

RESEARCH ARTICLE

# What can we learn about mental health from 10,933 patient lived experiences using a novel quantitative-qualitative network analysis?

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## Abstract

**Objective:** The study aims to build a comprehensive network structure of psychopathology based on patient narratives by combining the merits of both qualitative and quantitative research methodologies. **Research methods:** The study web-scraped data from 10,933 people who disclosed a prior DSM/ICD11 diagnosed mental illness when discussing their lived experiences of mental ill health. The study then used Python 3 and its associated libraries to run network analyses and generate a network graph. **Key findings:** The results of the study revealed 672 unique experiences or symptoms that generated 30023 links or connections. The study also identified that of all 672 reported experiences/symptoms, five were deemed the most influential; “anxiety,” “fear,” “auditory hallucinations,” “sadness,” and “depressed mood and loss of interest.” Additionally, the study uncovered some unusual connections between the reported experiences/symptoms. **Discussion and recommendations:** The study demonstrates that applying a quantitative analytical framework to qualitative data at scale is a useful approach for understanding the nuances of psychopathological experiences that may be missed in studies relying solely on either a qualitative or a quantitative survey-based approach. The study discusses the clinical implications of its results and makes recommendations for potential future directions.

**Keywords:** mental illness; narrative; network; conceptualization; nosology

## 1. Introduction

Mental illnesses represent an enormous disease burden in terms of human suffering and economic cost (Trautmann, et al., 2016). Yet our current understanding of psychopathology is still limited. We therefore argue that there is an urgent need for methodological advances which will allow us alternative routes to study and better our understanding of mental illness.

### 1.1 Symptom as unit-of-analysis

Our current understanding of mental illness typically relates to discrete diagnostic categories of psychopathology comprising symptom sets published in diagnostic manuals such as the dominant Diagnostic and Statistical Manual of Mental Disorders (DSM, American Psychiatric Association, 2013). Consequently, these dominant systems of classification of mental illness drive the development of the tools used to measure psychopathology and in turn the studies that have been

published to facilitate our understanding of mental illness. Notably, much of the extant literature is based on the unit of analysis that is at the syndrome or disorder level. While doing so has both historical and current significance for improving communication and for stimulating thinking on the causes, phenomenology, and course of disorders, recent literature demonstrates that psychopathology may not be consistently organized according to such discrete diagnostic categories (e.g., Kotov *et al.*, 2017). Indeed, a large body of evidence exists pertaining to diagnostic comorbidity and symptom overlap. For example, sleeping difficulty and concentration difficulty are symptoms present across many disorders (Armour & Shevlin, 2010; Roley *et al.*, 2015).

Concerning the measurement of psychopathology, much of the literature is quantitative in nature and as such relies on scales and questionnaires, aligned to the above-mentioned diagnostic categories, that ask participants to rate their experiences by reporting whether such is absent or present (e.g., 0 absent / 1 present) or by reporting via a Likert scale how often an experience occurs (0 never to 5 every day). Thereafter, the respondent's ratings for many disparate symptoms are utilized to create a sum score of a syndrome (e.g., depression and anxiety). Often, the resultant sum score is then interpreted to determine whether a respondent is displaying clinically relevant symptomatology (e.g., threshold scores / cut scores). Alternatively, the responses may be used in an algorithmic fashion to determine if an individual has answered the correct number and intensity of symptoms to infer diagnosis. The presumption is that mental disorder (e.g., depression) is a single condition, and the symptoms proposed to represent it (e.g., sad mood, insomnia, and suicidal ideation) are interchangeable and equally good indicators of the condition. Recent research investigating item (i.e., individual symptoms in the questionnaires and scales) level connections between psychopathological symptoms via network analyses has however concluded that this is not the case and that particular symptoms may be more central and/or connected within a network than others (Fried & Nesse, 2015). Contrary to the interpretation of equality of symptoms within a symptom set inferring a discrete diagnostic category, we argue that symptoms are distinct phenomena that may differ from each other in important dimensions such as underlying biology, their causative predictors, and their impact on chronicity and impairment. Therefore, we also argue that the unit-of-analysis (i.e., what it is that you are analyzing) for the furtherment of research studies and clinical interventions should be at the item level (e.g., individual symptoms) and their associations—instead of at the latent level (e.g., syndromes or disorders such as depression or schizophrenia).

As aforementioned, there is a preponderance of research aimed at further understanding psychopathology which is based within a quantitative framework. Quantitative methods collect data using the administration of questionnaires, checklists, and rating scales. The purpose is often to quantify a problem or address the “what” or “how many” aspects of a research question. There are many benefits to this methodological approach including that it is economical, and a large amount of data can be collected from a large sample of respondents in a timely fashion. In turn, large sample sizes can provide a good approximation to the total population and are thus typically more representative of the population under study. Furthermore, the use of appropriate sampling frames and data weighting can result in representative samples. However, the information obtained from such data-collection methods, is often represented by binary (e.g., TRUE/FALSE) or numeric (e.g., 0 to 5) responses across a multitude of questions. The use of such questionnaires reduces the complex detail of a person's experience and thus response (e.g., mental health experiences) to numbers. It also restricts the person's responses to specific items of the questionnaire (e.g., what if the person also experiences other symptoms that are critical to understand the mental health condition but not queried via the questionnaire / standardized measure?). Responses can often be devoid of potentially important contextual information (e.g., what if the questionnaire measures the absence or presence of panic attacks but the person experiences panic attacks only at their workplace, on certain days, and in certain situations but not at home?).

There has been a plethora of useful research and advancements in our understanding of psychopathology, resulting from a this methodological approach. For example, most studies still use

these psychiatric diagnostic categories as inclusion criteria and present interventions to people diagnosed with X disorder Vs healthy controls (e.g., Ehlers et al., 2023; Lin et al., 2023; Moncrieff et al., 2023), even when psychiatric diagnostic manuals, such as the DSM, propose categories that provide a structured approach, listing symptoms for each disorder. However, questions have been raised about the adequacy of these categories. Recently, there has been debate over whether these categories adequately represent the full spectrum of psychopathology. This issue was highlighted in Kotov's (2017) study. One existing alternative approach to understanding the nuances of psychopathological experiences at a more personalized and individual level is to employ a qualitative enquiry. In qualitative research the line of enquiry is often more explorative and by the very nature of the methodologies it allows for a much greater depth of understanding of an individual's experience and thus allows for a personalized and nuanced understanding of psychopathological symptomatology than that afforded by the abovementioned more structured and standardized quantitative methodologies. Typically, when employing a qualitative investigation, the data collection methods are in the form of semi structured interviews that are completed on an individual or small group basis. The interview is semi-structured as it is used only a guide for a discussion which simultaneously allows the researcher to probe points of interest that are articulated by the respondent during the dialogue. It is of course pertinent to note that given the time-intensive nature of such methods they are generally regarded as expensive in terms of labor and capital and they tend to yield small sample sizes. Such sample size insufficiency is seen to threaten the validity and generalizability of studies' results. But while qualitative methods can be time-intensive and often involve smaller sample sizes, it is important to recognise the unique strengths they bring to psychopathological research. It is also worth noting that the combination of qualitative and quantitative methods can provide a more holistic understanding of psychopathology, leveraging the strengths of both approaches to gain a comprehensive view of mental health issues.

### 1.2 Source of data

In an ideal world, we would conceive new methodologies that merge the merits of both the quantitative framework in which we can inexpensively collect data at scale and in the qualitative framework in which we can collect nuanced and meaningful data from each and every participant within the study.

Implementing such quantitative methodologies on qualitative data for exploratory studies will have several merits. First, qualitative data lends thick (detailed) description of participants' feelings, opinions, and experiences; and interprets the meanings of their actions (Denzin, 1989). Second, qualitative data has a special ability to contextualize human experience in specific settings and understands people's unique voices, meanings, and events. Both of these merits are missing from numeric (quantitative) data which represents an attempt to assign a number to the variables under question (e.g., survey-based methods).

Arguably, doing so would enhance our understanding of psychopathology and provide us with confidence around the generalizability of our results to those outside of the immediate sample from which we have collected the data. Data from digital sources, such as social media forums which are accessible free-of-cost in the public domain (e.g. blog posts, in text format) offer a potential solution to researchers in that we can now collect large volumes of rich qualitative data on peoples' experiences. But with such data, there are two potential challenges: technical and legal. The researchers must have the technical expertise to automate web-scraping process, and thereafter must know Natural Language Processing using Python or R or relevant software to analyze the scraped data. In relation to the legality, the website's "terms of use" document must allow you to scrape the data (e.g., Facebook does not allow data-scraping) or you should have a written permission from the website owner. Unless otherwise specified, usually the copyright of such user-generated content is owned by the content creator, but when researchers are collecting data from thousands of people it is unreasonable to expect them to contact each user personally

(plus it is unlikely that you will be able to get their contact information). Therefore, to avoid copyright violation the scraped data must be substantially modified or filtered and identity-related information to be removed (to maintain anonymity).

### **1.3 Analysis of data**

While it is undeniable that large volumes of qualitative data (e.g., written forum statements and interview transcripts) will be invaluable in furthering our understanding of mental ill health experiences, the current methods of analyzing such data (e.g., thematic analysis) are potentially problematic when implemented at scale. For example, the reliance on the researcher's manual effort to read and re-read the patients' narratives (data), moving back and forward constantly between the entire data set to identify, and interpret patterns from it, restricts the size of sample, in terms of practicality and economy. It is difficult to imagine doing thematic analysis on 10,000 narratives (for example). Furthermore, the outcome of such human-driven manual analysis is argued to be less "scientific" as it is difficult to replicate and is open to researcher's bias. Indeed, many qualitative data-analysis methods have been traditionally criticised for lacking rigor, and producing impressionistic and biased results (Mackieson, *et al.*, 2018).

On the other hand, quantitative methods of data analysis use statistical inferences and the outcomes are often regarded as more reliable, valid, and acceptable in the scientific community. This higher regard is attributable to several characteristics of quantitative data analyses over qualitative data-analysis. For example, in quantitative methods, the results are regarded as are more objective and less subjective, thus there is less likelihood that quantitative results will have multiple interpretations. For example, if the correlation coefficient is 0 (i.e., no association between X and Y) then it is unlikely that two different researchers would interpret it any differently. Such statistically driven methods are less reliant on the researcher's personal experiences which reduces research bias. In a similar vein, the objectivity of quantitative data-analysis methods also offers more scope for replicability (where similar studies and analyses produce reliably similar results). Furthermore, through the use of larger sample sizes quantitative results offer generalizability to the wider population from which samples have been drawn. Finally, from an economical perspective, quantitative data collection methods allow for data collection at scale, in lesser timeframes and at lesser to no costs compared to their qualitative data collection method counterparts (Carr, 1994).

### **1.4 The network approach: a complementary approach to the study of psychopathology**

As alluded to above when discussing individual symptoms as the preferred unit of analysis for future studies, one particularly effective methodological tool which takes this approach is Network analysis. Network analysis, as applied to psychopathological symptomatology, allows for the exploration of specific individual symptoms and their item-level interactions. The network approach to psychopathology was first proposed by Borsboom (2008) and empirically demonstrated by Borsboom and Cramer (2013). Therefore, the use of network analysis as a methodological tool to facilitate our understanding of psychopathology can be regarded as relatively new. Of note there has been a proliferation of psychopathological network analysis studies in recent years (e.g., Armour, *et al.*, 2017; Armour, *et al.*, 2017; Beard *et al.*, 2016; Contractor, *et al.*, 2017; Fried *et al.*, 2018; Ross, *et al.*, 2018; Zamani Esfahlani, *et al.*, 2018).

From a network analysis perspective, the manner in which symptoms associate to one another is core to our understanding of the disorder rather than the commonly held perspective that each individual symptom is an equal and interchangeable underlying representative of the overarching disorder. The principle is that the more connected a symptom is to other symptoms in the network the more central or pertinent it is to that disorder. Consequently, being more connected also equates to a greater ability of the symptoms to spread activation to other symptoms within the network. Symptoms that are less connected are believed to be peripheral to the disorder as their

ability to impact on other symptoms is lessened. In the language of Networks analysis symptoms are referred to as nodes and connections (association between nodes) are referred to as edges (Armour et al., 2017; Fried 2015).

We argue that a key strength of Network analysis is its ability to find important and potentially clinically meaningful associations between psychopathological symptoms in addition to identifying symptoms which are most central thus influential within a diagnostic network. It is important to note that we use ‘influential’ in a descriptive, rather than a causal, context. This means that while these nodes are prominent or central within the network, their “influence” is not meant to imply a direct causal relationship with other nodes or outcomes within the network. Doing so can generate hypotheses for future experimental studies including the direct targeting of individual symptoms in clinical treatment plans (which may or may not uncover causative relationships). It is, however, pertinent to note that a recent study found that commonly reported node centralities measures (i.e., degree, betweenness, and closeness) were weak (Dablander & Hinne, 2019). The same study pointed out that Eigenvector Centrality is an exception to this (and can indicate causality); interestingly, not many network studies in psychopathology have focused on eigenvector centrality (further reading on eigenvector centrality, see Bonacich, 2007) to date.

### 1.5 Current study

To conclude, we argue that a research methodology which allows researchers to 1. focus on mental illness at the symptom-level, 2. use large volumes of qualitative data collected from relevant sources (e.g., digital platforms) and 3., analyze large volumes of qualitative data using quantitative data-analysis procedures has the potential to further our understanding of psychopathology by merging all the advantages of qualitative and quantitative methodological techniques whilst simultaneously removing a number of the above noted criticisms of both.

In this study, we present an empirical investigation of the broad spectrum of psychopathology (without restricting to any specific DSM/ICD categories) from a network perspective. We investigated associations based on co-occurrences of psychopathological experiences, using patients’ undirected, freeform first-hand narratives, rather than survey responses. In doing so, we had three aims, all of which were uniquely facilitated by our use of narrative data on patients’ lived experiences. First, we aimed to describe the overall structure of the undirected network graph. This was expected to generate insight into the number of relationships that connect the number of symptoms/experiences in the network, as reported by patients, as a starting point for further study. Our choice of undirected-type links was based on the rationale that in textual data (sourced from the narratives), the sequence of paired words does not necessarily indicate a temporal sequence. For example, a person might mention “anxiety” and “low mood” in an active voice. In contrast, the same sentence can be written in passive voice by another patient, altering the sequence of symptoms “low-mood” and then “anxiety.” Thus, it is not possible to infer, unambiguously, directions between symptoms.

Second, we aimed to assess the relative importance of nodes (e.g., symptom descriptions) in the network using node-centrality (in this case primarily eigenvector, but also degree centrality), which may, in turn, be used to inform interventions (e.g. Robinaugh et al., 2016, and McNally et al., 2016).

The extant literature suggests that a symptom’s centrality is positively correlated with the strength of association between change in the symptom and change in the remainder of the network (Robinaugh, et al., 2016; Rodebaugh et al., 2018), although this, of course, does not tell us that change in that symptom causes a change in the remainder of the network. Since the literature often uses the term “influentiality” to refer to the importance of the node in the context of eigenvector centrality, we will use the term “influential node” in this article to maintain lexicographical consistency. However, it is important to note that the word “influence” should not be interpreted in a causal sense. A node will have a high eigenvector if it is associated with many other nodes in

the network either directly or via multiple other nodes. A node will have high degree centrality if it has many direct links. Therefore, the word “influence” is to be interpreted as a measure of linkages throughout this paper. We then selected the nodes with the ten highest-scoring eigenvalues (suggesting the ones with the greatest influence in the network) for further analysis. These high influencers were prioritized over others because such symptoms and experiences are the ones that are linked with most of the other conditions in the network, indicating potential co-morbidity. Evidence suggests co-morbidity is associated with greater impairment, more treatment-seeking, and worse outcome in patients (Noyes, 2001).

Third, we examined another property of the network graph related to the frequency with which we observed co-occurrences of symptoms; the *weighted strength* of relationships (edges) between symptoms (e.g., A is more strongly connected to B than B is connected to C). We present the five most frequently co-occurring pairs of symptoms (i.e., dyads) and describe the total number of co-occurrences mined from the patients’ free form narratives. This offers insight into reported co-occurrences that could help efforts to discover potential targets for combination drugs or interventions or to design more comprehensive questionnaires, scales, or interview schedules. Finally, we discuss some of the unusual linkages in the context of the existing literature to demonstrate the potential of this novel research methodology to discover hidden patterns or associations that are under-researched.

## 2. Method

### 2.1 Participants

The study was based on the personal narratives of 10,933 people who noted a prior diagnosis of a mental illness. Given the nature of the data, we do not have the patients’ sociodemographic information or their geographic location. No directly identifiable data were collected, and narratives were disassociated from usernames before analyses. We collected only English text, indicating that the patient knows how to write in English (inclusion criteria). Our sample covers narratives from the patients diagnosed with different disorders, spanning 84.2% of all the diagnostic categories mentioned in the DSM 5. However, our sample lacked any narratives for 3 out of the 19 categories, likely owing to stigma, lack of knowledge, or inability to recall or write memories due to the nature of the condition. Specifically, the database does not include patients who have explicitly mentioned being diagnosed with neurocognitive disorders (e.g., dementia), paraphilic disorders (e.g., pedophilia), or elimination disorders.

### 2.2 Procedure of data-collection source of data

**Identification of data:** The first step involved scraping the data from an online journal (i.e., live journal, <https://www.livejournal.com/>). The online communities within Live Journal works on user-generated content. That is, the website relies on the general public to share the stories of their lived experiences with mental illness (allowing them to do so anonymously). Based on the interests of people, there are several communities ranging from toys and games, to people talking about fashion. We included the data from the communities which are interested in “mental illness,” “mental health” along with search terms of specific disorders and their abbreviations (e.g. “Borderline Personality Disorder” or BPD and “Major Depressive Disorder” or “MDD”) of all disorder names mentioned in the traditional diagnoses.

However, this should not be inferred as if we are sanctioning the use of the traditional diagnostic categories (of DSM and ICD). Instead, we used narratives which received a DSM/ICD diagnosis as a measure to ascertain that they are from people who sought mental healthcare service, and experienced significant psychopathological symptoms for a prolonged period of time



(e.g., to qualify for MDD, the person needs to experience the symptoms for at least 2 weeks). Note, we used the DSM-5/ICD-11 diagnosis as the inclusion criteria to ensure that the studied narratives are from patients who sought help and received a diagnosis from the conventional mental healthcare system. However, there might be several people who chose to suffer in silence or could not afford and access mental healthcare facilities. This study did not include them and therefore the findings are based on people whom the conventional psychiatric system would label as mentally ill. This is different from the above-mentioned studies, which studied DSM/ICD categories because those studies (ones we reviewed) tried to understand mental disorders through the lens of the traditional diagnostic manuals. But the current study uses the DSM/ICD diagnosis as an inclusion criterion in its attempt to understand psychopathological experiences (at symptom-level) of people labelled as mentally “ill” irrespective of the diagnosis they received.

**Reviewing the data:** After it was scraped and downloaded on the computer, we chose to analyze the narratives coming from patients who received a diagnosis of mental disorder (based on DSM/ICD) to ensure that they have psychopathological conditions (assuming that otherwise, they would not have consulted the psychiatrist). That being said, it is pertinent to note that throughout this study, the DSM/ICD-based diagnostic labels were not utilized for analysis and irrespective of the diagnosis the patients received they were treated in the sample pool. Thus, the utility of the DSM/ICD diagnostic categories remained limited to the inclusion criteria (indicative of people who sought or was referred to mental healthcare facility which resulted in reception of the diagnosis) of the sample in this study.

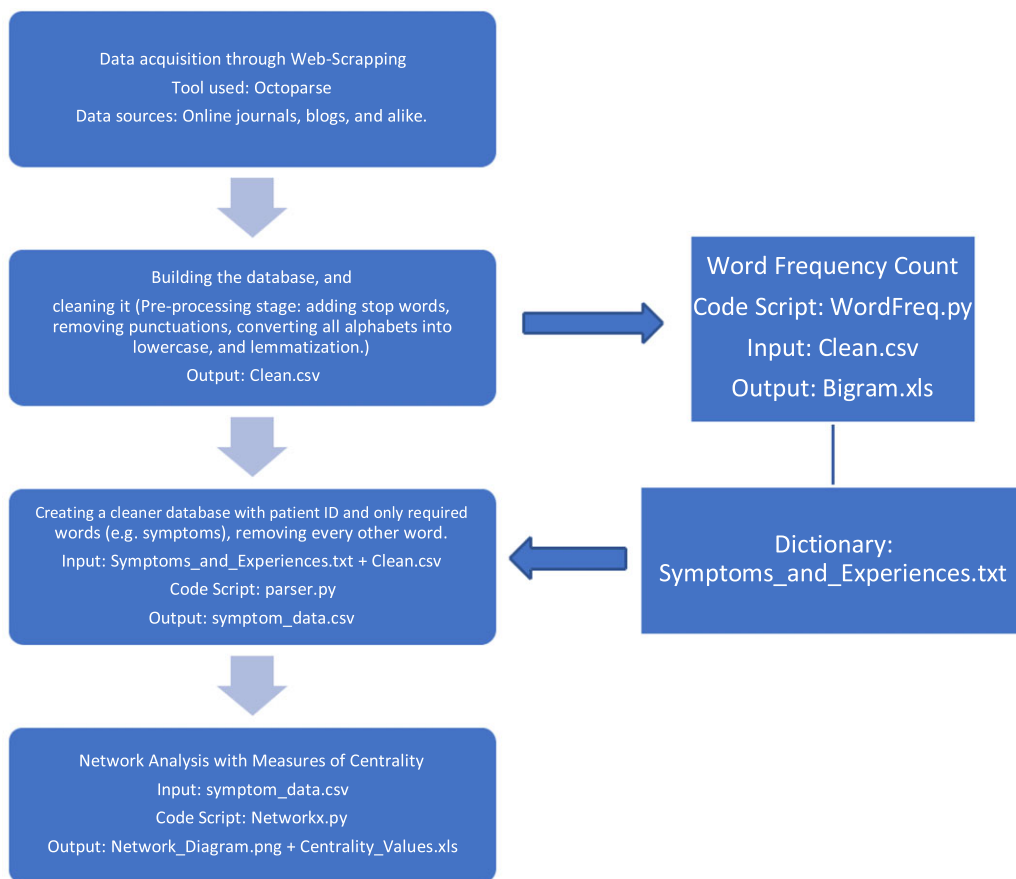
**Selection of the data:** Data from communities with at least 200 posts are included from LiveJournal. The exclusion criteria for the narratives was a minimum of 15 words (that means, if they wrote less than 15 words they were excluded). Narratives which had a couple of words (e.g. “Hi friends, good morning. Wish you have a good day!”) and which did not have contents about the patients’ lived experience were removed from the dataset. The communities with specific interests were identified through the “Search communities by interest” provided by LiveJournal (<https://www.livejournal.com/interests>).

### 2.3 Procedure of textual analysis

Ten thousand nine-hundred and thirty-three narratives were drawn from the online communities using convenience sampling because there is no single systematic register from which to select randomly. The network graph was built using Python 3.7 (on Spyder development environment) and several libraries such as NLTK, Networkx, Matplotlib, Seaborn, and Pandas. Figure 1 describes the stages of the network graph building process.

Figure 1. All code scripts (with .py file extensions), datasets (.csv), results (.xls, .png), and dictionaries (.txt) are available in the appendix folder.

**Data Cleaning:** When it comes to posting on online forums, participants can be creative in their ways of expression. For example, there are short-forms (“tbh” to indicate “to be honest”), poetic expressions, inconsistent use of punctuations, use of alphabets/signs and symbols in a creative fashion (such as use of “@home” to indicate while at home) and thus the raw data needed to be transformed into a cleaner format that was understandable by the computer. We ran a code script to enlist the frequently used words. On manual inspection of that list, we noted the above-mentioned words that are irrelevant or inappropriate for our further analysis. Thereafter, those words were removed from the MS Excel file using “Find and Replace” option. Such words were replaced with blank spaces. Therefore, the corpus was cleaned. Using the same method of using “Find and Replace” option on MS Excel, certain words were collaged (to ensure that they are treated as a single entity). For example, words such as depressed, mood, loss, interest, mania,



**Figure 1.** Building the network graph.

and depression as “depressed\_mood\_and\_loss\_of\_interest” and “mania-and-depression” were collaged together with under-spaces and hyphens to inform the algorithm that these were an individual entity. We also transform a word to its root form. For example, depress and depressive both becomes depression. This step is called “stemming” in the literature.

**Preparing dictionaries:** After the corpus was preprocessed (i.e., cleaned), a code script (i.e., “wordfreq.py”) was run to generate one-word (unigram) frequencies to determine the most common words. This was performed to learn the words which would indicate themes in the sample corpus and to remove uninformative words (such as “howdy,” “burning,” and any other words that might have multiple meanings and do not indicate symptoms/experiences) from further analysis. The words in the dictionary were based on a manual screening of the word frequency table using domain knowledge, combined with reference to the DSM-5 (APA, 2013), ICD-10 (WHO, 1992), and mental health websites (e.g. [www.mind.org.uk](http://www.mind.org.uk)). Note, while we did refer to the DSM and ICD for gathering collections of words (as one of the sources of words), but we majorly focused on manual scanning of the words the patients wrote about their mental ill health experiences. These words were identified by a male, Early Stage Researcher in about 20 hours. The outcome was checked by three senior academicians. Discordances were resolved through mutual discussions and agreement. The level of analysis did not presume any manifested or latent content.



Instead, it included words that are clear representative of expressed symptoms (e.g., worry and sleeplessness). The relevant words can be found in the “symptoms and experiences.txt” file.

**Parsing with symptom/experience-based dictionary:** The purpose of this dictionary was to clean the corpus further using the Parser function (Parser.py), keeping only the dictionary words in the corpus and minimizing the number of irrelevant words. This is important to avoid unnecessary words from creating noise in the network structure.

To wrap it up, so far, we have collected the data, cleaned the data, and have generated a version of the dataset that only consists of symptoms and experiences of patients.

## 2.4 Preprocessing

The next step is to do the final preprocessing of the data and then to generate the network graph with the appropriate estimation of the parameters. Both of these steps are explained below and was compiled together in a single code script (i.e., network.py). Note, all of the following process and steps were done by the algorithm using an automated process without human intervention.

The standard procedure for preprocessing of data in natural language processing consists of the following four steps:

1. **Tokenization:** We start with splitting the sentences into words (entities).
2. **Lower casing:** At this stage, we also converted all words into lower case. So, words like “Depression” and “DEPRESSION” were converted into “depression”. This was necessary because although both the words mean the same to us, humans but computer treats them as different words when not converted to the lower case.
3. **Stop words removal:** Here, we will remove the irrelevant or non-sensible words from the document). Examples of stop words we removed are “ing,” “name,” “#,” “injunctions,” and “ful.”
4. **Lemmatization:** In this step, the words were reduced to a word existing in the language. For example, caring becomes care and saddening becomes sad. This is similar to the stemming process we did in preliminary cleaning of data (as mentioned above).

## 2.5 Network analytics

Finally, when the required corpus was ready to be analyzed, the Networkx (Python) package was used to create and study the structure of the network. We used degree centrality (Freeman, 1979), and Eigenvector centrality (Newman, 2003) to estimate the relative centrality of each node. Degree centrality refers to the number of links that a node has or the number of direct neighbors. The higher the degree, the greater number of total connections a node has. Eigenvector centrality refers to the measure of the influence of a node in a network. Therefore, a higher score indicates a node that is connected to many nodes themselves with high numbers of edges. The generated network graph is available online for further reference ([https://chandrill.github.io/psychopathology\\_network/network/](https://chandrill.github.io/psychopathology_network/network/)).

The total runtime of the program, or the total time it took our algorithm to analyze personal narratives of 10,933 people was about 19 s (to be precise 18 secs 53 milliseconds). Within this time-frame, the algorithm also generated the network graph and estimated the measures of centrality for all the symptom or experience.

Ethical approval was awarded by the Queen’s Management School Ethics Committee. We followed the guidance for internet-mediated research from the British Psychological Society (2017) and adhered to copyright laws in conducting this work. The Queen’s Management School Ethics Committee also agreed that it was not necessary for individuals (consent waiver) whose accounts,

posted on public fora, constitute the data used in the research, to give consent for the data to be used for the research purposes. And the study was conducted in accordance with relevant guidelines and regulations.

### 3 Results

#### 3.1 Description of the data

The average length of each narrative (before processing) was 586.5 words ( $SD = 48.8$ ). After cleaning the data (i.e., keeping only the symptoms and removing other parts of the sentences), the patients reported an average of 4.8 symptoms with an  $SD$  of 3.8. From the text accounts of people diagnosed with mental illness, we realized that the authors of these narratives are at different phases of their illness and recovery process. The raw data of peoples' lived experiences cannot be made public over privacy concerns. For example, even though the names of people are anonymized from the patients' end, but there are occasional mentions of the locations, gender, race, organizations, and other peoples' names in those narratives. However, a preprocessed version of the data can be acquired from [https://github.com/Chandril/patient\\_narratives\\_processed\\_data](https://github.com/Chandril/patient_narratives_processed_data) (data-file titled as data29.csv).

#### 3.2 Description of the sample

Figure 2 depicts the distribution of diagnostic categories across the narratives. Note that many people received multiple diagnoses, either at the same time or overtime—indicating diagnostic heterogeneity—so we report these statistics as the number of cases (i.e., the number of narratives) rather than in percentage form.

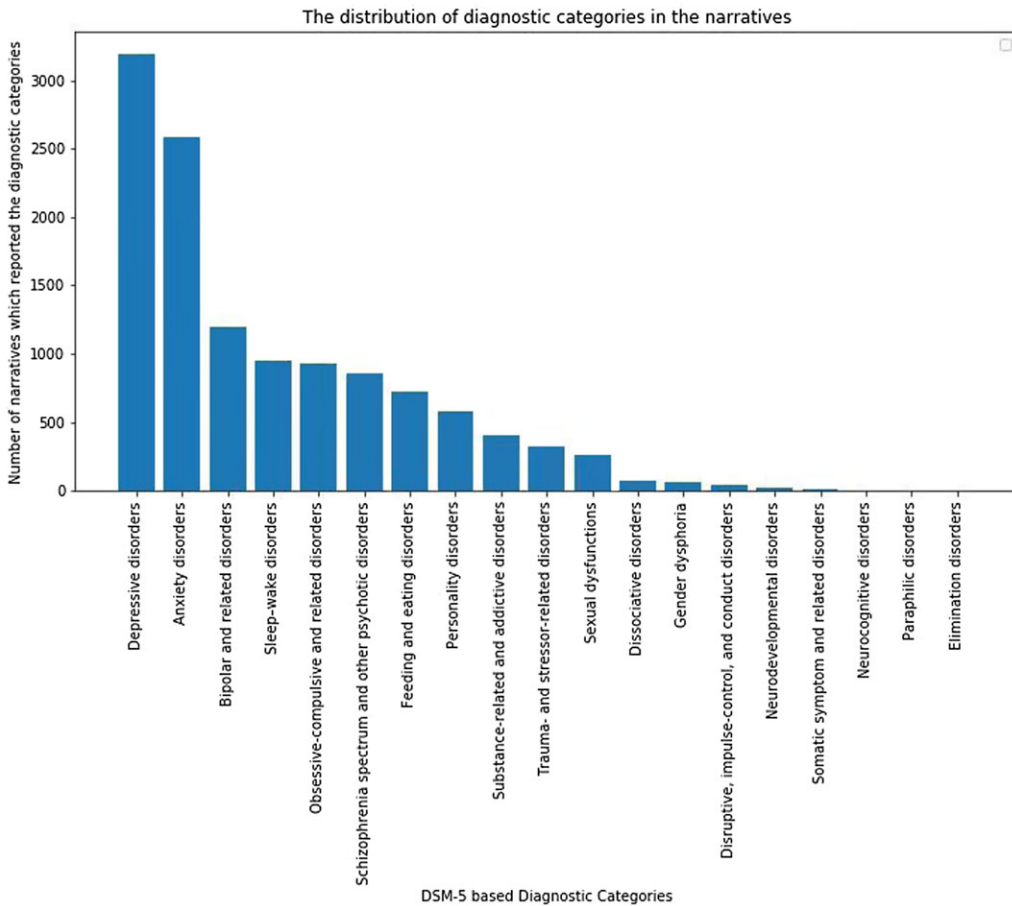
#### 3.3 Description of the network graph

A preliminary analysis of the resultant network structure revealed that 39,689 combinations of words (co-occurring pairs) were generated from the complete list of most-frequently co-occurring symptoms. We then subtracted the repetitive pairs (A-B and B-A were counted as one), and likewise, A-A and B-B were also removed. The filtered list has 30,023 edges. The edges in this study should be inferred as co-occurrences. If A and B occur together, then they have an edge/link between them. We restricted our discussion to the top 5 most-frequently co-occurring pairs out of the 39,689 linkages—for conciseness. However, we acknowledge that studying rare/infrequent linkages may also be informative because it might indicate uncommon health conditions that nonetheless may require greater understanding. To this end, although we do not discuss any such infrequent linkages, we have presented an interactive online network graph.

#### 3.4 Network-level analysis

The network generated 672 nodes (variables or symptoms), 30023 edges (links or connections), with the average degree (number of edges per node) being 89.35. The network graph was built on the results of the bigram-word frequency count of the narratives (as depicted in the procedures in figure 1).

The online animated network graph can be found here ([https://chandril.github.io/psychopathology\\_network/network/](https://chandril.github.io/psychopathology_network/network/)). It is an undirected network graph where the color of nodes represents eigenvector centrality, or the measure of a symptom or experience's influence on the network, with the darker shades representing higher values of eigenvector centrality. The degree centrality is shown by the size of the node, with more central nodes shown as larger. Some of



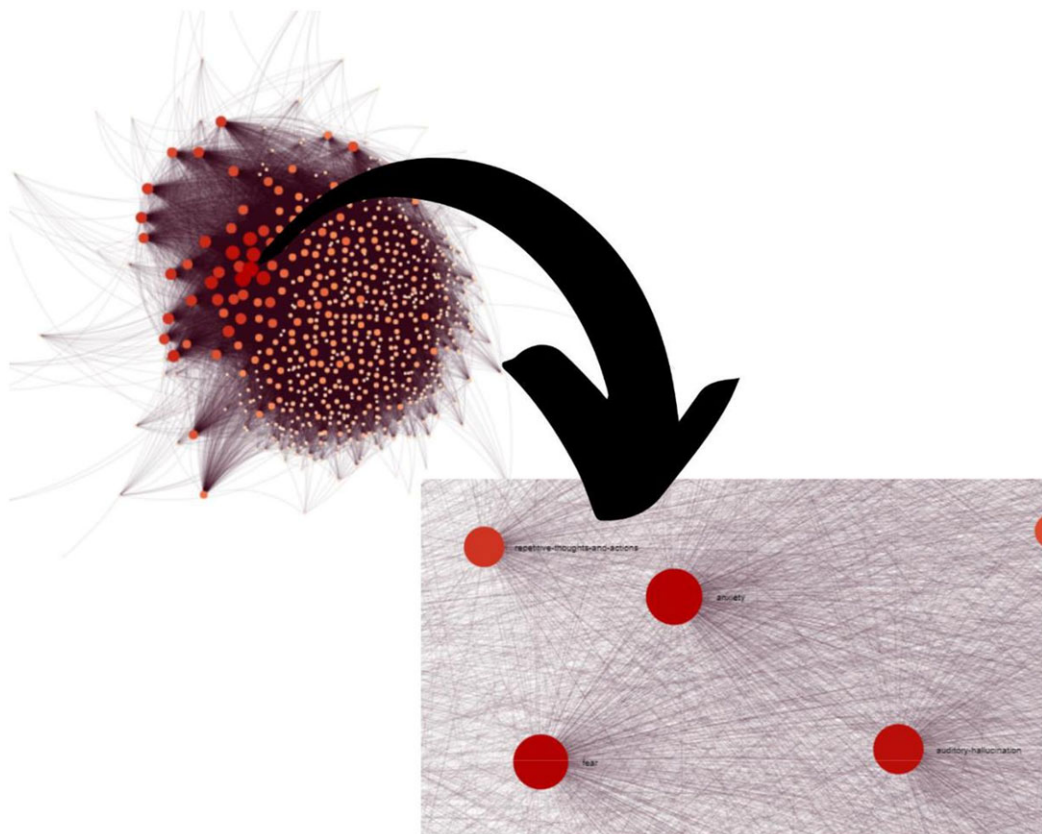
**Figure 2.** The distribution of diagnostic categories in the narrative sample.

the edges have been highlighted in yellow for convenience of visualization. The network graph displays how influential a node is in the network by node size (degree centrality) and color (eigenvalue centrality).

### 3.5 Symptom (or node)-level analysis

Figure 3 shows how influential a symptom, or an experience was in the network graph consisting of 30023 bigrams (co-occurring pair of words). A correlation coefficient of 0.98 suggested there was a strong correlation between a node's degree and its eigenvalue.

Table 1 shows that anxiety was the symptom or experience that was most connected to other high-linkage nodes, making anxiety the most central node in the network. Likewise, the experience of fear and auditory hallucination were the second and third most central nodes in the network. For example, anxiety has the highest eigenvector centrality indicating that it is likely to co-occur with the symptoms/experiences (e.g., fear and sadness) that happen to frequently co-occur with other symptoms/experiences (e.g., loss and loneliness) in the network. In that way, anxiety becomes the node that is connected to most other nodes in the network directly or via another node.



**Figure 3.** The network of psychopathological experiences.

### 3.6 Relational-level analysis

The frequency of co-occurrences of symptoms demonstrates the commonality of each relationship. The most frequently reported linkages—shown in Table 2—are those that a larger proportion of patient’s report. Combined, in the database, there were 30023 dyads or pairs of words with each dyad reported three times on average (ranging from “low-mood/loss-of-interest and anxiety” reported 583 times to “trauma and nightmare” being reported only once).

## 4. Discussion

Our approach to conceptualizing psychopathology proposes no classification at all (neither hard boundaries like DSM nor soft boundaries like HiTOP). Instead, we posit symptoms as interacting between themselves and over time. In this study, we aimed to describe the resulting network of psychopathology, to identify which symptoms most influenced the network, and to explore how those symptoms interacted with each other.

### 4.1 Which type of patients does the sample represent?

Figure 2 shows that anxiety and depressive disorders were the most common in our database, consistent with other studies which similarly found them to be the most common disorders in 56 countries (e.g., Steel, et al., 2014 and James et al., 2018). However, depressive disorders were

**Table 1.** Top five symptoms and experiences with the highest values on measures of centrality in the undirected graph

Rank by influence (eigenvalues: Descending order)	Nodes	Eigenvalues	Degree Centrality (direct neighbours)	Frequency of term-occurrence
1	anxiety	1	572	5301
2	fear	0.992979	557	1862
3	auditory hallucination	0.945722	499	1309
4	Depression mood and loss of interest	0.935859	492	7440
5	sadness	0.932454	492	244

**Table 2.** Five examples of frequently co-occurring symptoms in the patients' narratives

Pairs of reported symptoms	Frequency of co-occurrence
depressed mood and loss of interest, anxiety	583
anxiety, fear	312
disinhibition antagonism negative affectivity, personality	309
anxiety, repetitive thoughts and actions	156
auditory hallucination, fear	138

more common than anxiety disorders in our data, in contrast to James et al., 's (2018) conclusion that anxiety disorder had a higher prevalence than depressive disorders. Compared to these earlier prevalence studies, our data seemed to under-represent patients with substance-related and addictive disorders and people with a neurodevelopmental disorder (e.g., intellectual disability and attention-deficit/hyperactivity disorder). Also, our data appeared to over-represent patients with bipolar disorder and schizophrenia spectrum and other psychotic disorders.

#### 4.2 Which symptoms or experiences were the most important?

Our results on term-frequency—number of narratives reporting a term— complements existing evidence suggesting that generalized anxiety disorder (nodes like anxiety and fear) and major depressive disorder (nodes like sadness and depressed mood and loss of interest) are the most common comorbid conditions with other disorders, both in community and clinical populations and both in children and adults (Noyes, 2001). Furthermore, the data on global prevalence suggest that anxiety disorders (6.7% in 122 studies covering the sample of 586043) and mood disorders (5.4% in 148 studies covering the sample of 693722) are the most common disorders in 56 countries (Steel et al., 2014). Likewise, auditory allucinations are common too (up to one in ten individuals, mean lifetime prevalence = 9.6%) in the general population during lifetime (Maijer, et al., 2017). These and other highly central nodes may be particularly useful in directing further research or potential targeting of clinical interventions.

#### 4.3 Why anxiety and depression are highly comorbid (have high eigenvalues)

In daily life, an individual need to regulate his/her activity in response to information s/he gets from the environment, and we need an optimal behavioral strategy to be able to do so efficiently. This strategy sometimes produces instances of low mood and anxiety as by-products (Trimmer, *et al.* 2015), which might sustain even after the situation has improved. From another perspective, it can be argued that pathological anxiety and “depressed mood and loss of interest” are an exaggerated/dysregulated/dysfunctional response of two basic universal emotions: sadness (reaction to loss) and feeling afraid (reaction to threat). Therefore, they are related to the primal instincts of survival and are more prevalent (and probably more debilitating) than the pathological conditions related to thoughts produced/processed by the frontal lobe (especially neocortex) such as dissociation. Finally, the high influentiality of anxiety and “depressed mood and loss of interest” might be explained with the argument that they stem from the basic emotions of fear and sadness (coupled with other basic emotions). People are likely to experience the basic emotions (and their pathologies) as a response to any other psychopathology or even medical condition/disability. For example, if someone is experiencing an auditory hallucination, they might experience fear of the unknown (e.g., from where this voice is coming from?).

Future experimental studies can utilize these highly central nodes and their edges to determine their independent and dependent (treatment and outcome) variables. Additionally, our findings might also help researchers focus on these specific nodes/edges drawn from patients’ experience while collecting data from patients (using questionnaires/interviews). Such data-driven inclusion of symptoms/experiences in the data recording device is expected to remediate the concerns as mentioned above over current survey designs—where researchers include variables they may subjectively find important.

Future research can investigate if and to what extent the person’s overall experience of mental ill-health is alleviated when such highly central nodes are intervened upon. If this strategy is found to help patient well-being significantly, then future drugs and interventions could focus on targets in this way.

#### 4.4 Relationships between nodes

In this study, we found that there are 30023 pairs of co-occurring words. Among the five most frequently co-occurring dyads, the combination of auditory hallucination and fear is not consistent with the DSM-based categorical boundaries where they are treated as elements of different disorders, such as schizophrenia and anxiety disorders, respectively. This demonstrates comorbidity or the problem of diagnostic heterogeneity with the DSM. However, such relationships can be discovered using NA on unrestricted patient narratives depicting their illness experiences.

Each node is connected to several other nodes in a pearl beads necklace fashion, presenting themselves as trajectories or pathways of psychopathology. Future studies on experimental manipulation of individual nodes to evaluate its impact on other nodes on the necklace structure are expected to reveal how to tackle the prioritization of the treatment in a patient on this particular trajectory of illness.

#### 4.5 Discovering associations

We found that dissociation was associated with panic-attacks (a symptom in anxiety disorders as per the DSM). We found only three empirical studies on this, two dating from two decades ago and the third more recent. These studies paint a mixed picture; one suggests an association (Ball, *et al.*, 1997), one suggests no association (Marshall *et al.*, 2000), and the third suggests panic attacks do not predict dissociative symptoms (Myers & Llera, 2020). Finally, a review paper discussed dissociation in anxiety disorders (Mula, *et al.*, 2007). But overall, the literature in this area is very sparse. Further exploration of this link and the mechanisms behind it appears warranted



and vital—because patients with panic disorders (as per the DSM) with co-existing dissociative symptoms might respond to psychopharmacological treatment negatively (Ural, et al., 2015).

Another interesting finding was the discovery that repetitive thoughts and compulsions (traditionally classified as obsessive-compulsive disorder, OCD) was found to be associated with auditory hallucination in 47 narratives. The conventional wisdom suggests that OCD is not classified as a psychotic disorder, so it would not generally cause auditory hallucinations which are a form of psychosis. Additionally, intrusions (of thoughts) and voice hearing are perceived with different intensity by patients (Moritz & Laro, 2007)—although they share similar perceptual qualities and impairment in the intentional cognitive inhibition (Badcock, Waters, & Maybery, 2007). But the high co-occurrence raises the possibility that there might be a direct/indirect causal relationship that underpins this association—and it could be significant interventional merits.

Some of the co-occurring symptoms are not consistent with the DSM or understudied in our current literature. For example, the relation between auditory hallucination and fear. More such relationships were discovered and discussed later in the next section.

Based on closer inspection of the nodes with the highest eigenvalues, we found several unusual direct connections, of which two particularly interesting ones were that dissociation was connected to experiences of auditory hallucination, and repetitive thoughts/compulsions were connected to auditory hallucination.

#### 4.6 Clinical application

Our approach has the potential to directly benefit clinicians by helping them ask more relevant questions and probe into the symptomatic experiences, which otherwise might go missing and unreported. A resultant scale or questionnaire from this study might benefit clinical work. Our approach also has the potential to aid the pharmaceutical industry to develop drugs that are targeted toward a series of interconnected symptoms.

#### 4.7 Limitations

We used the patients' lived experiences with mental illness as the source of data. It is to be understood that all our findings relate to the patients' viewpoint, and what she or he chooses to report, and remember. So, it is vital to acknowledge the possibility that the patients' narratives may have been informed/influenced by extraneous factors such as reading online about the illness (including DSM/ICD categorizations of illness), expectations, social-desirability, memory, and cognitive biases (e.g., confirmatory bias). Furthermore, such self-reported narratives focus on the internal experiences/struggles of individuals (e.g., sensory experiences like hearing voices, emotional distress, and disturbances) rather than how they interact or cope with their external world (e.g., specific behavioral patterns, such as narcissism or manipulation). For example, how a person labeled with narcissistic personality disorder (or any other diagnosis) experiences his or her inner world, instead of focusing on how they interact with their external world (e.g., manipulate others to get their job done). It is unlikely that people will be aware which of their beliefs are delusional, and even more unlikely that they will be aware of their pride, egotism, and a lack of empathy (for example). They might not be aware of the fact that they engage in manipulation/exploitation of others, engage in antisocial behavior, demonstrate impulsivity, selfishness, callous and unemotional traits, remorselessness, and so forth. So, given the nature of our data, we did not inspect these aspects of psychopathology in our study.

Another limitation is that we cannot distinguish between the root and leaf nodes (lack of directionality) from an undirected network like the one we built. However, the rationale for our choice lies with the fact that we have used textual data and people tend to write both in active and passive voices which might blur the sequence of symptoms. Therefore, we claim neither directionality nor causality.

We build the network graph that estimated more than 30k edges/links, and this could be highly problematic for the stability and replicability of the network. However, our aim for this study was more inclined toward exploratory analysis (to learn what it is to live with a mental health condition) than to build a model of mental illness.

We acknowledge that at the end we do not know who these patients are (e.g., sociodemographic characteristics) and owing to the lack of contextualization of data the generalizability of the results is limited. The published first-person narratives from patients and such published work likely mean that not all types of patient, at all stages of their illness, and from all backgrounds were included. Instead, these sources of data seem likely to disproportionately draw on patients who are more expressive, out-going, literate (enough to write in the English language), insightful, and perhaps most importantly, who have recovered to the extent of being able to write their retrospective accounts. This might mean a section of patients with psychopathology might not be represented in the study.

#### 4.8 Future directions

Future studies can probe into generating lists of symptoms and experiences related to a node using the complete list. We expect our findings to motivate future studies interested in specific symptoms or experiences and relationships between them. Future studies could also identify which people (e.g., parent), aspects of society (e.g., religion and employment), and coping mechanisms (e.g., drugs and talk-therapy) were most influential to certain symptomatic experiences of the patients. In-depth interviews with patients might help inform this network model of psychopathology further.

Since the data were gathered cross-sectionally from patients in different phases of their illness and recovery process, we cannot derive any temporal inferences from the present study. However, future studies based on specific phases of the illness course with either cross-sectional or longitudinal data perhaps might. That might also help in making causal inferences, which in turn could inform interventions.

## 5. Conclusions

With this study, we have presented an alternative route to understand psychopathology, that is, without relying on the DSM or ICD categorical diagnoses. We demonstrated that rich amount of information can be harvested by analyzing patients' lived experiences. In doing so, we demonstrated a relatively novel method using network analysis to study psychopathology, one which enables researchers to collect huge volumes of rich-qualitative data, and analyze it using a quantitative method. Overall, our findings might complement the recent advances of HiTOP and RDoC. More direct application domain involves development of scales and questionnaires based on the symptoms found to have higher eigen-values in the network structure. Such experience/data-based scales in turn might benefit the different stakeholders such as insurance companies, charities, and government by reducing ineffective expenditures through the more informed allocation of resources, ultimately increasing patient well-being, reducing consumer dissatisfaction, and avoiding potentially misleading diagnostic categories. Finally, with this study, we hope to underscore the importance of "listening to our patients" in order to further the future toward personalized patient-centric mental healthcare.

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