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Munchausen by Internet and Nursing Practice: An Ethnonetnographic Case Study

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Abstract

This paper used Feldman's clues to factitious illness behavior on the Internet (FIBI), to determine whether the online behaviour of one member of an online breast cancer support community www.breastcancerclick.com.au, moderated by a specialist breast cancer nurse (SBCN), could be Munchausen by Internet (MBI) and why identification of this behaviour is important for online nursing practice. This was a focused ethnonetnographic and qualitative research study whereby the online behaviour of one member was observed and compared with Feldman's clues to factitious behaviour on the Internet. The online data showed that nine out of ten of Feldman's clues were applicable to the member's behavior in the Click online community. The relevance of these findings are discussed in relation to the effects this behaviour can have on other community members, the attendant legal ramifications and the necessity for nurses and other health professionals, who are employed or who participate in online support communities, to be aware of this behaviour and how to recognize it.

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Introduction

In 2014, approximately three billion people accessed the Internet [1]. Many of them will be search for information to maintain their health, diagnose their illness, identify treatment options or gain socio-emotional support [2]. Others will search for the same information, but with a different motive, to obtain information that enables them to pretend to have an illness, and assume the 'sick role' [3]. Offline, this behaviour is known as a Factitious Disorder (FD) and in its extreme form it is referred to as Munchausen Syndrome (MS) [4].

Further, some individuals have now moved their factitious illness behaviour, to the online environment, that is, by pretending to have the illness which is the particular focus of an online illness support community, such as the breast cancer online support community www.breastcancerclick.com.au (the Click), which is the online community that lies at the heart of this paper.

People join online disease support communities to access information and socio-emotional support as they battle with the symptoms and treatment of their disease and it is not unreasonable for them to expect that the other members of the support community are truly in a similar situation to them [5]. Online support community members must take on trust, the validity of the information they receive and the authenticity of the person they interact with. Not all members are who they say they are, nor do they provide information that is truthfulbut member authenticity can be difficult to determine and manage [6]. More generally the illness or disease specific information that individuals find on the Internet, may not be reliable or accurate and cause individuals unnecessary stressif found to be inaccurate [7]. This medical information may also be a source of knowledge, albeit at times, unreliable information, for those seeking to formulate a deceptive online persona based on a particular illness [8]. The employment of a health professional, in an online support community, may go some way to ensuring the provision of evidence based health information and correction of member misinformation [9].

This paper provides an insightful look into a potentially increasing, and difficult to detect condition, that is suffered by some members of online communities. If nurses are employed to provide expert information, advice and support for online community members, as was the specialist breast care nurse (SBCN) employed in the Click, then it is important for them to be aware of MBI, how it can be detected and dealt with promptly, so that the individual is referred to appropriate help and the online community is not adversely affected.

Background and Literature Review

Factitious disorder and factitious illness behavior on the Internet

Factitious illness behaviour on the Internet, was first reported on by Feldman in 1998, and named Munchausen by Internet (MBI) by him in 2000. Feldman developed a set of clues for the detection of FIBI[4] from the details of more than twenty cases that were reported to him via his website http://www.munchausen.com [10]. Factitious Disorder (FD) more commonly known as Munchausen Syndrome (MS) is recognised as a mental disorder by the American Psychiatric Association (APA) and a person with this disorder "… feigns, exaggerates, aggravates, or self-induces physical and or psychological illness or injury with the goal of assuming the 'sick' or patient role" [11]. The person has the goal of assuming the 'sick' or 'patient' role in order to receive intrinsic rewards such as attention, nurturance and sympathy from others; to control others; or to express rage; or by displaying medical knowledge seek to enhance their self-esteem [11]. There is debate about the appropriateness of the use of FD and MS interchangeably [12], because some consider MS to be the more extreme and most dangerous form of FD, accounting for only approximately 10% of reported cases of FD [10,13,14]. The more elaborate and dramatic tales of illness and recovery or tragedy, are known as pseudologia fantastica, together with peregrination, where the individual moves about seeking different doctors and hospitals, are particular features of MS[13,4]. It would therefore be appropriate to refer to individuals, who do not include such tales or visits to numerous doctors, in their deception, as suffering from a FD but not necessarily MS.

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While there is a significant amount of literature relevant to Munchausen Syndrome in the offline situation, there is a dearth of literature on Munchausen Syndrome by Internet. Doctor Marc Feldman is the primary author/co-author of articles and books, such as 'Playing Sick' that focus on Munchausen Syndrome and Munchausen by Internet, therefore this literature has been the fundamental source of information underpinning and guiding this research study.

In order to assume an 'online sick role,' the individual writes text and posts false illness and personal history details and factitious illness behaviour on the Internet (FIBI), and to illness support websites particularly those that have forums, chat rooms, instant chat and personal messaging, such as the Click [11]. The most recently reported cases of MBI, have revealed a new way in which sufferers can avoid suspicion and discovery, that is, by using other identities or personas, known as "sock puppets" [11]. The individual can join many illness support communities, using the same or a different identity, or assume a number of different personas in one online community; potentially increasing the number of supportive responses they receive [3].

There are various theories used to explain an individual's motives for feigning illness one of these theories, which could apply to the person in this case study, refers to a longing for nurturance and a need for distraction from authentic life stressors [15].

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There is also the view that a person who practises online deception is either a narcissist who enjoys the responses and attention they receive from others online or a troll who posts or sends messages, to annoy others or disrupt an online community [3].

The prevalence of MBI is difficult to determine because it relies on the 'outing' or 'confronting" of the online community member, by other members or the moderator of the community, the admission of deceptive behaviour and the subsequent reportage of those instances. Pulman and Taylor [3] have noted that new cases are identified regularly, but do not say where, and by whom, the cases are identified or if there is a regulatory body recording statistical data of those cases.

While there is only a small number of well documented cases[11], it is likely that there is a much larger number of individuals with MBI who have remained undetected because the instances of 'outing' have occurred in isolation and are unknown to others, unless the case is widely publicized or brought to the attention of someone who is an expert in the field [8]. In the United Kingdom, a list of the names of individuals with a factitious disorder has been compiled and distributed to clinics and emergency departments [14]. Whether this list includes details of MBI cases could not be determined but in any case, such a list would be viewed as a breach of the person's privacy and confidentiality, if the person concerned, has not given written consent for their name to be included, on the list [14].

Often detection of the deception falls upon other members of the group or community, to determine and take appropriate action. With MBI it would be necessary for the moderator(s) to be aware of MBI and of Feldman's clues to FIBI. To compare the member's behaviour with those clues, confront the offending member with their deceptive behaviour and manage the member, without disrupting the harmony of the community. To illuminate this 'real-life' scenario, follows, it concerns Diana* (pseudonym), a member of the Click community and her behavior in relation to the FIBI clues.

A "ReaL-Life" Scenario

The Click online community had just formed, with six active members, known as Clickers, plus the research team, engaged in long, weekly Click Chat sessions and frequent popup or instant chats. The main protagonist in this scenario were and the SBCN. Diana aged in her late thirties, married with one young daughter, whose user photograph showed a plump woman, sporting a very short hairdo (which may have been a rubber cap) and gold-framed glasses.

The SBCN received 227 requests for chats from Diana, over a five-week period, and chatted with Diana on thirty-six occasions with each chat lasting between fifteen minutes and two hours. These chats indicated that Diana was a very 'needy' Clicker who consumed a considerable amount of the SBCN's limited work time. The chat textual is used to illuminate Diana's online behaviour.

Diana's online behaviour was initially to the learning disability she referred but over time, it became evident that Diana's description of her breast cancer and her many other health and family issues that occurred almost simultaneously, were physically, logistically, and medically impossible, which raised doubts about her authenticity as a breast cancer sufferer.

The Click research team had no knowledge of MBI, although the idea of Munchausen Syndrome had been discussed as a way of explaining her unusual online behaviour. It was only when Diana's textual data was seen as a gestalt, after she had left the click that a review of MS literature was conducted and MBI and FIBI were discovered together with Feldmans's clues to FIBI. The likelihood that in the future, more nurses would be employed to moderate and/or provide advice and support for members of illness focused online communities, was also a driver of this research.

The Study

Aim

The aim of this focused study was to determine whether the content of Diana's online textual data (her online behaviour) conformed to the clues of FIBI offered by Feldman et al.[4].

Design

This is a small, focused, qualitative research study and the methodology used was ethnonetnography, which sits in the centre of the netnography continuum devised by [16]. Netnography is a qualitative participant-observational research methodology based in online fieldwork in online communities and groups. The researcher was a member and moderator of the Click, and ideally placed to participate with the members, through online text and to observe and analyse the text of other members.

Three months of online transcripts of the personal messages and chat sessions between the SBCN and Diana were placed in chronological order from January 1 2012 to March 31 2012. The content was then compared with Feldman's clues to FIBI [4] and matched accordingly.

Data collection

Data collection included the totalling of chat requests, compilation of the Click Chat, popup chat sessions and personal message transcripts between the SBCN and Diana. Examination of Diana's

online photograph for congruence with the information she provided and an offline interview with the SBCN to clarify and validate the researcher's understanding of the interactions, between the SBCN and Diana. All data was stored on a password-protected computer.

Data analysis

The interview transcript was checked by the SBCN for content accuracy. All authors of this paper, crosschecked, the verbatim data for consistency of understanding, accurate attribution and congruency with Feldman's clues.

Reliability and dependability

Triangulation of the data occurred through, the review of the online transcripts, personal interviews and member checking with other Clickers including the research team members. The researcher remained in the online setting until information saturation was reached, in this instance until Diana, left the online community. The detail provided in this research study can facilitate others to repeat the study, thereby confirming its dependability [17].

Ethical considerations

This research is part of the research outcomes of a larger project, which was approved by the University's Research Ethics Committee.

Authenticity

The Click member application process does not prevent people from providing incorrect information, whether by mistake or design. Members are asked for correct information such as postcodes or if their name is obviously fabricated and email addresses are automatically validated/invalidated.

Honesty

There were no ethical concerns around what Kozinets [16] refers to as, entrée to an online community, because the researcher was a founding member of the Click and all members were provided with the research information.

Informed consent

The Click membership process required the individual to read and agree to be a part of the research project. The relevant research and website information was available at the bottom of each web page. Hard copy informed consent was obtained for the interview.

Trust

Click membership was based on trust. If improbable membership data was entered, then a personal message querying the content was sent, and if no response was received the member was deleted.

Anonymity

The name of the online community is given, but online pseudonyms, names and other means of identifying the person such as locality, and family member's names, are altered to protect participant anonymity [16]. Direct verbatim quotes are used in the research, but no details that might be harmful to the community or individual participants are provided.

Findings and Discussion

Feldman's clues to FIBI were used to examine the online and offline data and this information is summarised in Table 1. All Diana's posts are quoted verbatim to demonstrate the similarity in content and grammar, and the likelihood that the same person rather than a different person, was posting. These quotes also serve as a practical guide for nurses and other health professionals.

Table 1: Diana's Behaviour compared with Feldman's (2011) Clues to Factitious Illness Behaviour on the Internet

Diana's online behaviour in the Click community was congruent with the behaviour described in nine out of ten of the Feldman's clues. The one clue that didn't apply to Diana's behaviour was the avoidance of telephone contact. Diana did have one telephone conversation with Beryl and although the content is unknown, this was another way of telling her 'stories' and reinforcing her need for support.

Leaving and re-joining the Click

Diana left and re-joined the Click five times without explanation, resulting in five different member numbers and two different usernames: Diana and Diana1. This behaviour indicated that she either hoped to mislead the other Click members into believing she was a new member or she was genuinely confused about the site processes, due to her "learning disability".

Photograph

Diana claimed to have lost her hair due to chemotherapy and posted a user photograph purporting to show her without hair. The SBCN commented:"I believe Diana was wearing a rubber cap to simulate a bald head."

Distress score

On joining the Click, Diana's distress score, relative to breast cancer, was 0, which was unusual, when compared to the scores of 6 or 8 registered by other members, newly diagnosed with breast cancer.

Treatment in consistencies

Diana initially referred to an oral chemotherapy medication she was taking for her newly diagnosed primary breast cancer. SBCN commented: "This oral medication is used to treat cancer metastases and is not the first line of treatment for the early breast cancer stage" (SBCN). Diana's chemotherapy medication then became intravenoustherapy and she referred to common side effects, such as nausea, lack of appetite, mouth sores and "food tasting strange". This information can easily be gleaned from comments made in the Click forum or from other breast cancer support sites.

The grade of breast cancer changed from grade one [in her first Click Chat session] to grade two in her online signature, Diana also referred to staging of breast cancer that the SBCN noted: "…is not generally used in this (country name deleted)".

Effects on other Click members

Most of the interaction between the SBCN and Diana was invisible, except for on Click Chat but only by those Clickers who joined the chat session. If posted to the forum or home pageit could have cause the disruption described by Uridge et al. [6], where online community members became openly divided over the veracity of posts made by a member and her husband, argued with these members, left the community or logged off immediately when either of these members came online.

FIBI CLUES	Diana's Behaviour (including verbatim quotes)
The posts consistently duplicate material in other posts, in textbooks, or online health-related websites	Posted the same or similar information with the same username to three BC support sites. 1. "a mother of daughter Michaela 8 years old with breast cancer stage 2 grade2." 2." im a mum with breast cancer stage 2 grade 2
The length, frequency, and duration of the posts do not match the claimed severity of the illness e.g. a detailed post from someone claiming to be in septic shock).	Chatted with the SBCN at length, from hospital, shortly after a miscarriage and hysterectomy then after surgery for a brain tumour only on this occasion used her sister as a 'sock puppet'.
The characteristics of the supposed illness and its treatment emerge as caricatures based on the individual's preconceptions.	Changes her BC stage and grade from one chat to the next Refers to oral chemotherapy that is given at the hospital and that she has to stay in hospital for so that '… they can keep watch on me" and "i am bedridden still for another week or so" "daily tablets hospital said spoke to oncology" frequently refers to feeling tired and nauseated and food "….tasting funny…"
Near-fatal exacerbations of illness alternate with miraculous recoveries.	Recovers from brain and other major surgeries almost overnight yet continues to chat. "Meningitis under control now but had total hysterectomy last night 2.30 am long needle in arm and 6 drips!"
Personal claims are fantastic, contradicted by later posts, or disproved.	Claims to have a learning disability so her child was taken away at birth to live with her mother. States she is in one location then another, in a timeframe that is impossible. Claims to have lost her hair due to chemotherapy timeframes prove this to be unlikely. Claims her mother was killed and her daughter seriously injured in a car accident
There are continual dramatic events in the person's life especially when other group members have become the focus of attention.	As more people joined the Click and made claims on the SBCN's time Diana introduced more health conditions and underwent several surgeries while coping with the treatment for diabetes, asthma, breast infection due to cut from a mammogram, meningitis, breast cancer and cervical cancer, coeliac disease and a urinary tract infection plus the death of her mother and the serious injury of her daughter in a car accident.
The individual complains that other group members are not sufficiently supportive and warns that this insensitivity is undermining his/her health	Diana she did ensure that a major part of any Click Chat session was taken up by her comments by pretending to leave the session, then staying in the chat room and interrupting other members discussions with her claims to feeling nauseated and upset.
The individual resists telephone contact, sometimes offering odd justifications	One telephone contact is known to have occurred therefore the behaviour does not comply with this clue.
There is feigned blitheness about crises (e.g. a cardiac arrest) that will predictably attract immediate attention.	Reports that her father had a stroke then when asked for further information about his condition, comments on a sporting event. Turns the conversation back to herself with "oh i had to get another scan for my cevical check as bleeding strated again" but then asks "what's for dinner"
Others ostensibly posting on behalf of the individual have identical patterns of writing, such as grammatical errors, misspellings, and stylistic idiosyncrasies	SBCN Comment: "Pauline [Diana's sister] speaks in exactly the same fashion as Diana, and is in [A] one moment and with Diana in [B] the next! I am now doubtful 'Pauline' is sending any messages…she mayexist but I am not convinced she is 'sending' messages!). I have also had a nurse, social worker & specialist breast care nurse all 'send' me messages - they all speak in same fashion as Diana and many things do not add up - I suspect it is all just Diana …"

Table 1: Feldman's Clues to Factitious Illness Behaviour on the Internet and Diana's Online Behaviour .

The Click Chat sessions were without incident and members were generally sympathetic and supportive of Diana. However one member, Beryl, and became weary of her seemingly constant need for support and her monopoly of Click Chat. Beryl had engaged in a lengthy phone call from Diana that caused her to comment as follows:

Diana is in hospital for a few days, and I hope she is being linked in with some local supports. She can be very needy and quite demanding. Not sure how the chats will go with her, she seems to see them as her personal time and no one else gets much of a look in. I've seen her in the [other] site and she gets up their noses real fast lol.

Diana's incessant chat requests showed self-absorption, and further fed her apparent insatiable need for attention, nurturance and sympathy and at the same time she showed little regard for the chat needs of other Clickers. She may also have felt gratified by her ability to engage the SBCN in chats, thus monopolising her attention and limiting her online behaviour with others [18].

Confrontation

The SBCN had expressed doubts about the authenticity of Diana's stories and being aware of Diana's offline location, had conducted an online newspaper search, to determine whether the car accident that resulted in the death of Diana's mother and serious injury to her daughter, had been reported. She was able to verify that no accident or deaths had occurred in that location, so took the opportunity to confront Diana asking her if she had been 'telling lies' and 'stories' about her life. Diana insisted she did have breast cancer and questioned where the SBCN "…got her information and was "…worried" [that the SBCN] "…has spoken to the family, because mums too old…do i need a lawyer?" Confirming the SBCN's suspicion that Diana's mother and daughter were still alive and well. When asked if she knew the treatment for breast cancer Diana responded "I'm sorry but … im traped [sic] in all four walls all day long my marrage [sic] fell apart over lying …can you help me ask gp about my sore breast stuff then as [mammogram] came back ok", thereby acknowledging that she did not have breast cancer. The SBCN offered Diana the opportunity of an interview, to discuss her behaviour and to help her get some treatment. Diana agreed to the interview, and then withdrew, after advising the SBCN that she and her mother had sorted everything out with the GP. Diana later left the Click of her own accord.

The following is an excerpt from the interview with the SBCN:

Have you had any particularly difficult challenges since you've been doing this job?

Yes, Diana was an enormous challenge mostly because it was extremely demanding, not that it was challenging in the types of things she was raising, because nothing is too confronting, but I did know right from the start that it [she] wasn't your traditional [member] but I did think to begin with that it was more her understanding rather than necessarily anything else. Then the challenge was how to act upon my suspicions…. I will never confront someone without being absolutely certain. That is the most important thing on an online site – you don't have anything other than your words popping up on a screen, and therefore the risk of harm if you take a wrong angle is too great, so I could never do that….

The SBCN took a cautious approach in confronting Diana and her online posts were always supportive of Diana's feelings.

Lurking

Although Diana's left the Click her membership remained and she can login and 'lurk' on the site if she chooses. Schneider, von Krogh, and Jager [19] argue that ninety percent of online community members are 'lurkers', that is, passive members who read rather than write and post text. Whether Diana is a 'lurker' is unknown because the Click moderators are not logged in constantly to see who is online and the site while keeping posting statistics does not have statistics that show who logs in and how often. If lurking is the online behaviour of most community members it is not surprising that deceptive behaviour is not quickly and easily identified.

Lurking is not necessarily a harmful activity, and although Diana's did not have breast cancer she had developed a friendship, albeit based on untruths, with the SBCN, so she may want to lurk out of curiosity, but does not intend to interact with her again [19].

Factitious illness and the law

It is very easy for the online user, once their factitious behaviour is discovered, to logout and leaves the online support community without any consequences and/or without knowing they have a disorder for which there is treatment [14]. One individual did attempt to sue the organisers of a large online community for defamation of character, after they had challenged him and banned him from the community, for his deceptive behaviour. His case was unsuccessful because he refused to allow the judge to examine his medical records. The judge believed that these medical records lay at the heart of the matter because the litigant had personally posted information about his health crises to the Internet [20].

This case would not prevent someone who genuinely suffered life-threatening illnesses and had been unjustly accused of deceptive online behaviour, from suing for defamation. In Diana's case, although she did query whether she needed a lawyer, did not post that she had or was going to seek legal advice and her reference to a learning disability would seem to preclude any such action occurring.

Other health professionals

The diagnosis and treatment of Diana's real and/or imaginary illnesses involved numerous health and hospital personnel and resources. If Diana was exhibiting signs of factitious illness offline then her behaviour resulted in an unnecessary consumption of scarce health resources and highlighted the fact that the health professionals were unaware of the signs and symptoms of a factitious disorder and how to manage the patient [21]. Feldman's book Playing Sick provides guidelines for managing individuals with MS, which would assist health professionals both on and offline.

Limitations of this Study

This study focused on one member of one particular online support community therefore it is difficult to translate the findings to other communities however, given the plethora of online support communities the clues for identifying MBI or a less serious factitious disorder on the Internet will be useful for nurses and other health professionals who choose to practice online, participating in and/or moderating, disease focused online support communities.

Conclusion

Feldman's clues to FIBI lead to the conclusion, that Diana was suffering from a factitious illness disorder and because Diana's behaviour included fantastic stories and online peregrination, it could be Munchausen by Internet [13]. However, her behaviour also had troll-like and narcissistic aspects to it. Troll-like because of the constant harassment of the SBCN with personal messaging and chat requests and narcissistic because she may have enjoyed the number and supportive content of the responses she received, each time she reported on her worsening health status. Diana's online behaviour ultimately reached a nadir, when she posted on her mother's demise and son's serious head injury, which stretched the SBCN's credulity and resulted in the confrontation and exposure of her deception.

Fortunately, Diana's online behaviour and the subsequent exposure of her deception had little effect on the trust and supportive relationships developed within the Click community, because the majority of the textual interaction was between the SBCN and Diana therefore was invisible to other Clickers.

Of or their life circumstances, therefore it is important for members of online support communities in particular nurses and other health

professionals who provide online support and advice, to be aware of FIBI and MBI and its management.

Author Contributions

All the authors substantially contributed to the study conception and design as well as the acquisition and interpretation of the data and drafting the manuscript.

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