UNIVERSITÀ GIUSTINO FORTUNATO
D.M. 13 aprile 2006 - G.U. n° 104 del 6/05/2006 - TELEMATICA

UniforJob ACADEMY

Accademia Eraclitea
ENTE DI RICERCA E DI ALTA FORMAZIONE ACCREDITATO

Master Universitario di primo livello in "Deglutologia geriatrica" A.A. 2023/24

LA DISFAGIA NELLE MALATTIE NEURODEGENERATIVE

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OUTLINE

- Introduzione alla disfagia nelle malattie neurodegenerative: peculiarità della presa in carico
- La disfagia nella Malattia di Parkinson
- La disfagia nella Malattia di Huntington
- La disfagia nelle Demenze

  - Inquadramento clinico-diagnostico
  - Epidemiologia, fisiopatologia e complicanze
  - Peculiarità nella valutazione
  - Il trattamento della disfagia

- Esercitazioni pratiche: EMST, biofeedback con IOPI e sEMG
- Casi clinici: discussione in plenaria

Chi ha valutato/trattato una persona con Malattia di Parkinson, Malattia di Huntington o Demenza?

Introduzione alla disfagia nelle malattie neurodegenerative: peculiarità della presa in carico

Le Malattie Neurodegenerative

- Demenze
- Distrofie
- Sclerosi Multipla
- Malattia di Parkinson
- Sclerosi Laterale Amiotrofica
- Malattia di Huntington

No cura

Andamento progressivo

Genetica e epigenetica

Morte cellulare programmata

Aggregazione proteica

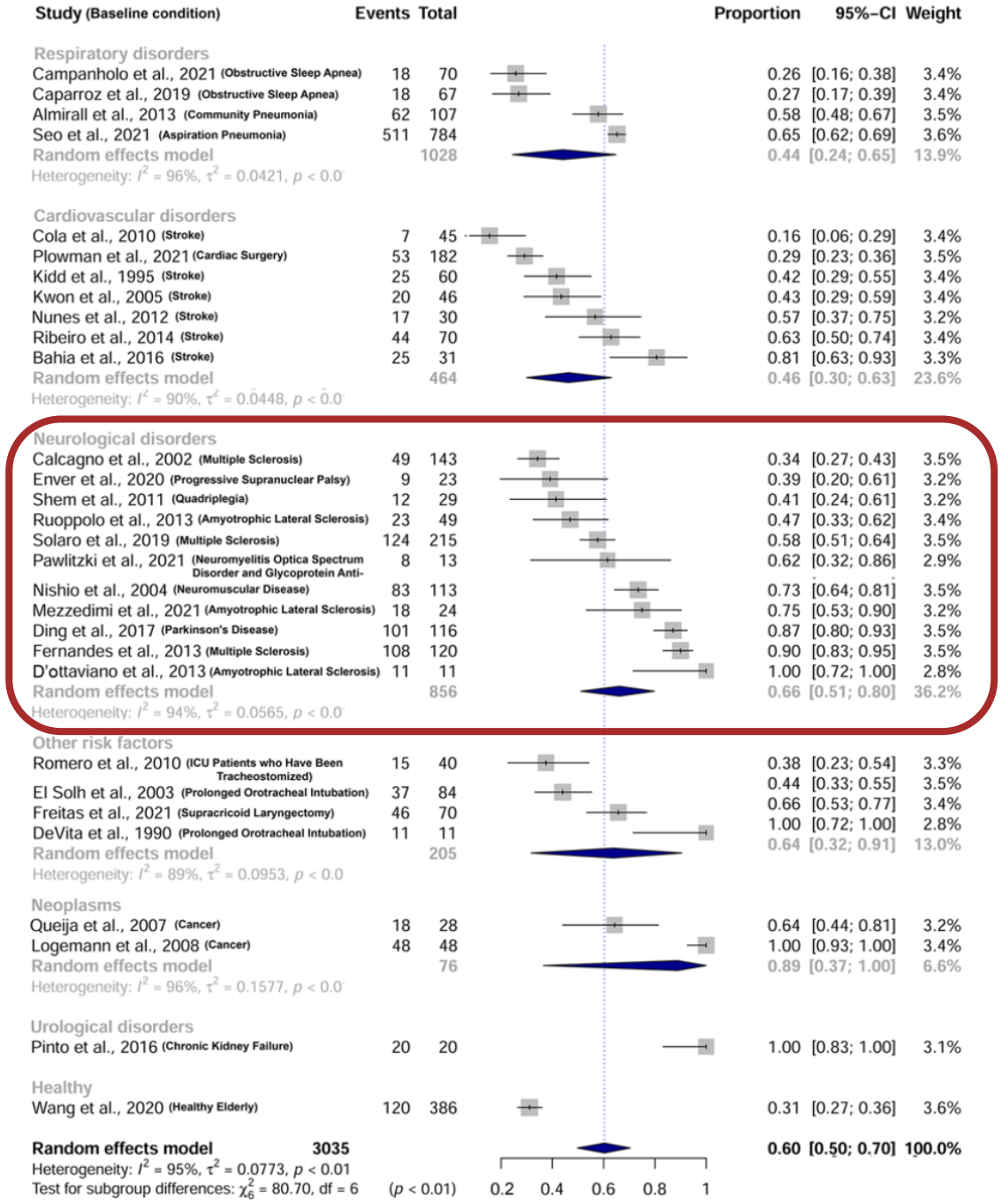
Alterazioni metaboliche

Perdita di peso non intenzionale

Prevalenza

66% [IC95% 51-80%]

Ribeiro et al, 2023



Rilevanza clinica

DEMENZA

Espinosa-Val et al, 2020

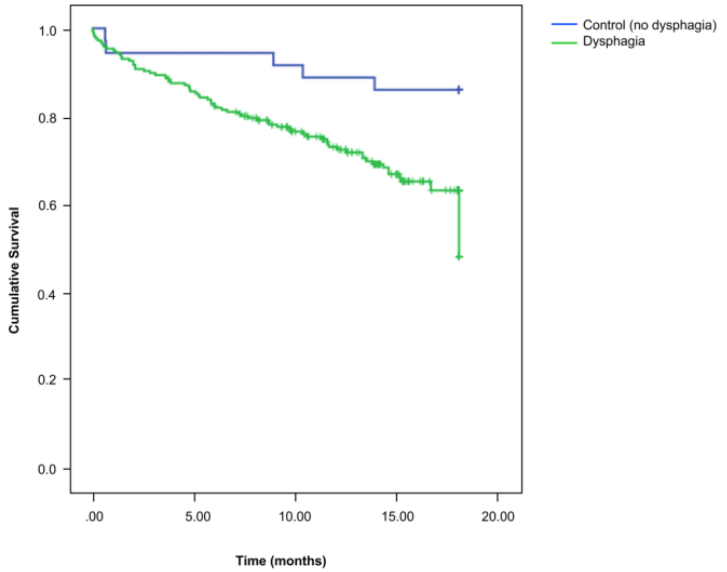


Figure 2. Eighteen-month survival curves for dysphagic and non-dysphagic patients. OD: oropharyngeal dysphagia patients; ND: patients without OD.

PARKINSON

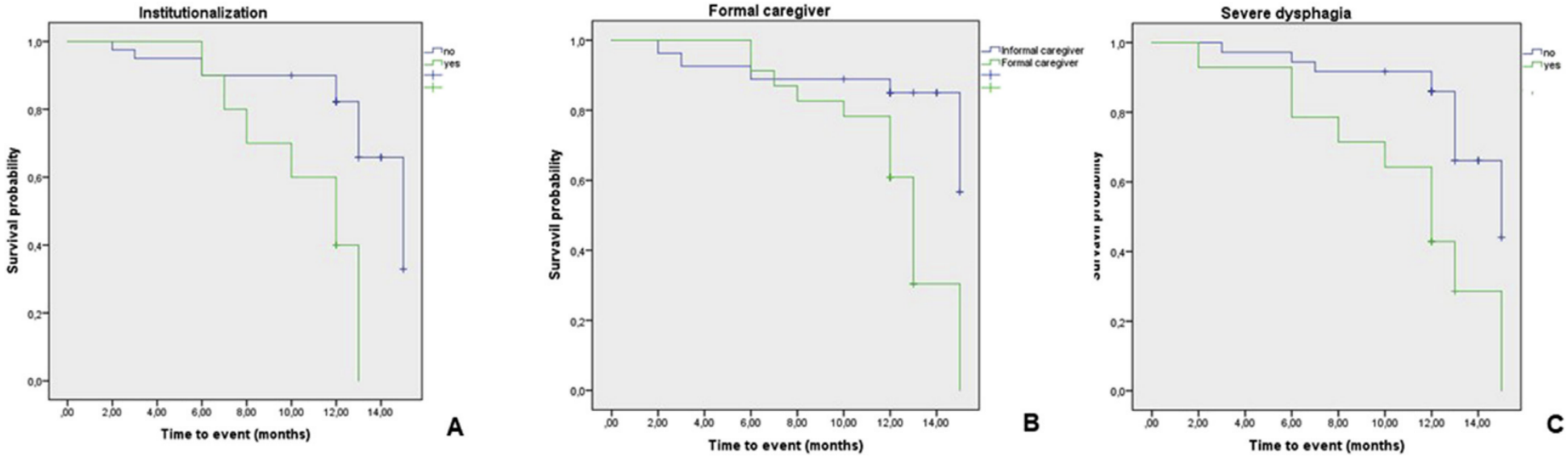
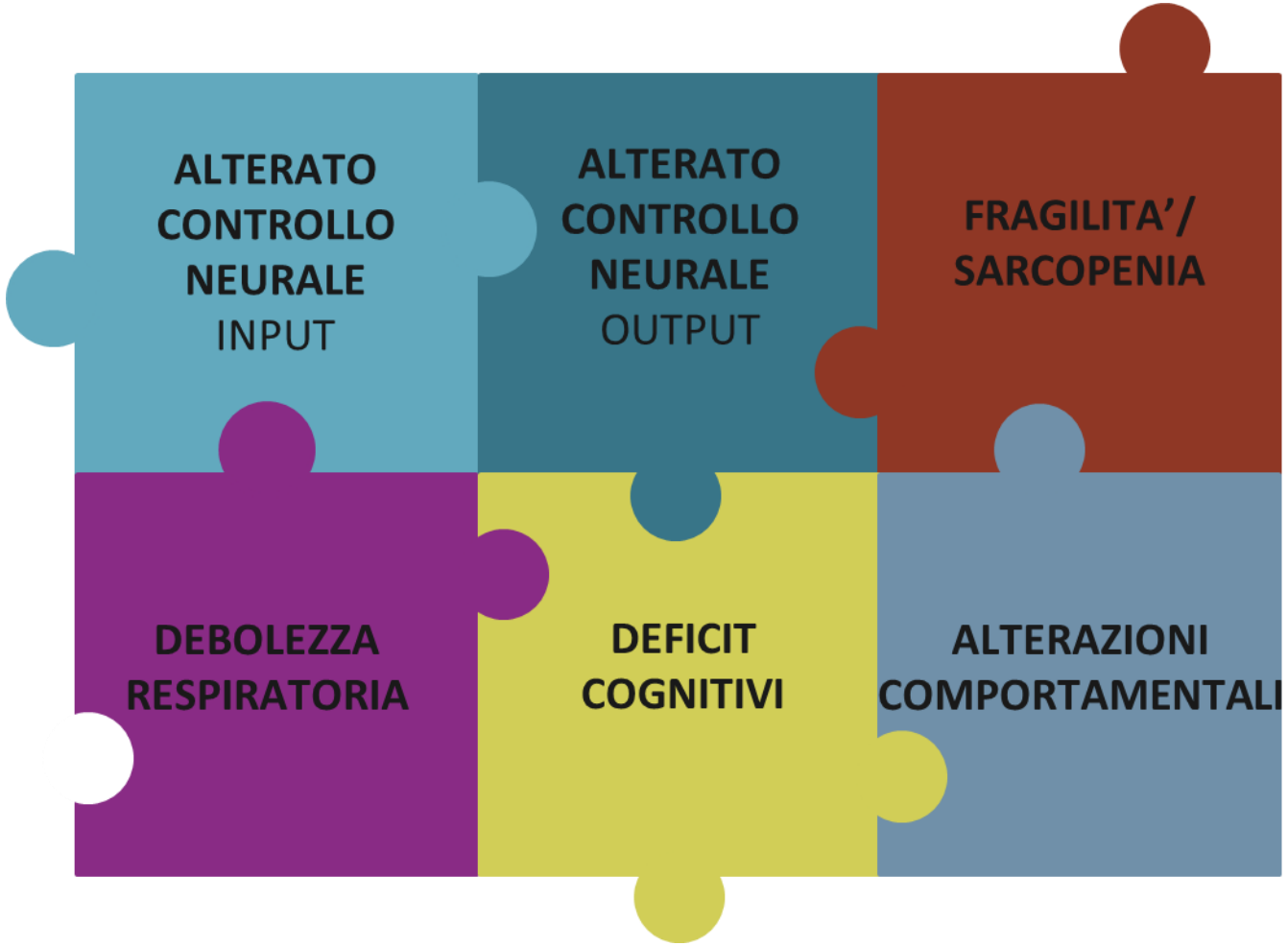


Fig. 1. Kaplan-meier curves for the occurrence of the combined poor outcome (death/be institutionalized/HY 5) at follow-up for patients who are institutionalized (A), need a formal caregiver (B) or have a severe dysphagia (C) (MDS.UPDRS item 2.3 ≥ 2) at baseline.

Fabbri et al, 2019

Fisiopatologia della disfagia nelle m. neurodegenerative



Interdisciplinarietà

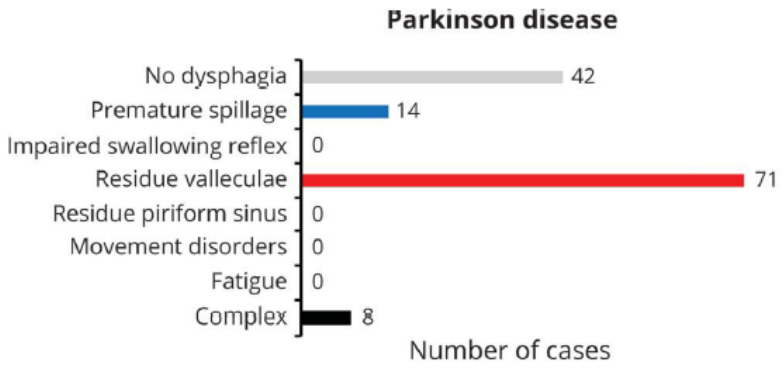
Logopedisti, Foniatri, Otorinolaringoiatri, Neurologi, Pneumologi, Fisiatri, Gastroenterologi, Fisioterapisti, Infermieri, Psichiatri, Psicologi, Dietologi, Dietisti, Odontoiatri, Igienisti dentali, ….

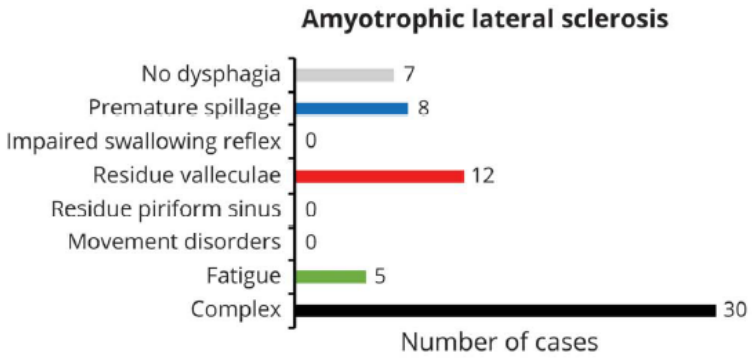
Un presa in carico interdisciplinare dei pazienti con SLA è stata associata ad un aumento della sopravvivenza, una riduzione delle ospedalizzazione e una maggiore soddisfazione del paziente

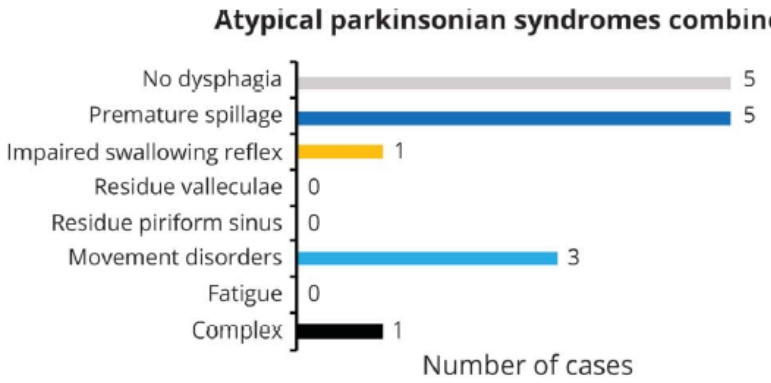
Chiò et al., 2006; Howard & Potts, 2019; L. Ng et al., 2009

Specificità per diagnosi

1. Quali sono il fenotipo ed i meccanismi patogenetici alla base della disfagia nella specifica patologia?







Warnecke et al, 2020

Neurogenic Dysphagia

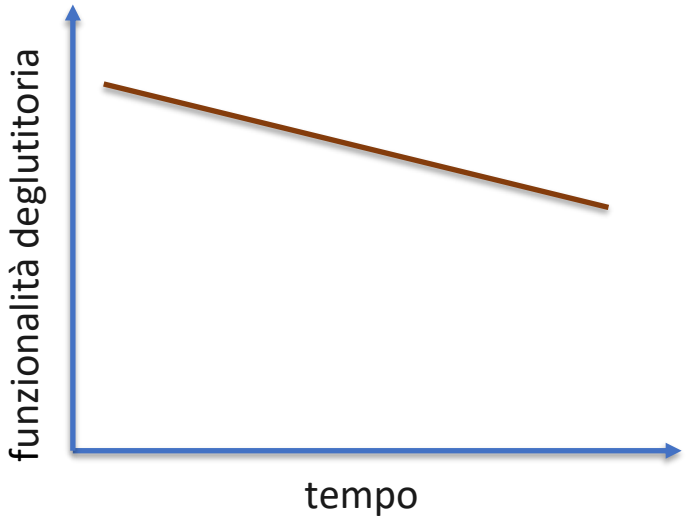
Systematic Review and Proposal of a Classification System

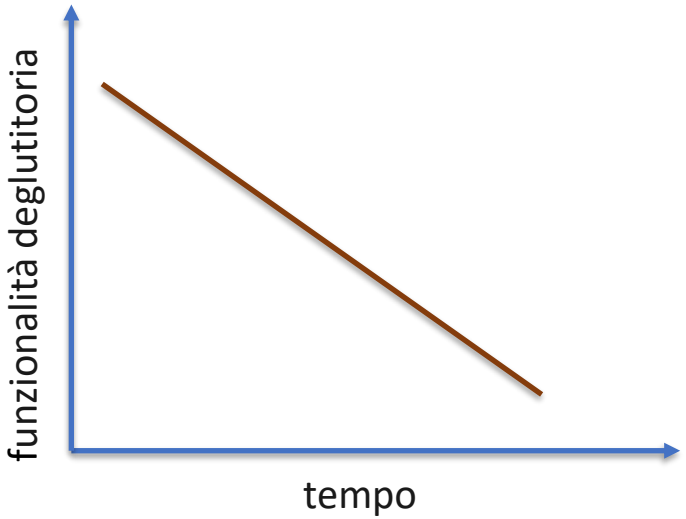
Tobias Warnecke, MD,* Bendix Labeit, MD,* Jens Schroeder, MD, Alexander Reckels, MD, Sigrid Ahring, Sriramya Lapa, Inga Claus, MD, Paul Muhle, MD, Sonja Suntrup-Krueger, MD, and Rainer Dziewas, MD

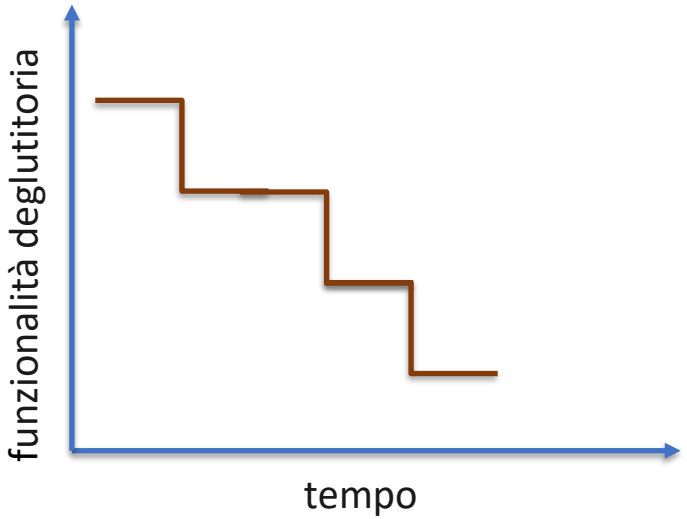
Neurology® 2021;96:e876-e889. doi:10.1212/WNL.0000000000011350

Specificità per diagnosi

2. Come e quanto velocemente progredisce la disfagia nella specifica patologia?





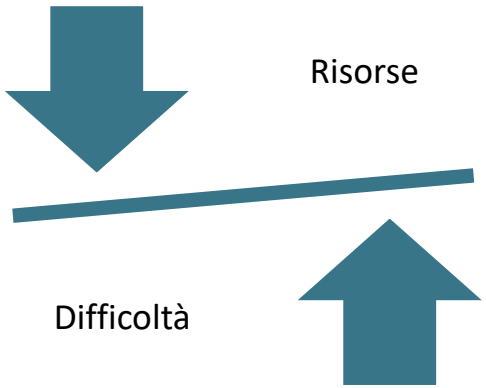


Unicità della persona

Response Shift *(Neudert et al., 2004):*

- ↓ HRQOL
- Benessere stabile nel tempo *(de Camargos et al, 2020; Delle Fave et al 2017)*

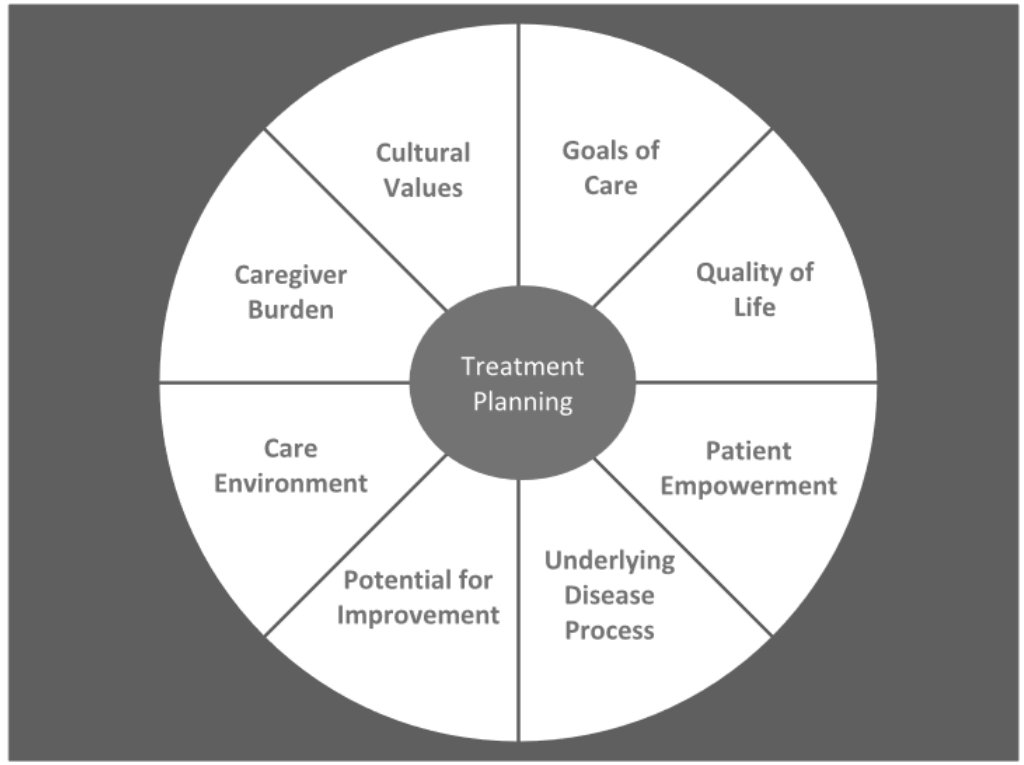
CONDIZIONE DI MALATTIA CRONICA



Nuovi bisogni di cura

Unicità della persona

Figure 1. Management of dysphagia in persons with neurodegenerative disease requires special consideration of various factors highlighted in this figure. The speech-language pathologist is responsible for carefully balancing these factors when making decisions regarding dysphagia treatment for these patients.



Rogus Pulia & Plowman, 2020

Quali sono i bisogni di cura dei pazienti con m. neurodegenerative?

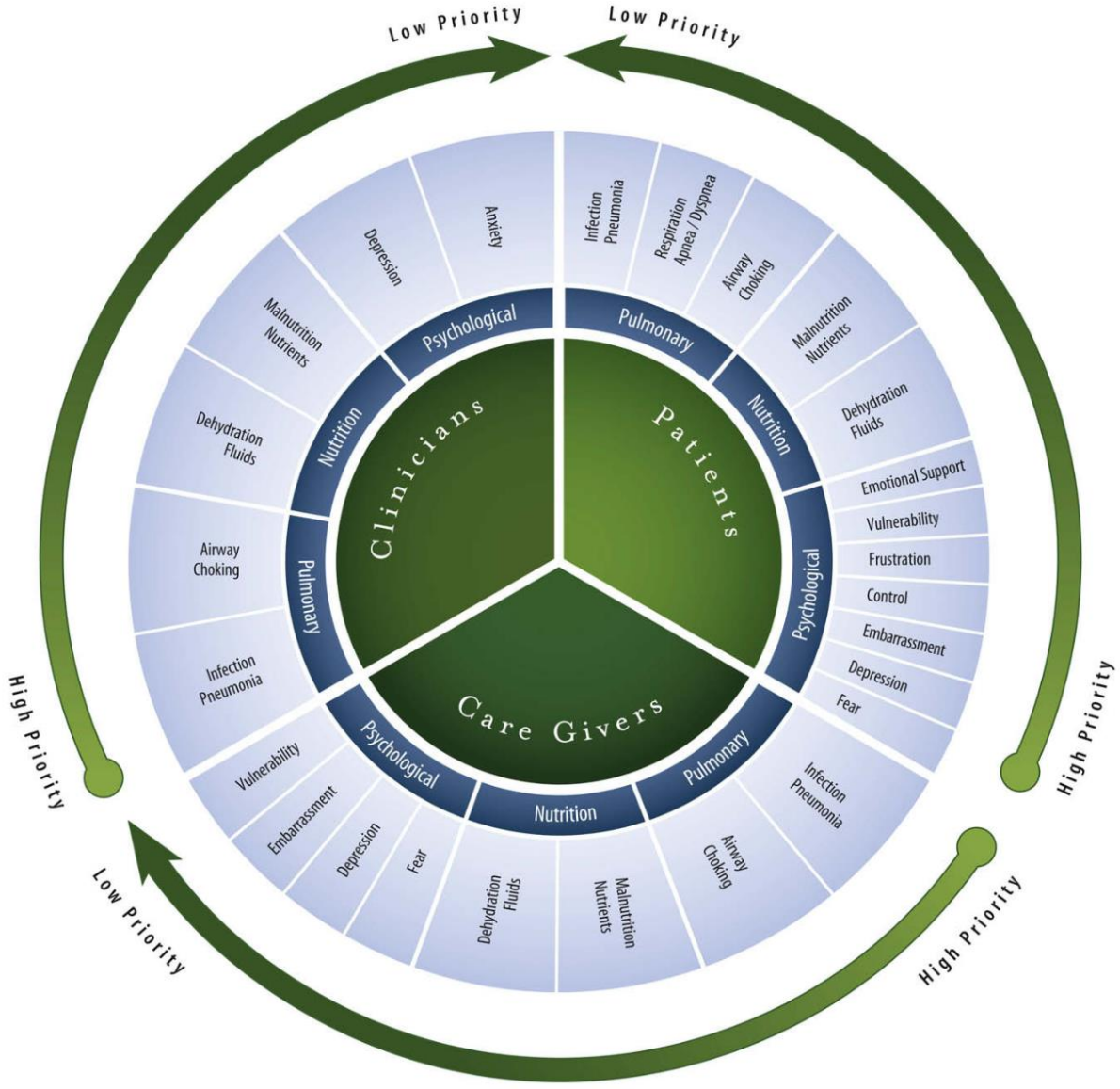


Fig. 1. Comparison of priorities in content according to varying perspectives.

Martino et al, 2009

PLOS ONE

RESEARCH ARTICLE

The care needs of persons with oropharyngeal dysphagia and their informal caregivers: A scoping review

Aurora Ninfa[1]*, Valeria Crispiatico[1], Nicole Pizzorni[2], Marta Bassi[2], Giovanni Casazza[2], Antonio Schindler[2], Antonella Delle Fave[1]

METHODS

- PRISMA guidelines
- 5 electronic databases searched for evidence dated 2000-21
- 2 independent raters + disagreement resolution
- Best fit framework synthesis approach, using the Supportive Care Framework (Fitch, 2008)

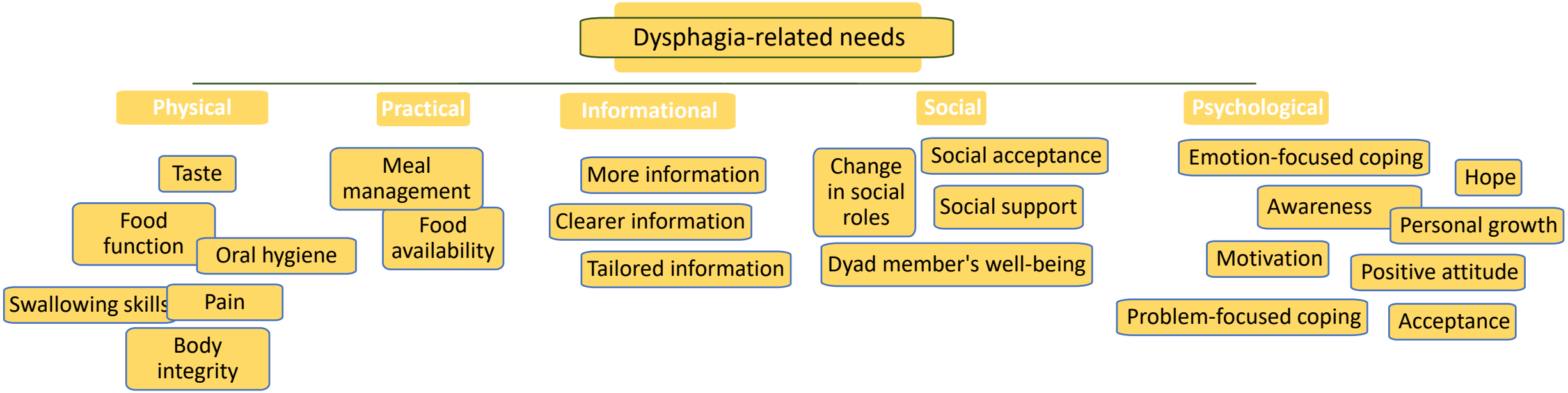
RESULTS

- 15 included studies (out of 2,534 identified)
- 266 care needs extracted
- Studies conducted in Western countries (100.0%), primarily on HNC patients (53.3%)
- Qualitative methods used (93.3%)
- Overlooked caregivers' perspective (33.3%)
- Wide variety of care needs reported

RESEARCH ARTICLE

The care needs of persons with oropharyngeal dysphagia and their informal caregivers: A scoping review

Aurora Ninfa[1]*, Valeria Crispiatico[1], Nicole Pizzorni[2], Marta Bassi[2], Giovanni Casazza[2], Antonio Schindler[2], Antonella Delle Fave[1]



Vivere con la disfagia cronica: bisogni, problemi e risorse

AIM To qualitatively explore needs, problems, and resources of patients living with chronic OD and their informal carers

METHODS - Qualitative study, semi-structured interviews

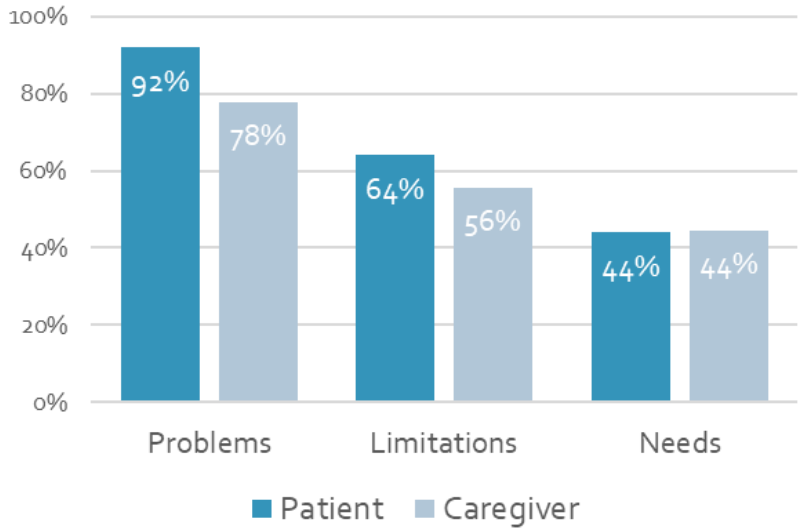
- Thematic analysis: 2 independent researcher, discussion with expert researcher

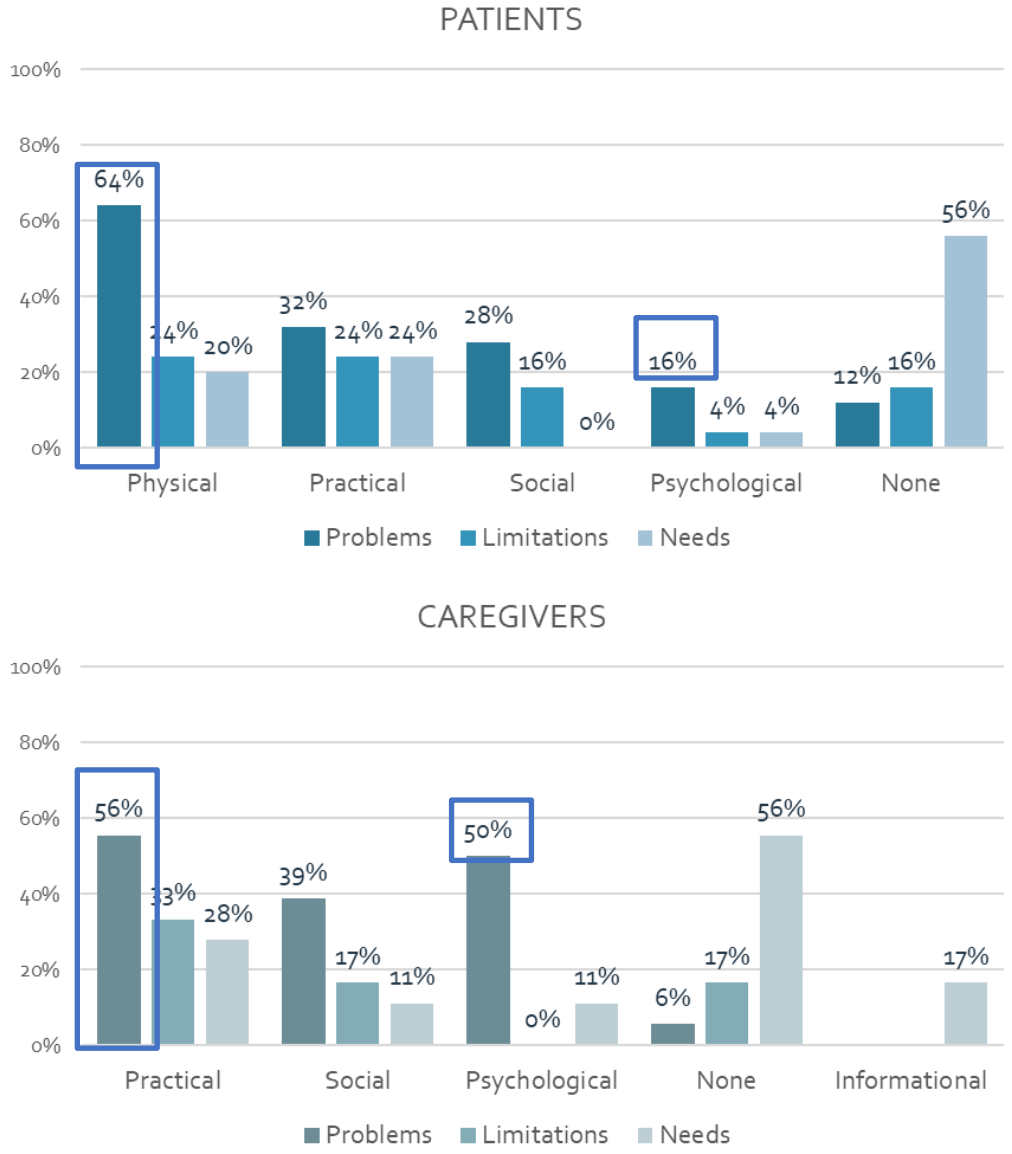
RESULTS

- Problems and needs beyond the physical and informational domain
- Problem-, emotion-, and meaning-focused coping, optimism, and resilient behaviours used to cope with patients' chronic OD

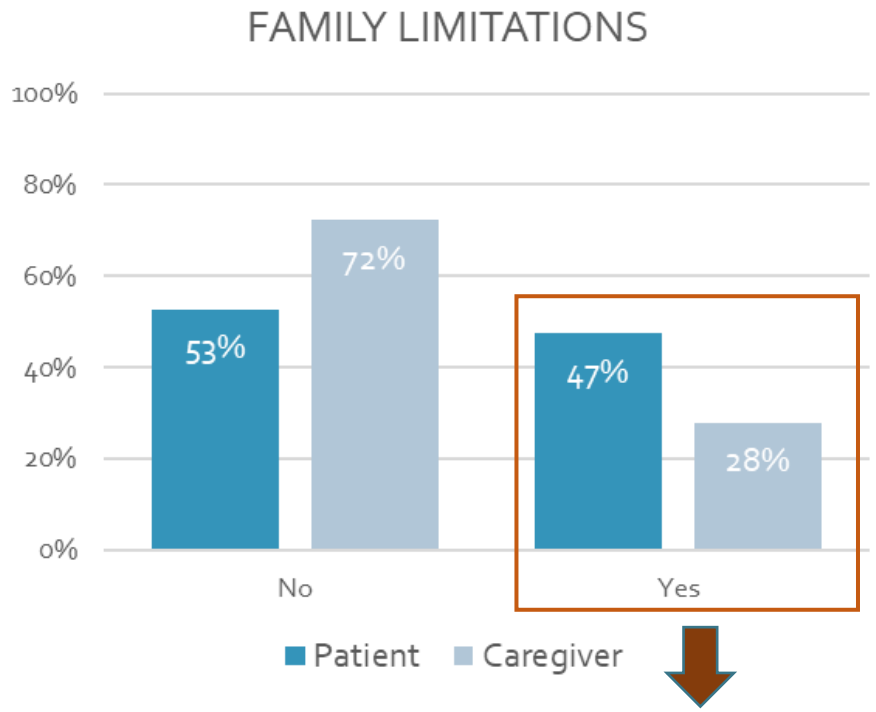
		Patients (N = 25)	Caregivers (N = 18)
		Mean (min-max) or N (%)	Mean (min-max) or N (%)
Age	Years	63 (33-86)	54 (25-74)
Gender	M	16 (64%)	7 (39%)
	F	9 (36%)	11 (61%)
Dysphagia/Caregiving onset	Years	4 (0.5-14)	2.5 (0.3-7)
Patient's Diagnosis	HNC	12 (48%)	6 (33%)
	Neurodegenerative diseases	**13 (52%)**	**12 (67%)**

QUALI SONO I TUOI PRINCIPALI PROBLEMI, LIMITAZIONI E BISOGNI NELLA GESTIONE QUOTIDIANA DELLE DIFFICOLTA' DI DEGLUTIZIONE?



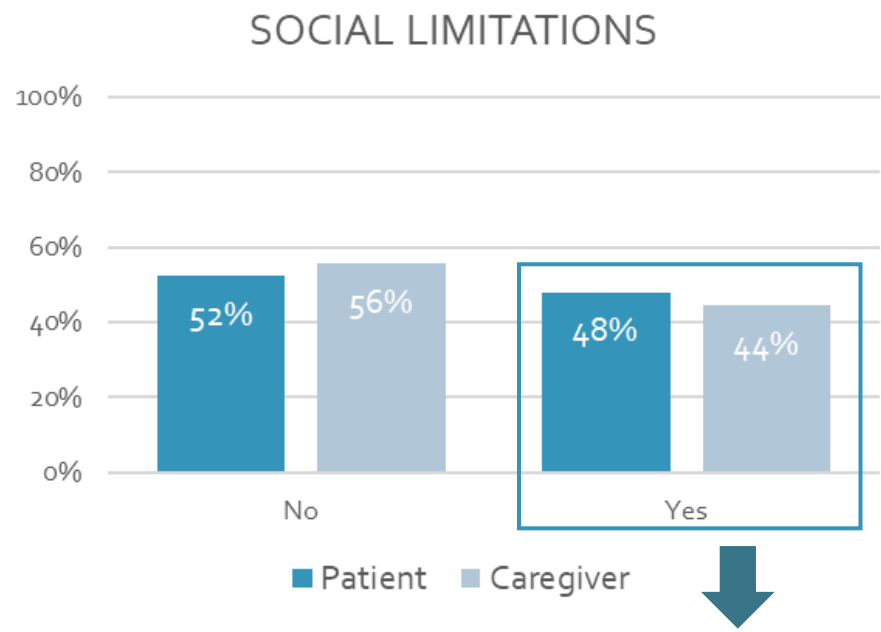


COME LE DIFFICOLTA' DI DEGLUTIZIONE LIMITANO LA TUA VITA FAMIGLIARE? E LA TUA VITA SOCIALE?



- Cambiamenti nei ruoli famigliari (21%)
- Supporto della famiglia (11%)
- Benessere della diade (11%)
- Non specificato (4%)

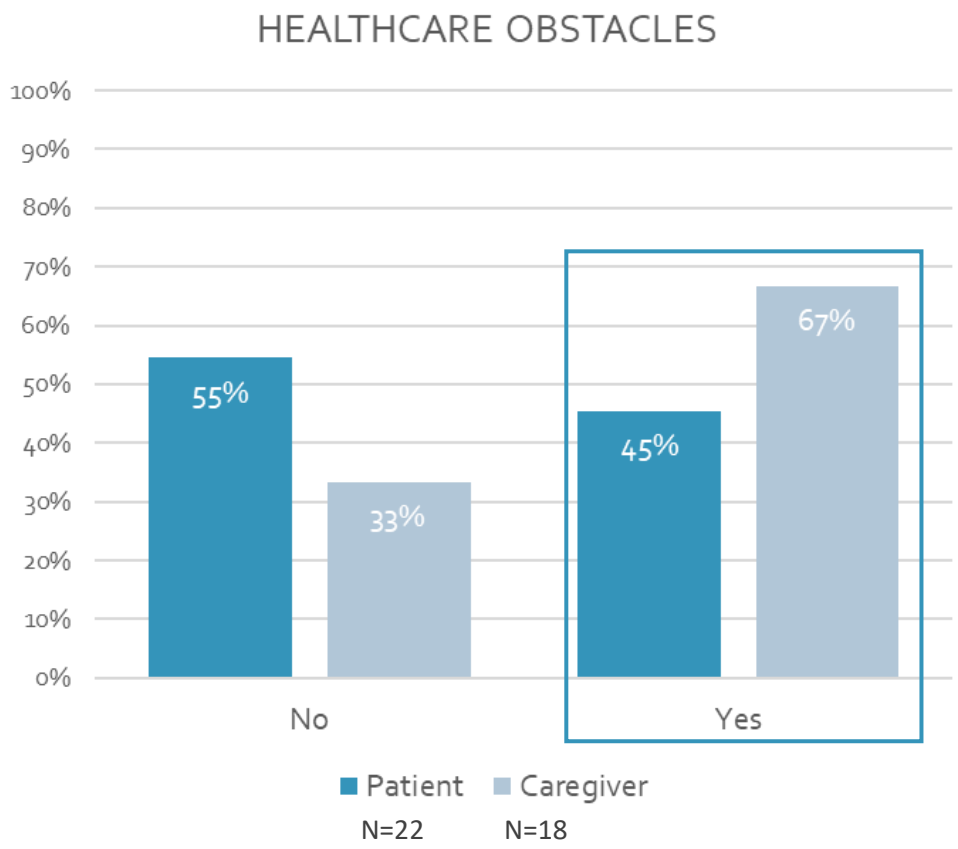
- Carico assistenziale (17%)
- Non specificato (11%)



- Cambiamenti nei ruoli sociali (31%)
- Accettazione sociale (17%)

- Cambiamenti nei ruoli sociali (33%)
- Accettazione sociale (11%)

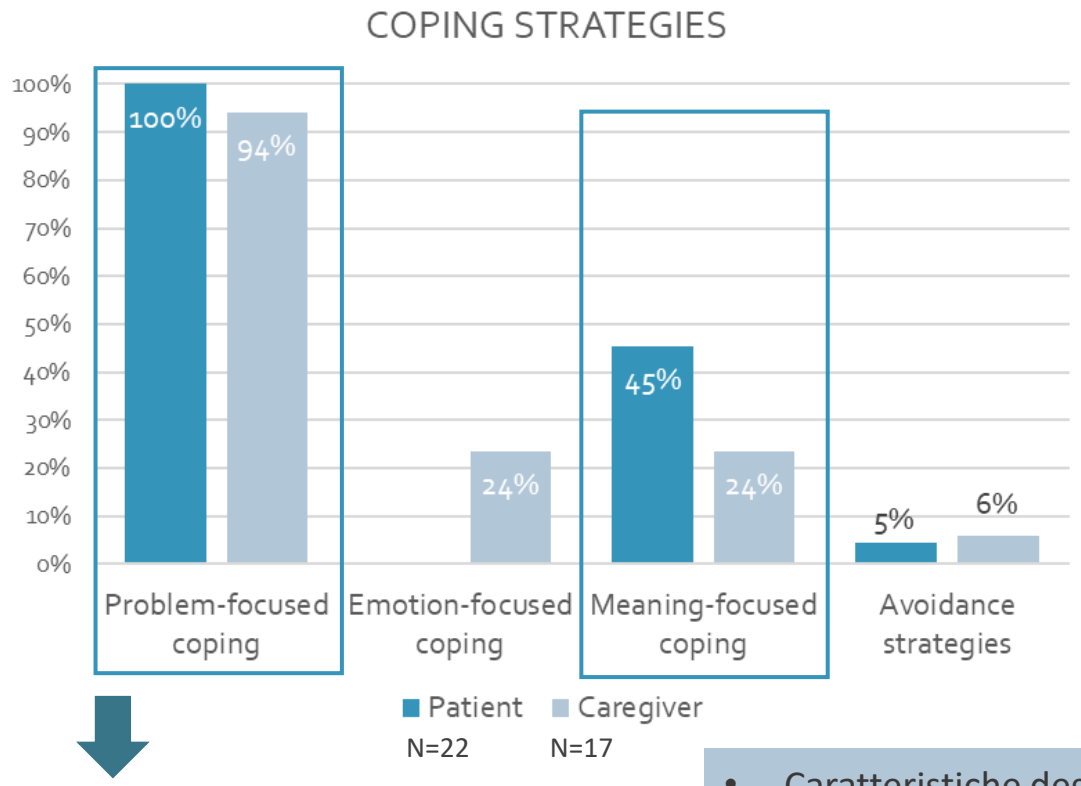
QUALI SONO STATI I MAGGIORI OSTACOLI CHE HAI RISCONTRATO NELL'UTILIZZO DEI SERVIZI SANITARI?



- Servizi centrati sulla persona (27%)
- Rete di cura (23%)
- Tempi (14%)
- Adeguatezza dei dispositivi PEG (5%)
- Mancanza di linee guida (5%)

- Rete di cura (33%)
- Tempi e burocrazia(33%)
- Servizi centrati sulla persona (17%)
- Informazioni (11%)
- Conoscenza della disfagia da parte dei medici (11%)
- Supporto psicologico (11%)
- Telemedicina (11%)

COME HA AFFRONTATO QUESTI PROBLEMI E LIMITAZIONI? QUALI SOLUZIONI HA TROVATO?



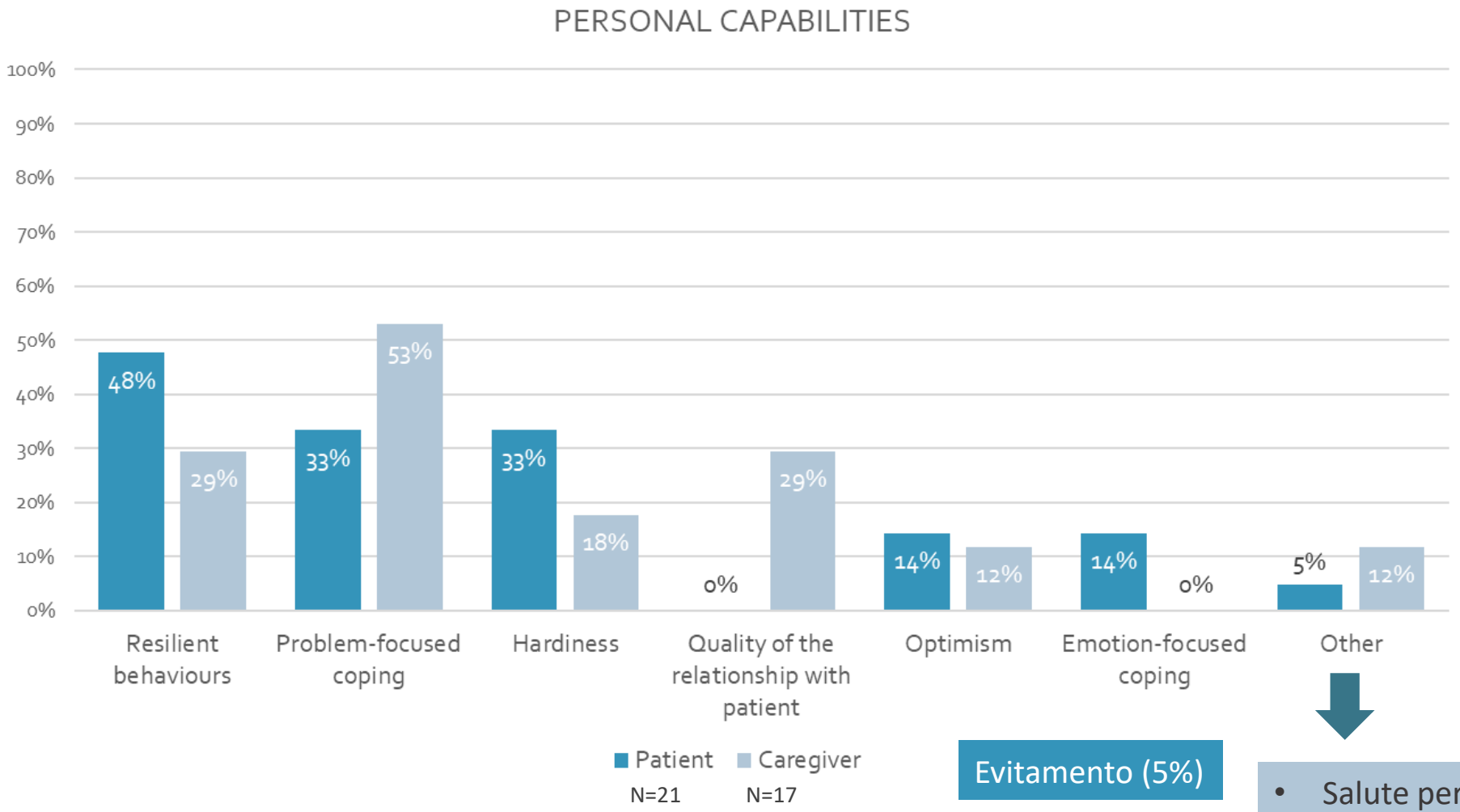
- Aggiustamenti positivi/Accettazione (36%)
- Accettazione sociale (5%)

- Aggiustamenti positivi/Accettazione (22%)
- Opportunità di crescita personale (5%)

- Comportamenti al pasto (64%)
- Caratteristiche degli alimenti (56%)
- Comportamenti sociali (36%)
- Gestione del tempo (8%)

- Caratteristiche degli alimenti (50%)
- Comportamenti al pasto (39%)
- Gestione delle emergenze (28%)
- Gestione del tempo (22%)
- Ricerca di informazioni (17%)
- Comportamenti sociali (17%)
- Gestione del trattamento(11%)

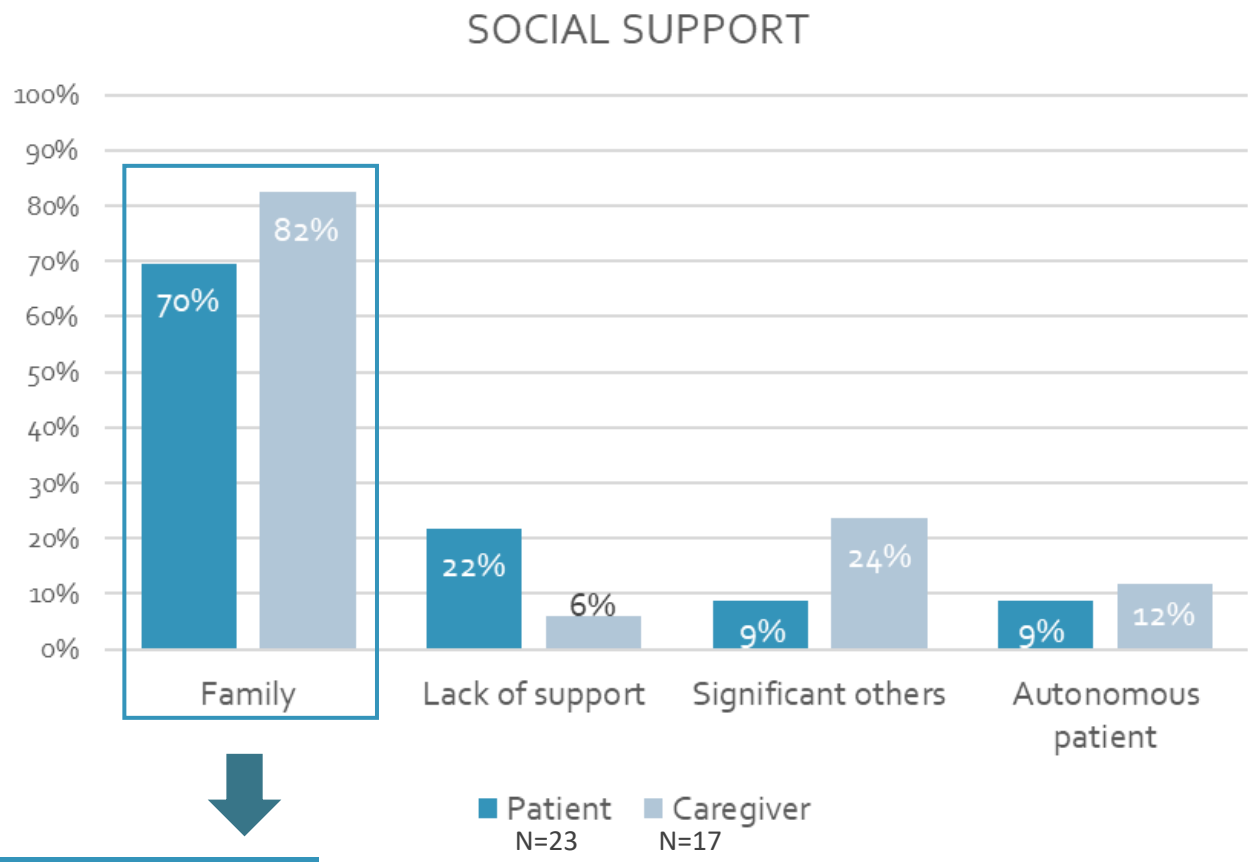
QUALI SONO STATE LE PIU' IMPORTANTI CAPACITA' PERSONALI CHE HA UTILIZZATO PER AFFRONTARE LE DIFFICOLTA' DI DEGLUTIZIONE?



Evitamento (5%)

- Salute personale (6%)
- Nessuna risorsa (6%)

I MEMBRI DELLA FAMIGLIA L'HANNO AIUTATA AD AFFRONTARE LE DIFFICOLTA' DI DEGLUTIZIONE? SE SI, COME?



- Supporto pratico (35%)
- Supporto emotivo (30%)
- Adattamento (22%)

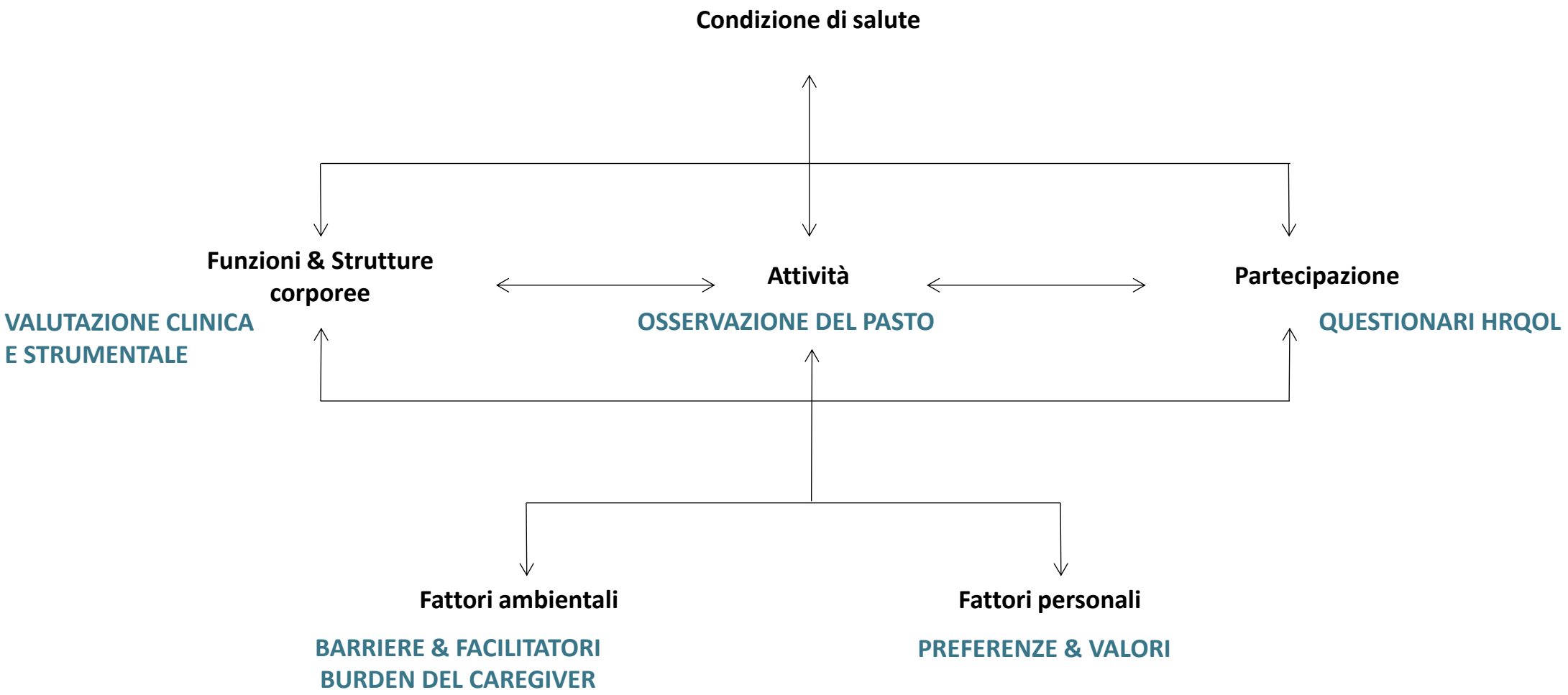
- Supporto pratico (47%)
- Supporto emotivo (12%)
- Aiuto domestico (29%)

PECULIARITA’ GENERALI NELLA VALUTAZIONE

Gli Obiettivi della Valutazione

a. Identificare la presenza di disfagia
b. Identificare la natura della disfagia (fisiopatologia)
c. Identificare la gravità della disfagia
d. Identificare le barriere e i facilitatori della performance deglutitoria nel pasto
e. Stimare il rischio di conguenze nutrizionali e polmonari
f. Valutare l'impatto sulla qualità di vita e sul benessere del paziente e della famiglia
g. Identificare i bisogni di cura del paziente e della famiglia
h. Identificare gli obiettivi del trattamento e della gestione della disfagia
i. Identificare le barriere e i facilitatori dell'aderenza alle raccomandazione

VALUTAZIONE MULTIDIMENSIONALE



International Classification of Functioning, Disability and Health (ICF, WHO, 2001)

Valutazione clinica

Clinical assessment of dysphagia in neurodegeneration (CADN): development, validity and reliability of a bedside tool for dysphagia assessment

Adam P. Vogel[1,2,3] · Natalie Rommel[1,4] · Carina Sauer[4] · Marius Horger[5] · Patrick Krumm[5] · Marc Himmelbach[7,8] · Matthis Synofzik[1,6]

J Neurol (2017) 264:1107–1117
DOI 10.1007/s00415-017-8499-7

Validazione della versione italiana in corso a cura di Castellari et al.

Summary

Patient:
examiner:
date:

Score part One (anamnesis)	□ 0 none □ 0.5 - 1 subclinical □ 1 - 1.5 mild	□ **2 - 3 moderate** □ **3.5 - 4 severe** □ **4.5 - 10 profound**	Signs of dysphagia in anamnesis
Score part Two (evaluation with consumption)	□ 0 none □ 0.5 - 1 subclinical □ 1 - 1.5 mild	□ **2 - 3 moderate** □ **4 severe** □ **5 - 7 profound**	Signs of dysphagia in examination with consumption

Final evaluation
(higher score of the two scores from above)

□ 0 - 1.5: no, subclinical or mild signs of dysphagia

□ **>1.5 - 3: moderate signs of dysphagia with aspiration risk**
(further instrumental diagnostic should be considered)

□ **3.5 - 10: severe or profound signs of dysphagia with high aspiration risk**
(further instrumental diagnostic is strongly advised)

CADN - Part One: Anamnesis - Questions relating to last 30 days (except item 4)

#		Comments	No impairment	Sub-clinical	Mild impairment	Moderate impairment	Severe impairment
			0	1	2	3	4
1	Does the patient cough or choke when **eating**? If so, how often?	When does it happen? (eg. towards the end of the day, when not concentrating, when distracted)	Less than once a month	Once a month	Once a week	Once a day	Each meal
2	Does the patient cough or choke when **drinking**? If so, how often?	When does it happen? (eg. towards the end of the day, when not concentrating, when distracted)	Less than once a month	Once a month	Once a week	Once a day	Each meal
3	Does the patient have difficulty managing saliva	Eg. does the patient cough or choke between meals, because of saliva; do they drool or dibble?	Less than once a month	Once a month	Once a week	Once a day	More than once a day
4	Has the patient had any chest infections in the past 12 months?	If so, how long the infection taken to clear? Did they use antibiotics? Did the chest infection follow a cold or develop independently?	Never	Once following upper respiratory tract infection (head cold)	Once requiring antibiotics to remediate symptoms	Twice	Three times or more or one not clearing after one month
5	Does the patient require assistance or medical aids/ devices while eating?	To make eating easier or safer do they use special cutlery or dinnerware? Do they require help with body/head positioning? Do they have a feeding tube?	No assistance required	Meets one of the criteria below: • Require positioning at table • Requires carer to assist when eating (eg. to cut up food) • uses additional tools (eg. non-slip plates or cutely with special handles) • Needs carer to help with jaw-control • other:	Meets two or more of the criteria described in 'subclinical'	safe swallowing is only possible for small amounts of food AND/ OR combined feeding via oral and PEG/nasogastric tube or intravenously	even small amounts of food can't be swallowed safely AND / OR all nutritional intake via PEG or nasogastric tube or intravenously
6	Does the patient require assistance or medical aids/ devices while drinking?	To make drinking easier or safer do they use special cups or straws? Do they need assistance while drinking? Do they require help with body/head positioning? Do they have a feeding tube or infusion? *excluding changes related to fine-motor- / and arm-motoric problems	No assistance required	Meets one of the criteria below: • Uses a straw • Uses a special cup (eg. controlled flow dinking containers, open cups) • Requires carer to help with jaw-control • Requires carer to assist when drinking (eg. to hold cup) • Others:	Meets two or more of the criteria described in 'subclinical'	safe swallowing is only possible for small amounts of liquid AND/ OR delivery of liquid combined via oral and PEG/ nasogastric tube or intravenously	even small amounts of liquid can't be swallowed safely And/ OR all liquids are given via PEG or nasogastric tube or intravenously
7	Does the patient modify their diet / eating /drinking habits to help their swallow?	Do they modify the texture or consistency of their foods (ie. use thickeners or change foods to make them easier to eat?). Did they change their behaviour/ do they have strategies to make swallowing safer or easier? Changes not related to taste.	No changes	One of the criteria below: • Avoid dry crumbly foods e.g. biscuits, nuts • Avoid hard to chew foods, e.g. meat, apples • Cutting food into small pieces before eating it • Mixing dry foods with emulsifiers, e.g. sauce, dips, condiments • concentration while eating/ drinking • altered posture eg. chin down • others:	Meets two or more of the criteria described in 'subclinical'	One of the criteria below • Fluids: thickening is required • Foods: Only one consistency can be eaten	Complete modification of diet including thickened fluids and only one food consistency OR nil per by mouth

CADN - Part Two: Examination with consumption

#		Comments	No impairment	Sub-clinical	Mild impairment	Moderate impairment	Severe impairment
			0	1	2	3	4
8	Free water trial (spoonful). Ask patient to drink water from spoon 3 times	Observe lip seal, time to initiate swallow, number of attempts to swallow, coughing or choking. Ask patient to say /ah/ before and after swallow.	No coughing / choking and no change in voice post swallow	No coughing / choking or change in voice post swallow + one of criteria below: Difficulty initiating swallow Oral spillage Others:	No coughing / choking or change in voice post swallow + two of criteria in 'subclinical'	Intermittent coughing and/or intermittent wet voice with spontaneous clearance that appears to be effective	Frequent coughing OR wet voice post swallow in absence of clearance that appears to be effective (no cough/very weak cough)
9	Free water trial (cup). Ask patient to drink 50mL of water. Use non-collapsible cup (i.e., not soft plastic/paper).	Observe lip seal, time to initiate swallow, number of attempts to swallow, coughing or choking. Ask patient to say /ah/ before and after swallow.	No coughing / choking or change in voice post swallow	No coughing / choking or change in voice post swallow + one of criteria below: Extended oral phase Difficulty initiating swallow Oral spillage Slow drinking or small sips Others:	No coughing / choking or change in voice post swallow + two criteria described in 'subclinical'	Intermittent coughing and/or intermittent wet voice with spontaneous clearance that appears to be effective	Frequent coughing OR wet voice post swallow in absence of clearance that appears to be effective (no cough/very weak cough)
10	Puree trial. 4 teaspoons. (if severe impairment SCORE 4) on water and/or puree tasks (ITEMS 9-10), skip biscuit (ITEM 11); and score biscuit with 4)	Observe lip seal, time to initiate swallow, number of attempts to swallow, coughing or choking. The oral cavity after swallowing Ask patient to say /ah/ before and after swallow.	No coughing / choking or change in voice post swallow	No coughing / choking or change in voice post swallow + one of criteria below: Extended oral phase Difficulty initiating swallow Oral spillage Oral residue More than one dry swallow after food has cleared from oral cavity Others:	No coughing / choking or wet voice post swallow + two or more criteria described in 'subclinical'	Intermittent coughing and/or intermittent wet voice with spontaneous clearance that appears to be effective	Frequent coughing OR wet voice post swallow in absence of clearance that appears to be effective (no cough/very weak cough)
11	One dry biscuit	Observe lip seal, time that is needed to initiate swallow, number of attempts to swallow, coughing or choking and oral cavity after swallow. Ask patient to say /ah/ before and after swallow.	No coughing / choking or change in voice post swallow	No coughing / choking or change in voice post swallow + one of criteria below: Extended oral phase Difficulty initiating swallow Oral spillage Oral residue More than one dry swallow after food has cleared from oral cavity Others:	No coughing / choking or change in voice post swallow + two or more criteria described in 'subclinical'	Intermittent coughing and/or intermittent wet voice with spontaneous clearance that appears to be effective	Frequent coughing OR wet voice post swallow in absence of clearance- reaction that appears to be effective (no cough/very weak cough)

Valutazione clinica

TEST OF MASTICATING AND SWALLOWING SOLIDS (TOMASS)

Standard cracker standard (Gran Pavesi™ senza sale)

- N morsi
- N deglutizioni
- N cicli masticatori
- Tempo

Huckabee et al, 2018

ToMaSSApp

In corso raccolta dati normativi italiani per 4+ anni (N=900)

Università degli Studi di Milano – Università degli Studi di Padova

TEST OF MASTICAT

Sex	Age	Discrete bites per cracker		Masticatory cycles per cracker		Swallows per cracker		Total time (in sec)	
		Mean	95% C.I.	Mean	95% C.I.	Mean	95% C.I.	Mean	95% C.I.
Males	20–40	1.74	1.43–2.06	35.85	31.88–39.81	2.15	1.84–2.46	27.75	24.33–31.17
	40–60	1.50	1.21–1.79	35.14	30.33–39.96	2.50	1.92–3.08	28.69	23.21–34.17
	60–80	2.19	1.86–2.53	49.19	42.98–55.41	2.53	2.10–2.96	39.61	32.24–46.99
	80+	2.94	2.44–3.43	62.68	50.70–74.65	3.19	2.51–3.88	52.62	39.91–65.33
Females	20–40	2.41	2.04–2.77	41.56	36.69–46.43	2.66	2.28–3.03	35.49	30.35–40.63
	40–60	3.00	2.57–3.43	46.71	41.17–52.24	2.85	2.45–3.26	39.49	33.83–45.16
	60–80	3.22	2.88–3.55	56.53	49.17–63.90	2.94	2.59–3.29	50.49	43.27–57.72
	80+	3.65	3.24–4.06	70.79	59.64–81.94	3.50	2.96–4.04	59.81	50.81–68.80

Masticatory cycles per bite		Swallows per bite		Time per bite (in sec)		Time per masticatory cycle (in sec)		Time per swallow (in sec)	
Mean	95% C.I.	Mean	95% CI	Mean	95% C.I.	Mean	95% C.I.	Mean	95% C.I.
24.75	21.19–28.31	1.49	1.19–1.70	18.62	16.15–21.08	.78	.73–.83	15.31	1264–17.97
26.08	21.86–30.30	1.89	1.43–2.35	20.96	17.46–24.46	.82	.73–.90	12.61	10.86–14.36
26.49	21.34–31.64	1.29	1.06–1.52	21.09	16.40–25.77	.79	.73–.85	17.97	14.46–21.47
24.97	19.92–30.01	1.27	.99–1.56	21.04	15.55–26.52	.84	.75–.92	18.58	14.54–22.62
19.43	16.80–22.06	1.28	1.03–1.53	16.81	14.04–19.57	.86	.78–.95	14.22	12.08–16.36
17.97	14.70–21.24	1.08	.85–1.32	14.83	12.52–17.14	.87	.79–.96	15.01	13.17–16.85
18.55	16.56–20.55	1.00	.87–1.13	16.56	14.48–18.64	.90	.84–.96	18.56	15.50–21.62
21.10	17.60–24.60	1.01	.84–1.17	17.45	15.23–19.67	.87	.79–.94	19.67	16.09–23.26

Valori patologici: **sopra** o **sotto** l'IC95%

Huckabee et al, 2018

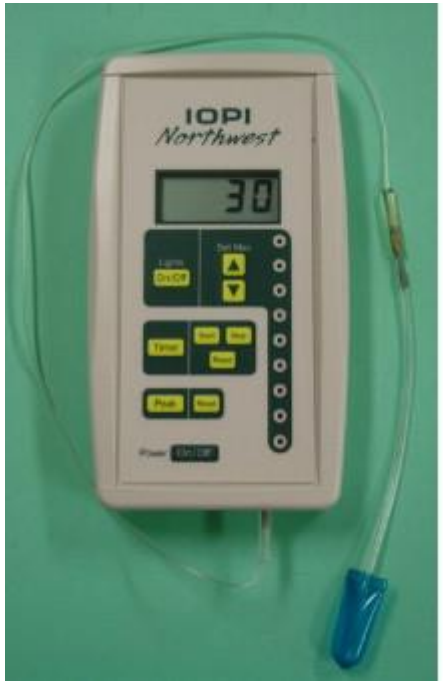
VALUTAZIONE CLINICA DELLA DEGLUTIZIONE

PRESSIONI LINGUALI

Fornisce informazioni su:

- Riserva funzionale linguale
- Affaticamento deglutitorio al pasto
- Criterio diagnostico di sarcopenia
- Outcome del trattamento

Steele, 2013; Brates & Molfenter, 2021; Wakabayashi et al, 2021



SOGLIE SPECIFICHE PER PATOLOGIA

Valutazione clinica della tosse

Curr Phys Med Rehabil Rep. 2016 December ; 4(4): 262–276. doi:10.1007/s40141-016-0134-5.

To Cough or Not to Cough? Examining the Potential Utility of Cough Testing in the Clinical Evaluation of Swallowing

Stephanie A. Watts[1,2], **Lauren Tabor**[2,3], and **Emily K. Plowman**[2,3]

Valutazione clinica della tosse

TOSSE VOLONTARIA

Spirometria della tosse

1. Inspiratory phase
2. Compression phase
3. Expiratory phase

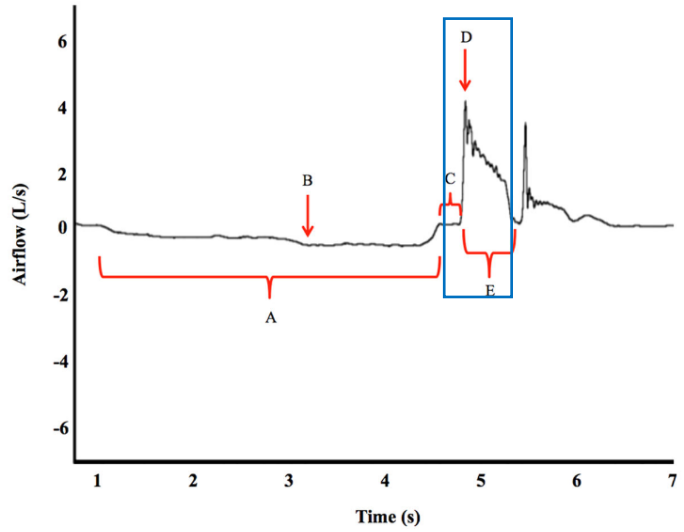


Fig. 1.
Example of voluntary cough waveform measured with cough spirometry. Selected derived objective measures are delineated on the waveform and referenced in Table 2 including *a* inspiratory phase duration, *b* inspiratory peak flow, *c* compression phase duration, *d* peak expiratory flow rate, and *e* cough expired volume. Expiratory rise time is calculated by subtracting time at end of compression from peak expiratory flow time. Cough volume acceleration is not depicted but is calculated by dividing peak expiratory flow rate by the expiratory rise time

Valutazione clinica della tosse

La misurazione della tosse volontaria non predice la tosse riflessa

Parkinsonism Relat Disord. 2014 November ; 20(11): 1226–1230.

Comparison of voluntary and reflex cough effectiveness in Parkinson's disease

Karen Wheeler Hegland, PhD, CCC-SLP[a,b], **Michelle S. Troche, PhD, CCC-SLP**[a,b], **Alexandra E. Brandimore, MA, CCC-SLP**[a,b], **Paul W. Davenport, PhD**[c], and **Michael S. Okun, MD**[b,d]

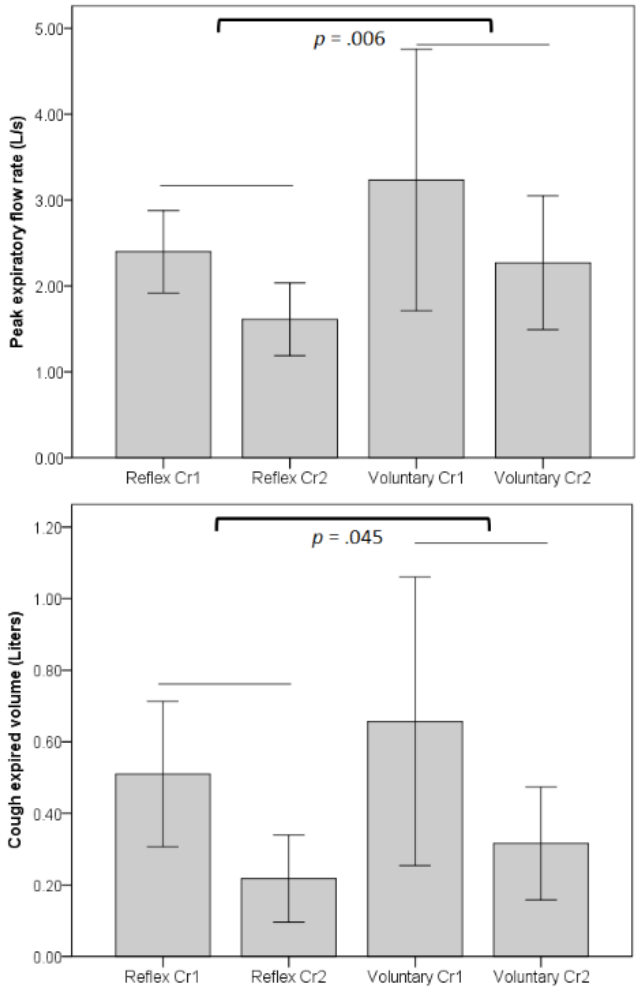
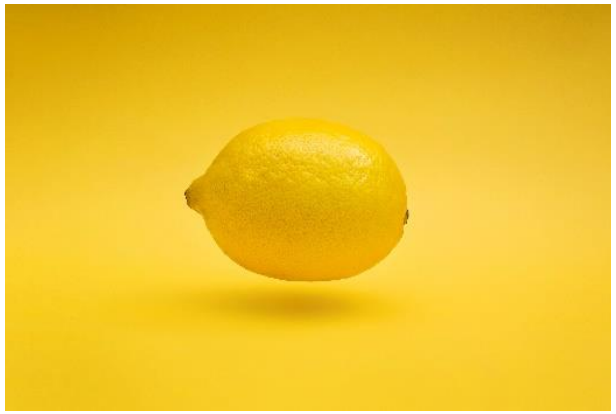


Figure 2.
Significant differences for peak expiratory flow rate (PEFR; top graph) and cough expired volume (bottom graph). Bars are means, and whisker bars are 1 standard error.

Valutazione clinica della tosse

TOSSE RIFLESSA

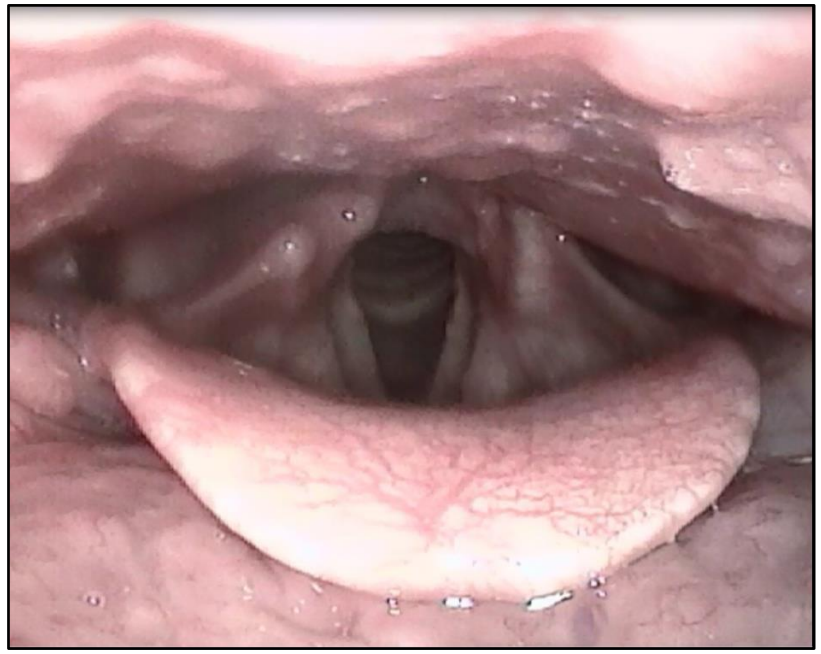
- Acido citrico
- Capsaicina
- Soluzione ipertonica



Ampia varietà dei protocolli di valutazione della tosse riflessa (dose singola vs dose/risposta, sostanza, nebulizzatore, cut-off)

Il numero di atti deglutitori sembra essere un miglior predittore del rischio di disfagia/aspirazione rispetto al picco di flusso espiratorio

Valutazione Strumentale della Deglutizione



FEES e VFSS sono considerati i «gold standard» della diagnosi di disfagia, con accuratezza diagnostica per la presenza di penetrazione/aspirazione e di ristagni faringei comparabile

L'aspirazione silente è stata riscontrata sin dagli stadi precoci delle malattie neurodegenerative e anche in pazienti asintomatici

MALATTIA DI PARKINSON

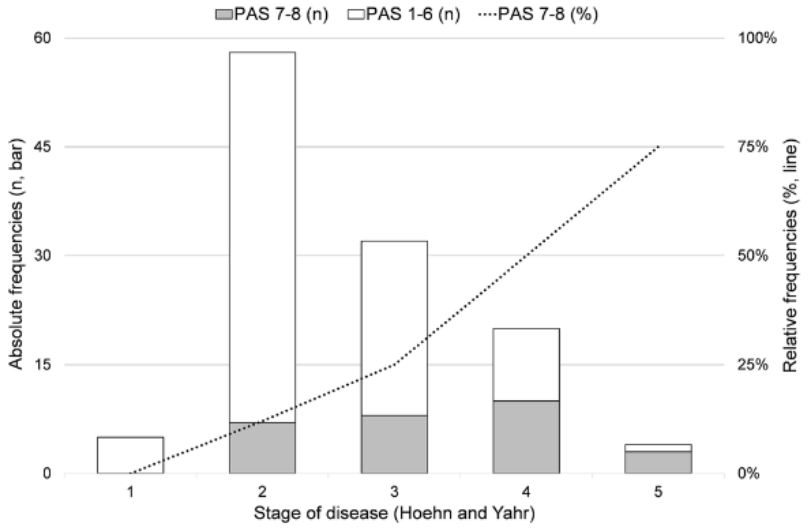
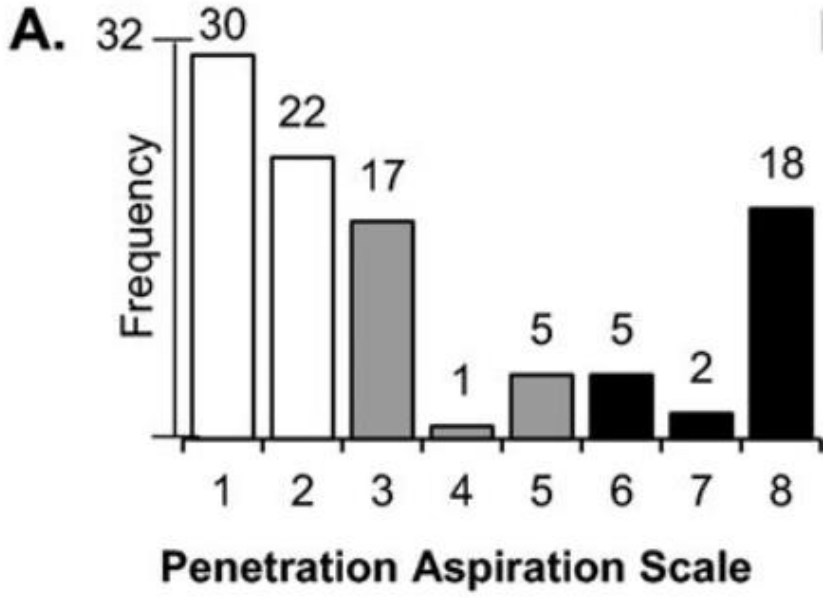


Fig. 3 Shows the critical aspiration (PAS 7–8) for at least one consistency of the swallowed agent depending on Hoehn and Yahr stage. Absolute frequencies are given as *bars*, relative frequencies are given as a *line*

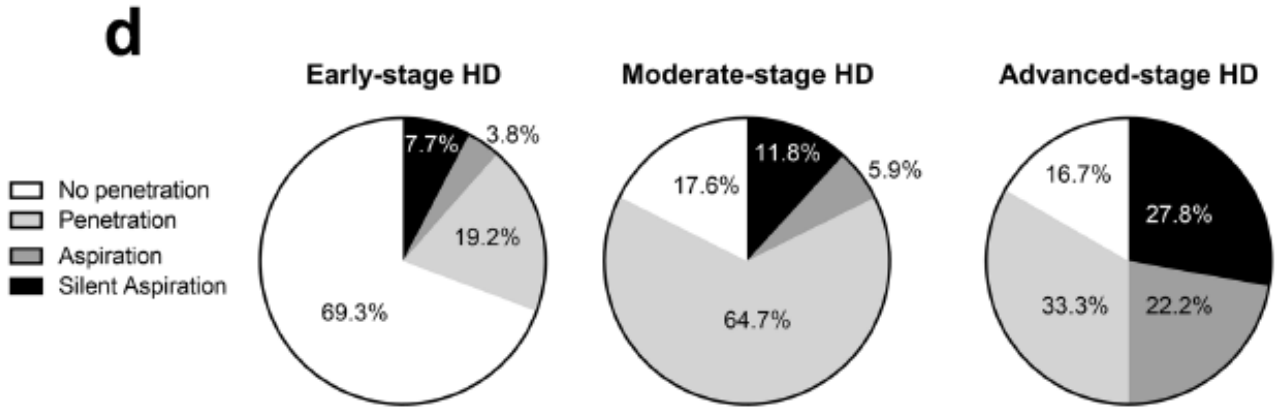
Pflug et al, 2016

SLA



Robison et al, 2022

MALATTIA DI HUNTINGTON



Schindler et al, 2020

Osservazione del Pasto

Valutazione della deglutizione

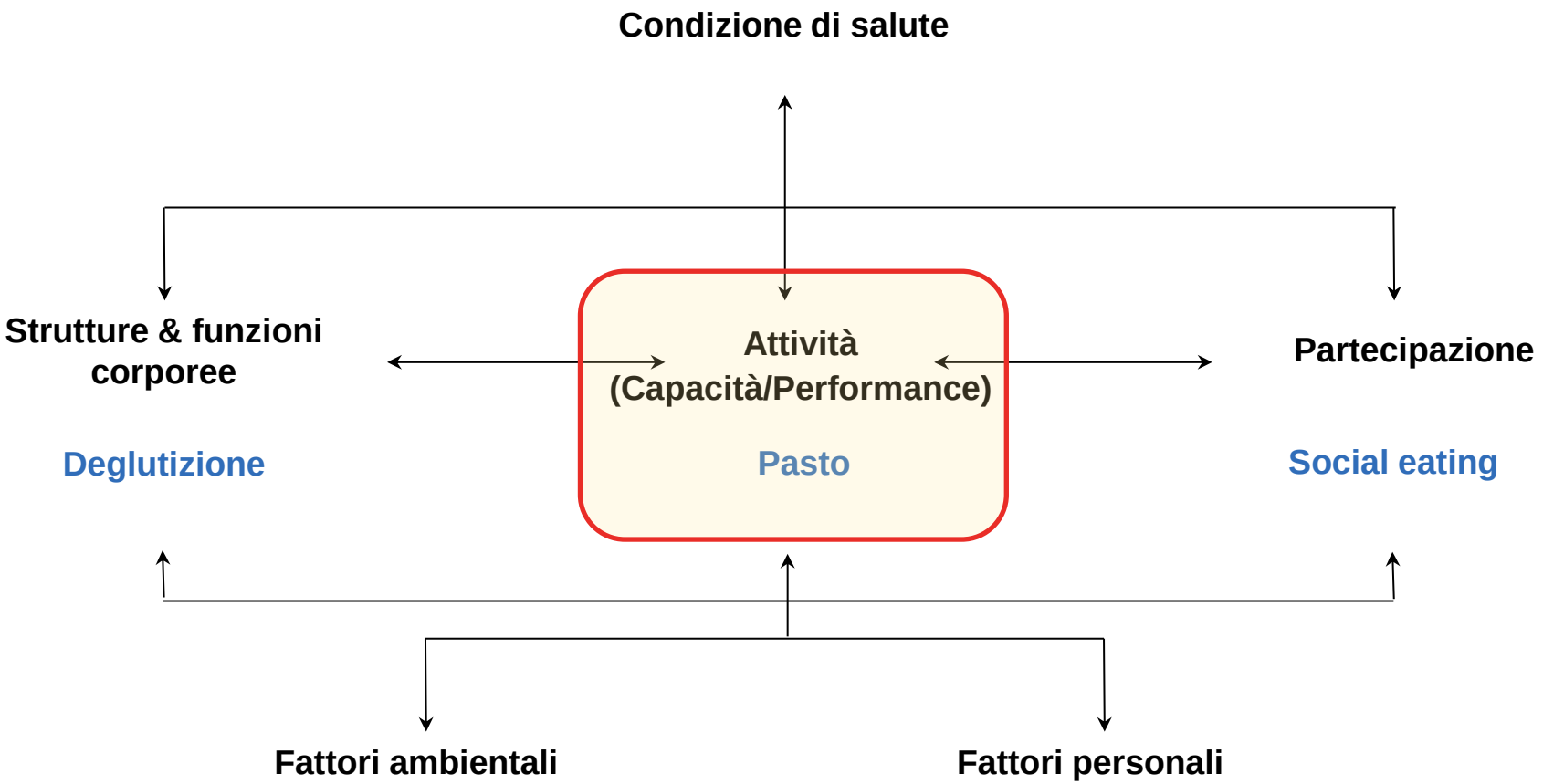
Osservazione del pasto

Valutazione della deglutizione vs del pasto

La breve durata e la standardizzazione della valutazione deglutitoria impedisce di identificare tutti i fattori che possono influenzare il funzionamento del paziente durante il pasto, quali ad esempio:

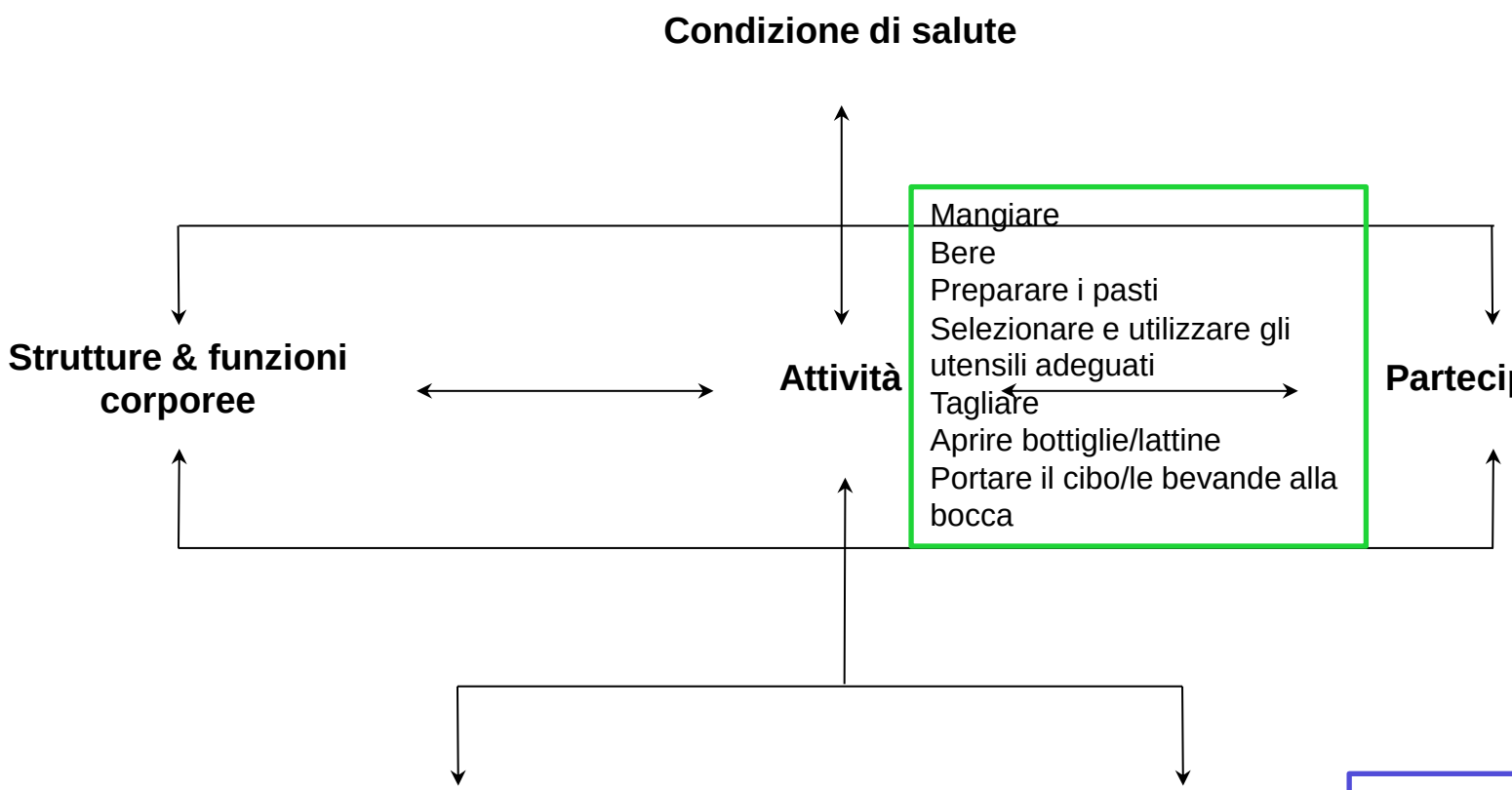
- Affaticamento
- Autonomia nell'alimentazione
- Postura del capo e del tronco
- Tempo necessario a completare il pasto
- Aspetti comportamentali

Cos'è l'osservazione del pasto?



International Classification of Functioning, Disability and Health (ICF, WHO, 2001)

Cos'è l'osservazione del pasto?



Cavo orale, faringe, laringe
Succhiare
Mordere
Masticare
Manipolare il cibo nel cavo orale
Salivazione
Deglutire
Vigilanza
Funzioni intellettive
Memoria
Attenzione
Comprensione linguistica
Motivazione
Appetito
Olfatto
Gusto
Funzioni psicomotorie

Mangiare
Bere
Preparare i pasti
Selezionare e utilizzare gli utensili adeguati
Tagliare
Aprire bottiglie/lattine
Portare il cibo/le bevande alla bocca

Consumare gli alimenti/bevande in una maniera culturalmente accettabile
Associazioni informali
Cerimonie
Piacere e passatempo

Alimenti
Utensili
Luce
Suoni
Famigliari
Amici
Professionisti sanitari

Preferenze individuali
Cultura
Religione
Influenze sociali e politiche

International Classification of Functioning, Disability and Health (ICF, WHO, 2001)

Mealtime assessment scale

1. STRUTTURE, FUNZIONI E ATTIVITA' CHE INFLUENZANO IL PASTO

	0	1	2	3
Dentatura	Completa	Parziale	Totale edentulia di un'arcata	Totale edentulia
Comprensione linguistica	Nella norma	Segue una conversazione ordinaria con poche difficoltà	Lievi difficoltà di comprensione di una conversazione	Gravi difficoltà di comprensione di una conversazione
Attenzione	Adeguata	Si distrae occasionalmente	Necessita di richiami frequenti	Non riesce a mantenere l'attenzione sull'attività
Memoria a breve termine	Adeguata	Necessita di saltuarie ripetizioni	Necessita di frequenti ripetizioni	Non ricorda alcuna indicazione
Contenimento orale basale	Nella norma	Un episodio di perdita di saliva	Perdita di saliva frequente ma detersa	Perdita di saliva frequente e incapacità a detergersi
Tosse volontaria	Efficace	Debole	Solo raclage	Assente
Qualità fonatoria	Nella norma	Lievemente soffiata	Marcata ipofonia	Afonia
Complianza del paziente alle istruzioni alimentari	Adeguata	Quasi sempre adeguata	Segue saltuariamente le indicazioni	Non segue alcuna indicazione
Desiderio di alimentarsi per os	Mangia volentieri	È indifferente verso il cibo proposto	Mangia solo se continuamente stimolato	Rifiuta il cibo
Controllo del capo e del tronco	Adeguato	Necessita di ausili per mantenere la postura	Mantenuto grazie agli ausili ma solo per pochi minuti	Impossibile da mantenere con qualsiasi ausilio
Autonomia nell'alimentazione	Totale autonomia	Minimo intervento del caregiver	Moderato intervento del caregiver	Completa dipendenza
Capacità di portare il cibo alla bocca	Adeguata	Saltuari episodi di perdita di cibo dalla posata	Frequenti episodi di perdita di cibo dalla posata	Incapace di portare il cibo alla bocca

2. FATTORI AMBIENTALI CHE INFLUENZANO IL PASTO

FACILITATORI	**0**	**+1**	**+2**	**+3**
Consistenza del cibo	Dieta libera	Dieta libera con limitazioni	Dieta solida morbida	Dieta semisolida
Dimensione del bolo	Cucchiaio	½ cucchiaio	Cucchiaino	½ cucchiaino
Caratteristiche reologiche del liquido	Normale (bicchiere o cannuccia)	Normale con cucchiaio	Normale dopo deglutizioni a vuoto	Addensato
BARRIERE	**0**	**-1**	**-2**	**-3**
Possibilità di far affidamento sul caregiver	Caregiver compliante o non necessario	Caregiver incostante nel seguire le indicazioni	Caregiver poco attento alle indicazioni del terapista	Caregiver assente al momento del pasto o non affidabile

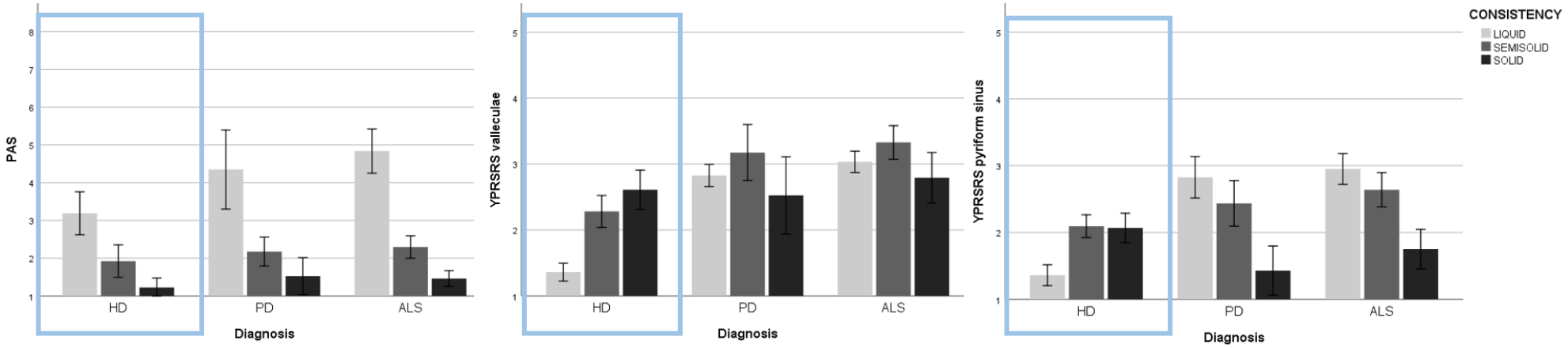
3. SICUREZZA ED EFFICACIA DELLA DEGLUTIZIONE DURANTE IL PASTO

		0	1	2	3
SICUREZZA	Gestione endorale del bolo	Adeguata	Quantità di cibo leggermente eccessiva	Quantità di cibo eccessiva	Impossibile
	Detersione orale dopo la deglutizione (se rimangono residue specificare la sede _____)	Adeguata	Pochi ristagni	Abbondanti ristagni in metà del cavo orale	Abbondanti ristagni in ogni parte del cavo orale
	Presenza di tosse o raclage	Mai	Raramente (2-5 volte)	Frequentemente (circa 1/3 delle volte)	Quasi sempre (più di ½ delle volte)
	Tosse riflessa □ forte □ debole				
	Qualità della voce postdeglutitoria (specificare con quale/i consistenza/e _____)	Nella norma	Voce raramente umida/ gorgogliante (2-5 volte)	Voce frequentemente umida/ gorgogliante (circa 1/3 delle volte)	Voce quasi sempre umida/ gorgogliante o non valutabile (più di ½ delle volte)
EFFICACIA	Contenimento orale in masticazione	Nella norma	Fuoriesce saltuariamente del cibo dalla commessura labiale (meno di 1/3 delle volte)	Fuoriesce frequentemente del cibo dalla commessura labiale (circa ½ delle volte)	Assoluta incontinenza dello sfintere labiale (più di 2/3 delle volte)
	Preparazione orale	Nella norma	Leggermente prolungata	Prolungata	Incapacità a formare il bolo
	Capacità di continuare il pasto senza sollecitazioni	Adeguata	Necessita di saltuarie sollecitazioni	Necessita di frequenti sollecitazioni	Sollecitazioni non efficaci
	Affaticabilità	Mai	Raramente (meno di 1/3 delle volte)	Frequentemente (circa ½ delle volte)	Quasi sempre (più di 2/3 delle volte)
	Percentuale del pasto assunta	Circa il 75% o più	Circa il 50%	Circa il 25%	Meno del 25%
	Quantità di cibo assunta al pasto	Adeguata	Scarsa	Insufficiente	Quasi nulla

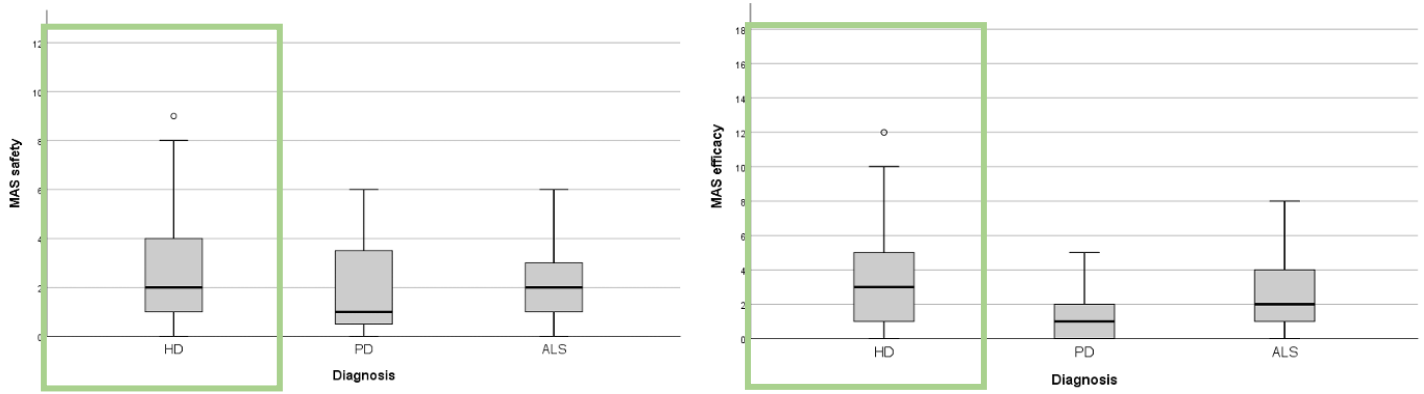
Pizzorni et al, 2019

Complementarietà FEES – osservazione del pasto

FEES



MEALTIME



Pizzorni, PhD dissertation, 2020

Complementarietà FEES – osservazione del pasto

Il pasto, ma non la presenza di penetrazione/aspirazione o di ristagni in FEES, è risultato essere indipendentemente associato al rischio di malnutrizione in pazienti con patologie neurodegenerative

TABLE 2 Demographic, clinical, and swallowing factors associated with malnutrition risk based on univariate and multivariate logistic regression analysis

	Univariate analysis, $N = 148$		Multivariate analysis, initial model, $n = 116$		Multivariate analysis, final model, $n = 116$[a]	
Factors	**OR (CI 95%)**	***p***	**OR (CI 95%)**	***p***	**OR (CI 95%)**	***p***
Demographic and clinical factors						
Age, <65 vs ≥65 years	2.60 (1.28–5.27)	0.008[b]	2.80 (1.07–7.34)	0.036[b]	3.16 (1.26–7.89)	0.014[b]
Gender, F vs M	1.53 (0.76–3.07)	0.236	–		–	
Diagnosis		0.185	–		–	
HD vs ALS	0.47 (0.21–1.05)					
PD vs ALS	0.65 (0.26–1.65)					
Disease severity		0.001[b]		0.008[b]		0.003[b]
Moderate vs mild	2.24 (1.03–4.86)		3.68 (1.34–10.06)		3.89 (1.47–10.29)	
Severe vs mild	10.63 (2.94–38.53)		10.85 (1.64–71.61)		9.71 (1.83–51.56)	
Diet type, modified diet vs no restriction	4.56 (2.17–9.56)	<0.001[b]	1.05 (0.39–2.86)	0.918	–	
FEES findings, present vs absent						
Valleculae residue, present vs absent	2.08 (0.99–4.34)	0.053	–		–	
Pyriform sinus residue, present vs absent	1.93 (0.96–3.88)	0.064	–		–	
Penetration, present vs absent	2.32 (1.10–4.90)	0.027[b]	1.56 (0.53–4.61)	0.418	–	
Aspiration, present vs absent	1.77 (0.76–4.12)	0.185	–		–	
Oral phase efficiency, continuous						
TOMASS bites	1.26 (0.99–1.60)	0.052	–		–	
TOMASS masticatory cycles	1.03 (1.01–1.06)	0.011[b]	1.04 (1.00–1.07)	0.082	1.03 (1.01–1.06)	0.044[b]
TOMASS swallows	1.25 (0.94–1.67)	0.131	–		–	
TOMASS time	1.02 (1.01–1.04)	0.012[b]	1.00 (0.98–1.02)	0.777	–	
Meal observation, continuous						
MAS safety	1.41 (1.11–1.79)	0.004[b]	1.42 (1.04–1.93)	0.028[b]	1.44 (1.07–1.94)	0.016[b]
MAS efficacy	1.11 (0.94–1.32)	0.205	–		–	
Meal duration	0.99 (0.95–1.03)	0.731	–		–	

Note: For categorical variables, OR > 1 means a higher probability of the reference group than the control group to be at risk of malnutrition. For continuous variables, OR > 1 means that an increase of 1 point in the value of the variable increases the probability of malnutrition risk.

Abbreviations: ALS, amyotrophic lateral sclerosis; CI, confidence interval; F, female; FEES, fiberoptic endoscopic evaluation of swallowing; HD, Huntington disease; M, male; MAS, Mealtime Assessment Scale; OR, odds ratio; PD, Parkinson disease; TOMASS, Test of Masticating and Swallowing Solids.

Pizzorni et al, 2022

PATIENT-REPORTED OUTCOME MEASURES

- *Functional health status* (FHS)
  - Swallowing Disturbance Questionnaire (Manor et al, 2007)
  - Huntington's Disease Dysphagia Scale (HDDS) (Heemskerk et a, 2015)
  - Dysphagia in Multiple Sclerosis (DYMUS) (Bergamaschi et al, 2008)
- *Health-related quality of life* (HR-QoL)
  - SWAL-QoL (McHorney et al, 2000, 2002)
  - Dysphagia Handicap Index (DyHI) (Silbergleit et al, 2012)
  - Deglutition Handicap Index (DHI) (Woisard et al, 2006, 2010)

L'uso delle PROMs nei pazienti con malattia neurodegerativa deve tenere in considerazione dello stato cognitivo del paziente e della suo livello di consapevolezza della disfagia. La somministrazione al caregiver può essere un'alterativa.

"Sono stati riscontrati livelli di affidabilità e accordo moderati nello SWAL-QOL tra pazienti con Malattia di Parkinson ed i loro caregiver (ICC 0.598, IC95% 0.358-0.748)"

Zimmerman et al, 2021

Burden del caregiver (screening)

Table 1. The Caregiver Analysis of Reported Experiences with Swallowing Disorders Questionnaire, Part A—Checklist of Behavioral and Functional Changes.

*For each of the following statements, please think specifically about your loved one/care recipient's eating or swallowing difficulties **during the past month**. Has the situation described in the statement bothered **you**? If it has not occurred, please indicate "N/A."*

In the past month, has this situation bothered you?			
Because of my loved one's swallowing difficulties, extra time is required for mealtimes (e.g., finding appropriate foods, cooking meals, preparing tube feedings, watching my loved one eat/drink).	Yes	No	N/A
Because of my loved one's swallowing difficulties, my mealtime- and nutrition-related responsibilities have increased (e.g., related to shopping, cooking, tube feeding).	Yes	No	N/A
Because of my loved one's swallowing difficulties, the costs associated with their nutrition-related needs have increased (e.g., supplies for tube feedings, thickening products or thickened liquids, supplements).	Yes	No	N/A
Other family members disagree with me about how to best manage my loved one's swallowing difficulties.	Yes	No	N/A
Managing my loved one's swallowing difficulties interferes with my daily routine (e.g., job, school work, household chores).	Yes	No	N/A
Managing my loved one's swallowing difficulties takes away from other things I would prefer to be doing (e.g., leisure activities).	Yes	No	N/A
Because of my loved one's swallowing difficulties, my loved one and I do not participate in meals together as often as we used to.	Yes	No	N/A
Because of my loved one's swallowing difficulties, I do not make plans with others as often as I would like.	Yes	No	N/A
Because of my loved one's swallowing difficulties, my loved one and I cannot go out to eat as much as I would like.	Yes	No	N/A
Because of my loved one's swallowing difficulties, I avoid eating or drinking items that they cannot have.	Yes	No	N/A

al, 2020

ogress)

Burden del caregiver (screening)

Table 2. The Caregiver Analysis of Reported Experiences with Swallowing Disorders Questionnaire, Part B—Measures of Subjective Caregiver Stress.

*For each of the following statements, please think specifically about your loved one/care recipient's eating or swallowing difficulties **during the past month**. Has the statement been true for **you**?*

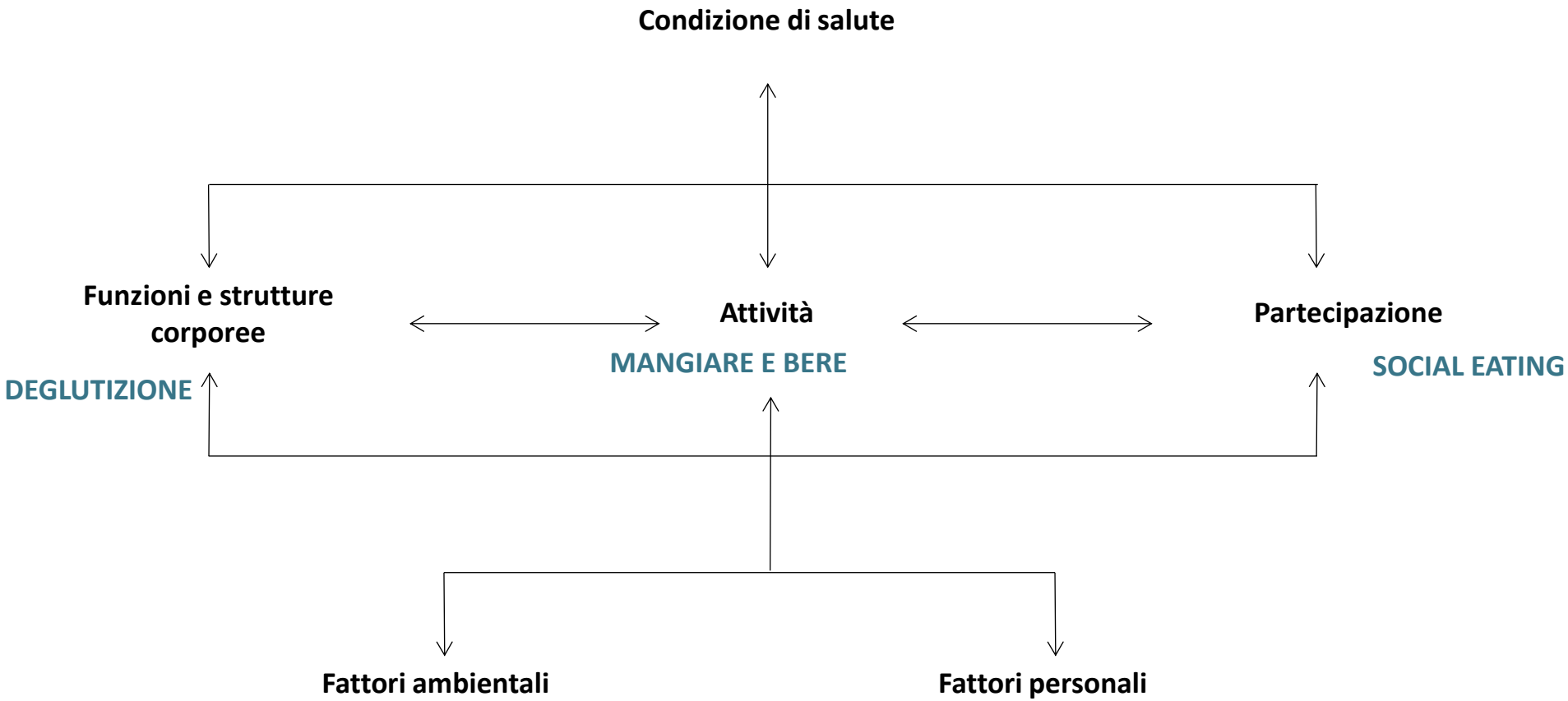
In the past month, has the statement been true for you?		
I do not feel prepared to help manage my loved one's swallowing difficulty (e.g., related to tube feeding, thickened liquids, Heimlich).	Yes	No
Because of my loved one's swallowing difficulties, I feel like it is hard to ensure they receive adequate nutrition.	Yes	No
I feel like my loved one does not do as much as they can to help with their swallowing difficulties.	Yes	No
Because of my loved one's swallowing difficulties, I am scared that they will choke.	Yes	No
Because of my loved one's swallowing difficulties, I feel guilty eating or drinking items that they cannot have.	Yes	No
Because of my loved one's swallowing difficulties, I feel like I don't have enough time to take care of my own physical health.	Yes	No
Because of my loved one's swallowing difficulties, I feel like I don't have enough time for activities that make me feel good.	Yes	No
Because of my loved one's swallowing difficulties, I feel depressed.	Yes	No
Because of my loved one's swallowing difficulties, I feel stressed.	Yes	No
Because of my loved one's swallowing difficulties, I feel anxious.	Yes	No
I feel embarrassed by my loved one's swallowing difficulties when other people are around.	Yes	No
I worry about how my loved one feels about their swallowing difficulties.	Yes	No
Because of my loved one's swallowing difficulties, I feel like the social and togetherness aspects of mealtimes are reduced.	Yes	No
Because of my loved one's swallowing difficulties, I feel isolated from family and friends.	Yes	No
I feel trapped as a result of managing my loved one's swallowing difficulties.	Yes	No
I worry that my loved one's swallowing difficulties will not improve.	Yes	No

Shune et al, 2020

Traduzione ed adattamento italiano in fase di validazione (Pizzorni, Basile, Romualdi, In progress)

PECULIARITA’ GENERALI NEL TRATTAMENTO

Qual e' l'obiettivo del trattamento?



International Classification of Functioning, Disability and Health (ICF, WHO, 2001)

Trattamento della disfagia

Approccio compensativo

- Modificazioni della dieta
- Strategie di gestione del pasto

Approccio riabilitativo

- Rinforzo muscolare
- Skill training

APPROCCIO COMPENSATIVO: tecniche

- POSTURE e MANOVRE DI COMPENSO
- MODIFICAZIONI DIETETICHE
- MODIFICAZIONI AMBIENTALI/COMPORTAMENTALI AL PASTO
- MODIFICAZIONI MODALITA’ DI ALIMENTAZIONE

APPROCCIO COMPENSATIVO: principi

1. Task deglutitori sembrano essere più efficaci di task non deglutitori sul recupero della funzione deglutitoria

LIQUIDI LIBERI A PICCOLI SORSI VS ADDENSATI VS ASSUNTI PER VIA ENTERALE

The best way to treat a **swallowing** disorder, is to **swallow**!

APPROCCIO COMPENSATIVO: principi

2. Alcune tecniche compensatorie, specialmente le posture, potrebbero essere non accettate dal paziente/scarsa aderenza

CONSIDERARE LE PREFERENZE DEL PAZIENTE

3. Non possiamo ritenere qualsiasi compenso completamente protettivo per il paziente anche se verificato strumentalmente

L'ASPIRAZIONE NON È L'UNICO FATTORE DI RISCHIO PER LA POLMONITE AB INGESTIS

OUTCOME A BREVE TERMINE ≠ OUTCOME A LUNGO TERMINE

Figure 2. A schematic of host variables that can increase the risk of an adverse event from aspiration. GI = gastrointestinal disease; GERD = gastroesophageal reflux disease; LPR =laryngopharyngeal reflux.

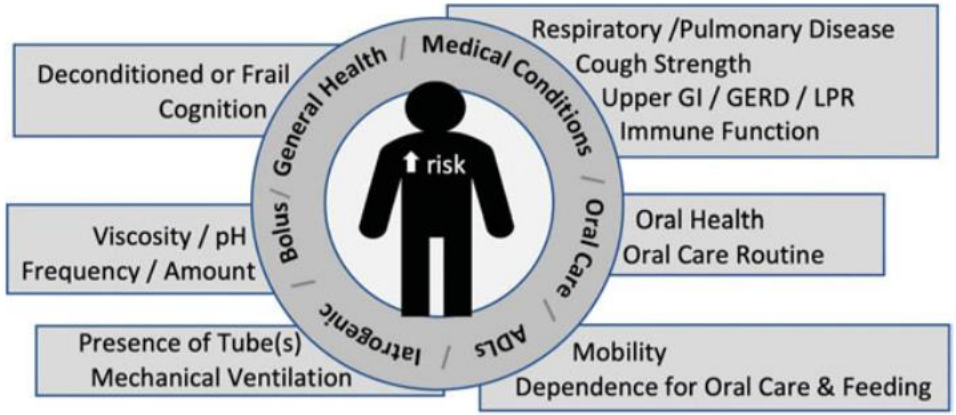


Table 1. Guiding questions to support the dysphagia clinician when assessing the level of risk of an adverse event from aspiration.

Risk category	Guiding questions
General health	• Is my patient in poor general health? • Is my patient frail or deconditioned? • Does my patient have reduced cognitive function that impacts swallow safety?
Medical conditions	• Does my patient have reduced respiratory function? • Does my patient have a weak cough? • Does my patient have GERD or GI disease? • Does my patient have a compromised immune system that alters their ability to fight infection?
Oral health	• Does my patient have evidence of oral cavity neglect? • Does my patient have a poor oral care routine?
Dependence for ADLs	• Is my patient dependent on others for oral care? • Is my patient dependent on others for feeding? • Is my patient active and mobile?
Iatrogenic concerns	• Does my patient have tubes (e.g., trach tube, NG tube, Dobhoff) that may harbor bacteria that can be transferred to the lungs during prandial aspiration or with microaspiration? • Is my patient receiving mechanical ventilation?
Bolus variables	• Is my patient aspirating thickened liquids or highly acidic materials? • Is my patient frequently aspirating large volumes?

Note. GERD = gastroesophageal reflux disease; GI = gastrointestinal; ADL = activities of daily living; NG = nasogastric.

Palmer & Padilla, 2022

APPROCCIO COMPENSATIVO: principi

4.Richiedono dei prerequisiti

- Ambiente favorevole alla preparazione dei cibi
- Disponibilità del caregiver
- Sufficiente livello cognitivo (consapevolezza, memoria, attenzione, abilità comunicativo-linguistiche)
- Adeguata coordinazione

Logemann, 1994, 1998; AHCPR, 1999

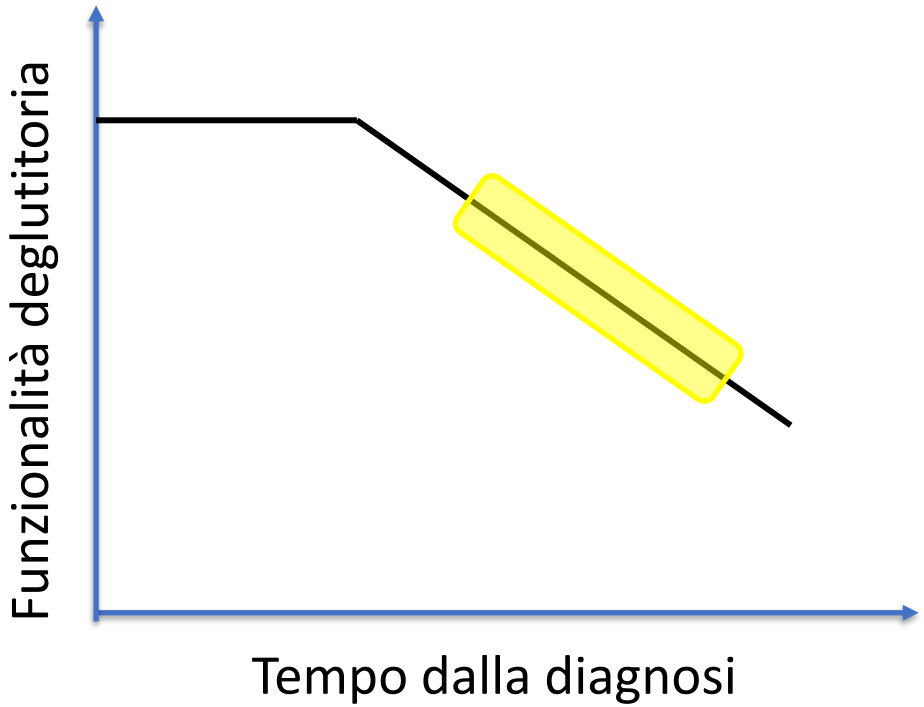
APPROCCIO COMPENSATIVO e Skill Transference

1. Generalizzazione = il comportamento acquisito deve essere applicato a differenti contesti e compiti
2. Mantenimento = il comportamento acquisito persiste nel tempo

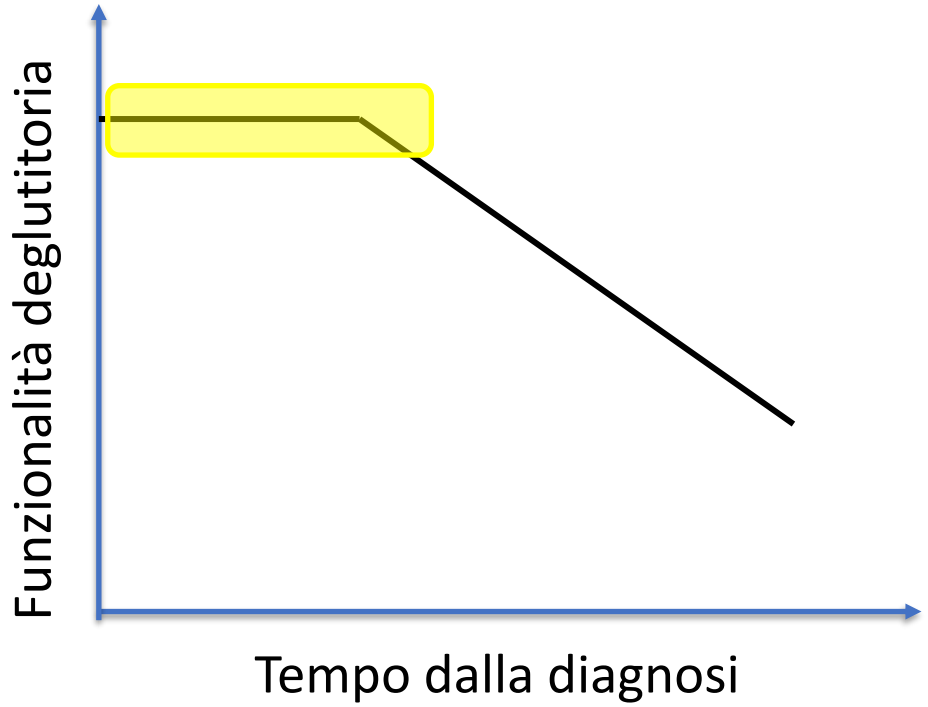
Guedes et al, 2017

Trattamento della disfagia da REattivo a PROattivo

APPROCCIO REATTIVO



APPROCCIO PROATTIVO



Rogus Pulia & Plowman, 2020

L’approccio PROattivo: obiettivi

1. Aumentare e/o mantenere il controllo bulbare e le reserve fisiologiche deglutitorie e respiratorie
2. Massimizzare l’intake orale nel corso della progressione della malattia
3. Mantenere e ottimizzare la QoL nel corso della progressione della malattia
4. Coinvolgere attivamente il paziente nel prendere decisioni nel percorso di malattia

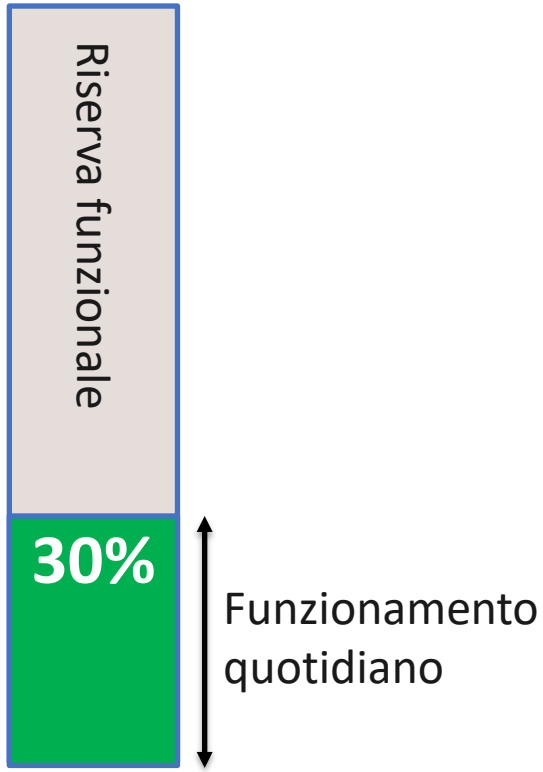
RISERVA FISIOLOGICA FUNZIONALE

Capacità di un organo di svolgere la sua attività fisiologica quando è sotto stress

Capacità massima di un organo o di una parte del corpo

Attività minima necessaria per funzionare quotidianamente base

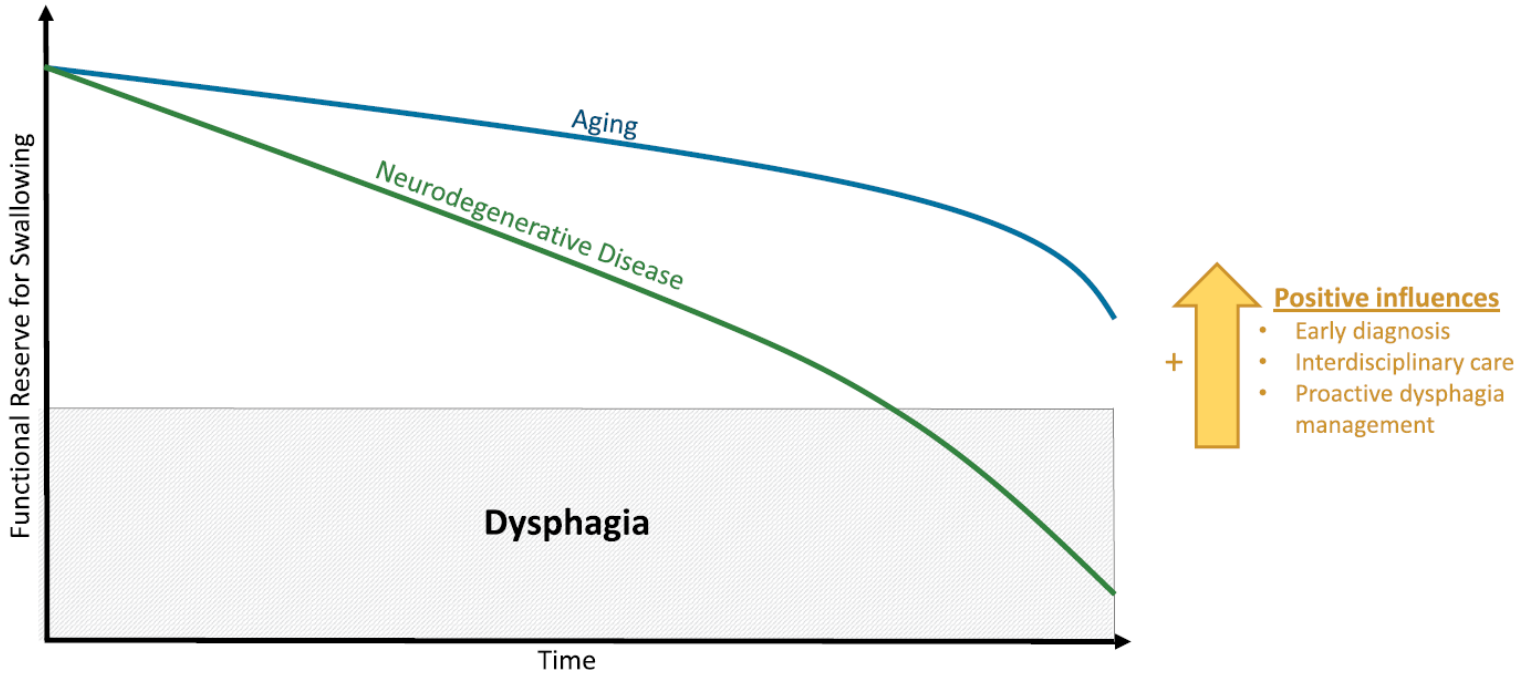
Arnett et al., 2008



RISERVA FISIOLOGICA FUNZIONALE

La deglutizione è un compito «submassimale»

Figure 2. The process of declining functional reserve (homeostenosis) with advancing age and even more so in persons with neurodegenerative disease is shown on this graph. Factors that will either result in increased functional reserve and improved functioning longer into disease progression are highlighted, as well as those factors that will have the opposite negative effects.



Rogus Pulia & Plowman, 2020

Principi di neuroplasticità

1. Use it or lose it
2. Use it and improve it
3. Specificità
4. Ripetizione
5. Intensità
6. Tempo
7. Salienza
8. Trasferibilità
9. Interferenza

Kleim and Jones, 2008

TABLE 1 Principles of neuroplasticity as they relate to speech-language pathology areas of treatment

Principles of Neuroplasticity	Speech-language Pathology Treatment
Use it or lose it	Intubation; prolonged NPO status; limited cognitive stimulation
Use it and improve it	Targeted treatment to improve swallowing or to improve voice
Specificity	Specific exercises that address specific physiologic/cognitive-linguistic/ behavioral impairments
Repetition	Sufficient repetitions to create patterned and meaningful change
Intensity	Increase intensity as treatment progresses (e.g., resistance, increased bolus viscosity, increased complexity of tasks)
Time	Early rehabilitation may capitalize on the hyper plasticity phase following neurologic injury
Salience	Using patient preferences of foods/liquids and discussion topics during treatment
Transference	Nonspecific but related exercises (e.g., swallowing: EMST, lingual resistance; language/cognition: drills)
Interference	Compensatory strategies and augmentative devices are beneficial but should be temporary and phased out as quickly as possible

Abbreviations: EMST, expiratory muscle strength training; NPO, nil per os.

Langton-Frost & Brodsky, 2022

STRENGHT/RESISTANCE TRAINING

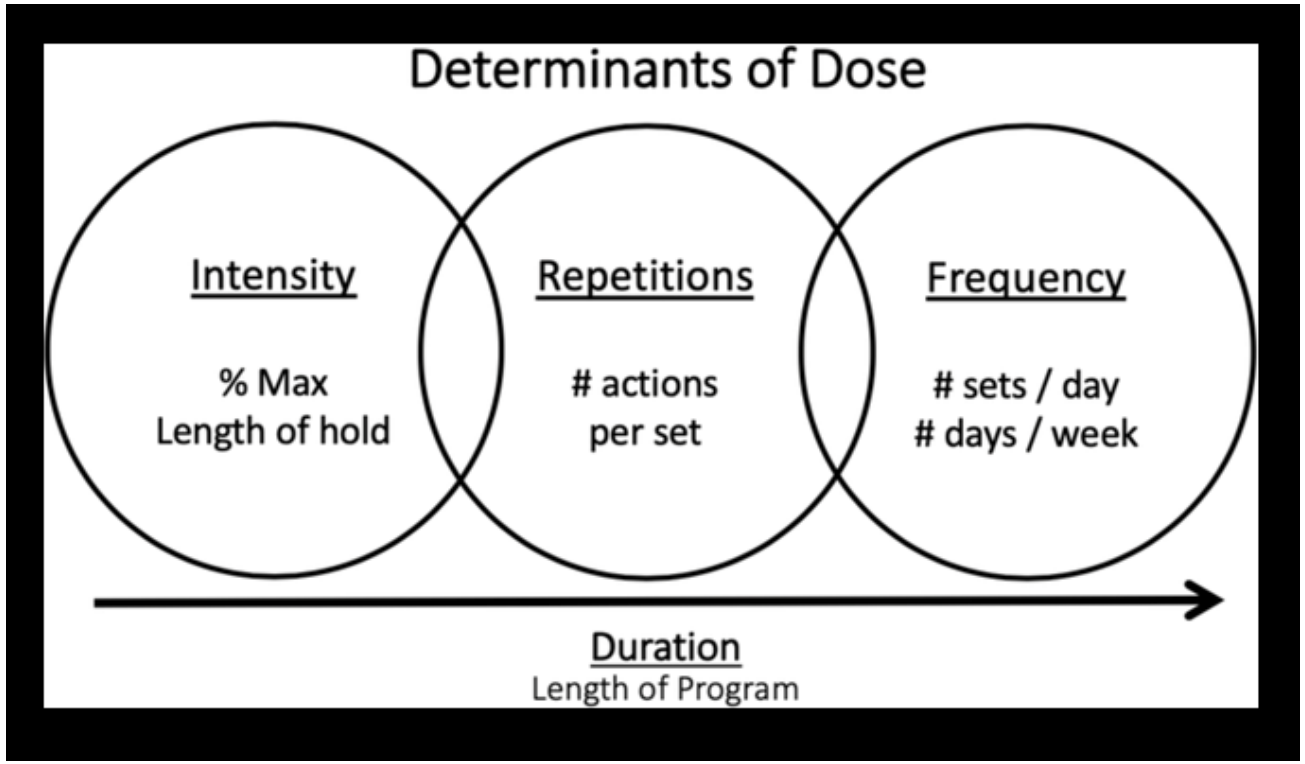
Trattamenti di rinforzo o resistenza possono essere utilizzati per costruire riserva funzionale (deglutitoria/respiratoria), al fine di sviluppare maggiore resilienza ai meccanismi patologia-relati che impattano sulla funzione muscolare

MA EFFETTI DETRIMENTALI DELL'ESERCIZIO?

- Storicamente, l'esercizio è stato associato a un peggioramento della funzionalità per sovrautilizzo dei muscoli
- Tuttavia, un ridotto utilizzo della muscolatura può essere detrimentale (atrofia da disuso)
- L'esercizio può avere effetti benefici sulla funzionalità del muscolo e dei motoneuroni (cambiamenti cellular e morfologici) che possono favorire il mantenimento della funzione più a lungo nel tempo se ad APPROPRIATA DOSE e MONITORANDO L'AFFATICAMENTO sul singolo paziente

Adkins et al., 2006; McCrate & Kaspar, 2008; B. P. Patel & Hamadeh, 2009; Plowman, 2015

Dosaggio dell'esercizio



Krekler et al.; 2020

Strenght vs Skill Training

- La deglutizione richiede una contrazione muscolare sub-massimale
- La debolezza non è sempre la causa sottostante la disfagia, nè sottostante un’inadeguata contrazione muscolare durante l’atto deglutitorio

SKILL-BASED TRAINING

Acquisizione di abilità attraverso la ripetizione funzionale e il perfezionamento di schemi di movimento attraverso una riorganizzazione corticale dei network motori

Dysphagia (2023) 38:756–767
https://doi.org/10.1007/s00455-022-10516-3

REVIEW

Expanding Rehabilitation Options for Dysphagia: Skill-Based Swallowing Training

Maggie-Lee Huckabee[1] · Ruth Flynn[1] · Madeline Mills[1]

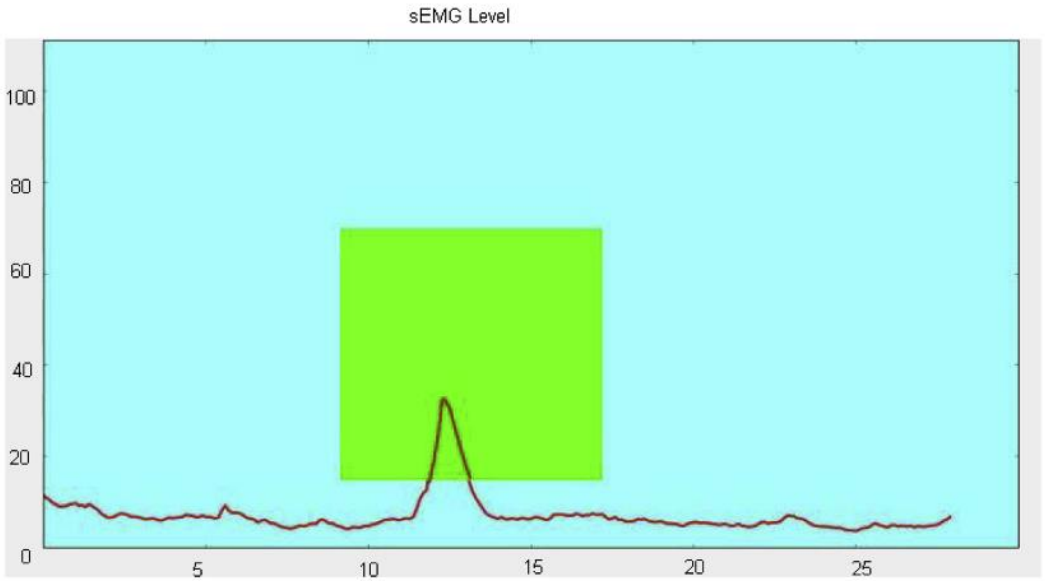
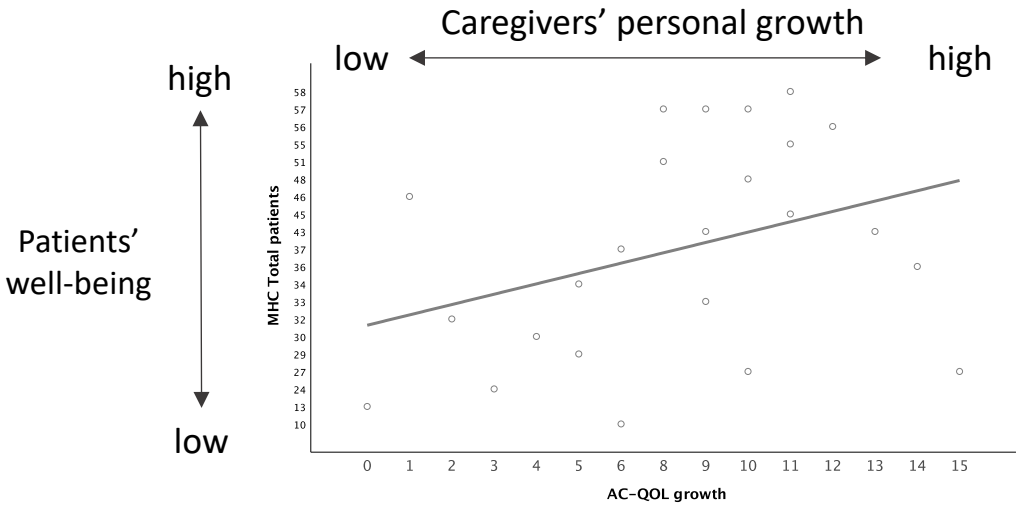
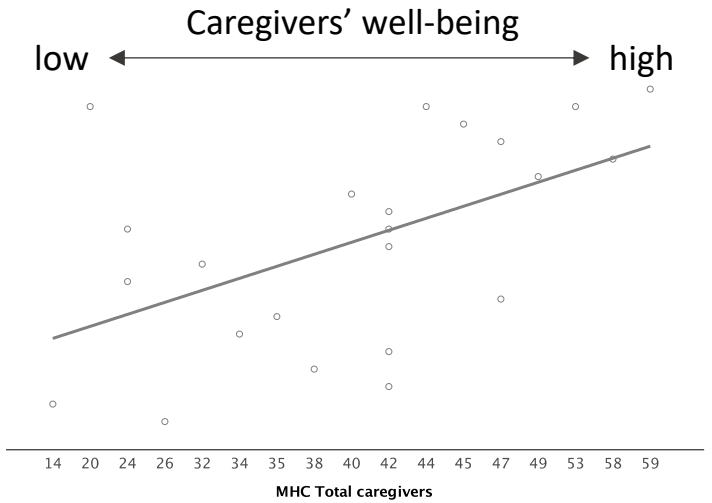


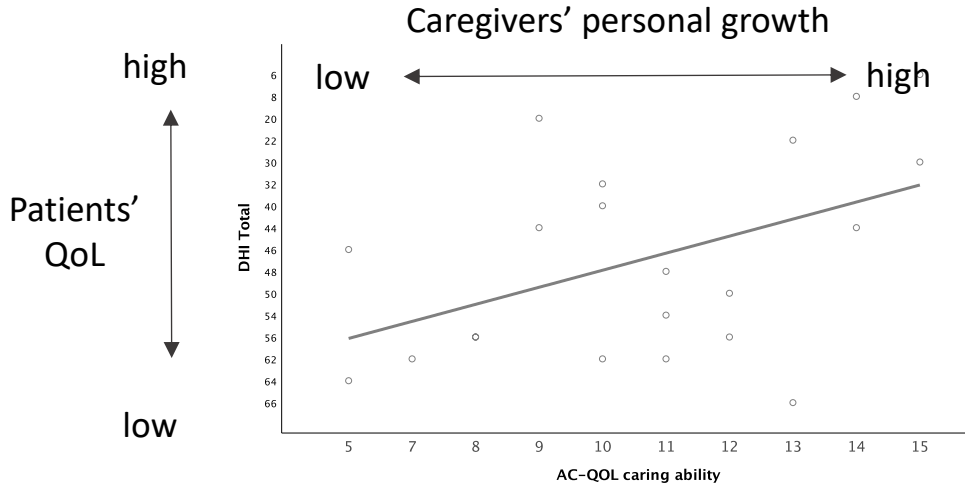
Fig 2 Skill training display (swallowing target) in the BiSSkiT software.

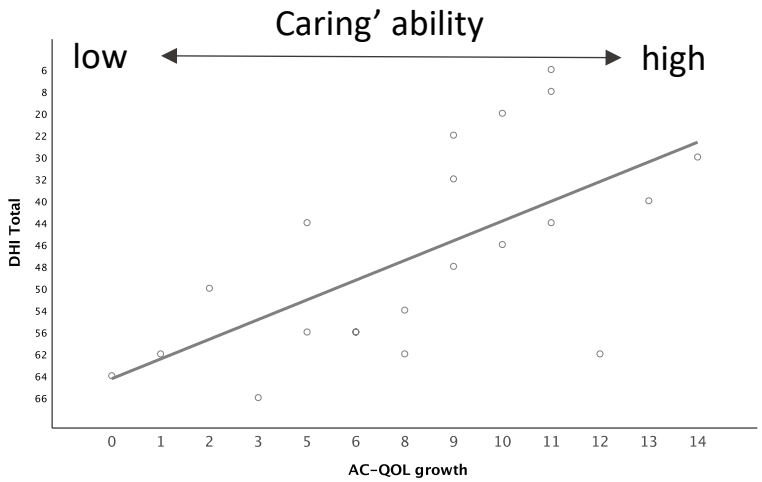
Il caregiver come oggetto di cura

Il benessere e la QoL del paziente e del caregiver sono intercorrelati









Ninfa, 2023

Il care-giver come oggetto di trattamento

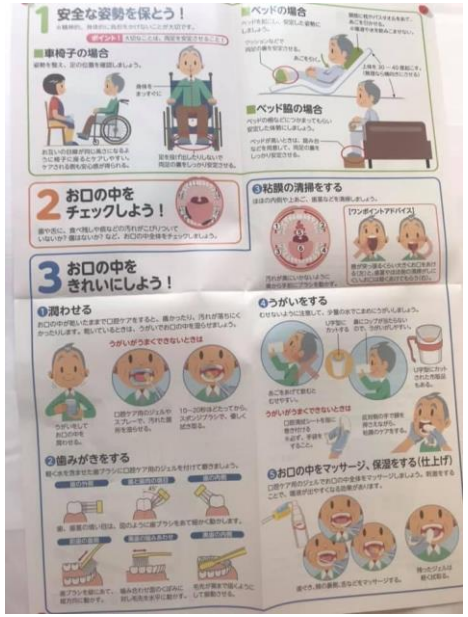
Interventi educativi al caregiver del paziente adulto a disfagia hanno l'obiettivo di:

- Rispondere ai bisogni di cura
- Migliorare la percezione di autoefficacia
- Ridurre lo stress nel caregiver

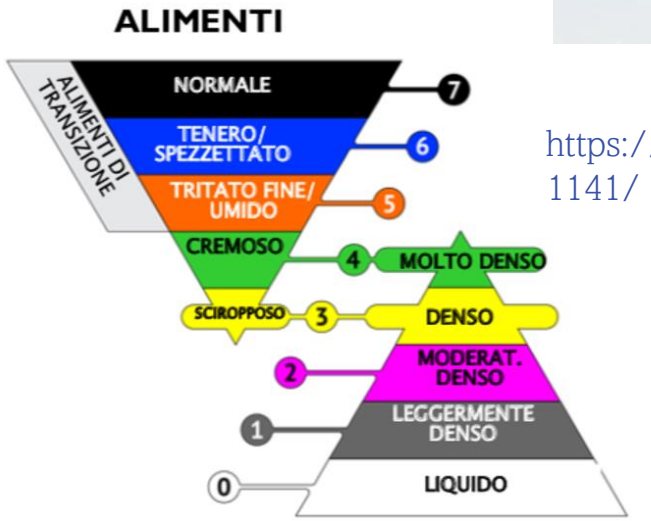
Il care-giver come oggetto di trattamento

Quali strumenti?

- Counseling informativo vs Counseling addestrativo
- Opuscoli, libri di ricette
- Programmi di skill-building (es cucina, igiene orale, manovre di disostruzione)



https://video.unimi.it/progetto/1141/



https://iddsi.org/Resources

Il care-giver come oggetto di trattamento

ASHA American Speech-Language-Hearing Association

AJSLP

Research Article

Preliminary Study of the Effects of a Dysphagia Support Group on Quality of Life

Emma Koster,[a] Zuleikha Wadhwaniya,[b] and Ashwini M. Namasivayam-MacDonald[a]

Table 5. Quotations from participants by theme and subtheme.

Main theme	Subtheme	Quotation	Individual identity
Informational	Coping skills	"It is. . .beneficial to be able to learn what strategies other have used to cope (both nutritionally and psychologically)"	IWD
	Information about resources and equipment	"Where to find products and equipment"	IWD
		"I felt that I could take away something new by listening to [the other participants'] experiences and recommendations such as reading the book by Julie Tuchman Dysphagia Naturally: Tips, Tools, and Resources for Patients with Swallowing Disorders"	CG
		Most beneficial aspects: "Caregivers seeking feedback or advice on navigating the medical system or patients sharing tales of trying to find foods that will 'slip down'"	IWD
	Professional advice	"[The two] Speech Language Pathologists. . .have offered a wealth of knowledge, resources, information, and strategies that we can incorporate into our lives."	CG
		Most beneficial aspects: "having the professionals explain major and minor issues"	CG
Psychosocial	Knowledge that individuals are not alone	"After finding support groups, I discovered that there are many others like me."	IWD
		Most beneficial aspects: "Understanding that others were dealing with weight loss and dental hygiene"	CG
		"It's really helpful to know that I am not alone and that there are other people who have to eat pureed foods or have to use thickened liquids"	CG
	Emotional benefit	*Most beneficial aspects*: "The opportunity to speak and be heard."	IWD
		"My heart opened in compassion for the others"	IWD
	Perspective	"I gained tremendous perspective on the breadth of challenges faced by people with dysphagia"	IWD
		"It really helped me to put things in prospective (sic)"	CG
	Connection	*Most beneficial aspects*: "Engaged participants"	IWD
		Most beneficial aspects: "Hearing everyone's story"	CG
		"[It is] beneficial to have peer support"	IWD

Note. IWD = individual with dysphagia; CG = family caregiver.

IL SUPPORTO DEI PARI

ASSOCIAZIONE ITALIANA PAZIENTI E CAREGIVER CON DISFAGIA

Il contatto con altri pazienti e caregiver promuove la condivisione di strategie di coping positive.

TAKE HOME MESSAGE

- La gestione della disfagia nei pazienti con malattie neurodegenerative deve essere interdisciplinare e prevedere sin dalle fasi precoci il coinvolgimento del logopedista nel processo di cura
- La valutazione della disfagia in queste popolazioni deve essere multidimensionale al fine di stimare adeguatamente le possibili conseguenze polmonari, nutrizionali e di QoL
- Il trattamento della disfagia nei pazienti con malattie neurodegenerative deve essere mirato sui bisogni di cura dei pazienti e dei caregiver
- L'approccio proattivo al trattamento della disfagia nei pazienti con malattie neurodegenerative sembra essere promettente (a basso dosaggio e con monitoraggio della funzione deglutitoria del singolo paziente) in pazienti in stadi iniziali, con adeguato livello cognitivo e motivati, seppur sia ancora da considerare sperimentale in attesa di più robuste evidenze di efficacia