Perceived Stigma and Quality of Life in Patients Following Recovery From Delirium

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ABSTRACT

Objective: To elucidate the factors related to perceived stigma and quality of life (QoL) in patients who have recovered from delirium.

Methods: This prospective cohort investigation of patients with delirium, as diagnosed according to *DSM-IV-TR* criteria, was conducted from July 2011 to May 2013. The perceived stigma level and QoL of each patient was assessed using the Perceived Stigma of Delirium Scale (PSDS) and European Quality of Life Visual Analog Scale (EQ-VAS), respectively, following recovery from delirium. Several clinical characteristics were assessed at baseline and after recovery from delirium, and a multivariate linear regression analysis was conducted.

Results: This study included 128 patients who completed a follow-up assessment after recovery from delirium. A multivariate analysis revealed that patients who had a history of depression (B = 3.34, *P* = .026), could recall their experiences with delirium (B = 1.71, *P* = .011), and had a longer duration from delirium detection to recovery (B = 1.39, *P* = .012) obtained higher PSDS scores than patients without these characteristics. The ability to recall delirium experiences (B = –7.17, *P* = .026) and the use of antipsychotics at follow-up assessment (B = –7.87, *P* = .039) were associated with lower EQ-VAS scores. Additionally, PSDS scores were negatively correlated with EQ-VAS scores (*r* = –0.37, *P* < .001).

Conclusions: This study found that patients who experienced an episode of delirium reported varying degrees of perceived stigma and that the ability to recall their delirium experiences was associated with a higher stigma and a poorer QoL. These findings suggest that care teams should pay more attention to perceived stigma in patients with delirium.

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Delirium is a common mental illness seen at most hospital admission offices that has a reported prevalence of 10%–31%.[1] Delirium is associated with significant adverse physical and psychological outcomes[2,3] and, although it is considered a transient, reversible syndrome, complete recovery from its symptoms is seen in only 52% of surviving patients.[4] Following recovery, approximately one-third of delirium patients suffer from recurrent episodes of delirium,[3] and many patients report a poor quality of life (QoL), cognitive problems, severe distress-related delirium experiences, shame, guilt, or fear of the recurrence of delirium.[5–9] Patients with delirium may be subject to the labeling and stigmatization associated with mental illness because delirium has features that include cognitive impairment, confusion, hallucinations, and delusions.[10] The experience of stigma may be enhanced in recovered patients due to improved cognitive functioning[11]; thus, management may be more important after recovery from delirium. Therefore, the National Institute for Health and Care Excellence (NICE) guidelines[12] recommend that patients who recover from delirium be informed that delirium is common and usually temporary and be given descriptions of the experiences of others with delirium as well as encouragement to share their experiences during recovery. However, our systematic literature review of electronic databases (PubMed and SCOPUS) identify no studies that have investigated stigma in delirium patients.

It is also possible that the experiences of individuals with delirium or the stigma related to those experiences could impact patients' QoL following recovery. However, the few studies[6,13] that have investigated the influence of delirium on the QoL of patients after recovery from delirium produced inconsistent results. These discrepancies may be due to the various characteristics associated with delirium (eg, hyperactive vs hypoactive), which may have different impacts on QoL.

Therefore, this study examined the perceived stigma and QoL experienced by patients who recovered from delirium to identify factors related to these phenomena. The relationship between perceived stigma and QoL was also analyzed.

METHODS

Study Design and Recruitment

This study was conducted as one component of an ongoing larger parent study that was designed to evaluate distress and disease course in patients with delirium and distress in their caregivers using a prospective cohort design. The subjects were nonpsychiatric inpatients (the majority of whom were cancer patients) referred to the consultation-liaison psychiatric service of Chonnam National University Hwasun Hospital in South Korea and consecutively enrolled from July 2011 to May 2013. Inclusion criteria for patients were a diagnosis of delirium made according to the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision (*DSM-IV-TR*) criteria[14] and confirmed by 2 psychiatrists using the Confusion

Clinical Points

- Patients with delirium may be subject to the labeling and stigmatization associated with mental illness, but there has been little or no investigation about perceived stigma by these patients.
- Patients who recovered from delirium reported that the experience of stigma was associated with their delirium experience. Higher scores on the Perceived Stigma of Delirium Scale were correlated with poorer quality of life.
- It is recommended that clinicians pay close attention to patients with a history of depression, as well as to those who can recall their delirium experiences or took longer to recover from delirium, because such patients may have perceived a greater degree of stigmatization than those without these characteristics.

Assessment Method (CAM)[15]; care provided by family members who were 18 years or older; and fluency in Korean. Patients were excluded if they had intellectual disability, dementia, or schizophrenia; communication difficulties that existed before they developed delirium; or delirium that was sustained for more than 6 months. Patients with delirium who were in the intensive care unit (ICU) or palliative care ward were excluded from this study because their physical condition might have limited their chance of recovery from delirium. After being provided with an explanation of the purpose and methodology of the study, all patients or their familial surrogates, depending on the patients' mental status, provided informed consent. In the case of consent from a familial surrogate, written informed consent was re-obtained from the patient after recovery from delirium. This study was approved by the Chonnam National University Hwasun Hospital Institutional Review Board.

Procedure and Follow-Up

Following the baseline assessment, the CAM was conducted by a psychiatrist every 2 days to determine the delirium status of each patient. A delirium episode was defined as resolved based on both a negative CAM result and the clinical judgment of a psychiatrist. Each patient who recovered from delirium received a follow-up assessment conducted by a trained research coordinator.

Demographic and Clinical Characteristics at Baseline

The baseline characteristics assessed in this study included age, sex, and years of education. The clinical characteristics evaluated included primary physical diagnosis (cancerous or noncancerous), current use of antipsychotics or benzodiazepines, and history of delirium or depression. To assess the physical status of each patient, Eastern Cooperative Oncology Group Performance Status (ECOG-PS) scores, which range from 0 (fully active) to 4 (completely disabled), were determined.[16]

The duration from delirium detection to consultation was defined using the clinical chart of each patient. The delirium motor subtype was determined using the Delirium Motor Subtype Scale (DMSS),[17] which includes 11 items that assess the motor behavior of delirium patients over the previous 24 hours; patients are classified as hyperactive, hypoactive, mixed, or no subtype.[17] The severity of delirium was assessed using the Korean version of the Delirium Rating Scale-Revised-98 (DRS-R98-K),[18,19] which comprises 13 severity items and 3 diagnostic items rated using a Likert scale.[18] The total severity score ranges from 0 to 39, and a higher score denotes greater severity of delirium. This measure was translated into Korean previously and has good reliability and validity.[19]

Demographic and Clinical Characteristics at Follow-Up

At the follow-up assessment, the patients' current use of antipsychotics or benzodiazepines was reviewed and their ECOS-PS and DRS-R98-K severity scores were measured again. The duration from delirium detection to recovery was defined as the total number of days that elapsed between delirium detection and recovery. Recall of the delirium experience was assessed using the Delirium Experience Questionnaire (DEQ).[7] In this study, the question, "Do you remember being confused? Yes or No?" was adopted to assess whether each patient recalled his/her delirium experience.

The personality of each patient was assessed using the 10-item short version of the Big Five Inventory (BFI-10),[20] which measures the Big Five dimensions of personality: extraversion, agreeableness, conscientiousness, neuroticism, and openness. Higher scores on this scale correspond to higher levels of each personality trait.[20] The BFI-10 has been translated into Korean and subsequently validated.[21]

Perceived Stigma and QoL After Recovery From Delirium

After recovery from delirium, the perceived stigma and QoL of the patients were evaluated at a follow-up assessment. Perceived stigma was assessed using the Perceived Stigma of Delirium Scale (PSDS),[22] which was developed to determine the perceived stigma experienced by patients who recover from delirium. The PSDS is conceptually grounded in modified labeling theory and focuses on negative stereotypes, negative social interactions, and the responses of the labeled individual.[23] The PSDS consists of 6 items: "I feel a sense of alienation from people after experiencing delirium"; "I seem to harm people around me with my delirium"; "People seem to be looking at me strangely"; "I am embarrassed or ashamed that I experienced delirium"; "I am nervous that I might have dementia or a mental disorder"; and "I am intimidated that my delirium could recur." These items form a single factor, rated on a 4-point Likert scale ranging from 0 (never) to 3 (strongly agree). The total score ranges from 0 to 18, and a higher score denotes a greater degree of perceived stigma. The PSDS has proven reliability and validity; the internal consistency of the scale was high (Cronbach $\alpha = 0.85$), and the overall test-retest reliability was 0.71.[22] The European Quality of Life Visual Analog Scale (EQ-VAS)[24] was used to assess subjective QoL in patients who recovered from delirium. The total score ranges from 0 to 100, and a higher score denotes a better QoL.

Table 1. Associations Between Baseline Characteristics and Perceived Stigma and Quality of Life (n = 128)

Variable	Total	PSDS	EQ-VAS
Categorical	n (%)	Median (IQR)	
Sex			
Female	44 (34.4)	7.5 (3.3–11.0)	60.0 (42.5–80.0)
Male	84 (65.6)	8.0 (5.0–9.0)	70.0 (60.0–80.0)
Physical illness			
Noncancer	27 (21.1)	7.0 (4.0–11.0)	70.0 (50.0–80.0)
Cancer	101 (78.9)	8.0 (5.0–10.0)	70.0 (50.0–80.0)
Past history of delirium			
No	117 (91.4)	8.0 (4.5–10.0)	70.0 (50.0–77.5)
Yes	11 (8.6)	8.0 (6.0–11.0)	70.0 (40.0–90.0)
Past history of depression			
No	121 (94.5)	7.0 (4.5–10.0)[a]	70.0 (50.0–80.0)
Yes	7 (5.5)	11.0 (8.0–14.0)	70.0 (40.0–90.0)
Delirium Motor Subtype Scale			
Hyperactive	74 (57.8)	7.0 (5.0–9.0)	70.0 (57.5–80.0)
Hypoactive	20 (15.6)	8.0 (4.0–11.0)	60.0 (50.0–67.5)
Mixed	25 (19.5)	8.0 (4.0–11.0)	70.0 (45.0–70.0)
No subtype	9 (7.0)	10.0 (7.0–13.5)	70.0 (45.0–82.5)
Use of antipsychotics			
No	96 (75.0)	7.5 (5.0–10.0)	70.0 (50.0–80.0)
Yes	32 (25.0)	8.0 (4.3–11.0)	70.0 (50.0–70.0)
Use of benzodiazepines			
No	91 (71.1)	8.0 (5.0–10.0)	70.0 (50.0–80.0)
Yes	37 (28.9)	7.0 (4.0–11.0)	70.0 (55.0–80.0)
Continuous	Median (IQR)	Correlation Coefficient	
Age, y	72.0 (65.0–77.0)	0.14	−0.10
Years of education	6.0 (6.0–12.0)	−0.05	−0.04
ECOG-PS score	2.5 (2.0–3.0)	0.11	−0.17[a]
Duration of delirium detection to consultation, d	2.0 (1.0–4.0)	0.03	−0.05
DRS-R98-K severity score	16.0 (12.0–20.0)	0.10	−0.01

[a]$P < .1$; *P* by Mann-Whitney *U* test, Kruskal-Wallis test, or Spearman rank correlation test as appropriate.
Abbreviations: DRS-R98-K = Korean version of the Delirium Rating Scale-Revised-98, ECOG-PS = Eastern Cooperative Oncology Group Performance Status, EQ-VAS = European Quality of Life Visual Analog Scale, IQR = interquartile range, PSDS = Perceived Stigma of Delirium Scale.

Table 2. Associations Between Follow-Up Characteristics and Perceived Stigma and Quality of Life (n = 128)

Variable	Total	PSDS	EQ-VAS
Categorical	n (%)	Median (IQR)	
Recall of delirium experiences			
No	66 (51.6)	6.5 (4.0–9.0)[a]	70.0 (60.0–80.0)[a]
Yes	62 (48.4)	8.0 (5.0–11.0)	65.0 (47.5–70.0)
Use of antipsychotics			
No	29 (22.7)	8.0 (5.0–9.5)	70.0 (55.0–80.0)[a]
Yes	99 (77.3)	8.0 (5.0–11.0)	70.0 (50.0–70.0)
Use of benzodiazepines			
No	99 (77.3)	8.0 (5.0–10.0)	70.0 (50.0–80.0)
Yes	29 (22.7)	8.0 (4.5–12.0)	60.0 (40.0–80.0)
Continuous	Median (IQR)	Correlation Coefficient	
ECOG-PS score	2.0 (1.0–3.0)	0.04	−0.23[b]
Duration of delirium detection to recovery, d	7.0 (5.0–11.0)	0.17[a]	−0.04
Personality score			
Extraversion	3.0 (3.0–3.5)	−0.19[b]	0.06
Agreeableness	3.5 (3.0–4.0)	−0.09	0.04
Conscientiousness	4.0 (4.0–4.5)	0.02	0.02
Neuroticism	3.0 (2.0–3.5)	0.09	−0.10
Openness	3.0 (2.5–3.5)	−0.01	0.13
DRS-R98-K severity score	3.5 (1.0–7.0)	−0.04	−0.02

[a]$P < .1$.
[b]$P < .05$; *P* by Mann-Whitney *U* test or Spearman rank correlation test as appropriate.
Abbreviations: DRS-R98-K = Delirium Rating Scale-R98-K, ECOG-PS = Eastern Cooperative Oncology Group Performance Status, EQ-VAS = European Quality of Life Visual Analog Scale, IQR = interquartile range, PSDS = Perceived Stigma of Delirium Scale.

Statistical Analysis

A univariate analysis was performed on the independent variables to identify the factors associated with stigma and QoL. This study analyzed non-normally distributed data using the Mann-Whitney *U* test or the Kruskal-Wallis test for categorical variables, and the Spearman rank correlation test for continuous variables. Factors that were significantly associated with each dependent variable in the univariate analysis ($P < .1$) were then entered into multivariate linear regression models to identify the factors related to stigma and QoL. The multiple coefficient of determination (R^2) was used as the goodness-of-fit statistic for the model; this value represents the proportion of variance in the dependent variable that can be accounted for by the predictors in the model. Additionally, a 2-tailed Spearman rank correlation test was used to determine the associations of stigma and QoL with recovery from delirium. The coefficient of determination was calculated by univariate linear regression analysis. Skewed continuous variables were normalized using a log transformation in all linear regression analysis. A *P* value < .05 was considered to indicate statistical significance, and all statistical tests were performed using SPSS version 18.0 (SPSS; Chicago, Illinois).

RESULTS

Sample Recruitment

During the recruitment period, 784 consecutive patients referred to our psychiatric services department were confirmed to have a diagnosis of delirium. Following the application of the inclusion and exclusion criteria, 382 patients were eligible for this study, and 224 of these patients (58.6%) agreed to participate in the cohort study. Of these 224 patients, 128 (57.1%) were followed up after recovery from delirium, and these patients were included in the study. Of the remaining 96 patients who were not followed up, 68 were discharged from the hospital before recovery from delirium, 24 died, and 4 refused to participate in the follow-up assessment. The rates of attrition did not significantly differ for the patients who were followed up in terms of their baseline demographics or clinical characteristics (all *P* values > .1).

Demographic and Clinical Characteristics

The demographic and clinical characteristics of the patients at baseline are shown in Table 1. Their median age was 72.0 (interquartile range [IQR] 65.0–77.0) years, 84 (65.6%) were male, and the median delirium severity score on the DRS-R98-K was 16.0 (IQR 12.0–20.0). The characteristics of the patients at the follow-up assessment are shown in Table 2. The median duration from delirium detection to recovery

Table 3. Multivariate Linear Regression Analysis of the Factors Related to Stigma (n = 128)

Factor	B	95% CI	*P*
Past history of depression	3.34	0.63 to 6.40	.026
Recall of delirium experience	1.71	0.43 to 3.02	.011
Duration of delirium detection to recovery[a]	1.39	0.29 to 2.41	.012
Extraversion[a]	2.86	−6.15 to 0.03	.073

[a]Log transformed.

Table 4. Multivariate Linear Regression Analysis of the Factors Related to Quality of Life (n = 128)

Factor	B	95% CI	*P*
Recall of delirium experience	−7.17	−13.46 to −0.87	.026
Use of antipsychotics, follow-up	−7.87	−15.35 to −0.39	.039
ECOG-PS score, baseline[a]	−6.13	−13.72 to 1.47	.113
ECOG-PS score, follow-up [a]	−9.83	−20.19 to 0.52	.063

[a]Log transformed.
Abbreviation: ECOG-PS = Eastern Cooperative Oncology Group Performance Status.

was 7.0 (IQR 5.0–11.0) days, and 62 patients (48.4%) were able to recall their delirium experiences.

Perceived Stigma and QoL Among Patients Who Recovered From Delirium

The median score on the PSDS for the total sample was 8.0 (IQR = 5.0–10.0; range, 0.0–16.0), and the median score of the patients on the EQ-VAS was 70.0 (IQR = 50.0–80.0; range, 10.0–99.0). The PSDS scores were negatively correlated with the EQ-VAS scores ($r = -0.37$, $P < .001$). In the univariate linear regression, R^2 was 0.120 (B = −10.52; 95% CI, −15.55 to −5.50).

Univariate Associations With Perceived Stigma

The findings of the univariate analysis regarding stigma are presented in Tables 1 and 2. Patients who had a history of depression and were able to recall their delirium experiences had higher PSDS scores than patients who did not. A longer duration from delirium detection to recovery was associated with higher PSDS scores, but an extraverted personality type was negatively associated with PSDS scores. None of the other characteristics was associated with PSDS scores.

Univariate Associations With Subjective QoL

The findings of the univariate analysis regarding QoL are presented in Tables 1 and 2. The ability to recall delirium experiences, use of antipsychotics at the follow-up assessment, and higher ECOG-PS scores at baseline and at follow-up were associated with lower EQ-VAS scores, but none of the other characteristics was associated with the EQ-VAS scores.

Factors Related to Perceived Stigma

The results of the analysis are summarized in Table 3. The multivariate linear regression model explained 14% ($R^2 = 0.138$) of the variance in perceived stigma. A history of depression, ability to recall one's experiences with delirium, and a longer duration from delirium detection to recovery were significantly related to higher PSDS scores in patients who recovered from delirium. An extraverted personality type tended to be related to lower PSDS scores, but this relationship had only a borderline level of significance.

Factors Related to Subjective QoL

The results of the analysis are summarized in Table 4. The multivariate linear regression model explained 13% ($R^2 = 0.126$) of the variance in subjective QoL. Ability to recall delirium experience and the use of antipsychotics at the follow-up assessment were significantly associated with lower EQ-VAS scores. Higher ECOG-PS scores at follow-up tended to be related to lower EQ-VAS scores, but this relationship had only a borderline level of significance.

DISCUSSION

The principal findings of this study were that patients who had a history of depression, who could recall their experiences with delirium, and who had a longer duration from delirium detection to recovery reported a greater degree of perceived stigma following recovery from delirium than those without these characteristics. Additionally, subjective QoL was associated with the ability to recall one's delirium experiences and the use of antipsychotics at the follow-up assessment, and perceived stigma had a significant negative correlation with QoL in these patients. To our knowledge, the present study is the first to report the experience of stigma among patients who recovered from delirium.

Conditions that cause patients to harm others and exhibit outward manifestations of their illness tend to be stigmatized.[25,26] In particular, the risk of aggressive behaviors associated with a mental illness determines the extent of the stigma placed on patients with that condition.[27] Thus, the symptoms of delirium may lead this condition to be stigmatized because the cognitive and behavioral symptoms are often noticeable to others, and these patients sometimes harm others due to their hallucinations or delusions.

The reactions of patients to stigmatizing conditions depend on patients' awareness of having a mental illness as well as their perception of stigmatization by other people.[28] Although the awareness and perceptions of these patients may be impaired during an episode of delirium, these abilities may be regained after the resolution of the delirium. For example, patients who are able to recall their delirium describe the experience as a stupid condition and report that they were afraid of becoming crazy.[29] In accordance with the public stereotypes of individuals with mental illness,[23] our study found that patients who are able to recall their delirium experiences are more likely to internalize the public stigma. Evidence suggests that patients who recall their delirium find their recollections to be generally distressing and related to relatively long-term psychological sequelae.[7,30] To reduce this distress and the resulting sequelae, provision of explanatory information would be helpful for both the patients and their caregivers.[12,30] The duration from delirium detection to recovery may be related to the experience of stigma because

a longer duration increases the chance that the cognitive and behavioral symptoms will be observed by others. A history of depression may reflect individual vulnerability to stigma.

In this study, the ability of participants to recall their delirium-related experiences was associated with a poor QoL after recovery from delirium. A previous study[31] showed that patients who recalled their delusional memories from the ICU reported a lower QoL after recovery than patients who could not recall their experiences. On the contrary, another study[32] reported the lack of an association between QoL and memories. Differences in the study populations could have produced the conflicting results. The previous studies[31,32] investigated only ICU patients, while we did not. Delirium experiences and stigma would differ in various environments because of societal influences on stigma formation.[23]

In this study, a greater degree of perceived stigma was associated with a poor subjective QoL in patients who recovered from delirium. It has been shown that patients with a variety of mental illnesses who experience perceived stigma also have a decreased QoL.[33] For example, patients with dementia who have a perceived stigma are more likely to have poor QoL outcomes.[34] The perceived stigma can lead patients to have low self-esteem, which leads to the low QoL.[28,35] These previous findings may explain the present results.

The use of antipsychotics during the follow-up period was also associated in this study with a poor QoL. Antipsychotics are frequently used for the symptomatic management of delirium, but there have been several reports of side effects of antipsychotics in the treatment of delirium.[36] However, we did not investigate side-effect profiles. A controlled trial is needed to elucidate the relationship between QoL and the use of antipsychotics in patients with delirium.

This study has several important clinical implications. Patients who recovered from delirium reported that the experience of stigma was associated with their delirium experience. In particular, the patients who were able to recall their delirium experiences reported a greater degree of perceived stigma and a poorer QoL than who those who could not. Therefore, it is recommended that clinicians pay more attention to the patients who are able to recall their delirium episode or who have a history of depression. The provision of information, the sharing of the experiences of patients with delirium during recovery, and the rapid control of delirium symptoms may help to reduce stigma, but the impacts of these various types of interventions require further evaluation.[12]

Several limitations should be considered when interpreting our results. First, a relatively small percentage of enrolled patients (57.1%) was followed up after recovery from delirium. Second, the sample consisted of patients who were referred to a consultation-liaison psychiatric service; thus, it is possible that some patients with delirium who were not referred were not surveyed. For example, because the hyperactive subtype of delirium tends to be detected more than the hypoactive subtype,[37] patients with hypoactive delirium may have been underrepresented in our sample. Third, the majority of the participants in this study were cancer patients. For these reasons, the results may not represent the entire population of delirium patients. Fourth, R^2 values in the univariate and multivariate linear regression models were 0.12–0.14, indicating that our models explained 12%–14% of the variance. In the behavioral sciences, this represents a small to midsized effect.[38] Thus, other variables that were not investigated in the study could affect perceived stigma or quality of life in patients who have recovered from delirium. Finally, the degree of stigma experienced by the patients was assessed relatively soon after the delirium recovery, which may have limited the clinical implications of the perceived stigma. Thus, long-term follow-up studies investigating the course and impact of the stigma associated with delirium are warranted. Despite these limitations, our results may be used as a foundation for subsequent longitudinal studies with larger study populations that will bring needed attention to the perceived stigma and subjective QoL in patients who recover from delirium.

In conclusion, delirium is a frightening and stigmatizing experience for both patients and their relatives and caregivers. A perceived stigma associated with delirium was reported to varying degrees and was very likely closely associated with QoL. Thus, health care providers should address the stigma and distress experienced by patients who have recovered from delirium.

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Editor's Note: We encourage authors to submit papers for consideration as a part of our Focus on Geriatric Psychiatry section. Please contact Helen Lavretsky, MD, MS, at hlavretsky@psychiatrist.com, or Gary W. Small, MD, at gsmall@psychiatrist.com.