Psychological Characterization of Demoralization in the Setting of Heart Transplantation

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Objective: The aims of this study were to examine the psychological features of demoralization and its overlap with major depressive disorder in a sample of cardiac transplant recipients, with special reference to psychological well-being, quality of life, and psychological distress. We also tested whether demoralization was significantly associated with demographic characteristics and clinical parameters, including survival status at a 6-year follow-up.

Method: From May to December 2002, 95 heart transplanted patients were administered the Structured Clinical Interview for *DSM-IV* and the Diagnostic Criteria for Psychosomatic Research, leading to the identification of major depressive disorder and demoralization, respectively. Patients also completed Ryff's Scales of Psychological Well-Being, Kellner's Symptom Questionnaire, and the World Health Organization Quality of Life–Brief Version scale.

Results: Demoralization was related to impairments in physical, psychological, social, and environmental quality of life and in psychological well-being, especially self-acceptance and environmental mastery (all $P \leq .05$). It was also associated with higher levels of psychological distress, and it was more frequent in women ($P = .027$) and in single patients ($P = .038$). The co-occurrence of a major depressive episode did not alter this pattern of associations. The addition of demoralization to major depressive disorder resulted in decreased Scales of Psychological Well-Being autonomy, positive relations, and self-acceptance (all $P \leq .05$). Demoralization and major depressive disorder were identified in 31 (32.6%) and 14 (14.7%) patients, respectively. Among depressed subjects, 5 (35.7%) were not demoralized, and 22 (71%) of those with demoralization did not satisfy the criteria for major depressive disorder. Nine patients were both depressed and demoralized.

Conclusion: Diagnostic Criteria for Psychosomatic Research–defined demoralization has some distinctive features that confirm previous phenomenological observations.

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Demoralization is a psychological state frequently described in the course of medical illnesses. Several authors have proposed different definitions of demoralization. Slavney[1] viewed it as a normal response to adversity. Dohrenwend et al[2] equated demoralization to nonspecific psychological distress. According to Frank,[3,4] demoralization is a common reason why people seek psychotherapeutic treatment. Klein et al[5] specified that demoralized patients are characterized by a subjective perception of being unable to deal with a specific stressful situation.

De Figueiredo[6] defined *demoralization* as a specific syndrome resulting from the convergence of distress and a subjective sense of incompetence. Subjective incompetence corresponds to what Klein et al[5] defined as demoralization and, as noted by de Figueiredo,[6] may negatively affect the course of both psychiatric and medical disorders.[7,8] Several subsequent studies[1,9–14] confirmed a high prevalence of demoralization among patients with medical disorders, especially if the disorders were threatening or disabling. Demoralization was found to precede the onset of serious diseases, such as cancer, acute coronary heart disease, myocardial infarction, and stroke,[10,11,15,16] and frequently occurred in the first year after heart transplantation.[17]

In the late 1960s, Schmale and Engel[18] described the pattern of psychological features of the "giving up–given up complex," the characteristics of which may be related to the concept of subjective incompetence: (1) feelings of helplessness and hopelessness; (2) perception of diminished competence and control in one's own functioning; (3) impairments in relationships with significant others; (4) external environment or one's own performances do not fulfill the subject's expectations given by previous experiences; (5) loss of the sense of continuity between past and future, with diminished hope and confidence in projecting oneself into the future; and (6) proneness to revive previous unsuccessful or frustrating experiences.

Schmale and Engel[18] hoped that their phenomenological description could be refined with operational criteria and the development of objective instruments for its identification. The definition of *demoralization* in the Diagnostic Criteria for Psychosomatic Research (DCPR; Table 1)[19] is based on Schmale and Engel's "giving up–given up complex." Studies using the DCPR found demoralization in 14%–44% of patients with cardiac,[16] oncologic,[20] dermatologic,[21] gastrointestinal,[22] and endocrine conditions[23–25]; in those recruited in primary care[26]; and in consultation-liaison psychiatry settings.[27,28] Another study[29] documented demoralization in only 3% of the general population, suggesting that it may be more prevalent in medical populations.

Table 1. Diagnostic Criteria for Psychosomatic Research for Demoralization (A through C are required)[a]

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

[a]Modified from Fava et al.[19]

A multicenter study[30] examined the overlap rates between demoralization, according to DCPR, and *DSM-IV* major depressive disorder in 807 outpatients recruited in several clinical settings (gastroenterology, cardiology, endocrinology, and oncology). Despite a considerable overlap, demoralization was distinct and not hierarchically related to major depression: 43.7% of depressed patients were not demoralized, and 69% of demoralized patients could not be classified as depressed.

Schmale and Engel's[18] hope for a better psychological characterization of the operational criteria for the "giving up–given up complex" has not been sufficiently explored, however, by empirical contributions. To this purpose, our aims were the following: (1) to examine the psychological features of demoralization, according to DCPR, with special reference to psychological well-being, quality of life, and psychological distress in medical patients (a sample of cardiac recipients); (2) to test whether the co-occurrence of *DSM-IV* major depressive disorder may significantly affect the relationships between demoralization and these psychological variables; (3) to evaluate whether, vice versa, the association between major depressive disorder and the above-mentioned psychological variables is significantly affected by the addition of demoralization; and (4) to make the same comparisons (demoralized vs nondemoralized patients, depressed vs nondepressed within demoralized patients, demoralized vs nondemoralized among depressed patients) according to demographic characteristics (age, sex, marital and occupational status, educational level) and parameters of clinical course, including survival status at a 6-year follow-up. We chose heart transplanted patients, as they are a population in whom both demoralization and major depressive disorder were previously found to be fairly frequent.[17,30]

METHOD

Subjects

All adult transplanted patients who had been transplanted at least 6 months before and who were undergoing a routine follow-up evaluation at the outpatient clinic of the S. Orsola Hospital (Bologna, Italy) were eligible for inclusion in the study. Patients were invited by their treating cardiologists to participate in a study about quality of life and psychological adjustment to heart transplantation.

According to these selection criteria, a total of 117 patients were eligible for the study. The sample was independent from and collected after the one that was included in a previous multicenter study.[30] After a complete description of the study and explanation of all procedures were given to the subjects, written informed consent was obtained. The study is in compliance with national ethical requirements and was approved by the local institutional review board.

Psychological Assessment

From May to December 2002, all participants were administered the Italian versions of the Structured Clinical Interview for *DSM-IV* (SCID)[31] and the following observer-based and self-report instruments.

Structured Interview for the DCPR. The Structured Interview for the DCPR[32,33] has very good interrater reliability[27] and correlations with dimensional measures of psychosocial distress.[23,24,34–36]

Ryff's Scales of Psychological Well-Being. The Scales of Psychological Well-Being (PWB)[37] are 6 scales assessing the dimensions of psychological well-being identified by Ryff's theoretical model: autonomy, environmental mastery, personal growth, purpose in life, positive relations, and self-acceptance. Each scale contains 14 items, with higher scores indicating better psychological well-being. Autonomy consists of self-determination, independence, and the ability to evaluate oneself by personal standards. Environmental mastery refers to a sense of competence in managing everyday activities and in taking advantage of environmental opportunities. Personal growth is a sense of continuous self-realization during all the phases of life. People with high levels of purpose in life have goals and a sense of direction and consider their life as meaningful. The scale regarding positive relations refers to the presence of warm, empathetic, and trusting relationships with others. Self-acceptance identifies a positive attitude toward oneself and the acceptance of both positive and negative qualities and experiences.[38] The PWB were found to be reliable for the characterization of positive psychological functioning both in the general population and in clinical settings.[38]

Kellner's Symptom Questionnaire. Kellner's Symptom Questionnaire (SQ)[39] consists of four 23-item scales concerning the main dimensions of psychological distress: anxiety, depression, somatization, and hostility. The higher a subject scores, the more he or she is distressed. The SQ is characterized by an excellent sensitivity in identifying both differences between groups and changes in psychological distress after diagnostic procedures and treatments.[40] It has been administered to normal controls, psychiatric patients, and subjects with several medical disorders. It can be completed very easily, as each of the 92 items consists of an adjective or a brief statement.

World Health Organization Quality of Life–Brief Version scale. The World Health Organization Quality of Life–Brief Version scale (WHOQOL-BREF)[41] is a 26-item cross-culturally validated instrument for the measurement of 4 domains of quality of life: physical, psychological, social, and environmental. High scores correspond to better quality of life. Physical quality of life refers to facets such as

mobility, work capacity, pain, energy, and dependence on medical aids. Psychological quality of life is chiefly identified by positive feelings, self-esteem, and good cognitive functioning in terms of memory and concentration. Social quality of life deals with social support, personal relationships, and sexual activity. People with high environmental quality of life are satisfied with their financial resources, home and physical environment (for example, pollution or noise), means of transport, security, and health care services.[41] Good-to-excellent validity, internal consistency, and reliability were demonstrated.[42,43]

Clinical Parameters

For each patient, we collected a set of clinical and instrumental parameters concerning the following main immunosuppressive-related complications from heart transplantation to the time of psychological assessment: acute rejection episodes (graded as 3A or higher by endomyocardial biopsy), infections, and diabetes. Infectious events were recorded according to positive microbiologic tests or when specific antimicrobic therapy was initiated.

At a 6-year follow-up, survival status of the sample was recorded. All data were retrieved from customized electronic databases or from patients' case sheets.

Statistical Analyses

Data were analyzed with the SPSS 13.0 package (SPSS Inc, Chicago, Illinois). Descriptive analyses were conducted to determine prevalence and overlaps between demoralization and major depressive disorder. Independent group *t* tests (2-tailed) were performed to compare (1) patients with and without demoralization, (2) depressed and nondepressed patients among those with demoralization, and (3) demoralization and nondemoralization among depressed patients.

Comparisons regarding the following categorical data required a series of χ^2 tests: occurrence of diabetes, survival status at a 6-year follow-up, sex, marital (married or living as married vs single patients) and occupational (employed vs retired) status, and educational levels (elementary school vs junior high school or high school vs college).

Bonferroni correction was not performed to adjust for multiple testing in view of the exploratory characteristic of our investigation. The conventional 5% level of probability was therefore chosen.

RESULTS

Of the 117 eligible patients, 95 (81.2%) agreed to participate. Reasons for refusal were having moved to another town (n = 15), having no time (n = 3), being too ill to complete questionnaires (n = 1), or unknown reasons (n = 3). Seventy-nine patients (83%) were male, and the mean ± SD age at the time of evaluation was 55.98 ± 10.09 years. Eighty percent of subjects were married or living as married. Seventy-four percent were unemployed or retired, and 26% were employed. Educational levels were as follows: 69.5% elementary school, 23.1% junior high school or high school, and 7.4% college. Patients were at a mean ± SD of 4.4 ± 3.2 years from transplantation. According to New York Heart Association functional status, 68% of patients were in class I, 29% were in class II, and 3% were in class III. Indication for transplant had been nonischemic cardiopathy for 67% of patients and ischemic cardiopathy for 33%. Before operation, the patients' illness had lasted for a mean ± SD of 9.1 ± 7.7 years.

After the structured interviews, *DSM-IV* major depressive disorder and demoralization according to DCPR were found in 14 (14.7%) and 31 (32.6%) patients, respectively. Among depressed subjects, 5 (35.7%) were not demoralized, and 22 (71%) of those with demoralization did not satisfy the criteria for major depressive disorder. Nine patients were both depressed and demoralized.

At the 6-year follow-up, survival status of the sample was retrieved, and 67 of 95 patients (70.5%) were alive. Causes of death were the following: cardiovascular events (46.4%), cancer (39.3%), and infections (14.3%). The 67 survivors were at a mean ± SD of 10.1 ± 3.3 years from transplantation.

Comparison Between Demoralized and Nondemoralized Patients

When demoralized and nondemoralized patients were compared according to scores on the PWB, SQ, and WHOQOL-BREF, the following scales yielded significant results: autonomy (PWB), environmental mastery (PWB), positive relations (PWB), purpose in life (PWB), self-acceptance (PWB), anxiety (SQ), depression (SQ), somatization (SQ), hostility (SQ), and physical, psychological, social, and environmental quality of life (WHOQOL-BREF). Results are shown in detail in Table 2.

Comparison Between Demoralized Patients With and Without Major Depressive Disorder

In the subsample with demoralization, patients both demoralized and depressed (n = 9) and those only demoralized (n = 22) did not significantly differ on the dimensional measures.

Comparison Between Depressed Patients With and Without Demoralization

Among the 14 depressed patients, the co-occurrence of demoralization (n = 9) was associated with significantly lower autonomy (PWB), positive relations (PWB), and self-acceptance (PWB). Means and standard deviations are listed in Table 3.

Comparison Between Groups According to Demographic and Clinical Variables

Demoralization was significantly more frequent in women ($\chi^2 = 4.88$; $P = .027$) and in single patients ($\chi^2 = 4.32$; $P = .038$). Among demoralized patients, those with the co-occurrence of major depressive disorder had a significantly higher number of acute rejection episodes ($t = 2.33$; $P = .027$). At the 6-year follow-up, no differences were found according to survival status. In the subsample with major depressive disorder, no significant differences in either the demographic

Table 2. Comparison of Psychological Well-Being, Distress, and Quality of Life Between Patients With and Without Demoralization

Assessment Score	Patients With Demoralization (n = 31), Mean (SD)	Patients Without Demoralization (n = 64), Mean (SD)
Scales of Psychological Well-Being		
Autonomy*	60.5 (10.7)	66.2 (9.7)
Environmental mastery***	55.1 (10.4)	65.3 (9.2)
Personal growth	53.6 (12.3)	56.1 (10.9)
Positive relations*	56.4 (10.4)	61.7 (10.5)
Purpose in life*	55.1 (14.2)	62.0 (10.3)
Self-acceptance***	50.8 (14.4)	63.6 (11.9)
Symptom Questionnaire		
Anxiety***	8.0 (4.5)	4.5 (4.5)
Depression***	6.6 (4.4)	3.4 (3.8)
Somatization***	10.7 (5.0)	6.6 (5.9)
Hostility*	6.0 (4.0)	4.2 (4.0)
World Health Organization Quality of Life–Brief Version scale		
Physical quality of life***	13.2 (2.7)	15.6 (2.7)
Psychological quality of life**	11.7 (1.1)	12.6 (1.4)
Social quality of life**	13.3 (2.3)	14.7 (2.2)
Environmental quality of life***	13.4 (1.9)	15.3 (1.9)

*$P \leq .05$.
**$P \leq .01$.
***$P \leq .001$.

Table 3. Comparison of Psychological Well-Being, Distress, and Quality of Life Between Depressed Patients With and Without Demoralization

Assessment Score	Depressed Patients With Demoralization (n = 9), Mean (SD)	Depressed Patients Without Demoralization (n = 5), Mean (SD)
Scales of Psychological Well-Being		
Autonomy*	58.1 (11.4)	70.0 (5.4)
Environmental mastery	49.7 (11.5)	63.8 (12.3)
Personal growth	52.8 (8.5)	53.8 (8.3)
Positive relations*	51.2 (9.7)	62.2 (7.4)
Purpose in life	51.9 (11.8)	61.2 (15.1)
Self-acceptance*	50.9 (10.8)	64.4 (8.4)
Symptom Questionnaire		
Anxiety	8.3 (4.6)	5.8 (4.1)
Depression	7.7 (4.8)	2.6 (3.7)
Somatization	12.6 (5.8)	5.6 (6.8)
Hostility	5.3 (4.5)	2.4 (2.3)
World Health Organization Quality of Life–Brief Version scale		
Physical quality of life	12.9 (2.8)	15.5 (3.4)
Psychological quality of life	11.5 (1.1)	12.5 (1.2)
Social quality of life	12.9 (2.3)	14.4 (1.1)
Environmental quality of life	13.7 (1.5)	15.6 (1.8)

*$P \leq .05$.

or the clinical characteristics were found according to the presence of demoralization.

DISCUSSION

In this study, we examined the psychological features of demoralization according to DCPR, with special reference to psychological well-being, quality of life, and psychological distress in a sample of cardiac recipients. We also tested (1) whether the co-occurrence of *DSM-IV* major depressive disorder significantly affects the relationships between demoralization and these psychological measures; (2) whether the association between demoralization and the above-mentioned psychological variables was confirmed among depressed patients, by comparing depressed subjects with and without demoralization; and (3) whether the various subgroups significantly differ from each other according to demographic and clinical characteristics.

Demoralized patients were found to have more impairments in all of the dimensions of quality of life (physical, psychological, social, and environmental); lower psychological well-being, especially the components of environmental mastery and self-acceptance; and more severe anxiety, depressive symptoms, somatization, and hostility. Further, the addition of depression to demoralization did not alter the pattern of correlations with psychological impairments. On the contrary, the co-occurrence of demoralization significantly worsened the psychological status of depressed patients, in particular the well-being dimensions of autonomy, positive relations, and self-acceptance.

This study has limitations mainly due to its cross-sectional design (as to psychological correlates of demoralization) and sample size. We cannot determine the nature of the relationship between demoralization and psychological impairments. Longitudinal investigations could examine whether diminished psychological well-being precedes or is a manifestation of demoralization. Further, the sizes of the groups of patients both demoralized and depressed and those only demoralized or only depressed were small, and this may limit the generalizability of our results.

Despite these limitations, our study has the merit to be the first to expand previous phenomenological observations on the "giving up–given up complex," characterized by subjective perception of helplessness, hopelessness, loss of competence and control, impairments in relationships with significant others, failure to satisfy one's own or others' expectations, loss of continuity between past and future, and proneness to revive previous frustrating or unsuccessful events.[18]

Our findings seem to support de Figueiredo's[6] definition of demoralization as the convergence of psychological distress and subjective incompetence. As to psychological distress, the Symptom Questionnaire showed significant associations of demoralization with anxiety, depressive symptoms, somatization, and hostility. The presence of major depressive disorder did not significantly alter these associations. Ryff's Scales of Psychological Well-Being were chosen as they may reflect the main psychological features impaired by subjective incompetence. Demoralization was significantly (and independently from major depressive disorder) characterized by reduced autonomy, environmental mastery, purpose in life, positive relationships, and self-acceptance. These variables resemble both the description of the "giving up–given up complex"[18] and that of subjective incompetence.[6] Schmale and Engel's[18] observation of impaired relationships with significant others is confirmed by the PWB scale pertaining to positive relationships. Low purpose in life and autonomy

seem to reflect another feature of the "giving up–given up complex": loss of sense of continuity between past and future and lessened hope and confidence in projecting oneself into the future. Ryff[37] described purpose in life as the presence of goals and intentions that make life meaningful and give it a sense of direction.[37,38] Reduced levels of purpose in life according to Ryff's PWB in demoralized patients confirm de Figueiredo's[6] description of subjective incompetence as a feeling of being unable to carry out actions necessary for the achievement of goals, resulting in uncertainty about directions to take.

Differences in environmental mastery and self-acceptance were highly significant. The association with environmental mastery confirms the importance of subjective perception of the ability to cope with one's own environmental demands for the characterization of demoralization. According to Ryff's PWB, people with low environmental mastery feel themselves overwhelmed by their daily hassles and unable to plan, handle, and carry out their activities, affairs, and objectives.[37] If this feeling is protracted, people may become confused and uncertain about the appropriate direction of action, and a sense of demoralization probably arises.

Another psychological feature characterizing demoralization was diminished self-acceptance, described by Ryff[37] as the presence of positive attitudes toward self, with acceptance of both positive and negative qualities and experiences.[37,38] Feelings of self-blame and a lowered self-concept have been traditionally recognized as some of the cognitive features of major depressive disorder and dysthymia.[12,44] Our study suggests a decline of self-attitude even when demoralization is not necessarily associated with depression. Frank,[3,4] in his early work, recognized damage in self-esteem as a possible consequence of demoralization, resulting from a perception of having failed to meet one's own and others' expectations. Our results confirm Frank's[3,4] observation and suggest that the persistence of a sense of inefficacy in dealing with problems in demoralized patients may undermine the underlying self-esteem, with scarce acceptance for one's own personal characteristics in general. In other words, a demoralized person may not only be disheartened about his or her ability to face certain difficulties, but also feel that he or she is inadequate as a person. This matter should be addressed by further studies because a decrease in self-esteem has been widely recognized as a risk factor for both suicidal ideation and attempts.[45–48] Interestingly, the association between demoralization and some dimensions of psychological well-being seems to be confirmed also within the subsample with major depressive disorder. It is possible that with larger sample sizes, other significant differences would have been found.

Our results confirm previous phenomenological observations[18] on the psychological features of demoralization and also show they are not influenced by the co-occurrence of major depressive disorder. The growing body of research evidence suggesting a specific nosologic status for demoralization may pave the way for its inclusion in *DSM-5*. Demoralization was proposed to be added to the section of Psychological Factors Affecting Medical Condition in *DSM-5*, together with 1 *DSM-IV* somatoform diagnosis (hypochondriasis) and 5 other DCPR syndromes (disease phobia, persistent somatization, conversion symptoms, illness denial, and irritable mood).[49,50]

This study was the first examining whether demoralization was significantly related to markers of clinical course after heart transplantation. We did not find significant associations between demoralization and clinical parameters, including survival status at a 6-year follow-up. The higher number of acute rejection episodes in patients both demoralized and depressed should be interpreted with caution. The co-occurrence of major depressive disorder with demoralization may result in diminished compliance with immunosuppressive therapy, leading to an increased risk of rejection. It may also reflect the consequences of these clinical complications on patients' psychological adjustment.

Demoralization was significantly more frequent in women and in single patients. Previous findings, based on dimensional instruments, found a significant association between demoralization and female gender, even after controlling for other variables.[51,52] It has been suggested that personality traits, especially low self-esteem and self-confidence, may predispose women to demoralization.[52] This may also reflect the increased rates of depressive symptoms in women.[53] The higher prevalence of demoralization in single patients is in line with 2 studies suggesting a significant relationship between demoralization and poor family or interpersonal support.[52,54]

Demoralization seems to deserve appropriate clinical evaluation and specific therapeutic strategies within a biopsychosocial framework.[55,56] In medical settings, a regular and empathetic relationship between the patient and his or her health care providers has been suggested to reduce demoralization. Yet, if demoralization persists, structured therapeutic interventions are required.[1,12] It has been frequently suggested that demoralization is not responsive to psychotropic drugs, and a psychological approach has been preferred.[6,12,57] As proposed by Glick and colleagues,[58] demoralization may explain the inefficacy of antidepressants in chronic schizophrenia when concomitant depressive symptoms do not fulfill *DSM-IV* criteria for major depressive disorder.

However, specific psychotherapeutic programs for demoralization have not yet been developed.[59,60] According to de Figueiredo,[6] the distress component can be effectively treated with symptom removal, whereas subjective incompetence requires a more in-depth modification of subjects' attitudes. This introduces the hypothesis that demoralization may require therapeutic strategies based on a conceptual shift from symptom decrease to the promotion of well-being and positive functioning.[61] On the basis of our findings, sense of environmental mastery and self-acceptance should be the major targets of such strategies. The Well-Being Therapy approach, built upon Ryff's model of well-being, may provide specific techniques for promotion or reestablishment of these features.[62]

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