Please cite the Published Version

Monks-Woods, Alice, Andriopoulou, Panoraia on and Grogan, Sarah (2024) A phenomenological investigation of experiences of people who use YouTube to access support for Borderline Personality Disorder. Psychological Studies, 69 (1). pp. 135-144. ISSN 0033-2968

DOI: https://doi.org/10.1007/s12646-023-00781-z

Publisher: Springer

Version: Published Version

Downloaded from: https://e-space.mmu.ac.uk/634532/

Usage rights: Creative Commons: Attribution 4.0

Additional Information: This is an open access article which originally appeared in Psychological

Studies, published by Springer

Enquiries:

If you have questions about this document, contact openresearch@mmu.ac.uk. Please include the URL of the record in e-space. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.mmu.ac.uk/library/using-the-library/policies-and-guidelines)

RESEARCH IN PROGRESS



A Phenomenological Investigation of Experiences of People Who Use YouTube to Access Support for Borderline Personality Disorder

Alice Monks-Woods¹ · Panoraia Andriopoulou² · Sarah Grogan¹

Received: 26 August 2022 / Accepted: 27 November 2023 / Published online: 6 January 2024 © The Author(s) 2024

Abstract

Background Research suggests that individuals with a mental health diagnosis often engage in social media to access support for their diagnosis. However, there is a lack of information on online usage in those diagnosed with borderline personality disorder (BPD). Furthermore, there is little research using qualitative interviews to examine the use of social media, such as YouTube, for psychological support. Purpose The aim of the present study was to explore experiences of YouTube in individuals diagnosed with borderline personality disorder, including its impact on their offline lives.

Methods Six participants were recruited on social media; all those who contacted the researcher and met inclusion criteria were interviewed. Semi-structured interviews were used, lasting between 40 and 60 min. Data were transcribed verbatim and analysed using interpretive phenomenological analysis.

Findings The analysis produced two global themes: 'YouTube as a form of self-help' and 'YouTube transforming the self'.

Limitations All the participants were female, limiting transferability of the findings.

Panoraia Andriopoulou pandriopoulou@uoi.gr

Alice Monks-Woods alicemonkswoods@yahoo.co.uk

Sarah Grogan S.Grogan@mmu.ac.uk

Manchester Metropolitan University, Manchester, UK

Department of Psychology, University of Ioannina, 45110 Ioannina, Greece Originality This paper is the first to show that YouTube could be used in addition to regular support to initiate recovery for those with BPD. It could provide them with a way to reduce self-stigma, enhance self-awareness and learn coping techniques.

 $\begin{tabular}{ll} \textbf{Keywords} & Borderline\ personality\ disorder \cdot Support \cdot \\ Interpretative\ phenomenological\ analysis \cdot Social\ media \cdot \\ YouTube \end{tabular}$

Abbreviations

BPD Borderline personality disorder

IPA Interpretative phenomenological analysis

DBT Dialectical behavioural therapy

Introduction

Borderline Personality Disorder (BPD) is one of the most common personality disorders and is associated with "... mood instability, extreme sensitivity to abandonment, impulsivity, self-mutilating behaviour, and difficulty controlling anger..." (Sheehan et al., 2016). It is one of the most prevalent psychiatric disorders with a prevalence of 1% in the general population, 12% in outpatient psychiatric clinics, and 22% in inpatient psychiatric clinics (Ellison et al., 2018). Its main characteristics include difficulties with emotional regulation and interpersonal functioning (Herr et al., 2013). As a disorder it has been stigmatised by both the public and mental health professionals (O'Connell & Dowling, 2013; Sheehan et al., 2016). Professionals' views have led to individuals with BPD being described as attention seeking and manipulative (O'Connell & Dowling, 2013). Consequently, these individuals are often dismissed and unable to receive appropriate care (Windship & Hardy, 2007). Unsurprisingly,



they may turn to social media to access peer-to-peer support, challenge stigma and seek advice (Lawlor & Kirakowski, 2014; Naslund et al., 2014, 2016; Prescott et al., 2017).

Social media has become a popular mental health platform to seek advice from others with similar experiences, or to share personal experiences (Naslund et al., 2014). YouTube is a '...free online video streaming service that allows users to view, upload, and post ratings or comments on posted videos' (Stellefson et al., 2014). Although there is an abundance of research exploring social media's influence on severe mental illnesses, little is known about the effects of YouTube on its viewers (Sangerozan et al., 2019); despite YouTube being the third most visited social media site after Facebook and Google + (Dwivedi & Danver, 2016). There is also limited attention paid to those diagnosed with BPD's online interactions (Bernard et al., 2016; Marantz, 2017). The current study aims to explore the effect of watching YouTube videos for support on those diagnosed with BPD.

YouTube is accessed for a range of material, including educational videos and channels, and has information on nearly every academic area (Dwivedi & Danver, 2016). It has been found to provide both informational and emotional support for those with health conditions (Huh et al., 2014); these include pulmonary disease, chronic illness and cancer (Hassona et al., 2016; Huh et al., 2014; Stellefson et al., 2014). Videos available on YouTube include personal experiences and professional explanations of certain treatments and coping strategies (Huh et al., 2014). Video bloggers or vloggers provide a unique experience for viewers as they often include self-disclosure, which provides a strong supportive relationship (Huh et al., 2014). Conversely, using YouTube for support may also cause confusion about one's own experiences and unrealistic expectations of treatment (Naslund et al., 2014). Nevertheless, Huh et al., (2014) suggest that YouTube is unique in its potential to build a richer rapport through the use of nonverbal cues simulating faceto-face communication.

The use of YouTube for severe mental illness has been explored and has been found to provide a sense of hope, a coping strategy, to reduce isolation and provide learning from shared experiences (e.g. Naslund et al., 2014). Using surveys to explore social media and mental health support is common (e.g. Brunette et al., 2017; Easton et al., 2017; Naslund et al., 2019); however, this research method poses challenges in terms of leading or vague questions, and nonresponses, leading to problems in interpretation (Bicquelet, 2017). As an alternative, Sangeorzan et al. (2019) analysed videos of vloggers with severe mental illness who shared their experiences using YouTube, exploring why individuals used this platform to vlog about mental health, concluding that vlogging on YouTube can act as a therapy, fight stigma and minimise isolation. This method provides a higher degree of ecological validity as researcher bias cannot interfere with the data; however, the researcher is unable to ask follow-up questions to more fully understand data using this method, which is a significant shortcoming. There appear to be very few studies which explore social media use in the BPD population through interviewing the individuals who use these sites.

Purpose of Current Study

Using online support can be useful but the measure of its success also depends on what impact that online support has on real-world interactions. More investigation is needed into whether users benefit or decline as a result of social media usage (Easton et al., 2017; Naslund et al., 2016). This study investigated mental health and social media use using in-depth qualitative interviews analysed using interpretive phenomenological analysis. This approach develops a better understanding of whether users have meaningful improvements in recovery and mental and physical wellbeing due to social media. In addition, it allows a deeper exploration into the experiences of individuals using YouTube for support. It is important to involve active users of these social media sites to investigate and improve these networks (Naslund et al., 2016). Moreover, it is necessary to explore whether individuals access support through YouTube to improve their mental health, what they use and how this kind of support could be improved (Naslund et al., 2019; Prescott et al., 2017). Finally, this study will inform practitioners as to how social media such as YouTube could help support their clients.

Research Objectives:

- To understand both informational and emotional support, and the reasons people access these forms of support online.
- 2. To understand what impact this form of support has on their offline lives.
- 3. To investigate the advantages and disadvantages of You-Tube for support, through semi-structured interviews.

Methods

Sample and Procedures

After ethical approval was granted by the Department of Psychology Research Ethics Committee of Manchester Metropolitan University (approval number 7645), participants were recruited through social media, including Twitter and Facebook, to include a wider outreach (Robinson, 2014). Individuals who met the criteria and contacted the researchers first were recruited. The participants had to have been



diagnosed with borderline personality disorder by a mental health professional and also have used YouTube for support with their diagnosis. As interpretive phenomenological analysis was used for data analysis; we aimed for a sample size of between 6 and 8 participants (Amos et al., 2018; Connerty et al., 2016; Papagiannaki & Shinebourne, 2016; Smith & Osborn, 2007; Ware et al., 2015). Six participants were interviewed for this study, all of whom were female. See Table 1 for participant characteristics.

Participants completed a participation screening questionnaire before taking part to ensure that they did not have suicidal thoughts and they had professional support available if necessary; this included the first three questions from the National Institute of Mental Health Suicide Risk Screening Tool (2017). Participants then took part in a 45–90 min semi-structured Skype interview, a reasonable amount of time to understand fully what the participants thought and felt about their experience (Fylan, 2005). Interviews were conducted by the first author.

Data Analysis

Analysis was carried out following the IPA procedure outlined by Smith et al., (2012). IPA was considered the most appropriate analysis as it is grounded in phenomenology; this approaches experiences reflectively, allowing the researcher to interpret the participants' perspectives (Eatough & Smith, 2017; Smith et al., 2012). Interpretation is based on double hermeneutics as it allows participants to make sense of their worlds and the researcher to understand this (Smith & Osbourne, 2008). Finally, the ideographic aspect allows exploration of the participants' detailed perspectives before moving on to more general claims; found to be beneficial in healthcare research (Sangeorzan et al., 2019; Smith et al., 2012). IPA has been used in the past to explore the self in mental health recovery, as it requires an elaborate and deep

explanation of data (Smith & Eatough, 2011; Waite et al., 2015). Here, IPA enabled us to understand subjective experiences, and impacts of online support on recovery (Smethurst & Kuss, 2018), producing thick descriptive data, and enabling application of the findings (Schwandt et al., 2007).

Firstly, the six audio-recorded interviews were transcribed verbatim by the first author. Smith et al.'s (2012) steps most appropriately fit the aims of this research study. The first step in analysing the data involved the first author looking for themes, which was done by reading and rereading the transcripts, to engage with the data. Semantic content and language were explored by noting anything of interest in the margin; emergent themes were then noted in the opposite margin. This process was carried out for each individual; sub-themes were then noted for each participant, which encapsulated their experience. Lastly, the subordinate themes were clustered together to generate the final superordinate or global themes in line with the research questions. Data were then checked by the second author and finessed to produce an agreed set of themes. The third author then reviewed and agreed upon this set of themes.

Results and Discussion

Two global themes emerged from the data in relation to the experiences of those diagnosed with BPD using YouTube for support. These global themes will be explored in relation to their subordinate themes (see Table 2). Each subordinate theme includes quotes and previous research in support. Some of the participants knew the YouTube vloggers; therefore, to ensure anonymity, these names have been changed to 'vlogger'. It is important to highlight that these themes are the result of the researchers' subjective interpretations of these six individual's experiences, though all themes were agreed by all authors.

Table 1 Characteristics of participants

Pseudonym	Years since diagnosed	Therapies received	Employed	How long been watching YouTube videos	How often engage on YouTube
Katie	25 years	Dialectical Behaviour Therapy	Employed	5 and half years	20 min a week
Chelsea	2 years	None	Employed	2 years	Not anymore but used to be 3 times a week
Day	2 years	Psychotherapy	Employed	1 year	3 times a week
Chloe	1 year	Cognitive Behavioural Therapy (for depression and anxiety)	Student	7 years	Everyday
Rachel	4 years ago and again 1 year ago	Integrative Counselling/ Psychodynamic/ Dialectical Behaviour Therapy	Employed and Student	4 years	Once a week
Evelyn	4 Months	None	Student	1 year	Everyday



Table 2 Global themes and subordinate themes

Global themes	Subordinate themes
YouTube as a form of Self-help	Accessibility to offline support Informational support Emotional regulation
YouTube transforming the self	Reduce self-stigma Moving towards a recovered self-identity

Theme 1: YouTube as a Form of Self-Help

Accessibility to Offline Support

Chloe had an extremely long wait for support, supporting suggestions that seeking support for mental health diagnoses can be a difficult task, and that those who do are often met with long waiting times or high financial costs (Bridler et al., 2012; Reins et al., 2013):

"...I was told I've got a two years probably until I would be assessed to see if I could have therapy so that's not even a two year wait to have therapy, that's to see if I could have it...".

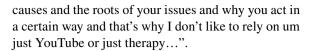
Evelyn had used social media such as YouTube to access support as a replacement for appropriate care:

"So I... I'd then been told to do like self-help and stuff so cause I've had no sessions and this is the sort of stuff that I'm meant to be learning with her and she's done nothing for me, I'm basically doing it myself and using YouTube finding research so I can understand symptoms finding self-help techniques...".

This supports suggestions that individuals are often dismissed and unable to receive the appropriate care (Windship & Hardy, 2007). Unsurprisingly, they may then turn to social media to access peer-to-peer support, challenge stigma, and seek advice (Lawlor & Kirakowski, 2014; Naslund et al., 2014, 2016; Prescott et al., 2017). This lack of professional support and information resulted in Evelyn using her own self-directed psychoeducation and support techniques, supporting the findings by Berry et al., (2017).

YouTube appeared to be used as a coping strategy while waiting for therapy, again supporting Berry et al., (2017). For instance, Chloe says: "So I kind of had to help myself in some way, sort of by doing that it was something in the meantime...". However, this form of support was not seen as a valid replacement for one-to-one therapy, supporting findings by Prescott et al., (2017). For instance, Day says:

"Uhh with professional help on YouTube um it's still it's still never one on one and you know obviously you you cannot get as personal and really dive into the



This suggests that YouTube is ideally best used in conjunction with traditional health services, although this is not always possible. When limited support is given from health providers, it is not always sufficient and is often inconsistent (Borzekowski et al., 2009). Chelsea felt that she was not getting enough information about BPD offline: "I watch them because I get more information about the diagnosis than I actually do from my own psychiatrist...". Again, this would imply that the participants may resort to YouTube, when there was a lack of support offline.

Informational Support

Informational support was received from both professionals and others who are "...experts by experience..." (Rachel), supporting Prescott et al., (2017)'s suggestion that online forums provide support to gain health information. Accessing this support could help with treatment advice and relieve fear (Love et al., 2012). An example of this is learning through shared experiences of medication use which was helpful for Chelsea:

"Yeah and what they give me for my borderline personality...so if I'm on a medication I will automatically go to YouTube and see the effects that it's had on other people...".

Psychoeducation on the aspects of BPD itself was an effective way to help improve symptoms, supporting findings by Berry et al., (2017). For instance, Chloe says:

"...more educational based you know kind of understanding BPD I think is one of the main things that actually helps you get better...". It was also useful in "...recommending resources like the DBT workbook...".

Finding other helpful resources and remaining informed about recent advances in clinical practice and current research on BPD was of particular importance to Katie who used YouTube often for this purpose (Berry et al., 2017):

"I guess on some of them yeah you can get yanno especially if its somebody that is a psychologist you know you can get information on what is being researched currently or what therapies that they're supporting or are being used...so I guess yeah that because they can also include links down below so a lot of that you know you can get links to somebody else's research or website that is doing...you know that has an interest in BPD or that is doing any kind of research or have any kind of books or anything on the topic...".



Emotional Regulation

Emotional regulation is used to describe a '...person's ability to manage and respond to an emotional experience' (Rolston & Lloyd-Richardson, 2017). Many participants in this study used YouTube as a regulating strategy in times of distress, for example, Rachel:

"...she's just hearing about her life is so relaxing to me you know there's been times when I've been like crying my eyes out and I've been like oh I'll just put a video by (Vlogger) on...".

This suggests that watching these videos can have a calming effect and support coping with emotions "...when I was low that that was one of the main things that kept me going" (Chloe). They provide an opportunity to escape as a distraction from difficult thoughts and feelings (Berry et al., 2017). This was the case for Evelyn:

"...I think for me the diagnosis and using YouTube as like part of self help distraction technique...".

When confronted with difficult situations and negative emotions, emotional regulation strategies are used (Sheppes et al., 2011). Individuals diagnosed with BPD have reported higher levels of difficulty regulating emotional distress (Dixon-Gordon et al., 2017). According to Kuo et al., (2016) individuals diagnosed with BPD can effectively regulate their emotions using mindful awareness or distraction strategies. Results suggest that YouTube provides an appropriate resource for their needs.

In fact, some of the participants used YouTube to find dialectical behavioural therapy (DBT) skills, Rachel used it for this: "So it was kind of like I didn't have DBT so I would go on YouTube to learn DBT so I would go on (Vlogger's) videos about like this is DBT skills to learn the skills...". Evelyn also used it for mindfulness techniques:

"Yeah so like um music a lot so if it's getting like too much I'll then put like my head phones on especially if I'm like anxious at being out I'll put my head phones on to like distract me and like I can't hear anything that's going on around me um I used like the mindfulness as well like if I feel like... horrible and like I need something um it's helped me in that way...".

This supports research by Lindenboim et al., (2007) who suggest that for individuals diagnosed with BPD distraction and mindfulness were two of the most commonly practised skills for emotional regulation. In fact, the beneficial effects of mindfulness programmes for those with BPD have been documented (Kay et al., 2018). This may be due to a deeper level of effective communication between body, thoughts, and feelings (Price & Hooven, 2018). Being able to cope with emotions was helpful for the participants in their offline

lives. For example, Rachel found the videos helpful for her to function in a social context:

"...I mean I guess watching the videos...helps me which helps me to function so that helps me you know it's one of my coping techniques so it enables me to go to work and... and go and socialise".

Evelyn also found watching the mindfulness videos helpful: "Just because the noise could like calm me down and do some mindfulness to help me relax to try and get me to sleep basically as well...". According to Price and Hooven (2018), emotional regulators lead to benefits in health, well-being, social connection and life tasks. This implies that YouTube has been helpful for the participants' emotional regulation and accordingly benefited their offline lives.

Theme 2: YouTube Transforming the Self

Reducing Self-stigma

Watching Videos on YouTube Allowed the Participants to Reduce Their Self-stigma. Chloe Portrays This

"...its helped um kind of bring down my own stigma that I had of BPD um cause obviously it was very scary when you first hear it and you first find out about it and it sounds horrible but I mean it just makes me feel more normal...".

It is well known that severe mental illnesses are highly stigmatised, particularly BPD, by both health professionals and the general public (O'Connell & Dowling, 2013). Many individuals internalise this stigma and believe the negative attitudes and stereotypes are not only true but also apply to them, known as self-stigma (Corrigan et al., 2011), and women diagnosed with BPD are at high risk for self-stigma (Rüsch et al., 2010). Previously, Sangeorzan et al. (2019) suggested that vloggers create videos on YouTube to combat inaccurate stereotypes and misconceptions of severe mental illness.

There Appeared to be an Increase in Self-esteem and Confidence After Watching Online Videos. This was Reflected in Greater Confidence to Discuss Their Diagnosis with Others. Katie Vocalises This

"I mean I understand it but I guess like it helps get you out of your, well for me any way, out of like not wanting to put myself out there".

According to Corrigan et al. (2012), the most successful method of challenging self-stigma is through self-disclosure. Watching others publicise their experience on YouTube encouraged the viewers to do the same. Rachel felt this way as she explains:



"When you watch somebody over time talking and actually saying the words you feel like maybe I can get in a position where I can say the words out loud...".

Chloe also Felt More Able to Talk About Her Diagnosis Online in Order to Reduce the Stigma for Others

"...it's helped me talk more about things as well so like I've been quite open on social media about it and just made a point of talking about things more so that the stigma is down for other people...".

According to Deaux's (1996) model of social identity, watching others talk about their stigmatised identity results in identification and connection with them. It becomes part of the self and compels the viewer to share their own stigmatised identity offline (Lawlor & Kirakowski, 2014). Self-disclosure has been suggested to be therapeutically important as it creates a sense of universality, develops personal insight and improves emotional well-being (Lawlor & Kirakowski, 2014).

Unfortunately, there are also very stigmatising videos on YouTube, which had the opposite effect on one participant and perpetuated her self-stigma. Rachel's experience on YouTube was not all positive:

"...I would say the disadvantages of going on You-Tube to get support is the other horrible videos that you can come across, so like the very very very stignatising ones...".

One of the Disadvantages is the Stigmatising Content, Which can have Damaging Consequences for Some Viewers Like Rachel

"But it's actually really hurtful because newly diagnosed people go on, go on to YouTube to look for support and come across that and watch it and think I'll never been happy in relationships um I'll never...live a life that I want to live nobody's gonna like me I'm unlovable I'm disgusting am I really too much to handle I'm terrible am I really that do I deserve to be treated like that...".

This underlines the harmful consequences of content stigmatising BPD; it can reinforce hurtful thoughts, which may cause a lot of distress for individuals. For this participant it had a negative impact on her self-image. However, this video was produced by individuals who were not experts and who had not been diagnosed themselves. Furthermore, this video was counteracted by all the positive videos watched by this participant on YouTube, which "...helped give me more confidence to express myself..." (Rachel).



Moving Towards a Recovered Self-identity

For Evelyn Her Identity and Her Recovery Appeared to be Intertwined

"...yeah it's helped me sort of accept it which I think is the first start of recovery and it's help me to try and understand myself a bit give me a sense of who I am cause I know one of the symptoms is like never really knowing really who you are...".

Identity can be defined as the construction of one's own sense of self (Forrester-Jones & Barnes, 2008). Individuals with a mental health diagnosis describe a loss of self and identity, which needs to be overcome to facilitate recovery (Wisdom et al., 2008). There are many experiences of individuals with mental health diagnoses who describe challenges managing identity, particularly BPD as it is characterised by an instability, which affects self-image (Richetin et al., 2017; Wisdom et al., 2008).

Katie Focused on Videos Which Were Encouraging and Optimistic About BPD and Recovery

"Um I guess overall you know it does have a positive effect um because obviously I'll tend to focus more on ones um... you know that are supportive and saying that people with BPD can have you know friendships relationships and so I guess that's good...".

According to Wisdom et al. (2008), the overarching sense of recovery from a mental health diagnosis is the redefinition of the sense of self, and gaining a perspective that it is simply one part of self. In addition, moving towards a more positive identity can facilitate the recovery process (Wisdom et al., 2008). Forrester-Jones and Barnes (2008) suggest that interacting with others who relate to a person's self-concept induces benefits such as better self-image and self-esteem. It could be interpreted that watching others with BPD on YouTube provides an image of a stable identity and hope for recovery (Wisdom et al., 2008).

Through watching professionals on YouTube, Day was able to understand that her black and white thinking was a symptom of BPD. This relates to the cognitive aspects of cognitive behavioural therapy (Beck et al., 2015) and schema therapy (Young, 1990). Both approaches use psychoeducation to help the patient recognise the consequences of maladaptive ways of thinking (Kellogg & Young, 2006).

Day was Able to Recognise Unhelpful Thinking and then was Able to Try and Alter Her Thoughts Accordingly

"...I think about it and I'm like girl you're stupid like what the heck its stupid thinking that way so I get up I don't have to be completely happy but I get out of bed I turn on a movie maybe like make myself some tea and I allow myself to be in a neutral mood...".

It has been suggested that understanding these cognitions allows the individual to break through unhelpful patterns of thinking (Arntz & van Genderen, 2009), mirrored in Day's experience as this allowed her to become more comfortable in herself and her identity:

"...I am more confident with my identity because I feel like I know myself better and why I act in certain ways and um...like it's just made me...like feel like it just made it easier for me to be with the world and like things like that...".

A key aspect of recovery is to become more knowledgeable about managing it and understanding its impact (Wisdom et al., 2008). Watching these videos seemed to affect this participant's self-perceptions, optimism and therefore ability to cope with symptoms (Wisdom et al., 2008).

Self-awareness of emotions and behaviours was present for a majority of the participants and it was one of the biggest benefits of going on YouTube. It allowed the participants to be "more wary of my own behaviour..." (Chelsea). Duval and Wicklund (1972) developed the theory and define objective self-awareness as attention that is focused on the self. It has many benefits including improved introspection, awareness of inner states, self-regulation and behaviour (Baumeister, 2019).

A Greater Awareness of BPD Made it Easier to Manage Symptoms and Enabled Hope for Improvement, Evelyn Exhibits This

"...actually having the listening and finding out information myself it's really helped me and understand me better and be like why I've reacted like this and this makes sense like I have this condition but I can work on it and actually it's given me like hope that I can recover...".

By Increasing Self-awareness, Offline Actions Became More Clear; and Therefore Easier to Alter, This was Day's Experience

"I'm gonna hear that I'm gonna think about that I'm not gonna let my like emotions control my words...I'm gonna calm down and then I'm gonna speak".

There appears to be an ability to actively change actions and attitudes because of this awareness (Silvia & Duval, 2001). Silvia and Duval (2001) submit that focusing attention on the self can break automatic behaviours, as self-aware people can consciously consider different action possibilities. Consequently, self-awareness is important to initiate recovery, which is one of the biggest offline impacts of YouTube, Chloe:

"Oh yeah definitely like I think I think I very much found the way to recovery and I definitely wouldn't have been if I hadn't have found those YouTube videos so it's been a huge part of it...".

Implications

The present study aimed to explore the reasons participants diagnosed with BPD resort to YouTube for informational and emotional support, identify the advantages and disadvantages of such usage, and consider the impact of this form of support on their offline lives. While those with mental health diagnoses use social media regularly, the use of YouTube for so many different aspects of support is an innovative discovery. YouTube was helpful as a catalyst towards the first steps of recovery. Previous research such as Naslund et al. (2014) suggested that peer support online provides coping skills, and Wisdom et al. (2008) suggest that recovery begins by regaining a sense of identity. In this study, recovery was initiated through better self-awareness and understanding of diagnosis through YouTube; possibly, it began through understanding that BPD was an aspect of their identity and not the whole, as the whole is bigger than the sum of its parts (Wisdom et al., 2008). Watching these videos resulted in improved mental well-being and ability to cope with the symptoms of BPD. YouTube was also helpful for emotional regulation. The use of YouTube for DBT techniques, mindfulness skills and as a distraction emphasises how an improvement in mental health can be achieved. As in previous research, there was a reduction in self-stigma; a stigmatising video had the opposite effect, showing the disadvantages of YouTube, and implying that more should be done to remove this kind of content. Nevertheless, watching peers, with the same diagnosis, self-disclose publicly encouraged the participants in this study to do the same, supporting the findings by Sangeorzan et al., (2019). Perhaps, the most surprising and unfortunate finding was the lack of support offline for individuals with BPD, which resulted in watching YouTube as a replacement. There are often long waiting times and high financial costs associated with seeking mental health care (Reins et al., 2013). Watching You-Tube may provide vital support to some individuals who are unable to access it elsewhere. Offline impacts included an increase in confidence and self-esteem. It additionally provided some of the participants with the skills to cope and thus function in work, social situations and everyday life.

Strengths, Limitations, and Future Research

This research is, to the best of the authors' knowledge, the first study to use IPA as a way to examine the offline impacts of YouTube for support, enabling understanding of the lived experiences of participants and the strengths



and limitations of YouTube (Hay-Smith et al., 2013). In any research study, there are limitations, which are important to recognise. All the participants were women, which limits the transferability of the research, possibly due to women being more likely being diagnosed with BPD (female-to-male gender ratio is 3:1; Silberschmidt et al., 2015). Also, our preconceptions and views may have affected data collection and analyses (Goodley & Smailes, 2011). The first author, who was also the interviewer, has first-hand experience that may have influenced the design and analysis of study, as she worked on a secure mental health ward with individuals diagnosed with BPD and has a friend diagnosed with BPD. However, the second author (clinical psychologist) and third author (health psychologist) checked and agreed all themes and quotes, so this may have been somewhat ameliorated through our team approach. Future research could investigate this issue on a larger scale using quantitative methods and could also examine the experiences and effect of YouTube on people with other mental health diagnoses. Finally, a useful step for future studies would be to identify and categorise the available videos that have been particularly supportive for participants so that they can be endorsed and promoted by mental health professionals. Stigmatising videos should also be identified in order to be removed.

Conclusion

While professional help is best as it can be tailored to the individual, YouTube could provide a beneficial temporary alternative. Though all may not benefit from YouTube, it is clear that the participants of this study did find it beneficial for self-help. It is also apparent that professionals could use it to enhance support for clients with BPD, by combining it with therapy, to assist individuals by reducing their self-stigma, helping with emotional regulation and aiding their recovery.

Acknowledgements None.

Author Contributions AMW & PA were involved in design of study; AMW contributed to collection of data and transcription of interviews; and AMW, PA and SG were involved in analysis of findings and article preparation/write-up.

Funding Open access funding provided by HEAL-Link Greece.

Declarations

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.



Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Ethics Committee of Manchester Metropolitan University (08/04/2019/No. 7645).

Consent to Participate All participants gave consent to participate.

Consent for Publication All participants gave consent for publication of findings.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/.

References

Amos, R., Morris, L., Mansell, W., & Edge, D. (2018). Clients' experiences of one-to-one low-intensity interventions for common mental health problems: An interpretative phenomenological analysis. Psychology and Psychotherapy: Theory, Research and Practice. https://doi.org/10.1111/papt.12200

Arntz, A., & Van Genderen, H. (2020). Schema therapy for borderline personality disorder. Wiley.

Baumeister, R. F. (2019). The Self. In E. J. Finkel & R. F. Baumeister (Eds.), Advance social psychology: The state of science (2nd ed., pp. 89–116). Oxford University Press.

Beck, A. T., Davis, D. D., & Freeman, A. (Eds.). (2015). *Cognitive therapy of personality disorders*. Guilford Publications.

Bernard, R., Sabariego, C., & Cieza, A. (2016). Barriers and facilitation measures related to people with mental disorders when using the web: A systematic review. *Journal of Medical Internet Research*, 18(6), 1–19. https://doi.org/10.2196/jmir.5442

Berry, N., Lobban, F., Belousov, M., Emsley, R., Nenadic, G., & Bucci, S. (2017). #WhyWeTweetMH: Understanding Why people use twitter to discuss mental health problems. *Journal of Medical Internet Research*, 19(4), 1–13. https://doi.org/10.2196/jmir.6173

Bicquelet, A. (2017). Using online mining techniques to inform formative evaluations: An analysis of YouTube video comments about chronic pain. *Evaluation*, 23(3), 323–338.

Borzekowski, D. L. G., Leith, J., Medoff, D. R., & Potts, W. (2009). Use of the Internet and other media for health information among clinic outpatients with serious mental illness. *Psychiatric Services*, 60(9), 1265–1268. https://doi.org/10.1176/ps.2009.60.9. 1265

Bridler, R., Orosz, A., Cattapan, K., & Stassen, H. H. (2012). In Need of psychiatric help–leave a message after the beep. *Psychopathology*, 46(3), 201–205. https://doi.org/10.1159/000341729

Brunette, M. F., Aschbrenner, K. A., Ferron, J. C., Ustinich, L., Kelly, M., & Grinley, T. (2017). Use of computers and Internet among people with severe mental insess at peer support centres.

- Psychiatric Rehabilitation Journal, 40(4), 405–408. https://doi.org/10.1037/prj0000247
- Connerty, T. J., Roberts, R., & Williams, A. S. (2016). Managing life, motherhood and mental health after discharge from a mother-baby unit: an interpretive phenomenological analysis. *Community Mental Health Journal*, 52(8), 954–963. https://doi.org/10.1007/s10597-015-9867-3
- Corrigan, P. W., Mueser, K. T., Bong, G. R., Drake, R. E., & Solomon, P. (2011). Examining a progressive model of self-stigma and its impact on people with serious mental illness. *Psychiatry Research*, 189(3), 339–342. https://doi.org/10.1016/j.psychres. 2011.05.024
- Corrigan, P. W., Michael, P. J., Vega, E., Gause, M., Watson, A. C., & Rüsch, N. (2012). Self-stigma of mental illness scale-short form: Reliability and validity. *Psychiatry Research*, 199(1), 65–69. https://doi.org/10.1016/j.psychres.2012.04.009
- Deaux, K. (1996). Social Identification. In E. Higgins & A. Kruglanski (Eds.), Social psychology: Handbook of basic principles (pp. 777–789). Guilford.
- Dixon-Gordon, K. L., Turner, B. J., Rosenthal, M. Z., & Chapman, A. L. (2017). Emotion regulation in borderline personality disorder: an experimental investigation of the effects of instructed acceptance and suppression. *Behavior Therapy*, 48(6), 750–764. https://doi.org/10.1016/j.beth.2017.03.001
- Duval, T. S., & Wicklund, R. A. (1972). A theory of objective self-awareness. Academic.
- Dwivedi, A. V., & Danver, S. L. (2016). YouTube. In S. L. Danver (Ed.), The SAGE encyclopedia of online education (pp. 2–5). SAGE Publications Inc.
- Easton, K., Diggle, J., Ruethi-Davis, M., Holmes, M., Byron-Parker, D., Nuttall, J., & Blackmore, C. (2017). Qualitative exploration of the potential for adverse events when using an online peer support network for mental health: Cross-sectional survey. *JMIR Mental Health*, 4(4), 1–5. https://doi.org/10.2196/mental.8168
- Eatough, V., & Smith, J. A. (2017). Interpretative phenomenological analysis. In C. Willig & W. S. Rogers (Eds.), *The SAGE hand-book of qualitative research in psychology* (2nd ed., pp. 193–211). SAGE Publications Ltd.
- Ellison, W. D., Rosenstein, L. K., Morgan, T. A., & Zimmerman, M. (2018). Community and clinical epidemiology of borderline personality disorder. *Psychiatric Clinics*, 41(4), 561–573. https://doi. org/10.1016/j.psc.2018.07.008
- Forrester-Jones, R., & Barnes, A. (2008). On being a girlfriend not a patient: The quest of an acceptable identity amongst people diagnosed with severe mental illness. *Journal of Mental Health*, *17*(2), 153–172. https://doi.org/10.1080/09638230701498341
- Fylan, F. (2005). Semi-structured interviewing. In J. Miles & P. Gilbert (Eds.), A handbook of research methods for clinical and health psychology (pp. 65–77). Oxford University Press Inc.
- Goodley, D., & Smailes, S. (2011). Positionalities. In P. Banister, G. Bunn, E. Burman, J. Daniels, P. Duckett, D. Goodley, & P. Whelan (Eds.), *Qualitative methods in psychology* (2nd ed., pp. 38–59). McGraw Hill.
- Hassona, Y., Taimeh, D., Marahleh, A., & Scully, C. (2016). YouTube as a source of information on mouth (oral) cancer. *Oral Diseases*, 22, 202–208. https://doi.org/10.1111/odi.12434
- Hay-Smith, E. J. C., Dickson, B., Nunnerley, J., & Sinnott, K. A. (2013). "The final piece of the puzzle to fit in": An interpretative phenomenological analysis of the return to employment in New Zealand after spinal cord injury. *Disability & Rehabilitation*, 35(17), 1436–1446. https://doi.org/10.3109/09638288.2012. 737079
- Herr, N. R., Rosenthal, Z., Geiger, P. J., & Erikson, K. (2013). Difficulties with emotion regulation mediate the relationship between borderline personality disorder symptom severity and interpersonal

- problems. *Personality and Mental Health*, 7(3), 191–202. https://doi.org/10.1002/pmh.1204
- Huh, J., Liu, L. S., Neogi, T., Inkpen, K., & Pratt, W. (2014). Health vlogs as social support for chronic illness management. ACM Transactions on Computer-Human Interaction, 21(4), 1–31. https://doi.org/10.1145/2630067
- Kay, M. L., Poggenpoel, M., Myburgh, C. P., & Downing, C. (2018). Experiences of family members who have a relative diagnosed with borderline personality disorder. *Curationis*, 41(1), 1–9. https://doi.org/10.4102/curationis.v41i1.1892
- Kellogg, S. H., & Young, J. E. (2006). Schema therapy for borderline personality disorder. *Journal of Clinical Psychology*, 62(4), 445–458. https://doi.org/10.1002/jclp.20240
- Kuo, J. R., Fitzpatrick, S., Metcalfe, R. K., & McMain, S. (2016). A multi-method laboratory investigation of emotional reactivity and emotion regulation abilities in borderline personality disorder. *Journal of Behavior Therapy and Experimental Psychiatry*, 50, 52–60. https://doi.org/10.1016/j.jbtep.2015.05.002
- Lawlor, A., & Kirakowski, J. (2014). Online support groups for mental health: A space for challenging self-stigma or a means of social avoidance? *Computers in Human Behaviour*, 32, 152–161. https://doi.org/10.1016/j.chb.2013.11.015
- Lindenboim, N., Comtois, K. A., & Linehan, M. M. (2007). Skills practice in dialectical behavior therapy for suicidal women meeting criteria for borderline personality disorder. *Cognitive* and Behavioral Practice, 14(2), 147–157. https://doi.org/10. 1016/j.cbpra.2006.10.004
- Love, B., Crook, B., Thompson, C. M., Zaitchik, S., Knapp, J., LeFebvre, L., Jones, B., Donovan-Kicken, E., Eargle, E., & Rechis, R. (2012). Exploring psychosocial support online: A content analysis of messages in an adolescent and young adult cancer community. Cyberpsychology, Behavior and Social Networking, 15(10), 555–559. https://doi.org/10.1089/cyber.2012.0138
- Marantz, L. N. (2017). An exploration of relationships between social media use and quality of life of adults diagnosed with borderline personality disorder. Unpublished Doctoral dissertation. [Online] [Accessed on 11th of September 2019] http://hdl. handle.net/10613/4883
- Naslund, J. A., Grande, S. W., Aschbrenner, K. A., & Elwyn, G. (2014). Naturally occurring peer support through social media: The experiences of individuals with severe mental illness using youtube. *PLoS ONE*, 9(10), 1–9.
- Naslund, J. A., Aschbrenner, K. A., Marsch, L. A., & Bartels, S. J. (2016). The future of mental health care: Peer-to-peer support and social media. *Epidemiology and Psychiatric Sciences*, 25(2), 113–122. https://doi.org/10.1017/S2045796015001067
- Naslund, J. A., Aschbrenner, K. A., McHugo, J. G., Unützer, J., Marsch, L. A., & Bartels, S. J. (2019). Exploring opportunities to support mental health care using social media: A survey of social media users with mental illness. *Early Intervention in Psychiatry*. https://doi.org/10.1111/eip.12496
- National Institute for Mental Health in England (NIMHE) 2017. Ask Suicide Screening Questions: ASQ tool. London: NIMHE. [Online] [Accessed on 8th January 2019] https://www.nimh.nih.gov/research/research-conducted-at-nimh/asq-toolkit-materials/asq-tool/screening-tool_155867.pdf
- O'Connell, B., & Dowling, M. (2013). Community psychiatric nurses' experiences of caring for client with borderline personality disorder. *Mental Health Practice*, *17*(4), 27–33. https://doi.org/10.7748/mhp2013.12.17.4.27.e845
- Papagiannaki, A., & Shinebourne, P. (2016). The contribution of creative art therapies to promoting mental health: Using interpretative phenomenological analysis to study therapists' understandings of working with self-stigmatisation. *The Arts in Psychotherapy*, 50, 66–74. https://doi.org/10.1016/j.aip.2016.06. 007



- Prescott, J., Hanley, T., & Ujhelyi, K. (2017). Peer communication in online mental health forums for young people: Directional and nondirectional support. *JMIR Mental Health*, 4(3), 1–12. https://doi.org/10.2196/mental.6921
- Price, C. J., & Hooven, C. (2018). Interoceptive awareness skills for emotion regulation: Theory and Approach of mindful awareness in body-oriented therapy (MABT). Frontiers in Psychology, 9(798), 1–12. https://doi.org/10.3389/fpsyg.2018.00798
- Reins, J. A., Ebert, D. D., Lehr, D., Riper, H., Cuijpers, P., & Berking, M. (2013). Internet-based treatment of major depression for patients on a waiting list for inpatient psychotherapy: Protocol for a multi-centre randomised controlled trial. *BMC Psychiatry*, 13(1), 1–9. https://doi.org/10.1186/1471-244X-13-318
- Richetin, J., Preti, E., Costantini, G., & De Panfilis, C. (2017). The centrality of affective instability and identity in border personality disorder: Evidence from network analysis. *PLoS ONE*, 12(10), 1–14.
- Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research* in *Psychology*, 11(1), 25–41. https://doi.org/10.1080/14780887. 2013.801543
- Rolston, A. and Lloyd-Richardson, E. 2017. What is emotion Regulation and how do we do it?. U.S.: Cornell Research Program on Self-Injury and Recovery. [Online] [Accessed on 16th September 2019] http://www.selfinjury.bctr.cornell.edu/perch/resources/what-is-emotion-regulationsinfo-brief.pdf
- Rüsch, N., Corrigan, P. W., Todd, A. R., & Bodenhausen, G. V. (2010). Implicit self-stigma in people with mental illness. *The Journal of Nervous and Mental Disease*, 198(2), 150–153. https://doi.org/10.1097/NMD.0b013e3181cc43b5
- Sangeorzan, I., Andriopoulou, P., & Livanou, M. (2019). Exploring the experiences of people vlogging about severe mental illness on YouTube: An interpretative phenomenological analysis. *Journal of Affective Disorders*, 246, 422–428. https://doi.org/10.1016/j.jad.2018.12.119
- Schwandt, T. A., Lincoln, Y. S., & Guba, E. G. (2007). Judging interpretations: But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Evaluation*, 2007(114), 11–25. https://doi.org/10.1002/ev.223
- Sheehan, L., Nieweglowski, K., & Corrigan, P. (2016). The stigma of personality disorders. *Curr Psychiatric Rep*, 18(11), 1–7. https:// doi.org/10.1007/s11920-015-0654-1
- Sheppes, G., Scheibe, S., Suri, G., & Gross, J. J. (2011). Emotion-regulation choice. *Psychological Science*, 22(11), 1391–1396. https://doi.org/10.1177/0956797611418350
- Silberschmidt, A., Lee, S., Zanarini, M., & Schulz, S. C. (2015). Gender differences in borderline personality disorder: Results from a multinational, clinical trial sample. *Journal of Personality Disorders*, 29(6), 828–838. https://doi.org/10.1521/pedi_2014_28_175

- Silvia, P. J., & Duval, T. S. (2001). Objective self-awareness theory: Recent progress and enduring problems. *Personality and Social Psychology Review*, 5(3), 230–241.
- Smethurst, L., & Kuss, D. (2018). Learning to live your life again: An interpretative phenomenological analysis of weblogs documenting the inside experience of recovering from anorexia nervosa. *Journal of Health Psychology*, 23(10), 1287–1298.
- Smith, J. A., & Eatough, V. (2011). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative* data in psychology (pp. 35–50). SAGE Publications Ltd.
- Smith, J. A., & Osbourne, M. (2007). Pain as an assult on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health*, 22(5), 517–534. https://doi.org/10.1080/14768320600941756
- Smith, J. A., & Osbourne, M. (2008). Interpretative phenomenological analysis. In G. Breakwell (Ed.), *Doing Social psychological research* (pp. 229–254). Blackwell Publishing Ltd.
- Smith, J. A., Flowers, P., & Larkin, M. (2012). Interpretative phenomenological analysis. Sage.
- Stellefson, M., Chaney, B., Ochipa, K., Chaney, D., Haider, Z., Hanik, B., Chavarria, E., & Bernhardt, J. M. (2014). YouTube as a source of chronic obstructive pulmonary disease patient education: A social media content analysis. *Chronic Respiratory Disease*, 11(2), 61–71.
- Waite, F., Knight, M. T. D., & Lee, D. (2015). Self-compassion and self-criticism in recovery in psychosis: An interpretative phenomenological analysis study. *Journal of Clinical Psychology*, 71(12), 1201–1217. https://doi.org/10.1002/jclp.22211
- Ware, K., Davies, J., Rowse, G., & Whittaker, S. (2015). The experience of hepatitis C treatment for people with a history of mental health problems: An interpretative phenomenological analysis. *Journal of Health Psychology*, 20(7), 990–1001.
- Windship, G., & Hardy, S. (2007). Perspectives on the prevalence and treatment of personality disorder. *Journal of Psychiatric and Mental Health Nursing*, 14(2), 148–154. https://doi.org/10.1111/j. 1365-2850.2007.01057.x
- Wisdom, J. P., Bruce, K., Saedi, G. A., Weis, T., & Green, C. A. (2008). Stealing me from myself': Identity and recovery in personal accounts of mental illness. *The Australian and New Zealand Journal of Psychiatry*, 42(6), 1–10.
- Young, J.E. 1990. Cognitive Therapy for Personality Disorders: A Schema-focused Approach. Sarasota, FL: Professional Resource Exchange.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

