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REVIEW

Identity and schizophrenia: Who do I want to be?

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Abstract

Many individuals with schizophrenia have occasional difficulty defining both to themselves and to others who they truly are. Perhaps for this reason they make attempts to change core aspects of themselves. These attempts may be delusional, but are too often unjustly dismissed as delusional before the potential value of the change is considered. Instead of facilitation, obstacles are placed in the way of hoped-for body modifications or changes of name or of religious faith. This paper discusses the various changes of identity sometimes undertaken by individuals with schizophrenia who may or may not be deluded. Ethical and clinical ramifications are discussed. The recommendation is made that, when clinicians respond to requests for help with identity change, safety needs to be the main consideration.

Key words: Schizophrenia; Identity; Body modification; Religious conversion; Name change

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Core tip: Everyone tries at times to change aspects of their identity. When people with schizophrenia do it, it should not necessarily be interpreted as delusional, but safety issues need always to be kept in the foreground.

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INTRODUCTION

Schizophrenia has been referred to as an "I am" illness^[1], meaning that this disorder affects an individual's core identity, the qualities, characteristics and continuities that distinguish one person from another. Identity, however, is never static and, particularly in the context of schizophrenia, it has been associated with fluidity and characterized by inconsistent autobiographical recall and changes in self-representation over time^[2-4]. The appreciation of a sense of self has been reported as deficient in this illness^[5-8]. This is illustrated in a study by Scharfetter^[9]. Persons with schizophrenia, when administered a standardized questionnaire about identity, endorsed items such as: "I didn't know who I was", "My ancestry changed", "I often had to look in the mirror", "I thought I had children", "I had to say



repeatedly "I am who I am", "My body or parts of it changed", "My sex changed". They showed an imprecise awareness of the continuity over time of their body, personal history, and social function.

Given a hypothesized fluidity of self-perceived identity, it is perhaps to be expected that some patients with schizophrenia, once over the acute stage of illness, might want to change their external appearance to conform to a changed self-image^[10]. They might also want to re-invent other aspects of who they perceive themselves to be: Their origins, their name, their faith. Reported examples of identity transformations in the schizophrenia literature include: Becoming a vegetarian^[11], changing religion^[12,13], acquiring identity-changing tattoos and body piercings^[14], seeking rhinoplasty^[15], changing names^[16], and changing genders^[17-19]. The question with which clinicians are faced is whether such seemingly abrupt identity changers are signs of psychotic exacerbation, decisions made on delusional grounds, or whether individuals with psychosis, like everyone else and for identical half-rational, half-irrational reasons, occasionally change diets and appearance, convert from one religion to another, and, at times, change genders. The clinician has to determine whether a sudden transformation of self-representation in a person with pre-existing psychosis calls for hospitalization or, instead, whether the person should be referred, as appropriate, to nutritionists, plastic surgeons, chaplains, or gender identity clinics? Because clinicians are often uncertain as to how best to respond to requests for assistance with proposed changes of this nature, I undertook a review of the literature on identity changes in the context of schizophrenia.

METHOD

My search strategy was to pair words representing aspects of identity (name, body, religion, dress, food, gender, ethnicity) with schizophrenia or psychosis in the multidisciplinary Google Scholar database. This yielded 200 abstracts, of which 60 appeared relevant to my purpose. Searching the references of these 60 papers, I found 15 further relevant papers. I will first discuss the various changes of identity reportedly undertaken by individuals with schizophrenia and subsequently I will address ethical and clinical ramifications.

NAME CHANGE

Ethnicity, religion, ancestry, gender, social class, birth order, physical appearance, time and place of birth all contribute to what is called identity, and most of these contributions can be reflected in a person's name^[20-22]. A name change is therefore a powerful way to assume a new identity. Changes of name can act as connections^[23], a way for instance, of blending in with a new environment, of marking a valued affiliation or being reborn into a new religion. Sometimes, however, changing one's name can serve as a separation. It can be a way to hide one's former identity, to repudiate one's ancestry. These different motivations apply to persons with schizophrenia as to anyone else with the added possibility that the wish to hide a previous identity in this population stems from paranoia and originates in delusional thinking. In a 12-year retrospective study of patients attending a psychiatric unit (31% of whom suffered from schizophrenia), it has been reported that 0.7% had at some time in life adopted an alias^[24]. In another study, Völlm et al^[25] found that up to one fifth of psychiatric offender patients had changed their names at least once, motivated by the wish to either consolidate or break family ties, make a fresh start in life, or simply to discard a disliked name. Persons with psychosis, more than other patients, gave idiosyncratic reasons for changing their name, and the names they selected were characterized by being relatively famous names or names that carried symbolic significance. Völlm et $al^{(25)}$ note that the reasons given for name changes by patients in their sample with a diagnosis of schizophrenia sounded as if they might be delusional "It was something mysterious, sinister. Sinister, mysterious name" (25; p. 46).

PHYSICAL APPEARANCE

It is generally acknowledged that facial features (eyes, nose, lips, ears, skin, hair) are fundamental indices of identity and human beings throughout history have attempted to enhance or camouflage these features by cosmetics, depilation, piercing, ornamentation, wigs, head coverings, veils, tanning, bleaching, dreadlocks, crew cuts, and plastic surgery.

With respect to tattoos, a higher than average prevalence of skin markings has been found among young adults who use mental health services^[26,27]. In an early study of visible tattoos on a psychiatric ward, Birmingham et al^[28] reported a 30% rate of schizophrenia. The percentage would be much lower today because, in many parts of the world, tattoos have become quite commonplace. An example of a tattoo motivated by a delusion is provided in Campo et al^[29] where a man with a tattoo states, "I thought I lived with Satan and therefore I needed his sign on my back" (29; p. 166). For the most part, however, the literature considers tattoos as non-delusional attempts to declare a new identity or to rebel against an old one. Like names, they can be marks of affiliation or differentiation or they can merely be efforts to stay in vogue with current fashion^[30]. Because they are considered to represent "toughness", tattoos often increase self-confidence and feelings of empowerment, especially when they are strategically situated so that their visibility is under the control of the wearer^[31,32]. This can serve important morale-boosting purposes in persons with schizophrenia. Whether people with schizophrenia choose specific configurations or themes for their tattoos has not been investigated.

The treatment of schizophrenia can sometimes



transform a person's appearance, weight gain being a prime example^[33] and the illness itself can significantly change a person's voice, accent, and language use, markedly affecting the responses of others^[34-37] and, therefore, secondarily, influencing one's self-evaluation.

Drastic changes in appearances have been reported in schizophrenia^[29], often precipitated by major life events^[38] and sometimes achieved through plastic surgery. Cosmetic surgery for nose or breast is widespread in the general population, but actively seeking it is particularly common in those with body dysmorphic disorder^[39-41], a condition that shows some overlap with schizophrenia^[42-44]. While some common changes, such as hairstyles^[45], are frequent and ubiquitous and harmless, the drive to change appearance can sometimes have dangerous results^[46]. Major selfmutilation, defined as individuals amputating their limb or their genitals or removing an eye, has been strongly associated in the literature with the presence of psychosis^[47,48].

Body modifications include taking hormones or undergoing sex-reassignment surgery. A recognizable minority of individuals with gender identity disorder are said to suffer from a psychotic illness^[17-19,49-51]. Gender identity disorder patients who are psychotic are often denied gender surgery in the same way that people with psychosis were once denied bariatric surgery for morbid obesity^[52,53]. Decisions on what is right under these circumstances can be very difficult for clinicians.

CONSUMMATORY BEHAVIORS

Humans use belongings and personal effects to create and recreate an identity and to show themselves to others in a selective fashion^[54]. Personal identity is often expressed in what one owns, how one dresses, where one lives, and even what one eats. The decision to become a vegetarian, for example, is taken by a large percentage of the population. It is usually seen as the mark of an animal rights devotee or a fitness enthusiast, but obsessive attention to diet can, at times, represent a form of psychotic eating disorder^[55-58].

Dress, a well-recognized symbol of identity^[59,60], is often described as idiosyncratic in individuals with schizophrenia^[61-63]. A way of dressing that strikes others as odd may be deliberate (as a form of identification with a particular subculture or a renunciation of a previous identification) or it may simply be the result of economic constraints and needing to make do with second hand clothing^[64]. Dishevelment can also result from apathy and negative symptoms and cognitive deficits. In addition, problems with thermal regulation leading to redundant clothing have been postulated in schizophrenia^[65]. In other words, it cannot be assumed that dressing in an "odd" way is intentional or indicative of wanting to assume an "odd man out" identity. On the other hand, the symbolic self-completion theory^[66] proposes that, when people feel incomplete in an identity - persons who are newly homeless for instance - they may deliberately adorn themselves with symbols associated with that identity (rags, layers of clothes, unwashed clothes) in order to more fully embrace the new role and achieve a sense of completeness. This may apply even when the new identity is unwanted.

IDENTITY BY ANCESTRY

Many people nurture a fantasy about being adopted, about having a long lost twin, about their "true" hidden parentage; many renounce their national or ethnic identity and adopt a new one, usually for safety or economic reasons. Many do so for delusional reasons as did John Nash when he renounced his United States citizenship upon developing psychosis^[67]. Motives can include a desire to individuate or a desire to assimilate. Identification with an idealized other may be responsible^[68]. There is at least one report in the literature of distorted ethnic identity in the context of psychosis^[69]. An attempt to change ethnicity is more dangerous than the other changes discussed in this paper because it may arouse political suspicion and potential retaliation.

RELIGIOUS IDENTITY

In the Western world, many contemporary men and women choose, at some point in their lives, to leave the religion of their parents and establish a different religious identity for themselves^[70]. They do so for a number of different reasons, rational, emotional, and spiritual^[71]. Conversion to a new religion is often experienced as a transformational change, and has been described with vocabulary that is similar to that used to describe an episode of psychosis. Conversion is said, for instance, to give people a new sense of life's meaning and a new relationship to God^[72-77]. Individuals with psychotic illness use very similar terms when they talk about their beliefs, making it difficult to distinguish religious conversion from delusional thinking. In fact, conversion experiences in the context of schizophrenia are not rare^[13,78]; individuals with psychosis appear to be attracted, more than others are, to new religious movements^[12], perhaps because such movements offer explanation of and salvation from the distress of psychotic symptoms. They have been described as capable of fulfilling emotional needs and stimulating spiritual growth^[79]. New religious movements are also, as social communities, more welcoming than traditional religions to relatively isolated persons. Religious delusions have been reported to trigger conversion^[80]. Interestingly, in a study of 14 forensic psychiatric patients who had changed faiths^[81], one person with a diagnosis of schizophrenia gave as his reason for converting the conviction that his former religion was responsible for fueling his delusions.

LIMITATIONS OF THE REVIEW

This review of the literature skips over many difficulties



(such as definitions of identity) and does not mention political, professional, and social class identities. Nor does it discuss personality and behavior changes that can seemingly transform a person, especially in the context of psychotic illness. This paper should be viewed as exploratory, with much important territory left uncovered.

DISCUSSION

The literature suggests that individuals with schizophrenia sometimes make fundamental changes to their identity and sometimes ask clinicians for assistance. It is acknowledged that change decisions can, at times, be grounded in delusional thinking, leaving clinicians in a quandary as to how to respond. Sanati et al^[82] argue, however, that not taking a person's statements at face value constitutes an act of testimonial injustice^[83], an unjustified devaluation of a person's word. Individuals with a diagnosis of psychosis are often exposed to this form of injustice because the term, schizophrenia, is linked in many people's minds with personal attributes such as irrationality and untrustworthiness. It is well known, however, that decisions and acts can at times, in everyone, be made on irrational grounds; to discredit them a priori, based on a person's diagnosis, is manifestly unjust. The assumption that a person's thinking in a given circumstance is affected by having once been deluded about a different matter, may be correct, but may not be. Once a person has been diagnosed with delusions, to subsequently dismiss all their stated beliefs is an example of unfair bias^[84,85].

Clinicians, of course, form their opinions about a patient's credibility on more than the diagnosis and the psychiatric history. They have their own prior opinions about what is believable and what is not. The credibility of patients with schizophrenia who declare, "I've decided from now on to take my medication as prescribed" will go unquestioned. This decision will be deemed wise. "I've decided to become a vegetarian" may also be met with approval, given that vegetarianism is likely to lead to weight loss, often necessary in individuals with schizophrenia who have gained weight as a result of treatment. But the vegetarian decision may be appraised differently if the clinician does not believe in it^[86].

Clinicians' responses also depend on what they perceive to be the logic behind the intended change. For instance, wanting to change one's name because the original name is hard to pronounce^[87] makes sense to a clinician, but wanting to be renamed Clark Kent "Because I am able to unleash supernatural powers", will arouse alarm. Psychiatrist and philosopher, Karl Jaspers (1883-1969) wrote, "the mentally ill person surely has as much right to be illogical as the healthy one"^[88], and this is worth keeping in mind, but what is more important than logic is safety.

Most clinicians would agree that individuals with

schizophrenia should be as free as anyone else to engage in acts of self-redefinition^[89], but the line is drawn where safety is called into question. One important aspect of safety is reversibility. Shaving off one's hair to look like a favorite movie actor makes for a decisive change in one's appearance, but hair grows back. Another matter altogether is identifying with and wanting to emulate a film star who has undergone a mastectomy. Such a body modification would be, for all intents and purposes, permanent, a form of self-mutilation that leaves an irreversible mark^[90].

How then, should clinicians react to requests for help in changing identity? There are no hard and fast rules; the following are suggestions based on the limited literature: (1) the clinician should not assume that the request is delusional and signals illness deterioration; (2) the clinician should not discredit or dismiss the request out of hand; (3) asking about the reasons behind the request is always in order. Staying actively interested encourages the patient to discuss motivations at length; (4) risk assessment should be carried out after considering the person's track record, the person's demonstrated knowledge about the choice she or he is making, and the coherence of the argument presented; (5) self-reflection is important. The clinician should try to be consciously aware of personal biases with respect to the person, to the nature of his/her illness, and to the choice being made; (6) the clinician must be able to recognize the effects of age and culture on choices and decisions. In the end, safety has to be the prime consideration; (7) safety issues need to be discussed with the patient; (8) the clinician is advised to inquire about and become familiar with published outcome studies of all proposed body modifications, and to share these results with the patient; (9) a family meeting to expand the discussion and learn about ramifications for family and for community is always useful; (10) recommendations for specialist referral are usually needed; (11) if distance travel is involved in the proposed change, travel precautions need to be ensured^[91]; (12) the issue of the patient's competence to make significant decisions must be assessed; and (13) should there be imminent danger of injury to the patient or to others, hospital treatment must be arranged, against the patient's will if necessary.

CONCLUSION

When individuals with schizophrenia ask their care providers to assist them in changing their identity through body modification or religious conversion or name change for instance, clinicians have difficulty deciding how to react. This review suggests that whether the request is delusional or not, it should always be taken seriously and the motivation for it thoroughly investigated. There may be risks, however, when acceding to such requests. Safety considerations should always be borne in mind.

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