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(Article begins on next page)

Dignity-related existential distress in end-of-life cancer patients: prevalence, underlying factors and associated coping strategies.

Running title: Dignity-related existential distress in end-of-life cancer patients

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Abstract

Objective: Cancer patients often have to face increasing levels of existential distress (ED) during disease progression, especially when nearing death. This cross-sectional study aimed to assess the prevalence of the dignity-related existential distress (DR-ED) in a sample of end-of-life cancer patients, and to explore the “Existential distress” Patient Dignity Inventory (PDI-IT) subscale internal structure and its associations with different coping strategies.

Methods: 207 cancer inpatients with a Karnofsky Performance Status (KPS) ≤ 50 and a life expectancy of four months or less, have been examined with the following self-report measures: PDI-IT, Demoralization Scale (DS-IT) and Brief Coping Orientation to Problem Experienced (Brief-COPE). The “Existential distress” PDI-IT subscale factor structure was explored through principal component analysis, and the DR-ED associations with the other considered variables were examined through X^2 -tests, MANOVA and multivariate regression analysis.

Results: DR-ED was a problem/major problem for 18.8% of the patients, especially for the younger ($F(1, 205) = 3.40$; $p = .020$) and more demoralized ($F(1, 205) = 20.36$; $p < .001$) individuals. Factor analysis supported two dimensions labelled “Self-Discontinuity” and “Loss of personal autonomy”, accounting for 58% of the variance. Positive reframing ($\beta = -.146$, $p < .05$) and self-blame ($\beta = .247$, $p < .001$) coping styles emerged as DR-ED significant predictors.

Conclusions: This study showed how DR-ED often is a relevant problem for patients nearing death and furthermore highlighted two underlying factors. Finally, the research has shown that positive reframing and self-blame coping styles might be clinically relevant elements for interventions on ED.

Keywords:

Cancer; demoralization; dignity; end-of-life; existential distress; oncology; palliative care; psycho-oncology, styles of coping.

Introduction

Advanced oncological illness may imply different challenges for patients, not only regarding the worsening health conditions and physical symptoms, but also a profound existential suffering, related to multiple existential concerns associated to the disease¹. When exposed to a life-threatening and potentially life-limiting disease such as cancer, people are often forced to face existential worries such as a perceived lack of control, the loss of important social roles and life goals, feeling of being a burden to others, fear of an uncertain future and death, as well as the loss of meaning²⁻⁵.

In this context, the existential distress (ED) is defined as a multidimensional phenomenon and as a distinct dimension of the cancer distress, which can result from fundamental loss and change^{2,6}.

Existential concerns may represent a strong risk factor for the maintenance of terminally ill patients' well-being and several are included in Chochinov et al.'s dignity model⁷: loss of dignity showed negative associations to existential well-being⁸⁻⁹

The Patient Dignity Inventory (PDI)¹⁰ is a valid and reliable instrument based on this dignity model, structured to routinely detect end-of-life dignity-related distress and promote tailored interventions. In many of its validations, a subscale specifically referred to the ED was proposed as representative of one of the crucial dignity dimensions¹⁰⁻¹³.

Another perspective on the existential suffering in cancer patients comes from the demoralization syndrome¹⁴, which develops from the maladaptive responses to existential challenges and is defined as a state of lowered morale and of perceived inability to cope associated with hopelessness and the loss of meaning and purpose¹⁵.

Loss of dignity and demoralization are two constructs which were shown to be strictly and positively correlated¹¹⁻¹². Moreover, it has been hypothesized that they are part of the same continuum representing the existential distress¹⁶.

Coping strategies represent a crucial resource for cancer patients when facing advanced illnesses. Thus, it has been suggested that an effective coping style is one of the essential aspects, together with medical, familiar, and spiritual support, for the mitigation of the existential concerns^{5,17}. Few studies reported findings concerning coping strategies in relation to the cancer patients existential suffering, but they were always investigated through a non-specific categorization of the coping styles¹⁸⁻²⁰.

Therefore, the present study aimed to investigate the dignity-related existential distress (DR-ED), in a sample of 207 end-of-life cancer inpatients with a life expectancy of four months or less, in the following manner: 1) describing its prevalence, in relation to demoralization and other socio-demographic and clinical variables, 2) exploring the "Existential distress" Patient Dignity Inventory-Italian Version (PDI-IT) subscale internal structure, to highlight the DR-ED possible underlying factors, and 3) analyzing which coping strategies were associated to the DR-ED.

Method

Study design and participants

Patients were recruited from November 2015 to December 2017, at "Città della Salute e della Scienza" Hospital of Turin.

The inclusion criteria were being hospitalized, having received a diagnosis of cancer, and meeting the criteria to access palliative care stated in the Piedmont regional legislative decree n.45/2002 and in the National law on palliative care and pain treatment (n.38/2010): presence of an advanced stage of disease (terminal phase) for which every curative treatment is not possible or appropriate and with an unfavorable/poor prognosis,

having a presumed life expectancy of four months or less and a Karnofsky Performance Status (KPS)²¹ of 50 or lower. The life expectancy was estimated based on the “surprise” question (CIT Moss, A. H., Lunney, J. R., Culp, S., Auber, M., Kurian, S., Rogers, J., ... & Abraham, J. (2010)), the Palliative Prognostic Score (PaP) (CIT Maltoni e Nanni 1999) and the clinical experience of the palliative physician.

The exclusion criteria were not speaking Italian fluently, having been diagnosed with any severe psychiatric disorders and having obtained a score ≤ 19 at the Mini Mental State Examination (MMSE)²², which implies an inability to provide a valid informed consent and responses to the study tools.

A total of 283 patients were identified as candidates, twenty of them did not meet the inclusion criteria (16, KPS >50 ; 4, could not speak Italian well enough). Forty patients refused to participate in the study (due to scarce motivation or to the burden of cancer), 10 had incomplete data and 6 died before the interview. The final sample consisted of 207 patients.

The patients were assisted by a multidisciplinary équipe composed by physicians, nurses and psychologists trained in palliative care and all the patients received psychological support.

At the beginning of the study, the following information were gathered: personal data, data concerning the patient's state of illness, clinical information related to the terminal phase, such as prediction of survival, prognostic information and performance status. All the information were recorded by a palliative physician of the multi-professional équipe.

The patients were interviewed at their bedside during the first consultation by the psychologists, who used the Italian validated versions of a set of rating-scales.

Regarding the PDI-IT, we opted for the validation obtained from our previous study⁽¹²⁾, because of its specificity for end-of-life patients, like the ones in this study, and for the presence of the ED subscale. It differs from previous Italian validations in the oncological setting^(11,8) because they are referred to, respectively, advanced and nonadvanced cancer patients and patients with active oncological treatments, and present different factor structures. The socio-demographic information were gathered during the interviews, the clinical data were collected consulting the patients' medical charts.

All the participants provided written informed consent. The present study was approved by “Comitato Etico Interaziendale A.O.U. San Giovanni Battista di Torino A.O. C.T.O./Maria Adelaide di Torino”: protocol number 0073054, procedure number 255, date of approval: 04/10/15. The authors state that the research conforms to the Declaration of Helsinki.

Measures

The Patient Dignity Inventory – Italian Version (PDI-IT) is a 25-item self-report questionnaire designed to investigate various sources of dignity-related distress^{8,11}. For each of the items the patient indicates on a 5-point Likert scale: 1 (Not a problem), 2 (A slight problem), 3 (A problem), 4 (A major problem), 5 (An overwhelming problem). Every item describes a theme or a sub-theme of the Dignity Model in the Terminally Ill⁷. The version we administered, validated for end-of-life patients⁽¹²⁾, includes the following five subscales: Psychological Distress, Social Support, Physical Symptoms and Dependency, Existential Distress, Loss of Meaning and Purpose. The ED subscale consists of eight items, some of which differ from the previous studies^(chochinov2008,grassi2017): IT4.Feeling that how I look to others has changed significantly; IT9.Not being able to think clearly; IT11.Feeling like I am no longer who I was; IT12.Not feeling worthwhile or valued; IT13.Not being able to carry out important roles; IT18.Feeling that I am a burden to others; IT19.Feeling that I don't have control over my life; IT20.Feeling that my illness and care needs have reduced my privacy.

The Demoralization Scale – Italian Version (DS-IT) is a 24-item measure²⁰. The patient is asked to rate on a 5-point Likert scale, ranging from 0 (Never) to 4 (Always), each statement, indicating how strongly it has applied

to him/her over the last two weeks. As for its validation for palliative care, the questionnaire is divided into four subscales: Disheartenment, Sense of failure, Dysphoria, Loss of meaning/purpose. The total score of the DS enables to assess the presence and the intensity of the demoralization syndrome²⁴. In this study, the following cut-off scores were used: 0-25th percentile low demoralization, 25th-75th percentile medium demoralization, >75th percentile high demoralization¹⁵.

The Brief Coping Orientation to Problem Experienced (Brief-COPE)²⁵ is an abbreviated version of the COPE inventory, which is especially suitable for fatigued cancer patients or people with a severe state of health. It is a 28-item self-report questionnaire, which assesses specific coping strategies. The items are divided into 14 subscales, which measure conceptually different coping styles: active coping, planning, positive reframing, acceptance, humor, religion, use of emotional support, use of instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement and self-blame. Each coping scale consists of two items; for each of the items the patient answers on a 4-point Likert scale, ranging from 1 (I have not been doing this at all) to 4 (I have been doing this a lot).

Statistical analysis

The ED was operationalized as the “Existential distress” PDI-IT subscale¹². To examine the prevalence of different degrees of the DR-ED severity, the sample was divided into three subsets. According to a similar methodology applied by Chochinov et al.²⁶, we used the following thresholds: an average score between 1 and 1.9 (8 – 15) = Not a problem; between 2 and 2.9 (16-23) = A slight problem; ≥ 3 (24-40) = A problem/A major problem.

The sample socio-demographic and medical characteristics, as well as the demoralization and coping styles measures of were analyzed with respect to the three groups. Descriptive statistics included frequencies, means and standard deviations, and the associations were explored through X^2 tests and multivariate analysis of variance.

To determine the possible factor structure underlying the DR-ED, a principal component analysis (PCA) with oblique rotation (oblimin) and Kaiser normalization was conducted on the eight items of the “Existential distress” PDI-IT subscale. The sampling adequacy and the assumption of sphericity were tested by calculating the Kaiser-Meyer-Olkin (KMO) measure and through the Bartlett’s test²⁷. The optimum number of factors was determined through to the Guttman-Kaiser criterion (eigenvalue of 1.00 or greater as cut-off point) and the visual examination of the scree plot.

To further explore the association between the coping styles and the “Existential distress” PDI-IT subscale, a standard multiple linear forced-entry regression model was executed to identify which one of the coping styles were DR-ED predictors, while controlling for demoralization and age, which were identified as possible confounders, because of their significant association with the DR-ED. Then, a standard multiple block-wise regression model followed to further analyze their contribution to the explanation of the dependent variable’s variance. In the model, demoralization and age were inserted in step one, and the coping styles, emerged as significant predictors in the previous regression, were inserted in step two.

The tests were two-sided and all the assumptions of the tests were verified. P values less than .05 were considered statistically significant. In the ANOVAs, *post hoc* analyses followed Bonferroni correction. Missing data were lower than 0.5%. Statistical analysis was executed using the software SPSS Statistics Version 24.0 (IBM Corp. Armonk, NY, USA).

Results

Socio-demographic and medical characteristics and their associations with DR-ED

The participants' average age was 67.95 years ($sd = 14.15$, range 30-91). Most patients were female (51.2%, $N = 106$), married (59.4%, $N = 123$), with a secondary school diploma (30.4%, $N = 63$), and practicing catholic (48.3%, $N = 100$). The average KPS score of the sample was 41.26 ($sd = 23.48$); according to the PaP scores the patients were classified in three risk groups: A, 58(28%); B, 101(49%); C, 48(23%) and the average hospitalization was about 27 days. See Table 1 for results.

Dignity-related existential distress prevalence

The average score at the "Existential distress" PDI-IT subscale was 18.23 ($sd = 6.27$). Eighty-two patients (39.6%) did not consider DR-ED as a problem, 86 (41.5%) considered it as a slight problem and 39 (18.8%) as a problem/a major problem. The most frequent answer given to items 4, 9, 11, 12 and 20 was "Not a problem", while the most frequent response to the item 13, 18 and 19 was "A problem". Item 19 had the highest average score in all three groups, together with item 13 in the last one ($m1 = 2.07$, $sd = .10$; $m2 = 3.07$, $sd = .09$; $m3 = 4.21 / 4.23$, $sd = .14 / .16$) (Table 2).

Associations of DR-ED with demoralization, coping styles and sociodemographic and medical characteristics.

The DS-IT scores were significantly associated with the "Existential distress" PDI-IT subscale, except for the "Sense of failure" DS-IT subscale ($p = .075$). The scores significantly and gradually increased, from the group who did not consider the existential distress as a problem to the group who considered it as a problem/major problem. Using Pillai's trace, there was a significant association between the DR-ED severity and the scores of the Brief-COPE, $V = 0.34$, $F(28, 378) = 2.79$, $p < .001$. Separate univariate ANOVAs performed on the outcome variables revealed significant differences amongst the three groups related with DR-ED severity in the scorings of the following coping styles: active coping, positive reframing, self-distraction, venting, behavioral disengagement, and self-blame (Table 2).

The active coping, positive reframing, and self-distraction subscale scores significantly and gradually decreased from the group who did not consider the existential distress as a problem to the group who considered it as a major problem; while the venting, behavioral disengagement, and self-blame subscale scores significantly and gradually increased (Table 2). In addition to demoralization ($\beta = .449$, $p < .001$) and age ($\beta = -.189$, $p < .05$), the coping styles "Self-blame" ($\beta = .247$, $p < .001$) and "Positive reframing" ($\beta = -.146$, $p < .05$) significantly contributed to the explanation of the "Existential distress" PDI-IT subscale variance (Table 3).

None of the socio-demographic and clinical variables were significantly associated with the "Existential distress" PDI-IT subscale scores, except for age ($F(1,205) = 3.40$; $p = .020$), which was significantly lower in those patients who considered the existential distress a problem for the maintenance of their own dignity compared to those for whom it was not a problem.

Factor analysis: factors underlying DR-ED

The KMO measure verified the sampling adequacy for the analysis ($KMO = .83$) and the Bartlett's test of sphericity $X^2(28) = 513.01$, $p < .001$, indicated that the correlations between the items were sufficiently large for PCA (Field, 2009). The optimum number of factors comprehended two components that together accounted for 58.03% of the variance. This solution was determined through the Guttman-Kaiser's criterion (eigenvalue of 1.00 or greater as cut-off point) and the visual examination of the scree plot.

The KMO measure of 0.83 and the Bartlett's test of sphericity ($X^2 = 513.01$; $p < .001$) confirmed the adequacy of the sample and that the relationship between the items was significantly large.

Table 4 shows the factor loading after the rotation. The items that cluster on the same components suggest that component 1 (items 9, 10, 18, 19, 20) represents the patient's perception of the loss of personal autonomy and component 2 (items 4, 11, 12) the sense of Self-discontinuity.

Discussion

The present study aimed to describe the prevalence of DR-ED in end-of-life cancer patients, in relation to demoralization and other socio-demographic and clinical variables; analyze the internal structure of the "Existential distress" PDI-IT subscale to find potential underlying factors; and find associations between DR-ED and different coping strategies. Based on previous studies stating the correlation between the PDI and ED (Chochinov 2008; Grassi 2017), in this research the PDI-IT ED subscale was used as a specific tool to assess DR-ED in dying cancer patients.

Firstly, almost one in five (18.8%) examined patients expressed the DR-ED as a problem for the maintenance of their own dignity. In details, the dignity-related existential concerns most frequently reported as a problem were: not being able to carry out important roles, feeling to have lost control over his/her own life and feeling to be a burden to others. Data suggested that the DR-ED may be a crucial phenomenon that strongly affects the well-being preservation of patients nearing death.

Based on these findings, which are in line with previous work⁹, the most vulnerable patients to DR-ED were those with a younger age (62.77 ± 14.59) who felt to have lost the control on their own life and the ability to preserve important roles in their life. These patients may be more likely to consider their death as premature or untimely, making it more difficult to ascribe a meaning to their experience of the final phase of illness.

According to the meaning of the clustered items in the factor analysis, "Loss of personal autonomy" might refer to the loss of personal independency and agency, meant not as physical, as described in a different subscale of the PDI-IT, but in a more relational way, characterized by the salience of self-determination. "Self-discontinuity" depicts the interruptions in the "*arc of life*" that can hinder the achievement of dreams, milestones, ambitions and goals²⁸ and the notion of disintegration of Self²⁹. Hence, further developing previous conceptualizations, the DR-ED might be constituted by these two components.

Moreover, the two factors can be linked to two sub-themes of Chochinov et al.'s dignity model⁷, namely "*Level of independence*", belonging to the category of the physical and psychological illness-related concerns, and "*Continuity of self*", belonging to the dignity conserving repertoire. Therefore, it might be possible to theorize a link between these two themes of the dignity model and the DR-ED.

Regarding demoralization, the DR-ED and DS-IT scores followed almost the same trend, both describing about one fifth of the individuals (18.8%; 23.6%) in the high distress group. Considering the low and medium distress groups, most patients were grouped in the low distress group with the DS-IT, while they were equally distributed among the two groups through the DR-ED. This could be explained considering the partial overlapping of these two tests on certain existential issues (e.g. items regarding loss of meaning and purpose)¹⁶.

Finally, our study deepens the knowledge about the relationship between coping strategies and ED: positive reframing and self-blame were the only coping styles which contributed to the explanation of the DR-ED variance besides demoralization.

As regards positive reframing, patients who find a new meaning for their situation, by looking at it from a distinct perspective or by trying to get the best out of it, tend to have a higher level of well-being.

Self-blame was found positively associated to the DR-ED, providing useful evidence to detect the variables that can lead to a clinically relevant degree of existential distress. Furthermore, end-of-life patients, who do not share their illness-related relevant concerns, are more likely to blame themselves, which can lead to an increased risk of depressive symptoms³⁰.

Our study provides the framework for future studies in order to assess the existential distress in cancer patients and an insight into the possible theorization of the DR-ED as a dimension constituted by the loss of autonomy and the Self-discontinuity. These aspects should not be considered as isolated elements, but in an integrated perspective, in which the physical experience of the terminal illness is not separable from its influence on the personal identity and on the relationship with others. These data could be useful in the attempt to fulfil the need for conceptual advances in the field of palliative care and benefit the clinical practice ³¹.

Limitations

Further investigations on more specific cancer and non-cancer population are needed to deepen the understanding and determine if other characteristics are associated with the ED in terminally ill patients.

We will integrate this approach evaluating the relationship between coping styles and personality to relate specific personality traits to functional or dysfunctional coping strategies. In this way, we seek to better understand the potential psychological events underlying existential distress.

Clinical application

As clinical implications of the present study, early identification and tailored interventions focused on concerns regarding loss of autonomy, self-discontinuity and the emotional experiences underlying the self-blame coping might prevent the DR-ED to emerge in terminally ill cancer patients. In this context, approaches such as the Dignity Therapy³² and Meaning Centered Psychotherapy³³ might be useful. Therefore, healthcare providers in oncology and palliative care, need to assess ED in their multidimensional assessment, to preserve patients' existential well-being and promote a better quality of death. This approach can be applied to patients affected not only by cancer, but by life-limiting or life-threatening disease in general.

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Disclosures

The manuscript has not been and will not be published elsewhere or submitted elsewhere for publication. Authors mention that there is no conflict of interest in this study.

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Table 1. Socio-demographic and clinical characteristics of the sample (N=207).

Characteristics	N(%)
Age	67.95 ± 14.15
Sex	
Male	101(48.8)
Female	106(51.2)
Marital status	
Married	125(60.4)
Single	24(11.6)
Divorced	12(5.8)
Widow(er)	46(22.2)
Education	
Primary	60(29.0)
Secondary	71(34.3)
Higher secondary	65(31.4)
Graduate	11(5.3)
Profession	
Unemployed	12(5.7)
Employed	55(26.6)
Freelance	11(5.3)
Housewife	8(3.9)
Retired	121(58.5)
Caregiver	
Spouse	92(44.4)
Partner	5(2.4)
Son/Daughter	72(34.4)
Relative	27(13.0)
Friend	2(1.5)
Nobody	9(4.3)
Religious affiliation	
Catholic	160(77.3)
Atheist	29(14.0)
Other	18(8.7)
Type of cancer	
Colon-rectal	25(12.1)
Breast	26(12.6)
Uterus-Ovary	11(5.3)
Gastric	19(9.2)
Lung	52(25.1)
Hepatic-Pancreatic-VBC	27(13.0)
Prostate	12(5.8)
Other cancers	35(16.9)
Karnofsky Performance Status	41.26 ± 23.48
Stage	
Local	25(12.1)
Loco-regional	25(12.1)
Metastatic	157(75.8)

Table 2. Scores at the ED (PDI-IT) and their association with the other continuous variables.

PDI-IT
Existential distress

M=18.23; sd=6.27 N=207			
	Existential distress-Total score		
	Not a problem (8-15) N=82 39.6%	A slight problem (16-23) N=86 41.5%	A problem/ A major problem (24-40) N=39 18.8%
Item	mean(sd)	mean(sd)	mean(sd)
4. <i>Feeling that how I look to others has changed significantly</i>	1.59(.09)	2.17(.11)	3.64(.19)
9. <i>Not being able to think clearly</i>	1.28(.06)	2.07(.11)	2.97(.18)
11. <i>Feeling like I am no longer who I was</i>	1.66(.09)	2.66(.11)	4.13(.15)
12. <i>Not feeling worthwhile or valued</i>	1.05(.02)	1.40(.07)	2.54(.19)
13. <i>Not being able to carry out important roles</i>	1.90(.11)	3.05(.14)	4.23(.16)
18. <i>Feeling that I am a burden to others</i>	1.89(.10)	2.66(.11)	4.13(.15)
19. <i>Feeling that I don't have control over my life</i>	2.07(.10)	3.07(.09)	4.21(.14)
20. <i>Feeling that my illness and care needs have reduced my privacy</i>	1.18(.05)	1.76(.11)	2.82(.20)
Age	70.46 (14.36)	67.93(13.24)	62.77 (14.59)
Karnofsky Performance Status	39.81(9.44)	42.50(34.72)	41.54(9.04)
Demoralization (DS-IT)	29.27 (14.03)	37.44 (12.53)	45.49 (14.26)
Coping styles (Brief-cope)			
Active coping	5.93 (1.14)	5.27 (1.61)	5.38 (1.60)
Planning	5.56(1.30)	5.12(1.61)	5.44(1.67)
Positive reframing‡	4.85 (1.60)	4.62 (1.70)	3.77 (1.91)
Acceptance	5.55(1.25)	5.10(1.27)	5.38(1.18)
Humor	3.01(1.32)	3.11(1.47)	2.79(1.30)
Religion	4.16(2.06)	4.26(1.99)	3.92(2.02)
Emotional support	5.71(1.22)	5.95(1.40)	5.54(1.79)
Instrumental support	5.78(1.23)	6.01(1.28)	5.46(1.65)
Self-distraction‡	6.27 (1.47)	6.07 (1.80)	5.18 (1.80)
Denial	3.09(1.32)	3.47(1.56)	3.91(1.43)
Venting‡	5.16 (1.18)	5.17 (1.37)	5.90 (1.80)
Substances use	2.10(.46)	2.05(.43)	2.31(.98)
Behavioral disengagement	3.20 (1.66)	3.93 (1.60)	3.56(1.60)
Self-blame‡	2.78 (1.00)	3.24 (1.53)	4.00 (1.93)

Notes: means which significantly differ each other are in bold (ANOVA); ‡no difference between scores of the first and second group, but both groups differed from the third group.

Table 3. Existential distress (PDI-IT) significant predictors.

	B	SE B	β
Step 1			
Constant	17.056	2.086	
Demoralization total score (DS)	.192	.026	.449**
Age	-.084	.027	-.189**
Step 2			
Constant	15.855	2.294	
Demoralization total score (DS)	.153	.027	.357**
Age	-.059	.027	-.133*
Self-blame (Brief-Cope)	1.034	.255	.247**
Positive reframing (Brief-Cope)	-.528	.229	-.146*

Notes: Summary of standard multiple linear block-wise regression. (N=207).

Adjusted R^2 = .222 for Step 1, Δ Adjusted R^2 = .63 for Step 2 ($p < .05$).; *, $p < .005$; **, $p < .01$.

Table 4. Summary of the exploratory factor analysis: PCA, Oblimin-rotated, two-component solution (N=207).

Rotated factor loadings: pattern matrix (structure matrix)		
Item	Loss of personal autonomy	Discontinuity of Self
4. Feeling that how I look to others has changed significantly	-.098(.383)	-.918(-.866)
9. Not being able to think clearly	.477(.551)	-.141(-.391)
11. Feeling like I am no longer who I was	.160(.550)	-.744(-.828)
12. Not feeling worthwhile or valued	.077(.479)	-.765(-.806)
13. Not being able to carry out important roles	.783(.737)	.087(-.323)
18. Feeling that I am a burden to others	.640(.714)	-.141(-.477)
19. Feeling that I don't have control over my life	.930(.862)	.129(-.359)
20. Feeling that my illness and care needs have reduced my privacy	.550(.610)	-.113(-.402)
Eigenvalues	3.64	1.01
% of variance	45.45	12.58

Notes: Factor loadings over .40 appear in bold.