Subtyping demoralization in the medically ill by cluster analysis

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ABSTRACT – Background and Objectives: There is increasing interest in the issue of demoralization, particularly in the setting of medical disease. The aim of this investigation was to use both DSM-IV comorbidity and the Diagnostic Criteria for Psychosomatic Research (DCPR) in order to characterize demoralization in the medically ill.

Methods: 1700 patients were recruited from 8 medical centers in the Italian Health System and 1560 agreed to participate. They all underwent a cross-sectional assessment with DSM-IV and DCPR structured interviews. 373 patients (23.9%) received a diagnosis of demoralization. Data were submitted to cluster analysis.

Results: Four clusters were identified: demoralization and comorbid depression; demoralization and comorbid somatoform/adjustment disorders; demoralization and comorbid anxiety; demoralization without any comorbid DSM disorder. The first cluster included 27.6% of the total sample and was characterized by the presence of DSM-IV mood disorders (mainly major depressive disorder). The second cluster had 18.2% of the cases and contained both DSM-IV somatoform (particularly, undifferentiated somatoform disorder and hypochondriasis) and adjustment disorders. In the third cluster (24.7%), DSM-IV anxiety disorders in comorbidity with demoralization were predominant (particularly, generalized anxiety disorder, agoraphobia, panic disorder and obsessive-compulsive disorder). The fourth cluster had 29.5% of the patients and was characterized by the absence of any DSM-IV comorbid disorder.

Conclusions: The findings indicate the need of expanding clinical assessment in the medically ill to include the various manifestations of demoralization as encompassed by the DCPR. Subtyping demoralization may yield improved targets for psychosomatic research and treatment trials.

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Introduction

Several studies confirmed a high prevalence of demoralization among patients with medical disorders, especially with life-threatening or disabling disorders\(^1\)\(^-\)\(^7\). Demoralization was also found to precede the onset of serious diseases, such as cancer, ischemic heart disease and stroke\(^1\)\(^,\)\(^6\)\(^,\)\(^8\). Despite its clinical and prognostic relevance, demoralization has not been adequately recognized by traditional psychiatric classifications and very few dimensional instruments have been specifically developed for its assessment\(^9\). A substantial problem of research in demoralization lies in the various way in which it is defined\(^10\) ranging from a non-specific psychological distress\(^11\) and a normal response to adversity\(^3\) to a specific syndrome resulting from the convergence of distress and subjective incompetence\(^12\) that may negatively affect the course of both psychiatric and medical disorders\(^13\)\(^,\)\(^14\).

Schmale and Engel\(^15\) described the pattern of psychological features of the “giving up-given up complex”, whose characteristics may be related to the concept of subjective incompetence: feelings of helplessness and hopelessness, perception of diminished competence and loss of mastery and control\(^15\). The giving up-given up complex was found to frequently occur in the life setting immediately preceding the onset of disease and can also be exacerbated by the course of illness\(^16\). Frank\(^17\) suggested that demoralization results from the awareness of being unable to cope with a pressing problem or of having failed to meet one’s own or others’ expectations and is the main reason why individuals seek psychotherapeutic treatment. All these subclinical aspects, which cannot be identified by psychiatric categories\(^3\), are included in the concept of demoralization according to the Diagnostic Criteria for Psychosomatic Research (DCPR)\(^18\)\(^,\)\(^19\) (Table 1). DCPR were developed about 15 years ago by an international group of investigators\(^18\) with the aim to translate psychosocial variables, issued from a wide body of psychosomatic literature, of prognostic and therapeutic value in the course of physical conditions, into working categories whereby individual patients could be identified. The application of the DCPR operational criteria has permitted to document the occurrence of demoralization across different medical settings, substantiating previous findings that used dimensional tools\(^20\)\(^,\)\(^21\). In studies utilizing the DCPR, demoralization was found in 14-44% of patients with cardiac\(^22\), oncological\(^23\), dermatological\(^24\), gastrointestinal\(^25\) and endocrine conditions\(^26\)\(^-\)\(^28\), in those recruited in primary care\(^29\) and in consultation-liaison psychiatry settings\(^30\)\(^,\)\(^31\).

| Table 1 |
| DCPR criteria for demoralization |
| A through C are required |
| A. A feeling state characterized by the patient’s consciousness of having failed to meet his or her own expectations (or those of others) or being unable to cope with some pressing problems; the patient experiences feelings of helplessness, or hopelessness, or giving up. |
| B. The feeling state should be prolonged and generalized (at least 1-month duration). |
| C. The feeling closely antedated the manifestations of a medical disorder or exacerbated its symptoms. |

DCPR demoralization appeared to be far less frequent in the general population.

The aim of this investigation was to use both DSM and DCPR comorbidity in order to examine the feasibility of subtyping in a highly heterogenous group of medical patients diagnosed as suffering from DCPR demoralization, by a cluster analysis technique.

Methods
Design, procedures and subjects

Patients were recruited from different medical settings in an ongoing multicenter project concerned with the psychosocial dimensions of medical patients. Even though studies involved in the research project had different aims and sample sizes, they shared a common methodology in the assessment of psychopathology and psychosocial syndromes. Patients were recruited consecutively, with the intent of being representative of their respective patient populations:

1. Consecutive outpatients with functional gastrointestinal disorders (N = 190, 12.2% of the total sample) from the Functional Gastrointestinal Disorders Outpatient Clinic of the Scientific Institute of Gastroenterology at Castellana Grotte, Italy.

2. Consecutive outpatients with heart diseases (N = 351, 22.5%) from 3 different sources: 1) 198 patients who underwent heart transplantation from the Heart Transplantation Unit of the Institute of Cardiology at S. Orsola Hospital of Bologna, Italy; 2) 61 consecutive patients with a recent (within 1 month) first myocardial infarction diagnosis from the Cardiac Rehabilitation Program of the Bellaria Hospital in Bologna, Italy; and 3) 92 consecutive patients with a recent (within 1 month) first myocardial infarction diagnosis, from the Institute of Cardiology of University Hospital in Modena, Italy.

3. Consecutive outpatients with endocrine disorders (N = 162, 10.4%) from the Division of Endocrinology of the University of Padova Medical Center, Padova, Italy.

4. Consecutive outpatients who had received a diagnosis of cancer within the past 18 months (N = 104, 6.7%) from the S. Anna University Hospital in Ferrara, Italy.

5. Consecutive outpatients with skin disorders (N = 545, 34.9%) from the Dermatologic Institute of the Immaculate (IDI-IRCCS), Rome, Italy.

6. Consecutive inpatients referred for psychiatric consultation in 2 large university-based general hospitals (N = 208, 13.3%) from the University of Perugia and University of Foggia, Italy.

The study was approved by institutional review boards and local ethics committees, and written informed consent was obtained from all patients. The patients who were approached were 1700; 140 (8.2%) declined to participate. The most common reason for refusal was lack of time. The total sample included 1560 patients (712 men, 45.6%, and 848 women, 54.4%), with a mean age of 45 (SD = 15.02) years, and a mean of 10.6 (SD = 3.85) years of education. There were no significant differences in terms of sociodemographic variables between the patients who accepted and those who refused.

Assessment

All patients underwent two detailed semi-structured interviews by clinical psychologists or psychiatrists with extensive experience, including psychosomatic research. Psychiatric disorders were investigated with the Structured Clinical Interview for DSM-IV (SCID). Diagnoses were grouped according
to diagnostic categories such as mood disorders, anxiety disorders, somatoform disorders, adjustment disorders, and other disorders (including psychotic disorders, eating disorders, sexual dysfunctions and substance use related disorders). Psychosomatic syndromes were diagnosed with the Structured Interview for DCPR35. The DCPR encompass various diagnostic rubrics: abnormal illness behavior (disease phobia, thanatophobia, health anxiety, illness denial), somatization syndromes (persistent somatization, functional somatic symptoms secondary to a psychiatric disorder, conversion symptoms, anniversary reactions), irritability (irritable mood, type A behavior), demoralization, and alexithymia. The interview for DCPR consists of 58 items scored in a yes/no response format evaluating the presence of 1 or more of 12 psychosomatic syndromes. The interview has shown excellent inter-rater reliability, construct validity, and predictive validity for psychosocial functioning and treatment outcome30.

Data analysis

Data were entered in SPSS (SPSS Inc., USA), after which descriptive statistics were calculated. Two-step cluster analysis was performed to organize observations into two or more mutually exclusive groups, where members of the groups shared properties in common36. The following variables were included in the analysis: DSM mood disorders, anxiety disorders, somatoform disorders, adjustment disorders, other disorders (psychotic disorders, eating disorders, sexual dysfunctions and substance use disorders), absence of any DSM disorder absence of any DSM disorder, DCPR abnormal illness behavior, somatization, irritability and alexithymia.

The two-step cluster method is a scalable cluster analysis algorithm designed to handle large data sets. It can handle both continuous and categorical variables. The two steps are: 1) pre-cluster the cases into many small sub-clusters; 2) cluster the sub-clusters resulting from pre-cluster step into the desired number of clusters. The log-likelihood distance measure was used, with subjects assigned to the cluster leading to the largest likelihood. No prescribed number of clusters was suggested. The Bayesian Information Criterion (BIC) was used to judge the adequacy of the final solution. Differences in sample characteristics were compared according to cluster membership using independent sample t-tests and chi squared tests for continuous and categorical variables, respectively. For all tests performed, the significance level was set at 0.05, two-tailed.

Results

A total of 373 patients (23.9%; 60.3% female) received a diagnosis of demoralization according to DCPR criteria, with a mean age of 48 (SD = 14.57) years, and a mean of 10 (SD = 3.90) years of education. Of these, 263 (70.5%) had at least 1 comorbid Axis I disorder (mainly mood and anxiety disorders), and 308 (82.6%) presented at least 1 comorbid DCPR syndrome. Frequencies for each of the diagnostic categories of psychiatric disorders and psychosomatic syndromes are shown in Table 2.

Two-step cluster analysis yielded 4 clusters, with no exclusion of cases. The composition of the clusters (Figure 1) and the importance of variables within a cluster were then examined.

The first cluster had 27.6% (N = 103) of the total sample and was characterized by the presence of DSM-IV mood disorders (mainly major depressive disorder); this cluster was named demoralization and comorbid depression.
Table 2
Frequencies of diagnostic categories of psychiatric disorders and psychosomatic syndromes

<table>
<thead>
<tr>
<th>Diagnostic category</th>
<th>Frequency N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DSM mood disorders</td>
<td>130 (34.9)</td>
</tr>
<tr>
<td>DSM anxiety disorders</td>
<td>91 (24.4)</td>
</tr>
<tr>
<td>DSM somatoform disorders</td>
<td>29 (7.8)</td>
</tr>
<tr>
<td>DSM adjustment disorders</td>
<td>50 (15.5)</td>
</tr>
<tr>
<td>other DSM disorders</td>
<td>8 (2.1)</td>
</tr>
<tr>
<td>no DSM disorders</td>
<td>110 (29.5)</td>
</tr>
<tr>
<td>DCPR somatization</td>
<td>141 (37.8)</td>
</tr>
<tr>
<td>DCPR abnormal illness behavior</td>
<td>130 (34.9)</td>
</tr>
<tr>
<td>DCPR irritable mood and type A behavior</td>
<td>135 (36.2)</td>
</tr>
<tr>
<td>DCPR alexithymia</td>
<td>52 (13.9)</td>
</tr>
</tbody>
</table>

Figure 1. Distribution of diagnostic categories within each cluster.
The second cluster had 18.2% of the cases (N = 68) and contained both DSM-IV somatoform (particularly, undifferentiated somatoform disorder and hypochondriasis) and adjustment disorders; this cluster was named *demoralization and comorbid somatoform/adjustment disorders*.

In the third cluster (N = 92; 24.7%), DSM-IV anxiety disorders were predominant (particularly, generalized anxiety disorder, agoraphobia, panic disorder and obsessive-compulsive disorder); this cluster was thus named *demoralization and comorbid anxiety*.

The fourth cluster had 29.5% (N = 110) of the patients and was characterized by the absence of any DSM-IV comorbid disorder; this cluster was named *demoralization without any comorbid DSM disorder*.

The frequency and the importance of the remaining variables (e.g., other disorders listed in DSM, DCPR somatization, abnormal illness behavior, irritability, alexithymia) were comparable among the groups, indicating that these diagnostic categories did not make a substantial contribution to cluster formation.

When differences among the cluster groups were examined, no significant differences were found with regard to both gender and years of education. Age differed among the clusters (F\(_{3,246} = 4.186; \ p < 0.01\)), with patients in the fourth cluster being the oldest (mean age 52 years; SD = 1.76), and those in the second cluster the youngest (mean 43.2 years; SD = 1.88).

With regard to specific medical settings, there were significant differences among the clusters (\(\chi^2_{18} = 121.710; \ p < 0.001\): a greater proportion of patients from the Functional Gastrointestinal Disorders Outpatient Clinic were found in the first two clusters (N = 14; 32.6% and N = 16; 37.2%, respectively); patients who had received a diagnosis of cancer within the past 18 months were mainly represented in the second cluster (N = 19; 55.9%); a number of patients with skin diseases were contained in both the first and the fourth clusters (N = 22; 29.3% and N = 24; 32%, respectively). The vast majority of inpatients from psychiatric consultation services were present in the first three clusters (N = 19; 35.2%, N = 16; 29.6% and N = 16; 29.6%, respectively). Patients with endocrine disorders were mainly represented in the third cluster (N = 22; 40.7%), as well as those who underwent heart transplantation (N = 27; 42.9%), even though the latter were also present in the fourth cluster (N = 25; 39.7%). About half of patients with a recent first myocardial infarction diagnosis (N = 24; 48%) were found in the fourth cluster.

**Discussion**

This study has found that almost 24% of patients with various medical illnesses received a diagnosis of demoralization according to DCPR criteria. These results confirm that demoralization is frequent across different medical settings.

The first cluster (demoralization and comorbid depression) encompassed about 30% of cases. This is not a new finding. In fact, previous studies suggested that demoralization can be found in major depression: Klein\(^{37}\) claimed that demoralization may develop in “endogenomorphic depression”, and Galeazzi *et al.*\(^{30}\) and Mangelli *et al.*\(^{10}\) observed demoralization in more than 50% of medically ill patients with major depression. In a study conducted by Marcheschi and Maggini\(^{38}\), the presence of major depression was related to an increase of demoralization scores. Even though demoralization and depression are distinct clinical phenomena\(^{10,39-41}\) in many
cases they coexist. A patient’s diminished frustration tolerance and increased mood reactivity while in the hospital are likely due to a sense of demoralization caused by circumstances beyond his control in the hospital. However, his or her more chronic symptoms of anhedonia, social isolation, and poor concentration are suggestive of a coexisting depressive disorder. There is growing opinion that, within clinical depression, traditional diagnostic systems do not allow differentiation between different mood states commonly experienced in medically ill patients.

Clarke and colleagues found evidence for different dimensions or types of depression, primarily distinguished by levels of demoralization (hopelessness, helplessness) and anhedonia (diminished interest and ability to experience pleasure). Anhedonia is evident in a number of clusters but did not correlate strongly with the demoralization score.

If on one hand severe and debilitating medical illness can frequently lead to demoralization, on the other hand chronic and disabling mental illness can also be associated with demoralization. In major depression, demoralization can be viewed as a step in a sequence, starting with the loss of interest and pleasure, the psychopathological core alteration of this disorder. If the loss of pleasure and interest becomes very severe and pervasive, demoralization can follow.

Therefore, demoralization in major depressive patients may represent a psychological response to a prolonged and severe loss of interest and pleasure. However, in other medically ill patients the relationship between major depression and demoralization might be characterized by a different sequence. In fact, a chronic, severe, incapacitating medical illness may induce feelings of poor self-esteem, helplessness, hopelessness and subjective incompetence. It cannot be excluded that demoralization, once occurred, may predispose medically ill patients to suffer from major depression, which in turn worsen the feelings of poor self-esteem, helplessness and hopelessness. Moreover, it could be that demoralization, when associated with clinical depression, individuates a subgroup of patients at a greater risk of a worse outcome.

This could happen since the addition of demoralization to major depressive disorder results in decreased psychological well-being dimensions, such as autonomy, positive relations and self-acceptance as recently found in a population of heart transplanted patients.

The second cluster encompassed 18.2% of the cases and was characterized by both DSM-IV somatoform (particularly, undifferentiated somatoform disorder and hypochondriasis) and adjustment disorders. Both diagnostic rubrics have recently undergone considerable criticism as to their clinical usefulness. Clarke et al. found that in 312 patients admitted to hospital with a range of medical conditions (cardiovascular, gastrointestinal, respiratory, rheumatological and neurological), clusters of high self-reported distress (demoralization and demoralized grief) were significantly associated with DSM-IV somatoform disorders. Patients with somatization syndromes might present a bias to interpret minor physical changes as a possible sign of a severe illness. Affective consequences such as demoralization might present a negative feedback loop that helps to maintain the problem. On the other hand, adjustment disorders have been found to be the most frequent psychiatric diagnosis in the medically ill. Problems have been raised, however, as to their clinical value. In the study by Grassi et al. one hundred patients with medical illness and a diagnosis of DSM-IV adjustment disorder were interviewed according to the DCPR system. A considerable overlap was shown between adjustment disorders and DCPR clusters related to som-
atization (37%) and demoralization (33%), confirming our findings. While researchers have highlighted the need to include demoralization in the psychiatric nomenclature, currently it is often referred to as adjustment disorder. However, it has been argued that adjustment disorder does not place sufficient emphasis on the personal narrative of incompetence that characterizes the lives of demoralized individuals.

In the third cluster (24.7%), DSM-IV anxiety disorders (particularly, generalized anxiety disorder, agoraphobia, panic disorder and obsessive-compulsive disorder) in comorbidity with demoralization were predominant. Since anxiety disorders can be severely disabling and impairing, it is not surprising that a number of patients experience demoralization. The phenomenon of demoralization has been largely applied to clinical populations to explain a developmental spectrum of psychopathology. Frank observed both anxiety and depressive symptomatology as direct expressions of demoralization. Research indicates that if an individual endures internal or external stressors that are perceived as severe, then anxiety levels increase. When anxiety levels increase, an individual may feel the situation is uncontrollable, leading to helplessness. If the feeling of helplessness is not attended to, then hopelessness and the inability to cope will develop. Anxiety then might evolve into subsequent depression by a sort of process of demoralization. The relation between symptoms of anxiety/depression and demoralization, as suggested by Grassi et al., reopens the question whether demoralization is part of the anxious-depressive spectrum.

The fourth cluster had 29.5% of the patients and was characterized by the absence of any DSM-IV comorbid disorder. This finding is clinically relevant. Through the use of the DCPR among medically ill patients, it has been confirmed that demoralization is a construct that is not necessarily related to psychiatric disorders. In a large study of 809 medical patients, the frequency of DCPR demoralization was 30%, whereas the frequency of DSM-IV major depression was only 17%. Of interest, 44% of patients with major depression did not meet the DCPR criteria for demoralization, whereas up to 69% of those with demoralization did not meet the criteria for major depression. Patient’s inability to cope with some pressing problems, feelings of helplessness, or hopelessness, or giving up could represent key factors for the development of illnesses or contributing factor to the expression of physical or mental disease activity. Demoralization should thus be examined carefully, avoiding the common tendency to dismiss it as an understandable (and thus not requiring attention or treatment) condition in patients with medical illnesses. Preliminary clinical findings suggest that a careful diagnosis of demoralization may lead to effective treatment of both psychological and somatic symptoms. There remains the need to further investigate if treating sub-clinical syndromes can improve quality of life and reduce the risk of morbidity and mortality in these patients.

The study has limitations due to its cross-sectional nature. We do not know, in fact, the longitudinal course of these clusters. However, the findings of this study highlight the importance of detecting demoralization alone or in comorbidity with major depression, somatization, adjustment and anxiety disorders. Exclusive reliance on psychiatric diagnostic criteria has impoverished the clinical process and does not reflect the complex thinking that underlies decisions in psychiatric practice. Identifying and subtyping demoralization in the setting of medical disease may yield improved targets for research and treatment trials, as is currently advocated in major depression.
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References


52. Wise TN. Diagnostic criteria for psychosomatic research are necessary for DSM V. Psychother Psychosom 2009; 78(6): 330-332.


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