

Talking about personal recovery in bipolar disorder

Background and research questions

Personal recovery, 'a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness' (Anthony, 1993) may be particularly important in bipolar disorder, where symptoms often persist despite adequate treatment. Several quantitative and qualitative studies had demonstrated this. The first question, this project addressed was:

- 1) What do we know about the experience of personal recovery in bipolar disorder from qualitative research?

However, all this research stems from researcher-controlled settings such as interviews, focus groups or questionnaires, which might impact what people say and how they say it. Prior to this project, little had been known about how people with a bipolar disorder diagnosis talk about personal recovery outside of research environments. It is tricky to gather naturalistic data where people act spontaneously without the presence of researchers. Looking at public online posts is one way to capture interactions that are not influenced by a research setting. Therefore, the project analysed public online posts of people who stated on the online discussion platform Reddit (reddit.com) that they had a bipolar disorder diagnosis. The dataset collected for this research project consists of 20M online posts by about 20K people, and roughly 1B words. The project used a mix of qualitative and quantitative methods to answer three additional research questions:

- 2) What are the characteristics of Reddit users with a self-reported disorder diagnosis?
- 3) Are there differences in terms of the expressed emotions and mood of the posts and users in mental health and non-mental health forums?
- 4) What can we learn from online posts about the experience of personal recovery in bipolar disorder?

Below are brief summaries for the studies we conducted to answer each of these four questions. You can find more information in our publications and the full thesis "" (see the end of this page for references).

We would also like to mention that it is not uncontroversial to analyse online posts without the explicit consent of the users who wrote them, even if it is data is in the public domain such as all public Reddit posts. Due to the large volume of the data, it was not feasible for us to ask the post authors for their explicit consent. Therefore, we did not disclose any usernames in our publications. In this kind of research, we need to weigh up the benefits of doing it vs its risks. We hope that this research did not cause undue harm to anyone whose posts were used to inform this work. Rather, we hope that this research led to a better understanding of personal recovery in bipolar disorder and may eventually contribute to better support and treatment for people living with bipolar.

What do we know about the experience of personal recovery in bipolar disorder from qualitative research?

This systematic review literature review combined the evidence of 12 qualitative studies on personal recovery in bipolar disorder from 2010-2020. The CHIME recovery framework has been mainly developed in the context of schizophrenia and comprises the main domains Connectedness, Hope & optimism, Identity, Meaning & purpose, and Empowerment. Our literature review found that it also captures many aspects of personal recovery in bipolar.

However, it overly focuses on the positive aspects of the personal recovery journey. Yet, we also found a lot of evidence for negative experiences and difficulties. Therefore, the POETIC framework (Purpose & meaning, Optimism & hope, Empowerment, Tensions, Identity, and Connectedness) extends CHIME with a Tensions domain to capture some of the tensions and ambivalences that people with bipolar disorder often need to navigate in their personal recovery.

The below table shows the six main domains of the POETIC framework along with its subcategories. You can find more information in our publication [Personal recovery in bipolar disorder: Systematic review and "best fit" framework synthesis of qualitative evidence - a POETIC adaptation of CHIME](#) (see here for a [freely accessible version](#)).

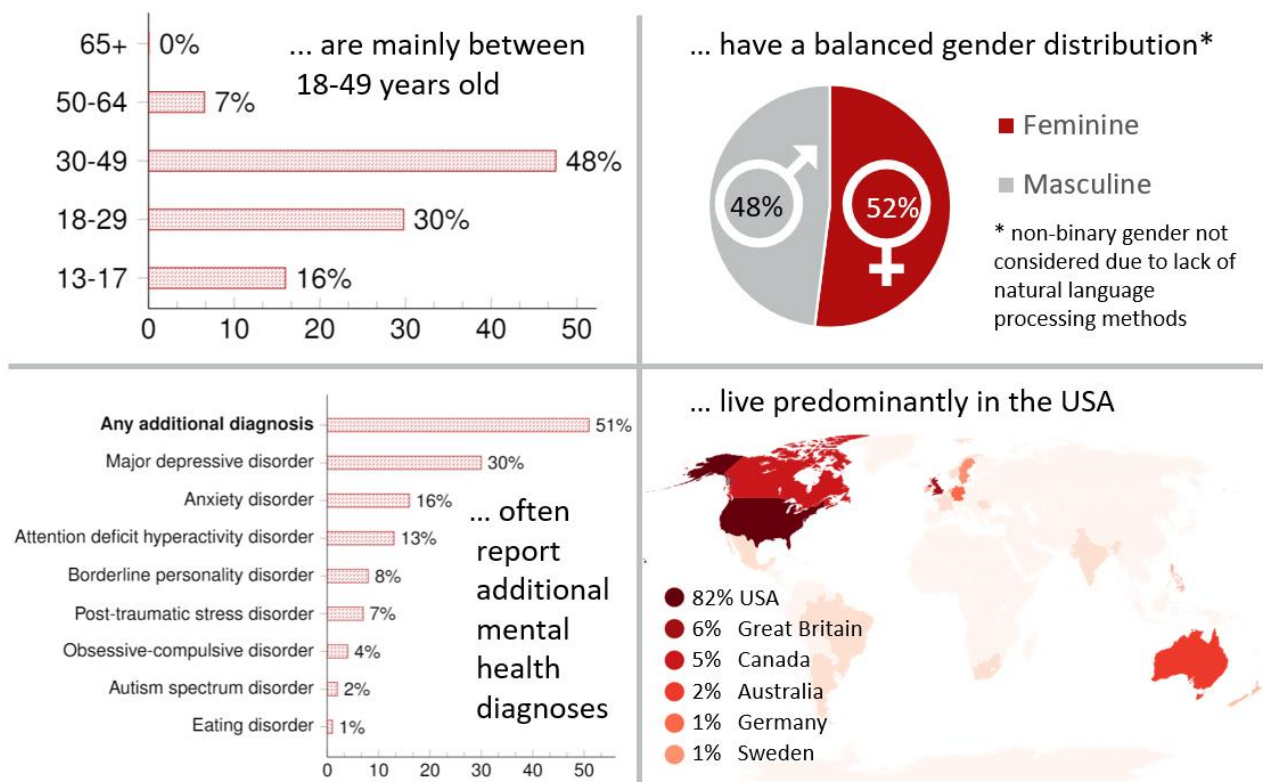
POETIC: Lived experience of personal recovery in bipolar disorder					
New Tensions domain added to CHIME in green					
P	Purpose and meaning	Meaning of mental illness experiences	Paid or voluntary work	Quality of life	Meaningful life and social roles
O	Optimism and hope	Belief in possibility of recovery	Positive thinking and valuing success	Hope-inspiring relationships	Having dreams and aspirations
E	Empowerment	Self-management & personal responsibility	Controversial role of medication	Control over life	
T	Tensions	Balancing acceptance with ambitions	Openness enables support, but also stigmatisation	Ambivalence around (hypo-) mania	
I	Identity	Rebuilding positive sense of self	Over-coming stigma	Dimensions of identity	
C	Connectedness	Support from others	Relationships	Peer support and support groups	Being part of the community

What are the characteristics of Reddit users with a self-reported disorder diagnosis?

Little is known about the characteristics of social media users who disclose a bipolar disorder diagnosis. For this study, we used natural language processing methods to automatically infer clinical, demographic and identity characteristics of almost 20K Reddit users who self-reported a bipolar disorder diagnosis. The figure below summarises our findings of their age, gender, country and comorbidity distributions.

You can find more information in our publication [Understanding who uses Reddit: Profiling individuals with a self-reported bipolar disorder diagnosis](#).

Reddit users who disclose a bipolar disorder diagnosis ...



Are there differences in terms of the expressed emotions and mood of the posts and users in mental health and non-mental health forums?

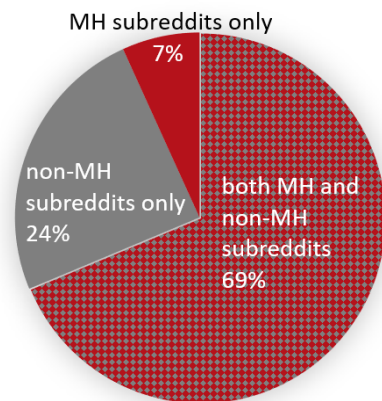
In this study, we took a closer look at the posting behaviour of Reddit users with a self-reported bipolar diagnosis. Reddit hosts thousands of subforums for various topics, called subreddits. They include general topics such as news or politics, funny memes, but also health, mental health and bipolar-specific subreddits. First, we wanted to know what percentage of them posted in mental health and non-mental health specific subreddits. Second, we used the lexicon-based tool LIWC to automatically determine the percentage of words in a post that are associated with specific emotions (e.g. positive emotion, sadness, anxiety). We

found that users tend to express more negative and less positive emotions in mental health subreddits. Finally, we compared users who posted in mental health subreddits to those who only posted in subreddits on other topics. We found that users who posted in mental health subreddits tended to use more words associated with emotions in their posts overall, including positive and negative emotions.

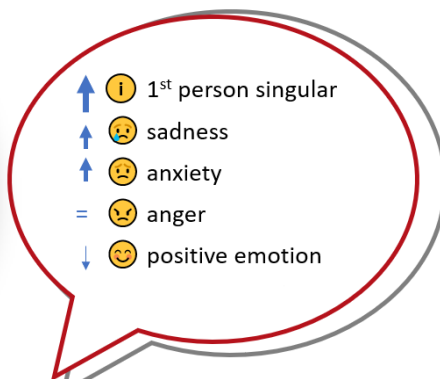
The figure below summarises our findings. You can read more on this in our publication [Posting patterns in peer online support forums and their associations with emotions and mood in bipolar disorder: Exploratory analysis.](#)

Posting patterns in peer online support forums and their associations with emotions and mood in bipolar disorder

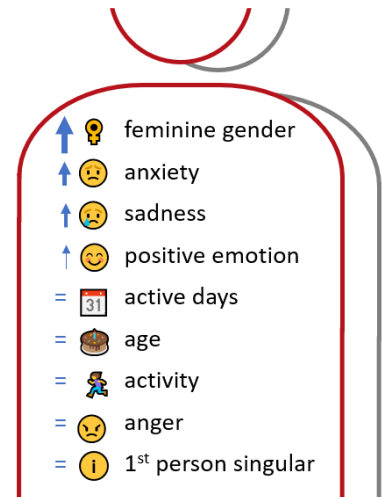
What proportion of Reddit users with a BD diagnosis posts in MH and non-MH subreddits?



What differences exist in the emotions that Reddit users with a BD diagnosis express in MH and non-MH subreddit posts?



How does mood differ between Reddit users with a BD diagnosis who post in MH subreddits and those who only post in non-MH subreddits?



What can we learn from online posts about the experience of personal recovery in bipolar disorder?

The first three studies paved the way for our final study. Here, we finally delved into what Reddit users with a self-reported bipolar diagnosis share about their personal recovery experiences. Again using natural language processing methods, we automatically identified 4.5K posts by 2K users that were likely relevant to personal recovery. We compared them to nearly five times as many posts that were relevant to bipolar but not personal recovery. We then used the POETIC framework to categorise keywords, that is terms that were significantly more frequent in the personal recovery posts. Overall, the POETIC framework also worked well to capture personal recovery experiences shared online. Interestingly, the online data also contained candid in-the-moment experiences that traditional qualitative experiences via interviews or focus groups had not retrieved. For example, one user posted about their experiences in a current manic episode during two consecutive days. Some users also seemed more comfortable to discuss sensitive topics anonymously online, such as personal spiritual experiences, and struggles with intimate relationships.

The figure below illustrates the main domains and subcategories of the POETIC framework and their frequency in the online posts. You can find more information on this study, including many quotes from the online posts in our publication [How People With a Bipolar Disorder Diagnosis Talk About Personal Recovery in Peer Online Support Forums: Corpus Framework Analysis Using the POETIC Framework.](#)

How people with a bipolar disorder diagnosis talk about personal recovery in peer online support forums								
P	Purpose and meaning	Meaning of mental illness experiences	Work or formal education	Quality of life	Meaningful life and social roles	Spirituality	Meaningful life and social goals	Rebuilding of life
O	Optimism and hope	Belief in possibility of recovery	Positive thinking and valuing success		Hope-inspiring relationships		Having dreams and aspirations	
E	Empowerment	Self-management & personal responsibility	Controversial role of medication		Control over life			
T	Tensions	Balancing acceptance with ambitions	Openness enables support, but also stigmatisation		Ambivalence around (hypo-) mania			
I	Identity	Rebuilding positive sense of self	Over-coming stigma		Dimensions of identity			
C	Connectedness	Support from others	Relationships		Peer support and support groups		Being part of the community	
X	Not POETIC	Other MH issues	Storytelling		Forum interaction		General discussion	
Colour key: category frequency		159	350	1000	1300	2000	4000	6500

Further reading

Jagfeld, Glorianna; Lobban, Fiona; Marshall, Paul; Jones, Steven H. (2021): [Personal recovery in bipolar disorder: Systematic review and "best fit" framework synthesis of qualitative evidence - a POETIC adaptation of CHIME](#). In: Journal of Affective Disorders 292, S. 375–385. DOI: 10.1016/j.jad.2021.05.051. ([freely accessible version](#))

Jagfeld, Glorianna; Lobban, Fiona; Rayson, Paul; Jones, Steven (2021): [Understanding who uses Reddit: Profiling individuals with a self-reported bipolar disorder diagnosis](#). In: Proceedings of the Seventh Workshop on Computational Linguistics and Clinical Psychology: Improving Access, S. 1–14. DOI: 10.18653/v1/2021.clpsych-1.1.

Jagfeld, Glorianna; Lobban, Fiona; Davies, Robert; Boyd, Ryan L.; Rayson, Paul; Jones, Steven (2023): [Posting patterns in peer online support forums and their associations with emotions and mood in bipolar disorder: Exploratory analysis](#). In: *PloS one* 18 (9), e0291369. DOI: 10.1371/journal.pone.0291369.

Jagfeld, Glorianna; Lobban, Fiona; Humphreys, Chloe; Rayson, Paul; Jones, Steven Huntley (2023): [How People With a Bipolar Disorder Diagnosis Talk About Personal Recovery in Peer Online Support Forums: Corpus Framework Analysis Using the POETIC Framework](#). In: JMIR medical informatics 11, e46544. DOI: 10.2196/46544.

Full thesis: Jagfeld, Glorianna (2023): [Talking about personal recovery in bipolar disorder: Integrating health research, natural language processing, and corpus linguistics to analyse peer online support forum posts](#). PhD thesis. Lancaster University. Faculty of Health and Medicine.

Contact

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