THE VALIDITY OF DISORGANIZED BEHAVIOR AS AN INDICATOR OF SCHIZOPHRENIA IN ADULTS WITH AUTISM AND INTELLECTUAL DISABILITY: A SINGLE CASE STUDY

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Schizophrenia in adults with intellectual disability and autism is rarely detected due to the patients’ limited ability to report psychotic symptoms, and due to the complex task of differentiating between behavioral problems, psychotic disorders and depression in these patients. Behavioral indicators are therefore needed in the assessment process. Disorganization is one of the main symptoms of schizophrenia. It is observable and therefore of special interest for investigation. This paper examines the co-occurrence of behavioral disorganization and disorganized speech in a patient with schizophrenia, autism and mild intellectual disability. Data on the presence of disorganized behavior and disorganized speech was rated by two experienced nurses through observation of video-taped patient-staff interaction. The strong relationship between disorganized behavior and disorganized speech generate a hypothesis of a general concurrence of the two. Valid behavioral indicators will facilitate the recognition of schizophrenia in patients with limited verbal skills. The results from this study support behavioral disorganization as a valid indicator.

Keywords: intellectual disability, autism, psychosis, schizophrenia, behavioral disorganization

Schizophrenia is known to occur in individuals with autism and intellectual disability (ID) but identification is complex, especially due to the difficulty of differentiating schizophrenic symptoms from the core symptoms of autism. The diagnostic process is also difficult due to the complex task of differentiating between behavior problems and psychotic disorders in patients with limited verbal skills.

The impaired language and communicative skills and the reduced capacity for introspection that characterize individuals with both autism and ID, also represent challenges for the identification process. Furthermore, individuals with autism are known to act and communicate in idiosyncratic ways, a phenomenon that will complicate the diagnostic process further. It is also a problem that psychiatric symptoms in general seem to be more atypical the more intellectually disabled the patient is. It might also be difficult to separate psychosis in the schizophrenia spectrum from psychosis with mood origin. Therefore, we need behavioral indicators of schizophrenia in the assessment of intellectually disabled and autistic patients.

Schizophrenia is normally assessed through patient-reported delusions, hallucinations, thought disorder (disorganized speech) and disorganized behavior, and observation of negative symptoms and bizarre behavior. The features of disorganized behavior have been associated with peculiar behavior such as singing in the library or inappropriate behavior like urinating in public places. However, disorganization has gained renewed interest in the research of schizophrenia. The understanding of the term disorganization is widened and includes the impairments of task performance. Patients with schizophrenia, ID and autism may display severely disorganized behavior concurrent with other psychotic features. The following features of the patient’s behavioral disorganization can be observed: task derailment (task interruption by change in focus), gross disorientation (aimless wandering or other aimless acts) and impaired sequential organization.

The diagnostic obstacles presented above, especially the verbal limitations, generate a need for behavioral indicators. Behavioral disorganization is found to separate between psychotic and non-psychotic individuals with ID and autism. People with moderate, severe or profound ID will also display disorganized speech (mainly impoverished language and confused way of using known words), but it might be hard to detect because of the patients’ initially impaired communicative language.

However, patients with mild ID will display disorganized speech, which might be observed and
analyzed when schizophrenia is suspected. It might be questioned if both disorganized behavior and disorganized speech are indicators of the underlying phenomenon of thought disorder. They might be seen as equivalent manifestations of thought disorder as both disorganized speech and disorganized behavior share features of fragmentation, derailment, incoherence and sequencing problems.\textsuperscript{9}

Disorganized speech is found in patients with autism but significantly less prominent than in patients with schizophrenia.\textsuperscript{25} Newer research underpins thought disorder (manifested by disorganized speech) as absent in patients with autism and present in patients with schizophrenia.\textsuperscript{18,21} Although there is some disagreement on which and how many features are comprised by the phenomenon of thought disorder (disorganized speech), there seems to be agreement about incoherence, derailment and pressure of speech (talking incessantly and quickly) as core indicators.\textsuperscript{2,12,25}

Few studies have been published on prevalence of schizophrenia in patients with both ID and autism. Studies published tend to conclude that the prevalence of schizophrenia in this population is not higher than in the normal population.\textsuperscript{13,19,29} However, these estimates will appear tentative as long as schizophrenia in the population of patients with ID and autism remains undetected, especially as long as schizophrenia is assessed conventionally without a special focus on behavioral indicators.

Validation of behavioral indicators is an important issue because behavioral indicators are often more likely to be misinterpreted than verbal reports from patients (i.e., hallucinations).\textsuperscript{14} For example, when patients make noises or cover their ears to mimic hallucinations, their signals are more easily misinterpreted than when they describe their hallucinations. In our clinical experience, severely disorganized behavior might frequently be mistaken for agitated behavior caused by, for example, depression or long standing pain or other medical conditions.

We present a single-case study to investigate the relationship between disorganized behavior and disorganized speech in a patient with ID and autism. The patient was part of a previously reported study in a larger group. Symptoms were clearly defined and examined using two independent raters. The study was conducted in a specialized psychiatric in-patient unit for adults with ID.\textsuperscript{6} It was approved by the Regional Ethical Board of Eastern Norway.

**Methods**

**Setting**

The present study is a part of a larger one investigating behavioral indicators of schizophrenia in intellectually disabled patients with autism. The larger study has two main aims: first, to investigate the reliability and validity of behavioral indicators, with a special emphasis on behavioral disorganization, and second, to examine the effects of staff communication skills related to schizophrenic patients with ID and autism.\textsuperscript{4} Reliability of features of behavioral disorganization has been examined in a previous study and the reliability was found to be satisfactory.\textsuperscript{5}

**Participants**

One patient with autism, mild ID, and schizophrenia, and fourteen staff members were recruited for this study occurring on a specialized unit in a psychiatric hospital in Oslo, Norway. The patient, Ms. A, and staff members were participants in a larger study investigating staff communication skills encompassing four patients with ID, autism and schizophrenia, and 34 staff members.\textsuperscript{4} Ms. A was chosen because of her ability to report on prominent symptoms of schizophrenia.

The staff included nurses and nurse’s aides. They were invited to participate on a voluntary basis and their confidentiality was guaranteed. All participating staff signed a written consent. The average work experience of staff members was 3.2 years (range 1-8 years). Two experienced psychiatric nurses who knew the patient and staff members well were recruited for the scoring process.

Ms. A was 46-years-old during the videorecording. She was not treated by drug therapy in the study period. She had been hospitalized for psychiatric care for many years when the data collection started, and she was not in the most acute phase of a psychotic episode. Ms. A’s global functioning was severely impaired. She displayed delusional thoughts about herself being executed and staff stealing from the hospital. She was behaviorally disorganized. She displayed disorganized speech; incoherence, pressure of speech and derailment. She displayed negative symptoms of passivity, lack of motivation and...
Ms. A was mildly intellectually disabled with an IQ of between 60 and 70. There was no known mental illness in her close family. She had spent most of her adult life in psychiatric institutions. She had shown aberrant behavior since early childhood. Her mother believed that something was wrong with her daughter at infancy. Ms. A lived with her parents until her first admittance to adult psychiatric in-patient treatment at the age of 18. In childhood she did not play with other children, and displayed unusual and strange interests. For instance she used to occupy herself with looking at pairs of Wellingtons. She mostly stayed home with her mother. She showed severe temper tantrums, and was obsessively focused on how the food was served. She was admitted to child psychiatric assessment at five years of age. At primary school, she did not attend the regular classes. She had no further education.

She was never able to communicate with others in a conventional way and used idiosyncratic words and expressions. For example, she had a total idiosyncratic way of “ranging” people she liked and trusted (significant others), by their kidney size. People she trusted and got attached to were described with large kidneys. “You are pissing like the Niagara Falls” means “You are a likeable and trustworthy person.” In contrast, people she disliked were said to have pea-sized kidneys. This idiosyncratic behavior had been stable since childhood. She had further severely impaired social skills, for example, how close or far was proper when you meet with strangers, or how to communicate with strangers versus close relatives. She had no understanding of other individuals. She had further cognitive impairments associated with autism spectrum disorders like concrete thinking, weak sense of coherence and weak contextual understanding. Since primary school she had an amazing ability to predict the weekday of dates within future or past.

At her first psychiatric admittance, she displayed delusions about being executed, along with severely disorganized language and negative symptoms of lack of motivation, passivity and social withdrawal. She was given conventional antipsychotic medication. She experienced more psychotic episodes and was diagnosed as schizophrenic. At the age of 35, Ms. A was re-diagnosed and found to suffer from infantile autism. Her schizophrenic diagnosis had to be abandoned, according to current diagnostic criteria in DSM-III/ICD-9. In 1995 she was admitted to the specialized psychiatric in-patient unit where the present study occurred. She was then more thoroughly assessed by an interdisciplinary team of clinicians and found to suffer from schizophrenia co-morbid to ID and autism. (The criteria in DSM-IV and ICD-10 allow co-morbidity of autism and schizophrenia.) A few years ago she experienced a new episode of schizophrenia, and was eventually medicated (after this study). Ms. A now lives in a community-based group home and is satisfied with her life.

Measures

Disorganized speech is measured by the following: incoherence, derailment and pressure of speech.

Disorganized behavior is measured by the following: repetitive behavior, aimless wandering, task interruption by change in focus, unexpected violent behavior, meaningless response (words or gesture), does not follow directive.

Disorganized behavior is manifested by difficulties with motor and sensory coordination and aggression without any observed reason, as “lightening from the clear sky.” The patient will appear as motor or verbally restless, disoriented or unsystematic. The patient will have problems with sequencing within task performance. Aimless wandering can be observed. The patient might show task derailment (defined as task interruption by change in focus). Derailment of task performance appear as a behavioral equivalent to derailment of speech. Derailment of speech is described as “ideas slip off the track on to another which is obliquely related or unrelated.” A similar description applies to task performance. An example will illuminate the similarity of speech derailment and task derailment:

Ms. A is asking for coffee at the breakfast table. The nurse gives her a cup. Ms. A takes the cup and starts to move it around on the table. She then leaves the cup, looks out of the window, and reaches out for a knife, hands it to the nurse and starts to serve herself jam with the fingers.

Although impaired organization of sequence is a core element of disorganized behavior, it was not examined in the staff communication study and thereby excluded from the present study. The staff measures, developed for the communication...
study, were not included in the present study. These measures are thoroughly described in the staff communication study. The measures used in the present study are:

1. The patients’ measures of disorganized behavior from the staff communication study presented in Table 1.

2. All verbal utterances from both staff and patients that were originally transcribed (but not analyzed) in the staff communication study. In the present paper, only the patient’s verbal utterances were scored according to the measures in Table 1 below. Utterances by the staff were transcribed in order to evaluate whether patient verbal acts were coherent to staff verbal acts or not.

Scoring categories of both staff communication and patient behavior were defined prior to the observations.

Table 1. Patient Measures

<table>
<thead>
<tr>
<th>Disorganized Behavior</th>
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<tbody>
<tr>
<td>Repetitive behavior</td>
</tr>
<tr>
<td>Aimless wandering</td>
</tr>
<tr>
<td>Task interruption by change in focus</td>
</tr>
<tr>
<td>Unexpected violent behavior</td>
</tr>
<tr>
<td>Meaningless response, words or gesture</td>
</tr>
<tr>
<td>Does not follow directive</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Disorganized speech</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incoherence</td>
</tr>
<tr>
<td>Derailment</td>
</tr>
<tr>
<td>Pressure of speech</td>
</tr>
</tbody>
</table>

Procedure

Data were based on observations of interaction between patient and staff. These observations on behavioral level are defined as “turns” and this system based on turn-taking is widely used in psychological research. Observation of turn-taking is based on a coding system where all behaviors of interest for the actual study are systemically defined prior to the observation and then scored. Data in the present study were organized on two levels—turns and episodes. **Turns** are defined by an act, exclusively performed by caretaker or patient. Examples of turns are asking a question, gaze initiative from the patient, pouring milk from a bottle, etc. **Episodes** are defined by “start” = interaction initiated either by patient or staff and “end” = a natural end of an interaction sequence.

Data were collected over a six month period in naturalistic settings of interaction between patients and staff within a dyadic frame. Situations of interaction between staff members and the patient, naturally occurring during the day, were chosen at random, recorded by videotape and then scored; for example, meals, dressing and school lessons. The observations were scored according to the measures presented above. The verbal utterances of both the patient and the staff members were transcribed. All data were then organized within episodes.

No instructions were given to staff or the patient prior to recording, except for the general information given about the study. All participating staff members were blind to the scoring categories.

Statistical Analyses

Reliability was estimated as observer agreement by use of Kappa. Two experienced psychiatric nurses who knew the patient well were recruited for the scoring process.

Agreement was examined separately on the presence of disorganized behavior and disorganized speech within each episode of interaction. For disorganized behavior, agreement was computed based on 40 episodes and for disorganized speech the number of episodes was 84. The data on disorganized behavior and disorganized speech and subcategories were analyzed by contingency-tables and significance test were performed as Chi-square or Fisher’s Exact tests.

Results

A total of 84 episodes were scored. The number of turns scored in the episodes of patient-staff interaction ranged from 5 to 32 with a mean of 10.9 turns per episode and a SD of 4.56 for the mean. **Observer agreement** on disorganized behavior was computed by Kappa = 0.77. The result for disorganized speech was Kappa = 0.87.

Table 2 shows the relationship between disorganized behavior and disorganized speech. The conditional probability of disorganized speech, which is contingent on disorganized behavior, was .78 (78.1% in Table 2). In comparison, a conditional probability of .42 was found when disorganized behavior was not present. The difference was statistically significant ($\chi^2=6.9, df=1, p=0.009$).
Reliable behavioral indicators will facilitate the recognition of schizophrenia in patients with limited verbal skills, who cannot report delusions and hallucinations. The procedure of diagnosing schizophrenia in patients with ID and autism will depend on accurate observations and reports from staff members and/or informal caregivers on the different symptoms displayed by the patient. When the patient is severely verbally impaired and cannot report, psychiatric symptoms, agitated behavior, anxiety reactions and frustration caused by communicative misunderstandings may easily be taken for psychotic behavior. This is most likely when the patient’s behavior appears as severely altered. It is therefore most important that reports from clinicians and staff members, and also informal caregivers, if possible, are specific enough to make the clinician able to differentiate between agitated behavior and severely disorganized behavior caused by a schizophrenia. An ideal report will encompass descriptions of symptoms on behavioral level; e.g.,: “Patient A seemed quite confused this morning. He started out with his jeans and put his underwear on top when he dressed. He was pouring milk from the bottle and out on the floor when he was having breakfast. He was leaving the table every two minutes and he did not finish his meal.”

The foundation for accurate reports on disorganized behavior will be dependent on thoroughly defined features of the phenomenon of disorganization. Therefore, it is important that indicators used in the diagnostic process are reliable and valid.

The present study might be a first step on the path of validation of severely disorganized behavior related to schizophrenia in adults with ID and autism. The clinical implications are closely related to staff members, who daily interact with the patients. The staff members ought to master and be aware of the particular ways each and every patient communicates because adults with ID and autism are exceptionally different even though they share core features of impaired communication, they often act and talk in idiosyncratic ways. The patient might display daily dramatic shifts in the ability of self-care, which includes both decision-making and also self-care related to activities of daily living. These shifts in self-care require that staff must be able to observe and interpret the patients’ symptoms level at different times from day to day and even through the same day. When the staff members possess knowledge on

### Table 2. Conditional Probabilities of Disorganized Speech During 84 Episodes

<table>
<thead>
<tr>
<th>Sub-Category</th>
<th>Disorganized Behavior</th>
<th>Disorganized Behavior</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not Present</td>
<td>Present</td>
<td></td>
</tr>
<tr>
<td>Disorganized speech</td>
<td>n=7 58.3 %</td>
<td>n=16 21.9 %</td>
<td>n=23</td>
</tr>
<tr>
<td>Not present</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disorganized speech</td>
<td>n=5 41.7 %</td>
<td>n=56 78.1 %</td>
<td>n=61</td>
</tr>
<tr>
<td>Present</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>n=12</td>
<td>n=72</td>
<td>n=84 100.0 %</td>
</tr>
</tbody>
</table>

Table 3 shows the relation between disorganized behavior and disorganized speech, and also the relationship between disorganized behavior and the subcategories of disorganized speech contingent on disorganized behavior. The results showed significant co-occurrence for disorganized speech, and for the subcategories of disorganized speech, incoherence, and derailment but not for pressure of speech.

### Table 3. Conditional Probabilities of Subcategories of Disorganized Speech in Presence of Disorganized Behavior (N=84)

<table>
<thead>
<tr>
<th>Sub-Category</th>
<th>Disorganized Behavior</th>
<th>Disorganized Behavior</th>
<th>P-value (Fisher’s Exact)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incoherence</td>
<td>41.7 %</td>
<td>74.0 %</td>
<td>0.04</td>
</tr>
<tr>
<td>Derailment</td>
<td>25.0 %</td>
<td>38.4 %</td>
<td>0.05</td>
</tr>
<tr>
<td>Pressure of speech</td>
<td>16.7 %</td>
<td>41.1 %</td>
<td>0.09</td>
</tr>
</tbody>
</table>

### Discussion

Behavioral and speech disorganization occur clearly concurrently. The contingent probability is almost 80%, which is a high value, especially considering the difference in observer agreement between observation of behavior and speech (0.77 and 0.87 respectively). This supports a hypothesis of co-occurrence of behavioral disorganization and speech disorganization in schizophrenic patients with ID and autism.

For the patient in this study, concurrent behavior and speech symptoms provided information on the same underlying condition of cognitive disorganization. This suggests that behavioral disorganization can be an indicator of thought disorder in patients with both ID and autism.
phenomenology of severe disorganization in these patients, staff will interact more smoothly and effectively related to the shifts in the patients’ symptoms.

References


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