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Disrupting the Cycle of Medical Distrust Between Caregivers and the Health Care System For Persons Living With Serious Mental Illness: What Does Misinformation Have To Do With It?

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Disrupting the Cycle of Medical Distrust Between Caregivers and the Health Care System For Persons Living With Serious Mental Illness: What Does Misinformation Have To Do With It?

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Disrupting the Cycle of Medical Distrust Between Caregivers and the Health Care System For Persons Living With Serious Mental Illness: What Does Misinformation Have To Do With It?

Persons living with a serious mental illness (SMI), which can include affective disorders, psychotic disorders, bipolar disorders, and major depressive disorders¹ face significant challenges in communicating their preferences for treatment during a mental health crisis. SMI is defined as;

a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities. The burden of mental illnesses is particularly concentrated among those who experience disability due to SMI.²

In the United States, there were an estimated 14.1 million persons aged 18 or older who live with SMI.² Moreover, young adults aged “18-25 years had the highest prevalence of SMI” compared to their older counterparts.² Annually, for the 5.5% of all persons living with SMI, the National Alliance for Mental Health reported that, in 2021, approximately “2 million times a year, people with serious mental illness are booked into jail”.³ Added to this are the decisions made by first responders regarding who is hospitalized or jailed. When arrest is the decision a cascade of criminal justice interactions including coercion and/or involuntary commitment can occur leading to alienating individuals with SMIs from seeking care, and compounding patient distrust of health care providers.⁴

Regrettably, when individuals do seek treatment, they too often have experienced stigmatizing interactions with providers.⁵ Such considerable systemic barriers, patient uncertainty, and communication challenges, associated with seeking treatment, creates a pressing need to develop not only a care plan for people living with serious mental illness but a care plan that carries legal integrity regarding its use. This reality raises additional concerns for adolescent transitional age youth, ages 15 to 17, who are approaching the age of majority. Whether or not one is an adult, reliance on a family or friend (i.e., caregiver) during an incapacitating mental health crisis remains a central component of the process raising questions about caregivers’ experiences as proxy decision makers.⁶

As such, caregivers’ experiences, serving as proxy decision makers, during a mental health crisis, reflects a range of challenges including difficulty reviewing health information scattered across numerous health institutions, making the sharing of a complete health history reliant on inadequate data thus limiting caregiver involvement in the collective decision-making process.^{7,8} Lavoie, describes such experiences as silencing the “invisible experts”.⁹ It is important to note that access by a caregiver, typically a parent or family member to health information of a loved one age 18 or older, is no longer automatic and thus requires the authorization by the person experiencing the mental health crisis to grant permission for the caregiver to access health care records during a medical emergency.¹⁰⁻¹²

Omission of these invisible experts from the decision-making process, despite their firsthand expertise advocating for their loved one's care contributes, we argue, to a cycle of misinformation exchange between and among health care providers, caregivers serving as surrogate decision-makers and the health care system. Persons experiencing an incapacitating mental health crisis are unable to provide informed consent for treatment and thus rely on a triad of expert resources to carry out their previously capacitated statements for care. Overlooking caregiver expertise from this process, not only contributes to the stigma caregivers report regarding advocating for a loved one living with mental illness,¹³⁻¹⁵ it fuels distrust of the health care system thereby contributing to caregivers engaging in disclosure avoidance tactics. Avoidance tactics are operationalized as the ways in which in this case caregivers evade giving health information to health care professional.

This paper reports caregivers experiences of how medical distrust contributes to the scientific misinformation exchange that can occur when readily available information is not accessed and incorporated into the health care decision-making process of persons experiencing a mental health crisis.

Health Care and Disclosure Decision-Making Considerations

This study expands the understanding of scientific misinformation to the realm of caregiver decision-making on behalf of a loved one experiencing an incapacitating mental health crisis and the consequences that arise from the omission of caregiver expertise in clinical decision-making. Scientific misinformation is understood "...as publicly available information that is misleading or deceptive relative to the best available scientific evidence that runs contrary to statements by actors or institutions who adhere to scientific principles".¹⁶ For purposes of this discussion, the actors and institutions referred to represent caregivers serving as surrogate decision makers, medical practitioners, and the medical institutions (e.g., hospitals, clinics) all of whom rely on *the best available scientific evidence* to inform care decisions. Caregivers, serving as surrogate decision-makers, hold an ethical responsibility to speak on behalf of someone, in this case a loved one during an incapacitating mental health crisis. By definition, caregivers use an autonomy-based standard when acting as surrogate decision-makers when they "don the mental mantle of the incompetent" when answering the question *what are my loved ones stated wishes and preferences for care, should they become unable to answer these questions for themselves during an incapacitating mental health crisis*.¹⁷ Simply put, caregivers engage in substituted judgement when replacing their own wishes and preferences for care with the previously capacitated statements for care stated by their loved one. For transitional aged youth nearing the age of majority, accustomed to decision-making for care being done by parents, the need to plan for their eventual emancipation, the making of autonomous choices, and ensuring those choices are respected and implemented is imperative.

In the clinical setting, shared decision-making reflects a course of action described as collaboratively engaging health care providers, patients, and their caregivers into the decision-making process that emphasizes reflecting the patient's treatment wishes and preferences in the medical decision-making encounter^{18,19} Moreover, shared decision-making allows for the act of, as Goldman states, "...balancing our knowledge of medicine and scientific practice with

collaboration and humanistic respect for the views of those who come to us for help”.²⁰ Caregivers engage in shared decision-making when they are tasked with retrieving information from health care providers, sharing said information across health care systems, all while managing to whom to disclose information on behalf of a loved one experiencing an incapacitating mental health crisis. This process can create an array of challenges for caregivers serving as surrogate decision-makers, during a mental health crisis, when deciding with whom and what information to disclose during a mental health crisis. As previously stated, the omission of these invisible experts despite their firsthand knowledge and expertise in advocating for their loved one’s care from the decision-making process contributes, we argue, to a cycle of misinformation exchange between and among, health care providers, caregivers, and health care systems. The Disclosure Decision-Making Model (DD-MM) an information management theory, provides a useful framework of analysis for this exchange.²¹

Caregivers, when confronted with disclosing sensitive and often stigmatizing information on behalf of a loved one experiencing a mental health crisis, report concerns regarding how health care providers will react to the information they share including how their own abilities to share information can influence their likelihood of disclosure.²² This hesitancy further complicates caregiver decision-making regarding whether to share or withhold health care information on behalf of a loved one experiencing a mental health crisis. Added to this is the realization that a stigmatized diagnosis can contribute to individuals, living with an SMI, to negatively view their diagnosis and in turn contribute to their limiting or withholding of the health information they share with others.²² Applying the definitional lens of misinformation, to these findings, expands our understanding of how disclosure avoidance strategies is driven by caregivers’ distrust of the health care system and not the stigma associated with persons living with mental illness. We further discuss how care giver experiences contribute to distrust of the health care system and the resulting scientific misinformation that can occur when readily available information is not accessed and incorporated into the health care decision-making process, a process, heavily reliant on “. . . statements by actors or institutions who adhere to scientific principles. . . . where claims should be based on scientific evidence and relevant expertise”.¹⁶

We argue that by expanding the unit of analysis beyond the “. . . convenient sources of misinformation such as social media content”¹⁶ to include the retrieval and use of information found in electronic medical records and discussions with heretofore invisible experts, can disrupt the cycle of misinformation that can arise during a mental health crisis thereby enhancing the patient centered process. Using a mixed methods approach, this paper provides the results of a Texas wide online survey regarding disclosure of health care information during a mental health crisis. Quantitative measures revealed disclosure avoidance strategies regarding sharing health care information during a mental health crisis. Simply put, participants revealed how distrust of the medical system led to their selectively sharing or omitting health care information. Open ended responses suggested a relationship between how lack of information can lead to misinformed decisions by the health care team.

We share our findings and conclude with strategies for expanding the definition of scientific misinformation to include not only health care information exchanged between relevant parties but also offer how addressing such omissions can be addressed by advancing the use of

psychiatric advanced directives to ensure the expertise of patients and their surrogate decision-makers are included as part of the shared decision-making process. Practical recommendations call for applications in which capacitated persons living with serious mental illness and their caregivers collaborate on the creation and memorialization of care using a psychiatric advanced directive (PAD).

Materials and methods

Study design and setting

This convergent, mixed methods observational study explored distrust towards health care systems and attitudes around disclosing health information from Fall 2020 in the state of Texas and in collaboration with a national grassroots mental health organization. All data collection occurred online.

Recruitment

A purposive convenience sample was used to recruit participants for the study. The study recruited participants from mental health advocacy organizations in the state of Texas that asked to share study information and the survey link. Additionally, participants were recruited from various Facebook mental health focused organization pages. This non-probability sampling method was justified as the population of interest is rare and geographically spread.²³

Inclusion criteria consisted of individuals who were at least 18 years old or older, living in the state of Texas, who either had experienced a mental health crisis or were the caregiver of someone who had experienced a mental health crisis. The informed consent document and questionnaire were administered online via Qualtrics. Procedures were approved by the university's Institutional Review Board (IRB). Participants completed the web-based questionnaire after receiving the link from an online source. The only forced response items were the consent form and verification questions. Individuals were required to answer, "I agree" before clicking through to the survey content. Participants were provided definitions of a mental health crisis and private health information to ensure a more uniform understanding of the terms.

At the end of the survey, demographic information was collected with no identifying information such as names or emails. After participants submitted their response, the data were saved securely for analysis on the lab's password protected and encrypted cloud-based server. Participants had the option to participate in a separate questionnaire in which they could enter their email for a \$15 gift card as an incentive for providing responses.

This analysis included 269 individuals from Texas who identified as caregivers of someone living with a serious mental illness. Of the 269 participants, 19 (7.1%) shared that they live with an SMI as well. The participants ranged in age from 20 to 75 years of age, with a mean age of 36.5 ($SD = 10.3$). More than half the sample identified as racially White ($n = 203$; 75.5%), heterosexual, ($n = 232$; 91%), female ($n = 149$; 55.4%), married ($n = 197$; 73%), employed ($n =$

233; 86.6%), and had health insurance ($n = 241$; 90%). Of the employed participants, 31.1% ($n = 55$) shared that their paid work involves mental health care.

Table 1: Sample Characteristics

Variable	Mean (SD) or n (%)
<i>Age</i>	35.6 (10.3)
<i>Gender</i>	
Female	149(55)
Male	104(38)
Fluid	1(>0)
<i>Race/Ethnicity</i>	
White	203(75)
Black	20 (7)
Hispanic/ Latinx	18(7)
Asian	3(1)
Native American	3(1)
Pacific Islanders	1(>0)
Other	9(3)
<i>Sexual Orientation</i>	
Heterosexual	232(86)
Gay	1(>0)
Lesbian	7(3)
Bisexual	7(3)
Pansexual	4(1)
Queer	2(1)
<i>Education</i>	
Less than High School	1(>0)
High School/ GED	28(10)
Associate's/Vocational	46(17)
Bachelor's	115(42)
Graduate Degree	26(10)
<i>Insured</i>	241(89)
<i>Married</i>	197(73)
<i>Employed</i>	204(75)
<i>Caregiver Lives with SMI</i>	19(7)

Questionnaires

Disclosure Avoidance Strategies. Disclosure avoidance strategies were measured with four 5-point Likert items adapted from literature on disclosing a health condition.^{22,24} This scale includes items such as “I don't talk about certain topics with my health care provider because I

worry who might be able to see my answers in my health record.” Higher scores on this measure indicate more avoidance of disclosing health records to health care professionals. Disclosure Avoidance Strategies used the following five-point Likert scale where 1 = *Does not describe me* to 5 = *Describes me extremely well*.

Health Care System Medical Distrust. Medical system distrust was measured using all nine items in Shea’s revised scale of Medical Distrust.²⁵ Each of the nine items in the scale were further classified into either the values or the competence subcategory. The value subscale contained five items and the remaining four items contained the competence subscale. The value subscale questions reflected the themes of honesty, motives, and equity, while the competence subscale included questions that asked about perception of competence within the health care system. The phrase “health care system” was understood as “. . . including hospitals, community clinics, labs, insurance companies, and drug companies. . .”.²⁵

The health care system distrust scale included questions such as “Patients receive high quality medical care from the health care system,” and “The health care system experiments on patients without them knowing.” The Medical Distrust Scale used the following five-point Likert scale where 1 = *Strongly Disagree* to 5 = *Strongly Agree*. Response set bias was addressed by alternating between negative and positive wording. Higher scores on this measure indicated higher distrust of the medical system. Criminal justice system distrust was also measured; however, it was dropped due to high correlation and collinearity with medical distrust.

Mental Health Caregiver Stigma. Mental health caregiver stigma was measured from and adapted from King’s scale.²⁶ This scale includes items such as “I worry about what others think about my mental health condition” and “I worry that I will be treated worse by police because of my mental health condition”. This measure used a five-point Likert scale where 1 = *Strongly Disagree* to 5 = *Strongly Agree*. Overall mean scores were calculated for analysis. Higher scores on this measure indicated higher caregiver stigma.

Open Ended Responses

Open ended questions explored behaviors related to the availability of health information during a mental health crisis (e.g., perceived quality of care, perceptions of emergency response). The question and prompt were: If someone’s health record is not available, what might be some problems that come up during a mental health crisis? If you are comfortable, please include examples of your professional or personal experiences.

Quantitative Analysis

Covariates

In order to determine covariates, we first examined the demographic characteristics in the survey that may be predictive of responses of disclosure such as age, marital status, income, and reported SMI diagnosis. Theoretical underpinnings also served to inform our decisions. Specifically, the DD-MM served to help frame the study of caregivers' assessments regarding with whom and what health information to share when serving as a surrogate decision-maker.²¹ This theory describes the process of an individual’s assessment to disclose health information to others, when taking into consideration stigma, prognosis of diagnosis, relevance, and preparation

of diagnosis.²⁷ DD-MM has been applied in a variety of interpersonal and health contexts, including disclosures of stigmatized health information such as an HIV diagnosis or a mental health diagnosis.^{22,28-31}

Additionally, understanding how intersectionality, the experience and interconnectedness of individuals traits (i.e., race, class, and gender) is an approach used to analyze multiple categorizations of identity and differences in order to make meaning in associate social outcomes.^{32,33} Disrupting inequitable practices and the underlying structural condition of society relies on research and modeling scientific practices that are in line with theories of intersectionality.³⁴ In an effort to take into account the multiple marginalized social categories, participants that identified as white, heterosexual cisgender male (n=171) were placed in a non-marginalized category (Marginalization =0). All other races/ethnicities, genders and sexual orientations were placed in a marginalized category (Marginalization =1).

Studies have shown that members of marginalized groups experience additional stressors related to holding a stigmatized identity.²⁸ Stressors include experiences of prejudice and discrimination or may be expressed as internalized attitudes and the corresponding fear which arises from such marginalization may affect participants' scores of disclosure strategies and contribute to medical distrust.^{35,36} In this study we sought to not only recognize the role of intersectionality we chose to address this issue by controlling for both caregiver stigma and marginalized group membership.

Statistical Analysis

Data was analyzed using SPSS, version 27. Demographic characteristics in the survey that may be predictive of responses of health information disclosure were chosen as control covariates. Control covariates included: age, income, self-reported caregiver SMI status (1= Caregiver with SMI, 0= Caregiver with no SMI), marriage status (1=Married, 0= Not Married), caregiver stigma average, medical distrust average, and if they belonged to a marginalized group status (1= Marginalized, 0= Not Marginalized). In order to make the negatively worded items compatible with the other items in the medical distrust scale, we used reverse scoring in order to compute the average.

Disclosure avoidance scores were recategorized into a dichotomous variable based on the sample size average, scores above the average were coded as 1= "High Avoidance Disclosure" and scores below the average were coded as 0= "Low Avoidance Disclosure". Reliability analysis was completed on all scales. Initial inspections for assumptions such as homoscedasticity, sparseness, and outliers were conducted to examine the dispersion and distributions of the data. Data was analyzed using hierarchical binary logistic regression due to the multiple factors influencing the outcome of sharing or not sharing health information. Bivariate correlation analysis revealed the magnitude, direction, and statistical significance of the paired relationships. Independent variables showed no collinearity (e.g., $r \geq .80$) and data was fully represented with no outliers. In order to explain the variance or likelihood of disclosing health information, hierarchical rather than stepwise analysis was used. For each of the steps, coefficients as well as the statistical significance of the overall model are reported. The first level is composed of the sociodemographic variables as well as caregiver stigma score. The second level included medical distrust scores.

Qualitative and Mixed Method Analysis

Caregiver data with high disclosure avoidance strategies (1= “High Avoidance Disclosure”) was analyzed using inductive thematic analysis as a way to identify the themes through the data.³⁷ We first reviewed the open-ended responses individually to observe categories of potential interest to create potential themes. After meeting and discussing where our open coding converged and diverged, the thematic analysis revealed one theme. Authors met and discussed differences in coding and the coding frame was revised after operationalizing definitions of the theme.^{38,39} This resulted in the creation of two subthemes. Of the 144 responses, 74 completed the open-ended questions. Qualitative quotes were integrated into the quantitative data for their connection to the original purpose of the study, which was to explore how those with high disclosure avoidance scores experienced care for a loved one experiencing a mental health crisis when information was not readily available.⁴⁰

Results

To test our hypotheses, we examined the compositional and contextual variations of health care information disclosure across members sampled from the state of Texas. First, we examined the bivariate relationships between medical distrust and disclosure avoidance variables. The following covariates were controlled during the first step of hierarchical regression: marginalized identity, marriage status, age, and caregiver stigma ratings, income, and SMI status. Medical distrust was added in the final step of the regression.

For each of the regressions, we reported the statistical significance of the coefficient for medical distrust as well as the statistical significance of the overall model and the percentage of variance in the discrepancy explained by variation disclosure variables. Table 2 shows the simple descriptive statistics and internal consistency estimates for the following measures: disclosure avoidance, caregiver stigma, and medical distrust. Cronbach alpha coefficients obtained from all the dimensions range from 0.64 to 0.87. All these measures were above the recommended levels (i.e., 0.5 for Cronbach's alpha) indicating acceptable levels for the reliability of constructs and supporting the validity of scales.⁴¹

Table 2

Descriptive Statistics, Reliability for Study Variables		
<i>Variable</i>	$\mu(SD)$	α
1. Disclosure Avoidance	2.66(0.70)	0.64
2. Medical Mistrust	2.81(0.78)	0.87
3. CG Stigma	3.43(0.75)	0.76

The values of the regression coefficients and their statistical significance were obtained by hierarchical logistical regression and are included in table 3. Entry of medical systems distrust into the model fit was significant (Block1-2LL = 245.76, Block2-2LL = 235.84 $\chi^2_2 = 48.49$, $p < 0.001$). The model explains 27% (Nagelkerke R^2) of variance in disclosure avoidance and correctly classified 72.0% of cases. The relationship of distrust ($\beta = 0.68$) indicated a positive association; as distrust in health care systems increased, disclosure avoidance also increased. Caregiver stigma showed to be poor predictor of disclosure avoidance.

Table 3
Coefficients from binary logistic regression for Disclosure Avoidance

Outcome= Caregiver Disclosure Avoidance	Model 1	Model 2
Predictors:		
Age	-0.46*	-0.51*
CG Stigma	-0.03	-0.13
Income	-0.11	-0.02
CG Lives with SMI	-0.83	-1.164
Married	0.77	0.89*
Marginalized	-1.71**	-1.61*
Medical Distrust		0.68*
R ²	0.223**	0.274**
R ² Change		+0.051

Note: * $p < .05$; ** $p < .01$.

Qualitative Results

Qualitative responses for participants, who reported high disclosure avoidance strategies ($n = 74$), were categorized into one theme and two subthemes. As previously stated, disclosure avoidance strategies describe one's avoidance (i.e., hesitation) in relation to disclosing health care information to health care professionals. Now that medical system distrust has been established as contributing factor of disclosure avoidance strategies, we turn our attention to caregiver experiences, as proxy decision-maker, when health care information was not readily utilized during a mental health crisis. Themes are illustrated using participant quotes, which also include their reported gender, age, and race/ethnicity. Respondents' professions were included only if they worked in the health care field.

Thematic review

Delays and timing

The theme delay, in accessing health information, offers insight into expanding the application of misinformation to the health care setting. Delay is understood as not only the failure to use readily available health information from sources such as trusted caregivers it is also the disregard, by health care providers, of not accessing readily available health care records such as electronic medical records or caregivers' expertise. Such information gaps in decision-making provides insight into how *misinformation* may contribute harm by either inaction or wrong and potentially harmful treatment to someone experiencing a mental health crisis. Caregiver participants expressed a range of examples about their experiences in relation to problems that arise when their loved one's health record was not available during a mental health crisis.

While medical records are accessible to the health care providers in order to treat, participants report that they too often experience that records are not readily accessed during these mental health emergencies. Participant #88 [38yo, White, female] described her experience accessing

records during a mental health crisis this way, “If you have an emergency, you may not be able to arrange treatment in time because you cannot access your health records”. Participants talked about the inability to access and share their loved one’s health information in a timely manner and how it caused delays in treatment. To this discussion, participant #69 [40yo, American Indian/Alaska Native, male, mental health advocate] offers an overall summary in relation to the theme of *delay* that expressed experiences many people faced during a mental health emergency of a loved one this way: “You can’t look at the health records and you can’t look at the disease and you can’t treat it.” Despite the fact that health professionals are covered entities when it comes to obtaining protected health information from another health care provider or institution for treatment purposes, such delays continue.⁴²

Poor Outcomes

The above description includes elements around the absence of information caused by such delays and the poor outcomes that may arise. As participant #251 [22yo, Asian, female, health care provider] explained, that as a mental health professional without health information “We could make the wrong decision.” This quote is particularly insightful in that they are not only a mental health professional but also a caregiver of someone with SMI and thus as a caregiver/professional she readily understands the importance of timely interventions. Moreover, participants report a range of negative outcomes due to delays in treatment. Participant #204 [29yo, White, male, mental health advocate] noted “Correct health care may be delayed because the wrong assumption is made causing further damage”. Participant #110 [36yo, Black, female] extends such harm to include “Even lose your life”. In summary, the delays that arise regarding accessing readily available medical information impacts the timeliness of treatment which in turn can lead to a range of poor outcomes, the most deleterious of them being death.

Discussion

Our results show the mechanism by which medical system distrust is formed and the effect on disclosure avoidance strategies when it comes to sharing medical health information. Although previous literature attributed stigma as a factor for withholding health information, the results in this study show that higher medical system distrust leads to withholding medical information with health care professionals (i.e., disclosure avoidance). In particular, the current study unfolds the expansion of misinformation to the health care setting in several respects.

First, this study clarifies the differential role that distrust contributes to misinformation (i.e., disclosure avoidance). As previous literature argues, socially disadvantaged groups may be more distrusting of the medical system due to a history of misinformation and harm within these communities. However, the results also indicate that distrust is not exclusively tied to marginalization, the experiences shared by caregivers reveals that their previous interactions within the health care system is likely to have contributed to a distrust-avoidance strategy towards the medical health system as a whole regardless of what their social disadvantage or advantage might be.

Additionally, the effects of misinformation are shown across multiple dimensions within the health care system. In particular, the impact of misinformation around outcomes in turn reduces trust and self-disclosure in future interactions. This indicates that caregivers who do not trust the medical system that is providing treatment to their loved one, would consider not disclosing

relevant medical information in the future if given the chance, continuing the cycle of poor outcomes as a result of the misinformation exchange. Such decisions, we surmise, reflects the frustration of caregivers at being overlooked as sources with vital expertise and as indicated, as distrust in health care systems increases, disclosure avoidance also increases. In short, what solutions are available to interrupt this cycle?

Caregivers as experts

Undeniably, caregivers have the potential to contribute a tremendous amount of expertise, experience, and knowledge in emergency care situations including consultations in which they become involved.⁴³ Regrettably, when relegated to silence, the risks to obtaining a truly informed consent for decision-making is dubious. Caregivers carry a tremendous responsibility to speak on behalf of a loved one who, during a mental health crisis, lacks the ability to speak and share their health care wishes and preferences. The need to balance the burdens and benefits of any proposed care plan, one that places the person, in this case the patient, at the center of the conversation is fundamental to respecting the autonomous choices of those living with serious mental illness and the person they have entrusted with the responsibility to speak on their behalf.

Person centered care plans focus on the engagement of the patient, family, and treatment team in the decision-making process. This process emphasizes physical and emotional well-being including family preferences, values and cultural traditions, among other features and provides the basis upon which the disruption of misinformation, the resulting distrust, and corresponding disclosure avoidance tactics can be built.⁴⁴ Essential to patient centered care, where patients rely on a caregiver to act as their proxy decision-maker during times of incapacity, begins by ensuring that the voice of the caregiver becomes heard. Caregivers know, first person, the wishes and preferences for care and treatment for their loved one. Specifically, care givers when acting as proxy decision makers, engage in *substituted judgement*, meaning that the proxy is the agent designated to act on another's behalf who speaks with firsthand knowledge when asked "What would the patient want in this circumstance".¹⁷ Any response less than a first person retelling of the patient's wishes and desires does not reflect a first-person consent, and is thus relegated to best interests standard that, as the name implies, reflects a standard of care that weighs the benefits and burdens of a proposed treatment plan with a focus on a good outcome.¹⁷

Practical Implications: Disrupting the Cycle of Misinformation, Distrust, and Disclosure Avoidance

The exclusion of caregivers in care planning often leaves families isolated and disregarded, resulting in the perception that health care providers used protecting patient confidentiality as an excuse to withhold information and avoid engagement with them.⁴⁵ The mismatch of communication between, for example, psychiatric and social services regarding the need for involvement of caregivers (as proxy decision-makers) in treatment planning highlights the need to identify not just whether a specific intervention is effective but what pathway or sequence of intervention steps is most effective for specific clients. Assuring that caregivers as proxy decision-makers are heard and their knowledge and expertise incorporated in the decision-making process rests on the creation of a psychiatric advance directive (PAD).

PADs are a medical legal document that promotes a more collaborative and thereby a less paternalistic engagement with health care providers. Wishes and preferences for care, including

medication, seclusion and restraints, and the use of electroconvulsive therapy during a mental health crisis are examined in the process of creating a PAD. Moreover, this process results in the discovery, convergence, and articulation of the values and preferences that not only undergird one's individual choices regarding care during a mental health crisis, but this process also makes this information transparent to others as well.^{46,47} In addition to memorializing preferences regarding care, PADs allow capacitated persons living with serious mental illness to designate a caregiver as a proxy decision-maker to speak on their behalf during an incapacitating mental health crisis. Caregivers, when authorized via a Medical Power of Attorney, have the legal authority to make decisions on their loved one's behalf, including managing health information, conveying preferences for care, medications, and information regarding past hospitalizations.

PADs promote the exploration by and between proxy decision-makers, health care providers, and patients thereby enhancing the designated health care proxy decision-makers confidence and ability to advocate, legally, that they are indeed representing the stated wishes and preferences for care of their loved one. Caregiver involvement is central to the process of advocating for the autonomous and self-directed choice of persons living with serious mental illness during a mental health crisis.

Implications and Recommendations for Transitional Age Youth

After the first psychotic episode, adolescence with serious mental illnesses face different burdens of direct and indirect costs than those with other mental illnesses.²³ Direct costs are treatment-related which may include amount of money spent on hospitalization and emergency department admissions which are two to three times higher than the amount spent by those in the general population using these services. Indirect costs may include costs from criminalization of persons living with SMI, lost opportunity cost of untreated SMI, and in many cases lost labor productivity for the patient and caretakers (often family/loved ones). There is an immediate need to improve the treatment and outcomes of those living with serious mental illness. Shifting focus away from intervention treatment toward crisis prevention could produce substantial long-term cost-savings, improve accessibility to early mental health care, and undoubtedly improve the quality of life for those living with serious mental illness.

Recommendations for youth, as early as the age of 16, include developing a transition plan, one that builds self-advocacy skills including how to advocate using a psychiatric advance directive once they turn 18. Figure 1, *Be Your Advocate: For Your Health, For Your Future* illustrates a process to identify, create, and memorialize choices for care in the event of a mental health crisis.⁴⁸

Beginning with the tab decide, identifying the person who best knows your needs and is willing to take on this responsibility as a proxy decision-maker is essential. Establishing a medical power of attorney for health care, a component of the PAD, allows capacitated persons living with serious mental illness at the age 18 to choose who will speak for them should they lose capacity during a mental health crisis. Creating this document, in collaboration with the health care team, assures that existing crisis plans for care are reflected in the PAD. The National Resource Center on Psychiatric Advance Directives (NRC-PAD) maintains state by state information including PAD forms that can be downloaded, at no cost, for review and use.⁴⁹ The resulting independence that can be realized when care plans and designated proxy decision-

makers are empowered to speak on behalf of a loved one using a psychiatric advance directive could enhance wellness and empowerment for persons living with serious mental illness.

Figure 1



Limitations

This study was originally intended to collect data in person, however due to the limitations presented by COVID-19, we quickly reconceptualized how to collect information. This study was reimagined as a concurrent mixed methods study which respondents completed entirely online. Since participants were recruited via an advocacy organization, we suspect consent rates were fair. Those with healthcare distrust are less likely to participate in research, therefore selection bias is also possible. Nonetheless our sample still showed high distrust scores. The open-ended responses did not consider the reintroduction of trauma around their experiences in the hospital system and may have contributed to the low number of open-ended responses. Over half of respondents who reported high disclosure avoidance strategies also refused to respond in regards to their experiences as a proxy decision maker during a mental health crisis. In the future, conducting interviews via video or in person allows for a more trauma informed lens around these sensitive topics as well as allow for a more conducive and safer environment.⁵⁰

Future direction of this study suggests investigation into health care provider experiences regarding the exchange of information during a mental health crisis. At present, experiences show challenges remain regarding how health care providers utilize and access health information during a mental health crisis. Exploring how health care provider decision making is built on misinformation and how the corresponding consequences fuel distrust by caregivers when serving as proxy decision-makers for a loved one experiencing a mental health crisis has the potential to improve treatment outcomes.

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