



## ETHICAL, LEGAL, AND CLINICAL CONSIDERATIONS WHEN DISCLOSING A HIGH-RISK SYNDROME FOR PSYCHOSIS

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### Keywords

*ultra high-risk, prodrome, psychosis, schizophrenia, disclosure, diagnosis*

### ABSTRACT

*There are complex considerations when planning to disclose an attenuated psychosis syndrome (APS) diagnosis. In this review, we evaluate ethical, legal, and clinical perspectives as well as caveats related to full, non- and partial disclosure strategies, discuss societal implications, and provide clinical suggestions. Each of the disclosure strategies is associated with benefits as well as costs/considerations. Full disclosure promotes autonomy, allows for the clearest psychoeducation about additional risk factors, helps to clarify and/or correct previous diagnoses/treatments, facilitates early intervention and bolsters communication between providers but there are important considerations involving heritability, comorbidity, culture, and stigma. Non-disclosure advances nonmaleficence by limiting stigma and stress (which may inadvertently exacerbate the condition), and confusion (related to the rapidly evolving diagnosis) in a sensitive developmental period but is complicated by varying patient preferences and the possibility that, as new treatments without adverse effects become available, the risk with false positives no longer justifies the accompanying loss of autonomy. Partial disclosure balances ethical considerations by focusing on symptoms instead of labels, but evidence that laypersons may interpret this information as a pseudo-diagnosis and that symptoms alone also contribute to stigma limits the efficacy of this approach. In addition, there are notable societal considerations relating to disclosure involving conservatorship, the reach of insurance companies, and discrimination. We advocate a hybrid approach to disclosure and recommend future research aimed at understanding the effects of stigma on clinical course and a renewed focus on those help-seeking cases that do not transition but remain clinically relevant.*

### INTRODUCTION

When communicating diagnostic information to patients and their families, clinicians are often faced with conflicting bioethical considerations. In this article, we discuss competing ethical considerations surrounding the disclosure of attenuated psychosis syndrome (APS), a label that involves subtle disturbances in thought, emotion, and behavior in adolescents and young adults, while simultaneously denoting elevated risk for developing a serious mental illness such as schizophrenia. APS is identified by criteria in the Diagnostic and Statistics Manual of Mental

Disorders-5 (DSM-5) Conditions for Further Study (Section III) or by a series of specialized structured clinical interviews<sup>1</sup> and is most often defined as recent or escalating symptoms such as unusual thoughts, suspiciousness, grandiosity, perceptual aberrations, and coupled with a marked decline in socio-occupational functioning.<sup>2</sup> While these symptoms can seem puzzling or troubling, they do

<sup>1</sup> M.V. Seeman. Breaking bad news: schizophrenia. *J Psychiatr Pract* 2010; 16: 269–276.

<sup>2</sup> T.D. Cannon et al. Prediction of psychosis in youth at high clinical risk: a multisite longitudinal study in North America. *Arch Gen Psychiatr* 2008; 65: 28–37.

not reach the frequency and duration seen in formal psychotic disorders such as schizophrenia, and do not yet accompany the hallmark conviction, distress, and impairment characteristic of full psychotic disorders.

For some individuals, the duration and frequency of symptoms escalates while the experiences become more realistic and impairing, and this subgroup ultimately will meet criteria for a psychotic disorder. The APS label applies regardless of whether the person goes on to develop a psychotic disorder, while those persons who do transition to a formal psychotic disorder are categorized retrospectively as 'prodromal'. While a majority of the research literature focuses on the subgroup of patients who do go on to transition, APS is a disorder in itself (defining a population of youth who are currently suffering from a number of impairing symptoms and related characteristics which may be relieved by treatment) and not simply just a risk factor for another category of more serious mental illnesses. In contrast to a case presenting with an established disorder, such as generalized anxiety disorder in which there are several options for empirically supported clinically efficacious treatments, a person receiving an APS diagnosis is faced with an uncertain prognosis that potentially involves a future of more serious symptoms, a developing conception of the diagnosis, and contentious treatment options. Given these issues, providers are often uncertain of what the most helpful or least harmful course of disclosure is for this type of case.

Two leading ethical questions related to APS are 'can telling patients about their high-risk status harm them?' and in relation to that question 'what are the best ways to inform someone of their high-risk status in order to prevent harm?' In this article we review the critical issues relating to an APS diagnosis and describe the strengths and limitations or considerations for different strategies of clinical communication, including full disclosure, non-disclosure, and partial disclosure. Further, we report on other unique complicating social factors, including legal rights/conservatorship, the growing reach of insurance companies, and discrimination. Finally, we conclude by advocating a hybrid disclosure method based on the relative strengths and considerations for each reviewed strategy as well as the supporting APS literature, and detailing priorities for future research.

## 1. BACKGROUND OF THE APS DIAGNOSIS

Psychotic disorders are the most crippling of the psychiatric illnesses. This class of mental illness typically strikes as adulthood is approaching and is likely to be disabling for a lifetime. Psychosis occurs in all countries, cultures, and socioeconomic classes. It affects both sexes equally, and the prevalence is commonly accepted to be about 1%

of the population. The high-risk period for psychosis is of interest both as a window for investigating processes involved in disease onset, and also as a potential point of intervention and prevention.<sup>3</sup> More specifically, recent studies have suggested that adolescents with a prodromal syndrome are at imminent risk for conversion to a psychotic disorder, up to 35% will convert to a psychotic disorder within a two-year period.<sup>4</sup> This is significant from a clinical perspective as detecting those most likely to convert will help to implement early intervention and guide treatment decisions with the potential to reduce the duration of untreated psychosis,<sup>5</sup> ameliorate course of illness, and delay or potentially prevent onset of psychosis.<sup>6</sup> Because schizophrenia eliminates or severely limits the most productive years of an individual's life and may require lifelong family or institutional care; its costs to society are enormous<sup>7</sup> and this promise of early detection and intervention represents a major breakthrough. While these developments reflect significant promise, a number of new ethical issues relating to disclosure of a high-risk syndrome have not been critically reviewed.

<sup>3</sup> N. Haroun et al. Risk and protection in prodromal schizophrenia: ethical implications for clinical practice and future research. *Schizophr Bull* 2006; 32: 166–178; V.A. Mittal et al. Identification and Treatment of a Pineal Gland Tumor in an Adolescent with Prodromal Psychotic Symptoms. *Am J Psychiatry* 2010; 167: 1033–1037; T.H. McGlashan et al. Recruitment and treatment practices for help-seeking 'prodromal' patients. *Schizophr Bull* 2007; 33: 715–726.

<sup>4</sup> Cannon, *op. cit.* note 2, 28–37; T.J. Miller, T.H. McGlashan, S.W. Woods, K. Stein, N. Driesen & C.M. Corcoran. Prospective diagnosis of the initial prodrome for schizophrenia based on the Structured Interview for Prodromal Syndromes: preliminary evidence of interrater reliability and predictive validity. *Am J Psychiatry* 2002; 863–865; T.J. Miller et al. Prospective diagnosis of the initial prodrome for schizophrenia based on the Structured Interview for Prodromal Syndromes: preliminary evidence of interrater reliability and predictive validity. *Am J Psychiatry* 2002; 159: 863–865; T.J. Miller et al. Symptom assessment in schizophrenic prodromal states. *Psychiatr Q* 1999; 70: 273–287; T.J. Miller et al. The PRIME North America randomized double-blind clinical trial of olanzapine versus placebo in patients at risk of being prodromally symptomatic for psychosis. II. Baseline characteristics of the 'prodromal' sample. *Schizophr Res* 2003; 61: 19–30.

<sup>5</sup> T. White et al. The schizophrenia prodrome. *Am J Psychiatry* 2006; 163: 376–380.

<sup>6</sup> Haroun, *op. cit.* note 3, pp. 166–178; T.H. McGlashan et al. The PRIME North America randomized double-blind clinical trial of olanzapine versus placebo in patients at risk of being prodromally symptomatic for psychosis. I. Study rationale and design. *Schizophr Res* 2003; 61: 7–18; P.D. McGorry et al. Randomized controlled trial of interventions designed to reduce the risk of progression to first-episode psychosis in a clinical sample with subthreshold symptoms. *Arch Gen Psychiatry* 2002; 59: 921–928; S.W. Woods et al. Randomized trial of olanzapine versus placebo in the symptomatic acute treatment of the schizophrenic prodrome. *Biol Psychiatry* 2003; 54: 453–464; A. Morrison et al. Cognitive therapy for the prevention of psychosis in people at ultra-high risk: Randomised controlled trial. *Br J Psychiatry* 2004; 185: 291–297.

<sup>7</sup> E.Q. Wu et al. The economic burden of schizophrenia in the United States in 2002. *J Clin Psychiatry* 2005; 66: 1122–1129.

The widely covered debate about the inclusion of a high-risk syndrome in the recently published DSM-5 (APA) provides insight into some of the challenges surrounding the conceptualization of APS. The DSM, published by the American Psychiatric Association (APA), provides standard definitions of mental disorders, and is relied upon by clinicians, researchers, drug regulation agencies, health insurance and pharmaceutical companies, and the legal system, as well as policy-makers in the United States. The manual is often used in conjunction with the International Statistical Classification of Diseases and Related Health Problems (ICD), produced by the World Health Organization (WHO), which covers health as a whole (as opposed to mental illnesses alone) and is primarily used in Europe and other parts of the world. The DSM is designed to correspond with codes used in the ICD, although codes do not always match, as the publications are not revised simultaneously. As the DSM has been recently revised (the new edition appearing in May 2013) and the formal edition of upcoming ICD-11 will not be released for several years, related changes have wide relevance as new disorder classifications in the DSM can be seen as a test case for influencing future manual development. As the DSM is the primary source for clinical and research diagnoses in a range of medical settings here in the United States, inclusion of a disorder in the manual has significant ramifications for the legitimization and dissemination of a given disorder.

The impetus for including a rapidly evolving APS diagnosis involved the accumulating evidence that high-risk patients are currently ill and at elevated risk for more serious mental illness,<sup>8</sup> the criteria for a risk state could be made with reliability and validity in a research setting, and no DSM-IV diagnosis accurately captured the current illness or future risk.<sup>9</sup> The proponents argued that providing a DSM-5 diagnosis could help patients and their families to access insurance benefits, and to promote better general practitioner education.<sup>10</sup>

Those who argued against the new label suggested that inclusion was premature due to lack of information from community-based trials and significant concern about stigma.<sup>11</sup> Opponents also questioned the clinical validity of the syndrome because the label is a non-specific initial stage; APS is predictive of a number of disorders outside

schizophrenia, for example affective psychoses. There was also considerable concern that because 60–80% of those diagnosed under the APS criteria will not convert in the two to three years following their baseline diagnosis, a label could expose a disproportionate number of youth to unnecessary medications and stigma.<sup>12</sup> The ultimate decision to place APS in the research section of DSM-5, a section that recognized the importance of a disorder but still stresses that more research is required before it can be formally included in the main text, speaks to the valid points on both sides of this debate, and to the complex issues accompanying the diagnosis (see Table 1).

Given the complexity surrounding APS, it is not surprising that clinicians can face a challenging dilemma when deciding what type of information, or how much, to impart when disclosing to patients and their families. The legal standard governing what a doctor must disclose varies by state. About half the states require that the doctor disclose what a *reasonable* doctor would disclose; in the other half, the doctor must disclose what a *reasonable* patient would consider material to his or her decision. In this article, we aim to tease out the nature of the information to be disclosed based on the costs and benefits of varying levels of disclosure. Considering these costs and benefits may lead to a recommendation of what reasonable doctors will want to disclose, or to a recommendation of what the reasonable patient will want to know.

Beauchamp lays out ethical principles from which the costs and benefits of different disclosure strategies for APS can be approached.<sup>13</sup> Autonomy is conceptualized as respecting the decision-making capacities of a person, nonmaleficence seeks to avoid causing harm, and beneficence seeks to provide benefits for patients while balancing those benefits against potential risks and costs. In the following sections, we evaluate how ethical dilemmas and relevant case law surrounding APS relate to disclosure strategies.

## 2. FULL DISCLOSURE

Full disclosure of an illness, which is the strongest approach in terms of supporting the ethical principle of autonomy, is often referred to as truth telling.<sup>14</sup> However, telling the patient the truth can be difficult when the truth of the illness itself is poorly understood, and the

<sup>8</sup> Cannon, *op. cit.* note 2, pp. 28–37.

<sup>9</sup> J. Addington et al. North American Prodrome Longitudinal Study: a collaborative multisite approach to prodromal schizophrenia research. *Schizophr Bull* 2007; 33: 665–672; A.R. Yung et al. Declining transition rate in ultra high risk (prodromal) services: dilution or reduction of risk? *Schizophrenia Bull* 2007; 33: 673–681.

<sup>10</sup> S.W. Woods et al. The case for including Attenuated Psychotic Symptoms Syndrome in DSM-5 as a psychosis risk syndrome. *Schizophr Res* 2010; 123: 199–207.

<sup>11</sup> A. Shrivastava et al. 'Attenuated psychotic symptoms syndrome' as a risk syndrome of psychosis, diagnosis in DSM-V: The debate. *Indian J Psychiatry* 2011; 53: 57–65.

<sup>12</sup> C.M. Corcoran et al. The psychosis risk syndrome and its proposed inclusion in the DSM-V: A risk-benefit analysis. *Schizophr Res* 2010; 120: 16–22.

<sup>13</sup> T.L. Beauchamp. Methods and principles in biomedical ethics. *J Med Ethics* 2003; 29: 269–274.

<sup>14</sup> L.J. Blackhall et al. Bioethics in a different tongue: the case of truth-telling. *J Urban Health* 2001; 78: 59–71; A. Surbone. Telling the truth to patients with cancer: what is the truth? *Lancet Oncol* 2006; 7: 944–950; A. Zugman et al. Brain tumor in a patient with attenuated psychosis syndrome. *Schizophr Res* 2013; 144: 151–152.

Table 1. Arguments for Including or Excluding the Attenuated Prodromal Syndrome as a Formal Disorder in Diagnostic and Statistical Manual of Mental Disorders Five

#### Arguments for Inclusion

1. Patients are currently experiencing distressful symptoms and there isn't an official diagnosis that currently includes this group.
2. The label identifies a subgroup of participants who will imminently develop a serious mental illness (e.g. schizophrenia) at a rate that is substantially greater than the incidence in the general population and this facilitates efforts for early intervention and encourages a lowered duration of untreated psychosis.
3. The criteria for APS can be identified with reliability and validity in a research environment.
4. A DSM-5 diagnosis would help to ameliorate confusion for the patient/family and with treatment providers (who are not aware of the syndrome).
5. Insurance eligibility

#### Arguments for Non-Inclusion

1. Inclusion is premature as there has been little information from community-based trials (it is unclear if the research data that APS is based upon will generalize to the context of diagnosis or to non-specialized clinical practice).
2. APS may be difficult or tricky to diagnosis without the intensive training seen in expert settings (critical factors pertaining to diagnosis involve tricky time course and severity/impairment evaluations that come with regular experience with this population; APS symptoms may be easily confused with subthreshold psychosis occurring across a continuum in a sizeable contingent of otherwise healthy individuals).
3. APS is a non-specific stage, predictive of a number of disorders (e.g. affective disorders).
4. APS includes a high number of false positives (a large majority does not go on to transition to psychosis).
5. Labeling individuals with a disorder that implies risk for future serious mental illness, even though a majority of patients are not actually at-risk, exposes a vulnerable population to unnecessary and potential harmful treatments and stigma.

promotion of autonomy can sometimes come at the expense of promoting the principle of beneficence and nonmaleficence. In the case of APS, full disclosure means telling the patient the APS label, and going over what research can and cannot explain about the premorbid and prodromal period of the illness as well as the uncertainty of the prognosis. A substantial body of research and theoretical work has been conducted on the ethical issues surrounding truth telling in terminal cancer patients and clinical efforts to address end directives.<sup>15</sup> In these cases, which are also informative to our discussion of APS (as it involves risk for a series of devastating life-long illnesses), full disclosure provides laypersons with the information and advice they need to make a sound treatment decision.<sup>16</sup> The argument is that competent patients should be encouraged to make informed choices about their medical treatment. Although informed consent usually benefits patient and protects clinicians from legal risks, the main justification for this doctrine is that it promotes autonomy.<sup>17</sup>

Communicating a diagnosis may be beneficial for both the patient and the family, as this can lower anxiety about the illness, provide relief by explaining symptoms, validate experiences,<sup>18</sup> and offer opportunities for providing critical information.<sup>19</sup> Because APS is not yet well known

by community providers and the symptoms of early psychosis are diffuse, many patients and families are frustrated by a series of previously incorrect diagnoses. Full information about the syndrome and related risk for psychosis can be helpful in removing confusion and may reduce stronger reactions to the patient's symptoms.<sup>20</sup> This is important because families may place blame or search for reasons behind their child's illness within themselves. Indeed, studies suggest that the turmoil that comes with accepting and adjusting to an ill family member's deteriorating condition is a risk factor for relapse in schizophrenia.<sup>21</sup> Disclosure of a diagnostic label also opens doors to a host of information that may help to placate feelings of guilt or remorse and provide family treatment opportunities, such as multi-family group therapy.<sup>22</sup> This can also facilitate the opportunity to inoculate caretakers who may be at increased risk of stress and inflammatory-based illness.<sup>23</sup> When

Experience of caregiving: relatives of people experiencing a first episode of psychosis. *Br J Psychiatry* 2000; 177: 529–533.

<sup>20</sup> J.E. Levene et al. Family and patient predictors of symptomatic status in schizophrenia. *Can J Psychiatry* 2009; 54: 446–451; T. Uchino et al. Psychoeducation may reduce self-stigma of people with schizophrenia and schizoaffective disorder. *Kurume Med. J* 2012; 59: 25–31.

<sup>21</sup> J.A. Kymalainen & A.G. Weisman de Mamani. Expressed emotion, communication deviance, and culture in families of patients with schizophrenia: a review of the literature. *Cultur Divers Ethnic Minor Psychol* 2008; 14: 85–91; W.R. McFarlane & W.L. Cook. Family expressed emotion prior to onset of psychosis. *Fam Process* 2007; 46: 185–197.

<sup>22</sup> M.P. O'Brien et al. Family problem solving interactions and 6-month symptomatic and functional outcomes in youth at ultra-high risk for psychosis and with recent onset psychotic symptoms: a longitudinal study. *Schizophr Res* 2009; 107: 198–205.

<sup>23</sup> S.K. Lutgendorf & M.L. Laudenslager. Care of the caregiver: stress and dysregulation of inflammatory control in cancer caregivers. *J Clin Oncol* 2009; 27: 2894–2895.

<sup>15</sup> Blackhall, *op. cit.* note 14, pp. 59–71; Surbone, *op. cit.* note 14, pp. 944–950; A. Surbone. Truth telling to the patient, 1: *Virtual Mentor: VM* 1999; A. Surbone. Persisting differences in truth telling throughout the world. *Support Care Cancer* 2004; 12: 143–146.

<sup>16</sup> D.B. Resnik. Ethical dilemmas in communicating medical information to the public. *Health Policy* 2001; 55: 129–149.

<sup>17</sup> A. Jonsen et al. *Clinical Ethics*. 4 edn. New York: McGraw; 1998.

<sup>18</sup> Y.M. Hayne. Experiencing psychiatric diagnosis: client perspectives on being named mentally ill. *J Psychiatr Ment Health Nurs* 2003; 10: 722–729.

<sup>19</sup> J. Addington et al. The first episode of psychosis: the experience of relatives. *Acta Psychiatr Scand* 2003; 108: 285–289; L. Tennakoon et al.

communicating to patients or family about APS symptoms, it is also important to keep in mind the salient potential for stigma that is strongly attached to mental disorder labels such as 'psychotic' or 'schizophrenic'.<sup>24</sup> The diagnostic process itself may be helpful in clarifying what symptoms are causing distress and provide clear directions for treatment. Labeling, on the other hand, can connote negative stereotypes, hopelessness, and may hinder treatment if a person strongly identifies with an APS label.<sup>25</sup>

Full disclosure also provides an opportunity to impart psychological hygiene by informing the patient about risk factors that might exacerbate the illness, such as cannabis abuse.<sup>26</sup> Extant treatment strategies can also be clarified or specified during the course of diagnosis. Many of the symptoms associated with APS may resemble other mental illnesses for which the patient may already be receiving medication regimens that are deleterious or excessive. For example, negative symptoms confused with inattention or depression, may be treated with SSRI or stimulants.<sup>27</sup> Positive symptoms such as grandiosity may resemble a mood disorder and be treated with mood stabilizers. Early detection and treatment planning during the course of establishing an explicit label for the APS diagnosis can facilitate clear communication between the family and treatment team, and ultimately prevent expensive and unnecessary treatments.

### Caveats

The significant heritability of psychosis spectrum illnesses presents complexities for full disclosure. A family member with psychosis imparts higher risk for other relatives, particularly those who have not yet passed through the mean age risk period. Indeed, one of the most prevalent recruitment strategies to study psychosis risk is to follow individuals with family members who have psychosis.<sup>28</sup> Given that full disclosure involves providing the patient all the information about possible risk, genetic risk is information that should be presented to the APS individual. Substantial legal precedent bolsters this rule. In *Plate v. Threkel*, the highest state court in Florida

unanimously held that a physician has a duty to warn a third party about a genetically inherited disease.<sup>29</sup> Family members, especially younger siblings, of the APS individual may wonder about their risk of developing psychosis. However, continuing research suggests that the heritability of psychosis, and psychiatric illnesses in general, is difficult to estimate because of epigenetic processes and de novo mutations, found in schizophrenia.<sup>30</sup> Furthermore, discussion of genetic liability and heritability may cause harm to relatives of the APS individual, either through an increase in anxiety about possible risk or guilt from parents who may have imparted that genetic risk. Clinicians may choose to refrain from talking to a patient and their family members about specific aspects of heritability as more research is needed to understand these processes and it may do more harm than good.

Individual cultures and subcultures are highly relevant when considering full disclosure. Many cultures and races view the wisdom of full-disclosure differently. In one relevant study, European-American and African American participants were more likely to view truth telling as empowering, enabling the patient to make the best choice regarding treatment.<sup>31</sup> Participants in these groups espoused beliefs that disclosure was good because: 'information about their bodies is theirs to know, good or bad, simply because it's "their body"', 'patients know intuitively that they are very sick or even dying, so there is no harm in telling them,' 'the importance of getting one's things in order,' and 'getting it right with god'. In contrast, Korean and Mexican-American participants viewed the patient as in need of protection by the doctor and espoused the notion that 'if you know you die faster', 'some people can't take it', and espoused 'not the truth but hope'.<sup>32</sup>

Stigma and the related stress is a major consideration when providing any diagnosis. This is a complex issue with regard to APS, and has been expertly reviewed elsewhere.<sup>33</sup> It is important to note that full disclosure opens a patient to a deeply discrediting attribute that reduces a person from whole and normal to tainted and discounted.<sup>34</sup> A psychotic disorder label evokes the most negative stereotypes, emotional reactions, social distance,

<sup>24</sup> M.C. Angermeyer & H. Matschinger. The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatr Scand* 2003; 108: 304–309.

<sup>25</sup> S. Dinos et al. Stigma: the feelings and experiences of 46 people with mental illness. Qualitative study. *Br J Psychiatry* 2004; 184: 176–181.

<sup>26</sup> M. Machielsen et al. Cannabis use in patients with a first psychotic episode and subjects at ultra high risk of psychosis: impact on psychotic- and pre-psychotic symptoms. *Aust N Z J Psychiatry* 2010; 44: 721–728.

<sup>27</sup> B.A. Cornblatt et al. Can antidepressants be used to treat the schizophrenia prodrome? Results of a prospective, naturalistic treatment study of adolescents. *J Clin Psychiatry* 2007; 68: 546–557.

<sup>28</sup> B. Cornblatt et al. The schizophrenia prodrome: treatment and high-risk perspectives. *Schizophr Res* 2002; 54: 177–186.

<sup>29</sup> S.J. Wood, et al. Proton magnetic resonance spectroscopy in first episode psychosis and ultra high-risk individuals. *Schizophr Bull* 2003; 29: 831–843.

<sup>30</sup> J. van Dongen & D.I. Boomsma. The evolutionary paradox and the missing heritability of schizophrenia. *Am J Med Genet B Neuropsychiatr Genet* 2013; 162B: 122–136.

<sup>31</sup> Blackhall, *op. cit.* note 14, pp. 59–71.

<sup>32</sup> *Ibid.*

<sup>33</sup> L.H. Yang et al. Potential stigma associated with inclusion of the psychosis risk syndrome in the DSM-V: An empirical question. *Schizophr Res* 2010.

<sup>34</sup> E. Goffman. *Stigma: Notes on the management of spoiled identity*. New York: Prentice-Hall: 1963.

and general pessimism among all mental disorders.<sup>35</sup> The stigma associated with a psychiatric illness label is accompanied with lower self-esteem, poor treatment adherence, and constricted sociality.<sup>36</sup> At-risk individuals anticipating rejection may respond by secrecy (concealing one's treatment history) and withdrawal or limiting contact to those not accepting of one's condition. The progression of illness and prodromal symptoms may also invoke stigmatization from others, as behavior related to symptoms such as odd thinking, increasing suspiciousness, and negative symptoms, such as avolition and anhedonia, are likely to invoke awkward social interactions.<sup>37</sup> In an effort to avoid potentially negative reactions from others, an APS individual may withdraw from social contact. This is particularly worrisome amongst youth at risk for psychosis, not only because it may promote the sense of self-stigma; peers may be less willing to contact or provide support as their emotional connection decreases.<sup>38</sup>

### 3. NON-DISCLOSURE

In contrast to a full disclosure strategy, the non-disclosure approach favors avoiding telling a patient the diagnostic information pertaining to the illness. This approach can be seen as promoting the principle of beneficence and nonmaleficence at the cost of the principle of autonomy. Historically, medical professionals have preferred not telling a patient the diagnosis of a severe illness, such as cancer, dementia or psychiatric disorder.<sup>39</sup> This decision has become less popular recently; however, there are still good reasons for not telling the patient about their diagnosis. With non-disclosure, the medical provider decides when and how much to tell the patient. Specifically, the clinician may provide the family with the label instead of informing the patient, or decide to tell no one, and move forward with treatment without sharing any information about the specific label. This approach can appear to be paternalistic and severely restricts autonomy.<sup>40</sup> However, a paternalistic communication of diagnostic information may be an effort to not cause additional harm (nonmaleficence). In practice, it is often difficult to avoid talking about a diagnosis, as many

people want to understand why their family member or themselves have developed APS symptoms. The challenge for not disclosing a diagnosis can often become a challenge not to lie. In some cases of APS, researchers have argued that benevolent deception is acceptable when the truth would cause more harm than good or when disclosing the truth would result in the patient making a decision that would cause harm to that individual.<sup>41</sup> The harm-principal is a widely recognized legitimate restriction on autonomy, through which one can override or restrict an individual patient's autonomy in order to prevent that individual from harming themselves or others.<sup>42</sup> For example, requiring parents to send their children to school is an example of a restriction on parental autonomy aimed at promoting a highly valued social consequence.<sup>43</sup>

While most ethicists stipulate that health providers should not manipulate, distort, exaggerate, or conceal relevant information, or use coercive means to induce treatment decisions,<sup>44</sup> many also agree that autonomy can be violated when treatment providers have strong evidence that specific items of information will cause the patient severe harm.<sup>45</sup> Indeed, physicians can be protected by the therapeutic privilege, which recognizes that under some circumstances, disclosure of certain medical risks may cause harm and is not in the patient's best medical interests.<sup>46</sup> A doctor is not under the obligation to describe in detail all possible consequences of a disease or treatment, and '[t]here is probably a privilege, on therapeutic grounds, to withhold the specific diagnosis where the disclosure of cancer or some other dread [sic] disease would seriously jeopardize the recovery of an unstable, temperamental or severely depressed patient'.<sup>47</sup> However, the standards of informed consent are prefaced on the policy, decided by a supreme court case involving consent to examine but not remove a malignant tumor, that 'every human being of adult years and sound mind has a right to determine what shall be done with his own body'.<sup>48</sup> This creates clear issues when the patient is a child or adolescent who may already exhibit attenuated symptoms of a psychotic disorder. It is also important to note that the therapeutic privilege is recognized as a factually specific issue with regard to each particular patient, and would not be a defense to a physician if the provider made a regular practice of withholding certain troubling

<sup>35</sup> M.C. Angermeyer & H. Matschinger. Public beliefs about schizophrenia and depression: similarities and differences. *Soc Psychiatry Psychiatr Epidemiol* 2003; 38: 526–534.

<sup>36</sup> Yang, *op. cit.* note 33.

<sup>37</sup> Dinos, *op. cit.* note 25, pp. 176–181; Yang, *op. cit.* note 33.

<sup>38</sup> T. Moses. Self-labeling and its effects among adolescents diagnosed with mental disorders. *Soc Sci Med* 2009; 68: 570–578.

<sup>39</sup> G. Pinner. Truth-telling and the diagnosis of dementia. *Br J Psychiatry* 2000; 176: 514–515; C.J. Ryan et al. Becoming none but tradesmen: lies, deception and psychotic patients. *J Med Ethics* 1995; 21: 72–76.

<sup>40</sup> Beauchamp, *op. cit.* note 13, pp. 269–274; T. Walker. Respecting autonomy without disclosing information. *Bioethics* 2013; 27: 388–394.

<sup>41</sup> Ryan, *op. cit.* note 39, pp. 72–76.

<sup>42</sup> Jonsen, *op. cit.* note 17.

<sup>43</sup> Resnik, *op. cit.* note 16, pp. 129–149.

<sup>44</sup> *Ibid.*

<sup>45</sup> Shrivastava, *op. cit.* note 11, pp. 57–65.

<sup>46</sup> D. Sun et al. Progressive brain structural changes mapped as psychosis develops in 'at risk' individuals. *Schizophr Res*; 108: 85–92.

<sup>47</sup> *Natanson v. Kline*, 186 Kan. 393 (1960).

<sup>48</sup> *Schloendorff v. Society of New York Hospital*, 105 N.E. 92, 92 (1914).

information.<sup>49</sup> Indeed, case law suggests that a uniform system could subject practitioners to liability were they not to disclose certain facts, and a youth were then to develop a psychotic disorder.

The primary argument for non-disclosure relates to nonmaleficence. Because a significant body of literature suggests that stress plays a key role in the etiology of psychosis,<sup>50</sup> it can be argued that providing a diagnostic label indicating imminent risk for psychosis would be such a stressor. A neural-diathesis stress conceptualization of schizophrenia posits that both genetic and environmental factors contribute to vulnerability in intrauterine and perinatal periods. The resulting vulnerability then later interacts with both neuroendocrine, neurodevelopmental and environmental factors – psychosocial stress and substance use – during adolescence.<sup>51</sup> Finally, emergence of clinical symptoms, cognitive dysfunction, and psychosocial role decline during the prodrome eventually cross the threshold into formal psychosis by late adolescence or early adulthood.<sup>52</sup> This theoretical framework suggests the possibility that adding additional stress through a label could ultimately be harmful. In support of this concern, a growing body of literature suggests that elevated psychosocial and biological stress is highly predictive of a poor course of illness for youth with APS.<sup>53</sup> In a relevant study of psychometric risk for psychosis, college students rated a diagnosis of schizophrenia very stressful, on par with being told they had cancer, suggesting that the anticipated stigma and perhaps disability associated with schizophrenia is even more salient in those who may have a predisposition to psychosis.<sup>54</sup>

Another consideration unique to APS relates to the sensitive developmental age of the majority of cases. Importantly, adolescence is defined by a period in which young people must negotiate developmental goals including strengthening an autonomous self-concept, attaining educational milestones, and forming social networks. Non-disclosure would protect an individual from mental illness stigma that may interfere with the acquisition of personal assets or competences needed for successful

<sup>49</sup> K.H. Karlsgodt et al. Diffusion tensor imaging of the superior longitudinal fasciculus and working memory in recent-onset schizophrenia. *Biol Psychiatry* 2008; 63: 512–518.

<sup>50</sup> E.F. Walker et al. Stress and the hypothalamic pituitary adrenal axis in the developmental course of schizophrenia. *Annual Review of Clinical Psychology* 2008; 4: 189–216.

<sup>51</sup> Ibid; E.F. Walker & D. Diforio. Schizophrenia: a neural diathesis-stress model. *Psychol Rev* 1997; 104: 667–685.

<sup>52</sup> Ibid.

<sup>53</sup> K.D. Tessner et al. Longitudinal Study of Stressful Life Events and Daily Stressors Among Adolescents at High Risk for Psychotic Disorders. *Schizophrenia Bull* 2009; E.F. Walker et al. Longitudinal changes in cortisol secretion and conversion to psychosis in at-risk youth. *J Abnorm Psychol*, 2010; 119: 401–408.

<sup>54</sup> R.J. Linscott & F.V. Cross. The burden of awareness of psychometric risk for schizophrenia. *Psychiatry Res* 2009; 166: 184–191.

passage to adulthood.<sup>55</sup> Because self-concepts are less formed, being labeled with a mental illness has the potential to permeate one's social identity at a critical time that will affect future functioning throughout the life-course.<sup>56</sup>

## Caveats

It is important to note that a decision for non-disclosure can also arise from clinical observations that some individuals may prefer to not be informed. In the case of an illness without effective treatments, ethicists argue that patients have a right not to know.<sup>57</sup> In a study that asked patients if they would prefer to be told about a life-altering illness, a third of respondents said it would depend on the circumstances.<sup>58</sup> Knowing a diagnosis and trying to conceal it from others can induce shame, guilt, and confusion about how to disclose.<sup>59</sup> Because of adverse media representations that increase stigma, negative reactions of others toward mental illness especially psychosis, and difficulty trying to cope with or conceal a diagnosis, it may not be therapeutically beneficial for someone beginning to experience APS symptoms to be given a diagnosis.

One of the most persuasive arguments for non-disclosure of APS is that the disorder is still technically considered a research diagnosis, and because we are still striving to understand the optimal assessment procedures, diagnostic boundaries, and course of this syndrome, the risk of false positives is too great. In addition to subjecting a person to unnecessary stigma,<sup>60</sup> the most common concern about false positives is exposure to medications with high side-effects.<sup>61</sup> However, it should be noted that recent years have seen significant development of promising and cost-effective treatments with low side-effect profiles, including Omega-3 fatty acids, exercise, and cognitive behavioral therapy.<sup>62</sup> While more work is clearly necessary for effective treatment options,

<sup>55</sup> N. Zarrett & J. Eccles. The passage to adulthood: challenges of late adolescence. *New Dir Youth Dev* 2006; 13–28, 17.

<sup>56</sup> L.H. Yang et al. Culture and stigma: adding moral experience to stigma theory. *Soc Sci Med* 2007; 64: 1524–1535.

<sup>57</sup> G. Terrenoire. Huntington's disease and the ethics of genetic prediction. *J Med Ethics* 1992; 18: 79–85.

<sup>58</sup> P. Dalla-Vorgia et al. Attitudes of a Mediterranean population to the truth-telling issue. *J Med Ethics* 1992; 18: 67–74.

<sup>59</sup> Dinos, *op. cit.* note 25, pp. 176–181.

<sup>60</sup> C. Wong et al. Stigma in families of individuals in early stages of psychotic illness: family stigma and early psychosis. *Early Interv Psychiatry* 2009; 3: 108–115.

<sup>61</sup> Haroun, *op. cit.* note 3, pp. 166–178.

<sup>62</sup> G.P. Amminger et al. Long-chain omega-3 fatty acids for indicated prevention of psychotic disorders: a randomized, placebo-controlled trial. *Arch Gen Psychiat* 2010; 7: 146–154; V.A. Mittal et al. Physical activity level and medial temporal health in youth at ultra high-risk for psychosis. *J Abnorm Psychol* 2013; 122: 1101–1110; F.G. Pajonk et al. Hippocampal plasticity in response to exercise in schizophrenia. *Arch Gen Psychiat* 2010; 67: 133–143; Morrison, *op. cit.* note 6, pp. 291–297.

Table 2. Vignette Depicting a Common Attenuated Positive Syndrome (APS) Case Presentation

A young adult male (age 17, high-school junior) presents to a psychiatric clinic with his parents. He reports performing poorly in school: while he had previously been a 'B' level student, in the past semester his grades have dropped to low 'Cs' although there have been no notable recent life-events. In addition, the patient reports feeling mistrustful of his friends over this past month, and when pressed, he reluctantly endorses a belief that they are all taking about him behind his back. In addition, the patient has lost interest in watching movies – his favorite hobby until this last few months. The patient reports that once or twice a week, for the past month, he sees a vague figure of a person out of the corner of his eye, and explains that at first he thought it was just his imagination but lately he is wondering if this is happening for a reason. Asked to elaborate, the patient exhibits some frustration when reporting feeling as if there is some sort of message he is missing. However, additional attempts to illicit information indicate that this is a vague impression. The patient's parents are visibly concerned by the recent changes in their son, particularly as he has started to carry a flashlight around the house in the evening/night-time, and is becoming more and more discouraged about his difficulties in concentrating on schoolwork. In addition, the patient indicated that just in this past week, he has started to experiment with marijuana, and he has found this helps him to relax and take his mind off of these problems. Reportedly the patient recently told his parents that he is rethinking going to college although he had always been enthusiastic about wanting to study medicine up until this past semester. The mother also reports that her grandmother spent some time in a mental institution but the family would never discuss the details. She wonders aloud if this might be related to what is going on with her son.

the severe loss of autonomy that accompanies non-disclosure may no longer be justified as these alternatives continue to build promising support.

With this point in mind, it is important to consider the current status of APS as part of the DSM-5 section termed 'Conditions for Future Study.' Syndromes in this section typically have some research base but are not understood fully enough to be included with the formal clinical diagnosis sections of the DSM-5. Importantly, the text says, *These proposed criteria sets are not intended for clinical use; only the criteria sets and disorders in Section II of DSM-5 are officially recognized and can be used for clinical purposes*.<sup>63</sup> If the DSM essentially sets the standard of care in the United States, it can be argued that perhaps using the APS diagnosis clinically is below the standard of care. A reasonable doctor might not reveal something of such uncertain scientific status, particularly because of the costs of doing so; and a reasonable patient would not consider material information that is of such uncertain status in terms of understanding and treatment recommendations. In essence, if it may not even turn out to be a formal condition, and if disclosure should have no management or treatment ('clinical') implications, why would a reasonable person want to know?

#### 4. PARTIAL DISCLOSURE

The strategy of partial disclosure, in which a clinician focuses on the symptoms and presenting problems but avoids imparting a diagnostic label, can be seen as an attempt to balance the ethical principles of autonomy and beneficence/nonmaleficence. Diagnosis can be a powerful tool to share information with clinicians and other medical health providers. However, as noted, a label carries the potential for stigma and sometimes informa-

tion about the disorder can be more than what a patient needs or wants. Some parts of the diagnostic process may be helpful in clarifying recent changes in thinking or behavior, as well as an opportunity to address symptoms that are important for understanding the risk of psychosis. Many times, family members and the patients themselves are confused about why they or their relative is experiencing symptoms related to APS.<sup>64</sup> It can be a great help to parents and patients to be informed about the individual symptoms (i.e. unusual thoughts, suspiciousness, grandiosity, perceptual aberrations, and disorganized communication as well as negative and disorganized symptomatology) and characteristics (e.g. declines in social and academic functioning, difficulty concentrating, exhibiting unusual movements or clumsiness, difficulty initiating or maintaining sleep, difficulty with reacting to everyday stressors) that are associated with risk of psychosis, as this provides a clear unified conception of homogenous and upsetting experiences as well as a viable target for monitoring and treatment. The partial disclosure method can be seen as an attempt to balance benefits and harm/cost fairly, as well as to avoid some of the epistemic uncertainty that is a part of the at-risk label and developing research. In medicine, a syndrome is the association of several clinically recognizable features, signs, symptoms or characteristics that can often occur together, so that the presence of one or more features alerts the provider to the possible presence of the others. By definition, a prodromal syndrome is vague and transitory and the label covers a wide range of symptom frequency and severity (see Table 2 for a vignette depicting a typical APS case presentation).

In utilizing a partial disclosure strategy, the clinician in charge of this case would not explicitly provide the APS diagnosis, but rather suggest that the suspiciousness and perceptual abnormalities concern experiences that may reflect thought disorder (a collection of symptoms that sometimes progresses into more serious mental illness)

<sup>63</sup> American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders 5th ed. 783. Arlington VA: American Psychiatric Association; 2013.

<sup>64</sup> H.P. Lefley. Family burden and family stigma in major mental illness. *Am Psychol* 1989; 44: 556–560.



and make treatment recommendations accordingly. In this case, partial disclosure would provide a sense of autonomy – the patient still receives the information needed to make choices and is educated on the symptoms that indicate risk – while reducing the potential harm of the explicit APS label.

As noted, while APS diagnosis has demonstrated good reliability and predictive validity for imminent conversion to a psychotic disorder in a research setting, the majority of these individuals do not go on to develop psychosis. Although recent declines in transition rates may suggest that seeking treatment for APS is helpful – some of this decline is likely due to true cases that benefited from early identification and treatment – the transition rates, commonly measured from a baseline time and follow-up visits over two to three years, have always been less than 50%.<sup>65</sup> At the present time, the conversion rate is centered on 20% and therefore the corresponding false positive rate is around 80%.<sup>66</sup> The course of this latter group remains largely unexplored but it is important to report that the few studies to follow the non-converting youth noted substantial clinical improvement over the period of the follow-up.<sup>67</sup> Partial disclosure may balance limiting harm with providing autonomy, as a majority of these individuals are not at risk for further more serious mental illness, while the diagnostic label implicitly stresses that they are. In addition, since the distinction between susceptibility and a disease itself is subtle and may not be well understood by the public, vulnerability may also be seen as a quasi-diagnosis or the disorder itself.<sup>68</sup>

### Caveats

Although it can be argued that a partial disclosure approach limits the stigma specific to that of a psychotic disorder label by focusing on individual symptoms, it is also true that those who meet criteria for APS already suffer from psychiatric symptoms that evoke stigma in and of themselves.<sup>69</sup> For example, investigations have found that negative societal reactions are more closely linked to symptomatic behavior than by stereotypes asso-

ciated with labeling.<sup>70</sup> Studies of participant responses to vignettes describing disruptive behavior versus a psychiatric label reveal that behavior has a significant effect that is more robust than the label alone.<sup>71</sup> Thus, having a diagnostic label, receiving and interpreting the psychoeducation within the weighted context of a formal diagnosis, and being able to research related treatments more easily could be more effective in reducing symptoms (and the related stigma), especially if a patient is suffering from stigma without any support. Whether the disclosing symptoms in comparison to disclosing the label itself provides a differential level of stigma remains an empirical question (sorely in need of future research in this area) but it is highly likely that individual factors specific to a given case moderate the relationship. Table 3 reviews the benefits and caveats of each of the three disclosure methods.

## 5. SOCIETAL FACTORS

Disclosure is often handled on a case-by-case basis, where the factors weighing in on the disclosure are multifaceted and require sensitivity for every unique patient. In the world of medicine the term ‘disability’, is used within the context of a treatment and/or study. However, society often ascribes negative connotations to the word ‘disability’, There have been strides to correct such stigma, such as the ratification of the protocol dictated in the United Nations Convention on the Rights of Persons with Disabilities (the ‘Convention’) by a number of national states including the United Kingdom, Australia, France, Mexico and Sweden. However, many world-power national states such as the United States, China, and Russia have ratified the Convention, yet decline to ratify the protocol the Convention mandates for treatment of persons with disabilities.

Despite the steps some national states are taking to eliminate bias, societal, rather than medical factors continue to play a larger role in how patients are treated once they receive any type of disclosure.<sup>72</sup> This topic has been of great interest recently for APS and ethical considerations surrounding the act of screening for and treating the

<sup>65</sup> Yung, *op. cit.* note 9, pp. 673–681.

<sup>66</sup> A.E. Simon et al. Prodromal schizophrenia in primary care: a randomised sensitisation study. *Br J Gen Pract* 2010; 60: e353–e359.

<sup>67</sup> B.A. Cornblatt et al. Preliminary findings for two new measures of social and role functioning in the prodromal phase of schizophrenia. *Schizophrenia Bull* 2007; 33: 688–702; D.A. Schlosser et al. Recovery from an at-risk state: clinical and functional outcomes of putatively prodromal youth who do not develop psychosis. *Schizophrenia Bull* 2012; 38: 1225–1233.

<sup>68</sup> C. Corcoran et al. Prodromal interventions for schizophrenia vulnerability: the risks of being ‘at risk’. *Schizophr Res* 2005; 73: 173–184.

<sup>69</sup> Wong, *op. cit.* note 60, pp. 108–115.

<sup>70</sup> J.A. Clausen. Stigma and mental disorder: phenomena and terminology. *Psychiatry* 1981; 44: 287–296.

<sup>71</sup> B.G. Link, et al. The effectiveness of stigma coping orientations: can negative consequences of mental illness labeling be avoided? *J Health Soc Behav* 1991; 32: 302–320.

<sup>72</sup> N.J. Breitborde, et al. Self-determination and first-episode psychosis: associations with symptomatology, social and vocational functioning, and quality of life. *Schizophr Res* 2012; 137: 132–136; S.A. Kidd. From social experience to illness experience: reviewing the psychological mechanisms linking psychosis with social context. *Can J Psychiatry* 2013; 58: 52–58.

Table 3. Benefits and Caveats for Three Strategies of Disclosure for an Attenuated Positive Syndrome (APS) Diagnosis

<p><b>Full Disclosure</b></p> <p><b>Benefits</b></p> <ol style="list-style-type: none"> <li>1. Promotes autonomy</li> <li>2. Being aware of a label can relieve anxiety and isolation</li> <li>3. Allows the patient and family to research the disorder on their own and locate emerging treatments</li> <li>4. Provides the strongest and clearest context for interpreting psychoeducation around expressed emotion and limiting exposure to risk factors (e.g., cannabis)</li> <li>5. Allows for the provider to remove confusion around previous diagnoses and to correct any previous ineffective or iatrogenic treatments</li> <li>6. Allows for clear communication between the family and treatment team</li> </ol> <p><b>Caveats</b></p> <ol style="list-style-type: none"> <li>1. The significant heritability of psychotic disorders creates a complex legal and ethical issues around informing family members of their own shared risk</li> <li>2. Different cultures and subcultures may hold varying preferences with regard to disclosure</li> <li>3. While it opens the possibility for targeted treatments, a label can create significant stress and stigma</li> </ol> <p><b>Non-Disclosure</b></p> <p><b>Benefits</b></p> <ol style="list-style-type: none"> <li>1. Promotes beneficence and nonmaleficence</li> <li>2. Limits frustration and confusion associated with a rapidly evolving and poorly understood diagnosis</li> <li>3. Attempts to reduce stigma and related stress that may accompany a label (a factor that may inadvertently exacerbate the progression of illness)</li> <li>4. May protect patients during adolescence- a particularly sensitive developmental period</li> </ol> <p><b>Caveats</b></p> <ol style="list-style-type: none"> <li>1. Therapeutic Privilege creates complex legal and ethical issues around provider responsibility and culpability when not tailored on a case by case basis</li> <li>2. Patients have the right <u>not</u> to know about a life altering illness</li> <li>3. Concerns about the negative consequences of false positives that justify a severe limit on autonomy are diminished by recent developments in potentially efficacious treatments with lower side effect-profiles</li> </ol> <p><b>Partial Disclosure</b></p> <p><b>Benefits</b></p> <ol style="list-style-type: none"> <li>1. Balances considerations of autonomy and beneficence and nonmaleficence</li> <li>2. Conveys important information about symptoms</li> <li>3. Reduces harm that may be associated with an explicit label</li> </ol> <p><b>Caveats</b></p> <ol style="list-style-type: none"> <li>1. Lay persons may interpret this information as a pseudo-diagnosis or legitimate diagnosis in any case.</li> <li>2. Symptoms may actually contribute more to a stigma and peer-rejection than a label</li> </ol>
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syndrome have been expertly reviewed elsewhere.<sup>73</sup> Several societal issues surrounding the effects of disclosure should be also carefully considered as research advances and the APS diagnosis becomes more commonplace. Of particular concern when focusing on disclosure is imparting information and weighing considerations for protecting persons with APS from harm, either in terms of encroachment of legal rights, financial burden, and discrimination.<sup>74</sup>

### Legal and ethical issues surrounding minors

As a preliminary matter, there does not appear to be a legal requirement for a clinician to disclose a medical

condition (whether physical or mental) that is not accepted by the medical community. Courts hold ‘[r]ather than mandate the disclosure of specific information as a matter of law, the better rule is . . . that a physician is under a legal duty to disclose to the patient all material information . . . information which the physician knows or should know would be regarded as significant by a reasonable person in the patient’s position when deciding to accept or reject a recommended medical procedure . . . to make an informed decision regarding a proposed treatment’.<sup>75</sup> This view is based on the policy that ‘[t]he contexts and clinical settings in which physician and patient interact and exchange information material to therapeutic decisions are so multifarious, the informational needs and degree of dependency of individual patients so various, and the professional relationship itself such an intimate and irreducibly judgment-laden one . . . it is unwise to require *as a matter of law* that a particular species of information be disclosed.’<sup>76</sup> It follows, disclosure becomes a balance of what

<sup>73</sup> B. Cassetta & V.M. Goghari. Ethical considerations of screening and early intervention for clinical high risk psychosis *Ethics and Behavior*; DOI: 10.1080/10508422.2014.880920:1-42 (Forthcoming).

<sup>74</sup> N. Rusch, et al. What is a mental illness? Public views and their effects on attitudes and disclosure. *Aust N Z J Psychiatry* 2012; 46: 641–650; M.V. Seeman. Employment discrimination against schizophrenia. *Psychiatr Q* 2009; 80: 9–16; H. Stuart & J. Arboleda-Florez. Community attitudes toward people with schizophrenia. *Can J Psychiatry* 2001; 46: 245–252.

<sup>75</sup> *Arato v. Avedon*, 5 Cal. 4<sup>th</sup> 1172, 1186–1187. (1993).

<sup>76</sup> *Ibid*:1185.

information would a reasonable patient want to know, balanced by what a reasonable doctor would want to discuss, taking into account the negative emotional reaction a patient may have. Notably, California courts do not mandate disclosure of probabilities based on statistical data.<sup>77</sup> This suggests that disclosure of APS, and other research diagnosis, may not be required. However, should treatment for APS be required, it appears a clinician must disclose as much information as is necessary for a person to make an informed decision about such treatment.

Furthermore, unique issues relating to disclosure of APS exist because APS overlaps with the period of transition from a minor to a legal adult – adolescence. In addition to determining whether a clinician has a duty to disclose the APS diagnosis, the clinician must also determine to whom he or she must disclose – the adolescent, the parent, or both; and whether such a disclosure is justified. The legal issues revolving around disclosure to adolescents concern an adolescent's capacity to make decisions about his or her treatment and the adolescent's liberty and privacy interests. Like adults, a minor or adolescent has a legal right to make informed consent to any treatment for APS. Yet, whether the adolescent has the legal capacity to make such a decision is often circumstantial, and different states employ different standards. Many states have standards for determining an adolescent's capacity to make informed decisions about his or her mental health treatment including (1) understanding of the facts of the diagnosis and treatment options; (2) ability to make rational decisions; (3) appreciation of the personal implications of the decisions; (4) ability to communicate his or her decision; (5) making a reasonable choice; and/or (6) general competence.<sup>78</sup> Older adolescents are often empowered to make mental health treatment decisions, and most have capacity to make treatment decisions. In New York (NY code-Section 33.21), minors 16 and older can consent to treatment with psychotropic medications if a parent/guardian is not reasonably available, requiring consent of a parent/guardian would have a detrimental effect on the minor, or the parent/guardian has refused to give consent but the medications are in the best interest of the patient. Accordingly, to whom the clinician must disclose likely requires a legal analysis of the capacity of the adolescent patient.

Yet, the ethical implications of disclosing to a minor create additional concerns that weigh into the legal duty to disclose. Minors can understand, appreciate, reason,

and evidence a choice. However, treatment decisions often require maturity, insight, and the competence to understand those decisions.<sup>79</sup> As some APS individuals have diminished cognitive capacity and insight during the prodromal phase or once they convert, there may be a need for informed treatment decisions or consent to participate in research to be made by a responsible party.<sup>80</sup> Were early disclosure given, whether or not the patient developed psychosis, plans could be set in place in advance. For example, the patient can express what he/she would wish if he/she were to transition to schizophrenia. These decisions could help guardians and courts determine the 'substituted judgment' – namely, what would the patient want if competent. Indeed, it would allow extensive advance planning as detailed in an Advanced Directive document. Finally before patients become floridly ill, they could appoint a health-care proxy to make medical decisions in the event they become incompetent. All of these strategies would spare the government, families, courts, and the patients themselves substantial costs (both social and financial). It may also prevent some of the direct health and non-health issues discussed above.

### Insurance and healthcare benefits

In many cases a patient will require a formal diagnosis to be eligible for healthcare benefits. Receiving an APS label may help defray initial costs with support from select insurance providers and for those who remit or do not convert to psychosis, there may not be a need for expensive or rejected applications that accompany a chronic mental illness label.<sup>81</sup> However, the potential threat of discrimination by insurance companies is a large concern. Once given a diagnosis, state statutes find that 'it is the applicant's duty to disclose . . . every fact bearing on or pertaining any way to the insurability of [a person's] life, especially where specific questions are put to the applicant calling for such information.'<sup>82</sup> Indeed, the *Morely* court held that an insurance company was justified in rescinding the life insurance policy issued to the insured because the insured withheld information relating to her mental disorder. Further, this duty to disclose medical conditions continues after the issuance of an insurance

<sup>77</sup> Ibid. at 1186 (holding doctor not required to disclose life expectancy projections for cancer patient based on statistical samples).

<sup>78</sup> R. Redding. Children's Competence to Provide Informed Consent For Mental Health Treatment. *Washington & Lee Law Review* 1993; 50(2): 695, 710; <http://scholarlycommons.law.wlu.edu/wlulr/vol50/iss2/13>

<sup>79</sup> L.A. Weithorn & S.B. Campbell. The competency of children and adolescents to make informed treatment decisions. *Child development* 1982: 1589–1598; R.E. Duncan et al. Is my mum going to hear this? Methodological and ethical challenges in qualitative health research with young people. *Soc Sci Med* 2009; 69: 1691–1699.

<sup>80</sup> B.K. Brent et al. Insight into illness in patients and caregivers during early psychosis: a pilot study. *Schizophr Res* 2011; 127: 100–106.

<sup>81</sup> Schlosser, *op. cit.* note 67, pp. 1225–1233.

<sup>82</sup> E.F. Walker et al. Developmental neuropathology and the precursors of schizophrenia. *Acta Psychiatr Scand Suppl* 1999; 395: 12–19.

Table 4. Disclosure of an Attenuated Psychosis Syndrome (APS)

Attenuated psychosis syndrome is unique in that while it categorizes a current clinically significant disorder, a key feature also relates to the potential of a serious mental illness outcome. Because the label is new, information about assessment, categorization parameters, and prognosis, is still being developed. Further, because a majority of these patients are in a critical psychosocial developmental period (the transition from adolescence to adulthood), good evidence suggests that the progression of psychosis is affected by stigma/stress, the label has ramifications for family members as well (heritability of psychotic disorders), and there are limited empirically supported treatment options, diagnosing treatment providers are faced with a significant ethical dilemma as well as complex legal and clinical considerations. One solution that balances these issues involves a hybrid disclosure strategy, which weighs the factors of each case individually and focuses on discussing specific symptoms with a patient and family, thereby maximizing clarity (in a context of a rapidly shifting classification), empowering the patient/family to track symptoms (which may be more stigmatizing than a label) and promoting a collaborative relationship (improving treatment adherence and open communication). The approach also advocates full disclosure to parents/legal caretakers (in the cases of minors) and adult patients, but this should be provided in the context of clear communication about what a research diagnosis entails, and with suggestions to use this label to learn more about the disorder and to facilitate a fully informed search for developing treatment options. Consistent with common practice for other highly heritable medical disorders, family members should also be informed of their own-shared risk. In specific cases where a patient is a minor engaging in high-risk activities (e.g. using cannabis) the label should also be fully disclosed in an effort to provide the clearest and most direct context for interpreting the potential harm of these behaviors.

policy.<sup>83</sup> Thus, it is highly likely that should a practitioner inform a youth at risk of a psychotic disorder of that risk, insurance companies would prejudice the patient. In light of these issues as well as the social benefits of identifying and treating a psychotic disorder early on, it has become an emerging priority to protect this by statute.

### Discrimination

Social distance increases with a diagnosis of psychosis, and many people suspect that psychotic people are violent.<sup>84</sup> This problem is exacerbated by media representations of individuals with psychosis that are very often disparaging.<sup>85</sup> With the growing incidence of rampage and school shootings in the United States and Europe, there is increased coverage of mental illness linked, particularly schizophrenia, to violent crime and horrific shootings. This type of profiling clearly places those labeled with APS at increased risk for discrimination – particularly as the diagnosis covers the adolescent age group often implicated in these events. However, this perception is not accurate. While common conceptions of schizophrenia in the media focus on the statistic that individuals with schizophrenia are more likely to be violent than other members of the general population, the absolute risk (the proportion of societal violence attributable to schizophrenia is quite small) is all but ignored.<sup>86</sup>

<sup>83</sup> M. Xu et al. Dopamine D3 receptor mutant mice exhibit increased behavioral sensitivity to concurrent stimulation of D1 and D2 receptors. *Neuron* 1997; 19: 837–848.

<sup>84</sup> B.A. Pescosolido et al. The ‘backbone’ of stigma: identifying the global core of public prejudice associated with mental illness. *Am J Public Health* 2013; 103: 853–860; Tanay E. Virginia Tech mass murder: a forensic psychiatrist’s perspective. *J Am Acad Psychiatry Law* 2007; 35: 152–153.

<sup>85</sup> A. Preti. School shooting as a culturally enforced way of expressing suicidal hostile intentions. *J Am Acad Psychiatry Law* 2008; 36: 544–550.

<sup>86</sup> E. Walsh et al. Violence and schizophrenia: examining the evidence. *Br J Psychiatry* 2002; 180: 490–495.

Informed media coverage, particularly during the aftermath of this type of violent crime, is essential for limiting this type of discrimination.

### CONCLUSION

There are interactions in medicine that take place between the patients, the disease, the doctor, the medications (with their efficacy and lack of efficacy) and finally with the societal context of the disorder.<sup>87</sup> For APS, a classification where the data underlying our understanding of the disease is still being developed, and the prognosis is entirely uncertain, the disclosure strategy may have critical implications for the patient and family. While striving for a balance between the principles of biomedical ethics, and incorporating the legal and clinical factors presented in this review, we propose a hybrid disclosure approach, which favors different aspects of each of the three noted strategies, and tailors disclosure based upon the factors specific to each presenting case (see Table 4). Specifically, with a hybrid approach, we advocate that the parents/legal guardians (in the case of minors) and adult patients are given full disclosure and then the decision to provide full or partial disclosure to the underage patients should be based on case-specific factors. In the concluding section, we discuss several important caveats and considerations that accompany this approach, and provide an example applying it to the case presented in Table 2.

Given that APS is under development, one potential solution is focusing on the specific presenting symptoms and individual aspects of each case. However, consistent with the full-disclosure strategy, parents of patients (legal guardians) and adult patients should also be informed of the APS diagnosis to meet legal obligations, promote autonomy, and improve the likelihood that the clinical

<sup>87</sup> Surbone, *op. cit.* note 14, pp. 944–950.

issues are taken seriously in cases where they are being downplayed. Specifically, a clinician should disclose as much information as necessary for the patient, or if the patient lacks capacity, the patient's parent to make an informed decision about the necessary treatment.<sup>88</sup> Thus, this information should be provided in the context of empowering the patient and family to learn more about the condition or to find treatment resources as they continue to develop. Along these lines, the patient and family should carefully be informed of what a research diagnosis entails, and family members should also be informed of their own shared risk as well as behaviors and environments which could potentially exacerbate this vulnerability. It is also important to consider that APS typically occurs with a number of comorbid mental disorders,<sup>89</sup> and these other illness may also effect disclosure decision.

In specific cases, underage patients should receive full disclosure.<sup>90</sup> As the available evidence suggests that individuals will experience stigma and stress because the behaviors and symptoms are isolating in themselves (this is likely to be escalated in the sensitive social structure of adolescence),<sup>91</sup> the additional stress a label could provide is mitigated by the other potential benefits of full disclosure. This is particularly true for instances where the youth is likely to be exposed to additional risk factors. For example, a diagnosis will provide the clearest and strongest framework for interpreting and incorporating information about potential harm associated with risk behaviors – using cannabis and other environmental stressors – leading to a greater likelihood of conversion to psychosis.<sup>92</sup> In the case of the young adult male presented in Table 2, a hybrid approach would involve providing full disclosure to both the parents and the 17-year-old patient. The adolescent patient in this case does not exhibit characteristics that would preclude a full disclosure (e.g. poor insight or limited intellectual capacity),

<sup>88</sup> *Arato v. Avedon*, 5 Cal. 4th 1172, 1186–1187 (1993); *Nixdorf v. Hicken*, 612 P. 2d 348 (Utah 1980); *Barcai v. Betwee*, 50 P. 3d 946 (Haw. 2002).

<sup>89</sup> A. Bechdorf, et al. Experience of trauma and conversion to psychosis in an ultra-high-risk (prodromal) group. *Acta Psychiatr Scand* 2010; 121: 377–384; J. Murphy et al. Childhood sexual trauma, cannabis use and psychosis: statistically controlling for pre-trauma psychosis and psychopathology. *Soc Psychiatry Psychiatr Epidemiol* 2013; 48: 853–861; T.A. Niendam et al. Obsessive compulsive symptoms in the psychosis prodrome: correlates of clinical and functional outcome. *Schizophr Res* 2009; 108: 170–175; J.T. Wigman et al. Evidence that psychotic symptoms are prevalent in disorders of anxiety and depression, impacting on illness onset, risk, and severity – implications for diagnosis and ultra-high risk research. *Schizophrenia Bull* 2012; 38: 247–257.

<sup>90</sup> Zugman, *op. cit.* note 16, pp. 151–152; M. Koelch & J.M. Fegert. Ethics in child and adolescent psychiatric care: An international perspective. *Int Rev Psychiatry* 2010; 22: 258–266.

<sup>91</sup> J.A. Clausen. Stigma and mental disorder: phenomena and terminology. *Psychiatry* 1981; 44: 287–296.

<sup>92</sup> A.R. Yung et al. Risk factors for psychosis in an ultra high-risk group: psychopathology and clinical features. *Schizophr Res* 2004; 67: 131–142.

and sharing the label may help to ensure that this situation is taken seriously, and that self-medication with illicit drugs is firmly discouraged. In addition, the hybrid approach would also then involve focusing on the symptomatology with both the parent and the minor. This discussion can promote autonomy, reduce confusion, and provide a sense of control.<sup>93</sup>

In addition, focusing on symptoms will help enlist the patient and family into a collaborative relationship with the provider, as they can help monitor insidious symptoms and track course. Patients who feel they are in a collaborative relationship tend to adhere to treatment and more importantly, are much less likely to hide future symptom development.<sup>94</sup> As noted above, another good reason to focus on communicating symptoms is that stigma is particularly related to these features and shifting focus and targeting treatment to them is a good strategy.<sup>95</sup> In addition, focusing on symptoms instead of the diagnostic label would limit confusion for the patient and family as the field continues to refine classification.

In the cases of younger adolescents or poorer insight, a strategy that focuses on providing education about symptoms to the minor but does not provide the label may be preferable.<sup>96</sup> Specifically, non-disclosure is advisable in cases where the patient is a minor who is acutely suicidal or has either temporary (e.g. delirium, closed head injury) or long-standing comorbid conditions that severely limit understanding or insight. For example, if the person in the case vignette noted above also presented with moderate to severe autism, showed poor insight (e.g. believing the symptoms such as having special powers were real and that there wasn't a problem), limited intellectual and adaptive capacity (moderate to severe pervasive developmental disorder) or was extremely guarded (e.g. exhibiting significant paranoia about trusting the motives of parents or the medical profession), a clear and specific approach to discussing each symptom individually may help to limit further harm and confusion. Similarly, if the person in the case was acutely suicidal, the decision to disclose the label should wait until the symptoms have remitted. Unfortunately, these types of comorbid conditions often appear to be the rule with APS, rather than the exception.

While the hybrid approach aims to weigh the current legal precedence, promoting autonomy as well as adhering to principles of beneficence and nonmaleficence, it is

<sup>93</sup> V.A. Miller et al. Children's competence for assent and consent: a review of empirical findings. *Ethics Behav* 2004; 14: 255–295.

<sup>94</sup> T. Moses. Stigma and self-concept among adolescents receiving mental health treatment. *Am J Orthopsychiatry* 2009; 79: 261–274.

<sup>95</sup> Clausen, *op. cit.* note 89, pp. 287–296; P.D. McGorry et al. Ethics and early intervention in psychosis: keeping up the pace and staying in step. *Schizophr Res* 2001; 51: 17–29.

<sup>96</sup> K.J. Lee et al. Assent for treatment: clinician knowledge, attitudes, and practice. *Pediatrics* 2006; 118: 723–730.

important to recognize that the strategy is not perfect. One noteworthy limitation is the possibility that while it aims to limit the consequences of stigmatization, it by no means avoids stigmatization entirely. It is also possible that once parents learn of the label, this consideration may override clinician attempts to encourage the family to stay symptom-focused and limit the families participating in tracking symptoms as well. As a result, the clinician will need to be clear and careful when providing the full disclosure, and also work to maintain regular contact with the family in preceding months (to answer any questions, respond to any changes, and help the family to stay symptom-focused). The hybrid approach also relies heavily on careful and expert clinical decision-making, which may be limited by lack of experience or treatment settings that restrict client contact. In addition, based on the individual factors pertaining to a case, it will also be important to collaborate with respective experts, identify appropriate referral sources, and/or attain administrative consultation services to train a clinical staff to be adept in discussing legal issues regarding interest in setting up conservatorship, the pros/cons of sharing a diagnosis with an insurance provider, and any safety concerns. Finally, it is critical to emphasize that disclosure is just the first step, and regardless of the strategy, the patient and family will have to continue to deal with significant and sometimes escalating symptoms over the coming months. It is imperative to provide disclosure as part of a larger plan that will include appropriate support

and resources for individuals with APS as well as their families.

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