

“I can’t get no sleep”: Discussing #insomnia on Twitter

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ABSTRACT

Emerging research has shown that social media services are being used as tools to disclose a range of personal health information. To explore the role of social media in the discussion of *mental* health issues, and with particular reference to insomnia and sleep disorders, a corpus of 18,901 messages - or Tweets - posted to the microblogging social media service Twitter were analysed using a mixed methods approach. We present a content analysis which revealed that Tweets that contained the word “insomnia” contained significantly more negative health information than a random sample, strongly suggesting that individuals were making disclosures about their sleep disorder. A subsequent thematic analysis then revealed two themes: *coping* with insomnia, and describing the *experience* of insomnia. We discuss these themes as well as the implications of our research for those in the interaction design community interested in integrating online social media systems in health interventions.

Author Keywords

Twitter; Microblogging; Self-Disclosure; Mental Health; Insomnia; Health

ACM Classification Keywords

H.5.m [Information Interfaces And Presentation]: Miscellaneous;

INTRODUCTION

Social media has been considered as a means to disseminate health information [2, 6] and as a way to provide online social support for health issues [3, 28, 59]. Mental health is traditionally stigmatised by society [4], meaning that those suffering from such illness may find it harder to disclose details of their disorders [21]. However, the reduced social presence afforded by the Internet may assist individuals to disclose details about their mental health [42]. In the work presented here, we investigate the degree to which people are using social media to discuss their mental health conditions, and how exactly they are doing this. Our work

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makes particular reference to insomnia and to the microblogging social media service Twitter.

Insomnia is one of the most prevalent mental health symptoms reported to health professionals in the UK [39] and is estimated that insomnia affects 30% of the world’s population at some point during their lifetime [27, 43]. However, it is estimated that only a small proportion of insomnia sufferers actually seek medical help other than over-the-counter sleep aids [29]. One of the challenges, therefore, facing sleep experts is that of dissemination of accurate information regarding healthy sleep routines and the promotion of sleep therapy.

Twitter has over 100 million active users, who generate 230 million tweets each day [55]. Recent research from the web and data mining communities indicates that Twitter has been casually employed by users (“Tweeters”) to discuss a wide range of health information, including information on insomnia [40] and other mental health conditions. Other researchers studying this behaviour have shown that Tweeters use Twitter to disclose symptoms [53], give advice [47] and disseminate information [40]. Such research suggests that Tweeters with chronic conditions, such as insomnia, may not have sought help from health care advisors and thus use Twitter as a repository for information specific to their disorder [40].

This paper focuses upon how individuals use social online spaces that are not specifically dedicated to insomnia to discuss their sleep disorder symptoms, and how they describe their experience with insomnia to a wider audience. We wish to know whether i) individuals are making insomnia related disclosures, and ii) if so, what they are disclosing. The over-arching aim of our research is to explore the implications of these disclosures for those in the interaction design community who are interested in integrating online social media systems in health interventions.

BACKGROUND AND RELATED WORK

Seeking health information online is not a new phenomenon and, in the case of sleep disorders, is seen on numerous discussion boards/forums such as those found at www.talkaboutsleeeep.com and www.sleepassociation.org. Many of these forums give advice on sleep hygiene; e.g. to reserve the bedroom for sleeping and sex, to refrain from stimulating activities before bedtime, and to establish a

relaxing pre-sleep routine [37]. However, in some forums it is possible to find threads initiated by members who are awake and want to reach out and talk with someone in the middle of the night. This is contrary to one of the principles of good sleep hygiene, which is to avoid stimulating environments [37].

A study that examined Twitter use related to antibiotic medication [47] found similar behaviour relating to improper use of antibiotics. Tweeters discussed using antibiotics to cure influenza, which is a viral illness. Hence, whilst social media and online forums may provide a positive support network with regards to health concerns [47], it would seem that there is a potential alternative use that does not have such a positive outcome. Researchers have suggested that those advocating behaviour contrary to medical advice could be targeted and auto-responded to on Twitter with correct advice [47].

The “unknown audience” aspect of broadcast communication allows a Tweeter to address their communication to anyone that they choose. The obvious question is “who do the Tweeters have in mind as their imagined audience when they disclose their insomnia?”. The Tweeters in Marwich and Boyd’s study [25] were asked quite simply “who do you tweet to?”. They described Tweeting to multiple audiences, but some did talk about Tweeting to themselves and rejected the notion of Tweeting to anyone else. This seems counter intuitive when Twitter is considered as a social application, and that these Tweets were public and thus could be read by anyone accessing the site.

Twitter posts have recently been extensively data mined to identify political and economic trends [54, 38, 7], track natural disasters [46] and diseases [5], and to measure consumer opinion [48]. However, whilst this type of research can tell us about the different subjects that Tweeters are discussing, it doesn’t tell us *how* Tweeters are using Twitter. We are interested, from an HCI perspective, in the different purposes in which social media is being used in order that subsequent designs and affordances of such services can be improved. Knowledge of purpose will inform the development and design of social media and, with particular regards to insomnia related use, can provide useful information for researchers looking to implement online mental health interventions.

The body of research examining health related Twitter use has employed both qualitative and quantitative methodology. Hand coded content analysis was used to examine antibiotic use [47] and public health issues [40], in which the researchers identified key words and phrases and examined relationships between word clusters and other measures. In contrast, Sullivan *et al* [53] used a thematic analysis of tweets related to concussion using a team of researchers to categorise tweets before extracting themes and applying meaning to the data. We have used a mixed

methodology here, using both content and adopting the thematic analysis method used by Sullivan *et al* [53].

The remainder of this paper is outlined as follows. First we describe our method of data collection. Then we describe the content analysis, followed by a short discussion paying specific attention to the degree in which Tweeters are making disclosures. Next, we describe the thematic analysis in which we address the second research question pertaining to the role of Twitter in mental health disclosure. Finally, we discuss the implications of our research for those in the interaction design community interested in integrating online social media systems in health interventions.

DATA COLLECTION

Using a tweet archiving application, 23,119 tweets containing the exact phrase “insomnia” were collected over a 24-hour period; this therefore found anything hash tagged with #insomnia. We will henceforth refer to these tweets as “insomnia tweets.” Our insomnia tweets were firstly filtered as follows: a total of 112 tweets were removed from the sample because the Tweeter’s twitter profile was listed as a language other than English or was specified as “unknown”. A total of 114 tweets that only included the word insomnia as part of the Tweeter’s username (e.g. “insomniac342”) were also removed. There were 3,992 tweets that were simply duplications or “retweets” (denoted by RT at the beginning of the message). These retweets were removed as the archiving application would have already collected the original tweet. After the filtering process was completed a total of 18,901 tweets remained for analysis.

A content analysis of the insomnia tweets was used to confirm that individuals were using Twitter to disclose details of their sleep disorder. However, analysing only these tweets would not allow us to determine the unique characteristics of tweets about insomnia and how they differ from messages generally posted on Twitter. Therefore, for the purposes of comparison, a control group consisting of 1% of all tweets posted in the first 30 seconds of each hour over a 24-hour period were archived, producing 59,370 tweets. These will be referred to as “non-specific tweets”. As in the case of the insomnia tweets, only those tweets from Tweeters whose language was listed as English or “unknown” were selected, leaving a sample size of 40,959. Unlike the insomnia tweets, these randomly sampled tweets could consist of purely ASCII characters (e.g. “} { | ~ ~ | } { / ^ ^ ”) which contained no analysable words; therefore these tweets were also filtered, producing a sample size of 40222. In line with the filtering procedure applied to the Insomnia tweets, “retweets” were removed, giving a sample size of 35064. To produce a similar sized sample to the 18901 insomnia tweets, every second tweet was omitted from the non-specific sample, resulting in a sample of 17532 tweets for analysis.

Variable	Group Mean (Standard Deviation)		<i>t</i>	<i>p</i>	<i>r</i>
	Insomnia ^a	Non-specific ^b			
Character Count	68.11 (40.75)	64.76 (38.56)	8.05	<.001	.01
Word Class					
Pronouns	8.07 (10.08)	6.14 (9.04)	19.31	<.001	.02
Verbs	9.55 (11.25)	6.02 (8.69)	33.67	<.001	.03
Auxiliary Verbs	6.01 (8.45)	3.39 (6.05)	34.12	<.001	.03
Sentiment Analysis					
Negative Sentiment	3.13 (7.75)	1.35 (4.41)	27.19	<.001	.03
Positive Sentiment	2.55 (5.64)	3.29 (6.63)	11.50	<.001	.02
Word Root Type					
Health	0.68 (2.77)	0.31 (2.04)	14.21	<.001	.02
Time	4.41 (8.02)	2.49 (5.55)	26.73	<.001	.03
Sad	0.35 (1.96)	0.23 (1.69)	6.04	<.001	.01
Anger	1.91 (6.62)	0.66 (3.13)	23.22	<.001	.03
Anxious	0.24 (1.70)	0.15 (1.44)	5.50	<.001	.01
Past Tense	0.99 (3.19)	0.95 (3.19)	1.26	.209	.001
Present Tense	7.55 (9.96)	4.35 (7.15)	35.50	<.001	.03

^a*n* = 18901, ^b*n* = 17532

Table 1. Percentage of Word Type per Tweet.

STUDY 1. LINGUISTIC CONTENT ANALYSIS

Analysis

A content analysis was performed using the Linguistic Enquiry and Word Count (LIWC) software [41]. The software produces the percentage of analysed text that contains a particular word class. For instance “I hate having insomnia” would receive a score of 25% in the word class of negative affect, whereas “I really really hate insomnia” would receive a score of 20%. To ensure that the non-specific tweets were suitable to be compared to the insomnia tweets, the length of the insomnia tweets was compared to the non-specific sample (see Table 1). The character count distribution of both samples was bimodal, (which is typical of tweets in general [e.g. 16]) but due to the very large sample size, independent *t* tests were considered to be a suitable method of comparing the two samples [23]. This bimodality is in itself interesting, it shows that both samples of Tweeters had peaks at around 140 characters (the character limit for Twitter), however the lower peak for the insomnia tweets was around 8 characters (essentially “insomnia” or “#insomnia”) whereas the non-specific tweets peaked at around 40 characters. Of the 2004 insomnia tweets under 17 characters, 1484 (74%, 8% of the who insomnia sample) consisted of just the word insomnia, or insomnia accompanied by punctuation or an emoticon.

The tweets in the insomnia sample contained a statistically greater number of characters than those within the non-specific sample. However this is to be expected as no insomnia tweet contained less than 8 characters as they, of course, contained the word “insomnia” as a necessity. The non-specific tweet sample was therefore deemed to be a suitable comparison for insomnia tweets for the purposes of a content analysis.

To test for any difference in content between the groups, a content analysis performed using the LIWC software [41]. The use of pronouns, verbs, and auxiliary verbs was compared between the insomnia sample and non-specific sample. The statistics are reported in Table 1 and the analysis shows that the insomnia tweets contained a higher and statistically significant (*p* <.001) percentage of all word classes tested.

A basic sentiment analysis was carried out using the LIWC software. There were statistically significant differences between the groups; compared to the non-specific group the tweets within insomnia sample contained a higher incidence of words with negative valence and lower incidence of words with positive valence (see Table 1). This result is to be expected as the symptoms of insomnia are co-morbid with mood and anxiety disorders [52].

The overall research question of this study is concerned with whether individuals are actually disclosing information about their mental health online. The health category in the LIWC 2007 English dictionary consists of 236 word roots relating to health (examples include ache, medic, sore, and doctor). This category includes the word “insomnia”, which we removed from the dictionary for this analysis. The percentage of words related to health within tweets was significantly higher in the insomnia group compared to the non-specific group (see Table 1), which suggests that those within the insomnia group had disclosed symptoms of their insomnia.

To investigate this further, the percentage of words falling within the Sad, Anger and Anxious categories were compared between the groups; these statistics are also reported in Table 1. The words in these categories relate to a negative emotional state (e.g. tense, hateful, hopeless) and

it would be reasonable to use these as a proxy for negative disclosures. The insomnia group uses significantly more words within the Sad, Anger and Anxious categories compared to the random group ($p < .001$ in all cases). In the insomnia group a weak relationship exists between the percentage of words in the Health category and those within the Anxious category ($r = .053, p < .001$) and Health and Sad category ($r = .09, p < .001$), and only in the Health and Sad category for the non-specific group ($r = .042, p < .001$). A Fisher's r to z transformation showed that the relationship is significantly stronger for the insomnia tweets ($z = 4.6, p < .001$), suggesting that those Tweeters were disclosing more negative health information.

Individuals with insomnia have been found to be preoccupied with time [20]. This is reflected in our sample through the references to time within the insomnia tweets being almost double that of non-specific tweets (see Table 1). When we examine the use of tense in the tweets, we can see there is no significant difference between the usage of past tense across groups. However, present tense is used more within the insomnia tweets. The difference between the use of past and present tenses in the insomnia tweets (*Mean difference* = 6.56, *SD* = 10.42) is much larger than in the non-specific group (*Mean difference* = 3.40, *SD* = 7.76). This is a significant interaction ($F(1)=1069.94, p < .001$) albeit with a very small effect size (*partial* $\eta^2 = .03$). When we look at the use of time in conjunction with tense, a correlation analysis shows us a stronger relationship between time and present tense in the non-specific tweets ($r = .166, p < .001$) than in the insomnia tweets ($r = .112, p < .001$). A Fisher's r to z transformation shows that this difference is significant ($z = 5.25$). This strong use of present tense with regards to time could be an artefact of Twitter itself. When a user publishes a Tweet using the Twitter website they are asked "What's happening?" which may predispose the Tweeter to write in the present tense.

Discussion

The described linguistic content analysis provides strong evidence to support the notion that individuals are making self-disclosures about their mental health symptoms with regards to insomnia and sleep disorders. Whilst we can speculate about the nature of these disclosures in terms of qualitative content, this analysis does show us that those tweeting about insomnia are behaving as the literature regarding insomnia would lead us to expect. Specifically Tweeters show a preoccupation with time, and a strong relationship between anger and health disclosure emerges.

The evidence to suggest that disclosures are being made should lead to any online health intervention targeting insomnia to include areas where users can make disclosures about their sleep behaviour. The bimodal distribution of the insomnia sample, specifically the lower peak compared to the non-specific tweets, would suggest that the insomnia Tweeters are using Twitter in different way to the non-

specific sample. For instance, the high incidence of tweets similar to "Insomnia!" may mean that these Tweeters are using Twitter as a virtual pillow to shout into. Individuals with insomnia are commonly (and quite understandably) frustrated [10], and appear to be using the platform to vent this frustration.

STUDY 2. INDUCTIVE THEMATIC ANALYSIS

Whilst the linguistic content analysis confirms that individuals are self-disclosing about their mental health issues, caution is advised when interpreting the results as individuals have a tendency to abbreviate and use alternatives to proper words when there is a character limit in place [35]. These abbreviations are not necessarily picked up by the LIWC software. There is also a question of the subjectivity and ambiguity of tweets; an individual may, for instance, tweet "My insomnia is back – oh great" which would be coded as having positive valence through a straightforward content analysis, when the opposite could be implied. Therefore we deemed it appropriate to conduct an inductive thematic analysis, in which subjectivity is acknowledged and content is interpreted, rather than taken at face value [9].

Because a hand coded thematic analysis would not be feasible on the entire sample of tweets, a subset of 749 tweets, consisting of every 25th tweet in the original list, was chosen for analysis. These tweets were compared with the Insomnia sample as a whole ($n = 18901$) on all the word categories analysed in the content analysis, there were no significant differences at the alpha level of $\alpha = 0.001$.

Analysis

The 749 tweets selected for analysis were read several times by one researcher, making annotations where appropriate. Category codes were then applied to the tweets. The tweets were read several more times and the categories were refined, producing 49 categories. The category codes, together with a description and examples of each code, were given to two other researchers. Following discussions, the category definitions were refined to 45 codes. To assess the reliability of the categories another subsample of tweets was taken from the remaining 18145 selected for analysis. The first of every 35 tweets was chosen for analysis producing a subsample of 514 tweets. The three researchers completed the coding separately. The majority of tweets were assigned one category per tweet, but some contained more than one piece of information and thus were segmented by the raters.

All segmented tweets were examined by the three raters together and a consensus was reached on the majority of the tweets. The codes were examined for inter-rater reliability using Fleiss' Kappa, $\kappa = .516$ which is classed as a moderate agreement using the guidelines produced by Landis and Kock [22], individual measures of reliability between the raters using Cohen's Kappa, producing statistics of $\kappa = .864, \kappa = .887$,

and $\kappa = .898$ which are classed as having high agreement [11].

The coding categories were then examined and cross-referenced with the data. Themes were identified and refined by the lead researcher and reviewed by all three researchers.

Findings and Discussion

Six first order themes were identified, which formed two second order themes; *Coping with Insomnia*, and *Describing the Experience*, which are illustrated in Figure 1. The themes are expanded upon below. All tweets employed to illustrate the theme are used with original spelling and grammar, usernames have been anonymised.

Second Order Theme1: Describing the Experience

Four interrelated first order themes make up the theme *Describing the Experience*. This second order theme represents the ways in which Tweeters with insomnia write about their experiences of the sleep disorder. The theme encompasses expressions of Tweeters' external experience in terms of their mental state and the sleep quality and quantity, together with interactions between other Tweeters and Insomnia as an entity. The following subsections discuss these first order themes in more detail.

First Order Theme 1.1: Sharing

The theme of Sharing the Experience emerged particularly from tweets that were directed towards another user. Whilst some users opt to lock their tweets, meaning that only designated Twitter users can read them, a huge amount of content is available publically, either to Twitter subscribers via the Twitter platform, or to anyone with an Internet connection via a third party client. Twitter can therefore be classified as a broadcast medium. However, Twitter has the facility to allow directed messages (known as DMs) which are only visible to the sender and receiver, and "mentions" (those featuring another user's @ prefixed name) which can be read by anyone. It can be argued that with respect to mentions, the author of those tweets is making a targeted communication. Tweets that fell into the theme of *Sharing* may have offered support or empathy "[4460580] Sorry you're feeling sad. Is the insomnia still hanging around?"

or in some cases suggested ways in which the insomnia Tweeter could fall asleep "[236324168] you have a serious case of insomnia...shame". This exchange is evidence of Twitter facilitating individuals who may not be otherwise connected to identify with each other over a common mental health disorder. The Internet allows individuals to connect with each other and access information directly relevant to their own experiences and needs, regardless of geographical location. Some of these 'Sharing' tweets such as "[147265787] insomnia~welcome to the club" suggest a form of validation and recognition of the target of the communication in that someone else has gone through the same experience. This type of validation is a strong theme in online support-groups [24, 12, 57]. Further, this interaction suggests some possible future use for social support. Whilst the exchanges highlighted here appear to be between individuals who follow each other on Twitter, the ability to search for phrases and words, and Twitter users voluntary use of the #insomnia tag allows Tweeter to interact with users who are discussing similar things, meaning that Twitter could feasibly function as an online support-group proxy.

Some Tweeters, rather than offering sympathy, berate those who claim to have insomnia when they are just having minor sleep disturbances "[27629153] insomnia?U're the person who sleeps A LOT!". Literature on discourse describes the notion of *normative sleep* [26]. Specifically, if an individual does not achieve what they consider to be the appropriate amount of sleep, they pathologize the experience. This highlights one of the fundamental problems with the use of the term "insomnia", common to the term "depression"; individuals may use it to describe a single occurrence of sleeplessness, or as in the case of depression, as a synonym for disappointed ("Twitter's down, I'm so depressed LOL!!!!1one").

Whilst directed tweets formed a strong component of this theme, there were other tweets that simply disclosed insomnia. The Tweeter was not asking for help, they were not talking about their coping strategies or talking about how their insomnia was making them feel they were simply saying "I got insomnia". The presence of "Insomnia..." has

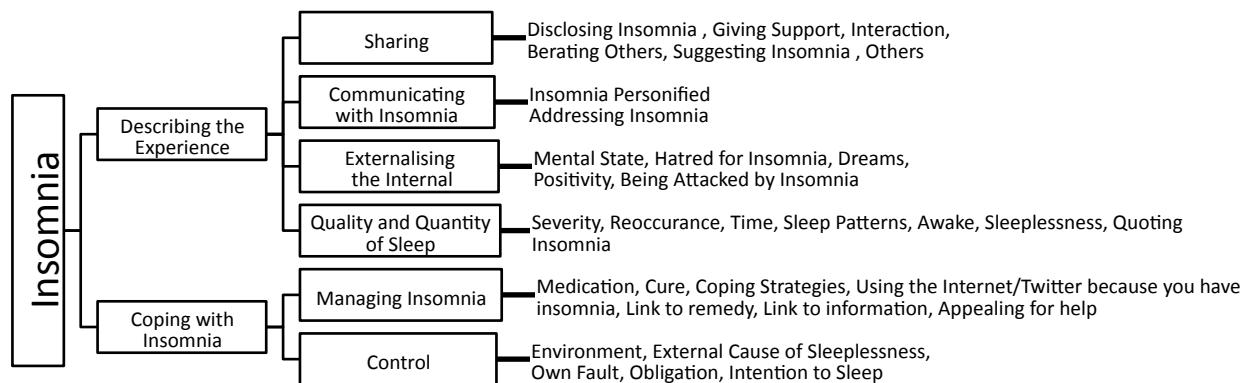


Figure 1. Hierarchy of Themes and Placement of Categories

been commented upon in the linguistic content analysis above, and it emerged as a strong theme in terms of *Sharing the Experience*, as the Tweeters seemed to need to simply a beginning of a potential conversation with another human being. Here we see users making the most of the broadcast format of Twitter. Tweets can of course be directed (which the theme *Describing the Experience* primarily concerns) but it also allows the Tweeter to address a wider and relatively unknown audience [25].

First Order Theme 1.2: Communicating with Insomnia

This theme highlighted a way that Twitter was used to address insomnia directly. Whereas those tweets falling under the *Sharing* theme were directed towards another user, the tweets under *Communicating with Insomnia* were addressed to Insomnia itself, “*Oh insomnia... Thou art a heartless bitch..*” or treated insomnia as a sentient being “*Insomnia is a bitch tonight!*”. The use of “*dear #insomnia...*” may be an exercise in catharsis, echoing the conclusions of a similar study by Sullivan *et al* [53] which looked at the disclosure of concussion-related information on Twitter.

The verbalization of emotions through writing is used in psychotherapy; it allows the patient to rationalize and accept their feelings as valid and reduces troublesome thoughts and emotions [19]. Websites like Dear Cancer¹ and Dear Mental Illness² exist, where individuals can write to their illness as if it is a hostile person. The letters are a mixture of stoicism, defiance, unrestrained emotion, and tenacity. Dear Cancer states that they are “here to help you finally get it all out”, emphasizing the cathartic function of addressing your illness. Perhaps Twitter is another platform upon which users can begin to come to terms with their illness or disorder. The “unknown audience” aspect may allow the users to make these potentially cathartic disclosures “to insomnia” without the risk of judgment.

First Order Theme 1.3: Externalizing the Internal

Whereas some of the tweets mentioned above simply stated that the Tweeter could not sleep, tweets which made up the theme *Externalizing the Internal* contained a lot more information regarding (i) the Tweeter’s mental state “*This feeling of nothingness is not new but I’m slowly getting used to it. #Insomnia #StopDenyingIt*”, (ii) their emotional state “*Hate insomnia!*”, and (iii) their experience fighting for sleep every night “*My insomnia is going to kill me*”. These disclosures echo the catharsis mentioned above. Once again we see strong emotional and quite intimate self-disclosure, which poses a question of to whom such tweets are addressed. It is tempting to apply the stranger-on-a-train analogy here [45], the Tweeter may be making incredibly personal disclosures, but they could be making them to strangers with no interest or investment in the disclosure.

¹ <http://dearcancer.org/>

² <http://www.dearmentalillness.com/>

share their frustrations with their sleep problems. It could almost be viewed as a precursor to interaction,

However this analogy is not a good fit as their username is attached to the tweet and the tweet is cached, recorded for posterity. Those that read the tweet may be strangers in the sense that they do not know the Tweeter, but unlike a stranger on a train, they can go back and read the tweet and even retweet it if they so wish. Whilst this analysis doesn’t answer the question as to why the Tweeters make such intimate disclosures, the findings do highlight the fact that it happens. It would be advantageous for any online social media intervention to include a function that allows users to make this type of disclosure.

First Order Theme 1.4: Quality and Quantity of Sleep

Tweeters wrote about the severity of their symptoms “*Bad insomnia really reallyyyyyy baddddd*” how their symptoms were increasing in severity “*my insomnia is getting worse.. yay me...*”. Individuals who seek help for their sleep disorders typically describe their symptoms with more severity than those with similar symptoms that do not seek help [13]. The Tweeters here may have been ruminating on their symptoms; something that has been found to be excessive in Internet communication from individuals exhibiting suicidal and parasuicidal behaviour [18].

Echoing the results of the linguistic content analysis a strong component of this theme was the frequent reporting of the time: “*Damn its 3am. Insomnia*”, “*4:26 & I’m still awake.. #insomnia*”. These are written in the present tense so we can be reasonably confident that these are real time Tweets. This produces further evidence that Tweeters who have trouble sleeping are not adhering to the principles of good sleep hygiene. Whether this is simply through lack of willpower, or lack of education is something that will need to be explored further.

Design Implications from “Describing the Experience”

As was suggested from the results of the linguistic content analysis, the findings here strongly suggest that any online intervention should have a space where users can simply disclose their experiences with insomnia and vent their frustrations at being unable to sleep. The notion of speaking directly to ‘Insomnia’ is interesting, and something that could easily be built into any system. This would fulfil two purposes, it would allow the users to vent frustrations resulting in catharsis, but it would also validate the frustrations of those reading it, they would see that what they are feeling is perfectly natural when challenged with insomnia.

These findings clearly suggest that individuals are sharing their experiences, not just with an imagined audience, but directly with targeted communication. They are supporting each other, suggesting practical and emotional ways of dealing with sleeplessness, and offering empathy to fellow sufferers. This social support aspect has been shown to be very successful in group therapy [17]. In this regard, an

online social network structure is an ideal choice for the delivery of online support. A social network structure promotes online closeness [50] and can promote engagement with online support systems [58]. Whereas online therapy suffers from high levels of attrition [30,56], an online support service with a social network structure could seek to improve this, together with providing a social support network for those undertaking any therapy or self-help guide.

Second order Theme 2: Coping with Insomnia

Whilst the second order theme of *Describing the Experience* contained first order themes that spoke of what it was like to have problems sleeping, the second order theme of *Coping with Insomnia* described how the Tweeters managed their insomnia, and how they attributed the difficulties they had sleeping. This theme has much in common with the theme of *Inferred Management* found in a similar study by Sullivan *et al* [53] exploring discussion of sports related concussion on Twitter. Whereas some of the tweets within *Sharing* contained advice given by others through directed means (@mention), the coping strategies and information on managing insomnia within *Coping with Insomnia* are volunteered without any elicitation from others.

First Order Theme 2.1: Managing Insomnia

This theme contained tweets that dealt with ways of managing the disorder, from simple coping strategies “*So last night while suffering from another insomnia attack I did what my friend suggested and read manga. Rosario + Vampire is my favorite*” to advertisements for cures “*Insomnia & Sleep Problems Tonight. No Medication [link]*”. Medication did make up a strong part of this theme, Tweeters either requesting it “*i have insomnia. are there pills for that?*” or simply disclosing their use of it “*Insomnia sucks! I have to Ambien it every night to sleep at all*”. Medication is only recommended for short periods and only in chronic cases [36], however sleeping pills are seen by insomnia sufferers as an immediate and easy solution to their sleep problems [33]. This attitude is echoed in the tweets relating to insomnia “*Anyone got sleeping pills for my insomnia stricken dudette*”, “*5:45 in the fucking morning and I'm not tired in the slightest #insomnia #needsleepingpills*”.

Some Tweeters claimed to be using the Internet and, more specifically, Twitter itself when they were suffering from a spell of sleeplessness “*Yep twittering at 5 am instead of sleeping*”. This is interesting as medical advice given to those diagnosed with insomnia would not advocate the use of the Internet when trying to sleep, which can be an engaging and stimulating activity [1,31]. Again, this mirrors the findings of Sullivan *et al* [53], who highlight the propensity for misinformation in advice given to those with sports related concussion. This may suggest that individuals who find themselves on Twitter at 5am, having had no sleep, have not yet sought medical assistance. Indeed,

insomnia sufferers commonly try to “fix” their sleep disorder themselves before seeking medical assistance [51]. Some of the coping strategies given here are maladaptive to quality sleep “*Catching up with on glee. I wish I were catching up on sleep.*” but some are in line with advice from sleep experts “*Awake at 4:45am. Cup of camomile go chase sleep catch it.*”, suggesting that some individuals are adhering to good sleep hygiene habits.

First Order Theme 2.2: Control

The tweets identified under the theme of Managing Insomnia illustrate the ways in which insomnia sufferers were living with the sleep disorder, this separate theme of Control illustrates the *ownership* of insomnia. The psychological concept of locus of control places individuals within an external or internal locus [44]. In an external locus the individual feels that their actions and circumstances are dictated to them by external factors, whereas those who possess an internal locus feel very much in control of their own actions. This scale of control from internal to external emerged as a strong theme.

Whereas within the *Managing Insomnia* theme Tweeters referred to using Twitter as a coping strategy, here we see them place Twitter as a cause of their sleeplessness “*but seriously twitter is my cause for insomnia.....no other reason causes my sleeping disorder*”. The ubiquitous nature of the Internet was an oft cited reason for staying awake with several variations on the message “*Some people can't sleep due to insomnia...i can't sleep because i have an internet connection!*”. This may seem strange as the Internet needn't be the overwhelming presence that these Tweeters seem to see it as (“*well i guess i wouldn't call it insomnia I could sleep if i tried its just hard with a laptop satellite tv and a DVD player in my room*”), this is a classic example of how someone with a strong external locus of control will view their ability to change.

This internal locus is displayed in tweets that talk about future obligations. Tweets that make mention of exams (for example “*Having insomnia the night before an important exam. #classic*”) are obviously related to stress induced transient insomnia [15]. However, Tweeters seem very aware of other obligations and the effect of their insomnia on these “*How the fuck will I be in time for this flight if insomnia wants her turn?*”, “*#insomnia is no joke! I have to get up for work in an hour and still awake!*”. Despite the strong presence of an external locus, some tweets exhibit characteristics of an internal locus of control. Here Tweeters seem to be using Twitter as a kind of affirmative platform telling the Twitterverse that they are going to sleep tonight “*Ok ima rendezvous with my pillow and hope to fall asleep in the next two hours*” “*Getting sleepy :D Good!!! No insomnia XD Will sleep soon :)*”. The internal locus of control was overwhelmingly associated with positive behaviour and outcome, however one Tweeter accepts responsibility for their disruption to their sleep patterns “*Didn't know insomnia sucks so badly. Hearing the*

morning trains makes it even worst. My bad for sleeping too long!".

The fact that individuals self-report maladaptive coping strategies could be exploited by health providers to target those that could benefit from cognitive behavioural therapy, particularly for the case of self-help therapeutic online services. Only a small proportion of individuals who suffer from insomnia seek medical help [29] and those that do often wait until symptoms are severe [34]. A targeted online self-help solution to the sleeping disorder could assist those suffering from initial and mild symptoms before the maladaptive strategies become entrenched.

Design Implications for "Coping with Insomnia"

This theme dealt with the practical aspects of insomnia. It is important to take these findings into account with regards to functions of any online social support system.

Tweets within this theme demonstrated a need for a controlled environment on any online support system. Tweeters blamed Twitter for their insomnia, suggesting that some kind of digital barrier should be in place to limit access during periods when the users should be sleeping, or engaging in non-stimulating activities.

Online therapy, or an online social support provision could influence control in another sense, in terms of locus-of-control. Typically, an individual suffering from sleep problems will complete a sleep diary [8, 49] consisting of a record of time spent in bed, time spent sleeping etc. This can be easily adapted and is apposite for a social network type environment. Immediate feedback could increase engagement with the online provision, in addition to helping the user regain ownership of their disorder.

A social network structure would be ideal to apply the principles of the expert patient to encourage the use of good sleep hygiene and discourage the use of harmful coping strategies. The use of peer-led programmes in the online management of chronic conditions has shown to be successful [14]

The strong presence of medication in the theme *Managing Insomnia* highlights the overreliance on medication as a cure. Pharmacological insomnia remedies are often prescribed in parallel therapy; however the focus of any online provision is self-managed care. Therefore it is important to be aware of this preoccupation with sleeping medication. In related work, Scanfield *et al* [47] suggests targeting individuals on Twitter who have misconceptions over antibiotic use. A similar strategy could be employed to address the overreliance on sleep medication, targeting individuals to provide information on behavioural solutions to insomnia.

CONCLUSION

A corpus of 18,901 Tweets were analysed using a mixed methods approach to understand how people are discussing sleep disorders on the microblogging service Twitter. A

content analysis showed that tweets that contained the word "insomnia" contained significantly more negative health information than a random sample, strongly suggesting that individuals were making disclosures about their sleep disorder. A subsequent thematic analysis revealed two themes; coping with insomnia, and describing the experience of insomnia. Our research, in a generic sense, contributes to the growing body of literature regarding online self-disclosure. We describe two analyses of a corpus of insomnia related tweets and demonstrate that individuals are using social media to make health-related disclosures online. We show that Tweeters are disclosing their symptoms and coping strategies and using the broadcast medium of Twitter to engage with their insomnia and release the frustration they feel towards their difficulties in sleeping.

Constructive opportunities and challenges for the use of social media to engage people with, and to treat, insomnia, are now summarised as follows: a social network structure would allow therapy to be delivered in a group. This structure would be a useful format for users to exchange support and practical information. To allow users to exercise catharsis, a space could be provided to disclose symptoms and frustrations together with an area where the users can "communicate with" insomnia. To comply with the principles of sleep hygiene, a digital barrier should be in place in any interactive platform, this would reduce the amount of access a user has to an online support network at times when they should be refraining from stimulating environments. However, rather than simply restrict all access a "life-line" should be kept open, providing information on good sleep hygiene and progressive muscle relaxation exercises [32] to aid sleep.

Our own future research will now exploit the findings presented here to improve access and adherence to online support for individuals with a sleep disorder. We aim to focus on creating a social network type platform upon which to deliver therapy aimed at insomnia sufferers, which will afford a basis for social support.

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