Perspective

Inside the black mirror: current perspectives on the role of social media in mental illness self-diagnosis

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Abstract

The purpose of this article is to analyze the existing literature on the role of identity in mental illness and self-diagnostic behavior among individuals on social media. In this paper, we consolidate existing frameworks for illness identity formation based on principles of social contagion and community formation principles to conceptualize abnormal behaviors related to social media use, including Munchausen's by Internet, mass social media-induced illness, and mass sociogenic illness. The importance of a diagnosis in personal identity formation and ingroup involvement is an emergent theme in this review. Social media communities represent a cultural antithesis of the medical establishment by rejecting healthcare expertise and creating spaces whose membership is only afforded through a psychiatric diagnosis for individuals to participate in shared experiences. Clinical implications of these findings include tools to identify and dismantle harmful self-pathologizing of normal behavioral variants in young adults who present with specific symptomatology.

Keywords Social media · Diagnosis · Mental health · Mental illness · Self-diagnosis · Psychopathology

1 Introduction

The rapid propagation of social media in recent years has given rise to emerging trends in self-diagnostic behavior among individuals in online mental health communities [9, 33, 43, 53]. On the online video-sharing platform TikTok, videos with the tag #mentalhealth have amassed over 17 billion views, providing easily accessible content such as psychoeducation, mental health tips, and anecdotal experiences with mental illness to the masses. While the spread of information regarding mental health diagnoses in online spaces can have positive impacts, such as fostering therapeutic communities, social support, and self-discovery, there are also underrecognized risks involving the spread of misinformation and stigmatizing content in online spaces occupied by young persons [42]. Often, these videos are posted by users whose credentials and mental health expertise are unknown [31]. Across the United States, mental health researchers have cited notable increases in "abnormal illness behaviors" associated with social media usage. Clinically, self-diagnosis can become problematic as it can lead to inappropriate treatment modalities, causing strain on the medical system and the risk of harm to the individual [51].

Mental health professionals must understand these trends comprehensively and establish best practices for approaching self-pathologization to avoid potential consequences such as unnecessary treatment or overmedicalization [1, 25; p. 270]. In this paper, we discuss the rapid development of mental health spaces within social media platforms and their interconnection to illness identity and emerging self-concept in adolescence. We will first examine the rise of social media

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spaces focused on mental health as potential incubators for pathologizing behaviors, including the role of algorithms and online communities. We then summarize the existing theoretical frameworks attempting to characterize self-diagnostic behaviors propagated online, such as malingering, social media-afflicted illness and Munchausen's by Internet. The intersection of self-diagnosis and online identity building during adolescence will be explored, drawing from case examples of communities centered around specific diagnoses like eating disorders as well as Tourette syndrome. We will conclude with relevant clinical implications along with proposed future research directions to better understand self-diagnostic motivations and how mental health professionals can approach this phenomenon appropriately. It is important to recognize the prevalence and complexity of these emerging trends and contextualize these behaviors from the lens of adolescent identity formation and meaning-making. While prior research has looked at online health communities more broadly, we focus on adolescents, given their particular vulnerability, developmental stage and use of social media platforms such as TikTok. This paper uniquely integrates relevant theories of self-pathologization and identity formation to describe potential drivers of self-diagnostic behavior in youth that can serve as targets of future clinical and public health intervention.

2 Social media spaces as incubators for pathology

2.1 The emergence of social media spaces

The coronavirus (COVID-19) pandemic uncovered a burgeoning mental health crisis while fostering increased reliance on social media and digital spaces to facilitate social connection during collective isolation and loneliness [43]. The broader societal recognition of the importance of mental health and self-care resulted in the rise of mental health help-seeking behaviors and technologically-derived mental healthcare through virtual psychotherapy and medication management. The higher mental health burden and decreased access to treatment options and services during the pandemic led to alternative avenues to cope with psychological stress. For U.S. adolescents, lockdowns related to the pandemic increased time spent online with an average of 8 h per day [25]. In 2020, TikTok was the most downloaded app, with over 1 billion monthly active users, most of whom were under 30 years old [31, 57]. Social media evolved into an outlet for normalizing mental health issues and a resource for psychoeducation and seeking treatment. As growing tides of young people sought refuge in TikTok to destigmatize mental health, a merging of personal advice, psychobabble, and professional help blurred the line between mental well-being and mental illness [3, 52]. Given the "viral" nature of social media content, behaviors that may have been perceived as fringe now have opportunities to disseminate quicker to individuals who have a specific interest in the subject, causing an uptick in concerning behaviors such as non-suicidal self-injury [1].

2.2 The diagnostic self-fulfilling algorithm

Platforms such as TikTok feed users an algorithmically derived 'For You' page in which users are shown videos and posts they are most likely to interact and engage with based on previous activity (e.g., sharing, liking, commenting) and immaterial factors such as attitudes, affect and beliefs [3, 23]. This content curation has allowed users to cultivate communities based on their individualized experience on the app and to form connections with other users with seemingly similar interests, such as mental health [23]. This sense of community is promoted among social media users using algorithm-based content because of a self-driven cycle of reinforcement of continuous mental health content for those who consistently interact with it [23]. The obscure and "unsettlingly personalized" mechanism behind the algorithm contributes to some users attributing their recommended content as 'mindreading' or, in some cases, 'diagnosing' [3, 56, 57]. Moreover, some users have reported feeling as if their For You page is a projection of their identity and subconscious beliefs, regardless of whether they held this self-concept before [42]. Through this cyclic pattern of mutual reinforcement, identity becomes increasingly and intrinsically linked with diagnosis in a phenomenon known as the "looping effect of human kinds." This process occurs when individuals conform or accommodate to the labels they are given [12, 32]. Therefore, the content and the individual symbiotically sustain one another through continual interactions.

2.3 The role of online mental health communities

In our prolific digital world, there are online mental health spaces for nearly all Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnoses [29]. The organization of these communities revolves around the diagnostic label set forth by DSM, though many have evolved newfound means to designate membership via diagnosis, reflecting both the acceptance and resistance to the medicalization of mental illness [27, 29]. Ironically, despite the deliberate development of these communities in non-clinical spaces and the exclusion of non-medical professionals, members are often found to adhere to the medical model with value placed on established DSM criteria and credibility ascribed by professional confirmation of a self-diagnosis [29]. The "pro-ana" community of individuals with eating disorders is a salient case example of an online mental health community that has attracted significant research interest [8, 24, 26, 34]. The emergence of these sites has been conceptualized as a countermovement to professional medical and mental health services and has faced criticism for the supposed glorification of anorexia [37, 46, 49]. Giles and Newbold describe the community aptly as what happens when the culture of "mental-illness-as-stigma" is inverted and the subsequent power restructuring within the users of these mental health sites [27]. Simultaneously, researchers have highlighted the potential for these communities to positively empower people with eating disorders and elevate the expertise of lived experience [16, 17, 20, 21]. While there may be some benefits to interacting with these communities, such as emotional support, esteem building, and information sharing, there are also considerable risks [38].

Fostering peer support through shared experience contributes to identity formation derived from the various community groups [26]. These forms of shared experience and support often lead to sharing informal medical advice and consulting with other members who have presumably experienced similar symptoms, sometimes offering diagnoses to others based on certain habits or behaviors shared online [29]. Giles states that psychiatric diagnoses have evolved beyond categorizing patients but have become interwoven within the societal blueprint of our consumer-driven healthcare system [27]. Given the newfound appeal of a psychiatric diagnosis, tensions can emerge surrounding what constitutes 'legitimate' membership in these mental health communities. Potential members may be subject to harsh initiation rituals to substantiate their credibility and 'prove' their diagnoses, while studies have observed stark ingroup/outgroup dynamics taking place between those with established clinical diagnoses and those without [6, 7]. Some members feel that inability to access mental health care and obtain a verified diagnosis should not preclude someone from 'identifying with' a diagnosis and have criticized others for 'gatekeeping' specific diagnoses and, therefore, membership in those online forums [25; p. 273]. Chambers notes that psychiatric labels are no longer bestowed by psychiatrists but rather are dictated by online influences driven by the underlying principles of autonomy and self-determinism (2004). Within online mental health communities, diagnoses can be adjudicated by the users themselves and are no longer bound by the definitions of the DSM. The merging of Asperger's syndrome within Autism Spectrum Disorder classification upon the publication of the DSM-5 led to conflict due to the elimination of a label from which individuals derived personal meaning [5]. Several online spaces representing Asperger's syndrome have also forged their specific identity as the "aspie" community [13, 19, 28].

3 Existing theoretical frameworks on self-diagnosis

Presently, there are varying conceptualizations of this self-diagnostic behavior concerning viewing or engaging with mental health social media content. Theories range from malingering, which describes an individual exaggerating symptoms of illness or being deceitful about their origin, to social media-afflicted illness, referring to a group of individuals who develop an affliction with no apparent cause [43, 48]. Another notion stems from a preexisting diagnosis and expands to account for the influence of social media, named Munchausen's by Internet or Virtual Factitious Disorder, suggesting that a user may adopt an illness persona online for a specific psychological benefit [15, 48]. Specific frameworks present new diagnostic subtypes as labels for this emergent form of 'abnormal' behavior, while others attribute it to broader social phenomena and identity theory [12, 15]. Due to this relatively new behavior pattern, there is minimal consensus about the most appropriate and clinically helpful label for these trends.

3.1 Malingering

An alternative theory points to malingering as the root cause of self-diagnostic behavior. There are several subtypes of malingering, including partial malingering, in which an individual exaggerates or amplifies their reported symptoms,

and false imputation, where an individual has symptoms but is dishonest about their cause. Perhaps most relevant to the topic at hand is simulation, where a person enacts symptoms of a specific disability or disorder, and dissimulation, where a person denies the existence of alternative explanations that may account for symptoms that they are experiencing, such as self-infliction or substance use [48]. Malingering differs from MBI based on the supposed motivations for performing specific symptoms or behaviors [54]. Other motivations might include the desire for an explanation for behaviors or potential deficits to avoid blame or accountability by having a diagnosis to point to as the cause [29]. Additionally, having a professional or otherwise a diagnosis may allow an individual entrance, particular rights, and potential credibility as an 'expert' on the illness within social media communities [26].

3.2 Social media afflicted illness

Mass sociogenic illness is a preexisting concept that describes symptomatology, which defines an illness or affliction with no clear identifiable cause. It occurs within multiple people who share ideology related to their symptoms [43]. Researchers have proposed a slight modification to this terminology to denote social media's role in this form of social contagion, 'mass social media-induced illness' (MSMI) [43]. Others have offered a more specific term for this abnormal behavior, 'social media associated abnormal illness behavior' (SMAAIB), which describes explicitly self-diagnosing behaviors [25]. The definition delineates a specific "maladaptive mode of experiencing, perceiving, evaluating, and responding to one's own health status despite the fact that a doctor has provided a lucid and accurate appraisal" [25; p. 275]. This theory points to the observed phenomena of not only rising numbers of individuals self-diagnosing based on information gathered on social media but also the corresponding observation of these individuals being upset or unaccepting of alternative professional diagnoses that do not line up with their perception [29].

3.3 Munchausen's by internet or virtual factitious disorder

An individual with a factitious disorder feigns or self-induces injury or illness whose motivation is to "assume the sick role" [2]. Currently, the DSM-5 separates factitious disorder into two subtypes: imposed on self and imposed on another. These diagnoses do not currently contain a subtype or specifier for Internet exposure. In response to observable trends, some researchers have proposed an additional diagnosis of 'Munchausen's by Internet' (MBI), coined in 2000, or 'virtual factitious disorder' in which an individual duplicates material from online sources and often presents with exaggerated illness symptoms [15, 25, 48, 54]. In cases of proposed MBI, users join online communities dedicated to a particular condition or illness and fake symptoms to garner support and sympathy.

In some cases, social media users have been known to create false personas online to enact these sick roles to reap the highest psychological benefit [15, 38]. If the perceived benefits start to wane, a user may attempt to provoke further interest by adding new information or characters to their story [15]. Due to the ease of access to resources online, such as journal articles, testimonials, and documentaries, users can better feign illness online with what seems to be high reliability [15]. In this proposed diagnosis, the intent behind the behavior distinguishes MBI from malingering or hypochondria, where the afflicted individual is specifically seeking attention and support for a false or exaggerated illness [38, 54]. These individuals may have predispositions, such as low self-esteem, childhood trauma, or poor self-concept, with assuming the sick or victim role assisting in fulfilling these deficits from early childhood through positive attention, nurturing, a sense of importance, and identity cultivation [38]. These behaviors have been hypothesized to allow the individual to establish a sense of perceived control to cope with emotional distress, which may have been exacerbated during the pandemic [33, 48].

4 The intersection of self-diagnosis and online identity building

Outside of the above-proposed labels for this self-diagnosing behavior, other professionals have turned to broader theories of identity and meaning-making to explain what appear to be socially contagious behaviors [29]. The concept of identity construction via social media communities is not new, a pertinent example being 'fandom communities,' subcultures constructed around common interests that notably allow space for users typically ostracized from traditional media communities [33]. Similarly, the characterization of online support groups for medical and mental health conditions contributes to the notion of the patient as the expert, emphasizing the linkage between patient expertise and self-efficacy, empowerment, and self-esteem [20, 21]. In the adolescent stage of identity development,

individuals commonly experience identity distress in which a person seeks to define a sense of self more clearly. Forums such as the example previously noted provide an avenue for collective identity cultivation, or a set of shared meanings and behaviors that can be accessed rapidly and immediately via social media [14]. As such, these forums became necessary for those who could now engage in community building and foster a sense of belongingness. This common interest has now since expanded and evolved into mental health content, some notable examples including the creation and rise of pro-eating disorder and pro-self-harm social media communities [14, 33]. Social media represents the critical intersection of the vastness of the Internet and escapism and intimacy with those seemingly afflicted by a unifying disease. In these outlined examples, individuals create and experiment with online identities in a previously unavailable way [29, 33, 42]. According to Bandura's social cognitive theory, observers are more likely to encode and reproduce behaviors after individuals who are similar to themselves, encompassing observable traits such as gender and race as well as values and interests [4, 39, 41]. Membership in these communities often involves self-disclosure from the user regarding their similarities, expertise, and personal experiences surrounding the topic. Social media provides a level of anonymity for individuals to perform this type of intimate self-disclosure and allows for exploring what might otherwise be taboo topics [29, 54]. It has been posited that self-disclosure on social media provides instant gratification through peer attention and a sense of community support [45]. It has also been proposed that current observable 'outbreaks' of MSMI are the modern-day cultural manifestation of a 'culture-bound stress reaction' of society's reinforcement of attention-seeking as a way to project an individual's uniqueness [43].

In mental health-oriented communities, diagnosis has become essential for community belongingness and membership [26]. In physician-philosopher Carl Elliot's book *Better Than Well: American Medicine Meets the American Dream*, he notes that "on the Internet, you can find a community to which you can listen and reveal yourself, and instant validation for your condition, whatever it may be" [18, p. 217]. The sense of identity garnered by a psychiatric diagnosis may be heightened through participation in online self-help communities and witnessing content dedicated to their pathology [12]. Social media reminds individuals they are not alone in their suffering, a sense of shelter and solace in the reminder that others share their experiences [14; p. 10, 30; pp. 21–22]. Particularly for suicide, previous studies have demonstrated the delicate balancing act of identity and self-preservation with posters needing to counterbalance presenting themselves as suicidal enough to warrant attention though not severe enough to where they would be accountable for not completing their suicidal behaviors [35]. Stigma is tied to an increased need for acceptance, a driving factor for participation in these communities where these labels are not stigmatized but shared and lauded [30; p. 8].

The pervasiveness of psychiatric disorder "virtual communities" is evident as most pathologies have a platform for patients to connect [12; p. 340]. Common themes of these communities include addressing the stigma of a diagnosis, opposing or endorsing specific treatment interventions, and debating the validity of various diagnoses [12, 14]. Users offer their first-hand experience or, sometimes, expert knowledge about the disorder, even calling out users who may be faking a diagnosis [26, 29]. Pushback against medical professionals who may disagree with a self-diagnosis is a pertinent feature of these groups. At the same time, paradoxically, mental health professionals are also respected for their authority to confirm a suspected diagnosis definitively [55]. In addition to glamorization and a sense of belonging, a diagnosis of a particular disorder can lend itself to user credibility, first-hand expertise, and undisputed membership in online mental health communities [26, 33, 42]. Despite many of these mental health conditions having many challenging symptoms and effects, members of these online mental health communities celebrate receiving a diagnosis [26, 29].

One suggested explanation for this phenomenon is the notion of 'madness for identity,' in which individuals crave the formation of a sense of self and identity, a common pursuit and challenge for adolescents and young adults [12]. Even within a community surrounding a specific diagnosis, users often label other intersecting identities on their profile, such as interests and hobbies, other mental health diagnoses, religion, or other markers indicative of who they are, and to signal additional forms of 'otherness' [31]. Specifically concerning self-diagnosis, these individuals may be settling into the 'sick role' identity, which often comes with positive social support and reinforcement by other community members [33]. As a person experiments with this sick role identity, they may begin to incorporate this into their self-concept, regardless of whether this persona aligns with their lived experience outside the social media sphere [33]. Within the sick role identity creation, there may additionally be an element of esteem building in self-pathologization and diagnosis. By identifying with a syndrome, a user has a tool for self-protection by 'blaming' perceived shortcomings or dissatisfaction with self on a legitimate disability [51]. Mental health care professionals have expressed concern for over-medicalizing normative behaviors as potential symptoms or signs of illness. This interpretation can lead to exaggerated maladaptive symptoms and worse outcomes for the individual [51].

4.1 Tourette syndrome and other case examples

A striking example of social media-propagated illness is the neurological condition of Tourette Syndrome, in which individuals exhibit unwanted and uncontrolled repetitive movements and sounds (tics). Both prior to and during the COVID-19 pandemic, an increasing number of cases of functional tic-like behaviors (FTLB) paralleled rising numbers of videos on social media platforms, such as YouTube, Instagram, and TikTok, of individuals stating that they suffered from Tourette Syndrome [22, 36, 43, 44, 47, 50]. Notably, most individuals posting this content had functional Tourette-like symptoms resembling videos posted by a famous German YouTube creator. Researchers noted epidemiologic patterns of bizarre, complex repeated movements, vocalizations, and functional behaviors with an overrepresentation of coprolalia, copropraxia, and non-obscene socially inappropriate behaviors (NOSI) in those claiming to have Tourettes [43]. Notably, young patients presenting to specialized Tourette's clinics expressed admiration for the influencer's openness and resilience in having Tourette's. This distinct emotional investment in content has been identified as a trigger for potential social contagion [43]. Social contagion, the spread of beliefs, attitudes, and behaviors across collective groups, is particularly relevant for adolescent populations susceptible to social media-driven influences [40].

Tourette syndrome is not the only example of a disorder spreading via social contagion. Tags like #DID, an abbreviation for dissociative identity disorder, #borderline personality disorder, and #bipolar disorder, have received billions of views. Another widespread mental health condition that has appeared in social media communities is attention deficit hyperactivity disorder (ADHD). In Ref. [57] found that most posted videos about ADHD sampled were highly understandable yet very misleading and rife with the oversimplification of the disorder. Often, these conditions are romanticized and glamorized; users have been observed to want these diagnoses despite their potentially impairing effects [33]. Some users have expressed that 'recognizing themselves' in mental health social media content has contributed to a sense of self-understanding and community, which led them to seek a specific diagnosis from their mental health care provider [42], p. 6.

5 Discussion

Due to the rapid increase of social media usage by adolescents in the United States, mainly driven by the coronavirus (COVID-19) pandemic, investigating the various components related to increasing self-pathologizing behavior in adolescents has become a burgeoning topic of interest for mental health professionals [43]. While some theories such as malingering, social media-afflicted illness, and Munchausen's by Internet suggest motivation driven by psychological reward or avoiding blame and accountability for perceived deficits, there are additional complexities related to adolescent identity development and desire for community building [15, 29, 48]. Adolescents endorse the benefits of fostered peer support by sharing challenging experiences with mental health online and exploring aspects of experience that may be stigmatized in other spaces [26, 42]. Similarly, users have gravitated towards forming communities around a shared experience of symptoms and illness, allowing the cultivation of a sense of belonging and identity related to a specific experience or diagnosis that may have previously been taboo or otherwise inaccessible [29, 33, 42]. From the lens of identity development frameworks, users may gain psychological rewards from peer validation, being perceived as an 'expert' in a particular condition, and peer support surrounding challenges related to their symptomatology [29, 54]. Due to the discussed notion of a 'madness for identity,' individuals may additionally be motivated to experiment with various identities related to mental illness in ways that conflict with mental health professionals' opinions and diagnoses [12, 26, 29].

While previous studies have evaluated the role of online support groups for medical illnesses, there have been few papers evaluating mental health spaces, particularly in a newfound age of destigmatization of mental health conditions.

Given the complicated relationship that exists between online mental health communities and mental health professionals, further nuanced by adolescent identity development and desire for community and connection, it is crucial to approach self-diagnoses and self-pathologizing behaviors from an informed perspective [10, 25]. While these behaviors have potential risk to the patient due to the possibility of unsuitable or contraindicated treatment and strain on the mental health care system, professionals must also be aware of ways to approach these clients without further alienation and mistrust in clinical processes [25, 51].

6 Conclusion and future directions

Despite the prevalence of mental health communities, attention has centered chiefly on suicide communities and the pro-ana community. This paper attempts to summarize and postulate the underlying drivers of self-diagnostic behaviors related to social media usage. Mental health professionals already report that young people are presenting to clinics and seeking specific diagnoses following media exposure [11]. Clinically addressing self-diagnosis in a mental healthcare setting is a nuanced issue that must be approached with care and an informed standpoint. As discussed, individuals presenting with a self-diagnosis may feel protective of this piece of their constructed identity and have the potential to feel judged by professionals who disagree with their self-assessment. Within online communities, medical professionals may be viewed as authoritative figures rather than experts [29]. Previous research has unveiled discussions and advice for concealing information from therapists, actively resisting treatment, and trepidation in utilizing services as joint tenants of these forums. These findings are relevant for clinicians engaging with these populations [29].

Diagnosis provides an avenue for identity building, solidarity, and social connectedness, a boon during an era of intensifying isolation. While there are concerns about the safety of engaging with these sites and the potential for promoting harmful behaviors, these communities also allow for a forum for belonging and open conversation about stigmatized topics, and therefore, the removal of a psychiatric self-imposed label may introduce unintended harms [12, 29]. However, medicalization and the diagnosis of pathology without thorough investigation have the potential to harm the patient and the potential misappropriation of intervention and treatment [51]. Accurate conceptualization of mental disorders evolves and shifts temporally. Therefore, diagnostic clarity in symptomology and presentation is vital to overall conceptualizations of a disorder, underscoring the importance of accuracy in diagnostics [51]. Additionally, misdiagnosis may lead to overlooking other contributors to a client's presentation that may be important to their treatment [51]. The rising trend of self-diagnostic behavior via online mental health communities is a complex and nuanced topic that requires meticulous consideration from mental health professionals to appropriately address the potential risk without perpetuating further harm to vulnerable individuals.

While this review illuminates a new perspective on viewing self-diagnostic behavior related to engagement with online mental health content, further exploration into the self-defined motivation of this behavior is necessary to understand how to formulate precise clinical approaches best. Adolescent users' input is necessary to clarify underlying motivations beyond theoretical propositions. It is also difficult to ascertain whether adolescents maintain these identities while progressing into adulthood. While digital conversation analysis based on online forums has been used as proxies for the broader community, conclusions based on these studies are extrapolations of siloed posts. Further research efforts should focus on adolescent populations and their direct experiences on social media. As social media changes and evolves rapidly, ways that content is spread, communities are cultivated, and individuals interact with one another online shift as well, creating a need for additional study regarding online mental health communities on various platforms. Social media platforms where an individual presents an online persona meant to represent themself with followers or friends known in their actual life vary from anonymous profiles to forums where individuals interface with strangers. Additionally, some research has been done on how adolescents evaluate information credibility and reliability; more rigorous study is needed to determine how users perceive and utilize mental health information consumed online.

Declarations

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