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MEDICINA DEL LAVORO

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Motoneuron diseases: impact on health professionals

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ABSTRACT. The approach to patients affected by motor neuron disease (MND) and their caregivers requires specific training for the care-team. In fact, the progression of the disease, with the decline of physical – and sometimes cognitive – function, the increasing difficulties in speaking, breathing, and swallowing and the need of invasive choices, as the artificial nutrition and tracheostomy, constitute a challenge for the health professionals, often generating distress. For this reason, their cohesion and sharing abilities are fundamental. Psychologist assumes a strategic role in supporting and facilitating the analysis of clinical cases and of the team's intra/interpersonal dynamics. For this aim, he/she needs specific training and instruments. We here present a semi-structured interview – the Motor Neuron Disease-Psychological Interview (MoNeDi-PI) – which may guide in the psychological assessment of patients affected by MNDs and their caregivers. It can also be a handy reference tool for other members of the healthcare team providing necessary information about the patient and caregiver in order to optimize clinical decision making about which health interventions to apply.

Key words: *motor neuron diseases, psychological assessment, patient, caregivers.*

RIASSUNTO. MALATTIE DEL MOTONEURONE: IMPATTO SUGLI OPERATORI. L'approccio a un paziente affetto da una malattia del motoneurone e al suo caregiver richiede al team di cura un'attenta preparazione. Infatti, la progressione della malattia, con l'inevitabile declino fisico e a volte psichico, le conseguenti difficoltà di deglutizione, respirazione e comunicazione e la necessità di scelte invasive, come la nutrizione artificiale e la tracheostomia, impongono agli operatori un confronto continuo con se stessi, generando distress. La capacità di coesione e discussione del team diventa pertanto fondamentale. All'interno del team, lo psicologo assume una posizione strategica di supporto e di facilitatore nella comprensione del caso clinico e delle relative dinamiche inter e intrapersonali. Per questo motivo, è necessario che disponga di strumenti adatti a favorire la comunicazione e la condivisione delle problematiche di paziente e caregiver tra tutti gli operatori. Viene qui proposta un'intervista semi-strutturata, Motor Neuron Disease-Psychological Interview (MoNeDi-PI), che può costituire una guida sia per l'assessment psicologico di paziente e caregiver, sia per il processo decisionale-operativo di tutti i membri del team.

Parole chiave: malattie del motoneurone, valutazione psicologica, paziente, operatori sanitari.

Introduction

Motor neuron diseases (MNDs) include a heterogeneous range of sporadic, inherited, and often fatal clinical disorders of the upper motor neurons, lower motor neurons or a combination of both (1). They are characterized by progressive degeneration and loss of cells that control essential muscle activity, such as those involved in speaking, walking, breathing, and swallowing. The most common MND is amyotrophic lateral sclerosis (ALS), with a worldwide annual reported incidence from 1.5 to 2.5 cases/100.000 population/year (2). ALS in itself presents different phenotypes, each affecting survival to a different extent: 2 to 4 years from the time of the first symptoms in the majority but up to 10 years in 10-20% of cases (3). In general, MNDs are highly variable regarding age and site of onset, and rate of progression (4). As there is no cure or standard treatment, symptomatic and supportive treatment can help patients and their caregivers to live more comfortably with the disease maintaining their quality of life. In fact, the progression of the disease, with the decline of physical – and sometimes cognitive – function, and the increasing difficulties in communication constitute a challenge for patients and caregivers, who have to adjust to the changes over time (5, 6). Moreover, the choices that have to be madeto manage the disease (e.g. whether or not to perform a tracheostomy) can cause significant distress to patients and the whole family (7, 8) and represent a controversial issue for health professionals in the field (7, 9, 10).

Many authors have recognized that patients and caregivers who benefit from a multidisciplinary approach have a higher quality of life and longer survival (11, 12), and a multidisciplinary team approach is recommended by the European Federation of Neurological Societies (EFNS) guidelines on the clinical management of ALS (2012). However, such approach requires specific training of the members of the team and, in particular, of the psychologists who have to assess and support patients and caregivers over the course of the disease. So far as we are aware, no guide is available to facilitate them in this task. We here present a semi-structured interview – the Motor Neuron Disease-Psychological Interview (MoNeDi-PI) – which may help guide psychologists, particularly those who do not have specific experience in the psychological assessment of patients affected by MNDs and their caregivers. It can also be a handy reference tool for other members of the healthcare team providing necessary information about the patient and caregiver in order to optimize clinical decision making about which health interventions to apply.

Materials and Methods

Motoneuron Diseases -Psychological Interview (MoNeDi-PI)

The MoNeDi-PI was created in response to frequent requests for specific psychological training in this field. In fact, two of the authors (first and second) are respectively the leader and one of the principal collaborators of an Italian group of psychologists involved in continuing education in the psychological approach to patients affected by MND. This national group is supported by the Associazione Italiana Sclerosi Laterale Amiotrofica (AISLA), the main Italian association for ALS. The MoNeDi-PI is the result of years of direct experience with patients and their caregivers. It is useful to assess patients and caregivers over time, in order to verify how the psychological adjustment changes. Initially composed of indicative questions (between 30 and 40) without a formal organization, it was subsequently modified with the help of a psychotherapist experienced in caregiving strain (the third author of this paper), in order to optimize its capacity to guide psychologists through the principal areas of assessment and possible ways to code the answers. The MoNeDi-PI (see Appendix) is administered separately to the patient and their caregiver, and consists of a personal information card (collecting information like age, education, diagnosis, etc.) and 8 areas of assessment:

Area 1: Knowledge of the disease and sources of information.
Area 2: Reactions to the communication of the diagnosis.
Area 3: Affective elaboration /Awareness of the disease.
Area 4: Physical wellbeing.
Area 5: Coping.
Area 6: Compliance/Adherence/Acceptance of help/aids.
Area 7: Family atmosphere.
Area 8: Perceived social support and involvement.

These areas represent the general picture which has to be continuously evaluated and shared between the members of the team, so that they can optimize their communication with the patient and caregiver and the specific interventions addressed to them. Each area comprises specific guide-questions and coding of the responses, useful to summarize the psychological profile for discussion with other members of the team (13). A Summary Sheet is included, which provides a synthetic rating on a 5-point Likert scale, (from 1 = not at all, to 5 = very much; score range 8-40) of the 8 areas based on what has emerged during the clinical interview. At the bottom of the sheet it is possible to add some comments. The Summary Sheet may bepresented during the care team's meetings and possibly given to the physician, who, in this way, has a rapid overview of the psychological situation of the patient and/or caregiver. In order to demonstrate the usefulness of the MoNeDi-PI, we administered it to a group of patients and their caregivers.

Subjects

Patients and caregivers were approached at the sites where the authors work, as part of the regular follow up provided by the multidisciplinary care team. The content of the follow up program varies according to the problems to assess and treat. Psychologists are always present. Patients and caregivers signed an informed consent, written in accordance with the Declaration of Helsinki and the study was approved by the Advisory Boards of authors' Institutes. The authors administered the MoNeDi-PI to patients and caregivers individually, using the coding suggestions provided and, at the end, filled out the Summary Sheet. As one or other of the psychologists might have known the individuals interviewed, to avoid inter-observer variability a discussion about the coding was conducted after the interview. No significant divergence arose, possibly because of the long term collaboration between them. In computing the data (as regards areas 2 and 3) the authors chose the best answers obtained. A total of 51 patients (23 M and 28 F) and 22 caregivers (7 M and 15 F) were interviewed between January 2013 and July 2014. There were no refusals to participate.

Statistical analysis

Descriptive statistics (mean, standard deviation and percentage) were performed using SPSS for Windows, Version 19.0.

Results

Subjects' characteristics are presented in Table I. Only 11/51 subjects had a patient-caregiver relationship: hence, we considered patients and caregivers as two independent samples. The majority of the patients (84.3%) and all of the caregivers were married and had children.Only 4 subjects declared they had a neurological comorbidity (2 ALS,1 Parkinson's disease and 1 fronto-temporal dementia). As shown in Table I, 30-40% of patients received the diagnosis of MNDafter one year from the onset of symptoms. The majority of the patients were in a sufficiently good physical condition, but one-third declared poor physical wellness. Seventeen patients were on non-invasive ventilation (NIV), 4 had a tracheostomy (6 chose not to undergo it) and 6 percutaneous endoscopic gastrostomy (PEG). In general, the caregivers considered themselves to be in good physical form. No substantial difficulties emerged from patients or caregivers concerning acceptance of aids, like wheelchair, NIV or PEG, indicating a good adjustment over time. While patients and caregivers reported similar reactions at the time of diagnosis (like mixed feelings such as anger, depression, anxiety, shame), their current reactions-at a distance of some months from the communication of the diagnosis-were different: many patients had become hostile while caregivers reported to be more sad (Table II). The majority re-

Table I. ***Characteristics of the subjects***

	Patients (N. 51)	**Caregivers (N. 22)**
Sex (M/F)	23/28	7/15
Mean age (yrs.)	58.5±11.6 (range 33-80)	55.6±14.3 (range 20-82)
Mean years of school education	9.5±4 (range 5-18)	9.5±4.1 (range 5-18)
Still working	n. 16 (31.4%)	n. 10 (45%)
Caregiver's relationship:		
Spouse/partner		17 (77.3%)
Son/daughter		4 (18.2%)
Parent		1 (4.5%)
Patient's disease onset:		
0-12 months b.i.*	7 (13.7%)	1 (4.5%)
13-24 months b.i.*	16 (31.4%)	2 (9.1%)
25-36 months b.i.*	8 (15.7%)	6 (27.3%)
Up to 37 months b.i.*	20 (39.2%)	13 (59.1%)
Kind of onset:		
Spinal	38 (74.5%)	16 (72.7%)
Bulbar	9 (17.6%)	6 (27.3%)
Spinal and Bulbar	4 (7.9%)	0
Time of diagnosis:		
Within one year from the onset	30 (58.8%)	15 (68.2%)
After one year from the onset	19 (37.2%)	7 (31.8%)
Unknown	2 (4)	0
Information received*:	N. (%)	N. (%)
Minimal	4 (7.8)	0
Partial	9 (17.6)	1 (4.5)
Complete	38 (74.6)	21 (95.5)
Physical wellness at interview:		
Poor	19 (37.3)	2 (9.1)
Adequate	31 (60.7)	9 (40.9)
Substantially good	1 (2)	11 (50)

* before interview

ported having found some form of adaptation or resignation, patients through compromise and caregivers through functional adaptation, as also confirmed by patients who reported the need for dialogue within the family or with friends while caregivers preferred to talk to physicians or to the members of the care team. Spirituality was reported as important more so by caregivers than patients, one third of whom did not think it was useful for them. Finally, almost one-third said they were unsatisfied about the social support received. As regards the Summary Sheet, subjects scored quite well: patients obtained a mean score of 30±4.5 (range 19-36) and caregivers 31±2.3 (range 22-35), indicating that at a psychological level they were in general well followed up.

Discussion

A number of observations emerge from our interview: first, the diagnosis of MND may still be a difficult process, as shown by the fact that between 30 and 40% of patients received the diagnosis after one year from the onset of symptoms. Second, patients affected by MNDs and their caregivers bear an intense burden in their daily life but there is evidence that some factors positively influence their adjustment and well-being. One of them is being cared for by a multidisciplinary team: there is scientific evidence that this may extend patients' survival, decrease medical complications (level B), and improve patients' quality of life (level C), with beneficial consequences for the caregivers (14). Our data confirm these observations: in particular, patients and caregivers seem well-adjusted to their condition. This does not mean that they are not emotionally burdened or that they do not encounter difficulties in their daily life. For example, a hostile attitude was declared by many patients after some months from the diagnosis, while sadness was referred by many caregivers and difficulties with social support emerged in one-third of our subjects; it is known that social support influences the quality of life (15). In any case, all subjects-patients and their caregivers-were listened to and followed-up over time by the care team so nobody felt alone and abandoned. In fact, these are subjects regularly contacted as part of the follow up by the

Table II. *Patients' and caregivers' reactions*

	Reactions at diagnosis		Current reactions	
	Patients	**Caregivers**	**Patients**	**Caregivers**
	n. (%)	**n. (%)**	**n. (%)**	**n. (%)**
Prevalent emotions:				
Anxiety/Fear/Worries	9 (18)	9 (41)	1 (2.0)	3 (13.6)
Irritability	0	0	3 (5.9)	0
Anger	2 (4)	1 (4.5)	0	0
Hostility	0	0	19 (37.2)	0
Sadness	5 (10)	0	3 (5.9)	13 (59.1)
Depressed mood	4 (8)	0	0	0
Shame	0			
Mixed feelings (anger, depression, anxiety, shame)	31 (60)	12 (54.5)	25 (49)	6 (27.3)
Prevalent thoughts:				
Thoughts of suicide	1 (2)	0	1 (2.0)	0
Catastrophic thoughts	4 (7.8)	1 (4.5)	3 (5.9)	0
Denial	4 (7.8)	1 (4.5)	0	0
Injustice	10 (19.6)	7 (31.8)	5 (9.7)	0
Incredulity/Underestimation	25 (49)	13 (59.2)	0	1 (4.5)
Positive resignation/Acceptance	3 (5.9)	0	41 (80.4)	21 (95.5)
Other	4 (7.9)	0	1 (2.0)	0
Prevalent actions:				
Crying	11 (22)	5 (22.7)	7 (13.7)	0
Shouting/Irritable or aggressive behavior	2 (4)	3 (13.6)	3 (5.9)	1 (4.5)
Avoidance	1 (2)	0	0	0
Mutism	8 (16)	3 (13.6)	1 (2)	0
Irony	1 (2)	0	0	0
Dialogue with family and friends	20 (38)	3 (13.6)	31 (60.8)	7 (31.9)
Dialogue with physician/team	8 (16)	8 (36.5)	9 (17.6)	14 (63.6)
Other	0	0	0	0
Prevalent inner experiences related to the disease*:				
Maladaptive			4 (7.8)	0
Partially adaptive/Adaptive			47 (92.2)	22 (100)
Coping:				
Maladaptive			5 (9.8)	0
Searching for compromise			21 (41.2)	1 (4.5)
Adaptive			25 (49)	21 (95.5)
Spirituality:				
yes			35 (68.6)	19 (86.4)
no			16 (31.4)	3 (13.6)

* *Maladaptive:* Anticipation of the death, Despair, Loneliness/Abandonment, Inadequacy/Low self-esteem, Blame/Punishment, Being a burden/Inutility, Loss of control/Helplessness - *Partially adaptive/Adaptive:* Resigned to loss (personal space, opportunities, goals, plans), Hope, Searching for meaning, Revaluation of significant others, Discovery of new resources, Fighting attitude, Peaceful acceptance.

team members who try to dedicate as much time as necessary for questions and answers. In particular, psychologists listen to patients and caregivers and help the family cope with their situation as it evolves. They are also available for telephone calls from patients and caregivers if advice or support is needed. Paradoxically, this is also the principal limit of our paper: we present data concerning a population sample that was very well followed. Another limit is that we did not administer any questionnaire for the evaluation of anxiety and depression to patients and caregivers. So we could not correlate our observations with objective measures. This, however, is a controversial point, as it is known that such questionnaires are in general not suitable for persons whose symptoms are an integral part of the disease. On the other hand, our findings indicate that the psychologist is a key figure within the care team, in that it is they who can help patients and their caregivers to cope with the course of the disease, from its onset until the end of life. The psychologist can also help the other members of the care team understand the on going psychological process and cope with their own difficulties, especially in relation to the therapeutic decisions and patient/caregivers' quality of life (16, 17). It could be argued that there is not always a psychologist available in the healthcare team. Regardless of this, the information provided by the MoNeDi PI is indispensable for the members of the team so that they can plan and decide what the best interventions for the patient and caregiver are at any given moment, based on the information it provides. During team meetings, the members of the équipe could also use the MoNeDi PI as a reference grid, i.e. a "check list" of the information that they need to have. In our opinion, entrusting the psychological assessment to other professional figures is a matter for caution: it would be desirable at least that the training of the team regarding the psychological approach to the patient and caregiver be conducted by an expert psychologist. The exploration of the MoNeDi-PI areas would consequently need to be simplified and supervised. Collaboration and consultation with university departments of Psychology could be a solution in such cases.

Conclusions

MND patients and caregivers pose a unique challenge to health professionals. In fact, their disease limits step by step the body and its functions, leaving the person like a prisoner in an unwanted 'shell': this may cause psychological projection and an inadequate approach; moreover, communication becomes progressively difficult and obliges the patient to find alternative resources which are not easily accessible; finally, ethical dilemmas have to be continuously faced. These reasons make specific training necessary for all of members of the care team and, in particular, for psychologists, in order to be fully prepared for supporting MND patients and their caregivers throughout the course of the disease. The MoNeDi-PI may help in this aim, especially by evidencing what type of information the care team requires so as to best carry out its own task, during which very often incredible resources are discovered, often where least expected.

Acknowledgement

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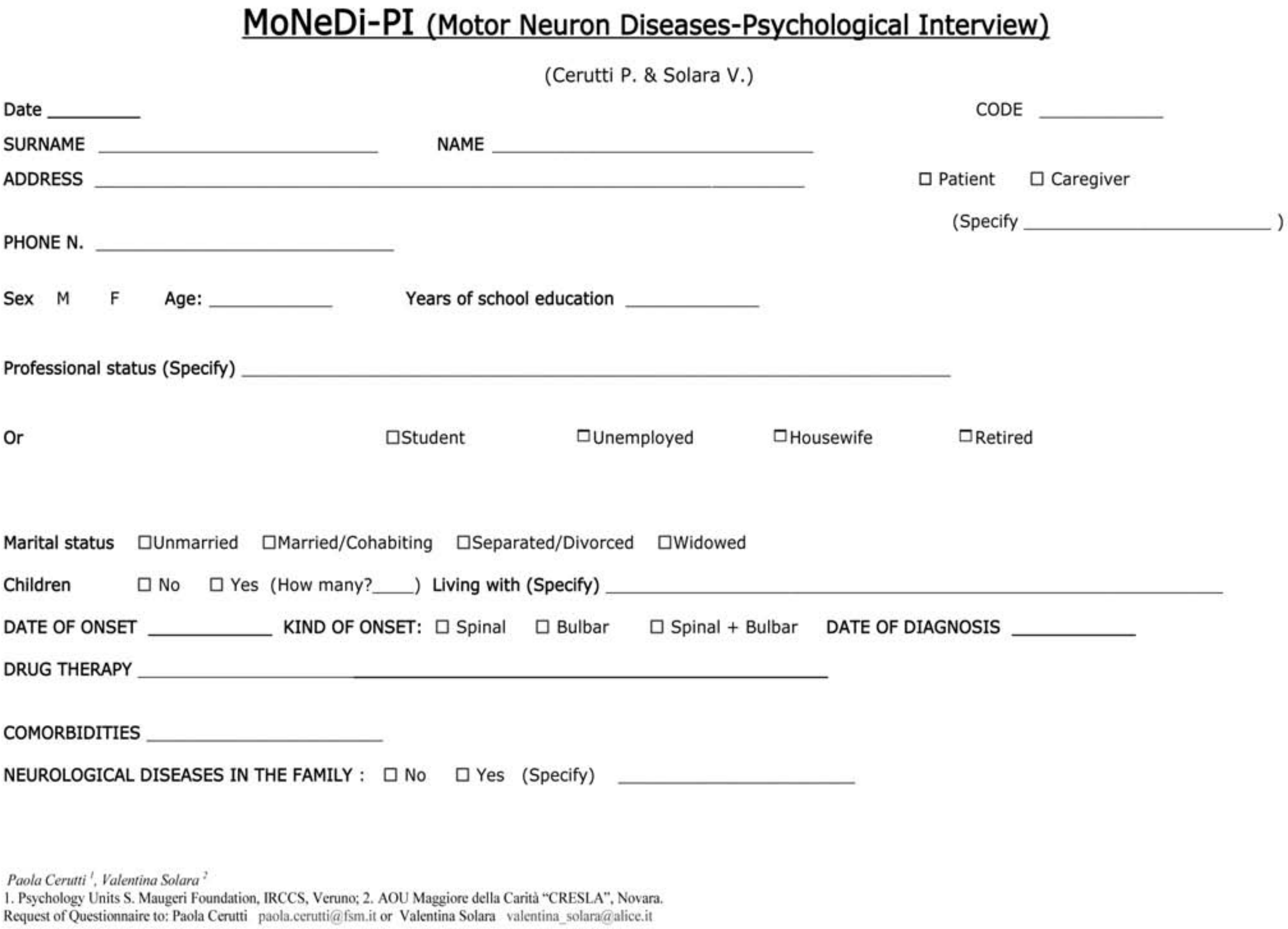
APPENDIX 1



MoNeDi-PI (Motor Neuron Diseases-Psychological Interview)

(Cerutti P. & Solara V.)

Date ________ CODE ___________

SURNAME ________________________ NAME ___________________________

ADDRESS ____ ☐ Patient ☐ Caregiver

(Specify _____________________)

PHONE N. __________________________

Sex M F Age: ___________ Years of school education ___________

Professional status (Specify) ____

Or ☐Student ☐Unemployed ☐Housewife ☐Retired

Marital status ☐Unmarried ☐Married/Cohabiting ☐Separated/Divorced ☐Widowed

Children ☐ No ☐ Yes (How many?____) Living with (Specify) ____

DATE OF ONSET ___________ KIND OF ONSET: ☐ Spinal ☐ Bulbar ☐ Spinal + Bulbar DATE OF DIAGNOSIS ___________

DRUG THERAPY ____

COMORBIDITIES _____________________

NEUROLOGICAL DISEASES IN THE FAMILY : ☐ No ☐ Yes (Specify) _____________________

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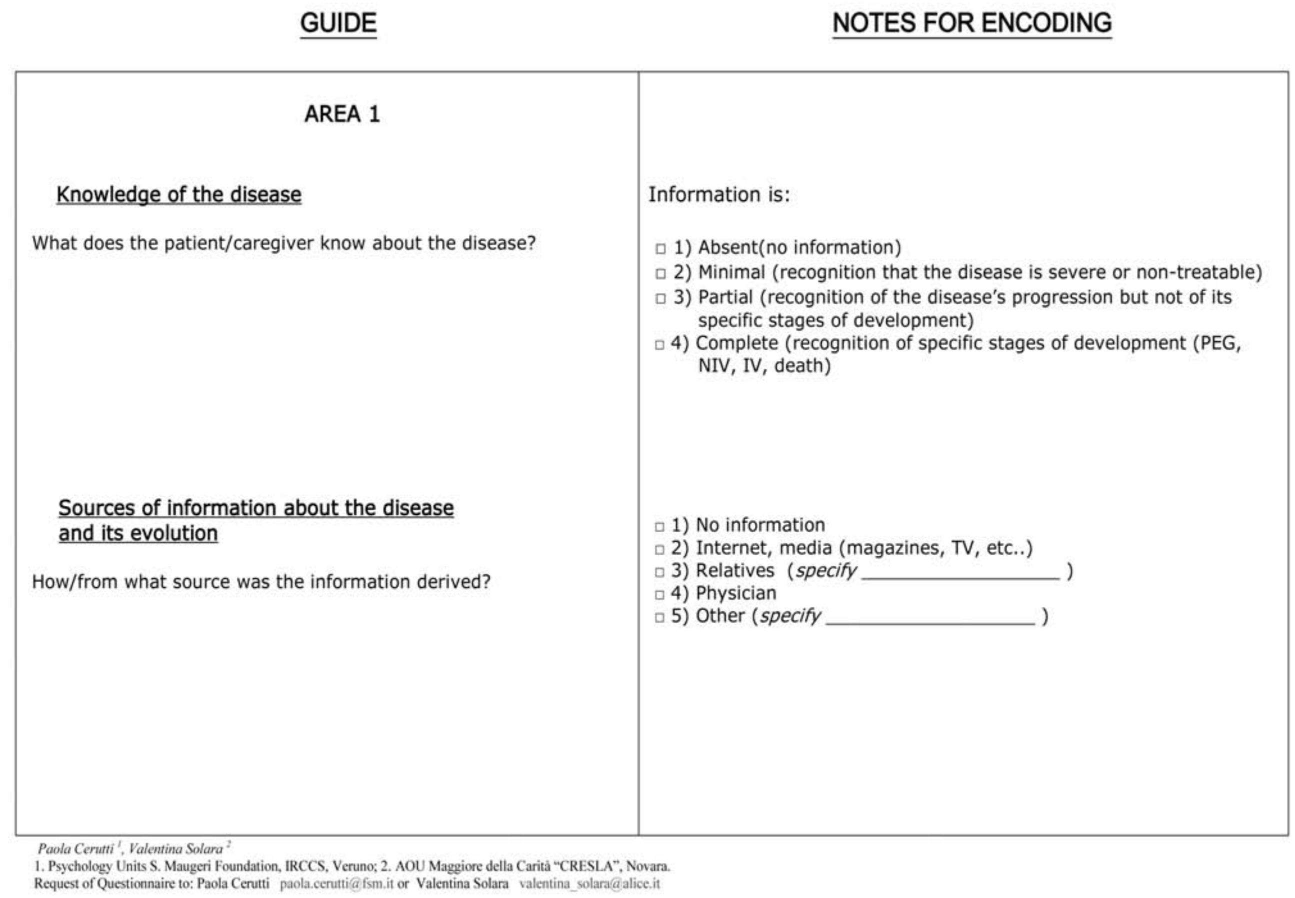

GUIDE	NOTES FOR ENCODING
AREA 1	
Knowledge of the disease What does the patient/caregiver know about the disease?	Information is: ☐ 1) Absent(no information) ☐ 2) Minimal (recognition that the disease is severe or non-treatable) ☐ 3) Partial (recognition of the disease's progression but not of its specific stages of development) ☐ 4) Complete (recognition of specific stages of development (PEG, NIV, IV, death)
Sources of information about the disease and its evolution How/from what source was the information derived?	☐ 1) No information ☐ 2) Internet, media (magazines, TV, etc..) ☐ 3) Relatives (*specify* ________________) ☐ 4) Physician ☐ 5) Other (*specify* ________________)

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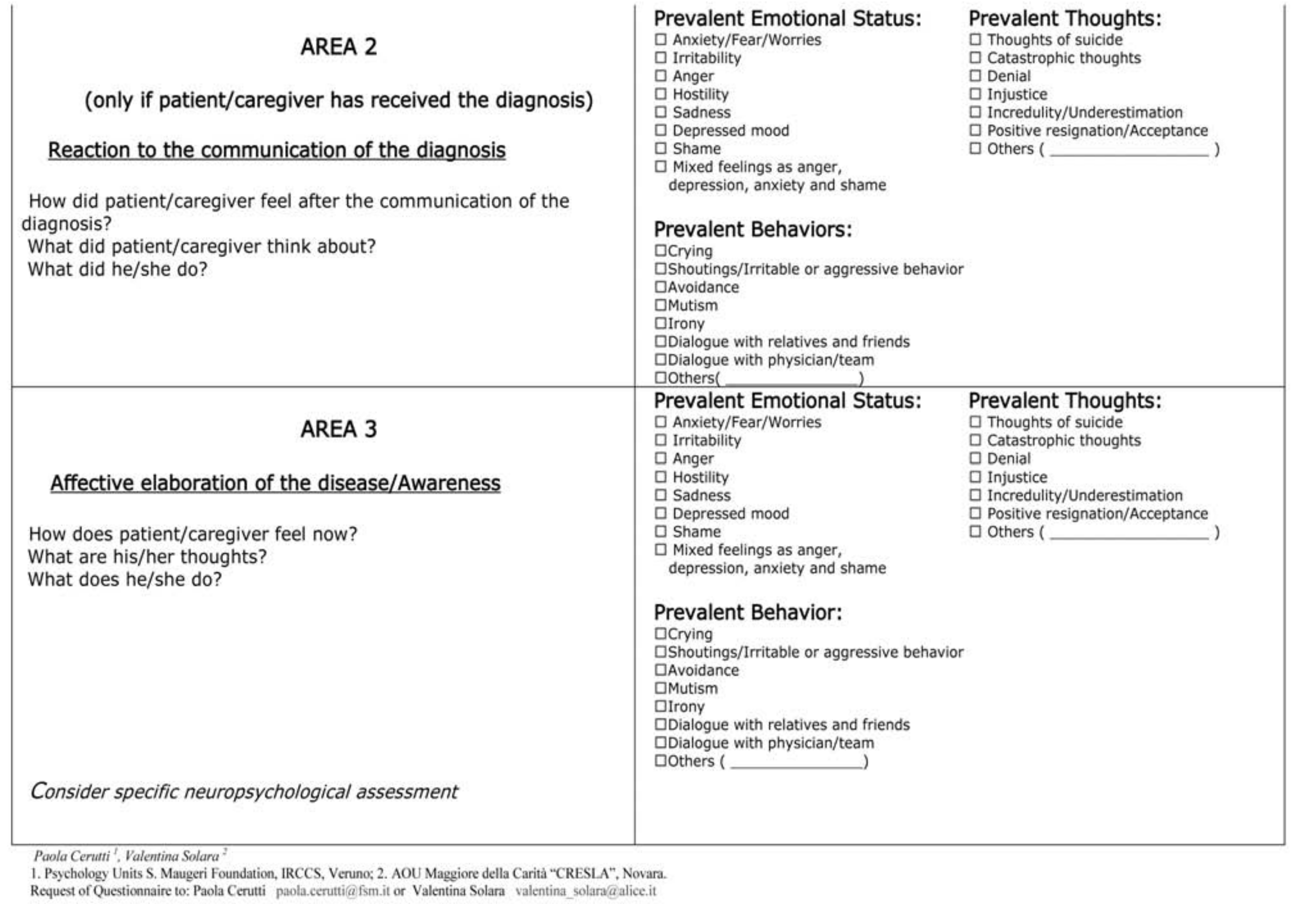

AREA 2 (only if patient/caregiver has received the diagnosis) **Reaction to the communication of the diagnosis** How did patient/caregiver feel after the communication of the diagnosis? What did patient/caregiver think about? What did he/she do?	**Prevalent Emotional Status:** ☐ Anxiety/Fear/Worries ☐ Irritability ☐ Anger ☐ Hostility ☐ Sadness ☐ Depressed mood ☐ Shame ☐ Mixed feelings as anger, depression, anxiety and shame **Prevalent Behaviors:** ☐Crying ☐Shoutings/Irritable or aggressive behavior ☐Avoidance ☐Mutism ☐Irony ☐Dialogue with relatives and friends ☐Dialogue with physician/team ☐Others(______________)	**Prevalent Thoughts:** ☐ Thoughts of suicide ☐ Catastrophic thoughts ☐ Denial ☐ Injustice ☐ Incredulity/Underestimation ☐ Positive resignation/Acceptance ☐ Others (________________)
AREA 3 **Affective elaboration of the disease/Awareness** How does patient/caregiver feel now? What are his/her thoughts? What does he/she do? *Consider specific neuropsychological assessment*	**Prevalent Emotional Status:** ☐ Anxiety/Fear/Worries ☐ Irritability ☐ Anger ☐ Hostility ☐ Sadness ☐ Depressed mood ☐ Shame ☐ Mixed feelings as anger, depression, anxiety and shame **Prevalent Behavior:** ☐Crying ☐Shoutings/Irritable or aggressive behavior ☐Avoidance ☐Mutism ☐Irony ☐Dialogue with relatives and friends ☐Dialogue with physician/team ☐Others (______________)	**Prevalent Thoughts:** ☐ Thoughts of suicide ☐ Catastrophic thoughts ☐ Denial ☐ Injustice ☐ Incredulity/Underestimation ☐ Positive resignation/Acceptance ☐ Others (________________)

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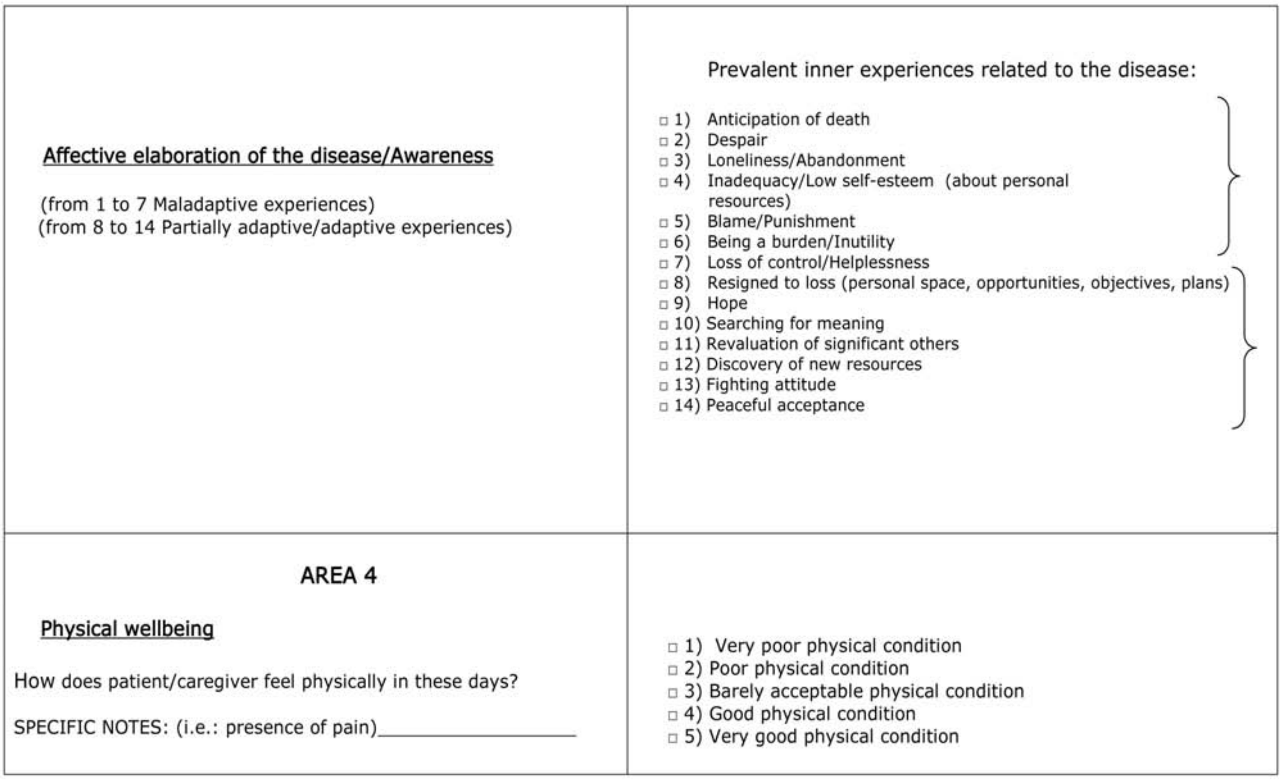

Affective elaboration of the disease/Awareness (from 1 to 7 Maladaptive experiences) (from 8 to 14 Partially adaptive/adaptive experiences)	Prevalent inner experiences related to the disease: ☐ 1) Anticipation of death ☐ 2) Despair ☐ 3) Loneliness/Abandonment ☐ 4) Inadequacy/Low self-esteem (about personal resources) ☐ 5) Blame/Punishment ☐ 6) Being a burden/Inutility ☐ 7) Loss of control/Helplessness ☐ 8) Resigned to loss (personal space, opportunities, objectives, plans) ☐ 9) Hope ☐ 10) Searching for meaning ☐ 11) Revaluation of significant others ☐ 12) Discovery of new resources ☐ 13) Fighting attitude ☐ 14) Peaceful acceptance
AREA 4 **Physical wellbeing** How does patient/caregiver feel physically in these days? SPECIFIC NOTES: (i.e.: presence of pain)___________________	☐ 1) Very poor physical condition ☐ 2) Poor physical condition ☐ 3) Barely acceptable physical condition ☐ 4) Good physical condition ☐ 5) Very good physical condition

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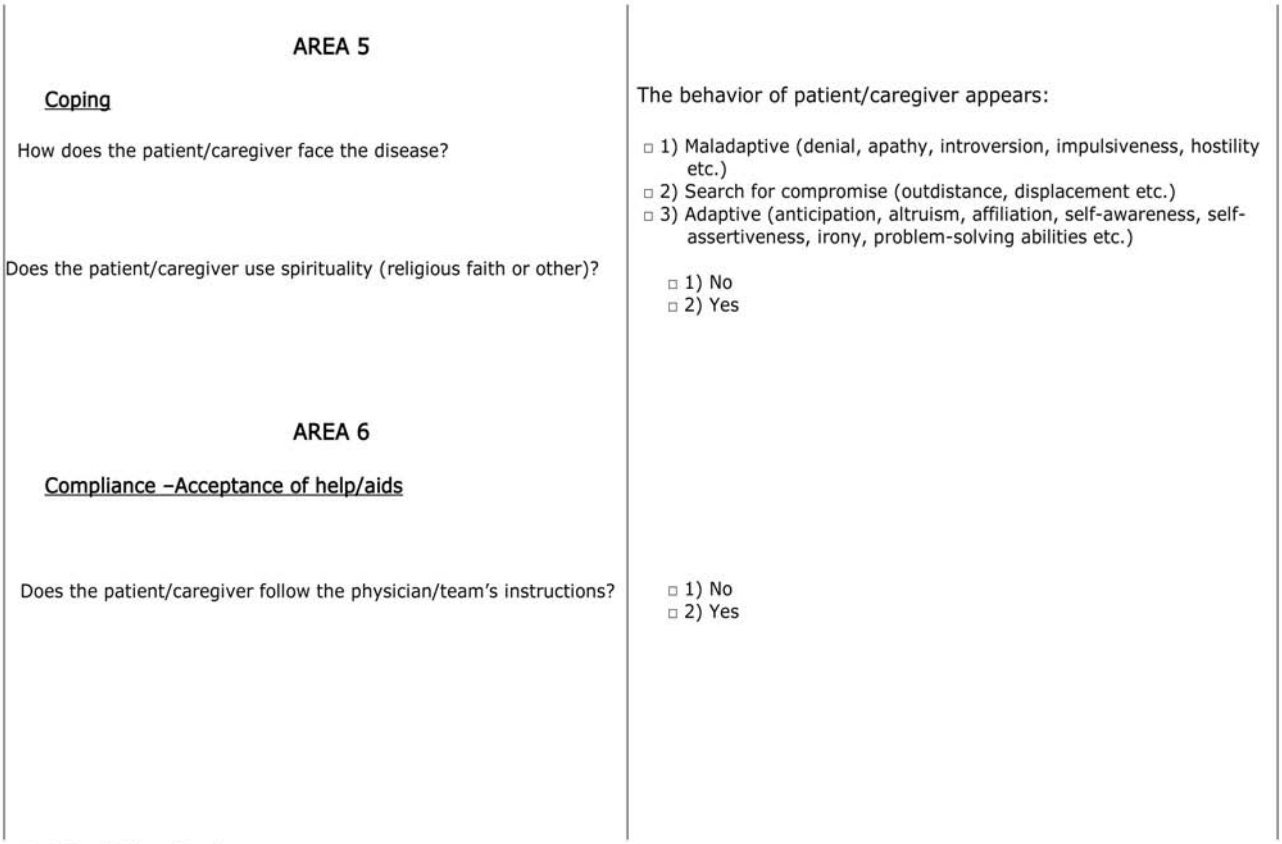

AREA 5 **Coping** How does the patient/caregiver face the disease?	The behavior of patient/caregiver appears: ☐ 1) Maladaptive (denial, apathy, introversion, impulsiveness, hostility etc.) ☐ 2) Search for compromise (outdistance, displacement etc.) ☐ 3) Adaptive (anticipation, altruism, affiliation, self-awareness, self-assertiveness, irony, problem-solving abilities etc.)
Does the patient/caregiver use spirituality (religious faith or other)?	☐ 1) No ☐ 2) Yes
AREA 6 **Compliance –Acceptance of help/aids** Does the patient/caregiver follow the physician/team's instructions?	☐ 1) No ☐ 2) Yes

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Acceptance of help, of therapeutic proposals, of aids/assistance

NN: Not Necessary
1 Very poor-2 Poor-3 Sufficiently-4 Good

	NN	1	2	3	4	Stress	Anger
Walker	☐	☐	☐	☐	☐	☐	☐
Wheelchair	☐	☐	☐	☐	☐	☐	☐
Eating devices (cutlery, etc...)	☐	☐	☐	☐	☐	☐	☐
Communicators (tablet,...)	☐	☐	☐	☐	☐	☐	☐
NIV	☐	☐	☐	☐	☐	☐	☐
PEG	☐	☐	☐	☐	☐	☐	☐
Other aids	☐	☐	☐	☐	☐	☐	☐
Assistential help (Specify __________)	☐	☐	☐	☐	☐	☐	☐

AREA 7

Family atmosphere

At this moment the relationships within the family are:	☐ 1) Indifferent ☐ 2) Hostile/Aggressive ☐ 3) Tense ☐ 4) Peaceful
Is the information about the disease shared within the family?	☐ 1) Not at all ☐ 2) Very little ☐ 3) Somewhat ☐ 4) To a great extent
Are the decisions concerning the disease shared within the family? (e.g. hospitalization, visits, participation in research, therapies, etc.)	☐1) Not at all ☐ 2) Very little ☐ 3) Somewhat ☐ 4) To a great extent

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AREA 8

Perceived social support and involvement

How does the patient/caregiver perceive the support from friends?	☐ 1) Absent, there is a perception of loneliness ☐ 2) Poor ☐ 3) Fair ☐ 4) Good
Does the patient/caregiver pursue leisure interests?	☐ 1) Never ☐ 2) Rarely ☐ 3) Sometimes ☐ 4) Very often ☐ 5) Always

COMMENTS:

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APPENDIX 2

MoNeDi-PI (Motor Neuron Diseases-Psychological Interview)

SUMMARY

(Cerutti P. & Solara V.)

Date: __________ ☐ Patient ☐ Caregiver Code ______________

SURNAME ________________________________ **NAME** ________________________________

ADDRESS ____

PHONE NUMBER __________________________________

Sex: M F **Age:** ______________ **School education (in years):** ______________

Professional status (Specify) ____

Or ☐Student ☐Unemployed ☐Housewife ☐Retired

Marital status: ☐Unmarried ☐Married/Cohabiting ☐Separated/Divorced ☐Widowed

Children ☐ No ☐ Yes (How many?__________) **Living with** ______________________________

DATE OF ONSET ______________ **KIND OF ONSET** ☐ Spinal ☐ Bulbar ☐ Spinal + Bulbar

DATE OF DIAGNOSIS ______________

DRUG THERAPY ____

COMORBIDITIES ___________________________

NEUROLOGICAL ILLNESSES IN THE FAMILY : ☐ No ☐ Yes (Specify) ______________________

1 Not at all **2** Little **3** Somewhat **4** Much **5** Very much

KNOWLEDGE OF THE DISEASE Area 1-2	1	2	3	4	5
AWARENESS OF THE DISEASE Area 3	1	2	3	4	5
PSYCHOLOGICAL WELLBEING Area 3	1	2	3	4	5
PHYSICAL WELLBEING Area 4	1	2	3	4	5
FUNCTIONAL/ADAPTIVE COPING Area 5	1	2	3	4	5
ACCEPTANCE OF HELP AND THERAPEUTIC PROPOSALS Area 6	1	2	3	4	5
AFFECTIVE RESOURCES Area 7	1	2	3	4	5
PERCEIVED SOCIAL SUPPORT AND INVOLVEMENT Area 8	1	2	3	4	5

NOTES:

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