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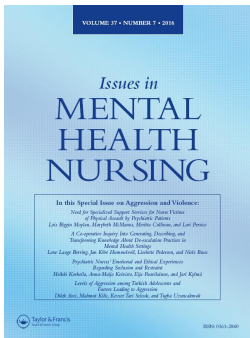
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## Personal Narratives of Mental Illness: From Hostage to Survivor

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### ABSTRACT

This study has delved into personal narratives extracted from online blogs to build a systematic view of mental illness trajectory through the portrayal offered by bloggers. One hundred and thirty-three blogs were reviewed and narrative analysis was used to interpret a final sample of 12 blogs. The results offer two main narratives—the hostage and the survivor—which illustrate, within the context of social and self-stigma, the need for an identity reformulation in order to reach recovery. The two narratives also led to the design of a model for mental illness trajectory (MMIT). The breaking down of mental illness trajectory into phases could be advantageous to promoting tailored interventions for specific stages of recovery. The importance of referring to lived experience when trying to understand and develop better treatments for mental illness has been well established. This study contributes to the growing body of research that includes the voice of the person with mental illness offering not only a vivid portrayal of life with mental health issues but also an understanding of the trajectory to recovery.

### Introduction

Mental illnesses can be defined as psychological conditions that affect how people behave and react to everyday situations. They can negatively impact thoughts, emotions and social interactions, leading to significant impairment in social, occupational and academic functioning (World Health Organisation, 2022). Terms such as mental health problems, mental health issues, poor mental health, poor emotional health, etc. are used interchangeably by individuals and professionals to describe mental illness (Mind, 2022). This research focussed on personal accounts of people who struggle with different types of mental illness, and were either formally diagnosed or feel uncomfortable with their mental health.

In England, one in six adults have experiences with anxiety or depression every week (Baker, 2021). Mental health disorders have become worryingly common and a large proportion of the population is familiar with them, either from personal experience or from witnessing others. Despite these elevated numbers, research that explores how the mentally ill see and represent themselves is limited. There is a need to focus more on how these individuals give voice to their own experience (Atanasova et al., 2019). Kotliar (2016) adds, that although many studies have investigated illnesses and the web, not many have focussed on personal representations of mental illness.

Historically, medicine and health research have generally been guided by a positivist perspective (Alderson, 1998), where doctors were considered the main experts with

knowledge acquired by education (Basset & Stickley, 2010; Karp & Birk, 2013), and the patient's voice and experiences were suppressed by the predominance of scientific discourse (Stephens, 2011). More recently, however, there has been a movement from mental health practitioners and researchers to include patients' voice to mental health research and treatment (Cargo & Mercer, 2008; Department of Health, 2017; Yuan, 2017). Karp and Birk (2013) assert that the experience of living with mental illness can be diverse and nuanced and therefore, research must be committed to systematically collect, organise and analyse data from the stories told by people who experience mental illness in order to capture this complexity.

From a practical point of view, giving voice to the mentally ill is a window into understanding the mindset and experiences of these individuals, and useful to informing practice and interventions designed to increase access to care (Marcus et al., 2012). It is also a shift of focus from the symptoms to the actual person, offering a different perspective on recovery, where the goal is to live better lives rather than aiming for a cure (Gillard et al., 2015; Jacob, 2015).

Despite being so prevalent in society, mental health issues are still represented negatively in different types of media, generating feelings of rejection towards the mentally ill (Klin & Lemish, 2008) and interfering with social integration. These representations have also been associated with prejudice, social and self-stigma (Atanasova et al., 2019; Klin & Lemish, 2008; Stuart, 2006; Wahl, 2004). Social stigma is defined by the reaction of the public towards a stigmatised group. According to the widely cited

definition produced by Goffman (2009), stigma refers to an “attribute that is deeply discrediting” (p. 3). Link and Phelan (2001) further developed the concept by identifying key components, that together, create stigma. These components go from the recognition of differences and labelling of people, to the association of the labelled people with undesirable attributes. This association is guided by dominant cultural ideology. Subsequently, labelled people are categorised, experiencing loss of social status and discrimination, which in turn lead to unfavourable outcomes. In short, social stigma is a mark that devaluates individuals and affects them adversely (Tsao et al., 2008), bringing consequences such as social isolation, poor health care, decreased job opportunities and inadequate housing (Corrigan & Watson, 2002).

Negative representations offered by the media can also be a catalyst for self-stigma (Corrigan & Watson, 2002), when the individual who is a member of the stigmatised group present stigmatising behaviours against themselves (Rüsch et al., 2005). Self-stigma has been widely cited as a root of shame and as an obstacle for help-seeking amongst mental health sufferers (Atanasova et al., 2019; Clement et al., 2015; Hugget et al., 2018; Koteyko & Atanasova, 2018).

Also important, is the influence that social and self-stigma have on identity development. Being the part of a stigmatised group can be identity-threatening, leading to different identity managing strategies—some positive and effective, some negative and adaptive (Illic et al. 2014). Although the study of identity development and management has been traditionally centred on the individual and their internal processes, other approaches have highlighted the importance of the cultural context in which the individual develops (McLean et al., 2018). By adopting a narrative approach, it is possible to access not only cultural discourses, but also how they are interpreted and internalised by the individual, shaping identities. McLean and colleagues (2018) offer the master narrative framework, which considers the critical role of culture in the development of identity, also useful to understand how master narratives around mental illness and the social and self-stigma carried by them, can affect identity management. According to this theory, master narratives must be: a) known by the majority; b) useful to define frameworks for the self; c) unconsciously internalised; d) imbued with power imbalances and difficult to change; and e) compulsory (those who deviate from it are less valued). Those individuals whose narratives conform to the master narrative, build identities that are accepted and valued. Those whose narratives deviate from the master narrative, are more at risk of being structurally marginalised and oppressed—exactly what happens to people who suffer from mental illness and are subjected to social and self-stigma. Therefore, stigma can be clearly characterised as a master narrative that can have great influence in how identities are developed and managed by individuals with poor mental health.

The aim of this study was to build upon this knowledge and investigate the personal and social perspectives of mental illness through the lenses of the protagonists. Within the

personal sphere, the objective was to understand how poor mental health is perceived, experienced, and portrayed by sufferers, and to collect information that would be useful in developing a systematic view of mental illness. Within the social sphere, focus was given to how these individuals locate themselves within the social discourses available to them and how they manage their identities in order to live with their conditions, given the negative representations of mental health revealed by previous research and the ever present social and self-stigma.

### ***Blogs: unsolicited narratives***

Qualitative studies have investigated subjective experiences by examining solicited and unsolicited accounts for many years (Burles & Bally, 2018). However, having access to personal views of lived experiences and first-hand accounts does not come without its challenges, especially when the topic, such as mental illness, is surrounded by stigma and prejudice (Burles & Bally, 2018). With this in mind, and inspired by other studies that have successfully given voice to protagonists (see Gonsalves et al., 2019; Kotliar, 2016; Mandla et al., 2017; O'Brien & Clark, 2012; Pitts, 2004), this research used data retrieved from online personal blogs.

Currently, the internet is an important platform where people share information about themselves and their health (Brossard & Scheufele, 2013; Marcus et al., 2012; Wilkinson & Thelwall, 2011). It also offers a space where people can find support for shared feelings and thoughts (Burles & Bally, 2018). With the arrival of such platforms, a channel for open conversations is now available and given their virtual nature, some of the difficulties involved in face-to-face disclosure are eliminated and the possibility of discussing stigmatised health topics is increased (Hookway, 2008; Joinson & Paine, 2007).

People with poor mental health have commonly used blogs to aid their recovery by openly talking about their struggles, dealing with feelings of powerlessness and also by unearthing emotional encouragement (Murphy et al., 2020). Blogs are very much like written diaries, but they are online. Users, also called bloggers, post their personal stories daily, monthly or yearly (Hookway, 2008). In research, this type of media allows access to exclusive sources of first-person and voluntary accounts of personal experiences (Hookway, 2017), offering the researcher a way into the perspective of the blogger. In addition, blogs can offer significant amounts of data supply that are not only readily available, but also publicly accessible and low cost (Markle et al., 2015).

This method of data collection has also addressed some of the challenges involved in accessing personal accounts of lived experiences, and has brought gains when compared to more traditional methods such as questionnaires and interviews. Firstly, the researcher's frame of reference does not have an impact on the access to the sufferers' accounts (Elliot, 1997). Secondly, retrospection recall problems, commonly seen during interviews, are avoided since accounts recorded on blogs are usually closer to the events itself (Toms & Duff, 2002). And most importantly, researchers

have access to sensitive information that is difficult to be shared in the presence of others, allowing for more candid accounts of the self (Hookway, 2017).

### The study of narratives

Bloggers who choose to write about their mental health, not only give themselves a place for self-reflection but also the possibility of exercising alternative emotional and social identities (Kurtz et al., 2017). In essence, these users are sharing stories that contain personal narratives, which are frameworks that sustain the individual's understanding of their own experience and expose how they want to be seen (Stephens & Breheny, 2013). In sharing these personal narratives, people also bring to light truths about their social reality. In mental health research, the study of narratives has grown and narratives offered by patients can now be seen as a point of reference and expert advice for others going through the same condition, carers and practitioners (Basset & Stickley, 2010).

Riessman (1993) deeply explored the field of narrative analysis, an approach which focus on the study of personal experience and meaning by the systematic analysis of personal accounts. Inspired by other scientists (see Bell, 1999; Breheny & Stephens, 2009), this research has used an integrated approach of narrative analysis (Murray, 2000) where the personal, interpersonal, positional and ideological levels were considered.

This analysis has emphasised identity as a result of how the self is positioned socially, thus based on a constructionist perspective (Bucholtz & Hall, 2005). This means that language was considered as a key element on the constitution of reality and that narratives were understood as the combination of two main elements: the individual's interior world and the social fabric they are immersed in.

In summary, research has established that mental illnesses have had negative representations in the media, fuelling prejudice and stigma and adversely influencing social opinions and attitudes around the mentally ill. A need for more research into the personal lived experiences of people with mental health issues was identified, together with the importance of understanding how they represent their own mental health issues and build their identities within the social scenario established by negative representations of mental illness. By analysing first-hand narratives extracted from online blogs, this research had access to lived experiences and representations of mental health issues portrayed by protagonists and aimed to offer a systematic view of these experiences. Narrative analysis was used to interpret the dataset and the following research questions guided the study: a) How are personal experiences of mental illness displayed by sufferers? b) How are identities constructed and presented amidst mental health turmoil? c) What is the impact of stigma for these personal representations? d) What are the issues that people with mental health problems advocate?

Finally, this closer look into first-hand experiences of mental illness offers important insights that could inform

recovery. It also aids the development of policies, practices and treatments that make sense for users and their families.

## Methods

### Sampling

Sampling was inspired by other successful studies that collected personal narratives from online blogs (see Hookway, 2008; Marcus et al., 2012; Markle et al., 2015). Data collection started with keywords such as "personal blogs", "anxiety", "anxious", "depression", "depressed", "mental health", "diary", "life of" being combined in different ways on a Google search. This first search was extended to other popular search engines, such as Yahoo, Duckduckgo and Bing, using the same combinations of keywords. Other keywords identified in some of the blogs, such as "PTSD", "bipolar", "borderline" and "social anxiety" enhanced subsequent searches. Blogs that were not from the UK or not recent were not included.

This initial search resulted in a list of 124 blogs. An additional nine blogs were added to this list through the method of virtual snowballing, where blogs are manually searched for recommendations of other blogs on the same topic (Kotliar, 2016; Marcus et al., 2012). Duplicated results were excluded and manual refining of this list was based on the inclusion criteria:

1. Blogs must be publicly accessible without requiring any passwords or logins.
2. Bloggers must be based in the UK.
3. Blogs must be written in English by users that declare being 18 years-old or older. If age was not disclosed in the user profile, the blog was excluded due to ethical reasons.
4. Blogs must be recent: only blogs that have been edited in the past two years were considered.
5. Posts had to be relevant to mental health topics.

This sampling strategy resulted in a final list containing 12 blogs.

Posts within each personal blog were sampled based on the prevalence of narrative and personal content, or as Riessman (2008, p. 7) defines, accounts in the first person, that have been structured "temporally, spatially or episodically"(see Appendix 1).

The 12 blogs can be characterised as follows: eight of them were written by women, and one was co-written by a man and a woman. The mental illnesses disclosed by the bloggers include: generalised anxiety, panic disorder, depression, PTSD (post-traumatic stress disorder), social anxiety, bipolar, OCD (obsessive compulsive disorder) and anorexia. Two of the bloggers also mentioned being diagnosed with ASD (autistic spectrum disorder). Some individuals declared having more than one condition and feelings of anxiety were mentioned by all bloggers. Eight bloggers disclosed being formally diagnosed. All bloggers had access to therapy or treatment at



some point, including medication, but only nine make it clear this was offered by the public mental health services.

### Analysis

Analysis started with an in-depth familiarisation of the dataset. The process of finding meaning in individuals' stories was based on Riessman's (2008) guide on how to construct narratives for inquiry. A Word document was created for each blogger (see Appendix 2 for an example) and was divided into three columns. The first column contained the original posts fully extracted from each blog. In the second column, the original text was transcribed into what Riessman calls "thematic stanzas" or "meaning units" (Riessman, 2008, pp. 35) and was labelled "raw narratives". This version of the narrative is achieved by cutting down speech and disfluencies, with the objective of exposing the main idea, feeling or image that the writer is trying to portray. The raw narratives were then analysed with focus on elements such as, nuances of speech and structural properties. Concepts were coded and recorded in the third column.

Once the analysis of this first layer of data was completed, recurrent codes were identified and clustered together providing access to the raw reality of mental illness: the building blocks for the construction of a vivid and rich portrayal of lived experiences. Identified themes included: negative feelings, loss of control, coping strategies, loneliness, stigma, impact on body and everyday life, recovery and lifelong battle.

With the data gathered into themes, a further analysis took into consideration Murray's (2000) four levels of narratives in health psychology: personal, interpersonal, positional and ideological. By considering the interaction of these levels, and guided by a constructionist approach, a connection was established between the themes and the master narratives socially available for the protagonists. This further interpretation of the data provided a deeper layer of meanings and highlighted a variety of subjective experiences.

Antagonist discourses were identified, bringing to the fore a distinction between two main approaches in relation to mental illness experience: one more optimistic, where recovery and focus on coping strategies and treatment are shared from a place of rehabilitation, hope, faith and commitment to healing. Another, more pessimistic, focussed on symptoms and repetition of lifelong vicious cycles, written from a place of pain, rejection, lack of hope and disbelief in recovery. These two contrasting approaches were respectively labelled: a) the survivor and b) the hostage.

Finally, by observing the dynamic between these two perspectives and exploring the paths taken and described by sufferers, a pattern was established for the trajectory of mental illness from its onset to recovery. This model of mental illness trajectory (MMIT) is an attempt to build theory from the perspective of the individual with lived experience and is considered in more detail in the discussion section (for a visual map of the analysis see Appendix 3).

### Results

The sample comprised of a variety of writing styles that differed in tone, length, density, and content. Below, results of the analysis are organised and presented in subsections, and illustrated with extracts of the raw narratives, chosen purposefully due to the depth of personal and cultural meanings they offer. Each block of extracts was taken from a different blog, representing the many voices captured by the dataset.

#### *A vivid portrayal of the experience of mental illness*

The hardships of living with a mental illness were salient in the whole of the dataset. Living with mental illness was strongly described as a catalyst for negative feelings such as incompetence, worthlessness, self-doubt, guilt, invisibility, fear, inadequacy, lack of hope, low self-esteem and low mood: "I don't see a way forward, I hate thinking about my future". "Everyday, everything is so exhausting. Everything I do is an uphill battle". "I still don't have the inspiration or motivation to work. I just feel so deflated and useless".

Many of these feelings appear as a consequence of internalised stigma which is shown in the data to be closely connected to the fear of judgement and consequent social ostracism. Lying about how they feel, hiding emotions, opting for non-disclosure and secrecy, withdrawing from or avoiding certain situations, were mentioned as ways of evading a stigmatised identity:

I was drowning in fear and low self-esteem. I desperately wanted to talk to someone, but I was too afraid to say something. I still feel this sometimes and lie about how I really feel. I'm scared of being a burden.

Some of these maladaptive coping strategies adopted by people suffering with mental illness can be physically and mentally harmful, and have been associated with increased vulnerability, reduced quality of life and decreased quality of social network (Ilic et al., 2014). Extracts from the data show the power that these coping strategies have of strengthening negative behaviours and reinforcing vicious cycles. The subsequent isolation and the ordeal of going through with them, only increase feelings of being misunderstood and of loneliness: "I've caught myself forgetting to eat or eating far less than normal, sabotaging myself." "Most of my coping strategies are based around being in survival mode, just making through the day."

Other negative aspects that characterise the experience of living with mental illness include the impact that these conditions have on the body and how they become a hindrance to common everyday activities, making life and mundane tasks difficult to navigate: "I only went shopping today, but even that made me feel anxious."

Physical symptoms and uncomfortable body sensations emerge to the individual as trustworthy signals that something is wrong with them. It is also how they identify when action needs to be taken: "Panic attacks were battering my

body, I was sleeping for hours in the daytime.” “I started to become physically unwell, my body’s way of telling me I needed to stop and take a break”.

Loss of control was also narrated as being characteristic of the experience of mental illness. The individual does not feel they are in control of any aspect of their lives, sometimes culminating with the loss of identity and of who they are: “With my mental diagnosis, my brain can become overwhelming to the point I no longer feel I can be rational about my actions.” “Many times, I have felt as if I have lost my mind, almost lost myself for good”.

### **Two distinctive narratives**

Besides offering a striking and valuable view of the raw experiences, feelings and hardships universally endured by the mentally ill, the analysis of the data also exposed two main narratives that describe how sufferers approach their conditions: the survivor and the hostage.

#### **The survivor**

The narrative of the survivor is fuelled by positivity. This sufferer’s recovery is usually underway. Their condition is in remission or under control, and they speak from a place of self-compassion, self-love, self-preservation and above all, acceptance: “I’m fine. I will be fine. I’m so happy. Anxiety and mental health [have] a funny way of making life a rollercoaster”.

In order to feel continuously empowered through what they describe as a lifelong battle, the survivor resorts to tools such as credible advice and self-affirmation discourse. The first is derived from medical or scientific authorities, the latter is developed from an inner voice of encouragement, that appears in moments of self-doubt or when negative feelings take over. Similar to a coping strategy, this self-affirming discourse appears to sustain the individual through their path to conquering the illness, soothing loneliness and giving encouragement. It can be interpreted as the bloggers’ quest for an identity which is detached from the mental illness. It is the expression of the re-building of the self. The extracts illustrate how this reformulation of the self goes through oscillations between being proactive and positive, and doubtful and fearful: “I can do it. I will do it. But the anxiety around a ‘double relapse’ is very real.” “It’s not my fault I’m ill. It feels unfair. I am sad and angry about it. I will not let myself feel ashamed”.

Also apparent is a great degree of self-reliance where the bloggers position themselves as the main responsible for managing their condition. In the next extract, the writer describes their responsibility for learning about their condition, and when they do not succeed in managing it, it is also on them to go through the pain and find the strength to seek recovery again:

I have learnt to identify and manage my triggers. Sometimes I can control them, avert a relapse. Other times I can’t. I end up in the black hole. Go through the pain until I find the strength to rise up again.

Besides being responsible for themselves, these individuals also show a strong sense of shared responsibility for others going through the same situation. As well as showing empathy for the hurdles of mental illness through messages of encouragement, bloggers clearly target stigma, engaging in tenacious advocacy and making clear that their advice comes from lived experience, which validates their own journey: “I feel obliged to spread as much awareness as possible, as well as educate those that are unaware, just as I was.” “Speaking out is courageous, it is breaking the boundary that shouldn’t even be there”.

Although seen as essential and viable, recovery is described as an arduous and time-consuming process, which is not linear. A complex net of intertwined elements, such as a strong support network, personal commitment and the right combination of treatments, make recovery or management of the condition achievable. Acceptance and a dissociation of the self from the mental illness are the overarching elements of recovery, that allow for a new identity to emerge, restoring confidence and hope for the future: “Recovery doesn’t take a day off. My family and psychiatrist saved me, as well as me trying to save myself”. “Mental health is not a linear process. Being well is not about continuous improvements and never stepping back”.

#### **The hostage**

In contrast, the narrative of the hostage is fuelled by darkness and lack of hope, conveying a message of perpetual imprisonment by a condition that will not ease, will not change and will not be helped or improved, regardless of their efforts: “It did never get any better. They tell you to have faith, hope. It’s bound to get better, but it didn’t”.

This narrative presents a conformist view of the condition that leads to negative coping strategies of withdrawal, isolation and at times, self-harm: “I wanted to curl up into a ball, fall into an everlasting sleep. They would be better off without me”. “I knew no other way but to hurt myself when I was hurting the most inside”.

These individuals perceive stigma as a standard social reaction to their condition, due to their differences. They describe themselves as being outcasts, who are not accepted and do not fit in, reinforcing intense feelings of loneliness and marginalisation: “Young people have a reputation for having fun. If you are an outsider, it’s a vile time to be alive. You never feel more disliked, left out”. “[Mental illness] Makes it hard to join clubs, make friends, join in”.

Recovery within this narrative is non-existent. The ‘hostage’ might have tried treatments or might have been exposed to therapies that were not enough, or that were inappropriate and therefore were judged inefficient, leading to a deep feeling of disbelief in recovery and discouragement: “CBT and all therapy ignore that evolution is ruthless, cruel, that survival of the fittest is just part of human behaviour as most animals”.

In common with the first narrative, these bloggers also bring a sense of shared responsibility for those who are going through the same situation. They share their

experience in the hope that it will be therapeutic to them and might help others too.

Contrary to the survivor, who developed self-reliance and resilience, the hostage craves societal changes, so they can be accepted as they are. They position themselves as victims of a ruthless social system that does not include or care for them and therefore, they are left with little but to conform to their predicament:

Society won't hire you for a job if you are very mad, yet still shames you for being unemployed as if it's simply laziness. If mental health is the reason [it is] almost impossible to claim benefits."

### **Model for mental illness trajectory (MITT): From hostage to survivor**

The survivor and the hostage narratives have overlapping areas between them. Although defined by the prevalence or certain characteristics, one is far from being independent from the other. Looking back at the raw narratives of the survivors, the individuals mention phases of their illnesses when they had a different approach, more in line with the hostage narrative. The analysis shows that both narratives will interchangeably give voice to the experience of mental illness, depending on the moment the individual finds themselves in within their journey. When side by side, the narratives of the hostage and the survivor constitute more of a path from one to the other, rather than separate and rigid approaches to mental illness.

This path was organised into a model for mental illness trajectory (MMIT). Phases 1 to 3 carry the discourses present in the hostage narrative and describe a chapter where the individual deals with poor mental health on their own and see little or no improvement. Phases 4 to 6 comprise the survivors' narrative. A chapter where other characters are involved, the individual finds support and eventually the route to recovery.

Below, a description of each phase with illustrative data extracts:

1. Awareness: The individual acknowledges atypical behaviours or feelings. At this point, their perception does not include the possibility of mental illness: "I recall when I had complete breakdowns. These episodes were happening mostly outside work. I thought was normal".
2. Rejection: Mental illness is dismissed and other reasons are found to justify atypical behaviours or feelings. The bloggers try to convince themselves that what they are going through is normal, or not urgent: "I can remember making [suicide] attempts and coming into work the next day. Same with self-harm. I didn't see it as something that needed urgent attention". "I can't be mentally ill. Look how high functioning I am! Look how well I manage stress".
3. Self-help: Atypical behaviours and feelings persist, and in order to deal with the discomfort they cause, the individual adopts negative coping strategies. These vary from person to person and can include

ignoring the problem, trying to 'brush it off' or investing in self-care: "Once I got myself back together, I would brush it off.

"It was a normal routine and coping mechanism". "I am trying to utilise my brain in such a way that I try to become accustomed to this way of life."

4. Acceptance: The individual does not manage to solve the problem with self-help and considers mental health issues. Accepting a mental illness is reported by bloggers as a process that includes welcoming symptoms, dealing with internal and external stigma and dissociating the self from the condition. The latter becomes essential for the individual to ascertain their new identity and gain control over their recovery and life with mental illness: "I have had two major depressive episodes in January and one suicide attempt. I am ashamed to admit, but in telling myself this truth, I can begin to find help". "I have been learning how to recognise emotions, how to cope with them. They are uncomfortable feelings. Shame, sadness, anger".
5. Treatment: With mental illness acknowledgement, help seeking behaviours occur. Having a support network is reported to speed up this process. Finding the adequate treatment is complicated as it involves trial and error, which in turn, requires emotional investment, commitment and resilience: "My mental health was fragile and unstable. It is no way to live. What saved me was being hospitalised, finding medication and therapy. That has helped me to live in remission".
6. Recovery: Recovery is complex and depends on many interwoven elements to bear fruit, however, once it takes-off, confidence in the self is gradually restored and the individual feels they are in control again: "This time last year I was waking up wishing I would die. [Now] I've never felt more alive. Not quite out of the woods yet, but on the exit trail". "Now, my brain chemistry is balanced. Even if I get sad or frustrated, I don't have those awful thoughts. If they ever come up, I can deal with them".

Although the phases of mental illness are presented here in a clear and progressive model, in practice, the boundaries of each stage are blurred. Bloggers describe going back and forth on this trajectory, even when they have reached remission or successful control over their condition. Ultimately, mental illness is portrayed by all sufferers as being lifelong. The illness evolves and changes, as does their understanding of it. Growth in managing conditions develops from acceptance, support, treatment, therapy and time: "It was the first time I ever had to face the fact that I will relapse". "This illness is lifelong". "My experience tells me this will pass and yet still remain".

## **Discussion**

The main aim of this study was to explore the lived experiences of people with mental illness in order to understand



how they perceive and portray their conditions, and how they build their social identities within the stigmatised master narratives of current society. Special focus has been given to generating a systematic view of mental illness through the bloggers' point of view.

The portrayal of mental illness offered by the findings, opens a window into the lived experiences of people who suffer with mental health issues and their identity struggles. Mental illness, in general, is marked by symptoms that make navigating daily life difficult. In addition to that, each mental illness will present its own set of symptoms and challenges for the individual. Besides the battles associated with symptoms, the thread of adversity that runs through all the narratives and is a constant presence in tales of suffering and recovery, is stigma. This makes mental illness a double battle and places stigma almost as a second condition that needs to be overcome (Finzen, 2017; Rüsche et al., 2005).

The present findings show that many of the negative feelings that characterise the sufferers' portrayals of mental illness, are inherently generated by social and self-stigma. The results identified feelings of incompetence, worthlessness, self-doubt, guilt, invisibility, fear, inadequacy, lack of hope, low self-esteem and low mood. These have appeared in previous research as consequences of three forms of stigma: stereotyping, prejudice and discrimination (Rüsche et al., 2005).

Another strong indication of the lack of social support for people with mental illnesses is the presence of shared-responsibility amongst bloggers. Across the data, individuals have shown a commitment to facilitating recovery for others by sharing sympathetic statements, through the building of a support network, and the creation of safe spaces where people can talk about mental health without judgement. The self-affirmative discourse, located within the narratives, also echoes the need for more social support.

Rüsche et al. (2005) investigated strategies used to reduce stigma and found that protest campaigns, educational programmes and contact with people who are mentally ill, have had some success in fighting stigma. However, a lot more research is needed in order to understand the mechanisms underlying stigma and what actions are needed to change discriminatory behaviours towards people with mental illness. To promote a real change that substantially decreases discrimination, power-groups and their stigma-related attitudes will have to be structurally changed (Rüsche et al., 2005).

Besides adding to the already onerous battle against mental illness, the main challenge with stigmatising processes is that they create significant difficulties for identity management (Wisdom et al., 2008), or the social perspective of living with mental illness.

The results provided two distinctive narratives that show how sufferers adopt different approaches to their mental illness.

The narrative of the hostage comes from people who have not yet found a path to managing their condition. These individuals tend to adopt identities constructed around vulnerability, that reflect and conform to the available social discourses of low expectations and limited chances for those with mental illnesses (Wisdom et al.,

2008). In contrast, the narrative of the survivor, drawn from stories of recovery and successful management of conditions, present identities that contradict the stereotypical representations of the sufferer as someone who is out of control and deprived of agency (Rüsche et al., 2005). On the contrary, they are knowledgeable about mental illness, confident in recovery and most importantly, they are not defined by their mental illness.

The adoption of these contrasting identities also has implications for the individuals' daily life and wellbeing. The predominant coping strategies associated with the hostage are withdrawal, secrecy, masking of characteristics or pretending, and avoidance of situations that might cause discomfort. These ways for approaching mental illness have been found by Ilic et al. (2012) to reduce experiences of stigma but to have a negative effect on wellbeing. On the other hand, the narrative of the survivor, is characterised by the search for credible advice and the development of a self-affirmation discourse, self-reliance and shared responsibility for others. Similar strategies were found by Ilic et al. (2012) to have no impact on reducing stigma experiences, but a positive effect on wellbeing.

Accordingly, when put together, the two narratives offer a model for mental illness trajectory (MMIT), where in order to find recovery, individuals go through a recreation of their social self, substituting maladaptive coping strategies and abandoning the narrative of the hostage, to embracing new forms of being in relation to their condition and adopting more positive coping strategies, thus becoming a survivor.

This shift in identity that allows for individuals to progress from hostages of their conditions to survivors, is called by Shih (2004) as an empowerment model of stigma resilience, where the individual becomes an agent in control of their interactions and resources. Rather than being passive targets of stigma, trying only to avoid negative outcomes as described in the hostage narrative, these individuals are active and interested in acquiring an understanding of their social world and engaged in producing positive outcomes.

The understanding taken from this dynamic is that in order to be ready to recover from their condition, the individual must first overcome social and self-stigma by constructing a new identity, where they dissociate the self from the condition and its stigmatised views. This means, that social stereotypes associated with mental illness—or cultural master narratives that surround these conditions—continue to create and maintain stigmatised identities. However, it is the self-view and the attitude that the individual has towards these social discourses that will support the formulation of a new self, able to provide wellbeing and recovery (Marcussen et al., 2019). As Wisdom et al. (2008) put it, “the overarching aspect of recovery from mental illness is the redefinition of the sense of self” (p. 490).

The MMIT conceptualised from the results of this study, demonstrates this reformulation of the self within six steps: awareness, rejection, self-help, acceptance, treatment and recovery. Similar to the transtheoretical model of change (TMC) that proposes five stages of change in recovering addicts (Prochaska & DiClemente, 2005), this model traces

a trajectory of change that allows individuals to emerge from the vicious cycle of stigma and negative coping strategies, to identifying mental illness, accepting it, seeking treatment and finding recovery.

The TMC has been useful in improving therapeutic outcomes by identifying where the patients are in their journeys of change. Equally, the MMIT can further develop to contribute to a more effective approach to treating patients with mental illness, by first establishing where they are on their journeys and consequently, offering tailored tools that would aid progression to the next phase. Prochaska and DiClemente (2005) state that incorporating stages of change to treatment can be an important guide for practitioners to develop a more systematic approach to recovery.

Across the whole data, bloggers described mental illness as being lifelong, and their journeys are characterised by going back and forth on this trajectory, transitioning through the phases of the MMIT, which means that the stages are not fixed and do not necessarily follow a rigid order. This finding supports an alternative concept of recovery (Gillard et al., 2015; Jacob, 2015), where the focus is on the person rather than the symptoms, and where recovery is more of a journey than a destination. A journey that entails the cultivation of resilience and personal commitment (Noiseux et al., 2010), as well as the involvement of a good support network, all elements that have been cited on the bloggers' narratives as indispensable for recovery.

Unfortunately, the MMIT also highlights the strength and effects of stigma, which put the responsibility of recovering from a mental illness solely on the shoulders of the individual. This is evidence that social discourses are still currently reproduced in an attempt to exclude these individuals and consolidate the existing social order (Ilic et al., 2013) and that more work should be done in order to disseminate knowledge. In addition, the personal narratives on which the model was based, reveal how these bloggers are equipped with inherited views that maintain the dominant discourse of downstream care, characterised by individual, pathological or biological problems and ignore the social and economical determinants of health (Lantz, 2019).

## Conclusion

It is known from other studies that illness disrupts lives and threatens identities. In addition, stigmatised attitudes and behaviours, make the mentally ill at risk of being considered as invalid members of society (Stephens, 2011). Current public views of mental illness misconceptualise individuals with poor mental health as being dangerous, irresponsible, unreliable, weak and dependent on others (Rüsch et al., 2005). When incorporated by people, these identities offered by social narratives foment internalised stigma and propagate further isolation, feeding a vicious cycle, where negative coping strategies become recurrent, mental wellbeing is damaged and the effects of social and self-stigma are reinforced.

The Model for Mental Illness Trajectory (MMIT) was conceptualised from the investigation of personal narratives,

and portrays how individuals are led to rebuild their identities and go through a profound change in how they see and approach poor mental health in order to achieve recovery. The model, developed from personal narratives, contributes to a better understanding of how people might face poor mental health. On the other hand, it also draws attention to how recovery is still heavily understood by these individuals as their own battle, due to oppressing social structural barriers, such as stigma.

The main strength of this study is the attempt of building theory from personal narratives. The investigation of personal accounts of mental illness and their subjective experiences, provides insight into what recovery and successful management of mental illness might look like, and has been recognised by researchers as an important step towards improving the lives of patients (Wisdom et al., 2008).

## Limitations and future research

Given the small scale of this study, further investigation is advised in order to ascertain the components of each phase within the model and also its applicability to the general population. Another limitation of this study is that data was collected from blogs, which limits the sample to people who have language and writing skills not necessarily readily available to everyone, excluding an important part of the population. Leonard and Ellen (2008) suggest extending research by using other types of media such as dance, music, photographs, in order to be more inclusive and maybe reveal more about the social imbalances that affect the experience of mental illness as well as access to care.

Although the present findings and other studies have established the devastating effects of social and self-stigma, the field of mental health research would benefit from future studies on how stigma affects people with different disorders (Rüsch et al., 2005). In this dataset, for example, preliminary findings suggest a division between severe mental illness (SMI) and other mental health conditions. People diagnosed with SMIs seem to have more sympathy and better access to care, whilst high-functioning patients diagnosed with other conditions, such as anxiety disorders, wait longer for treatment, relate more negative experiences with stigma and lack of support.

Also important, are the efforts to increase research that investigates social determinants of poor mental health. The sector would benefit from upstream changes (Castrucci & Auerbach, 2019), addressing social and economic barriers that contribute for mental illness.

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## Data availability statement

To ensure the anonymity and confidentiality of the bloggers, raw data was not made available. An anonymised sample of the data has been included in the appendices.

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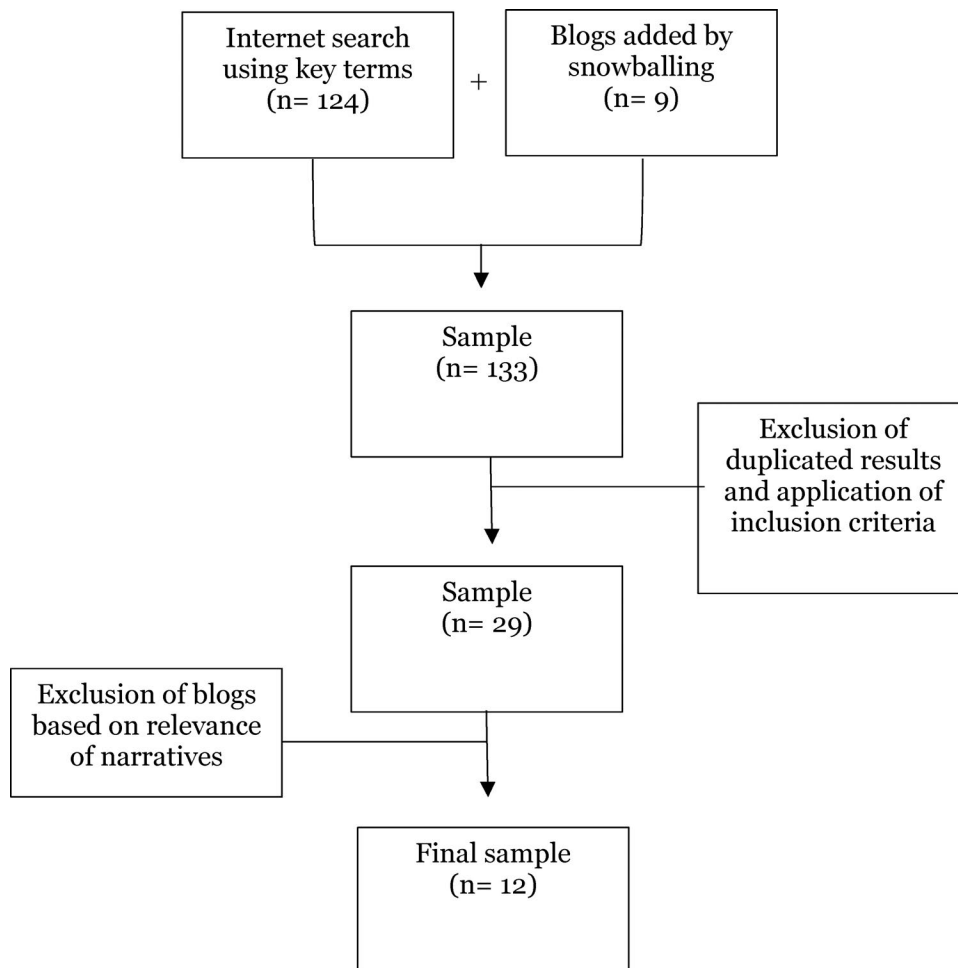
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## Appendix 1

### Sampling strategy



## Appendix 2

Example of how raw narratives were extracted from original writing

Original writing	Raw narrative	Meanings / themes
As some of you may know, I was first diagnosed with anxiety and depression when I was 17 and I am 25 now. Since then, I have taken and continue to receive medication and counselling. In reality, anxiety, depression, suicide attempts and self-harm have been a part of my life from a very young age and well before my diagnosis. I have never let it stop me from getting to where I want to be, even though there have been many times where I have felt as if I have lost my mind and almost lost myself for good. I feel I have had three key crisis points in my mental health journey; 2013, 2018 and now 2021. These are all points which I would document as myself having really reached an end-point or <i>so I thought</i> .	<p>I was first diagnosed with anxiety and depression when I was 17</p> <p>I am 25 now</p> <p>I have taken and continue to receive Medication</p> <p>And counselling</p> <p>Anxiety, depression, suicide attempts and self-harm have been a part of my life</p> <p>From a very young age</p> <p>Before my diagnosis</p> <p>I have never let it stop me</p> <p>From getting where I want to be</p> <p>Many times</p> <p>I have felt as if I have lost my mind</p> <p>Almost lost myself for good</p>	<p>Diagnosis and treatment: diagnosis seems to always come after a long time and after a lot has happened to the sufferer.</p> <p>Identity: Although anxiety and depression have been part of most of the sufferer's life, they do not feel that the illness defines them. If anything, it adds to their ability to deal with specific situations. The use of 'have been part of my life' makes a distinction between 'it has been my life'.</p> <p>Experience: feeling of having lost oneself.</p>



### Appendix 3

#### Visual map of analysis

##### Key

- Raw experience
- Subjective experience
- Main narratives
- Theory building

