

Being by Doing: Identity Constructs of Social Media Mental Health Activists

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Mariana Luna Lopez

First Supervisor: Yudit Namer

Second Supervisor: Martha Kreuzberg

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Abstract

This research paper analyses how mental health activists on social media construct their individual and social identities in connection to their spectator activities. A reflexive thematic analysis of 19 interviews of young adults of ages 19-25 was performed. From this, seven themes and eight subthemes of identity were identified. Participants varied in their identity constructions, expressing their personal roles within digital mental health activism and the roles of others. They also commented on their attributed importance to diagnosing and labelling, their perception of others and increased knowledge and awareness. Finally, they expressed the motives for self-improvement that often led to their engagement with mental health activism on social media. Overall, the themes of community and diagnosis and labelling were most frequent across this dataset. This showed how social media mental health activists perceive this activism as forming a culture of community and belonging. These frequent themes also highlight how diagnosis and labelling is a common topic within this activism. These findings support the potential of this form of activism for the promotion of mental health support and self-help, information seeking and sharing, and de-stigmatisation of mental health. Hence, this paper recommends further quantitative and qualitative research on the mental health content shared on social media and how it is perceived by users. Future findings could help achieve positive outcomes in the promotion of positive mental health and the de-stigmatisation of mental health issues by better informing the creation and consumption of mental health content on social media.

Keywords: social media, digital activism, mental health activism, social media content, identity, identities, social identity, collective identity, community, labelling

Being by Doing: Identity Constructs of Social Media Mental Health Activists

As social movements and health campaigns move towards digital spaces, so do research interests. Every day, millions of users make use of the platforms available online to connect with others, share their knowledge, inform themselves, and mobilise political and social activism. Consequently, digital activism, in its multiple forms, has been a growing object of inquiry in the last decade. The emergence of social media has facilitated novel forms of digital activism, and thus has transformed the experiences and possibilities of those who engage in it. A growing volume of research has focused on social and political digital activism, often focusing on case studies for singular political campaigns and protests occurring in online environments (Bennett & Segerberg, 2012; Marshall et al., 2022; Nguyen-Thu, 2022). Further, there is evidence for a growing interest in the potential and current use of digital mental health activism, whereby users share their knowledge and experiences with mental health issues and wellbeing in online environments (Dadich & Khan, 2021; Fergie et al., 2016; Meadows et al., 2020). As already suggested by George and Leidner (2019), qualitative and quantitative research exploring digital activism could help strengthen our understanding of its societal impact. This impact could include informing large audiences, influencing policy making, or individual behavioural and attitudinal changes. Therefore, such emergent form of activism should be investigated. This investigation involves analysing the implications of publicly sharing and advocating for mental health on social media, especially for young adults who are, globally, most involved in these platforms.

Ample groundwork has been made in defining what digital activism is and what its various activities may include. Digital activism can be defined as “social activism mediated through digital technologies to promote social movements” (George & Leidner, 2019, p. 4). George and Leidner (2019), propose three main activities at the lowest level of digital activism, which they call *digital spectator activities*. These activities are *clicktivism*, that is, to ‘like’, upvote or follow someone online; *metavoicing*, which means sharing, reposting and commenting content; and *assertion*, which is the creation of content. These activities are present at the highest volume in digital activism, and they are therefore the ones with which most digital activists participate in online platforms, like social media or websites (George and Leidner, 2019). The impact of this volume is ultimately measured when thousands or millions of users are reached in a short time with information or an invitation to action. Suwana (2020) also suggests how digital media is crucial for

information seeking, the sharing of accurate sources to dismantle false information, and the stimulation and amplification of social and political action. All of these activities are central to achieving the goals of digital activism. In general, technology allows for the finding of relevant information and social support by those who seek it, and for sharing of information from those who have it. Digital activism, thus, involves a series of activities which, together, allow for the promotion of social movements.

In the realm of virtual spaces, social media, including Facebook, Instagram, Twitter or recently TikTok, have gained a key position for digital activism. Social media have become a strategic means for activism, where individuals with similar ideas can come together and act collectively (Chon & Park, 2019). Further, social media are central communication and information tools in today's activism, where individuals can express their personal opinions and mobilize others (Chon & Park, 2019). Gerbaudo and Treré (2015) point to the large impact that social media has caused in the outreach of social movements. They also highlight the creation and spreading of protest identities in these platforms (Gerbaudo & Treré, 2015). With social media having millions of users, and, for example, with a large majority of 18–29-year-olds in the US using Instagram or TikTok (Auxier & Anderson, 2021), research must be directed towards clarifying what digital activism in social media entails, and which role it plays within the social movements that it promotes.

Importantly, digital activism on social media presents unique features and dynamics, different from those of other digital platforms. Social media has the defining characteristics of allowing users to create their own profiles, search for digital content, connect with other users with whom they share a relational connection, and to virtually interact with other people (Kane et al., 2014). This dynamic allows for the spontaneous connection of individuals who might not share a common ideology in the first place, such as a common political ideology or social goal. Users informally engage, usually in a self-motivated way, often sharing personalised content on social media without identifying with users, nor having a common purpose (Leong et al., 2019). The authors refer to this spontaneous process as *connective action*. They also point that it is different from collective action, differing from the latter by having a lower extent to which engaged users share an ideal or a common ideology (Leong et al., 2019). These unique features point to the

potentially different collective identity constructs that could exist between social media and non-social media activism.

Arising from this assumption of collective identity, authors have explored this concept in the scope of digital activism. Polletta and Jasper (2001) defined *collective identity* as:

An individual's cognitive, moral, and emotional connection with a broader community, category, practice or institution. It is a perception of a shared status or relation, which may be imagined rather than experienced directly, and it is distinct from personal identities, although it may form part of a personal identity. (p. 285)

This definition leads to some points of inquiry. First, the notion that the connection may be imagined rather than directly experienced points to the possibility that users may feel this connection without having tangible indicators as to why. For example, users might feel like they belong to a group of people even though they might not make use of the 'groups' function of a platform like Facebook or know any other users they interact with on a comment section. Secondly, the idea that collective identity may form part of a personal identity points to the existence of a complex relationship between personal and collective identities.

To understand the identity formation within digital activism, scholars have explored the connection to social and group identities emerging from the social media activism environment. For instance, Lüders et al. (2022) suggest how as one technological platform, like Facebook or Twitter, is used more, the use of its intentional or accidental affordances by users allows them to construct and express social and individual identities. In this context, affordances can be understood as what is offered by the technological platform to achieve the users' goals (Khazraee & Novak, 2018). These affordances include the ability to connect with large numbers of users, the ability to create normative representations of certain groups, and the ability to express and align emotions (Lüders et al., 2022). In this way, users not only forge collective identities, but may also explore their individual identities and emotions through the engagement in social digital movements. Overall, the authors point to the construction of agentic communities, that is, communities that act collectively, by linking previously unconnected users by using their common attitudes and beliefs (Lüders et al., 2022). This means that despite having a differing set of beliefs, the common engagement with the same content may facilitate the construction of a common identity.

Further research has explored the role of social media activism in individual and collective identity formation. For instance, Gerbaudo and Treré (2015) have recognised the central role of social media in forging new collective identities and creating protest identities, which is of great importance for digital activists. Nonetheless, the authors also acknowledge that collective identity remains a complex concept within digital activism, and that empirical evidence is needed to unravel this complexity (Gerbaudo & Treré, 2015). To contribute to this empirical evidence, Gerbaudo (2022) analysed how collective identity is formed in the social media campaign #MeToo on Twitter. The author discovered that the campaign articulated both individual and collective identities. The campaign encouraged users to share their personal testimonies with the goal of building a group identity that can help break stereotypes and stigmas attributed to sexual assault harassment survivors (Gerbaudo, 2022). Empirical evidence of this sort is needed, especially outside the realm of social movements. New and rapidly changing forms of activism, as is digital mental health activism, are to be investigated. As more users are sharing their testimonies with, for example, living with severe mental illnesses or with accessing the mental health care system, empirical research can help understand individual and collective identities within this context.

Furthermore, as suggested by multiple authors, social media can be a good approach for mental health interventions to reach a large number of people in a short time frame in promoting mental health (Latha et al., 2020; O'Reilly et al., 2019). Saha et al. (2019) suggest that as new digital mediums are used for mental health advocacy, there is a growing need for understanding this form of public discourse and the information and community dynamics involved in it. In a broader sense, social media-related interactions offer valuable insights into the evolving world of online psychological self-help and the new possibilities for peer support, information seeking and (de)stigmatisation of mental health issues (Saha et al., 2019). Given the use and potential of social media platforms for the promotion of mental health and the exchange of mental health information as a social movement, the dynamics behind digital mental health activism must be explored. Therefore, exploration on this topic is highly relevant and must advance rapidly, as this form of activism evolves.

Within the context of social media mental health activism, some qualitative and quantitative studies have been performed to comprehend its dynamics. Naslund et al. (2014), already pointed to the evidence that social media can have a supportive role for those suffering from health

conditions. Similar effects of social support, sense of connectedness and group belonging were identified in those suffering with mental illness who shared their experiences and sought advice from others on social media like Facebook, Twitter or YouTube (Naslund et al., 2016). However, their research did not cover the effect that widespread shared on these platforms can have on those who experience mild to no symptoms of mental illness but still interact with this content. Although the potential of social media for interventions for those with mental disorders is well supported (Naslund et al., 2020), the effect of such interventions in those who are not directly targeted is yet to be investigated more thoroughly. This is because these interventions shared publicly might have positive and negative consequences for non-targeted users who still see and interact with this content, but such consequences remain mostly unknown.

With this purpose, some authors have explored the effects of publicly sharing wellbeing and mental illness content on social media. For example, the ‘contagion’ of self-harm content on social media, such as Instagram and Tumblr, has been debated (Lavis & Winter, 2020). Although there are indicators for social support with this content among those who are already self-harming, there is a risk for other users might be in a vulnerable emotional state to follow these behaviours which are explicitly portrayed on social media (Lavis & Winter, 2020). Another found effect is the spread of misinformation and inaccurate representation of ADHD on TikTok, where this content reaches large engagement among all users (Yeung & Abi-Jaoude, 2022). This is an effect that could apply to other mental illnesses, and should be investigated as well, as suggested by the authors (2022). Furthermore, people with SMI who share their experiences on social media might be met with hostility and misinformation by other users who do not share the same experiences (Naslund et al., 2016). Therefore, research should also focus on the impact on those who engage with digital mental health activism but do not necessarily suffer from mental illness themselves.

In an opposing line of findings, some studies already point out the positive effects that digital mental health activism can have on users who interact with mental health activism on social media but do not always suffer from mental illness. For instance, Berry et al. (2017) examined how Twitter users responded to the hashtag #WhyWeTweetMH, where users were asked why they share mental health content on this platform. Respondents mentioned to do so in order to achieve a sense of belonging, raising awareness and combating stigma around mental illness, and creating a safe space for expression, coping, and empowerment (Berry et al., 2017). Instagram users, in a survey,

also positively rated mental health content on this platform which would make them feel boosted in their self-esteem and which would have a human touch in presenting mental health topics, such as someone sharing their story (Koinig, 2022). However, qualitative research on why this is the case would be needed to fully understand this preference. These studies point to the potential of digital mental health activism on social media to have a positive effect also for those who do not suffer from mental illness. Their findings also point to the potential of this activism to foster individual and collective identities in its activists. Since these studies focused on the content shared within digital mental health activism, qualitatively exploring the experiences and identities of those who are exposed to this form of activism remains unexplored.

In sum, there is a potential of digital mental health activism to create individual and collective identities. This suggests the value of exploring how this creation of identities occurs and is experienced by users. Therefore, this paper will explore two elements within digital mental health activism. The first is the highlighted connection between digital activism and personal and collective identities. The second is the importance of investigating the experiences, rather than the content, of digital mental health activism on social media across all users and platforms. Thus, the aim of this paper will be to qualitatively explore the construction of identities in those who engage in digital mental health activism on social media. More concretely, with the use of semi-structured interviews, I will investigate the construction of identities in young adults who perform digital spectator activities within mental health activism on social media platforms. These activities may include clicktivism, metavoicing, or assertion, as described by George and Leidner (2019). Thus, the research question that will be explored in this paper is “How are social and individual identities constructed by young adults who perform spectator activities within mental health activism on social media?”

Methods

This paper was part of a larger study which focused on exploring the engagement of young adults with mental health activism on social media. For this paper, a qualitative exploratory design was chosen, as this would better reflect the way in which people construct individual and social identities in conversation about digital mental health activism. Semi-structured interviews were conducted to find out how young digital mental health activists perceive their actions, roles, and thoughts on their activism. Semi-structured interviews also allow for great flexibility in probing

and guiding participants, while offering a standard guideline among interviewees. This flexibility is important to guide participants towards discussing important topics, while following the natural course of the conversation with them (Harrison & Rentzelas, 2021). Using this type of interview was an appropriate choice for this topic, as the personal experiences and thoughts of the participants were most important, therefore increasing the need of participants to explore these freely.

Participants

The participants for this study met two inclusion criteria. These were to belong to the target age group (18-26 years old), as well as the requirement to have engaged with mental health content on social media at any level of engagement, such as liking, sharing, saving, commenting on, or creating content. Participants mentioned to have been or being active in the social media platforms Instagram, TikTok, Facebook, Tumblr and YouTube. The ages of the participants varied between 19 and 26 years ($M_{age} = 22$). Participants also varied in their nationality, with Dutch, German, Polish, Swedish, American, Tunisian, Turkish, and Mexican as mentioned nationalities. The total number of participants was 20 (3 male and 17 female), 19 of which were used as a sample for this paper (3 male and 16 female; $M_{age} = 22$), as one of the participants was excluded from the analysis due to a low number of data relevant to the study. All participants were university students of different fields, with a majority being Psychology students. All participants indicated interacting with digital mental health activism by participating in clicktivism or metavoicing. They explicitly mentioned liking and saving posts, while only some participants discussed sharing content in their profiles or with others. None of the participants created their own content to post online.

The participants were recruited in two ways. The SONA system of the University of Twente was used to connect the researchers of this study to potential participants. This is a cloud-based service available for universities, from which Psychology and Communication Science students can be recruited and granted study credits for. The personal networks of the researchers were also reached via social media adverts and personal conversations. Thus, the sampling methods were a combination of opportunity, purposive and volunteer sampling.

Materials

Before the interviews, an information text was used as an advertisement for the recruitment of participants. An interview protocol containing 21 open questions, with some suggestions for

probing, was used for the interviews (see Appendix A). This protocol was developed by the two bachelor students involved in the larger study on digital mental health activism and revised by the supervisor of this study for feedback. A pilot test of the interview protocol was also performed with the two researchers conducting interviews, to test the flow and time length of the interviews. From this pilot the phrasing of some questions was changed, and some probe suggestions were added.

During the interviews, a digital informed consent form was used (Appendix B). Some of the interviews were carried out using Microsoft Teams, while others were carried out face-to-face. All of the interviews were recorded using the recording feature of Microsoft Teams as well as the researchers' personal devices. Once the data was collected, the transcripts were generated using the software Trint and Otter.ai, and these transcripts were transferred to the software ATLAS.ti (version 23.1.2.0) for analysis.

Procedure

Before the start of the data collection, the BMS Ethical Committee of the University of Twente had approved this study (application number 230463). During the interviews, participants first signed an informed consent form online. Then, demographic data was collected from the participants, such as age, gender, nationality, and occupation. The interview questions followed. The questions from the interview protocol included topics such as general views on mental health, actions on mental health, and the levels of engagement and motivation of the participants in relation to digital mental health activism. Thoughts and expectations of participants on self-diagnosis content were also explored. Also, questions regarding identity in connection to digital mental health activism were included. These questions covered the influence of digital mental health activism on the view of participants of themselves, mental health, others, and society as a whole. As a final question, participants were asked to add any final remarks that they wished to on the topic. Finally, participants were offered to request mental health resources from the researchers after the interviews if they needed them. The interviews were designed to last 60 minutes. The length of the interviews varied between 40 and 75 minutes. Once conducted, the interviews were transcribed using the software Trint and Otter.ai. These transcripts were revised by the researchers for accuracy, which was done by comparing the transcript to the audio recording. The transcripts were also slightly adjusted for increased readability. Such adjustments included deleting pauses in between sentences or deleting repeated words because of stuttering, as well as correcting words

interpreted incorrectly by the transcription tools. Participants were also assigned a pseudonym other than their real name to be used for data analysis and presenting the results. This was done to ensure anonymity of the interview data and to avoid traceability of the results.

Data Analysis

The analysis had the goal to identify the themes of identity that digital mental health activists mentioned during interviews. An appropriate method for this was using reflexive thematic analysis according to the guidelines by Braun & Clarke (2021), with a semantic and inductive approach.

The main goal of reflexive thematic analysis is to develop patterns of meaning, or themes, across a dataset. This development is done through a rigorous process of data familiarisation, coding, and theme revision, while reflecting on the role of the researcher in such development (Braun & Clarke, 2021). For the purpose of this paper, the goal of the analysis was to identify the patterns in meaning making by participants around individual and social identities within digital mental health activism. This analysis was performed following the semantic approach. The semantic approach to thematic analysis involves analysing themes only as they are mentioned by participants, without analysing meaning behind the participants' words in depth, and often resembling the way in which participants expressed their ideas (Braun & Clarke, 2021). Therefore, the answers of participants in relation to their role and actions within digital mental health activism, as well as some of their described opinions, were used to inform the understanding of users' constructs of identity in digital mental health activism. And finally, this approach is inductive, taking the dataset as the starting point for identifying meaning making (Braun & Clarke, 2021). Taking an inductive approach thus allowed for a closer resemblance to how the participants expressed their ideas, which in turn ensures a semantic approach.

To be able to make this thematic analysis in a reflexive way, I spent some time before analysing the interviews thinking about my own position as a researcher. This involved thinking about my own values, experiences and biases that could affect an impartial analysis of the data. For this process, I wrote a list of these, also thinking about how they might affect my analysis. For instance, being a Psychology student could affect the way in which I interpret what was said by Psychology students, as I might believe to understand their position better. Or it might affect how I interpret information from non-Psychology students, as I might judge this from my point of view

as a student. Furthermore, being a social media user myself who also interacts with digital mental health content, I might be inclined to interpret the results from the point of view of my own experiences. This could include the emotions that arise from this content, or my own identity within this activism. Thus, I also reflected on my own position towards this activism, concluding my general support for positive mental health content on social media, but a sceptic view on content with symptoms and disorders given. Taking this position helped me understand how others might see this form of activism in a different way, and thus try to understand these different views more carefully.

After my own reflective process, from which I drew some points to consider throughout analysis, I started to analyse the interviews. To achieve this, a sample of 19 interviews was analysed. In line with the guidelines by Braun and Clarke (2021), I followed a process of data familiarisation, coding, generation of initial themes, and a refining of the themes. First, an initial reading of all the transcripts allowed for the familiarisation with all the data, already identifying fragments that resemble themes of identity. Then, I used ATLAS.ti to further develop the analysis of the data. In this software, I marked any expressions in the conversation that reflect a connection to identity in the transcripts. These could be directly expressing a role within digital mental health activism, like “distributor” or indirect notions of identities, such as “I liked it because it felt validating” or “I felt like I belonged to something”. These expressions could then be labelled with code labels, which reflect the meaning transmitted by these expressions. At this point, an inter-coder reliability check was performed, to ensure that both researchers agreed on what expressions were considered relevant to the research question of this study. A fellow researcher and I independently coded two transcripts as described above. We then compared our coding results, arriving at a 68% agreement, meaning that from all marked fragments, 68% were independently identified as related to identity constructs by both researchers. For the remaining 32% of the fragments, these were discussed by the researchers and added to the data analysis only when agreed upon by both researchers. We then discussed these fragments to assign code labels to them. There were no disagreements among the researchers for the final codes. After this inter-coder check, I coded and revised all the transcripts. Finally, once all the transcripts were coded, I compared these to search for patterns, or similarities among them. Thus, I grouped codes into themes, which would reflect the patterns in meaning making between participants, as well as the variety of meanings

within these patterns. Finally, these themes were refined, also with the addition of subthemes, as these reflected better the variation within themes across the dataset.

Results

The results developed into seven different themes of identity and identity-related constructs in connection to digital mental health activism, four of which had two corresponding subthemes each (see Table 1). The themes and subthemes included notions of identity at the individual level, such as individual roles within activism, or collective notions of identity, such as community constructs, as well as some views on the self and others. All participants expressed identity constructs across at least one of these themes. The theme *Community* had the highest frequency in the dataset (N = 78), closely followed by the theme *Labelling and Diagnosing* (N = 75) (see Table 1).

In the following section, a description of each theme, and corresponding subthemes, will follow. Extracts from the interviews corresponding to these themes will be analysed as well, to represent the variety in the topics covered within themes and subthemes. This is because not all of the codes will be presented in detail. The themes are presented by frequency, as presented in Table 1.

Table 1

Themes and Subthemes and Corresponding Codes Developed from Interviews on Digital Mental Health Activism

Main theme	Constructed as...	Subthemes	Primary codes included	N
Community	Organisation of people into different groups or communities arising from the engagement with digital mental health activism	Culture of Belonging Group Creation	DMHA makes me feel less alone We, as a society, are more open to talk about mental health DMHA has made me more empathetic towards others DMHA has created a culture people want to belong to DMHA has made me feel that I belong to a group DMHA urges people to want to belong DMHA has created a supportive community DMHA has created a global community DMHA divides people into different groups DMHA has created a community of shared experiences DMHA has created a toxic community	78
Labelling and Diagnosing	The connection between diagnosing	Diagnosis as Identity	DMHA leads people to define themselves by their struggles People have a need to diagnose themselves	75

	or labelling and identity		<p>I do not label myself</p> <p>I have a need to diagnose myself</p> <p>I have a need to label others</p> <p>My diagnosis made me feel validated</p> <p>My diagnosis made me more knowledgeable</p> <p>DMHA has trivialized mental health</p> <p>DMHA leads to the victimization of diagnosed people</p> <p>DMHA labels me in incorrect ways</p> <p>DMHA makes me question my mental health status</p> <p>DMHA sets standards for living with a diagnosis</p>	
		Normative Depictions of Diagnosis		
Relatedness	The ability of users who engage with digital mental health activism to relate to each other and the feelings that may arise from this	Being Validated	<p>DMHA makes me feel listened to</p> <p>DMHA makes me feel understood</p> <p>DMHA makes me feel validated</p> <p>People have a strong need for acceptance</p>	68
		Relating to Others	<p>DMHA helps me relate to other people's experiences</p> <p>DMHA helps people relate to each other</p> <p>I expect to identify with DMHA content</p> <p>Relating to others makes me more open to information</p> <p>We, as people, seek DMHA to relate to others</p>	
Visibility	The visibility of different people and ways of living in relation to mental health		<p>DMHA gives a face to mental illnesses</p> <p>DMHA has challenged my view of normality</p> <p>DMHA shows me that some people struggle more than I do</p> <p>DMHA makes people who struggle more visible</p> <p>DMHA shows that we all share some struggles</p> <p>I am open to talk about my own experiences online</p> <p>People are open to talk about mental health online</p>	58
Knowledge	The acquisition of new knowledge about the self and others through digital mental health activism		<p>DMHA can help you know more about yourself</p> <p>DMHA challenges my deeply rooted beliefs</p> <p>DMHA changes how I look at others</p> <p>DMHA increases my awareness of others</p> <p>DMHA helps me learn about mental health</p> <p>DMHA helps me learn about others</p> <p>We, as people, seek DMHA to learn about mental health</p>	54
Activism Role	The roles taken by individuals in the digital mental health activism community	Me as an Activist	<p>I am a passive consumer of DMHA</p> <p>I am supporter of DMHA</p> <p>I am an active consumer of DMHA</p> <p>I am a distributor of DMHA</p> <p>I am a gentle mental health activist</p> <p>I am vocal within DMHA</p> <p>I want to be a mental health guru</p>	53
		Others as Activists	<p>People engaged in DMHA are often anonymous</p> <p>People on the internet are loud</p> <p>Some mental health activists are unverifiable experts</p> <p>Some people are too engaged in DMHA</p> <p>Some people try to profit from mental health content</p>	
Self-improvement	Activities and feelings related to improving the individual's life in connection to		<p>DMHA has encouraged me to improve my life</p> <p>DMHA has made me accept myself</p> <p>DMHA has made me feel supported</p> <p>DMHA has made me feel more confident</p> <p>DMHA has made me more self-empathetic</p>	47

digital mental
health activism

DMHA helps me overcome my struggles
DMHA has showed me that I deserve to ask for help
We, as individuals, seek DMHA to improve our lives
We, as individuals, seek DMHA to learn about ourselves

Note. “DMHA” stands for digital mental health activism. “N” stands for the frequency of fragments coded within each theme. The table presents the different themes developed from the coded fragments of this dataset, including a description of each theme, which codes were included for these, as well as the frequency of the theme across the dataset.

Community (N = 78)

Participants expressed this theme by describing the online communities that are created from digital mental health activism, the different purposes of these communities, as well as the sense of belonging and need to belong that comes with it. Most variations of this theme denoted positive communities that people benefit from, with some exceptions such as the urge that people might feel to belong to these communities, as well as the toxicity that can be created in these. From this theme, I identified two different subthemes, namely *Culture of Belonging* and *Group Creation*.

Culture of Belonging

Within this subtheme, there was a pattern for participants to refer to an online ‘culture’, described mostly implicitly, to which people try to belong to or feel like they already do. Some variations within this subtheme refer to the strong need of people to belong to this culture, while other variations showed what this culture is about. This culture was mainly described in terms of acceptance and openness to talk about mental health, empathy, as well as less frequent feelings of loneliness that come with belonging to this culture. “Gabriela” (female, 21), for example, mentions the actions that people take in order to belong:

Gabriela: They want to feel that they belong with this new culture that is the mental health culture. So, I think that maybe they want to feel seen. Or maybe they want to feel validated, too. And well, they are willing to go to that limit of faking a disorder just to feel that they are accepted in this new circle or group of people. And I think that’s worrisome.

Here, Gabriela is talking about a group of content creators online, especially on TikTok and YouTube, who have been discovered to fake symptoms of mental illness and, when asked why she thinks this might happen she refers to this “mental health culture”. She mentioned this culture in other sections of the interview, describing it as an online, abstract community where people share their experiences with mental illness, are advised by mental health professionals, and interact with one another. Yet, she did not consider herself as a member of this community. Even though this fragment mostly shows how the strong need of belonging can be perceived as negative by some, other participants, like “Hazel” (female, 23), talked about their own positive feelings of belonging:

Hazel: I felt I was, even though I would not comment yet anything or just liking, I felt like I was heard or supported. So, I felt very happy, and I felt like I belonged to something. Because everyone is also telling their experiences and stuff, just posting about it, you know?

When asked about her emotions from engaging with mental health content on Instagram, Hazel brings up how she felt as if belonging to a group, without needing to be active in the online community. This feeling of belonging to a group by interacting with mental health content on social media was shared by several participants.

Group Creation

Within this second subtheme, participants were able to describe and identify different groups created within digital mental health activism. These were identified in terms of the different groups that people are divided into depending on their view of mental health. They also described the different communities created online, either via direct online support groups, or just the general sense of community that arises from the interaction between people in the comment sections of mental health content. “Alina” (female, 22), for example, shares her experience with a supportive group on Facebook:

Alina: And the group was, I think, very helpful because some people were just writing their stories, the things they were struggling with, and it was just mainly for sharing, and people were responding “I feel sorry for you”, “but visit psychologists, they will help you”. So, it was more like a support group where people could just share their feelings, what they struggle with and ask for help, or just even to get positive comments.

In this fragment, Aline is referring to a Facebook group which was administered by a psychology student who wanted to offer the space for people to share their struggles and worries with mental health, and where they would receive help from each other. This group explicitly made use of the ‘groups’ function of Facebook to host their community, but people were joining voluntarily, out of interest, and taking part in this community by supporting each other. “Lydia” (female, 22), on a different account, points out her perception of the online mental health community:

Lydia: On the one hand, it’s a very positive community because people are overall very kind to each other and try to help each other. On the other hand, it can become a bit toxic because then they will talk myths and they are taking each other down with it. So that’s not really the parts of the online society you want to be in, but in most parts it’s pretty positive.

Lydia was asked about her view of society in their online behaviour and how it has changed through engagement with digital mental health activism. Her view of the different people online as either supportive or toxic was shared by other participants, who also shared that some online behaviours are more positive than others.

Labelling and Diagnosing (N = 75)

Constructions of this theme by participants consisted of the connection between labels and diagnoses and the individual’s identity. Other accounts showed the advantages and disadvantages of labelling or diagnosing, as well as the portrayal of diagnoses on social media. Some participants even expressed the rejection of labelling for themselves. From this theme, I identified two subthemes, namely *Diagnosis as Identity* and *Normative Depictions of Diagnosis*.

Diagnosis as Identity

Within this subtheme, there was an identifiable pattern of participants referring to labelling and diagnosis as directly connected to identity. Some participants described, for example, how getting a diagnosis made them feel validated, their need to diagnose themselves or others, and how many people define their identity based on their mental health diagnosis. “Cara” (female, 21), for instance, shares her experience with the definition of one’s identity based on one’s diagnosis:

Cara: (...) there is way too much emphasis on what you’re diagnosed as. The only reason why [you need] your diagnosis is to find appropriate treatment. It should not be a part of

your personality. I also struggled with that myself when I got diagnosed with borderline (...) because I kind of defined my character as having borderline in the beginning way too much, and I think that can be really harmful.

Here, Cara talks about her own experiences with self-diagnosing content online, especially on YouTube, which can lead people who watch it into defining their identity based on their diagnosis. She was referring to videos which portray mental illness as incurable and that, therefore, lead to mental illness playing a big role in people's identity. "Nienke" (female, 21), on a contrasting note, points out how her diagnosis, together with digital mental health activism, has been a positive experience for her:

Nienke: I got diagnosed with ADHD and now I can know that some of the struggles that I faced daily are not because I am more incompetent as a human but that I actually have a condition. And I've gained strategies and have learned strategies to help with that and help me in my everyday life to deal with it.

Here, Nienke is referring to these strategies as acquired through videos on TikTok of people who are also diagnosed with ADHD and share their experiences and ways in which they deal with their diagnosis. She thus expressed how her view of herself as a someone diagnosed with ADHD has evolved with this form of activism.

Normative Depictions of Diagnosis

As for this second subtheme of diagnosis and labelling, I identified a pattern in which participants would refer to the ways in which mental health struggles are portrayed on social media. They also mentioned how these depictions also set standards for living with mental health illness, make people doubt their own mental health status, or lead to the trivialisation of mental health issues, making it seem more normal or common and therefore less important. "Valerie" (female, 26), illustrates one of these points:

Valerie: Because when you know a lot about your mental health, and you engage in mental health a lot already in the past, then you may get confused by other videos that you see online and saying: but I have my diagnosis, is it wrong now?

Valerie refers to self-diagnosing content presented on social media, specifically on Instagram, and the doubts that emerge through the comparison that she makes to her own diagnosis,

which she did not explicitly disclose. Gabriela, on different view, shares how she perceives the depiction of mental illness:

Gabriela: The community on the internet really tries to give a certain impression and really tries to tell you the way in which you should live and experience your mental health (...) but we don't need to fit specifically into the way which people with this disorder portray that they live.

In this fragment, Gabriela is referring how the content where YouTube and TikTok creators shared their own experiences with mental illness impacted her. She also mentioned how she stopped interacting with this content when she realised that it was portraying a way of living with mental illness that did not correspond to her own experience.

Relatedness (N = 68)

Participants constructed their identity in terms of relatedness by talking about the way in which digital mental health activism helps them relate to other people and their experiences, as well as the feelings of validation that can come with this. There was also a mention of the need of some people to relate to others and be accepted as a reason to engage in digital mental health activism. The subthemes *Being Validated* and *Relating to Others* are recognisable within this theme.

Being Validated

Within this subtheme, participants mostly referred to the way in which they felt validated, recognised and understood by seeing people they could relate to on social media. They also mentioned the need for acceptance that might be felt within this activism. Gabriela, for example, mentions the validation, feelings of being listened to and understood that she experienced with digital mental health activism:

Gabriela: I used to feel very listened to and very understood because, as a kid, I struggled with anxiety. And I remember doctors telling, like my mom especially that maybe I had anxiety. (...) And to hear someone describing the things I was feeling and to know that it was real. I felt validated. So, for me, it was really important growing up to have that platform and YouTube of people talking about mental health.

Gabriela was referring to her early diagnosis of anxiety, which was difficult to accept by her parents, who lived in a context where mental health was highly stigmatised, as opposed to the support she felt on YouTube. “Fleur” (female, 20), on a variation of this subtheme, comments on her view of how some people seek recognition and acceptance online:

Fleur: And also, maybe people search for recognition that they might not be able to get from their own environments. And then they post about it and people do respond in the comments even though it's not always positive.

Here Fleur is answering why she thinks people post mental health content online, after saying that she notices that people increasingly sharing their mental health experiences on social media.

Relating to Others

Within this subtheme, participants shared a pattern of referring to how digital mental health activism is a means through which people can relate to one another, and how this might even become an expectation from this type of content. Participants generally considered this a positive experience. “Judith” (female, 22), for example, talks about how she relates to others online:

Judith: Sometimes when it's trauma related and I identify with it, because I have also experienced that, I get a bit sad, but I also feel like of recognized, which is a good feeling.

In this fragment Judith is reflecting on how she feels when interacting with the content and comments where people share their stories on Instagram or TikTok. “Meike” (female, 23) also expresses how relating to others can be important, by expressing how she does not engage with content she cannot relate to:

Meike: It depends on how important this topic is for me. So, if it's a diagnosis that I can't really do anything with, where I don't see anything in myself again or something, then I quickly sweep it under the carpet, then it doesn't really matter to me. But if it's a topic that's somehow already relatively present, then I think I'll think about it (...).

Meike was asked about how she interacts with self-diagnosis content and the impact it has on her own wellbeing. This was a common account of this subtheme, where participants expressed

being more open to information if they could relate to it, especially in relation to identifying with the symptoms of a mental health issue.

Visibility (N = 58)

This theme was constructed in terms of how participants perceived others and themselves as being visible on social media, as well as the realisations that come with this. Accounts included how they discovered that many more people than they initially thought struggle with mental health, or that their idea of normality was not exactly what they found with digital mental health activism. “Ron” (male, 19) expresses his views on the visibility of mental health:

Ron: But also, more attention on mental health is very good because a lot of people are struggling with mental health issues and to be more open about it, and talk more about it, I think really helps to really see it as a normal thing.

Here, Ron is talking about his generally positive view on the visibility of mental illness and openness online to talk about mental health issues, even though he does not interact with this content much. “Harper” (female, 21), on a different account, shares how she has realised, through social media, that some people struggle more than her, “*people have it much, much worse than I do*”, and she attributes this realisation to the content created within digital mental health activism. She also mentioned the positive things that come with this realization for her, such as avoiding “*investing energy*” into thinking that she might be severely depressed, for example, when her situation is not as bad as that of others.

Knowledge (N = 54)

Across the dataset, participants expressed their identity as knowledgeable individuals, who have learned about themselves, and others, as well as individuals with the ability to acquire more knowledge about mental health. Some variations of this theme also included how they challenge previously held beliefs through digital mental health activism, as well as changes in their perception of other people. “Henrik” (male, 25) expresses his change in perspective:

Henrik: I guess because you get new perspective on things and something that you previously have believed is wrong or something that’s not relevant. Perhaps you can see some content and you get confirmation or proof against your beliefs that you were wrong in a way.

This fragment is a response to being asked why he thinks he has become more acceptant of others through digital mental health activism, even though he clarified that this has not changed his opinions, but just made him aware of different perspectives. “Lisa” (female, 26) shares her own increase in self-awareness and how it shapes how she interacts with others, due to this acquired knowledge.

Lisa: (...) it's probably just made me more aware. And I do think it does have a better effect on how I engage with other people in the world. I think because the more self-aware I am about my actions and how I affect others, usually the better it will be for those around me, because I'll be less inclined to be in my own head.

Here Lisa reflects on how digital mental health activism has impacted her view of herself, and later reflected on how she has been able to apply this realisation. For example, in coaching her sports team or when interacting with her friends she has changed how she behaves as she is more aware of how it impacts those around her.

Activism Role (N = 53)

This theme compiled the different ways in which participants described their role within digital mental health activism. One common topic in this was the idea of content as a product that is consumed by users, either actively or passively. Other variations on roles included much more vocal or loud roles, as well as roles rising from self-interest. From this theme, I identified two subthemes, *Me as an Activist* and *Others as Activists*, as participants consistently talked about their own roles and those of others in different and separate ways.

Me as an Activist

Participants referred to their role within digital mental health activism. Most constructs involved the previously mentioned idea of ‘consuming’ content from social media, as well as their role in inviting others or being vocal about mental health. “Anna” (female, 23) explicitly expresses: “*I don't really feel like I have a role. I feel like more a passive consumer*” when asked about how she would describe her role within digital mental health activism. Judith, on a different note, when asked the same question, expresses her desire to become a ‘guru’ for mental health.

Judith: *A guru for me is someone that has knowledge on it and is also there to help people with it. And I would like to be some kind of guru in a sense, because I've experienced stuff myself, but also because I'm always interested in finding out more [...]*

She mentions how she wishes to achieve this role, but not only in online environment, but preferably in her daily interactions. Cara shared her role in a different way:

Cara: *But for now, if I see something and I think that's really cool because I think that should be way more of a positive angle than the clinical angle, then I like to share it with people. To spread some knowledge thing kind of.*

Cara is referring to how she shares only some mental health content online, even though she generally has a passive role and prefers to have conversations about mental health in person. She makes her decision to share content based on the perceived importance that she attaches to it.

Others as Activists

Within this subtheme, in contrast, people referred to others' roles as anonymous, unverifiable, and even untrustworthy, indicating that the fact that people online cannot always be identified makes them trust them less. Some others also identified the role of others as driven by the desire to profit from social media engagement. Fleur, for example, shares her concern with some creators of content who “*post it to get views and comments and likes, and not necessarily about the trying to help people figure it out*”. She perceives this role as someone who wants to benefit from the engagement with likes or shares of their posts, without having a real intention to help people with their mental health struggle by, for example, giving resources or advice. She is referring primarily to videos on self-diagnosis on TikTok and Instagram. Anna similarly talks about her perception of some activists as unverifiable experts:

Anna: *(...) a person that said she is a trauma coach. So, she represents herself as a trauma coach, but I didn't really know if she's really a trauma coach or if she just says she is. (...) in the comments (...) she replies, “I can help”. And I don't know if TikTok should be the platform for acquiring people for your work or not even your work. I don't really know if she works there. I don't know.*

Anna is referring to an account which posted a “put a finger down” challenge, a trend on TikTok, where participants could confirm or deny whether they have experienced childhood

trauma by putting their fingers down to symptoms to which they could relate. Anna explains how whenever users would comment “10 out of 10”, indicating that they experience all of the symptoms, the content creator would offer to help with her work as a trauma coach in a comment reply.

Self-improvement (N = 47)

The final theme, self-improvement, was built based on the commonality among participants to talk about their desire to improve themselves as a motivator to start engaging with digital mental health activism. They also discussed the good effects that this activism has had on themselves, such as confidence and self-acceptance. Henrik, for example, expresses his motivation behind engaging with positive mental health content on TikTok.

Henrik: (...) it's because I have a need for it, that I want to improve my life and I don't feel good about all things, and I want to improve it and this content has helped me, or at least inspired me. I know what I should try and do, but it's hard to do it in practice.

In this fragment, Henrik refers to why he engages with videos on TikTok where content creators share inspiration to create habits to improve one's life, such as working out or waking up earlier, and inform on the good effects that these habits can have on mental health. Lydia, with a different approach, shares the direct effect that challenging the beliefs about herself had on her, and how the acceptance of her situation allowed her to take a big life decision.

Lydia: I think it was mainly like, "oh, but I have problems myself so I cannot study Psychology." And it changed mostly because when you are on TikTok, you see a lot of mental health professionals also, but they are also very open about like I'm a mental health professional, but I still struggle. I take medication or whatever, and one of them said if doctors were not allowed to get sick, we wouldn't have any doctors left. So why would that be any different with mental health related professionals? So that was mainly what changed, like the belief that I wasn't allowed to study it because I had problems myself and then just realizing like, "Oh, that's fine."

Lydia expressed this when asked about how digital mental health activism had changed the views of herself, and she shared how mental health activism on TikTok had helped her decide to study Psychology after trying a different career with which she was not satisfied.

Discussion

The present paper has laid out how social media mental health activists discuss their identity constructs in relation to their spectator activities across various platforms. Concretely, there were seven themes and eight subthemes of identity recognised through the analysis of 19 interviews. Overall, participants described their identity in terms of the communities and need for belonging formed around digital mental health activism, the connection between diagnosis and labelling to their individual identity, as well as their role and the role of others within this activism. Other themes highlighted the visibility of people who struggle online, as well as the sense of relatedness to others and their experiences that comes with engagement with digital mental health content. Finally, participants not only discussed their roles and groups, but also mentioned the effects that these have on themselves. Examples of these effects included the increased knowledge of themselves and others, as well as the positive effects on their self-improvement, such as increased self-empathy and acceptance of mental health struggles. Together, these themes helped answer the research question of this paper, on how individual and social identity constructs are discussed by digital mental health activists who engage in spectator activities like clicktivism and metavoicing. Nonetheless, these results are not applicable to assertion, as none of the participants created their own mental health content to post on social media. In brief, this study contributed to the understanding of individual and social identities within mental health activism on social media.

In terms of how digital mental health activists construct their identity, even though participants are defined as activists according to the activities that they perform as framed by George & Leidner (2019), they did not identify themselves as such. Most participants described their roles as being consumers, either active or passive, of mental health content. This finding points to how even those who are performing digital activism activities might perceive a large volume of mental health content online as a product to be consumed, rather than activism. Therefore, future studies could focus on defining whether the same activities of digital activism as described by George and Leidner (2019) are applicable to mental health activism on social media. This research could also be complemented by investigating further how users perceive these activities and their role within this activism. Additionally, further research could also analyse the impact of the different activities in achieving the goals of wellbeing and de-stigmatisation of mental illness of digital mental health activism.

As for other identity constructs found, these support the notion of social media mental health activism as having the potential to influence discourse on mental health issues, information sharing, and on community dynamics. As Saha et al. (2019) suggested, social media has the potential to facilitate psychological self-help, offer peer support, information seeking and the (de)stigmatisation of mental health issues. All these potentials were also identified in the identity constructs laid out by participants. The theme *Self-improvement*, for instance, showed how digital mental health activists not only benefit from mental health content to improve their lives, but they also seek this content to do so. Further, the *Community* theme and its subthemes show how the culture of belonging, as well as the different groups created through digital mental health activism have the potential to offer peer support. Similarly, the theme *Relatedness* supports the potential of peer support, by means of more openness to information from users who can relate to content creators and other users online, as well as by creating a connection between otherwise unrelated people. The themes *Knowledge* and *Visibility*, on a different note, contributed to the understanding of how information seeking and information gathering, as well as the (de)stigmatisation of mental health occurs. This occurs primarily by making people who struggle more visible, and by making users feel more knowledgeable on mental health and their awareness of others' experiences. These findings are in line with already existing findings on the positive effects of digital mental health activism for those with mental illness (Naslund et al., 2014; Naslund et al., 2016; Naslund et al., 2020), as well as with the motivation of Twitter users to share mental health content (Berry et al., 2017). Thus, this research further supports the utilisation of digital mental health activism as a means to achieve the goals of self-help, peer support, information seeking and de-stigmatisation for all users who engage with it.

Despite these positive findings, the constructs of identity also suggest potentially undesirable aspects of digital mental health activism. For instance, the distrust in the roles of others within mental health activism came across with expressions on how some users might wish to profit from this form of activism, especially creators. They might do so by presenting themselves as experts who cannot be verified, or by falsely presenting themselves as experiencing a mental health issue. These portrayals can have immense consequences for users, particularly for those who struggle with mental health issues. As shown in the study by Wang and Liu (2016), a content analysis of discourses on Chinese social media on depression revealed that stereotypical presentations of depressive symptoms led to the promotion of stigmatisation or reduced support

for depressed individuals. Thus, the careful portrayal of mental illness might be necessary to achieve the goals of this activism. Future qualitative research could focus on analysing the content of posts informing about or sharing experiences with mental illness and how users perceive this content. This could be achieved by quantitatively and qualitatively investigating, for example, what type of information might be reducing the support to this content, and what information contributes to higher support. These further findings could ultimately inform, for example, mental healthcare professionals who use social media as their information sharing platforms to carefully create content that promotes wellbeing and support.

A second undesirable outcome identified through these findings is that activists can identify misinformation shared via social media and thus lose trust in the content shared within digital mental health activism. As already found by Yeung and Abi-Jaoude (2022), the inaccurate representation of ADHD on TikTok reaches high engagement in this platform. Participants of this study also identified interacting with such content, and commented losing engagement with it after identifying how it spreads misinformation. However, this finding could be biased by the large number of Psychology students in this sample, who might be more informed about symptoms of ADHD than others. Therefore, investigating the effects and perceptions of the representations of different mental illnesses on social media should consider other populations, especially those users of social media who do not have much experience or knowledge with mental illness.

Finally, the relatedness to those who experience mental health struggles and the attributed importance of labelling and diagnosing found within this study are relevant as well. The Theory of Social Stigma of Goffman (2009; as cited in Corden et al., 2021) suggests, for instance, how labels can have the power to “spoil” or disrupt an individual’s identity formation, leading to an isolation to society by being seeing by oneself and others as different. Nonetheless, the effects of labels, such as the label assigned by a diagnosis, may lead to positive outcomes when combined with the relatedness to others found in social media. As found by Cooper et al., (2017), for example, a stronger sense of autistic social identity was associated with positive self-esteem and thus better mental health. Therefore, having a sense of identifying with one’s diagnosis while identifying with others who are struggling with something similar might ultimately have a positive effect on individuals and the groups they belong to. Future studies could qualitatively investigate how

diagnosed individuals across multiple mental illnesses identify themselves in relation to their diagnosis and how they relate to others who share this condition.

Nevertheless, there are some limitations to this study that could have influenced the findings. The inclusion in the interview protocol of a section focused on self-diagnosis content might have increased the frequency by which participants mentioned this topic in relation to their individual and social identities. For example, participants like Henrik were not engaging with self-diagnosis content as much, but they still expressed their views on it during the interview when asked about this type of content. Further, views like his were mainly based on impressions triggered by the questions on this content, instead of based on their experiences from constantly interacting with this content. However, a few participants still mentioned diagnosis and labelling content and constructs before the section on self-diagnosis was asked. Thus, careful creation of an interview protocol should be considered in similar studies. A second limitation was the high number of Psychology students and female participants, as the findings of this study might not be transferable to other populations.

Despite its limitations and suggestions for future research, this study had multiple strengths which helped contribute to some of the gaps identified in literature. Participants, for example, showed engagement across multiple social media platforms. These participants particularly contributed to new findings about platforms such as Instagram and TikTok, which are only recently becoming popular platforms for mental health activism. Further, they also discussed a variety of digital mental health activism content, including wellbeing content, shared experiences of mental illness, as well as content from professionals who share their knowledge on social media. This allowed for a nuanced dataset, with different identity constructs identifiable in relation to different types of content. For example, self-diagnosis content was generally connected to the themes of *Labelling and Diagnosing* and *Relatedness*, whereas content where users share their experiences with mental illness were consistently connected to *Visibility*. Further, these findings were focused on the experiences of digital mental health activists and not the content of this activism, which was mostly unexplored in literature. Finally, future research could complement the strengths of this study by also exploring users who perform assertion activities, which is the creation of mental health content, as they might construct identity differently than the current participants.

In summary, this research paper contributed to the understanding of individual and social identities constructed by digital mental health activists who perform the spectator activities of clicktivism and metavoicing. The results of this paper showed how users often construct their identity not only in terms of their individual roles and self-views, but also in terms of their connection to others, their sense of community, and their perception of others. Overall, these findings can be used to support the use of social media to promote positive mental health and to discuss mental health issues. Most importantly, this paper suggests continuing to research the way in which creators, users, and informants of digital mental health activism can best act in a way that promotes wellbeing and that contributes to the de-stigmatisation of mental illness in society.

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Appendix A Interview Protocol

Digital Mental Health Activism: Interview Protocol

Read out the informed consent form together and let them sign it. Then explain that they will fill out the MHC-SF before the interview so we can gain some information about their mental state at the time of the interview.

Ask for their age and gender that they identify with.

Ask for their ethnicity and where they live in the world (if online), as well as occupation and education.

General Views on Mental Health:

1. Which role does mental health play in your daily life?
 - a. *How would you describe your views on mental health?*
2. How would you describe your actions in relation to mental health?

Digital Mental Health Activism:

Now we will discuss digital mental health activism and how you relate to it. Before we start, it is important to mention that by digital mental health activism, a form of digital activism whereby users share their knowledge and experiences with mental health issues in online environments. More specifically, we are interested in any forms of engagement, such as liking, sharing or creating content for the platforms Instagram and TikTok.

1. How would you describe your views on digital mental health activism?
2. How would you describe your actions in terms of this form of activism?
 - a. *Do you share content? Only like the content? Do you create content?*
3. How often do you engage with digital mental health content?
 - a. *Do you recall some of the content you engaged with lately? How did you engage with it?*
4. How long have you been engaging with digital mental health activism?
 - a. *Has your engagement changed over time? How? Here, it would be good to check if there are periods where they are less engaged and why so*

Experiences with Digital Mental Health Activism:

1. What do you think has made you engage with digital mental health activism content?
2. What kind of emotions have you felt when engaging with digital mental health activism?
3. How would you describe your role within digital mental health activism?

Experiences with Self-Diagnosing content:

An emerging type of digital mental health activism content is self-diagnosing content. In this type of content, a list of symptoms is given which consumers use to confirm or decline a certain condition or health state. Videos on TikTok include challenges such as “Put a finger down challenge” which present several symptoms or signs of mental health conditions such as ADHD. One video had symptoms like “Put a finger down if you’re a picky eater” or “Put a finger down if you practice conversations in your head”.

1. Have you ever engaged with self-diagnosis content? Could you show me an example (video) (Ask questions about the video and ask them to share it via email)?
 - a. *If yes, with which content? how often do you engage with self-diagnosis content? How do you engage with such content (e.g., like, share, comment)?*
 - b. *If no, what are your expectations of self-diagnosis content?*
2. What do you think about self-diagnosis content?
 - a. *How would you define self-diagnosis content? How do you identify yourself with self-diagnosis content? What role does it play for you? Personal examples/experiences with it?*
3. What are your expectations when engaging with self-diagnosing content?
 - a. *What do you expect to get out of engaging with self-diagnosing content? Probing --> Helpful? Insightful? Interesting? Informational? Pessimistic?*
4. How do you feel after encountering such content?
5. What do you think after encountering such content?
6. What do you do after encountering such content?

a. *What do you usually do after encountering such content? Probe examples --> Do you research the diagnoses/mental disorders? Do you talk with other people about the content? Do you share the content? Do you like the content? Do you comment on the content? Do you search for similar content?*

7. (maybe) How self-diagnosis content affect your mental health?

8. How long after you consumed the content do you still think about the content?

a. *Feelings of annoyance, curiosity, anxiety, etc./general effect of the content*

Final Views on Digital Mental Health Activism and Identity:

For the final part of this interview, I will ask you to think again about digital mental health activism content in general.

1. Has engaging with digital mental health activism changed your views on mental health?

a. *In what way? Has this changed over time or depending on the content?*

2. Has engaging with this type of content changed your views about yourself?

a. *How? Does it change over time?*

3. Has engaging with digital mental health activism influenced your views of others or society?

a. *In what way?*

4. Is there anything you would like to add in regard to digital mental health activism?

Appendix B

Informed Consent Form

Consent Form for Digital Mental Health Activism

YOU WILL BE GIVEN A COPY OF THIS INFORMED CONSENT FORM

Social media content related to mental health has become increasingly popular. Users and content creators have openly shared their knowledge and experiences with mental illness, well-being and mental health stigma on platforms such as TikTok or Instagram. This phenomenon is also known as digital mental health activism, often aimed at informing about, advocating for or destigmatising mental health. However, little qualitative research has been conducted to analyse the effect of digital mental health activism on those who engage with it. With this research, we want to analyse the effects on mental health and identity in young adults as expressed by users and creators during interviews. With this, we wish to comprehend better the interaction with this content, and how young adults react to it.

Please tick the appropriate boxes

Yes No

Taking part in the study

I have read and understood the study information, or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.

I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.

I understand that taking part in the study involves an audio- and/or video-recorded interview that will be transcribed verbatim and destroyed after the end of the study.

OPTIONAL (delete if not needed):

Risks associated with participating in the study

I understand that taking part in the study involves the following risks: mental discomfort arising from mental health and well-being topics as well as from filling out the Mental Health Continuum (Short Form)

Use of the information in the study

I understand that information I provide will be used for the researchers' Bachelor's theses and a possible publication

I understand that personal information collected about me that can identify me, such as [e.g. my name or where I live], will not be shared beyond the study team.

I agree that my information can be quoted in research outputs by using a pseudonym in place of my name.

UNIVERSITY OF TWENTE.

Consent to be Audio/video Recorded

I agree to be audio/video recorded. Yes/no

Signatures

Name of participant

Signature

Date

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

Researcher name

Signature

Date

Study contact details for further information:

Researchers:

Hadil Dewak h.dewak@student.utwente.nl

Mariana Luna Lopez m.lunalopez@student.utwente.nl

Supervisor:

Yudit Namer y.namer@utwente.nl

Contact Information for Questions about Your Rights as a Research Participant

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee/domain Humanities & Social Sciences of the Faculty of Behavioural, Management and Social Sciences at the University of Twente by ethicscommittee-hss@utwente.nl