interactions often on first name basis as if corresponding daily
  - QUESTION: Is there any form of social grooming, gossip, etc. or is it much more of a professional albeit supportive atmosphere?
- Private mail can be sent without interception
  - QUESTION: Can the hosts or original posters of certain threads delete unwanted comments or is the strictly up to the list managers/against the open-ness intent of the group?
- Commentators on medical issues or medical symptoms are rarely other medical professionals, yet many members directly rely on these types of narratives in dealing with their own symptoms (own)
- People scan through their mail based on sender and whether the header is cause of an immediate reply when deciding whether or not to interact/ add onto threads
- A lot of the messages are "Un-monitored" but subject to social control and it seems that some form of peer pressure allows the site to remain somewhat accurate and decrease the amount of personal attacks (see above question on monitored)

Lurking and Validating

- Not everyone receives much of a response form their initial postings/introductions and soon after will leave the group
- This is not simply a group for every person with MS, "new members are expected to contribute in a compatible way to existing message threads and there are many who do not find the support they are seeking"
  - QUESTION: Do you think this is an unconscious way of keeping the immediate numbers of active group members small, thereby keeping it as not really an "exclusive" group or support but overall more intimate?
- Very confused on the excerpt on bee sting therapy....
- Some members, (new members it seems especially) like to reference the MSN-L community as 'theirs', in a very possessive way because of the fact that they do not otherwise have the appropriate environment or forum to talk about or address or ask certain questions amongst their doctors and or family/friends

- Some new members, especially lurkers, that lack common interaction with others diagnosed with MS try to be perceived in the community as having spells of being "symptom free" or leading largely normal lives
- In rapid message swapping, can be difficult to keep track who is who, only occasionally reminded that some people are caregivers and speaking on their spouse or loved one's behalf.

Community Roles and List Identities
- Informal moderator contributes to frequent opinions, narrative, and private messages
    - QUESTION: What is the general structure of MSN-L? By this I mean do is there anyone that organizes or prioritizes feeds or new threads based on topic or time? The way you have described checking an inbox it seems like each person just kind of scans or sorts out what they deem important, worth reading or worthy of response, however I was just curious if there is any organization to this or if it is more of a free for all, including threads or messages from "lurkers"?
        - If so is there any software or features of the website that specifically allow for this that you know of?
- A role in the community defined as the "resident medical expert" this role was originally noticed to be 'Soloman' however, as members leave (he was contracted to mediate a separate MS forum), other members step into fill their place and give their two sense in requests and such when called up in threads and so on.
    - Expected that they have some form of medical credentials usually and not just going off about the unknown, however their advice is usually brought into question by people disagreeing on certain threads

MS Tales
- Participants write along with bios, a "narrative of eligibility" or confessional tale
    - QUESTION: You talk in the "MS Tales" portion about participants creating a 'narrative of eligibility' or confessional tale, what exactly does this usually pertain to? Is their experience with various treatments what gives them greater insight, acceptance, etc. into becoming an active member of the group? Or is the narrative of eligibility more or less a formality as you mentioned before about introducing themselves into the group in the hopes of being welcomed into the dynamic?
- Two drug groups Betaseron v. everyone who questioned its effectiveness, couldn't afford it or otherwise
- Another major topic of discussion is the use of Marijuana or Cannabis in substantially reducing both pain and spasticity

- However, no main point maintains center stage on the group for more than a couple weeks despite the ever-present discussion of the effects or various new and developing medications (own)
- FAQ Topics
  - MS Fatigue
  - Swank diet for MS
  - Clothing
  - What's Kurtzke?
  - Impairment of Cognitive
  - Function
  - If it Quacks like a duck
  - I always Wanted to Play the Violin
  - What harm Can it do?
  - Exercise and MS
  - Bladder Problems
- QUESTION: Do you think (based from personal accounts on those interviewed) that a lot of people use these FAQ pages, and if people do, would they most likely be caregivers, newly diagnosed or new members to the site? Based on what you said about most of them not being very relevant (and from the sound of it having more of a superficial medical tone rather than based on the experience of someone with MS) do they add a lot to the community or not?

Backstage talk: Private Posts
- "Even the medical student, the three doctors and the most prolific posters will use backstage messages if they are concerned about the accuracy or appropriateness of a post or a question, and wish to avoid front-stage scrutiny."
- Private posts are seen as "deeply personal" and not the type of thing you want public scrutiny for
  - QUESTION: Do public posts ever reach this level of being "deeply personal" or are there unspoken or unconscious rules or etiquette about what is strictly appropriate for public threads and what is appropriate for private threads? If so, why do you think this is?
- Aspects of a private message (such as the one shown) could be easily public, however when in reference to other members' ideas in the support group, they must remain private and for only personal use

Political Mobilization in Cyberspace
- Solomon threatens to leave, backlash of how vital and important his information is to the well being of the support group
- Brings into question the virtual expertise of members such as Solomon of Aristotle
  - QUESTION: as a member/participant of MSN-L, did you drastically question the postings of 'resident medical experts' by coming to the

realization that you don't in fact actually know these people, their credentials, etc. and have never really met them/never will? Or is this an integral mindset that needs to be overcome to be a participant?

- Much harder to mobilize the site to come to the aid of a notable support group member
  - o <mark>QUESTION:</mark> Do you think this is an effect of not actually meeting people? Versus people in churches or in communities where a bond is created by physical presence it might be easier to fundraise for a member in need?

The Conflict of Public and Private
- "Public airing" of the topic of sexuality/sexual frustration kept largely to private posts despite people's responses to accidental private-turned-public discussions
- Possible, common for people to project one image of how they are able to cope with certain things is completely different than their own 'deeply personal' struggles with coping on private messages
  - o <mark>QUESTION:</mark> Do you think the changes you have noted in how people publicly display the way they are coping (probably well) with certain symptoms when they are in fact privately discussing their great difficulty to adjustments in their lives inhibits the support of the rest of the group? Fromm my outside prospective, I would think that it might either alienate some member of the group that were not transitioning as easily as these posters made it seem, OR it would do the opposite and come off as optimistic or uplifting to viewers and other members.

Conclusions: The virtual Support Group