

Stigma and the Cycle of Avoidance: Why Young People Fail to Seek Help for Their Mental Distress

Illness behavior is the set of purposeful actions taken by someone when faced with being unhealthy. According to Dingwall,³ the three stages of illness behavior are: evaluating symptoms, deciding to act, and monitoring the effects of the chosen actions. Although presented in a linear fashion, these stages are in fact cyclical, as reassessment occurs when symptoms change or unsuccessful actions require new approaches.

However, it is common that people never act, or delay acting, on their symptoms; this is especially true for people experiencing mental distress. Young people in particular are unlikely to seek professional care for mental health concerns—it is estimated that as few as 17 percent of young adults with mental distress will seek professional care for their symptoms.⁶ Even among those with a clinically defined disorder, only about a third will seek professional help to address their symptoms.^{1,4}

There are many barriers that impact illness behavior in a person with a mental health condition. These include a lack of resources or insurance, a lack of awareness about mental health conditions, and poor access to and low awareness of possible treatments.⁵ Stigmatization also can negatively impact all stages of illness behavior. Given the stigma associated with having a mental health “problem,” people who might otherwise seek help may reframe their condition, reinterpreting their symptoms in order to define how they are feeling as unproblematic or “not that bad.” People may not seek help due to embarrassment or shame. Stigma may also prevent people from seeking different treatment options if their mental health is not improving, since they may be fearful to admit that they are not getting any better.² As a result, people who experience mental distress may try to cope with their mental



health conditions by themselves even though social support and treatment are likely to improve symptoms.

Understanding Help-Seeking Behaviors

Although the process of help seeking has been explained theoretically using Dingwall's three stages of illness behavior, very little has been done empirically to document this process. One exception to this is the work conducted by Lucy Biddle and colleagues.² Biddle interviewed 23 distressed young adults, aged 16-24 years, about their help-seeking behaviors and their reasons for not seeking help. The indicators of their severe distress included suicidal thoughts, cutting, overdosing, and elevated scores on the Clinical Interview Schedule. The major interview topics explored were:

- young adults' concepts of mental distress and theories about cause, prognosis, and curability;
- interpretation of and responses to symptoms; perceptions of need for help;

- perceived outcomes of help-seeking;
- reasons for help-seeking or other actions, including possible “barriers” and “triggers”;
- perceptions of help sources (both formal and informal); and
- involvement and responses of family, friends, and peers; and experiences of help-seeking.

The Cycle of Avoidance

Upon listening to the narratives of these young people, Biddle created a model to track the process of illness behavior in persons experiencing mental distress—the Cycle of Avoidance (COA, Figure 1). This model shows that young people will continuously push their threshold of tolerable distress to include extreme concepts of “normality,” in order to avoid accepting their symptoms as “real” illness requiring help and support. Oftentimes, young people experiencing mental distress will go to great lengths to avoid attributing their feelings and behaviors to mental health problems, and therefore delay seeking help of any sort. Instead, they will continue to cope on their own and normalize their psychological difficulties. Eventually, many of these young people cross this threshold into help-seeking actions via either a crisis or external pressure, or due to self-realization that support is needed.

Young People Interpret Mental Distress

Using excerpts from the 23 interviews of young people, the COA comes to life through narrative. When conceptualizing distress, participants placed mental health difficulties into two distinct categories—“normal” distress and “real” distress—as opposed to seeing distress along a con-

tinuum from slight to serious. While the former was seen as a phase that would eventually pass, "real" distress was seen as extreme, rare, and often permanent. This was the type of distress that participants perceived to be "mental illness." According to them, people who experience "real" distress either:

"Generally can't control themselves that well, either the way they act or the way they behave... (they) are people who generally can't hack it almost. Their minds generally kind of break down and go through certain problems that drugs can overcome sometimes, or, I don't know what they do in those places, electric shocks" (16 year-old male, p. 990).

Or, "Can kind of go over the edge of stress and it's like mental problems... you literally can't cope with getting up in the morning. You've got to that point then when you can't do anything... getting close to the edge and feeling life isn't worth living" (23-year-old female, p. 991).

Such extreme definitions of mental distress can understandably lead to a resistance to seek help and support.

The participants felt that "normal" distress should be dealt with by coping, whereas help and possible treatment should only be sought when experiencing extreme distress. This demonstrates a substantial gap between the beliefs of these young people and clinicians as to when is the best time to seek professional help for mental distress. Some of the young people regarded significant distress experiences as normal, and therefore not requiring professional support to alleviate:

"I wouldn't say I'm depressed, I would just say that I am really overstressed. But I suppose you could call it depression because the thoughts [of suicide] I get sometimes with it... I don't know because it is quite hard to decipher each one. I mean when do you say that stress is depression or depression is manic depression... and how do you say when somebody's upset or somebody's seriously depressed?" (18 year-old female, p. 993).

Others resisted seeking help to the point where it was almost too late:

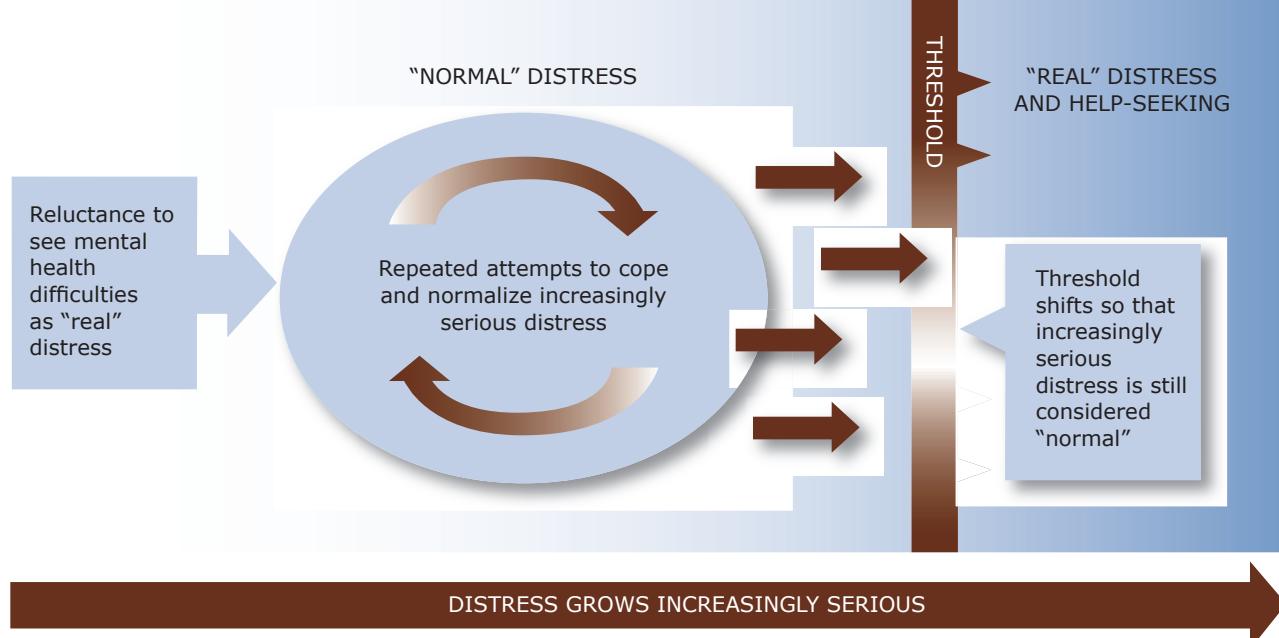
"I was really badly, like, depressed

and I didn't go to the doctor's because I didn't think... I was ill. I didn't think I was ill so it ended up that I ended up in hospital [overdose]... I really needed to see for myself there was a problem... It took me to go into hospital to realize" (20-year-old female, p. 996).

Stigma

Stigma is a key factor in determining how these young people come to define mental illness and when they seek help for it. They realized that there is a stigma against people with mental health conditions and felt that getting formal support for their distress would make them vulnerable to such judgments: "I just didn't think about speaking to the doctor because I didn't want to be sectioned [*in the UK, sectioning is the involuntary subjection of a person to mental health treatments or hospitalization*] or anything. You know there is a stigma about psychological health. There's like a black, black cloud and as soon as you sort of fall under it everyone else runs for cover"

FIGURE 1. CYCLE OF AVOIDANCE



Young people draw a sharp distinction between "normal" distress (which they see something temporary that can happen to anyone) and "real" distress (which they see as indicative of having a mental illness). As a result, they are extremely reluctant to see their symptoms as "real" distress, and they continually re-define "normal" to include increasingly serious distress. Often they are only willing to cross this psychological threshold—and admit that their distress is "real"—when they experience a mental health crisis.

(23-year-old male, p. 997). Concerns about being stigmatized were a prominent reason underlying not only the normalization of interviewees' mental status and avoidance of seeing their situation as "real" distress, but also their lack of help seeking.

Self-stigmatization was also apparent. Throughout Biddle's interviews, youth—who themselves had all demonstrated severe levels of distress—used many derogatory terms for mental illness including "screwy," "totally mental," "weird," "nutty," and "gone up there." Such interpretations of mental illness are bound to influence how young people perceive themselves and interpret their own symptoms, and whether or not they seek treatment. Because of these negative perceptions, it is understandable that young people would be motivated to dismiss their own distress as something that is "normal" and will eventually improve: "I wouldn't say I'm depressed. I'd say I've had a bad time of things for say longer than a couple of weeks or months or it's been a bad couple of months but I wouldn't say I'm actually depressed" (20-year-old male, p. 994).

Participants' corresponding resistance to seek help also makes sense as, according to their narratives, only people who are experiencing extreme symptoms should seek help. It is within this dichotomous framework of "normal" vs. "real" psychological distress that these young people make decisions as to whether or not they should seek professional support for their mental health. And if they do decide that their mental condition requires more formal help-seeking, they are placing themselves into the category of "screwy"—and vulnerable to self-stigmatization that may interfere with their treatment and chances for improvement.

Conclusion

This study is one of the few that addressed how both stigma and self-stigma affect young people's interpretations of their mental health and subsequent actions taken to address it. Using illness behavior as a starting framework, the COA model was created through listening to young

adults' narratives of understanding and responding to their own mental distress. It was found that young adults go to great lengths to avoid defining their symptoms as "real" mental illness, which in turn prevents them from seeking help to alleviate their distress.

Stigmatization plays a significant role in driving the non-help seeking behavior which dominates the COA. Attempts to avoid interpreting symptoms as something about which to be concerned, and delays in help seeking until crisis were often driven by negative perceptions of persons with mental health conditions. Not wanting to be perceived as "weird" or a "nutcase in a padded cell," young people who experienced indicators of serious emotional distress such as suicidality and cutting went to great lengths to avoid labeling their feelings and behaviors as in need of professional mental health services.

The social meanings attached to the label "mental illness" caused the interviewees in this study to avoid what perhaps they knew were the "correct answers" and to resist medicalization of their distress. Stigma appeared to be a deeply entrenched belief system that permeated every aspect of illness behavior, and feelings of self-stigma likely exacerbated the low self-esteem that often accompanies distress. Defining oneself as having "real" distress and seeking help posed a serious threat to interviewees' self-identity and social identity and, in an attempt to avoid this, some of the young people in this study instead adopted negative coping behaviours, leading to spiraling distress and comorbidity. Where help was eventually sought, fear of stigma sometimes impeded full disclosure of symptoms or willingness to engage with treatment.

Practitioners need to be aware of such meanings and the perceived change in status that accompanies what might appear to be the straightforward act of seeking help or becoming a "patient." In particular, they should be aware that by diagnosing a mental health condition, they are potentially marking a young person as "not normal." Supporting young people in managing the psychological and social consequences of this

should be paramount alongside any treatment actions.

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