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# A Moderator's Dilemma: Munchausen Syndrome by Internet?

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## Abstract

*This paper details events which took place a number of years ago on HeartNET, a research project which combines a therapeutic website and online community set up to support heart patients and their friends and family. It discusses what happened as one particular member began to experience such a succession of crises that she was eventually hospitalised in intensive care and the postings were taken over by her husband. Gradually the community began to believe that the personas and the situations described were fabrications. They demanded that the moderator act to challenge the 'fakers'. The moderator discussed this possibility with other members of the research team, and the ethics officer, and declined to intervene. Eventually one member decided to take matters into his own hands and acted to challenge the presumed fabricator. Discussing the situation as it developed, this paper considers the options open to the moderator and the impact of this sequence of events upon the community. Although there have been some minor changes to the case study reported here for the purposes of preserving confidentiality it is accurate in the majority of material particulars. This level of detail indicates the challenge to community posed by the events.*

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## Introduction

He prove[d] he was a fraud by leaving once he knew the jig was up he left he will move on to other groups and annoy them until they get sus and it will keep happening but there is nothing that can be done unless you go there and take away his computer (sic) (Henry, HeartNET member, about Jonah).

Henry's comment, above, posted online was the first time the moderator knew there was discontent amongst the members of the online support site HeartNET. The moderator was moderating the site as part of her PhD candidature. HeartNET was first set up in 2005 as the result of an ARC Linkage grant that combined resources and input from the National Heart Foundation (WA Branch) and Edith Cowan University. After a protracted attempt to create a genuine sense of online community had failed (Bonniface et al. 2006a), the membership gelled, and the online exchanges became characterised by genuine care and concern, support for others, and self-revelation (Bonniface et al. 2005). Eventually, the community began to function well and demonstrated positive benefits for many of its members (Bonniface et al. 2006b).

A further ARC Linkage research project, funded in 2007, investigated the construction of a heart patient identity with, and without, the benefit of online community support. That research involved Urledge as the Australian Postgraduate Award (Industry) (APAI) PhD candidate. The project is current and nearing conclusion. The events recounted in this paper happened soon after this second research project began. Names and some circumstances have been changed to protect individual identities, and it was decided to wait until all the participants involved in these events were no longer active on the site before publishing this research.

## **Research Methodology**

The two-phase HeartNET project uses a specially constructed online community which is clearly labelled as being used for research as well as offering a space for community interaction and support. A complex registration process includes details of the site's terms and conditions, together with processes to collect informed consent from participants. The research data collected as part of the project comprises all postings on the site – private messaging, live chat, bulletin board posts, blogs etc. – along with follow-up in-depth semi-structured interviews for some community members (Green 1999). The findings reported here use online posts but not interview data. The written posts and comments were initially analysed according to tone, content and intent in accordance with the principles outlined in Glaser and Strauss's (1967) grounded theory approach. The principal aim at this point was to identify recurring themes. After these themes had been identified, relevant posts were reconsidered with a view to investigating the understandings and meanings that participants had constructed to underpin their online communication.

One of the themes investigated was how trust works in an online community. For online communities, trust is important and has been identified by Fang and Chiu (2010) as believing in and relying on others' willingness to share advice, information and care – all necessary ingredients for maintaining relationships, whether online or face to face. Nichani and Hung (2002, p. 51) define trust as 'the glue that binds the members of [an online] community to act in [a] sharing and adapting manner'. They claim that if members are without trust then they 'would hoard their knowledge and experience and would not go through the trouble of sharing with or learning from others' (2002, p. 51). The case study recounted here reveals the effect that a betrayal of trust had on the community members' feelings of trust and belonging.

## **Literature review**

### **Online community**

While the nature and evolving form of online community has been extensively debated elsewhere (e.g. Miller and Slater 2000; Willson 2006), and investigated as part of the first phase of the HeartNET research, it is frequently described in Rheingold's terms as 'social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace' (2000, p. xx). Membership of an online community is similarly considered to be indicated through interactions: '[it] must be understood in terms of self-identification as a member, repeat contact, reciprocal familiarity, shared knowledge of some rituals and customs, some sense of obligation, and participation' (Kozinets 2010, p. 10). The important point is that belonging to an online community involves an investment of time and emotional honesty so that trust can develop between people who interact online but who may never meet face to face.

## Trust

Trust is a complex phenomenon since it involves an attitude in the present which projects into the future (Farrell 2005). The expectation of the truster is that the person trusted will be reliable and will act appropriately even though the person doing the trusting has no way of ensuring that this will be the case. While the outcome is uncertain, the person doing the trusting is willing to proceed with a course of action because of their belief that everything possible will be done to achieve a beneficial end-point. Trust is central to a well-functioning community, and it is impossible to feel at ease with people if you do not trust them.

While most self-help and popular culture treatments of broken trust occur in the context of infidelity and sexual betrayal, trust is central to almost all social interaction and human relationships. Even so, trust is often misplaced. Much has been written about online communities being places where participants can be whoever they want to be, due to the ease of being able to 'mask one's age, gender, etc. online' (Ridings, et al., 2002, p.275). For Ridings, closeness can also occur 'due to the strong mutual interest in the community's topic, especially in the case of health concerns or life events [...] which may foster the development of trust' (Ridings et al., 2002, p.275).

Alternatively, a person may choose to be untrustworthy and might deliberately let others down. This situation can be very damaging to the relationships of those people affected. Not only does untrustworthiness impact upon the connection between the trusting and the untrustworthy person, but the trusting individual might question all their relationships with others. Lack of trust can have such negative consequences that a range of books has been written suggesting strategies through which trust can be redeveloped. One of these, *Rebuilding trust in the workplace* (Reina and Reina 2010), suggests that trust can be restored through (these are the chapter titles): observing and acknowledging what happened; allowing feelings to surface; getting and giving support; reframing the experience; taking responsibility; forgiving yourself and others; letting go and moving on and, finally, renewing confidence, commitment and energy (Reina and Reina 2010 pp. vii-ix). The authors Reina and Reina (2010, p. 1) warn that 'betrayal is universal', which suggests that betrayal can occur in different communication contexts such as face to face, in virtual communities etc

Betrayal by others online may initially appear harmless, but it can have devastating effects for all parties involved. Feldman (cited in Shreve, 2001)—an expert in factitious disorders, including Munchausen by Internet—recognises the difference between: a) those that feign illness and make the effort to attend a medical practice or emergency department; and b) those that enter online communities with the intent to cause distress. He asserts that:

Online, one can quickly acquire an education, find a discussion group or some other online forum dealing with the phenomenon, and be accepted instantly. That's the explicit purpose of these groups: not to question. They [the fabricator] receive real care, concern, even love. There's a sense of power, and if it goes badly at any point, there's instant escape.

After the participant with a factitious disorder has moved on, the moderator's real work begins because, even though the instigators of the fraud have left, the original members of the group still feel betrayed, and may never recover. One such incident, which occurred on HeartNET several years ago, will be discussed in the next section of this paper.

## Munchausen syndrome

While Munchausen syndrome is generally discussed as a medical condition in 'real' life, participants in online communities also present with this disorder. The medical diagnosis of Munchausen's disease comes from the adventures of Karl Friedrich Hieronymus Freiherr (Baron) von Munchausen (1720-1797). He was a Prussian cavalry officer who served in military campaigns against the Turks (1737-1739) and then embellished his life and health stories to make himself appear more interesting (Artingstall, 1999). This term is now used to describe a condition where an individual may make him or herself physically ill on purpose to gain attention and support from medical professionals and others. Individuals present with obscure symptoms, which are difficult for medical practitioners to diagnose or treat and, after repeated presentations for help or advice, the medical professional may start to get suspicious and endeavour to ascertain the truth (de Christo Faro, 1995) with the intention of providing the psychological support that is truly needed to help them deal with their condition.

The new twist to this disorder is the person with Munchausen's who joins an online chat room or support group for people with serious medical conditions, such as heart disease, claims to be ill but then exaggerates or fakes additional symptoms. The aim is to keep the focus on themselves and to garner support and sympathy, even though they are not ill at all, or have only mild symptoms (Schimelpfening, 2004). In some cases the 'faker' may copy directly from medical websites. As Feldman, cited in Russo (2001) explains, 'it's very easy to fake. All you have to do is click and you go to another disease site. You can become an expert on anything in thirty minutes by visiting Google'. People with Munchausen syndrome often do this to ensure they get their facts straight and then personalise the symptoms to themselves or their loved one. Feldman et al (1998) identify these people as having a form of Munchausen's, or what he now identifies as 'Virtual factitious disorder' and 'Munchausen by internet' (Feldman 2000). People who fake symptoms may subscribe to online support groups, gaining comfort and support from other members and, in extreme cases, use different nicknames and user accounts to come onto the site as patient, parent, and even partner. In some cases, people with 'virtual factitious disorder' claim to have all these roles (at the same time), with the express purpose of convincing others—often through an extended range of lies—to gain more attention and vicarious pleasure out of the deception (de Christo Faro, 1995, Feldman, 2000).

Munchausen syndrome is distinguished from hypochondria or malingering because the person may well have some underlying medical condition, but they are seeking attention for mostly obscure or unconscious reasons (Grady, 1999). Determining why people develop Munchausen and then providing the correct treatment is difficult because as soon as a Munchausen sufferer is identified or caught out they will move doctors, or even towns, to continue their behaviour elsewhere. In one example, cited by Gray (1999), Wendy Scott was hospitalised more than 400 times and underwent more than 600 different procedures and operations only to find that when she was in genuine need of treatment for a legitimate medical condition she was not taken seriously. Facing a terminal illness, she had to seek treatment in the USA (Grady, 1999).

Doctors, and indeed moderators and members of support groups, do not like being manipulated by others. As well as being manipulative, Munchausen syndrome constitutes a gross betrayal of trust. The advantage of an online support group is the closeness that members develop with each other even though in many cases they will never meet. To accept someone on a site and give them encouragement, support and compassion (Shreve, 2001), and then discover that this

person has been manipulating the situation to their own ends, can result in a loss of faith in the process and the products of support. In one famous example, an early group of internet-users discovered that the online friend they thought was a disabled older woman 'Julie' was, in fact, a male psychiatrist. When Julie's confidantes learned about the deception their reactions 'varied from humorous resignation to blind rage', says Stone (1992, p. 82). 'Most deeply affected were the women who had shared their innermost feelings with Julie. "I felt raped", one said. "I felt that my deepest secrets had been violated."' (Stone 1992, p. 82) For some online community members, their site will never seem the same. In addition to being frustrated and angry, people who feel betrayed may start a flaming war, prompting members to take sides. In the most extreme cases the site may be forced to close down.

## Case study

It was a situation like this that occurred when Denise joined HeartNET. The moderator noted that Denise quickly became involved with the site and was often found posting messages of encouragement and support to other members. In particular, Denise engaged with the chat room, which is a regular meeting spot for HeartNET members. It thrives with upwards of seven to eight members chatting in real time to one other about anything and everything. Over time, Denise began slowly to divulge her heart history. It was never too much, just enough to elicit concern from other members.

One night, when Denise was in the middle of a chat session with Fred, there was a long silence. Fred became alarmed as Denise had trailed off in the middle of a conversation. He called his wife over to the computer to share his concern and they began writing message after message to Denise. Finally Denise responded, explaining that she was feeling really unwell. Fred tells the story in a private message to the moderator on the HeartNET site:

Denise and I were in HeartNET chat room, when everyone left for the night, Denise and I stayed on to chat. When she said, 'I have to check my blood pressure'. When she came back, she said it was okay, so we kept talking. About a 1/4 hr later she had to check it again, when she came back, I asked her what the reading was, and she said 50/30, so I told her to ring for an ambo right away, but she said she was okay but I insisted that she call an ambo. I was frustrated by the fact that Denise was in [another state], and being in Perth, I couldn't ring an ambo for her. and due to the lateness of night never gave a thought to ringing anybody else. As my main concern at that moment was to get Denise to phone for an ambo. Thankfully she did.

I'm glad to be a member of HeartNET, and for being here, for without this site 2 lives would've been lost as Denise is pregnant with her first child.

Denise was absent for some time, and everyone assumed she was in hospital receiving treatment for low blood pressure and her ongoing heart condition. When she returned she was greeted warmly and gave her side of the experience:

Fred and I were chatting as he has already said.. when i felt pain in my chest but assumed it was indigestion as I am expecting a baby in late september and its rather common for me to be experiencing indigestion as those of you who have had children know.. anyway back to the story.. as it didn't go away with the usual remedies and progressively got worse i figured it would be best that i check my

blood pressure with a monitor.. which thank god i just bought a couple weeks ago.. my blood pressure was low first 90 over 65 then 75 over 50 in the second test.. which to me was not all that uncommon as I had it lower than that before and been quite fine.. but with some heavy convincing from both Fred and his lovely wife Colleen.. I decided I would call an ambulance my other half was not at home so i figured I'd rather look like a pregnant idiot at the hospital than die.. so post calling an ambulance i was sitting waiting for them to arrive which around here takes 15 minutes or so and i must have panicked and opened my front door thinking they wouldn't be able to get it with the dead bolt on and I collapsed... and woke up in the ambulance on the way to the hospital before falling unconscious again.. next i knew I was in the hospital after being flown from the local hospital and was admitted into the ICU [intensive care unit] where I spent the next 4 days. I had a blocked aorta causing a near fatal heart attack caused by what they later found out was a massive blood clot after the angio showed that there was no plaque causing the problem. fortunately for me they gave me massive doses of blood thinners in the ambulance and in the hospital on arrival which had basically dissolved the clot. However there was severe scarring and bruising on the aorta which showed up on the little camera... which is how they came to the conclusion it was a clot. so that jumble over with I spent all told six and 3/4 days in hospital I haven't had any operations for stenting as they dont seem to think its required, I do now have an abnormal rhythm (ectopic beats) whatever that is... which they seem to think will resolve itself once the heart has rested some.. and if not they will do something to correct it. as most of you will know I have congestive heart failure and am on the transplant list. so while this has not done anything to improve my position on the list it is quite a common problem for those of us with severe heart failure.. meaning an ejection fraction of less than 20 percent.. mine is currently less than ten percent it was around 12 before.

My baby is doing just fine they were concerned for the first day or two and were prepared to an emergency C section as is only 18 weeks they wanted to give the chance for it to stay in there.. and the ultrasounds showed baby was ok in ICU and I had a further scan on Thursday showing baby was just as strong as ever... I am however on a foetal monitor for the remainder of my pregnancy and if it sends of some sort of alarm i am to go to the hospital immediately as baby is in distress.. which thank god the baby's heart is beating better than my own. I know many of you will have opinions on me being pregnant at this point with my heart problems but I have been trying to fall pregnant for 10 years and have been on IVF and this was the last implantation that we had and we were told it had been unsuccessful.. so I didn't really know until i was 13 weeks that there was a little [baby] growing in there... anyhow I hope this answers a lot of questions... I am doing okay, I am freaking out a lot, I am having a hard time sleeping and resting, I am extremely tired.

but last and most importantly

**I AM ALIVE!!!!**

Thankyou so much again Fred.. you know how much you will forever be in my life and in my thoughts.. Hugs

Also thankyou to HeartNET and its Creators.. for being here... and having this marvellous resource available to all of us

Thank you for saving my and baby's Life!!

Hugs and Much Love to all

Denise

This was the first time Denise had publicly told people on HeartNET that she was pregnant. The few people who had been told before this had been sworn to secrecy. There was an instant buzz of anticipation on the site, and everyone became engrossed in the saga of Denise's pregnancy with many expressing concern about the wellbeing of mother and child. Shortly after her initial announcement she let everyone know that she had been mistaken in thinking she was pregnant with one child; she was having twins. Not long after, Jonah (a new member) posted on the site saying that he was Denise's husband and Denise was now in hospital on life support, waiting until the twins were big enough to have a chance of surviving a premature birth by caesarean section. Jonah was welcomed since the site was designed for heart patients and their supporters, but behind the scenes the community was becoming increasingly divided.

Some HeartNET members had decided that Denise's story was a fabrication. They had done their own research and believed that no-one with her severity of heart failure could maintain a viable pregnancy, let alone with twins. They also disbelieved that any doctor would allow IVF in a situation where a patient was waiting for a heart transplant. Several members of HeartNET were getting very distressed over the perceived lying and fabrication of symptoms that Denise was presenting to the site. Central to this distress was the respect and care they felt for other members who, as far as they were concerned, really were dealing with life-threatening heart disease but were expending their limited energies in supporting Denise. The members, who disbelieved Denise and now Jonah, were sending private messages to each other and to the moderator, while also discussing their concerns and perceptions with members who were willing to give Denise and Jonah the benefit of the doubt.

The moderator recommended caution. She argued that although the situations facing Denise and Jonah sounded more and more bizarre there was no proof that these circumstances were either fabricated, or not happening. As the tensions behind the scenes rose, the moderator briefed the remainder of the research team and the university ethics officer. Given the absence of proof to the contrary, it was decided that Denise and Jonah needed to be allowed to continue on the site. If the version of events they had provided was true, then they needed help. If it was false, they were also in need of help. The team felt it was possible that the couple was legitimate and both had contributed to the site and helped other members by offering their personal insights into heart health. Over time, Denise and Jonah had actively provided relevant advice and support to people who had needed it and these members were among their most committed supporters.

Problems kept occurring. Another member reported flooding in the same area Denise and Jonah claimed to live, and this became woven into the narrative. Jonah was out of his mind with worry in case his wife Denise took a turn for the worst while he was trapped by the floods. She did have a crisis: Denise had had a stroke and was likely to spend the rest of her life in a vegetative state, but it was still too early to perform a caesarean. The medical staff were unsure how the babies



would be affected. Jonah could not wait until the flood waters went down; he had to get to the hospital. It was a miracle! Denise had stirred when Jonah had sat beside her in the ICU. The brain damage from the stroke was less extensive than had been feared, but it was probable she'd still be unable to walk. At least he was able to visit her every day now that the flood waters had gone down.

Interactions on HeartNET returned to normal, with members commenting on various issues related to their own health, and with Jonah continuing to post updates on his wife's condition. Over time the love and approval from the group waned. By now some members on the HeartNET site were not only sure that Denise wasn't as ill as they had been told, but also certain that 'Jonah' and 'Denise' were the same person. They wanted the research team to let them know whether the IP address had changed during posts from the hospital and were irritated and argumentative when the moderator refused to reveal this information on the grounds that it was contrary to the site's privacy policy. Many started to log off when Jonah logged on, and would not post comments on his thread. His continued activity on the site caused them to feel as though they had to withdraw. Sam said: 'Jonah is taking over the site, I hate it when he is on the site, I just log off straight away.' Although almost every one now believed that at least some of the Denise – Jonah saga was fictitious, opinion was divided about how to respond. One group of active members decided that people should freeze 'him' out. When the moderator posted a comment on one of Jonah's threads, one member used a private message to accuse her of 'complicity' in Jonah's 'lies'.

The moderator argued that withdrawing from the site was a negative response and it was much more constructive to pay minimal attention to Jonah's postings and allow the site to function as it used to. On their part, the aggrieved members accused the moderator and the research team of not doing enough to keep the site safe for 'genuine' members. Finally Henry, a HeartNET member who had spent considerable time in trying to determine if Jonah and Denise were legitimate heart patients, took matters into his own hands. The next time Jonah was online at the same time that he was, Henry sent Jonah a private message recommending that he visit a site about faking medical illness and suggesting that 'it might help you and Denise'. Jonah's response was immediate:

The fact that you even think that about us is the thing that has hurt the hell out of me... we have been through sheer hell... and where do you get off suggesting it was all bull shit... just because you are depressed... don't take it out on the rest of us. (Jonah)

While continuing the exchange with Henry, Jonah also sent a message to the moderator asking to be removed from the site because he had been accused of faking his wife's symptoms. In the meantime, Henry responded with an attack on the couple and mentioned in his posting some of the things that he and the other disbelieving HeartNET members had done to prove to themselves that this couple were lying about their heart health.

just in case U have another peek in hear [sic] Dude..

I checked with the hospital... Denise didn't exist. I checked out your street address, you don't live in a 2 storey house. all the other bull dust you posted, I was awake to you the second time we spoke... I was amazed that so many others were too. You seriously need help... let us help you with your sickness... we could all be happy then (Henry).

In a private message to the moderator, Henry wrote:

I got Jonahs address off Fred and went to google earth, Jonah claims he is in a 2 story house, the street addy... and the WHOLE SUBURB for that matter are all single story, and the chances of that area being able to flood, I believe is zilch. Fred agrees (Henry).

While Jonah and Denise did leave HeartNET and were not heard from again, the divisions in the community continued for some time and some members left the site while others posted much less frequently.

## Conclusion

How should online community members tell truth from fiction? The internet allows people to enter chat rooms and abuse the very structure of the support provided by people with genuine health conditions (Feldman, 2000). The HeartNET site has a statement on its front page stating that all information and comments contained on the site are personal opinions and must be treated with caution. The site's moderator reiterates this point every week to members. For example: 'It must be stressed that any discussion on medical matters and rehabilitation must be treated with caution [...] One patient's experience is never the same as any others. Any medical or health-related information [...] members might seek to rely upon should be discussed with their physician before making any changes to health behaviours' (Uridge, moderator).

The day after Henry challenged Jonah, the site was in a subdued and contemplative mood:

Fred: 'you have to remember that his is a sickness of the mind and probly doesnt know that what he is doing is causing harm or grief' [...]

Sue: 'It is the aftermath of accusations that hurts the site, As we have lived through before [...] Who knows how many fakers we talk to everyday on the net..I realise it is an issue of trust'

Henry: 'that's right. and I've been hurt so many times in the past, from ppl I thort were genuine, but only betrayed my trust'

Sue: 'But you will come across many more in life Henry.. You have to ignore and accept it happens mate'

Henry: 'thats why I like to call them, talk to them on the ph. send pix, get to know them. I stopped chatting because of it.'

In fact, the moderator is also a community member and the responses of the person acting in that role are impacted upon by the same concerns over lack of trust and loss of faith as affect other members. They have access to more 'evidence' than the general membership but are unable to use it, creating a rift between those who wish to publicly 'out' the 'faker' for lying, and those who feel that the terms and conditions of the site have to assume that people act in good faith. The moderator's concern has to be for members who have taken the 'fabricators' under their wing and invested in an online relationship. These are the people who need greatest support to see them through the resulting turmoil once the community begins to fracture. When the moderator has dealt with the emotive outpouring of angered members and asked them to

think carefully before saying anything, they are then left with a dilemma. The suspicious member may be exaggerating the truth, or telling lies, but how can anyone tell without invading their privacy? It is not a moderator's place to challenge a member and say 'I think you are lying'. The moderator cannot telephone members in the hope of catching them out; they only have suspicions, not facts, and if facts were available it would be a betrayal of trust to use them.

The Internet provides an ideal forum for people to share their hopes, dreams and fears and, in the case of online health support groups, their medical history and ongoing medical challenges. The forum provides an anonymous arena for individuals to log into under a pseudonym, and share as much or as little as they feel they need to. As a protection for themselves, members are advised not to use real names and not to reveal details that make them readily identifiable. The site operates with the assumption that people may not be trustworthy and that members have a responsibility to protect themselves. When the site's terms and conditions were re-examined in the light of these events, it was the HeartNET member Henry, rather than Jonah, who had more clearly breached them. Even so, it is important that moderators realise that these events are possible and that they become more likely as the site develops and is more established. It is worth developing protocols for dealing with the challenges that may arise before such an event occurs.

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