IL PASSAGGIO DA OSPEDALE A TERRITORIO

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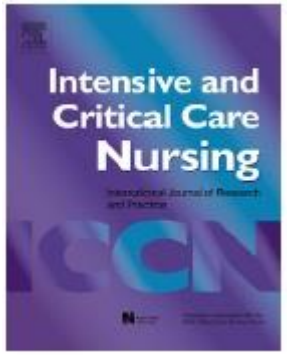


Recovery post ICU

Christina Jones [a,b,*]

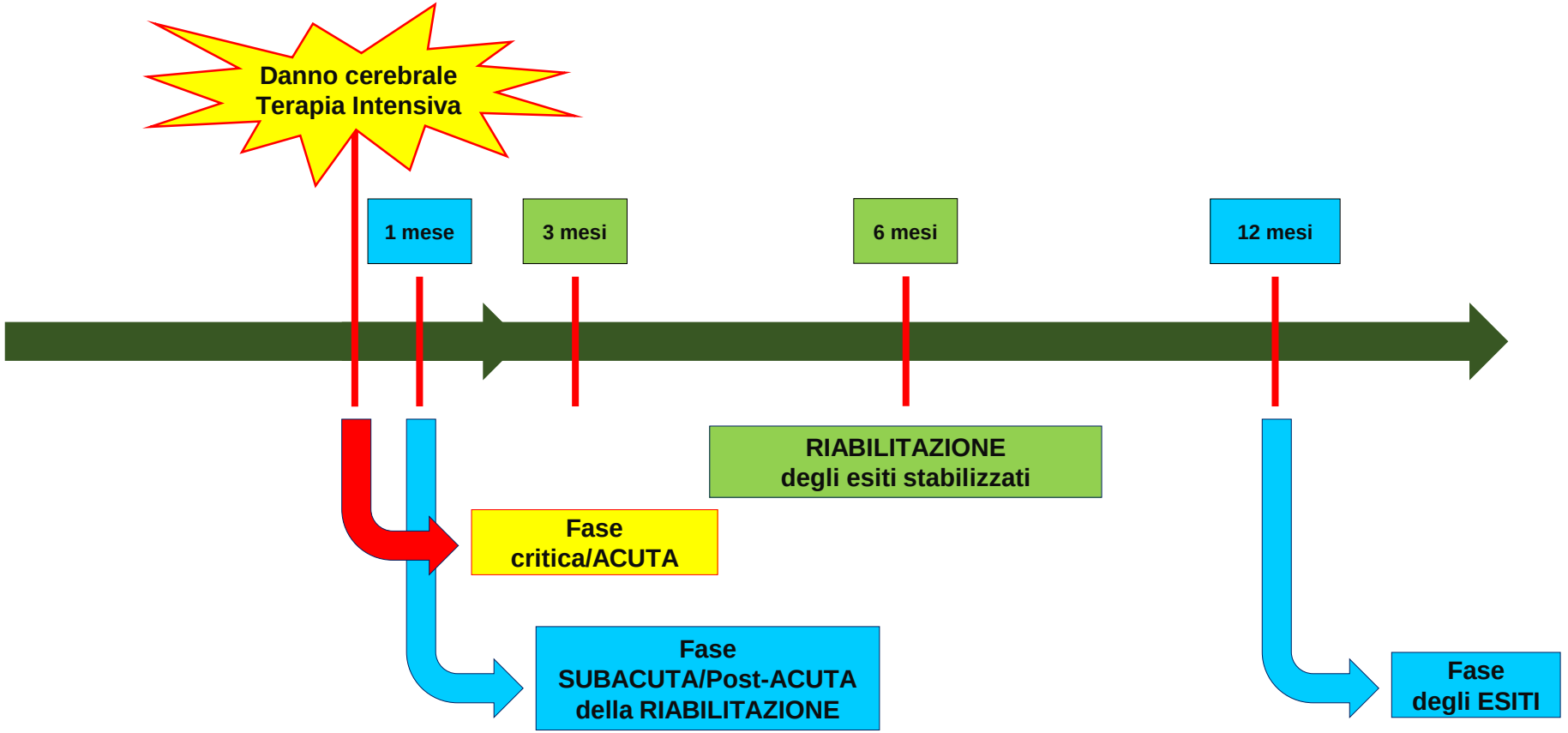
Intensive and Critical Care Nursing (2014) 30, 239–245

… change in the opinion of ICU clinicians …

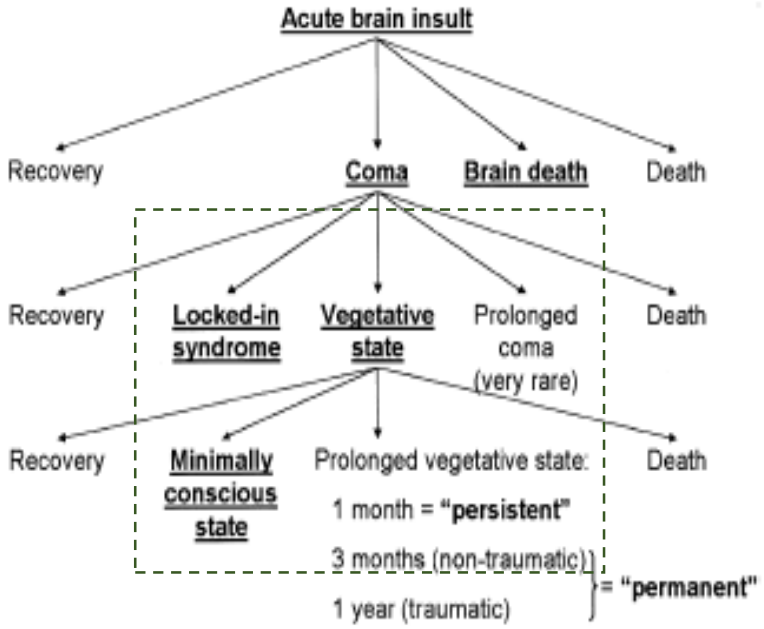
Mortality rates → **Recovery**

In 1990 the routine argument against this was that the general practitioner (GP) should be sorting out any problems patients have during their recovery. It soon became clear that GPs had little understanding of ICU and the problems patients faced. It is now clear that morbidity following an ICU stay can be high with a wide range of physical, psycho-logical and cognitive sequelae, which can persist for some months to years.

“coma to community”



“coma to community”



Gravissima disabilità

Terapia Intensiva/Neurorianimazione

Neurochirurgia

Riabilitazione Alta Specialità
UGCA Cod. 75 con programmi per pazienti con disordini della coscienza

Riabilitazione Generale/Estensiva

M.M.G.

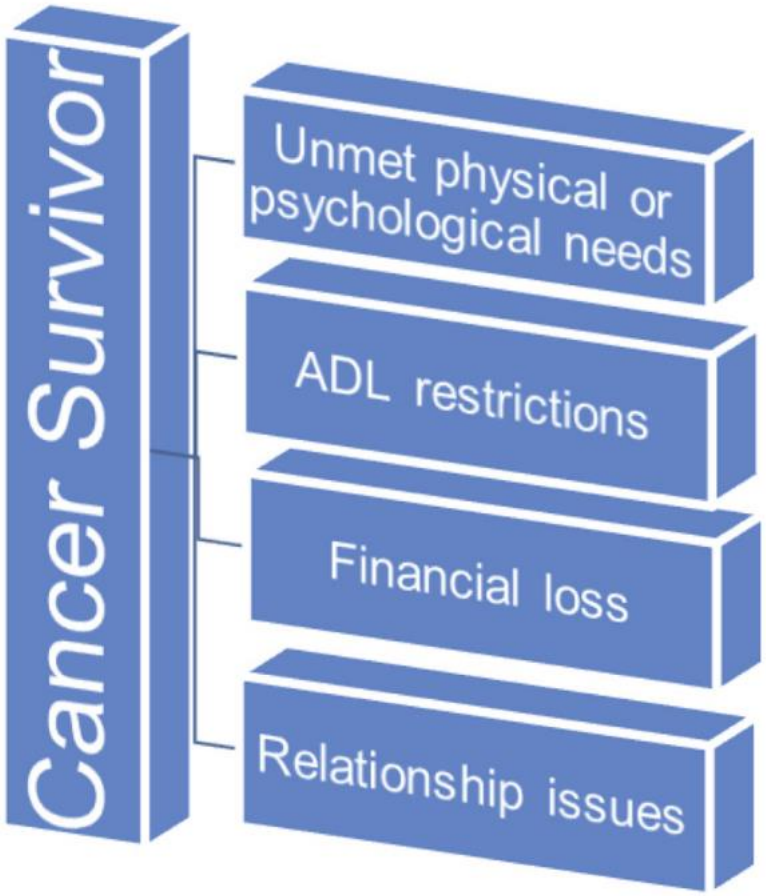
- **Domicilio**
- **Domicilio Protetto**
- **Lungodegenza**
- **SUAP**

- **Cure intermedie**

Servizi territoriali

1. *“Brain function in the vegetative state “, Steven LAUREYS et al. Acta neurol. belg., 2002, 102, 177-18*

Consequences of cancer and treatment for cancer survivors.



1. *Chowdhury RA et al. Cancer Rehabilitation and Palliative Care-Exploring the Synergies. J Pain Symptom Manage 2020;60:1239e1252.*

Componenti dell' ICF

Funzioni & Strutture Corporee	Attività & Partecipa-zione	Fattori Ambientali
		
Funzioni *Strutture*	*Capacity* *Performance*	*Barriere* *Facilitatori*

Physical

Social

Vocational

Emotional

NeuroRehabilitation goals

Prevent complications

Maximize functional capability and independence

Improving Quality of Life

Rebuilding own life plan

1. *Engel, G.L. The clinical application of the biopsychosocial model. Am. J. Psychiatry 1980, 137, 535–544.*
2. *World Health Organization - WHO (2001), ICF. International classification of functioning, disability and health, World Health Organization, Geneva.*
3. *Barnes MP. Principles of neurological rehabilitation. J Neurol Neurosurg Psychiatry 2003 Dec;74 Suppl 4(Suppl 4):iv3-iv7.*

Attività e Partecipazione

Qualificatore: Capacità

Abilità della persona nell'effettuare un compito o un'azione (ambiente standardizzato o uniforme)

Misurato in «ambiente standard «per neutralizzare gli effetti di differenti ambienti sulla capacità

Descrive la capacità di un individuo di effettuare un compito o svolgere un'attività

Indica il più alto livello possibile di funzionamento di una persona in un certo dominio e in un dato momento

Qualificatore: Performance

Abilità della persona nell'effettuare un compito o un'azione nel suo ambiente attuale

L'ambiente di vita è inteso con l'ausilio di tecnologie assistive o di assistenti personali, se la persona li utilizza per le sue regolari azioni quotidiane

Descrive ciò che una persona esegue nel suo ambiente di vita

Inteso come «»coinvolgimento» in una situazione di vita o «esperienza vissuta» dalla persona nel proprio ambiente di vita

Fattori ambientali

- *World Health Organization - WHO (2001), ICF. International classification of functioning, disability and health, World Health Organization, Geneva.*

Components of Neurorehabilitation

Physical rehabilitation

- Concerned with physical impairments and movement dysfunctions
- Aims to increase mobility and function

Occupational therapy

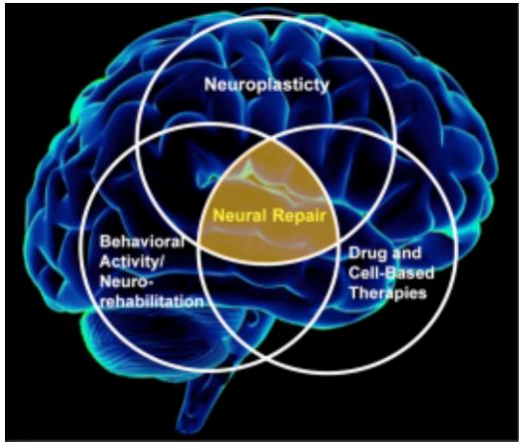
- Focus on evaluating and improving a persons functional abilities
- Aims at helping people live as independently as possible
- Might incorporate physical and cognitive aspects

Neuropsychological rehabilitation

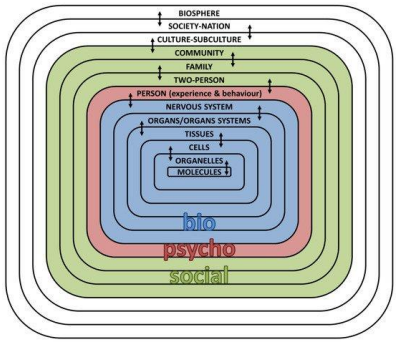
- Concerned with cognition impairments
- Cognitive submodalities / domains
- Emotional and behavioural aspects
- Aphasia rehabilitation: centered on language disorders

Social work

- Legal, financial issues
- Services and accomodation
- Counseling



1. *Trombly C. Anticipating the future: assessment of occupational function. Am J Occup Ther 1993 Mar;47(3):253-7.*
2. *Barnes MP. Principles of neurological rehabilitation. J Neurol Neurosurg Psychiatry 2003 Dec;74 Suppl 4(Suppl 4):iv3-iv7.*
3. *Law M, MacDermid J. Evidence-Based Rehabilitation. A Guide to Practice. 2008; SLACK, Thorofare, NJ.*
4. *Fisher AG. Occupation-centred, occupation-based, occupation-focused: same, same or different? Scand J Occup Ther 2013 May;20(3):162-73.*
5. *Selzer ME, Clarke S, Cohen LG, Kwakkel G, Miller RH. Textbook of Neural Repair and Rehabilitation. Cambridge University Press, 2014.*



#ABILITA
ROBOTICS HEALTHCARE

CAREGIVER BURDEN AND NEEDS IN COMMUNITY NEUROREHABILITATION

Michelangelo Bartolo, MD, PhD[1,2], Danila De Luca, MD[1], Mariano Serrao, MD, PhD[2,3], Elena Sinforiani, MD[4], Chiara Zucchella, PsyD[4] and Giorgio Sandrini, MD[5]

J Rehabil Med 2010; 42: 818–822

Caregiver Burden and Coping in Early-stage Alzheimer Disease

Chiara Zucchella, PsyD, Michelangelo Bartolo, MD, PhD,† ‡ Chiara Pasotti, PsyD,* Laura Chiapella, PsyD,* and Elena Sinforiani, MD**

Alzheimer Dis Assoc Disord 2011

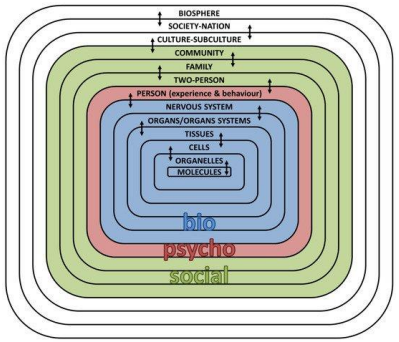
Burden of caregivers of patients in Vegetative State and Minimally Conscious State

Giovannetti AM, Leonardi M, Pagani M, Sattin D, Raggi A. Burden of caregivers of patients in Vegetative State and Minimally Conscious State. Acta Neurol Scand: 2013: 127: 10–18.

A. M. Giovannetti, M. Leonardi, M. Pagani, D. Sattin, A. Raggi
Neurology, Public Health and Disability Unit, Scientific Directorate, Neurological Institute Carlo Besta IRCCS Foundation, Milan, Italy

Acta Neurol Scand 2013: 127: 10–18 DOI: 10.1111/j.1600-0404.2012.01666.x

Sistema Sanitario Regione Lombardia



#ABILITA
ROBOTICS HEALTHCARE

Elevato e prolungato "CARICO" assistenziale
(*materiale ed emotivo*)

RISCHIO: assorbimento di tutte le "risorse" familiari

Familiari e "Ruolo di decisori"

Riadattamento e riprogettazione dei ruoli
(familiare e sociale)

Il "DOPO DI NOI"

Sistema Sanitario Regione Lombardia

J Rehabil Med 2010; 42: 818–822

ORIGINAL REPORT

CAREGIVER BURDEN AND NEEDS IN COMMUNITY NEUROREHABILITATION

Michelangelo Bartolo, MD, PhD[1,2], Danila De Luca, MD[1], Mariano Serrao, MD, PhD[2,3], Elena Sinforiani, MD[4], Chiara Zucchella, PsyD[4] and Giorgio Sandrini, MD[5]

Table I. *Study population*

Variables	Patients (n=105)	Caregivers (n=105)
Gender, n (%)		
Male	59 (56)	44 (42)
Female	46 (44)	61 (58)
Age, years, mean (SD)	66.87 (11.75)	63.01 (12.39)
[range]	[26–83]	[41–83]
Education, years, mean (SD)	8.25 (3.53)	9.94 (3.34)
Diagnosis, n (%)		
Stroke	47 (45)	
Parkinson's disease and parkinsonisms	36 (34)	
Post-polio syndrome	9 (8)	
Cerebral palsy	5 (5)	
Degenerative ataxia	3 (3)	
Neuro-oncology post-surgery	3 (3)	
Amyotrophic lateral sclerosis	2 (2)	
Disease duration, years, mean (SD)	13 (13.48)	
[range]	[3–59]	
Relationship to the patient, n (%)		
Spouse/partner		75 (72)
Son/daughter		13 (12)
Parent		5 (5)
Friend		12 (11)
Living with the patient		80 (76)
Additional help, n (%)		
Informal help		30 (29)
Formal help		14 (13)

SD: standard deviation.

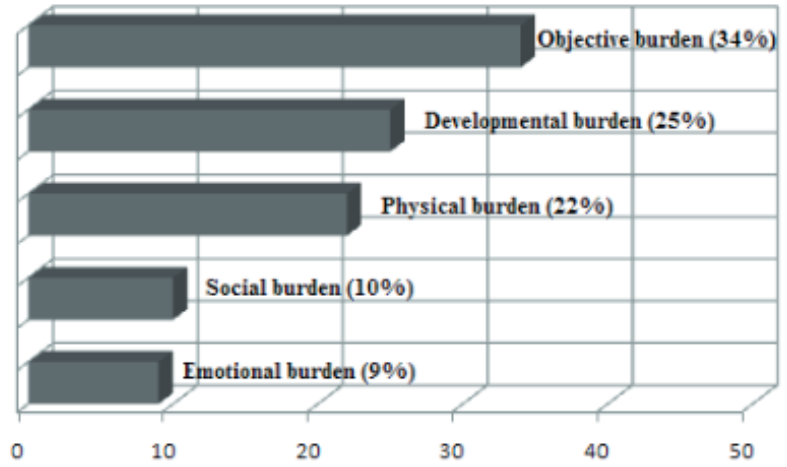


Fig. 1. The distribution of caregiver burden over the 5 domains considered in the Caregiver Burden Inventory, shown as percentage values.

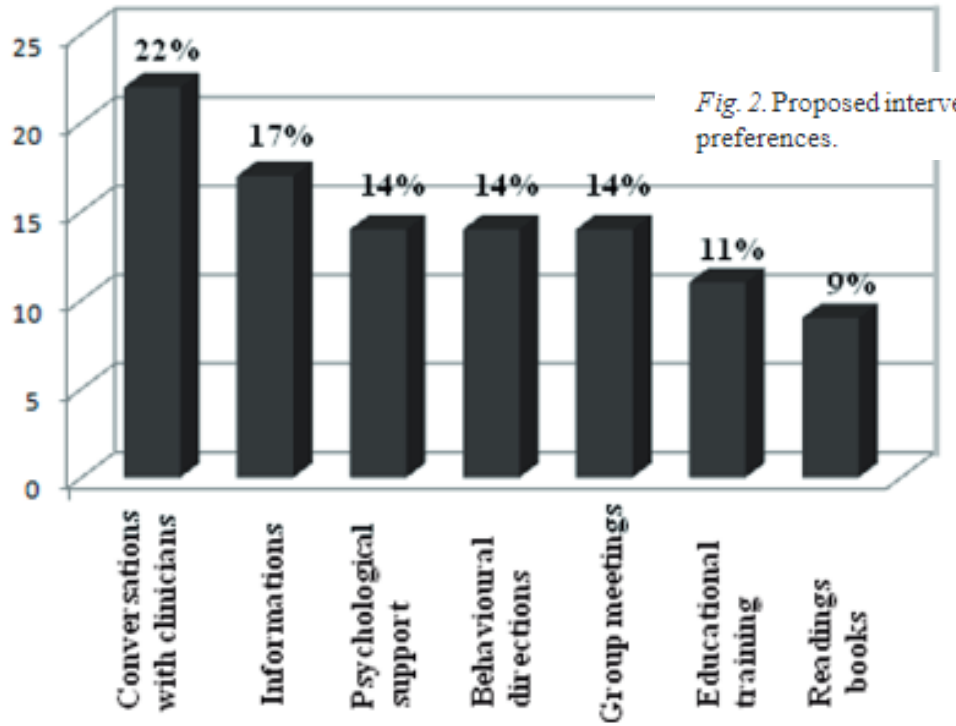


Fig. 2. Proposed interventions aimed at reducing burden of care: caregivers' preferences.

Observational Study > J Telemed Telecare. 2018 Jan;24(1):56-62.
doi: 10.1177/1357633X16673273. Epub 2016 Oct 12.

Is telemonitoring useful for supporting persons with consciousness disorders and caregivers? A preliminary observational study in a real-life population

Chiara Zucchella [1 2], Massimo Di Santis [3], Biagio Ciccone [2], Massimiliano Pelella [3], Marina Scappaticci [2], Giovanna Badalassi [4], Susanna Lavezzi [5], Michelangelo Bartolo [1]

Patient	Sex	Age (years)	Time from event (months)	Aetiology	Craniotomy	Tracheostomic tube	Spontaneous breathing	PEG	Bladder catheter	Baclofen pump	POA	Pressure ulcers	Sleep–wake rhythm	GCS	LCF	GOS	DRS
1	F	67.1	29	Traumatic (car accident)	•	•	•	•	•					6	1	VS	26
2	F	5.5	41	Traumatic (car accident)		•		•		•			•	5*	1	VS	26
3	F	80	11	Hypoxic (vascular)		•		•	•					9	1	VS	24
4	F	57.2	18	Hypoxic (cardiac arrest)			•	•				•		9	1	VS	24
5	M	22.7	63	Traumatic		•	–/•	•						6	1	VS	26
6	M	25.10	71	Traumatic (car accident)		•	•	•						5	1	VS	26
7	M	29.10	10	Hypoxic (cardiac arrest)			•	•					•	12	3	SD	21
8	M	28.5	26	Traumatic (car accident)	•		•	•					•	10	2	SD	25
9	M	59.2	22	Hypoxic (cardiac arrest)			•	•				•	•	9	1	VS	26
10	M	33.4	11	Traumatic (fall)			•	•	•		•		•	11	3	SD	22
11	M	48	70	Traumatic (car accident)			•	•					•	11	3	SD	22

PEG: percutaneous gastrostomy; POA: paraosteoarthropathy; GCS: Glasgow Coma Scale; LCF: Levels of Cognitive Functioning; GOS: Glasgow Outcome Scale; DRS: Disability Rating Scale; VS: vegetative state; SD: severe disability.
*Paediatric Glasgow Coma Scale for nonverbal children.

Table 2. Descriptive data about the additional connections.

Patient	Connections (*n*)	Time (minimum)	Time (maximum)	Mean	SD
1	15	10	29	19,60	6,288
2	14	13	26	20,00	4,297
3	16	11	27	18,44	5,228
4	14	9	29	18,93	6,032
5	16	12	26	18,38	4,801
6	14	12	30	19,36	5,458
7	15	12	28	18,53	5,181
8	14	14	25	19,36	4,162
9	15	12	27	18,53	5,370
10	14	10	26	18,93	5,470
11	14	14	26	20,43	4,415
Total	161	9	30	19,11	5,077

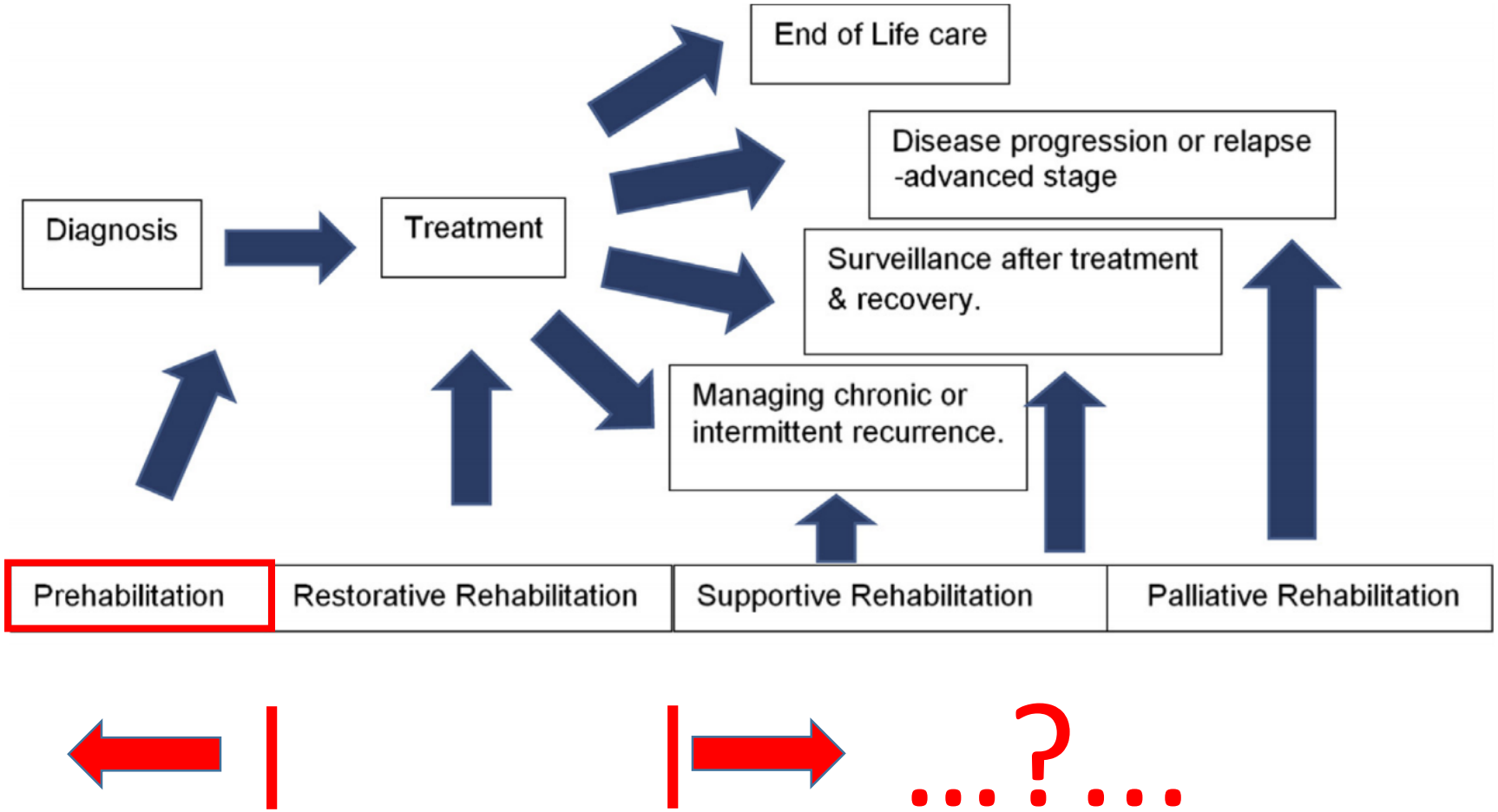
Time is expressed in minutes.
SD: standard deviation.

Table 3. Comparison (T0–T3) of caregivers' scores at the clinical scales.

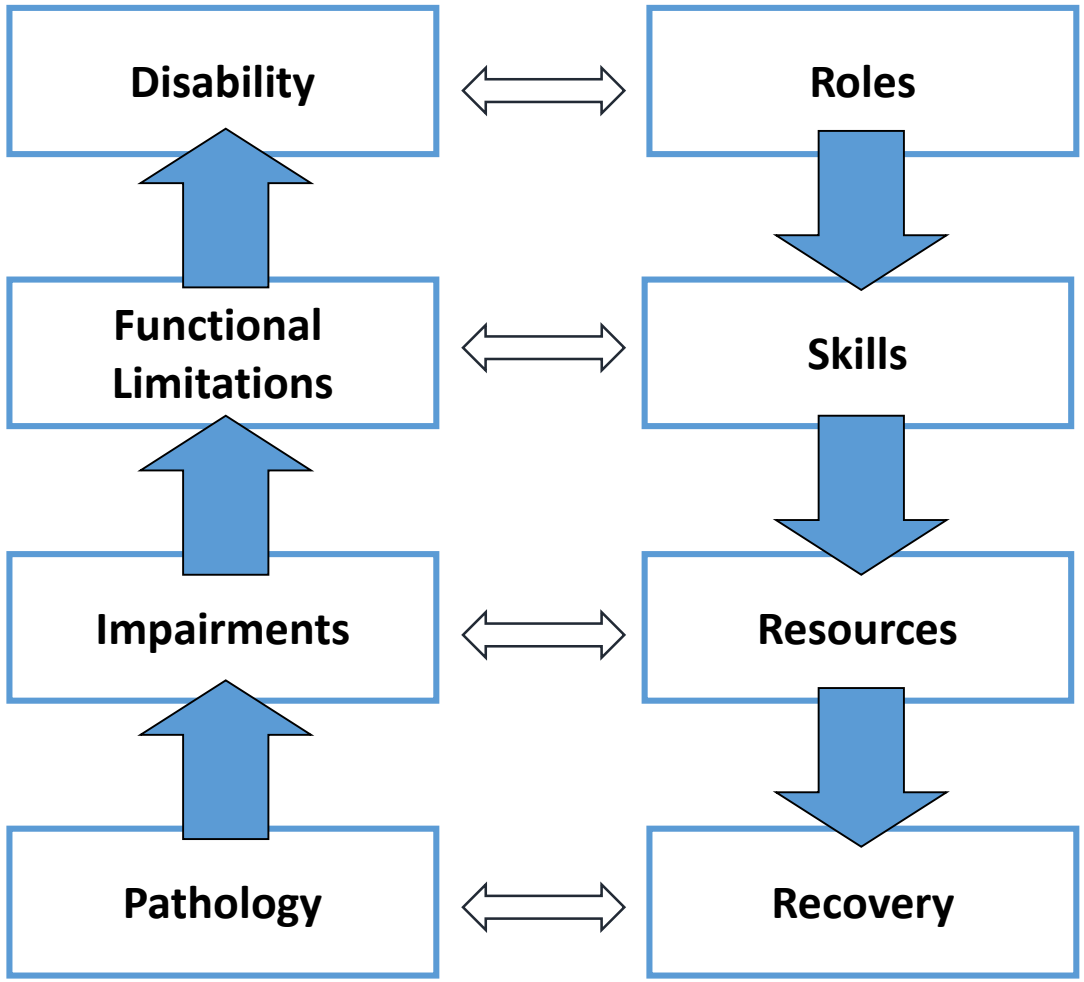
Measures	T0	T3	*p*
HARS	14.7 ± 3.8	12.7 ± 2.8	*ns*
HDRS	12.1 ± 2.6	10.9 ± 1.8	*ns*
WHOQoL			
Physical domain	59.6 ± 12	65 ± 11.4	*ns*
Psychological domain	58.3 ± 9.8	63.8 ± 7.4	*ns*
Social domain	46.6 ± 15.3	57.5 ± 13.9	*ns*
Environmental domain	46.6 ± 11.2	50 ± 10.8	*ns*
Level of satisfaction		3.6 ± 0.8 (range 2–5)	

HARS: Hamilton Anxiety Rating Scale; HDRS: Hamilton Depression Rating Scale; WHOQoL: World Health Organization Quality of Life; ns: not significant.

Dietz classification of cancer rehabilitation in the treatment continuum



Conclusioni.



Participation **in necessary and desired roles including self-care, social, occupational, and recreational.**

Ability to achieve *meaningful goals* with consistency, flexibility, and efficiency.

Physical and cognitive *mechanisms*, including musculoskeletal linkages, control of basic movement types, ability to plan, etc..

Active *physiological mechanisms* that support recovery and limit future disability.

(Gordon, 2000)