I livelli di intensità di cura

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Sperimentazione del sistema VAOR LTCF nelle RSA lombarde

## Presentazione dei dati finali

Brescia, 17 dicembre 2012

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Uno scenario di crisi

- Popolazione più anziana e più complessa

- Costi di gestione in crescita

- Costi amministrativi collegati a norme di legge e alle misure sulla vigilanza e controllo saliti al 27%, quasi un terzo del budget totale

- Tariffe da FSR ferme al 2003

- Tariffe alberghiere ai limiti della sostenibilità per le famiglie

Uno scenario di crisi?

Minuti medi settimanali di assistenza delle RSA lombarde
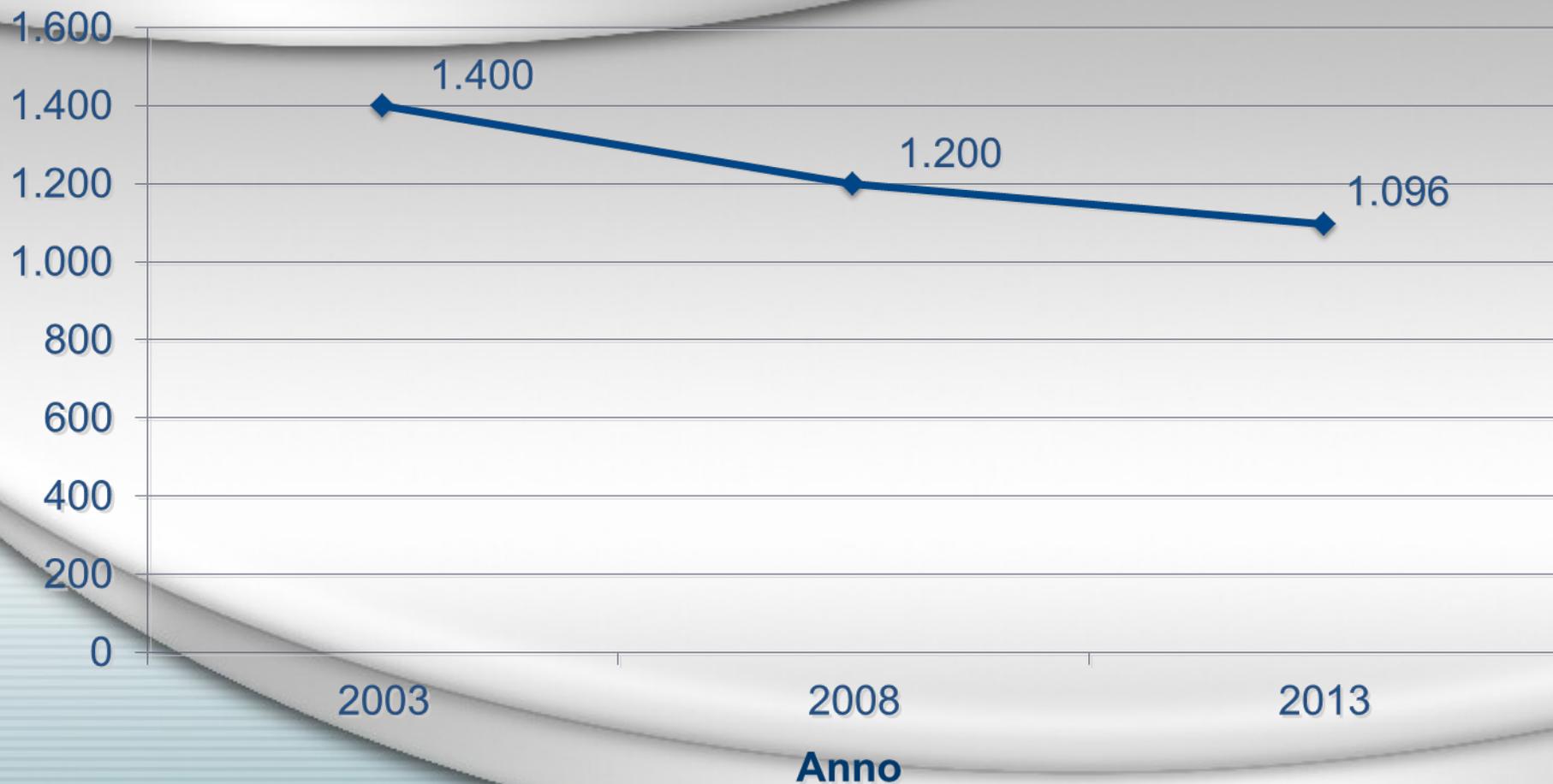
Distribuzione per classi di età. Popolazione totale, 3772 valutazioni
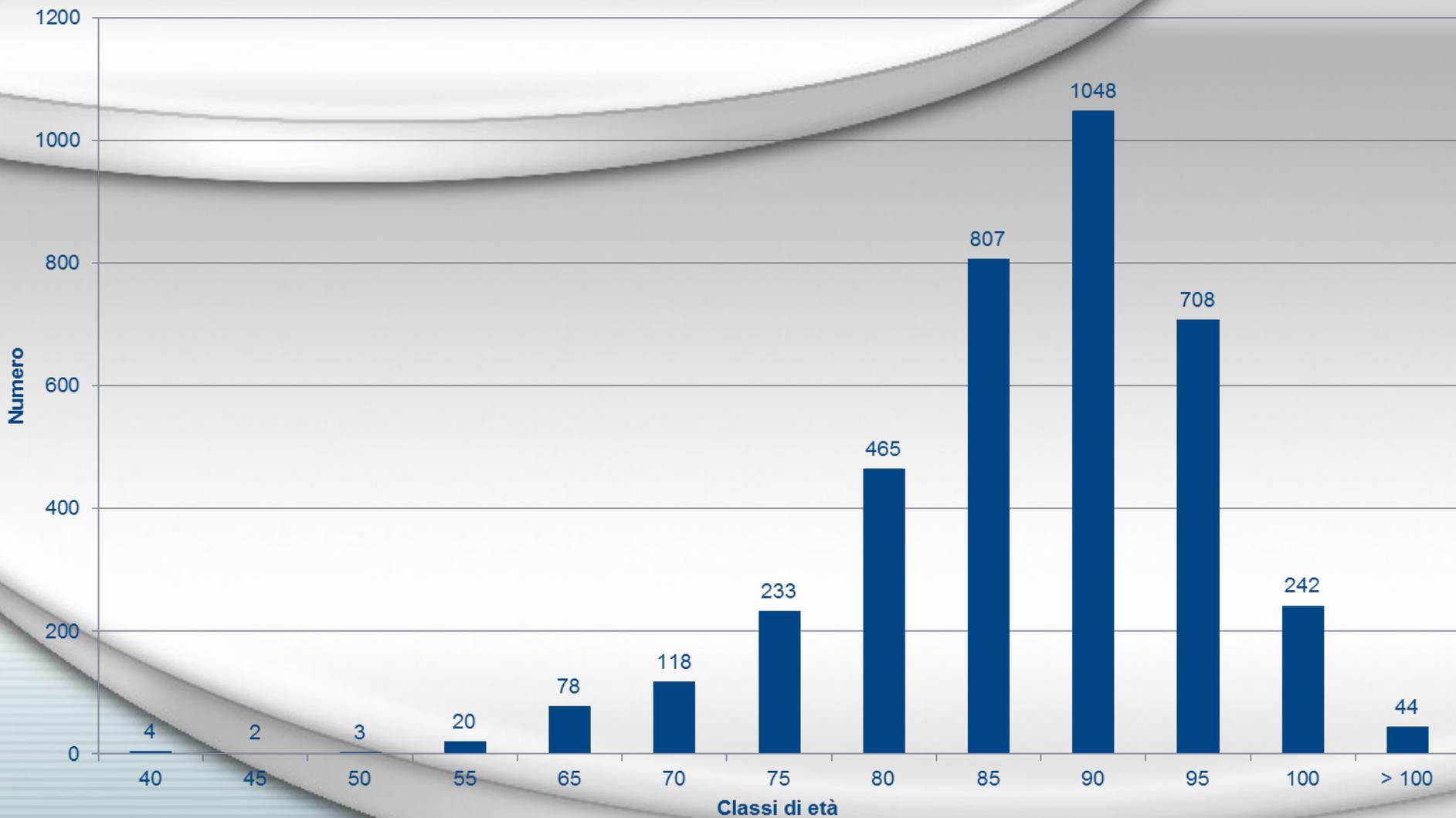
ADL Hierarchy Scale (3.772 valutazioni)
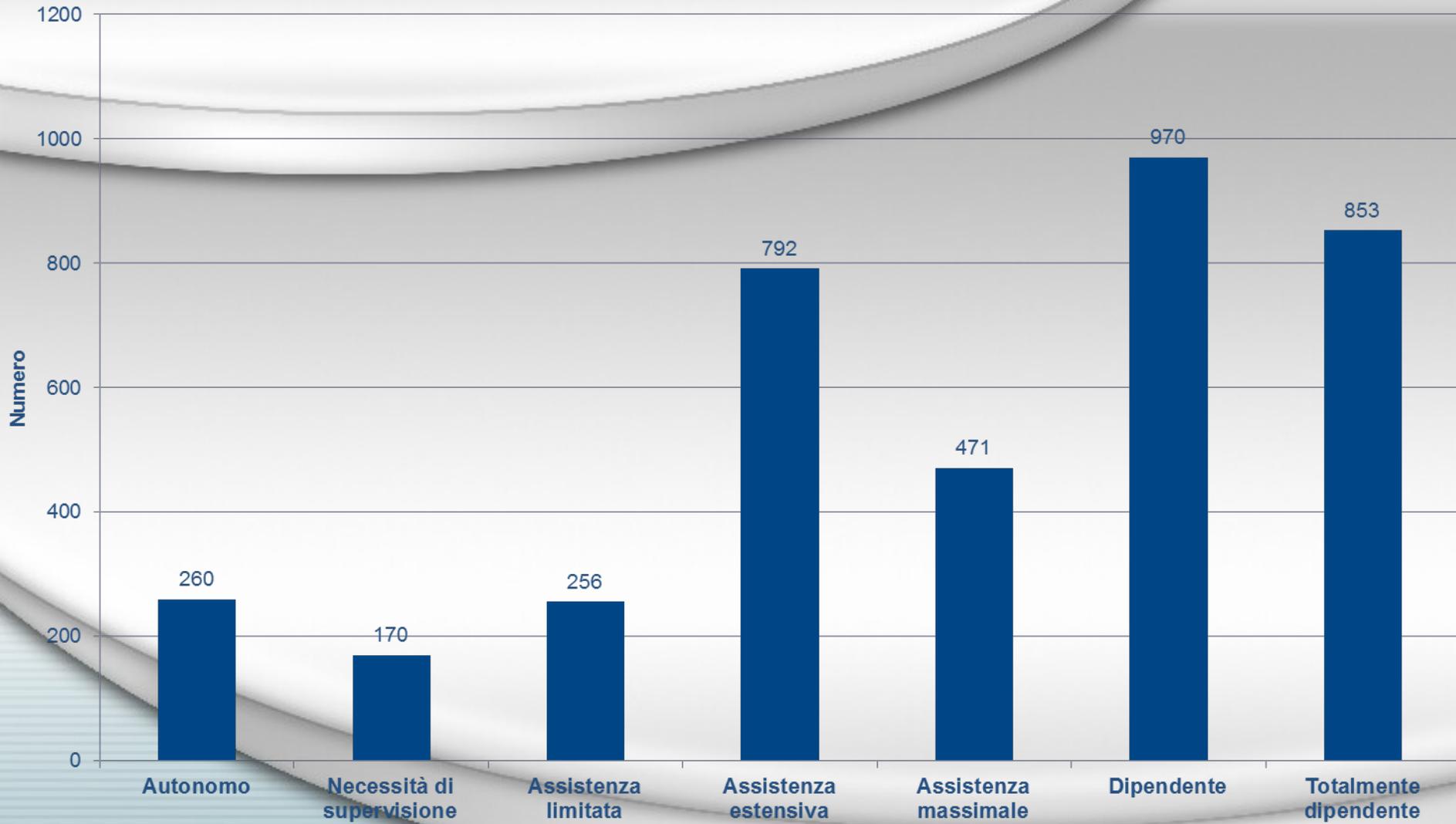
PHP CPS (funzioni mentali superiori) (3772 valutazioni)
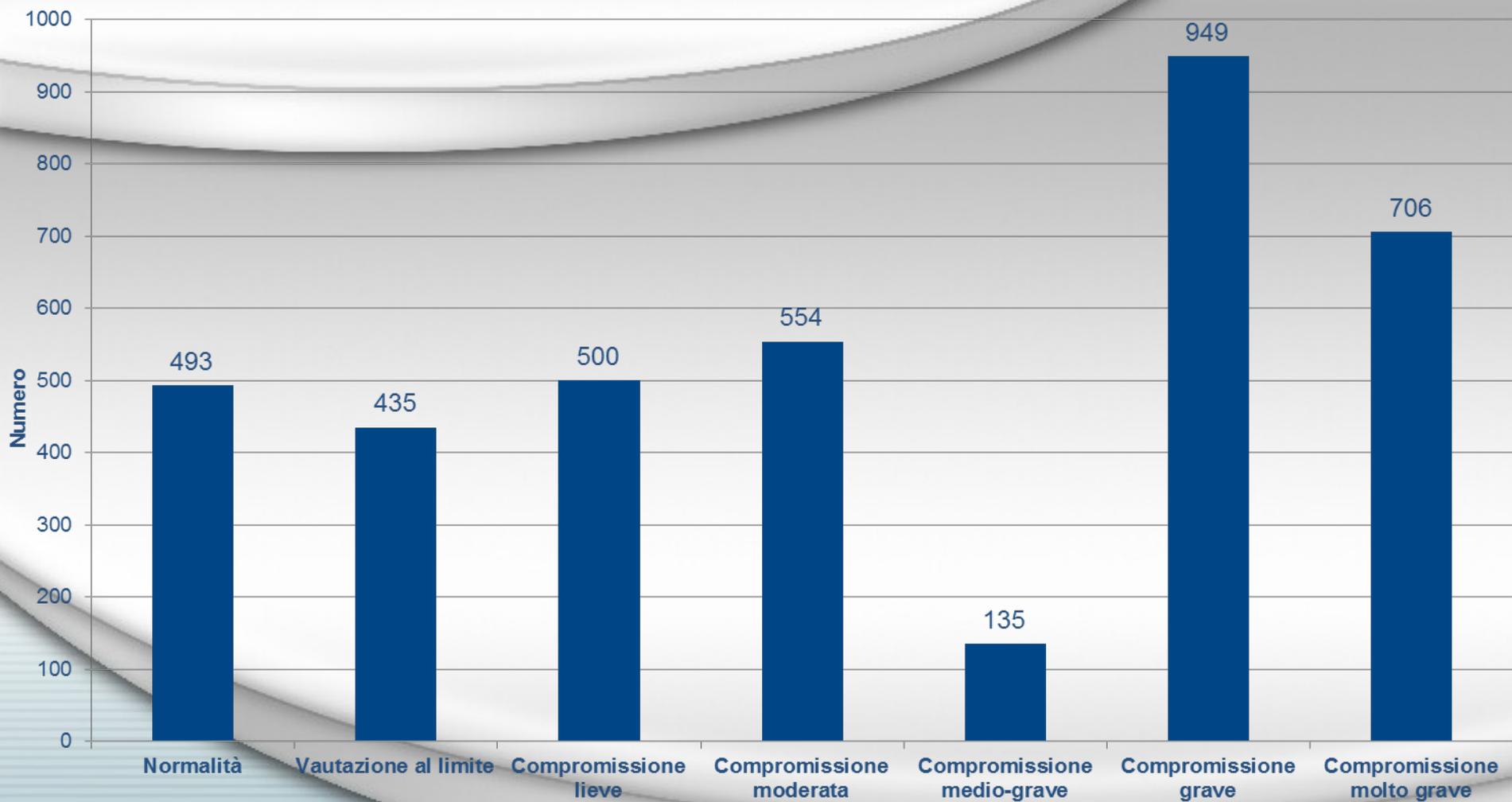
PHP CHESS (stabilità clinica) (3772 valutazioni)
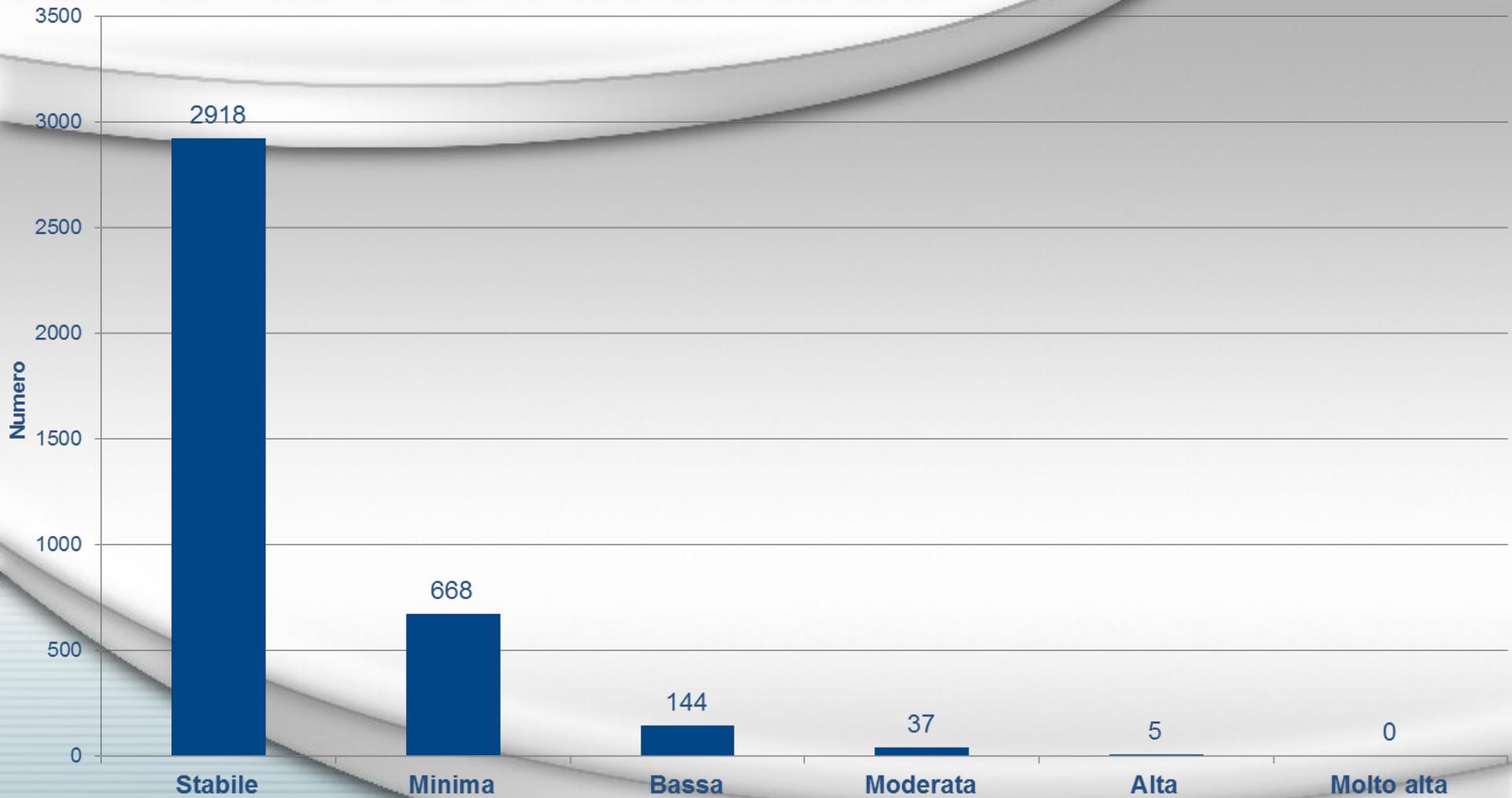
Divisione per raggruppamenti RUG (no BC1, n. 3.258)
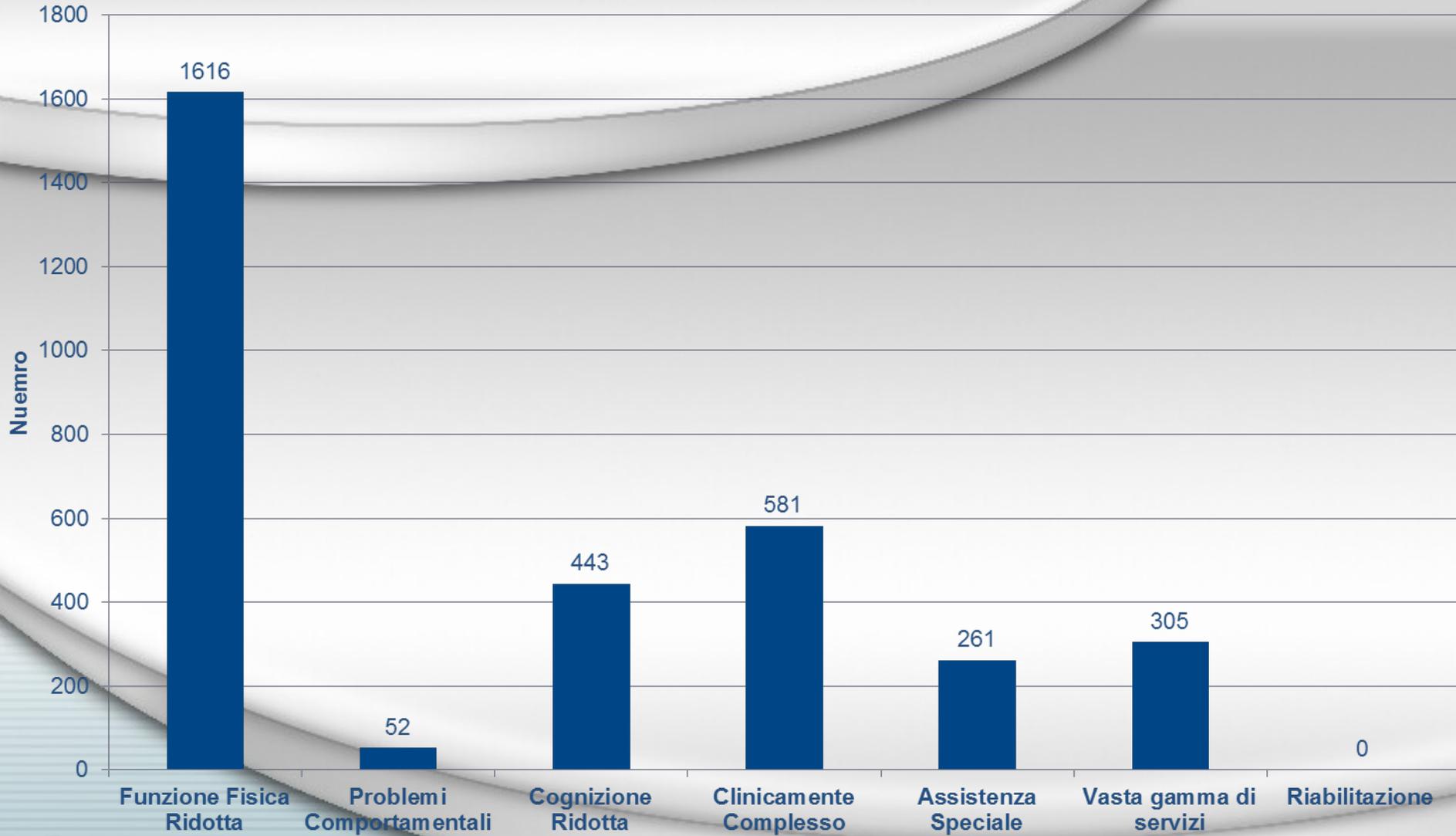
Divisione per raggruppamenti RUG (no BC1, dati in % di 3.258 valutazioni)
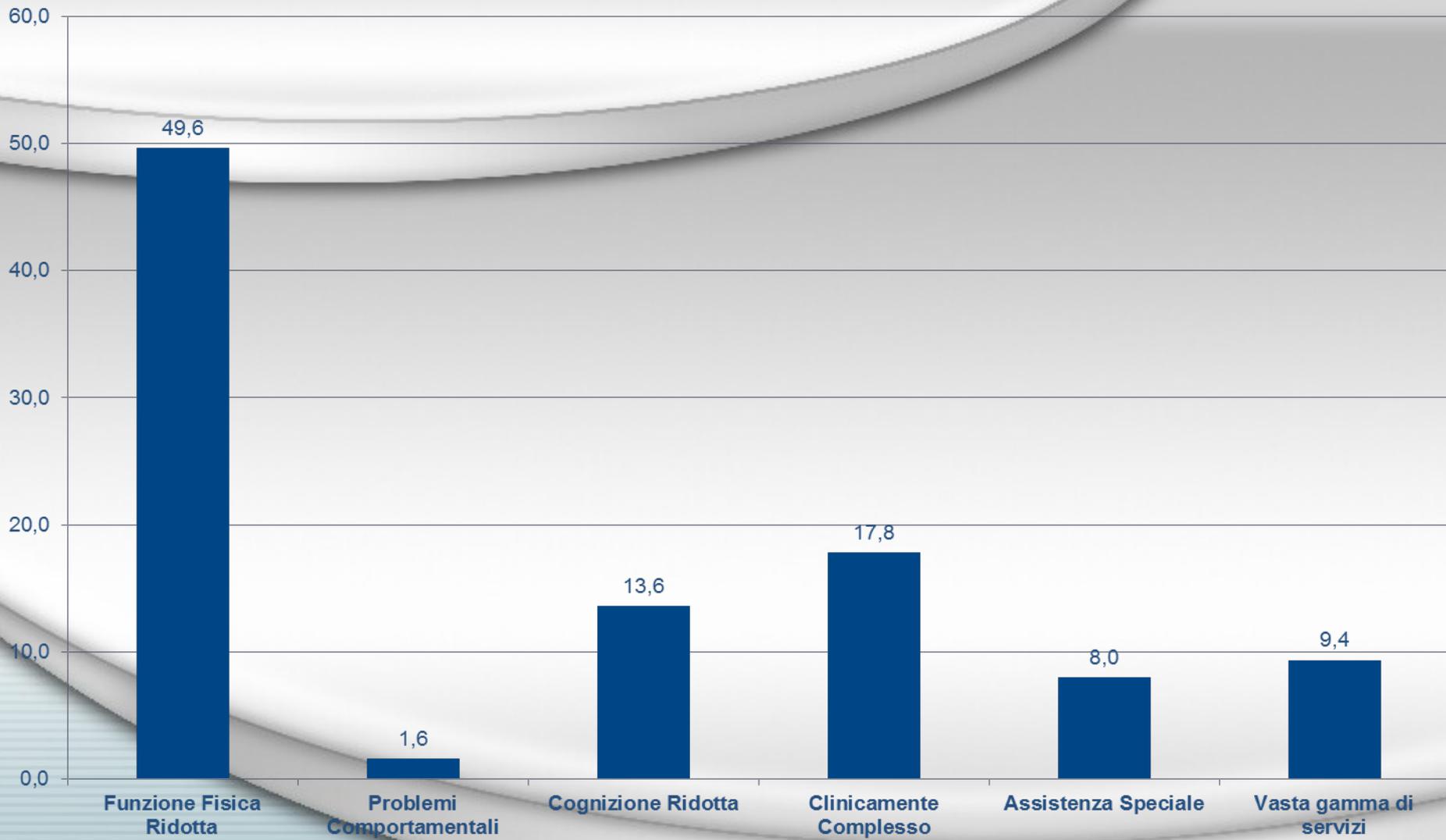
Distribuzione classi RUG (numero assoluto: 3.258)
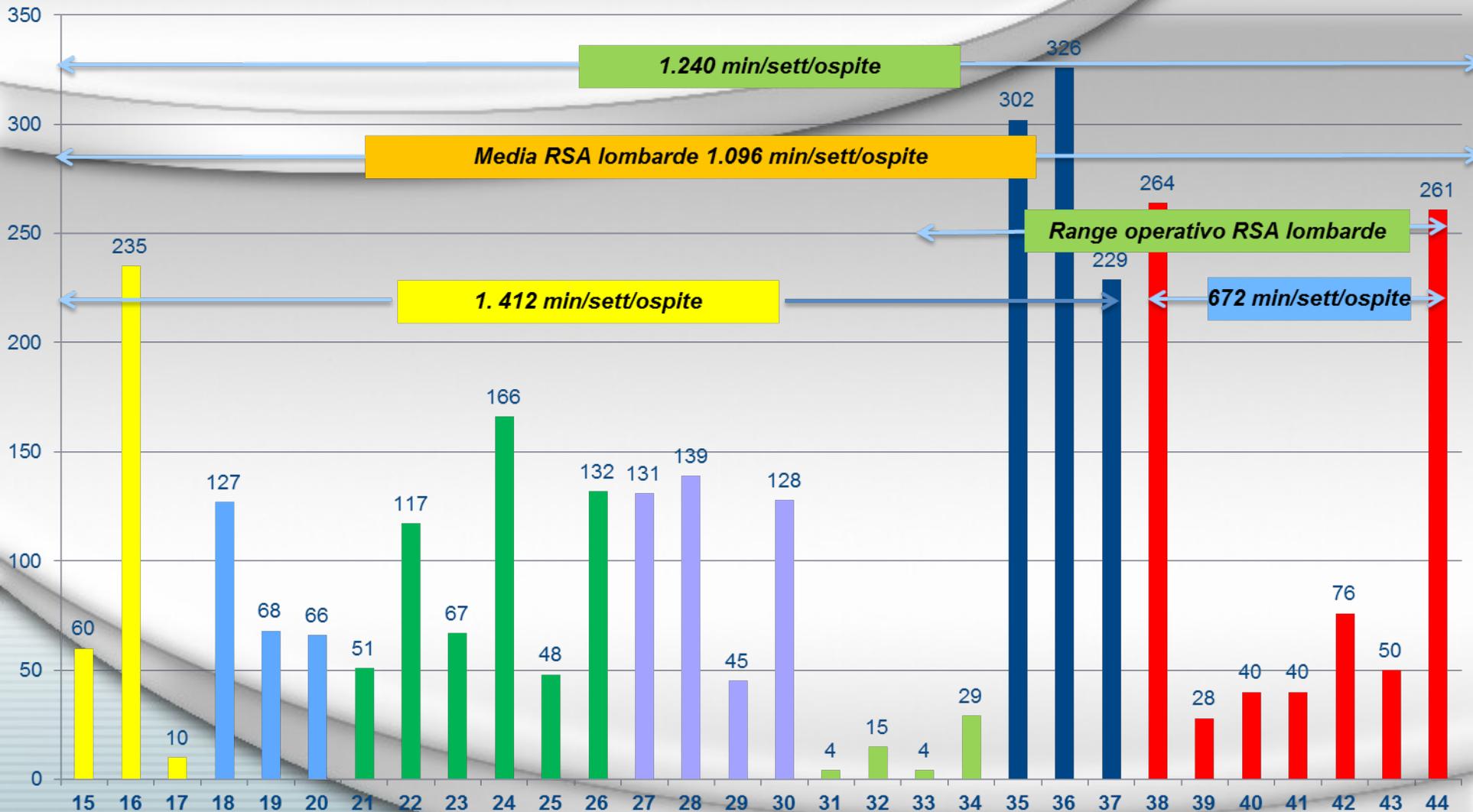
In dettaglio

- Si tratta di una fotografia dinamica

- Al contrario del sistema SOSIA - che valorizza soprattutto la disabilità motoria - il VAOR riconosce il maggior assorbimento di risorse collegato alla presa in carico delle persone con demenza e quello direttamente determinato da cambiamenti clinici

- Le persone valutate possono muoversi fra i diversi profili RUG, in relazione alla stabilità clinica o alla presenza di eventi clinici intercorrenti

- Le fasi di instabilità o di maggior impegno clinico sono più frequenti nei primi 90 giorni successivi all'ingresso e nell'ultimo anno di vita. Questi episodi possono comunque ripetersi più volte durante l'intero arco di accoglienza

Confronto RUG-SOSIA (valori percentuali su 2.781 valutazioni)
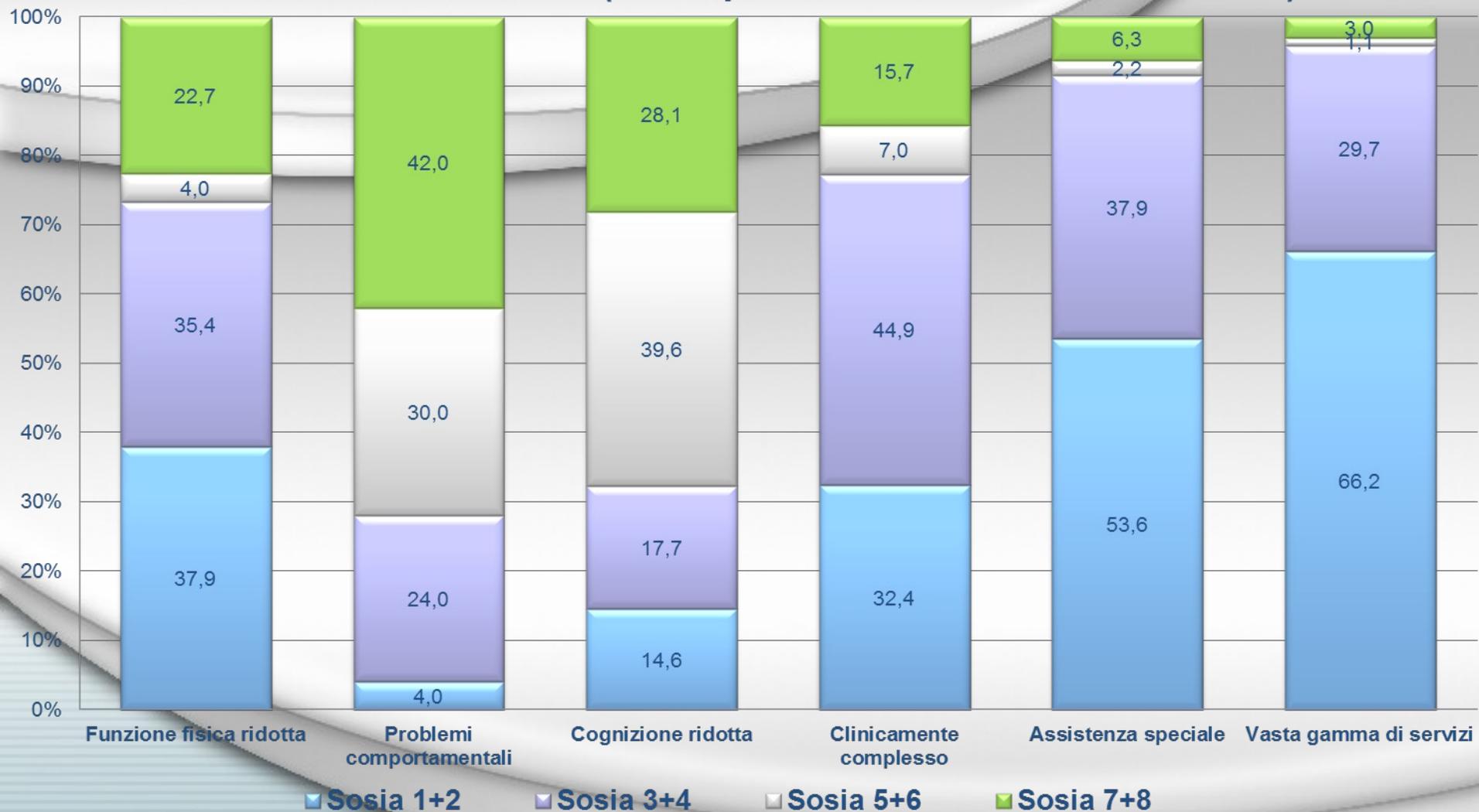
Malattie acute e malattie di lunga durata

Holman H. Lorig K. Patient as partner in managing chronic disease. BMJ 2000; 320:526

"Solo metà dei pazienti con malattie croniche sono identificati, solo metà di questi ricevono un trattamento e solo metà di quelli trattati sono trattati adeguatamente ..."

Editor's choice. Managing chronic disease.
BMJ 1999. 318:1090

	Malattia acuta	Malattia cronica
Comparsa	Improvvisa	Di solito graduale
Durata	Limitata	Lunga, indefinita
Causa	Di solito singola	Di solito multipla e mutevole nel tempo
Diagnosi e prognosi	Di solito accurate	Spesso incerta
Interventi tecnologici	Di solito efficaci	Spesso non decisivi, frequenti effetti indesiderati
Esito	Guarigione	Non guarigione
Margini di incertezza	Di solito ridotti	Pervasivi
Conoscenze	Professionali. Inesperienza pazienti	Pazienti e operatori hanno conoscenze complementari

- Nelle patologie di lunga durata né le malattie né le loro conseguenze sono statiche e cure ed assistenza richiedono frequenti adattamenti;

- l'approccio alla malattia coinvolge aspetti clinici ma anche biografici, relazionali, abitativi, economici, gestionali;

- la prognosi è incerta, muta nel tempo e l'obiettivo non è la guarigione ma il mantenimento della maggior autonomia e qualità di vita possibili.

- le conoscenze generali dei medici e del personale e quelle specifiche dei pazienti e familiari appaiono complementari e entrambi necessarie ad una corretta gestione della malattia;

- l'approccio alle patologie di lunga durata non può che fondarsi su una accresciuta e consapevole compartecipazione di ruoli e responsabilità fra pazienti, care-giver, operatori e sistemi di tutela della salute.

Ricerca, grandi anziani e complessità assistenziale

- Ambito *orfano*: povero di ricerca e di conoscenze acquisite, soprattutto nel campo dei percorsi di cura e dei sistemi integrati

- Ambito nel quale si opera per analogia, in assenza di evidenze derivanti dalla ricerca anche in settori tradizionali: ipertensione, diabete, chirurgia.

Clinical Practice Guidelines and Quality of Care for Older Patients With Multiple Comorbid Disease. Implication for pay of performance

Boyd C. JAMA 2005, 294:716

Linee guida indagate

- Ipertensione
- Scompenso cardiaco cronico
- Angina stabile
- Fibrillazione atriale
- Diabete mellito tipo 2
- Osteoartrite
- BPCO
- Osteoporosi

Paziente ipotetico

Donna di di 79 anni, con BPCO, diabete mellito di tipo 2, osteoporosi, ipertensione e poliartrosi

*"Most clinical practice guidelines (CPCGs) did not modify or discuss the **applicability** of their recommendation for older patient with multiple comorbidities. Most also did not comment on **burden**, short- and long-term goals, and the quality of the underlying scientific evidence, nor give guidance for incorporating **patient preferences** into treatment plans. If the relevant CPGs were followed, the hypotetical patient would be prescribed **12 medications** (costing her $406 per month) **and a complicated non pharmacological regimen.** Adverse interaction between drugs and disease could result"*

"This review suggests that adering to current CPGS in caring for an older person with several comorbidities may have undesirable effects. Basing standards for quality of care and pay for performance on existing CPGs could lead to inappropriate judgment of the care provided to older individuals with complex comorbities and could create perverse incentives that emphasize the wrong aspect of care for this population and **diminish the quality of their care***"*

Lavorare insieme: i profili di rischio

Pareti colorate, più casa, maggior presenza spirituale, più animazione

Pulizia, cura della persona, rispetto. Migliora la qualità di vita, se no che vita è …

Garanzia di cure mediche, umanità, personalizzazione degli ambienti, cercare di conservare il più possibile la dignità della persona. E' comunque la loro casa, la loro stanza. Potesse tornare al suo paese di origine...

Professionalità dei medici e degli infermieri, umanità, cortesia, rivolgersi ai malati con dignità, rispettare la loro intimità …

Trovare una casa?

Normalità

Quotidianità

Relazioni e legami

Accoglienza

Attenzione

Hanson LC. Needs of the dying in nursing homes. J Palliat Med 2002; 5(1):117

Le principali risorse

- Il valore della propria **esperienza** e della **relazione personale** con gli ospiti
- La **personalizzazione delle cure**
- L'effettiva **collaborazione** fra ausiliari, infermieri e medici
- Il **coinvolgimento** dei familiari
- Un **piano di cura individualizzato** che includa una corretta stima della prognosi, la presa in carico delle emozioni, l'uso proporzionato dei trattamenti medici

Demenza

Disfagia

Malnutrizione

Autonomia

Dolore

Caduta

Fragilità

Dispnea

Decubiti

Fine vita

Sonno

"E' necessario identificare tutti coloro che sono responsabili della prevenzione e descrivere il ruolo di tutti gli attori impegnati. Il livello e la completezza delle informazioni deve essere adeguato alle caratteristiche di chi dovrà applicarlo. La continuità del piano di cura è meglio garantita da un approccio di squadra, che individui per ogni attore un ruolo e una responsabilità specifiche"

(AHCPR, 1992)

Referenti profili di rischio e procedure collegate

Malnutrizione	IP
Disfagia	FKT
Cadute	FKT
Decubiti	IP
Dolore	Medico, palliativista
Demenza	Medico, geriatra
Fasi avanzate, fine vita	Medico, palliativista, geriatra

Referenti test

Barthel	Medico, FKT, OSS coordinatore
FAST	Medico, FKT, OSS coordinatore
Tinetti	FKT
MMSE, Clock drawing test	Medico
Indicatori prognostici	Medico, IP
Compilazione scheda cadute	Operatore sul campo, FKT
Analisi cadute, scelte organizzative	Medico, IP, FKT, animatore, OSS coordinatore
Braden, Norton Plus	IP
DOSS	FKT
MUST, MNA, GNRI	Medico, IP

Cadute

- **Caduta da? Perché? Quando?**
- **Tinetti, Berg**
- **Scheda cadute**
- **Ottimizzazione terapia farmacologica**
- **Analisi e adattamento degli ambienti, dell'organizzazione degli spazi e dei tempi di vita**
- **Protezione vs contenzione**

Cadute

Screening iniziale, valutazione periodica	FKT
Test (Tinetti, Berg, altri)	FKT
Valutazione clinica	Medico, fisiatra, neurologo, FKT
Ottimizzazione terapia farmacologica	Medico
Compilazione scheda cadute	Operatore sul campo, FKT
Analisi cadute, scelte organizzative	Organizzazione, équipe
Modificazioni ambientali	Animatore, FKT, OSS coordinatore
Registri clinici, schede dedicate, test	FKT
Processi, interventi, azioni preventive	Equipe

Malnutrizione

- **Malnutrition universal screening tool (MUST)**
- **Mini nutritional assessment (MNA)**
- **Geriatric nutritional risk index (GNRI)**
- **Diete speciali, integrazione alimentare**
- **Nutrizione artificiale**

Malnutrizione

Screening iniziale, valutazione periodica	Medico, IP
Valutazione antropometrica (peso, altezza, misure derivate)	IP, OSS, ASA, FKT
Screening di secondo livello, valutazione alto rischio	Nutrizionista
Registri clinici, schede dedicate, testistica	Medico, IP
Preferenze, gusti, approccio interpretativo, gestione dei tavoli	Animatore, IP, FKT, OSS, ASA, medico
Progettazione dietetica	Nutrizionista, dietista
Gestione menù	Animatore
Assistenza al pasto, osservazione	OSS, ASA

Valutazione nutrizionale
(Mini Nutritional Assessment MNA©)

Nome:		Cognome:		Sesso:		Data:

Eta:	Peso, kg:	Altezza, cm:	Altezza del ginocchio, cm:

Risponda alla prima parte del questionario indicando, per ogni domanda, il punteggio appropriato. Sommi il punteggio della valutazione di screening e, se il risultato è uguale o inferiore a 11, completi il questionario per ottenere una valutazione dello stato nutrizionale.

Screening

A Presenta una perdita dell' appetito? Ha mangiato meno
negli ultimi 3 mesi? (perdita d'appetito, problemi digestivi,
difficolta di masticazione o deglutizione)
0 = anoressia grave
1 = anoressia moderata
2 = nessuna anoressia ☐

B Perdita di peso recente (<3 mesi)
0 = perdita di peso > 3 kg
1 = non sa
2 = perdita di peso tra 1 e 3 kg
3 = nessuna perdita di peso ☐

C Motricita
0 = dal letto alla poltrona
1 = autonomo a domicilio
2 = esce di casa ☐

D Nell' arco degli ultimi 3 mesi: malattie acute
o stress psicologici?
0 = sì   2 = no ☐

E Problemi neuropsicologici
0 = demenza o depressione grave
1 = demenza o depressione moderata
2 = nessun problema psicologico ☐

F Indice di massa corporea (IMC = peso / (altezza)² in kg/m²)
0 = IMC <19
1 = 19 ≤ IMC < 21
2 = 21 ≤ IMC < 23
3 = IMC ≥ 23 ☐

Valutazione di screening (totale parziale max. 14 punti) ☐ ☐

12 punti o piu — normale, nessuna necessita
di continuare la valutazione.

11 punti o meno — possibilita di mal nutrizione –
continui la valutazione

Valutazione globale

G Il paziente vive autonomamente a domicilio?
0 = no   1 = sì ☐

H Prende piu di 3 medicinali?
0 = sì   1 = no ☐

I Presenza di decubiti, ulcere cutanee?
0 = sì   1 = no ☐

J Quanti pasti completi (colazione, pranzo, cena,
con piu di 2 piatti) prende al giorno?
0 = 1 pasto
1 = 2 pasti
2 = 3 pasti ☐

K Consuma?
- Almeno una volta al giorno
  dei prodotti lattiero-caseari?   sì ☐   no ☐
- Una o due volte la settimana
  uova o legumi?   sì ☐   no ☐
- Ogni giorno della carne,
  del pesce o del pollame?   sì ☐   no ☐
0.0 = se 0 o 1 sì
0.5 = se 2 sì
1.0 = se 3 sì ☐ . ☐

L Consuma almeno due volte al giorno frutta o verdura?
0 = no   1 = sì ☐

M Quanti bicchieri beve al giorno?
(acqua, succhi, caffe, te, latte, vino, birra...)
0.0 = meno di 3 bicchieri
0.5 = da 3 a 5 bicchieri
1.0 = piu di 5 bicchieri ☐ . ☐

N Come si nutre?
0 = necessita di assistenza
1 = autonomamente con difficolta
2 = autonomamente senza difficolta ☐

O Il paziente si considera ben nutrito? (ha dei problemi nutrizionali)
0 = malnutrizione grave
1 = malnutrizione moderata o non sa
2 = nessun problema nutrizionale ☐

P Il paziente considera il suo stato di salute migliore
o peggiore di altre persone della sua eta?
0.0 = meno buono
0.5 = non sa
1.0 = uguale
2.0 = migliore ☐ . ☐

Q Circonferenza brachiale (CB, cm)
0.0 = CB < 21
0.5 = CB ≤ 21 CB ≤ 22
1.0 = CB > 22 ☐ . ☐

R Circonferenza del polpaccio (CP in cm)
0 = CP < 31   1 = CP ≥ 31 ☐

Valutazione globale (max. 16 punti) ☐ ☐ . ☐

Screening ☐ ☐

Valutazione totale (max. 30 punti) ☐ ☐ . ☐

Ref.: Guigoz Y, Vellas B and Garry P.J. 1994. Mini Nutritional Assessment: A practical assessment tool for grading the nutritional state of elderly patients. *Facts and Research in Gerontology.* Supplement #2:15-59.
Rubenstein LZ, Harker J, Guigoz Y and Vellas B. Comprehensive Geriatric Assessment (CGA) and the MNA: An Overview of CGA, Nutritional Assessment, and Development of a Shortened Version of the MNA. In: "Mini Nutritional Assessment (MNA): Research and Practice in the Elderly". Vellas B, Garry P.J and Guigoz Y, editors. Nestlé Nutrition Workshop Series, Clinical & Performance Programme, vol. 1. Karger, Bâle, in press.

Valutazione dello stato nutrizionale		Score
da 17 a 23,5 punti	rischio di malnutrizione	☐
meno 17 punti	cattivo stato nutrizionale	☐

'Malnutrition Universal Screening Tool' ('MUST')

BAPEN — Advancing Clinical Nutrition

MAG — Malnutrition Advisory Group, A Standing Committee of BAPEN

BAPEN is registered charity number 1023927 www.bapen.org.uk

'MUST'

'MUST' is a five-step screening tool to identify **adults,** who are malnourished, at risk of malnutrition (undernutrition), or obese. It also includes management guidelines which can be used to develop a care plan.

It is for use in hospitals, community and other care settings and can be used by all care workers.

This guide contains:

- A flow chart showing the 5 steps to use for screening and management
- BMI chart
- Weight loss tables
- Alternative measurements when BMI cannot be obtained by measuring weight and height.

The 5 'MUST' Steps

Step 1
Measure height and weight to get a BMI score using chart provided. *If unable to obtain height and weight, use the alternative procedures shown in this guide.*

Step 2
Note percentage unplanned weight loss and score using tables provided.

Step 3
Establish acute disease effect and score.

Step 4
Add scores from steps 1, 2 and 3 together to obtain overall risk of malnutrition.

Step 5
Use management guidelines and/or local policy to develop care plan.

Please refer to *The 'MUST' Explanatory Booklet* for more information when weight and height cannot be measured, and when screening patient groups in which extra care in interpretation is needed (e.g. those with fluid disturbances, plaster casts, amputations, critical illness and pregnant or lactating women). The booklet can also be used for training. See *The 'MUST' Report* for supporting evidence. Please note that 'MUST' has not been designed to detect deficiencies or excessive intakes of vitamins and minerals and is of **use only in adults.**

Step 1 + Step 2 + Step 3

Step 1 — BMI score

BMI kg/m²	Score
>20(>30 Obese)	= 0
18.5-20	= 1
<18.5	= 2

Step 2 — Weight loss score

Unplanned weight loss in past 3-6 months

%	Score
<5	= 0
5-10	= 1
>10	= 2

Step 3 — Acute disease effect score

If patient is acutely ill and there has been or is likely to be no nutritional intake for >5 days
Score 2
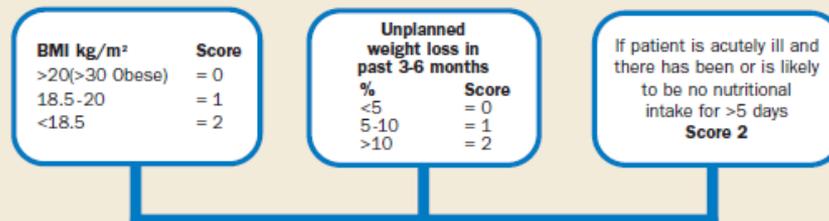
If unable to obtain height and weight, see reverse for alternative measurements and use of subjective criteria

Step 4

Overall risk of malnutrition

Add Scores together to calculate overall risk of malnutrition
Score 0 Low Risk   Score 1 Medium Risk   Score 2 or more High Risk

Step 5

Management guidelines

0 Low Risk
Routine clinical care

- Repeat screening
  Hospital – weekly
  Care Homes – monthly
  Community – annually
  for special groups
  e.g. those >75 yrs

1 Medium Risk
Observe

- Document dietary intake for 3 days if subject in hospital or care home
- If improved or adequate intake – little clinical concern; if no improvement – clinical concern - follow local policy
- Repeat screening
  Hospital – weekly
  Care Home – at least monthly
  Community – at least every 2-3 months

2 or more High Risk
Treat*

- Refer to dietitian, Nutritional Support Team or implement local policy
- Improve and increase overall nutritional intake
- Monitor and review care plan
  Hospital – weekly
  Care Home – monthly
  Community – monthly

* Unless detrimental or no benefit is expected from nutritional support e.g. imminent death.

All risk categories:
- Treat underlying condition and provide help and advice on food choices, eating and drinking when necessary.
- Record malnutrition risk category.
- Record need for special diets and follow local policy.

Obesity:
- Record presence of obesity. For those with underlying conditions, these are generally controlled before the treatment of obesity.

Geriatric Nutritional Risk Index: a new index for evaluating at-risk elderly medical patients[1,2,3]

Olivier Bouillanne, Gilles Morineau, Claire Dupont, Isabelle Coulombel, Jean-Pierre Vincent, Ioannis Nicolis, Simone Benazeth, Luc Cynober and Christian Aussel

Background:Patients at risk of malnutrition and related morbidity and mortality can be identified with the Nutritional Risk Index (NRI). However, this index remains limited for elderly patients because of difficulties in establishing their normal weight.

Objective:Therefore, we replaced the usual weight in this formula by ideal weight according to the Lorentz formula (WLo), creating a new index called the Geriatric Nutritional Risk Index (GNRI).

Design:First, a prospective study enrolled 181 hospitalized elderly patients. Nutritional status [albumin, prealbumin, and body mass index (BMI)] and GNRI were assessed. GNRI correlated with a severity score taking into account complications (bedsores or infections) and 6-mo mortality. Second, the GNRI was measured prospectively in 2474 patients admitted to a geriatric rehabilitation care unit over a 3-y period.

Results:The severity score correlated with albumin and GNRI but not with BMI or weight:WLo. Risk of mortality (odds ratio) and risk of complications were, respectively, 29 (95% CI: 5.2, 161.4) and 4.4 (95% CI: 1.3, 14.9) for major nutrition-related risk (GNRI: <82), 6.6 (95% CI: 1.3, 33.0), 4.9 (95% CI: 1.9, 12.5) for moderate nutrition-related risk (GNRI: 82 to <92), and 5.6 (95% CI: 1.2, 26.6) and 3.3 (95% CI: 1.4, 8.0) for a low nutrition-related risk (GNRI: 92 to 98). Accordingly, 12.2%, 31.4%, 29.4%, and 27.0% of the 2474 patients had major, moderate, low, and no nutrition-related risk, respectively.

Conclusion:GNRI is a simple and accurate tool for predicting the risk of morbidity and mortality in hospitalized elderly patients and should be recorded systematically on admission.

Disfagia

Segni e sintomi di allarme	ASA/OSS, IP
Valutazione clinica	Medico, IP
Test deglutizione	FKT
Osservazione, monitoraggio clinico	Medico, IP, FKT, OSS, ASA
Supervisione e avvio imboccamento	FKT
Assistenza al pasto	OSS, ASA
Dieta per disfagici	Nutrizionista, dietista, cucina
Decisioni avanzate (NE, TPN)	Medico, rappresentante legale, persona, familiari

Dysphagia Outcome and Severity Scale (DOSS)

Nutrizione orale: dieta normale

Livello 7: **Nutrizione orale normale. Livello di indipendenza normale**
Dieta normale. Non necessita di alcun intervento riabilitativo e non c'è incremento del tempo dedicato al pasto

Livello 6: **Minime alterazioni della deglutizione; indipendenza con funzionalità limitata**
Dieta normale; deglutizione funzionale. Il tempo dedicato al pasto può allungarsi. Il paziente può avere un lieve ritardo nella fase orale e faringea della deglutizione o un lieve ristagno ma compensati spontaneamente.

O'Neil KH, Purdy M, Falk J, Gallo L. The dysphagia outcome and severity scale. Dysphagia 14:139-145, 1999

Dysphagia Outcome and Severity Scale (DOSS)

Nutrizione orale: dieta modificata – livello di indipendenza modificato in maniera consistente

Livello 5: **Disfagia lieve. Supervisione a distanza.**
Può essere necessaria una dieta a consistenza ristretta. Lieve disfagia orale con masticazione ridotta o ritenzione orale che viene, pero', eliminata spontaneamente

Livello 4: **Disfagia lieve – moderata. Supervisione/indicazioni con minimo contatto**
Necessità di evitare una o due consistenza dei cibi. Ritenzione nella cavità orale che può essere eliminata su indicazioni

Livello 3: **Disfagia moderata. Assistenza totale e/o supervisione.**
Necessità di evitare uno o due tipi di consistenze. Moderata ritenzione nella cavità orale che può essere eliminata su indicazione

O'Neil KH, Purdy M, Falk J, Gallo L. The dysphagia outcome and severity scale. Dysphagia 14:139-145, 1999

Dysphagia Outcome and Severity Scale (DOSS)

Necessaria la nutrizione non orale

Livello 2: **Disfagia moderata-severa. Assistenza massima.**
E' possibile solamente una nutrizione orale parziale (può essere tollerata solamente una consistenza con utilizzo di posture di compenso o altre tecniche di deglutizione)

Livello 1: **Disfagia severa. Non si può impiegare alcuna nutrizione orale in maniera sicura**

O'Neil KH, Purdy M, Falk J, Gallo L. The dysphagia outcome and severity scale. Dysphagia 14:139-145, 1999

Lesioni da pressione

- **Igiene e cura della cute**
- **Nutrizione, idratazione**
- **Osservazione e valutazione standardizzata**
- **Norton, Norton Plus, Braden**
- **Organizzazione del letto, scelta e monitoraggio dei presidi**
- **Programmi di posture e mobilizzazione**
- **Medicazioni personalizzate e registrazione dei risultati**

Lesioni da pressione

Screening iniziale, valutazione periodica	Medico, IP
Valutazione della lesione, iniziale e periodica	Medico, IP
Scelta presidi	Medico, FKT
Organizzazione del letto	FKT, OSS coordinatore
Progettazione posture	FKT
Igiene della cute, tutela della cute	OSS, ASA, IP
Medicazioni, monitoraggio lesione	IP
Registri clinici, schede dedicate, test	IP

Agency of Health Care and Policy Research (AHCPR)

Pressure Ulcers in Adults:

Prediction and Prevention

Clinical Practice Guideline Number 3

AHCPR Pub. No. 92-0047: May 1992

Treatment of Pressure Ulcers

Clinical Guideline Number 15 *AHCPR Publication No. 95-0652: December 1994*

Dolore

- **Monitoraggio attivo, rilevazione tempestiva**
- **Scale standardizzate di rilevazione (VAS)**
- **Osservazione del comportamento e dei segnali di distress nel paziente con demenza(PAINAID, DS/DAT)**
- **Trattamento esperto (paracetamolo, codeina, morfina; via orale, via sottocutanea, via transdermica)**
- **Adeguamento piano di assistenza**

Pain Assessment for Older Adults

By: Ellen Flaherty, PhD, APRN, BC, Village Care of New York

WHY: Studies on pain in older adults (persons 65 years of age and older) have demonstrated that 25%-50% of community dwelling older people have persistent pain. Additionally, 45-80% of nursing home residents report pain that is often left untreated. Pain is strongly associated with depression and can result in decreased socialization, impaired ambulation and increased healthcare utilization and costs. Older adults tend to minimize or not report their pain or are unable to due to sensory and or cognitive impairments. A significant barrier in treating pain in older adults is inadequate pain assessment. Therefore, a proactive, consistent approach must be taken to screen and assess older adults for persistent pain.

BEST TOOL: Patients' self report is the most reliable measure of pain intensity as there are no biological markers of pain. Simply worded questions and tools, which can be easily understood, are the most effective, as older adults frequently encounter numerous factors, including sensory deficits and cognitive impairments. The most widely used pain intensity scales used with older adults are the Numeric Rating Scale (NRS), the Verbal Descriptor Scale (VDS) and the Faces Pain Scale-Revised (FPS-R). The most popular tool, the NRS, asks a patient to rate their pain by assigning a numerical value with zero indicating no pain and 10 representing the worst pain imaginable. The VDS asks the patient to describe their pain from "no pain" to "pain as bad as it could be." The FPS-R asks patients to describe their pain according to a facial expression that corresponds with their pain.

TARGET POPULATION: All three scales are used with both community and older adults in acute and long term care settings. While there are specific tools designed to capture pain in non-verbal cognitively impaired older adults, studies have shown that these tools can be used with cognitively impaired older adults. The choice of a scale may depend on the presence of a particular language or sensory impairment. The same scale should be used consistently with each individual patient.

VALIDITY AND RELIABILITY: Among these three scales, several studies have demonstrated concurrent validity between 0.56 and 0.90 with the lowest correlations found between the FPS-R and the other scales, suggesting that the FPS-R may be measuring a broader construct incorporating pain. Test-retest reliability was demonstrated with coefficients ranging from 0.75-0.89.

STRENGTHS AND LIMITATIONS: Overall, the NRS was the preferred scale with cognitively intact older adults and the FPS-R was the preferred scale with cognitively impaired patients. In addition, when considering race, African-Americans and Hispanics preferred the FPS-R. The FPS-R was also the scale that was preferred with mildly, moderately and severely impaired older adults. These brief assessment tools should not replace performing a comprehensive health history and physical exam, which may lead to the determination of etiologies of pain.

MORE ON THE TOPIC:
Best practice information on care of older adults: www.GeroNurseOnline.org.
American Geriatrics Society Panel on Persistent Pain in Older Persons. (2002). Clinical practice guidelines:
    The management of persistent pain in older persons. *JAGS, 50*, S205-S224. Available at
    http://www.americangeriatrics.org/products/positionpapers/persistent_pain_guide.shtml, from the American Geriatrics Society Web site,
    www.americangeriatrics.org.
Herr, K., Bjoro, K., & Decker, S. (2006). Tools for assessment of pain in nonverbal older adults with dementia:
    A state-of-the-science review. *Journal of Pain and Symptom Management, 31*(2), 170-192.
Herr, K., Spratt, K., Mobily, P., & Richardson, G. (2004). Pain intensity assessment in older adults: Use of Experimental Pain to Compare Psychometric
    Properties and Usability of Selected Scales in Adult and Older Populations. *Clinical Journal of Pain, 20*(4), 207-219.
Taylor, L., & Herr, K. (2003). Pain intensity assessment: A comparison of selected pain intensity scales for use in cognitively intact and cognitively impaired
    African American older adults. *Pain Management Nursing, 4*(2), 87-95.
Taylor, L.J., Harris, J., Epps, C., & Herr, K. (2005). Psychometric evaluation of selected pain intensity scales for use
    in cognitively impaired and cognitively intact older adults. *Rehabilitation Nursing, 30*(2), 55-61.
Ware, J. Epps, C., Herr, K., & Packard, A. (2006). Evaluation of the revised faces pain scale, verbal descriptor
    scale, numeric rating scale, and Iowa pain thermometer in older minority adults. *Pain Management Nursing, 7*(3), 117-125.

FACES PAIN SCALE – REVISED

Numbers are not shown to the patient

0   2   4   6   8   10
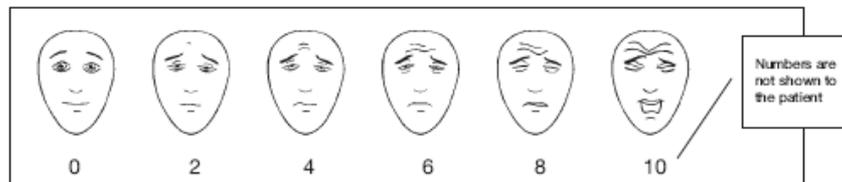
From PAIN, 2001, 93, 173-183 "The Faces Pain Scale – Revised. Toward a Common Metric in Pediatric Pain Measurement," by C.L. Hicks, C.L. von Baeyer, P.A. Spafford, I. van Korlaar, & B. Goodenough,. Reprinted with permission of the International Association for the Study of Pain®.

Note: This is a smaller sample of the actual scale. For further instructions on the correct use of the scale in order to get valid responses, please go to www.painsourcebook.ca

NUMERIC RATING SCALE

0   1   2   3   4   5   6   7   8   9   10
No Pain   Moderate Pain   Worst Possible Pain
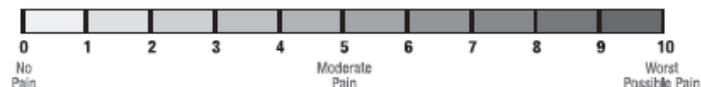
Please rate your pain from 0 to 10 with 0 indicating no pain and 10 representing the worst possible pain. _____

Adapted from Jacox, A., Carr, D.B., Payne, R., et al. (March 1994). Management of Cancer Pain. Clinical Practice Guideline No. 9. AHCPR Publication No. 94-0592. Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services.

VERBAL DESCRIPTOR SCALE

Please describe your pain from "no pain" to "mild", "moderate", "severe", or "pain as bad as it could be."

_____

_____

Adapted from Jacox, A., Carr, D.B., Payne, R., et al. (March 1994). Management of Cancer Pain. Clinical Practice Guideline No. 9. AHCPR Publication No. 94-0592. Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services.

> **try this:** Best Practices in Nursing Care to Older Adults

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alzheimer's association
Best Practices in Nursing Care
for Hospitalized Older Adults
with dementia
from The John A. Hartford Institute for Geriatric Nursing
and the Alzheimer's Association

Issue Number D2, Revised 2007

Series Editor: Marie Boltz, MSN, APRN, BC, GNP
Managing Editor: Sherry A. Greenberg, MSN, APRN, BC, GNP
New York University College of Nursing

Assessing Pain in Older Adults with Dementia
By: Ann L. Horgas, RN, PhD, FGSA, FAAN, University of Florida College of Nursing

WHY: There is no evidence that older adults with dementia physiologically experience less pain than do other older adults (American Geriatrics Society (AGS), 2002). Rather than being less sensitive to pain, cognitively-impaired elders may fail to interpret sensations as painful, are often less able to recall their pain, and may not be able to verbally communicate it to care providers (AGS, 2002). As such, cognitively impaired older adults are often under-treated for pain.

As with all older adults, those with dementia are at risk for multiple sources and types of pain, including chronic pain from conditions such as osteoarthritis and acute pain. Untreated pain in cognitively impaired older adults can delay healing, disturb sleep and activity patterns, reduce function, reduce quality of life, and prolong hospitalization.

BEST TOOLS:
Several tools are available to measure pain in older adults with dementia. Few have been comprehensively evaluated and each has strengths and limitations (Herr, Decker, & Bjoro, 2006). The American Medical Directors Association has endorsed the Pain Assessment in Advanced Dementia Scale (PAINAD) (Warden, et al, 2003).

We recommend the following:
- Ask older adults with dementia about their pain. Even older adults with mild to moderate dementia can respond to simple questions about their pain (American Geriatrics Society, 2002).
- Use a standardized tool to assess pain intensity, such as the numerical rating scale (NRS) (0-10) or a verbal descriptor scale (VDS) (Herr, 2002; See also Try This: Pain Assessment). The VDS asks participants to select a word that best describes their present pain (e.g., no pain to worst pain imaginable) and may be more reliable than the NRS in older adults with dementia.
- Use an observational tool (e.g., PAINAD) to measure the presence of pain in older adults with dementia.
- Ask family or usual caregivers as to whether the patient's current behavior (e.g., crying out, restlessness) is different from their customary behavior. This change in behavior may signal pain.
- If pain is suspected, consider a time-limited trial of an appropriate type and dose of an analgesic agent. Thoroughly investigate behavior changes to rule out other causes. Use the PAINAD to evaluate the pain before and after administering the analgesic.

TARGET POPULATION: Older adults with cognitive impairment who cannot be assessed for pain using standardized pain assessment instruments. Pain assessment in older adults with cognitive impairment is essential for both planned or emergent hospitalization.

VALIDITY AND RELIABILITY: The PAINAD has an internal consistency reliability ranging from .50 (for behavior assessed at rest) to .67 (for behaviors assessed during unpleasant caregiving activities). Interrater reliability is high (r - .82 - .97). No test-retest reliability is available.

STRENGTHS AND LIMITATIONS: Pain is a subjective experience and there are no definitive, universal tests for pain. For patients with dementia, it is particularly important to know the patient and to consult with family and usual caregivers.

BARRIERS to PAIN MANAGEMENT in OLDER ADULTS with DEMENTIA: There are many barriers to effective pain management in this population. Some common myths are: pain is a normal part of aging; if a person doesn't verbalize that they have pain, they must not be experiencing it; and that strong analgesics (e.g., opioids) must be avoided.

An effective approach to pain management in older adults with dementia is to assume that they do have pain if they have conditions and/or medical procedures that are typically associated with pain. Take a proactive approach in pain assessment and management.

MORE ON THE TOPIC:
Best practice information on care of older adults: www.GeroNurseOnline.org.
American Geriatrics Society Panel on Persistent Pain in Older Persons. (2002). Clinical practice guidelines: The management of persistent pain in older persons. *JAGS, 50,* S205-S224. Available at http://www.americangeriatrics.org/products/positionpapers/persistent_pain_guide.shtml, from the American Geriatrics Society Web site, www.americangeriatrics.org.
Herr, K. (2002). Pain assessment in cognitively impaired older adults. *AJN, 102*(12), 65-68.
Herr, K., Bjoro, K., & Decker, S. (2006). Tools for assessment of pain in nonverbal older adults with dementia: A state-of-the-science review. *Journal of Pain and Symptom Management, 31*(2), 170-192.
Warden, V., Hurley, A.C., & Volicer, L. (2003). Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) Scale. *Journal of the American Medical Directors Association, 4*(1), 9-15.

Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
			Total**	

* Five-item observational tool (see the description of each item below).
** Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

BREATHING
1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional labored breathing is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. Noisy labored breathing is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, or wheezing. They appear strenuous or wearing.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

NEGATIVE VOCALIZATION
1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.

5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

FACIAL EXPRESSION
1. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. Frightened is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
4. Frown is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. Facial grimacing is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

BODY LANGUAGE
1. Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. Tense is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched (exclude any contractures).
3. Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.

4. Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.
5. Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (exclude any contractures).
6. Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).
8. Pulling or pushing away is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.
9. Striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

CONSOLABILITY
1. No need to console is characterized by a sense of well being. The person appears content.
2. Distracted or reassured by voice or touch is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.
3. Unable to console, distract or reassure is characterized by the inability to sooth the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

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Pain Assessment IN Advanced Dementia PAINAD

	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations	
Negative Vocalization	None	Occasional moan or groan. Low level speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body Language	Relaxed	Tense. Distressed pacing. Fidgeting	Rigid. Fists clenched, Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
				TOTAL

Warden, Hurley, Volicer, JAMDA 2003; 4(1): 9-15

The Disconfort Scale- Dementia of the Alzheimer's Type (DS-DAT)

(Hurley AC, Research in Nursing & Health, 1992, 15, 369-377)

Indicatori comportamentali	Frequenza* N episodi 0, 1, 2, 3, >3	Intensità** Bassa/Alta	Durata Breve se <1minuto Lunga se >1minuto
Respiro rumoroso: rumori "anormali" all'inspirazione o espirazione; la respirazione sembra sforzata, faticosa, logorante; i rumori respiratori sono alti, aspri, il paziente ansima; la respirazione è difficile o il paziente fatica a mantenere un buon scambio gassoso; episodici accessi di respiro veloce.			
Vocalizzazione negative: suoni o verbalizzazioni con intonazione negativa, toni bassi sottovoce, come un costante borbottio con tono gutturale, suoni dal tono monotono, grave o acuto con un aspetto decisamente spiacevole; eloquio più veloce di una normale conversazione o emesso sotto forma di lamento o mormorio; ripete la stessa parola con tono molto triste; esprime sofferenza, dolore.			
Mancanza di espressione di appagamento: <u>Assenza</u> dei seguenti indicatori: faccia calma che esprime benessere, tranquilla, a suo agio, serena; espressione del viso rilassata, con la mandibola rilassata; aspetto generale di chi è in pace.			
Espressione del viso triste: il viso ha un'espressione preoccupata, come di chi è offeso, preoccupato, smarrito o si sente solo; aspetto sofferente di chi è "a terra", da "cane bastonato" con occhi spenti; piange, grida.			
Espressione del viso impaurita: il viso esprime paura, ansia; sembra annoiato, impaurito, preoccupato; aspetto allarmato, con gli occhi aperti e l'espressione implorante.			
Aggrottamento: l'espressione è tesa, arcigna, imbronciata, seccata; con le sopracciglia corrugate e la fronte aggrottata; angoli della bocca girati all'ingiù.			
Mancanza di linguaggio del corpo rilassato. <u>Assenza</u> delle seguenti: posizione rilassata, mani aperte; sembra in una posizione comoda e può essere rannicchiato o disteso; muscolatura con tono normale e articolazioni morbide; dà l'impressione di ozio, pigrizia, o di estremo relax; sembra che stia ammazzando il tempo, indifferente.			
Linguaggio del corpo teso: le estremità rivelano tensione; mani contratte, pugni serrati, o ginocchia fortemente spinte in su; posizione rigida e tesa.			
Affaccendamento: movimenti inquieti e senza sosta; gesti frenetici o contorcimenti; dà l'impressione di cercare di liberarsi da qualcosa che gli fa male; tocca con forza, sfrega o strattona parti del corpo.			

Demenza

- **MMSE**
- **Clock drawing test**
- **FAST**
- **PAINAD, DS DAT**
- **Approccio protesico (Gentle Care)**

Aree cruciali

- Diagnosi iniziale (sottostimata)
- Comprensione della sindrome: malattia evolutiva, inguaribile, a prognosi infausta
- Comunicazione (direttive anticipate)
- Stadiazione e previsione prognostica
  - Stadiazione (Fast)
  - Decorso clinico (chi decide, cosa offrire)
- Relazione dinamica fra approccio terapeutico e riabilitativo e medicina palliativa
- Corretta identificazione, interpretazione e gestione dei sintomi e dei comportamenti

FAST – Functional Assessment Staging of Alzheimer's Disease
(Reisberg B. Functional Assessmente Staging. Psychopharmacology Bullettin, 1998. 24:653)

| Stadio	Abilità – Funzione
1	Nessuna difficoltà, sia soggettiva che oggettiva
2	Lamenta di dimenticare dove ha riposto oggetti. Percepisce difficoltà soggettive nel trovare le parole
3	Colleghi e collaboratori evidenziano la riduzione delle capacità di lavoro. Difficoltà nel raggiungere nuove località. Riduzione delle capacità di organizzazione *(NB: le informazioni vanno raccolte da un caregiver o conoscente)*
4	Riduzione della capacità di eseguire compiti complessi (come organizzare un pranzo con ospiti), di gestire le proprie finanze (si dimentica di pagare cambiali o bollette) e di fare acquisti
5	Richiede assistenza nella scelta degli abiti adatti al giorno, alla stagione, all'occasione
6 a	•difficoltà a indossare gli abiti correttamente senza assistenza
6 b	•non riesce a fare il bagno correttamente (es.: non riesce ad adattare la temperatura dell'acqua), occasionalmente o più frequentemente nelle ultime settimane
6 c	•non riesce a gestire i dispositivi del bagno (es. dimentica di far scorrere l'acqua del water, non pulisce adeguatamente, non dispone correttamente salviette e asciugamani), occasionalmente o più frequentemente nelle ultime settimane
6 d	•incontinenza urinaria, occasionale o più frequente
6 e	•incontinenza fecale (occasionalmente o più frequentemente nelle ultime settimane)
7 a	Capacità di esprimersi limitata a non più di una mezza dozzina di parole durante una giornata media o durante una intervista intensiva
7 b	•capacità di esprimersi limitata all'uso di una singola parola comprensibile durante una giornata media o durante una intervista intensiva (la persona ripete continuamente la stessa parola)
7 c	•perdita della capacità di camminare (non può camminare senza assistenza)
7 d	•perdita della capacità di restare seduto senza assistenza (ad esempio, la persona cade dalla sedia in assenza di supporti laterali)
7 e	•perdita della capacità di sorridere
7 f	•perdita della capacità di sostenere la testa autonomamente

Clock drawing test
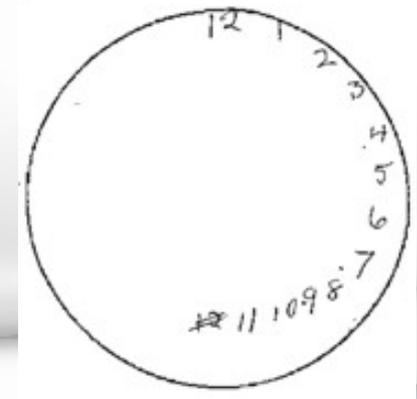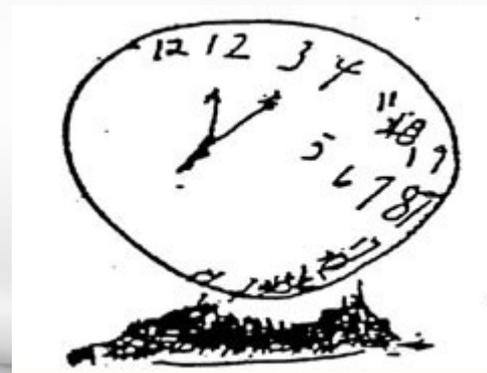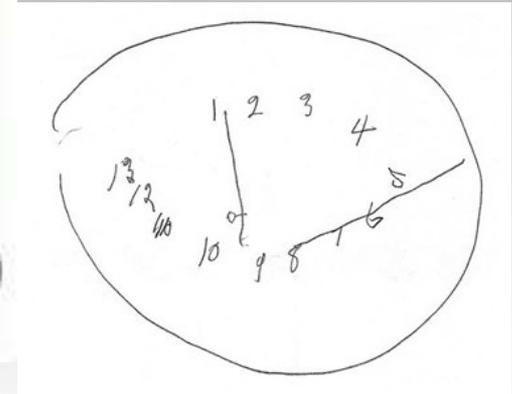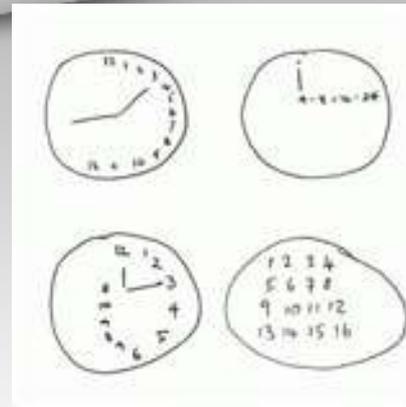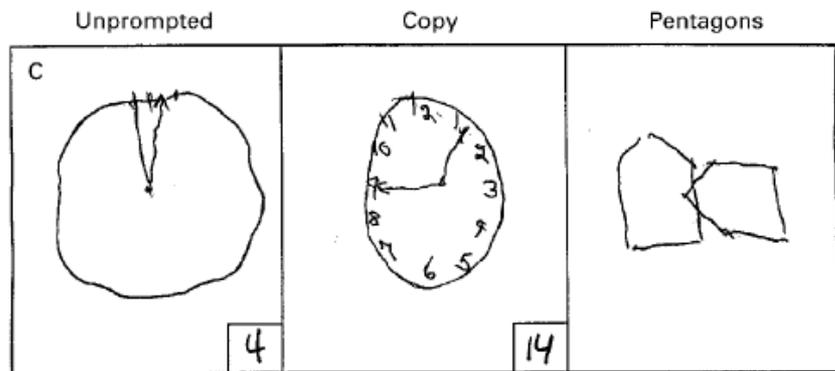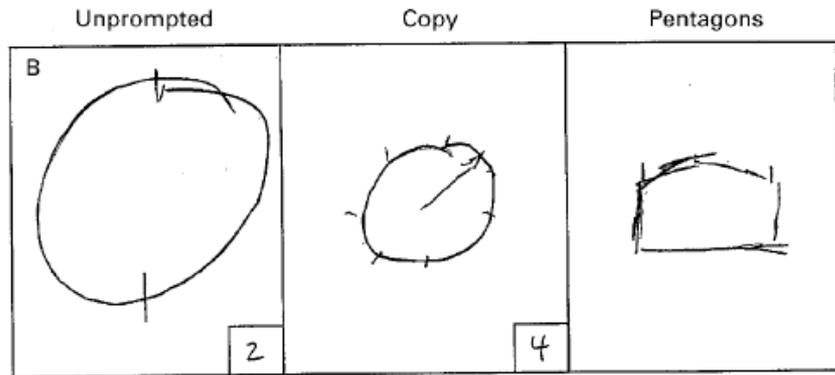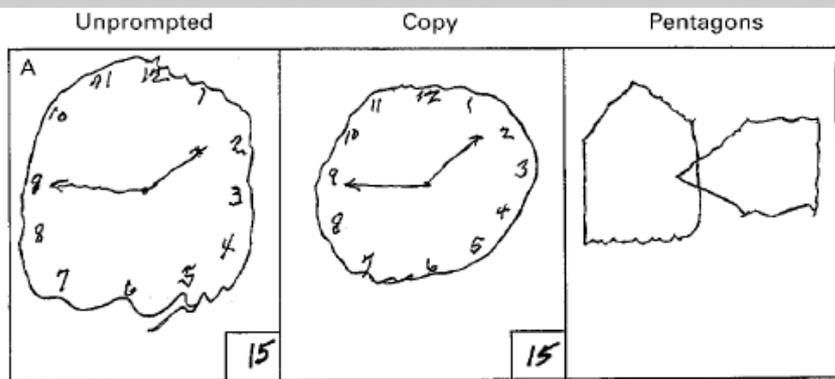
Figure 1   Qualitative differences in CLOX performance. in a normal elderly control, a patient with Alzheimer's disease, and a patient with non-cortical vascular disease. (A) An 82 year old elderly control. EXIT25=08/50 (scores>5/50 impaired), MMSE=29/30 (scores<24/30 impaired). (B) A 74 year old married white woman with Alzheimer's disease. EXIT25=21/50(24/50 comparable with six year old children or residents requiring skilled nursing), MMSE=12/30. (C) A 74 year old right handed white man with a history of coronary artery disease (status post myocardial infarction), hypertension, non-insulin dependent diabetes mellitus, and falls. EXIT22=24/50, MMSE=28/30.

Le cure di fine vita

Fasi avanzate, fine vita

- **Gold Standards Framework (GSF)**
- **Liverpool Care Pathway**
- **Indicatori prognostici: gli ultimi 6-12 mesi (GSF)**
- **Indicatori prognostici: gli ultimi 30 giorni (PapScore)**
- **Indicatori prognostici: le ultime 72 ore (LCP)**
- **Adeguamento dei piani di assistenza**
- **Condivisione delle scelte di cura**
- **Direttive anticipate, consenso alle cure**

V25

the gold standards framework
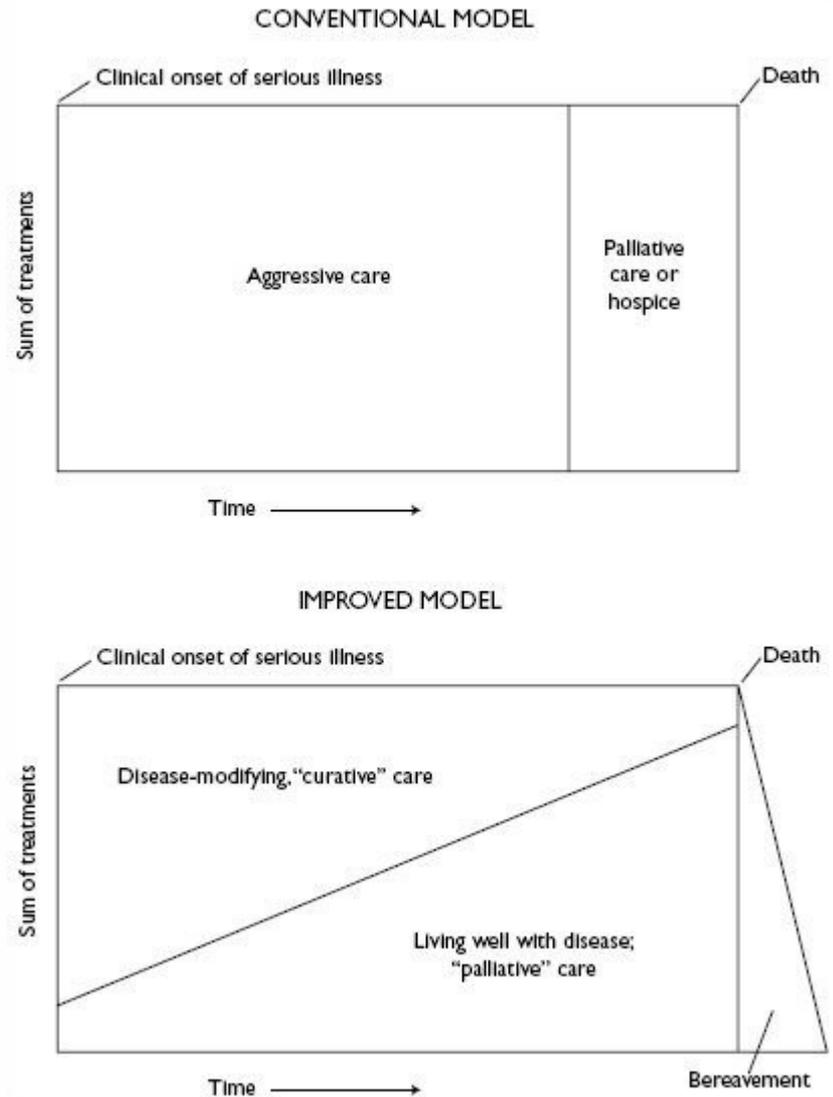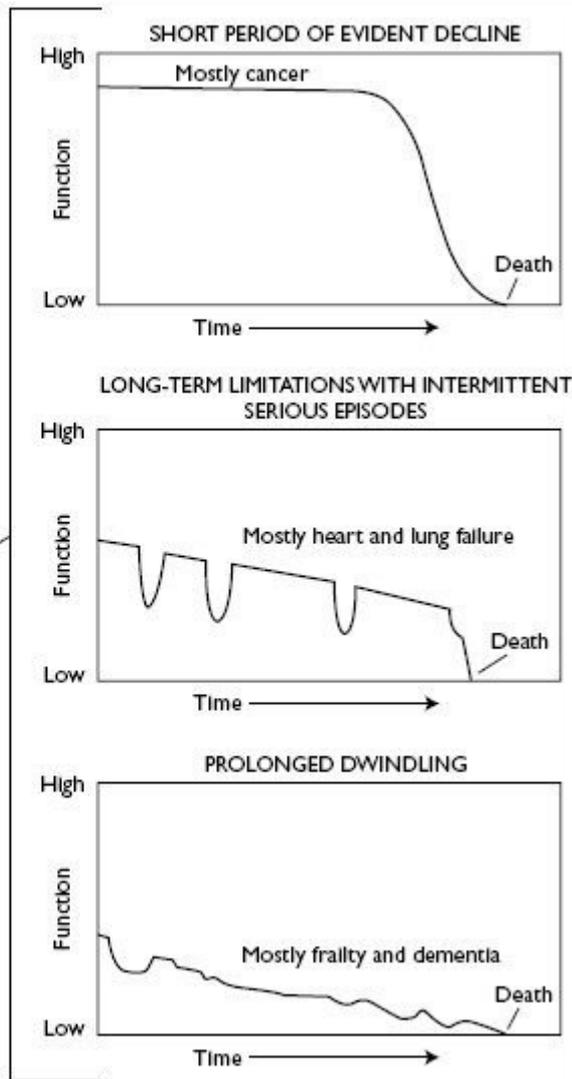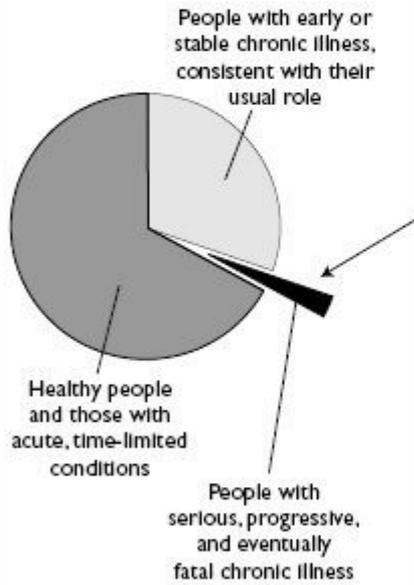
Full Guidance on Using QOF to Improve Palliative / End of Life Care in Primary Care

Guidelines for practices on the revised Quality Outcome Framework (QOF) points for Palliative Care and the Gold Standard Framework (GSF)

This Guidance may be of particular use to practice managers, enabling their practices to institute changes to claim QOF points in the GMS contract for April 06.

Drs Amanda Free, Keri Thomas, Wendy-Jane Walton and Teresa Griffin of The Gold Standards Framework National Central Team

NHS

End of Life Care Programme

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the gold standards framework

Prognostic Indicator Guidance
to aid identification of adult patients with advanced disease , in the last months/ year of life, who are in need of supportive and palliative care
Version 2.25   July 06

Introduction and use of prognostic indicators

About 1% of the population die each year, yet it is intrinsically difficult to predict or identify which patients may be in their last year of life. If we could better identify these patients, we would be more able to provide better end of life care for them. We know we are currently under-estimating numbers, especially for those with non-cancer end stage illnesses. Consequently, we are not always providing the best care, based on patient need and likely illness trajectory, or mobilising appropriate palliative/supportive care services that would benefit patients and their families as they near the end of their lives. The aim of this document is to enable better *identification* of patients nearing the end of their lives i.e. in the last 6-12 months of life, to trigger better *assessment* and *planning* and provision of care related to their needs. Although inherently difficult to accurately predict and only an approximate guidance, we know that some attempt to improve this prediction will lead to better patient care. We suggest three triggers:-.

Three triggers for Supportive/ Palliative Care - to identify these patients we can use any of the following methods:

1. **The surprise question,** "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.

2. **Choice/ Need** - The patient with advanced disease makes a **choice** for comfort care only, not 'curative' treatment, or is in special **need** of supportive / palliative care.

3. **Clinical indicators** - Specific indicators of advanced disease for each of the three main end of life patient groups- cancer, organ failure, elderly frail/ dementia (see over)

In broad terms, approximately a third of all deaths are from patients with organ failure, e.g. heart failure, COPD, and about a third are patients with generalised frailty and dementia, a quarter are cancer patients, and a twelfth sudden unpredicted deaths. All patients nearing the end of their lives may benefit from supportive and palliative care, and should be enabled to access care appropriate to their needs. However, many still not do so and there can be a disparity between levels of care provision according to different diagnoses, which we are attempting to redress.

GP's workload - Average 20 deaths/GP/yr (approximate proportions)

Typical Case Histories

1) Mrs A - A 54 year old woman with cancer of colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired

2) Mr B - A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home has had 2 hospital admissions in the last year and is worried about the prospect of any more emergencies and coping in the future

3) Mrs C - An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'

NHS – End of life care programme, 2006

"…extend the boundaries of palliative care provision … for all patients regardless of diagnosis … enabling more patients to live and die in their place of choice…"

GSF – 3 Processi

1. ***Identify*** patients in need of palliative/supportive care towards the end of life
2. ***Assess*** their needs, symptoms, preferences and any issues important to them
3. ***Plan*** care around patient's needs and preferences and enable these to be fulfilled, in particular allow patients to live and die where they choose.

http://www.goldstandardsframework.nhs.uk/gsf_in_practice.php
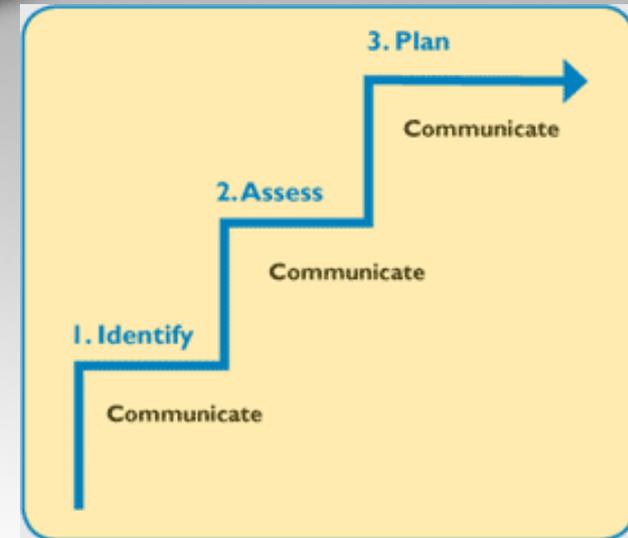
GSF - Prognostic indicator guidance

Introduction and use of prognostic indicators

About 1% of the population die each year, yet it is intrinsically difficult to predict or identify which patients may be in their last year of life. If we could better identify these patients, we would be more able to provide better end of life care for them. We know we are currently under-estimating numbers, especially for those with non-cancer end stage illnesses. Consequently, we are not always providing the best care, based on patient need and likely illness trajectory, or mobilising appropriate palliative/supportive care services that would benefit patients and their families as they near the end of their lives. The aim of this document is to enable better *identification* of patients nearing the end of their lives i.e. in the last 6-12 months of life, to trigger better *assessment* and *planning* and provision of care related to their needs. Although inherently difficult to accurately predict and only an approximate guidance, we know that some attempt to improve this prediction will lead to better patient care. We suggest three triggers:-.

Three triggers for Supportive/ Palliative Care - to identify these patients we can use any of the following methods:

1. **The surprise question**, "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.

2. **Choice/ Need** - The patient with advanced disease makes a **choice** for comfort care only, not 'curative' treatment, or is in special **need** of supportive / palliative care.

3. **Clinical indicators** - Specific indicators of advanced disease for each of the three main end of life patient groups- cancer, organ failure, elderly frail/ dementia (see over)

GSF – 5 obiettivi per garantire cure di alta qualità negli ultimi mesi di vita

1. Patients are as *symptom controlled* as possible
2. *Place of care* – patients are enabled to live well and die well in their preferred place of choice
3. *Security and support* – better advanced care planning, information, less fear, fewer crisis/admissions to hospital
4. *Carers* are supported, informed, enabled and empowered
5. *Staff* confidence, communication and co-working are improved

http://www.goldstandardsframework.nhs.uk/gsf_in_practice.php

GSF – 7 Azioni

C1 - Communication

C2 - Co-ordination

C3 - Control of symptoms

C4 - Continuity including out of hours

C5 - Continued learning

C6 - Carer support

C7 - Care in the dying phase

http://www.goldstandardsframework.nhs.uk/gsf_in_practice.php

GSF – Stadi di implementazione

Level 1   - C 1,2   **First Gear**

Set up SC Register, Primary Care Team Meeting and Coordinator

Level 2   - C 3, 4, 5   **Second gear**

Assessment Tools, Out of Hours Handover, Education Audit and Reflective Practice

Level 3   - C 6, 7   **Third gear**

Carer/family support, bereavement plan and care in the final days

Level 4   - Sustain embed extend   **Fourth gear**

Sustain and build on all developments as standard practice
Embed – develop a practice protocol, PCT LES etc
Extend to other settings e.g. care homes, non cancer, Advanced Care Planning,
pathway for the last days (LCP) and other areas
Then cruise on in fifth gear !

http://www.goldstandardsframework.nhs.uk/gsf_in_practice.php

For primary care teams, this is the first step towards developing a Supportive/ Palliative Care Register, now part of QOF palliative care points in the GMS contract. For more details of suggestions for claiming the QOF points, templates etc see the www.goldstandardsframework.nhs.uk/gp_contract.php. For those using the Gold Standards Framework (GSF), this might trigger inclusion of more non-cancer patients in the current Supportive Care Register. Of course, not all of these tests are performed in primary care, but GPs/DNs collate information from hospitals and, together with their own holistic assessment, form an overall view of a patient's likely prognosis. **N.B:** It can be much harder to predict whether patients in the third category of frail elderly patients are nearing end of their lives, as they are intrinsically more complex and vulnerable, with a more chronic variable illness trajectory. We do not suggest necessarily that all patients in this third category are included on the GSF Supportive Care Register, unless they fulfil the other criteria of need or predicted decline, but they may be considered in other contexts. But we are suggesting that more organ failure patients be included i.e. with Heart Failure and COPD, to the expected prevalence prediction.

For hospital teams, in addition to accessing supportive/palliative care services and consideration of supportive measures, it would also be helpful to notify the GP/Primary care team that this patient has advanced disease and could be included on their Supportive/Palliative Care Register.

For specialist palliative care/ hospice teams - Although traditionally focussed mainly on cancer patients, specialist palliative care now extends to patients with non-cancer illnesses. There is greater collaboration with other teams e.g. heart failure nurses, to provide best patient care, and these indicators may help clarify referrals.

For PCTs /Commissioners/managers etc - This could be used as part of an End of Life care strategic plan for the area, with improved provision of services for all patients nearing the end of life. **N.B. Long Term Conditions.** There is a strong overlap with care for patients with Long Term Conditions and prediction of unplanned admissions to hospital and that of patients with advanced disease in the last year of life. This is especially true for patients with heart failure or COPD. Close collaboration with Case Managers to support good end of life care is very important.

For Care Homes - Use of some broad prognostic indicators has been found to help identify patients most in need in some care homes, and help focus care and trigger key actions (see below and GSF Care Homes on website)

Examples of prognostic indicators used as part of patient needs assessment

Patients have differing requirements at varying stages of their illness. Some GP practices categorise their patients on the Supportive Care Register according to estimated prognosis and need, and colour code them accordingly. Care Homes using the GSF for Care Homes Programmes have also found the intuitive grouping of their residents to be very helpful. Although only a rough guide, this helps teams' awareness of patients' varying needs, focuses care to ensure that the right care is directed at the right time, ensures regular review, and triggers key actions at each stage. A needs/support plan is therefore developed. Suggested prognostic banding could be:

A - 'All' Blue Years prognosis	B - 'Benefits' Eligible eg DS1500 Green Months prognosis	C - 'Continuing Care' -Yellow Weeks prognosis	D - 'Days'- Red Days prognosis

The use of means of estimating approximate prognosis and need i.e. the intuitive ' surprise' question, needs/choice based care, and these clinical indicators, may help to ensure that patients with advanced illness receive higher quality proactive care and support as they near the end of their lives.

Clinical review

Illness trajectories and palliative care

Scott A Murray, Marilyn Kendall, Kirsty Boyd, Aziz Sheikh

When people with life threatening illnesses and their carers ask about prognosis ("How long have I got?"), they are often doing more than simply inquiring about life expectancy. Within this question is another, often unspoken, question about likely patterns of decline ("What will happen?"). One aid to answering both questions may be through the use of typical illness trajectories. Thinking in terms of these trajectories provides a broad timeframe and patterns of probable needs and interactions with health and social services that can, conceptually at least, be mapped out towards death.

Such frameworks may help clinicians plan and deliver appropriate care that integrates active and palliative management. If patients and their carers gain a better understanding by considering illness trajectories this may help them feel in greater control of their situation and empower them to cope with its demands. An important implication for service planners is that different models of care will be appropriate for people with different illness trajectories. We review the main currently described illness trajectories at the end of life and draw out key clinical implications.

Methods

We searched our own database of papers, conducted a Medline search, and approached experts for additional published references (further details available from SAM). We also re-examined primary data relating to illness trajectories from our previous studies investigating the palliative care needs of people with advanced lung cancer and heart failure.[1]

Different trajectories for different diseases

A century ago, death was typically quite sudden, and the leading causes were infections, accidents, and childbirth. Today sudden death is less common, particularly in Western, economically developed, societies. Towards the end of life, most people acquire a serious progressive illness—cardiovascular disease, cancer, and respiratory disorders are the three leading causes—that increasingly interferes with their usual activities until death.

Three distinct illness trajectories have been described so far for people with progressive chronic illnesses (fig 1)[2-4]: a trajectory with steady progression and usually a clear terminal phase, mostly cancer; a trajectory (for example, respiratory and heart failure) with gradual decline, punctuated by episodes of acute deterioration and some recovery, with more sudden,

Summary points
Three typical illness trajectories have been described for patients with progressive chronic illness: cancer, organ failure, and the frail elderly or dementia trajectory
Physical, social, psychological, and spiritual needs of patients and their carers are likely to vary according to the trajectory they are following
Being aware of these trajectories may help clinicians plan care to meet their patient's multidimensional needs better, and help patients and carers cope with their situation
Different models of care may be necessary that reflect and tackle patients' different experiences and needs

seemingly unexpected death; and a trajectory with prolonged gradual decline (typical of frail elderly people or people with dementia).

We now consider each of these three trajectories in more detail.

Trajectory 1: short period of evident decline, typically cancer

This entails a reasonably predictable decline in physical health over a period of weeks, months, or, in some cases, years. This course may be punctuated by the positive or negative effects of palliative oncological treatment. Most weight loss, reduction in performance status, and impaired ability for self care occurs in patients' last few months. With the trend towards earlier diagnosis and greater openness about discussing prognosis, there is generally time to anticipate palliative needs and plan for end of life care. This trajectory enmeshes well with traditional specialist palliative care services, such as hospices and their associated community palliative care programmes, which concentrate on providing comprehensive services in the last weeks or months of life for people with cancer. Resource constraints on hospices and their community teams, plus their association with dying, can limit their availability and acceptability. Box 1 illustrates this trajectory.

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Marilyn [...] research [...]
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Corres[...] S Murr[...] Scott.M[...] ed.ac.u[...]
BMJ 20[...]

Key challenges and ways forward in researching the "good death": qualitative in-depth interview

Getting services right for those sick enough to die

A model based on common trajectories of illness and associated care needs would improve the care of people with serious illness in the last phase of life, say **Sydney Dy** and **Joanne Lynn**

Most people believe their lives will be relatively healthy, punctuated by episodes of illness that last no more than a few weeks. On the rare occasions that we think about dying, we imagine short and overwhelming illness in old age. Healthcare systems are designed as if disability and ill health were aberrations, rather than a phase that lasts months or years near the end of our lives, despite the contrary evidence all around us. Because of improvements in sanitation, lifestyle, and medical care, only a small proportion of people in developed countries now die suddenly.[1] Most serious chronic illnesses cannot be catered for adequately by traditional hospital and surgical services, and substantial restructuring is needed. The numbers of people living with serious chronic conditions in old age will double in the next two decades in the United States,[2] and similar trends will be seen in many other countries.[3] Finding sustainable ways to improve comfort and meaning in this last phase of life is therefore a priority.

Although hospice programmes have been an important and instructive initial response, they do not meet the needs of most patients who are sick enough to die. A minority of people who die with chronic conditions use hospices, and then only for an average of a few weeks.[4] In the US, enrolling in a hospice requires acknowledging a prognosis of "less than six months" and forgoing "curative" treatments.[5] The inability of doctors to prognosticate with precision and the reticence of patients and doctors to accept these conditions restrict the use of hospice services. This has led to the conclusion, in the US[6,7] and in the United Kingdom,[8] that "end of life care" should encompass all people sick enough to die soon, even though some will live in fragile health for some years.

Many reforms redesign care for specific diseases or within specific settings. However, these approaches do not achieve continuity or comprehensiveness for the increasing numbers of patients with multiple chronic conditions who must use multiple settings of care, with their various methods of payment, and they rarely deal with end of life problems.[9] Preferences for care at the end of life are likely to vary more than those for acute injury or illness, so reformers often emphasise allowing patients to choose their course of care.[10] Patients' authority to refuse interventions is an important protection for dignity and autonomy, and the ability to shape the course of care is preferable to control by others. Yet, the greatest problem is that important services, such

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as home support and reliable transfers, often are not readily available or are unreliable. We have found it useful to identify the common patterns of care needs over time while living with fatal illnesses (often called "trajectories") and to design services to fit them.

The trajectories

The clinical course of patients with eventually fatal chronic illness seems to follow three trajectories, described in more detail elsewhere.[1,11,12] These trajectories provide a way to describe generalities about large and discernible groups of people, each with different time courses of illness, service needs, priorities for care, and current barriers to reliably high quality care.

The first trajectory is the maintenance of good function until a short period of relatively predictable decline in the last weeks or months of life. For these patients, planning ahead, aggressive management of symptoms at home, and the concerns of care givers often prevent unnecessary admissions to hospital and other disruptive, undesired, and potentially harmful interventions. This course is typical of common solid cancers in adults, although other diagnoses can have a similar course, and not all cancers fit into this category. Indeed, cancer is becoming a more chronic disease, often presenting as one more comorbidity among the chronic conditions of advanced old age (the third trajectory). About 20% of patients over 65 years in the US follow this trajectory, and they tend to die at a younger age than patients in the other trajectories.[1]

Eligible seriously ill people	Qualified and committed providers	Insurers or healthcare system
Metastatic or aggressive cancer	Offer treatments that are needed and limit those unlikely to be beneficial	Reimburse appropriately; for example, a base rate for each trajectory, plus co-insurance for costly outliers
Heart failure, class III or IV	Plan for worsening complications and death	
Emphysema with low resting oxygen saturation	Maximise continuity from diagnosis until death	Encourage appropriate distribution, training, and retention of providers
Dementia, non-ambulatory and minimally verbal	Move services to the home setting	Monitor quality on dimensions related to the goals of the trajectories
Stroke with pronounced self care disability	Answer urgent calls 24 hours a day, seven days a week	
Multiple serious chronic illnesses	Provide more support for care givers, more personal care, and less medical treatment	
Frailty or pronounced functional decline, older than 85, self care disability		

The MediCaring model (adapted from Lynn)[11]

Riferimenti

- www.goldstandardsframework.nhs.uk
- www.communityhospices.org
- www.mywhatever.com/cifwriter/library
- www.kingsfund.org.uk

Palazzolo - Decremento percentuale sopravvivenza rispetto a totale deceduti

Palazzolo 2012
Palazzolo 2013
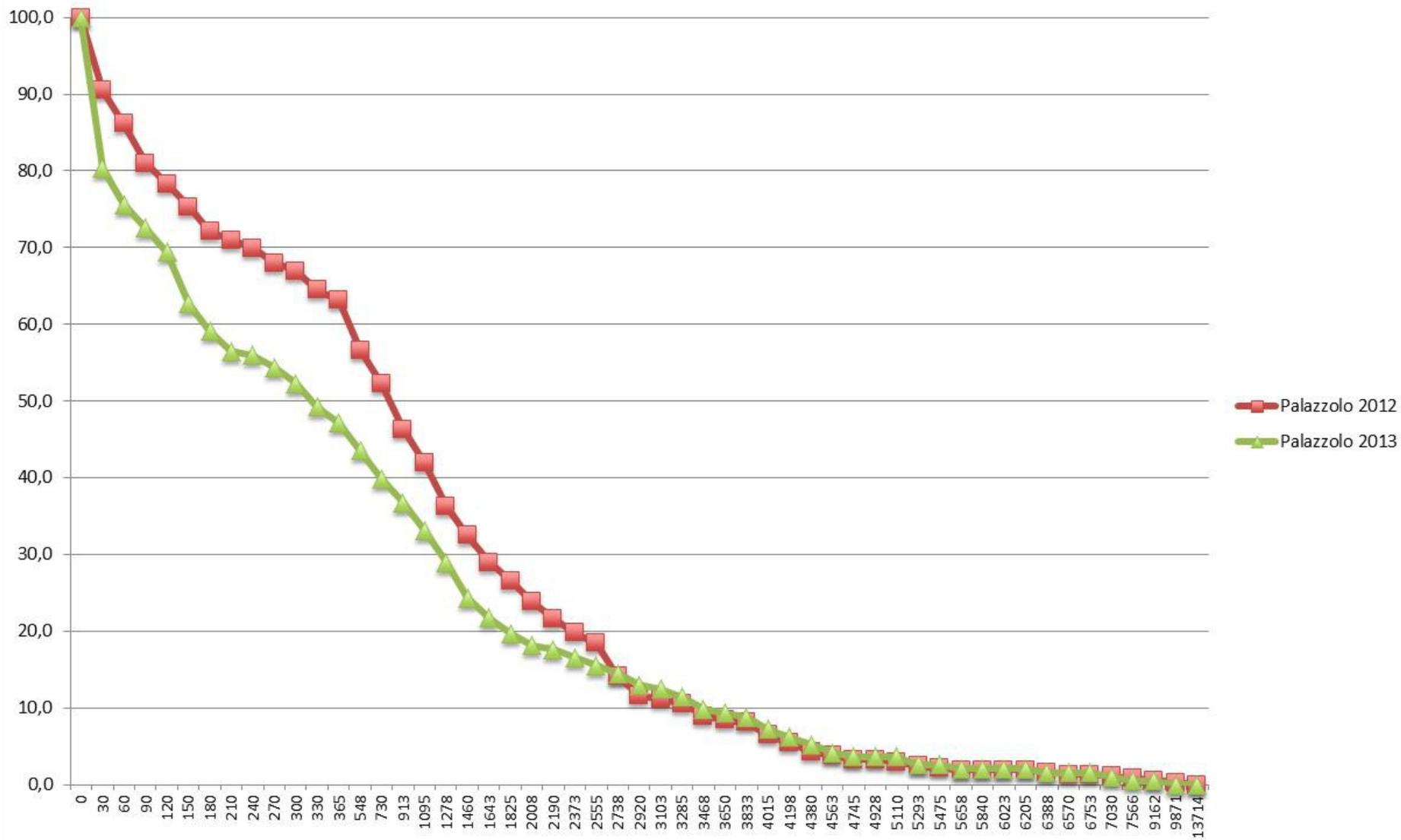
Percentuale decessi precoci - Confronto 2012-2013
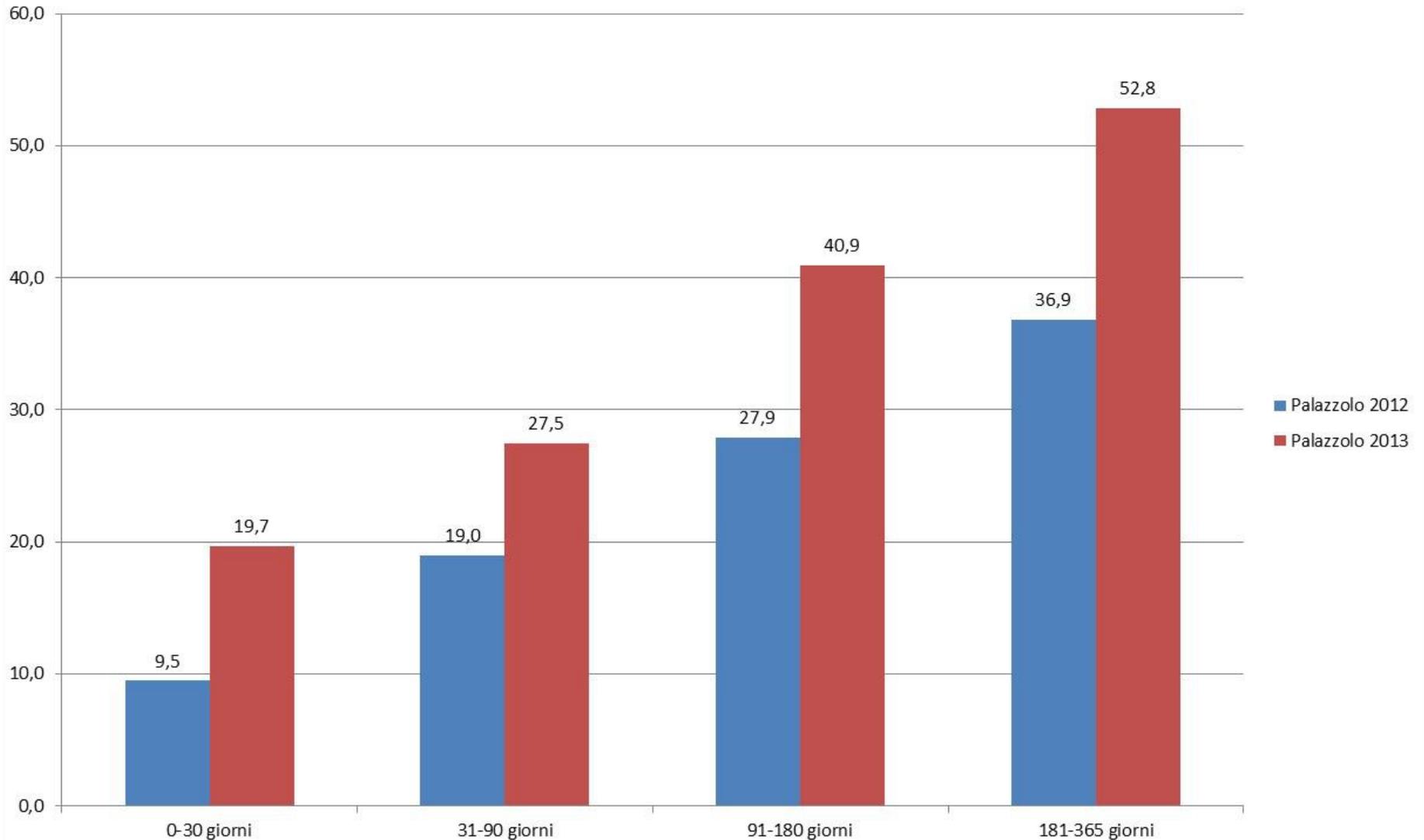
Odds Ratios decessi rispetto a provenienza (Direttamente vs Ospedale o Riabilitazione)
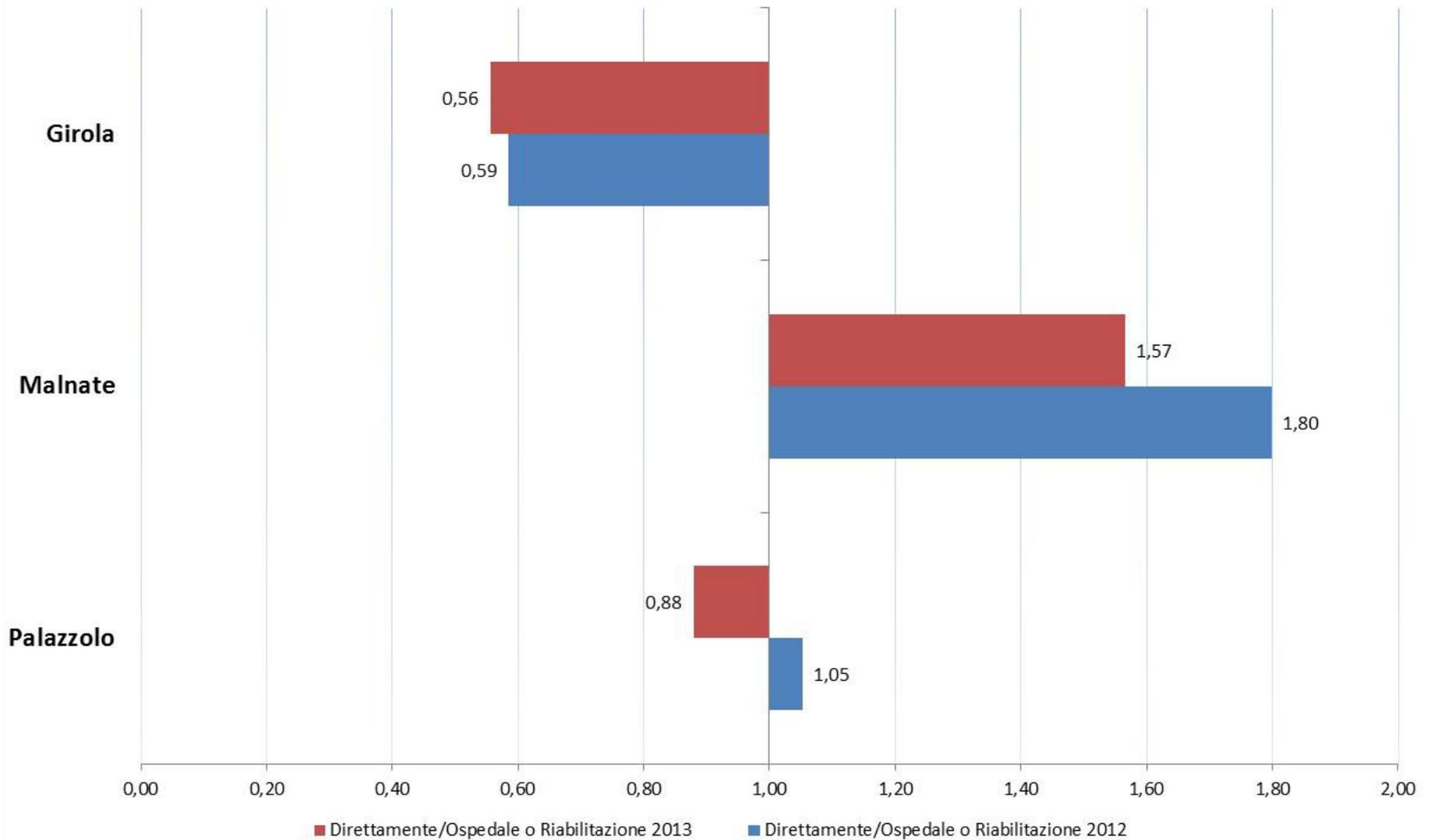
Odds Ratio decessi (confronto fra centri, per anno)
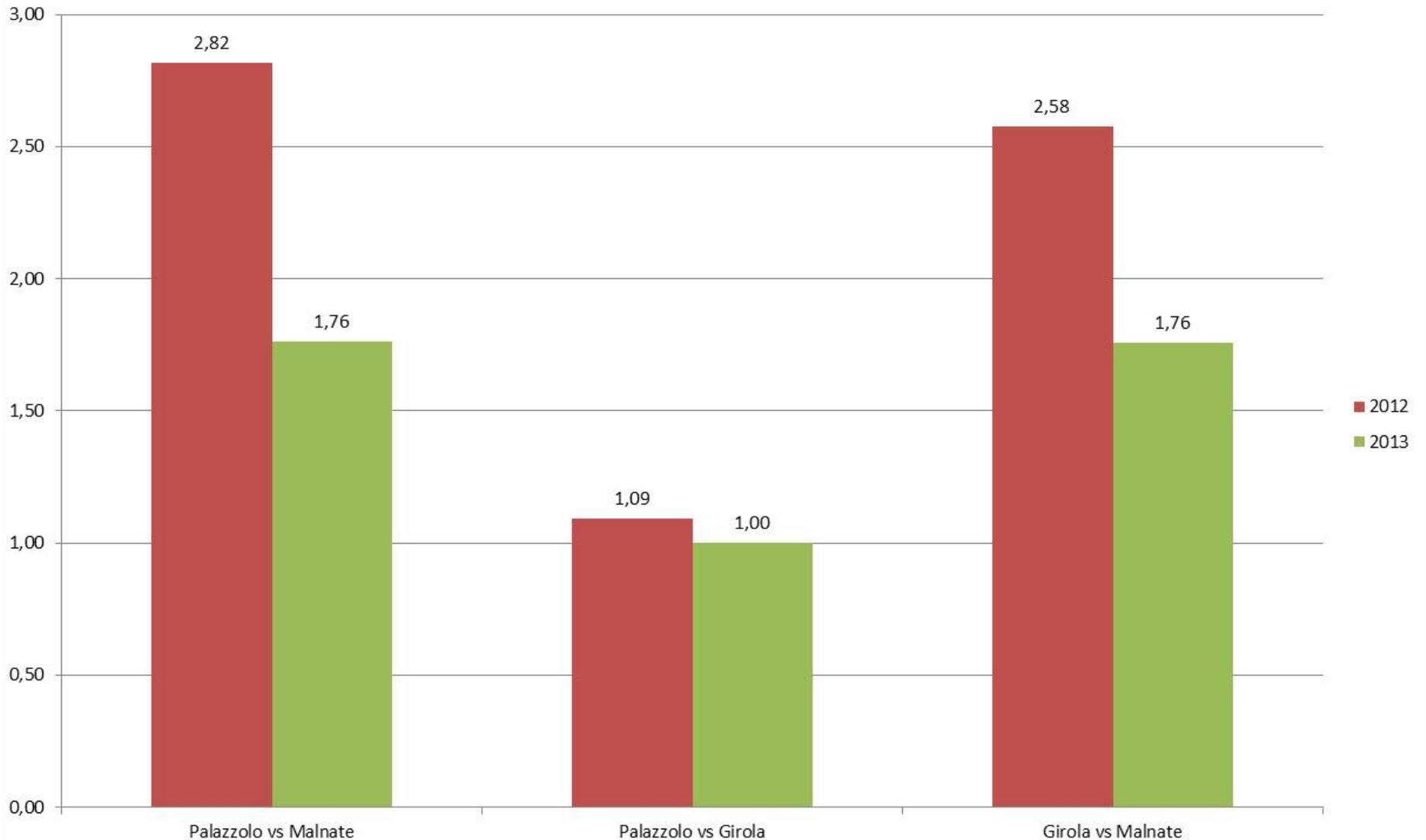
Deceduti (2013)	Palazzolo	Malnate	Girola
Totale deceduti (n.)	193	35	39
Deceduti su popolazione totale (%)	24,13	15,28	24,07
Deceduti primi 30 gg (% su totale decessi)	19,7	5,7	12,8
Deceduti a 90 gg (% su tot. deceduti)	27,5	14,3	20,5
Deceduti a 180 gg (% su tot. deceduti)	40,9	17,1	28,2
Deceduti a 365 gg (% su tot. deceduti)	52,8	34,3	38,5
Degenza media	1109,4	1434,2	1285,2
Degenza media ponderata (giorni)	1160,0	1515,4	1336,9
Degenza media ponderata (anni)	3,2	4,2	3,7
Odds (365 giorni)	0,32	0,18	0,32
Tasso grezzo decessi x 100 (365 giorni)	24,1	15,3	24,1
Tasso standardizzato per età (x 1000)	240,46	198,9	341,3
Tasso standardizzato per classe tariffaria (x 1000)	236,77	147,07	243,03
Incidenza cumulativa (Risk)	0,24	0,15	0,24