

Abbreviations

PD = psychiatric disability

LV = layers of vulnerabilities / CV = cascade-vulnerability

HCP = healthcare professional

PAD = psychiatric advance directive / AD = advance directive

Transcript of Slides

Slide 2

In clinical contexts, there are many layers of vulnerability that any patient could have, not just those diagnosed with mental health conditions.

There are factors in the broader society, such as socioeconomic conditions and stability and safety.

Within the walls of a hospital or clinic, health care costs and overwhelming information can add layers of vulnerability.

The bedside relationship can increase vulnerability when the patient feels alone due to perceived lack of compassion from their care team or the absence of other social supports.

If the patient's medical condition has caused pain, trauma, or diminished capacity, those can contribute to the patient's vulnerability in this environment.

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Here are some significant contextual features of a psychiatric diagnosis in my country:

There is widespread ableism, which occurs when someone is devalued in terms of their presumed level of flourishing, agency, or personhood in virtue of their disability status; our society is built around able-minded norms, and people with psychiatric disabilities often confront barriers to achieving well-being and receiving respect.

Due to deinstitutionalization, far fewer patients are admitted to psychiatric hospitals, especially for the long-term in US, but there are insufficient community resources and safety nets available to care for people with psychiatric disabilities when they need them.

The insurance market has poor mental health coverage; there are high incarceration rates; inadequate housing solutions; and laws that permit involuntary hospitalization and treatment.

***Note: Not all people with PDs will experience these contextual factors the same. PDs are heterogeneous and vary widely, and a person's socioeconomic position in terms of class, gender, race (for example) can make an enormous difference for how much these contextual factors affect them in their everyday life.

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Florencia Luna describes cascade-vulnerability (CV) as a "chained series of events that lead to harmful consequences" – CV exacerbates or leads to additional vulnerabilities. In this context, a psychiatric diagnosis can lead to a cascade of potential vulnerabilities.

A deep ethical analysis of these vulnerabilities, such as under what conditions involuntary hospitalization could be justifiable, is outside the scope of this presentation. My point here is that someone with a PD is more vulnerable in these ways due to the social, legal, and historical context of that diagnosis.

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Some patients will be more susceptible to layers of vulnerabilities, such as when they are in acute psychiatric settings; when they have a diagnosis that is considered a “serious and persistent mental illness,” when they have a history of multiple hospitalizations, when they have active hallucinations or delusions, when they have documented non-adherence, and when they are socially isolated.

When I say they have increased susceptibility, what I mean is there are more triggers for layers of vulnerabilities, a higher probability of being actually vulnerable, and both greater magnitude and greater duration of harms.

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I will focus on these layers of vulnerability in healthcare decision-making: capacity assessments, insight assessments, therapeutic pessimism, and conflicting views of recovery.

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In order to be authorized as their own decision maker, a patient needs to show that they have decision-making capacity – that is, they need to demonstrate they can sufficiently understand, reason through, appreciate, and communicate a stable choice. If the patient lacks capacity, the HCP should turn to a surrogate, agent, or guardian for decisions (local laws and policies can vary on some of these details and exceptions).

Capacity assessments can radically affect the direction of a patient’s care and the extent to which the patient is able to pursue or reject tests, treatments, and discharge options. Patients can therefore experience vulnerabilities in relation to these assessments. For one, the patient may be incorrectly assessed as incapacitated. This can be the result of misperceptions about certain diagnoses or symptoms. The HCP might also miss important nuances to what the patient does and does not understand. Communication barriers could prevent an HCP having confidence that a patient has capacity. The patient’s capacity status could fluctuate depending on a number of factors. If the HCP does not notice those fluctuations or what precipitates dips in capacity, then the patient might not be empowered as a decision-maker when they are most capable.

If the HCP makes an error with the capacity assessment, then the patient is at high risk for being wrongly excluded from decision-making. If the medical team is turning to someone else for decisions, the patient might not be given much information or invited to participate to the extent that they are able to participate. There may be increased likelihood of involuntary hospitalization or treatment, which could hurt the patient’s trust in healthcare, and which may or may not ultimately benefit the patient.

Vulnerabilities related to capacity assessments are exacerbated when HCPs are inadequately trained, when time is too constrained for an in-depth interview over time, and when the patient’s medical needs are acute.

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Insight refers to patients' self-understanding of their condition. From the HCP's perspective, a patient with poor insight rejects their diagnosis, disputes pathological attributions to their behavior or affective states, and/or refuses treatment that the HCP believes is beneficial. If the HCP believes that the pt's poor insight makes it impossible for them to understand the basics of their medical needs, then the HCP may additionally have doubts about the patient's capacity status.

The vulnerabilities a patient could experience in relation to insight assessments therefore have a lot in common with the vulnerabilities of capacity assessments. The patient may be incorrectly assessed as having poor insight. This can be due to misperceptions about certain diagnoses or symptoms (traditional "psychoses" used to be viewed as conditions of poor insight, for example, though now there is an appreciation of individual variation within any diagnostic category). HCPs can miss important nuances of the patient's self-awareness – which should be expected, given that another person's self-knowledge or self-awareness is not a simple thing to test! Although I have no doubt that HCPs strive to be sensitive to the possibility of reasonable disagreement and to the multifactorial nature of non-adherence, a patient with PD who disagrees or does not adhere to a prescribed regimen is still susceptible to being viewed as having poor insight when that evaluation is ultimately hasty or erroneous.

A patient with documented poor insight can be vulnerable to parentalism – that is, to having their preferences unsolicited or overridden out of concern for their best interests, as understood by the HCP. Numerous studies have found that HCPs consider poor insight to be a substantial barrier to their even attempting shared decision-making. A person with a PD is more vulnerable to epistemic injustice, which occurs when a person is wronged as a knower, when their testimony is immediately doubted as a result of systemic bias and prejudice. If the patient has been evaluated to lack insight, then the vulnerability to epistemic injustice is heightened, since HCPs and others may be less likely to trust *any* of the patient's reports.

Vulnerabilities related to insight assessments can be quickly exacerbated in clinical settings. Training on insight assessments may be inadequate, and there are no standardized bedside tools for these assessments. Clinical documentation for insight assessments, at least in the U.S., tend to be sparse with a single word – "poor," "partial," "full," etc. This sparse documentation means that nuances and dimensions of insight can be easily missed. Time may be too constrained for in-depth interviews, and some legal jurisdictions may make this assessment particularly high-stakes for the patient.

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Numerous studies over the years have shown that HCPs tend to have negative attitudes toward patients with certain diagnoses, especially personality disorders, and these attitudes manifest as doubts about treatment efficacy (therapeutic pessimism) and strong personal dislike.

The patient is vulnerable in this situation to being viewed as "hopeless." There can be missed opportunities to provide benefits or address sources of harms of distress as a result. Instead of having a therapeutic alliance, the patient could experience increased isolation, and there is a risk of the HCP terminating their relationship as a result of their therapeutic pessimism. Patients in this situation may find it particularly difficult to find engaged and empathic care, which could contribute to internalized stigma, shame, and lost opportunities for shared decision-making.

These vulnerabilities are exacerbated when clinicians experience negative countertransference. Some mental health conditions do not have a robust evidence base for how to treat them, which can (understandably) contribute to therapeutic pessimism. Acute care settings are far from ideal for handling complex psychiatric disabilities, yet these patients might not have good access to outpatient resources.

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HCPs tend to have a clinical orientation to what “recovery” looks like, so, for HCPs, getting better would likely include symptom alleviation and restoration of a patient’s ability to pursue activities of daily living independently. But a patient might prioritize self-esteem, hopefulness, or other conceptions of what it means to live well. If the HCP and patient cannot agree on what it means to “get better,” then therapeutic goal-setting could quickly come to an impasse. Some vulnerabilities can follow, such as the following: The HCP may be inclined toward a form of parentalism based on their own understanding of what the patient needs. The patient might not receive the therapeutic benefits that would be most valuable to them as a result. There can be stalled or inefficient care. Depending on the nature of the disagreement, the HCP might doubt the patient’s ability to participate in goal-setting or may terminate the relationship.

These vulnerabilities are exacerbated in acute care settings, where the focus is on immediate stabilization. If the patient’s goals radically challenge standard medical assumptions (for example, consider a voice hearer who values their voices and does not view them as pathological), conflict with HCPs may be more likely. If the HCP believes the patient lacks capacity or insight, the patient may not be invited to participate in goal-setting, which can be reinforced if the patient also does not agree with the therapeutic plan. If other people in the patient’s life, like a surrogate or guardian, agrees with the HCP, then that can alleviate the moral (and legal) concerns of the HCP even if it actually heightens the patient’s concerns.

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Luna argues that we should identify layers of vulnerability and find ways of addressing their harms, prioritizing vulnerabilities appropriately. Psychiatric advance directives hold some promise for helping to minimize the harmful effects of vulnerabilities. If you hold your phone’s camera over the QR code in the upper right corner, you will be directed to a website with more information about psychiatric advance directives.

The idea behind PADs is that a patient with a PD, while capacitated, can fill out this legal document to indicate what they want for their mental health care and who they want as their decision-maker if they lose capacity and are in a mental health crisis. This document is meant to capture the patient’s autonomy interests and enduring values across psychiatric episodes and prevent burdensome or coercive hospitalization or treatment. It could also improve the therapeutic relationship if used well.

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Ultimately, more research is needed to know to what extent psychiatric advance directives really do eradicate or minimize layers of vulnerability in mental health settings.

Some layers are going to be untouched, of course. We should guard against idealizing PADs as a solution; we should consider the actual context of these documents for different kinds of patients with psychiatric disabilities, and how effective they are at achieving their intended aims from multiple standpoints.

PADs are not widely disseminated or supported by explicit laws or statutes. Individuals who could benefit from these documents may have health literacy barriers to filling them out. In the U.S., HCPs rarely receive training on PADs, even when these documents exist in their jurisdiction, which poses a problem for making PADs available to patients and having them honored appropriately by medical teams. PADs also have the classic problem of any other AD – they may not capture the patient’s actual autonomy interests or changing view of self over time.

So even though PADs hold out some promise, more research and investment are needed for them to successfully and consistently address layers of vulnerability experienced by patients with PDs.

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For Questions or Comments

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