



Quale ruolo della persona in cura?

Relazioni di cura, innovazione digitale e cura di sé nel continuum di salute

What role should the cared-for person cover?

Care relationships, digital innovation and self-care in the health continuum

TAVOLA ROTONDA:

Esperienze di engagement e collaborazione curato-curanti nei percorsi riabilitativi e specialistici

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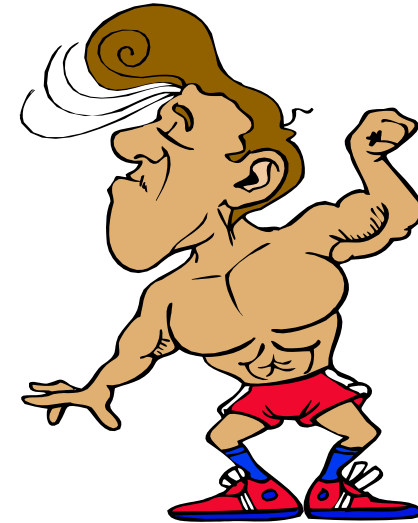
MISSION DELLA RIABILITAZIONE

Educare ed aiutare la persona disabile a raggiungere il miglior livello di vita possibile sul piano fisico, funzionale, affettivo, emozionale, relazionale con la minor restrizione possibile delle sue scelte operative, pur nell'ambito della limitazione della sua menomazione e della quantità e qualità di risorse disponibili

(Basaglia N., 2009)

LA RIABILITAZIONEOGGI

□ dalla terapia del “segno”



□ alla terapia della “persona”

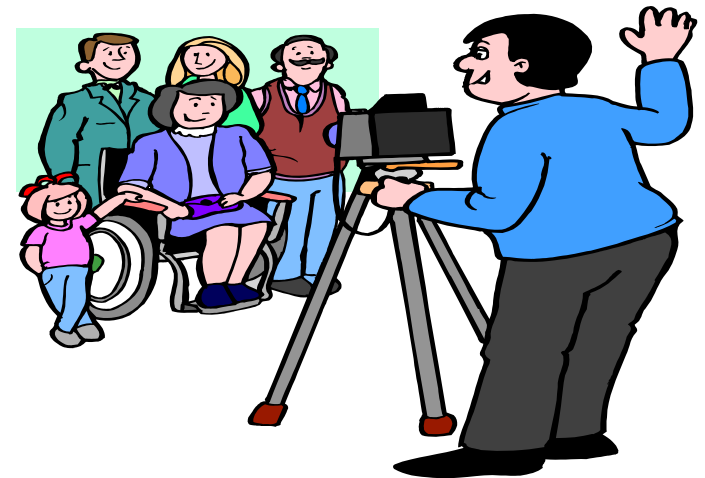


LA RIABILITAZIONEOGGI

□ dalla erogazione di una **“pillola”**-prestazione

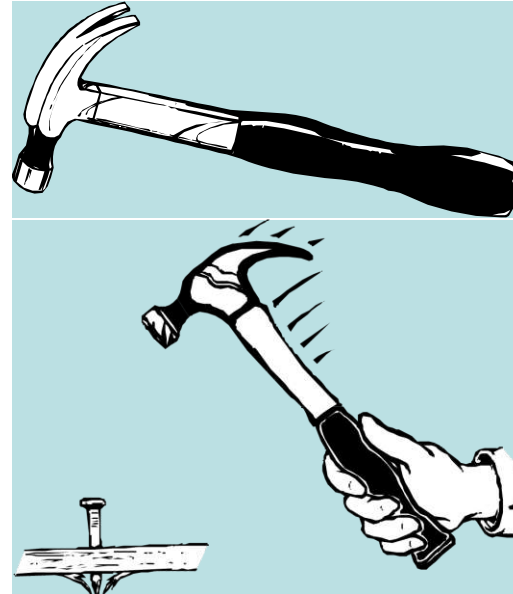


□ alla vera **“presa in carico globale”**



LA RIABILITAZIONEOGGI

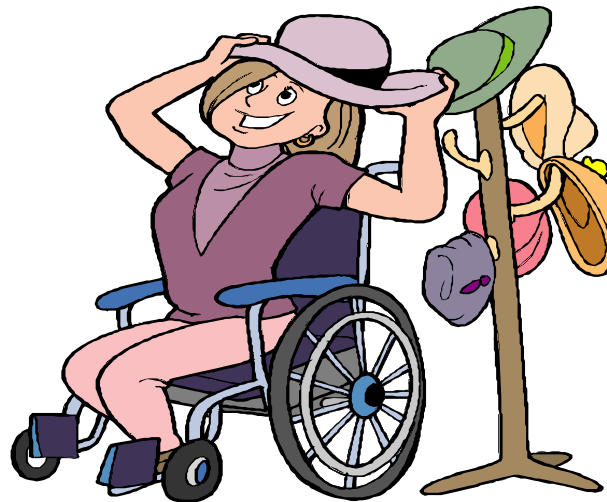
❑ dal dominio della **“tecnica”**



Se l'unico strumento che uno possiede è il martello

..... tratterà ogni problema come se fosse un chiodo !

❑ al dominio della **“persona”**



LA RIABILITAZIONEOGGI

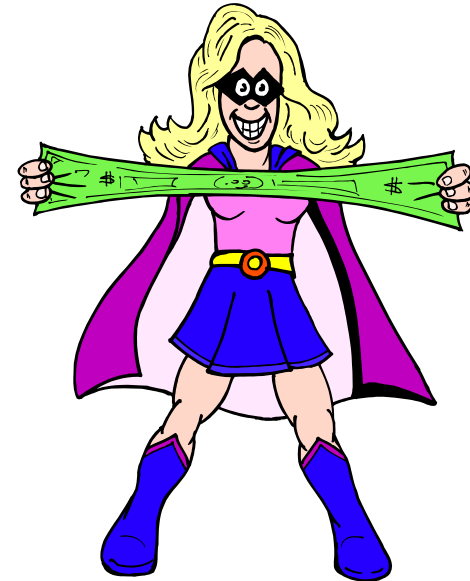
- dalla
“**pressapocometria**”,
“**nasometria**”,
“**mi-parometria**”
- allo sviluppo di **validi**
strumenti di misura e
di valutazione delle
conseguenze delle
malattie



LA RIABILITAZIONEOGGI

❑ dall'operatore
"unico"

❑ all'unicità
del progetto
riabilitativo di
persona



LA RIABILITAZIONEOGGI

dal lavoro
dei singoli
professionisti

al lavoro
in team



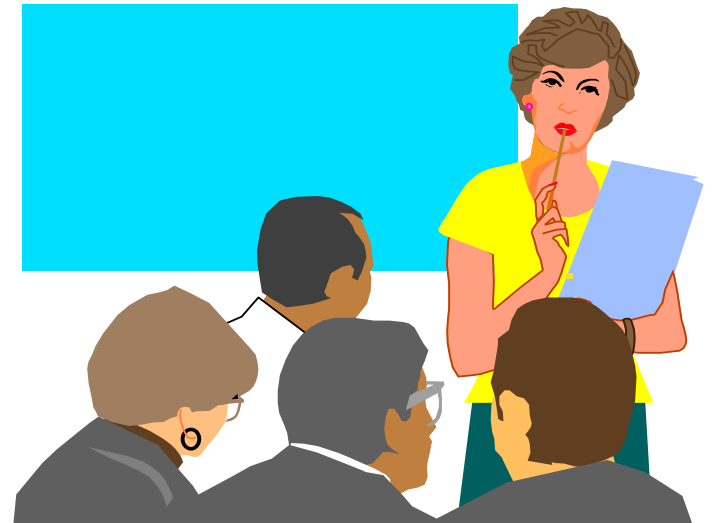
TEAM

Together (insieme)

Everybody
(ognuno, tutti)

Achieve (compie,
conduce a
termine,
raggiunge)

More (di più)



TEAM RIABILITATIVO

Coordinato dal Medico Fisiatra



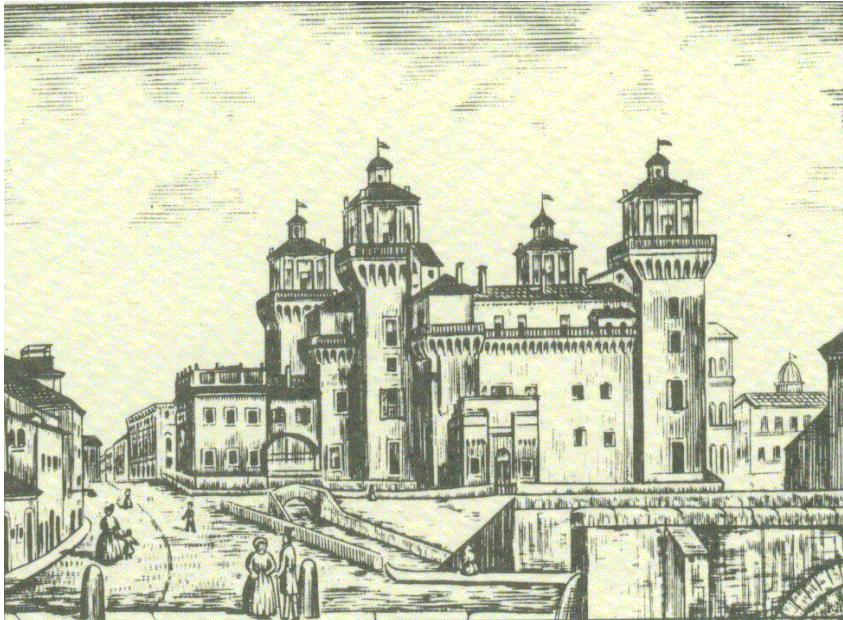
LA RIABILITAZIONEOGGI

❑ **dall'approccio
multiprofessionale**

❑ **a quello
interprofessionale**



**The rehabilitation process is
an **interdisciplinary** one
and that the **whole** is **grater**
than **the sum of its parts****



**Nella modalità di lavoro
multiprofessionale**

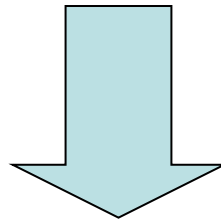
$$1+1+1+1+1 = 3$$

**Nella modalità di lavoro
interprofessionale**

$$1+1+1+1+1 = 8$$

Rehabilitation Medicine

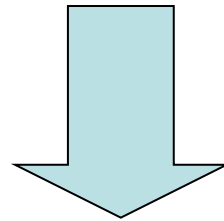
**Service-based
Rehabilitation**



**Outcome-based
Rehabilitation**

Rehabilitation Medicine

**process-based
rehabilitation**



**patient-based
rehabilitation**

OMS ICF

□ **International
Classification
of Functioning,
Disability and
Health**

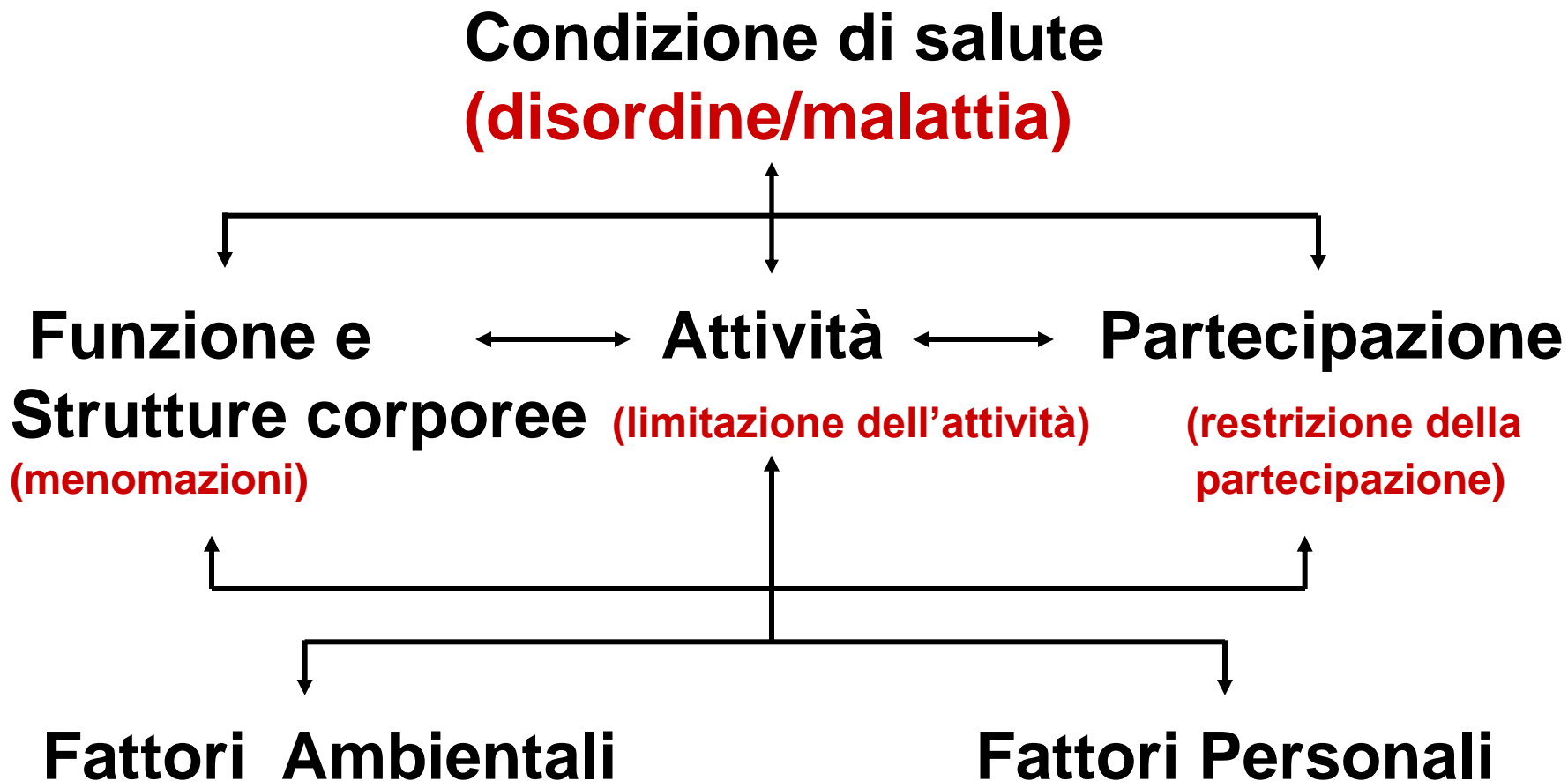
□ **Classificazione
Internazionale
del
Funzionamento,
della Disabilità e
della Salute**



OMS 2001

MODELLO CONCETTUALE dell'ICF

International Classification of Functioning, Disability, and Health, 2001



COMPREHENSIVE INPATIENT (CARF, 1996)

**comprehensive inpatient
program is a 24-hour
program of coordinated and
integrated medical and
rehabilitation services**



Category one: HOSPITAL

the persons served have the following characteristics:

- ❑ are at **high risk of potential medical instability**
- ❑ have **regular direct individual contact with rehabilitation physicians determined by their medical and rehabilitation needs**
- ❑ have **multiple and/or complex rehabilitation nursing needs and a potential high risk for needing high medical acuity skilled nursing**

./ Category one: HOSPITAL

the persons served have the following characteristics:

- ❑ based on their individuals needs, receive a **daily minimum of three hours** of services a minimum of five days per week from the interdisciplinary team, which includes an occupational therapist, a physical therapist, a psychologist, a social worker, a speech-language pathologist, and a therapeutic recreation specialist
- ❑ have **education and training opportunities** for themselves as well as family members on an ongoing basis

Category three: skilled nursing facility

the persons served have the following characteristics:

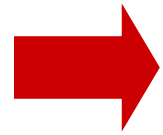
- ❑ are at **low risk** of potential medical instability
- ❑ have regular **direct individual contact with rehabilitation physicians** determined by their medical and rehabilitation needs
- ❑ have **routine rehabilitation nursing** needs and a **low risk** of needing high medical acuity skilled nursing



./ Category three: skilled nursing facility

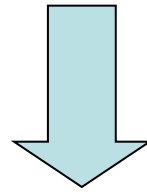
the persons served have the following characteristics:

- ❑ based on their individuals needs, receive a daily minimum of **one hour** of services a minimum of five days per week from the interdisciplinary team, which includes an occupational therapist, a physical therapist, a psychologist, a social worker, a speech-language pathologist, and a therapeutic recreation specialist
- ❑ have **education and training opportunities** for themselves as well as family members on an ongoing basis



PRINCIPI DELLA RIABILITAZIONE

operare secondo il principio
dell'**empowerment** della persona
(OMS Alma Ata, 1978)



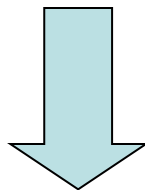
operare sempre più secondo il paradigma
dell'**empowerment del disabile** rispetto al
paradigma della **riparazione e del recupero
funzionale d'organo**

(Basaglia N, 2009)

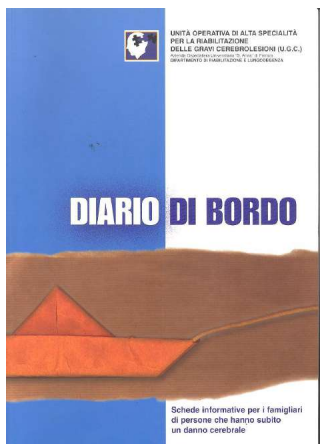
PRINCIPI DELLA RIABILITAZIONE

operare secondo il principio dell'**empowerment** della persona

(OMS, Alma Ata, 1978)



“empowerment come **educazione sanitaria** e promozione dei comportamenti favorevoli alla salute, per ridurre le diseguaglianze e **fornire alle persone strumenti critici per prendere le decisioni migliori per il loro benessere,** promuovere politiche pubbliche rispettose degli obiettivi della salute”



EDUCAZIONE TERAPEUTICA

□ può essere definita come **aiutare il paziente e la sua famiglia a comprendere la malattia, le sue conseguenze, le modalità di trattamento e di gestione al fine di collaborare attivamente alle cure, a farsi carico del proprio stato di salute ed a conservare e migliorare la propria qualità di vita**



DEFINING PATIENT EMPOWERMENT

What is patient empowerment?

- There are many definitions, with most relating in some way to patients conceived as self-determining agents with some control over their own health and healthcare, rather than as passive recipients of healthcare

(Aujoulat I, D'Hoore W, Deccache A: Patient empowerment in theory and practice: Polysemy or cacophony? Pat Ed Counsel 2007, 66:13–20; Aujoulat I, Marcolongo R, Bonadiman L, Deccache A: Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. Soc Sci Med 2008, 66:1228–39; Lorig K, Ritter PL, Villa FJ, Armas J: Community-based peer-led diabetes self-management: a randomized trial. Diabetes Educ 2009, 35:641–51; Lorig K, Holman H: Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003, 26:1–7; Funnell MM, Anderson RM: Patient Empowerment: A Look Back, A Look Ahead. Diabetes Educ 2003, 29:454–64.)



ASSOCIATED WITH THIS, ARE IDEAS OF PATIENT COMPLIANCE AND ADHERENCE

- ❑ **Compliance** refers to the patient submitting to the authority of their healthcare provider, and arguably belongs within the **paternalist paradigm**
- ❑ **Adherence** refers to the patient voluntarily agreeing with a healthcare plan, perhaps developed through shared decision-making and belongs more within the **empowerment paradigm**

(National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO): Concordance, adherence and compliance in medicine taking. 2005)

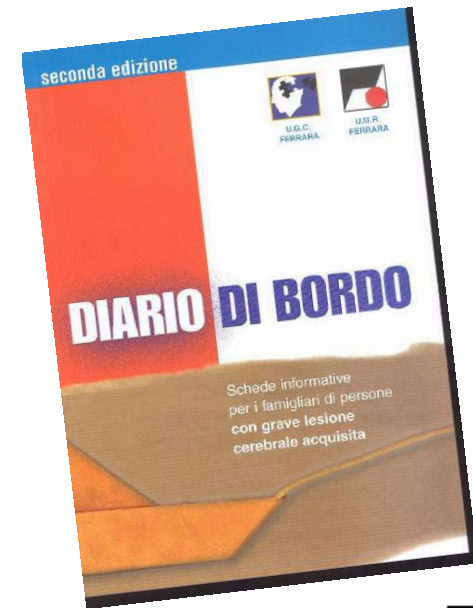
EMPOWERMENT

- ❑ Most patient empowerment definitions focus on **individuals' capacity to make decisions about their health** (behaviour) and to have, or take control over aspects of their lives that relate to health.

- ❑ Assumptions are that empowered individuals will
 - a) make **more rational healthcare decisions** to maximise their health and wellness
 - b) **decrease dependence** on healthcare services
 - c) ultimately **contribute to more cost-effective use** of healthcare resources.However, these consequences remain to be proven.

EMPOWERMENT

- **Some argue that empowerment may be context and population specific and that a universal definition may not be possible. Culture, age and socio-economic resources undoubtedly influence empowerment, and the degree to which different social groups can be, and wish to be, empowered will differ.**

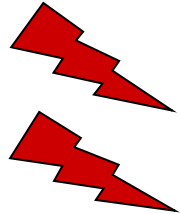


EMPOWERMENT

❑ Others have argued that:

❑ empowerment can be considered to be either a **process or an outcome**; that patients can be empowered by their healthcare providers **through education, counselling, patient-centred care, and use of community coaches**;

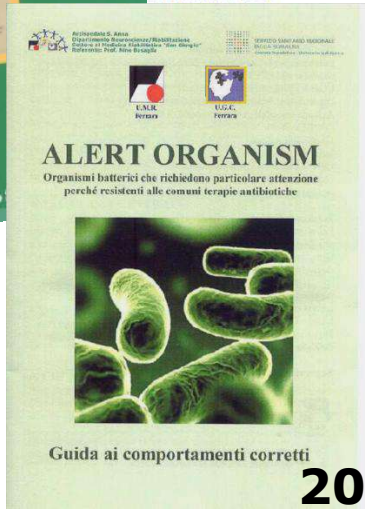
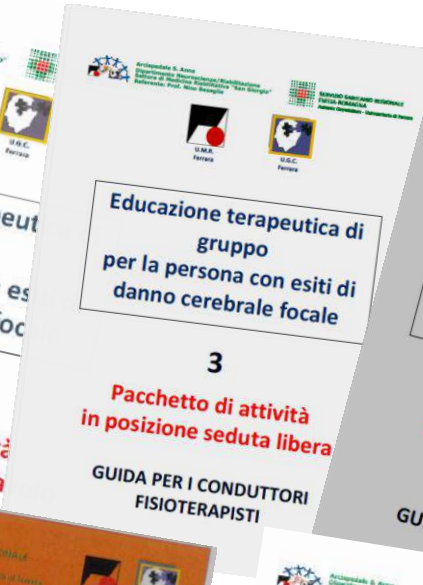
❑ and that patients can empower **themselves through selfeducation, facilitated by the internet, or by participating**



STRUMENTI PER L'EDUCAZIONE DELL'UTENZA



STRUMENTI PER L'EDUCAZIONE DEI PROFESSIONISTI



“NO DECISION ABOUT ME, WITHOUT ME”

The emergent model conceptualises empowerment as a multi-dimensional construct including:

- ❑ **cognitive control** (sense-making - understanding the condition, why it happened, what help & support is available - “knowledge is power”)
- ❑ **decisional control** (having some options for managing the condition/risk and able to make informed decisions between options)
- ❑ **behavioural control** (able to do something to reduce harm or improve life for self/child(ren)/at risk relatives/descendants)
- ❑ **emotional regulation** (reflecting effective coping and adjustment)
- ❑ **hope for the future** (for self/relatives/future descendants)

(McAllister et al. BMC Health Services Research 2012, 12:157)



OPERATIONALISING PATIENT EMPOWERMENT

The focus of many patient empowerment initiatives has been to encourage patient self-management of chronic conditions, although it is not always clear whether empowerment is being considered as a **process** or as an **outcome**



BMC HEALTH SERVICES

There have been recent calls for healthcare evaluation to take into account the perceived value of **non-health outcomes** such as **empowerment**, a psychosocial outcome

(Payne K, McAllister M, Davies L: Valuing the economic benefits of complex interventions: when maximising health is not sufficient. Health Econ 2012)



ES. DI QUESTIONARI PER VALUTARE L'EMPOWERMENT

Table 1 Some examples of validated questionnaires capturing (aspects of) patient empowerment

Measure	Conditions-specific or generic?	Construct operationalised	Reference
Patient Enablement Instrument	Generic	Aspects of perceived control over illness	Howie et al. 1998 [19]
Patient Activation Measure	Generic	Activation levels (skills, knowledge, and beliefs needed by patients to self-manage, collaborate with healthcare providers and maintain their health)	Hibbard et al. 2005 [20]
The Empowerment Scale	Conditions-specific: Mental healthcare	Self-efficacy, power-powerlessness, community activism, righteous anger, and optimism-control over the future	Rogers et al. 1997 [21],
Diabetes Empowerment Scale	Conditions-specific: Diabetes	Self-efficacy	Anderson et al. 2000 [22]
Patient Empowerment Scale	Conditions-specific: Cancer	Use of coping resources, an aspect of personal control	Bulsara et al. 2006 [23]
Genetic Counselling Outcome Scale	Conditions-specific: Genetic conditions	Perceived personal control (cognitive, decisional and behavioural control), hope and emotional regulation	McAllister et al. 2011 [24]

McAllister et al. *BMC Health Services Research* 2012, **12**:157

ESEMPI



STROKE REHABILITATION

Long-term rehabilitation after stroke

NICE Clinical Guideline 162, 2013

Patient-centred care

If the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care. Families and carers should also be given the information and support they need.

LINEE GUIDA SIGN SULLA RIABILITAZIONE DELLA PERSONA COLPITA DA STROKE 2010



7. PROVISION OF INFORMATION

SIGN N.118/2010

7.1 Informazioni necessarie al paziente e ai suoi assistenti:

- ❑ ai pazienti affetti da stroke e ai loro assistenti devono essere offerte **informazioni** relativamente allo stroke e alla riabilitazione.

(Grado D)

7. PROVISION OF INFORMATION

SIGN N.118/2010

7.1 Informazioni necessarie al paziente e ai suoi assistenti:

- ❑ **l'informazione** deve essere **disponibile** per i pazienti e i loro assistenti **in modo routinario** ed offerte utilizzando strategie informative attive, che includono un mix di tecniche educative e di counselling.
(Grado A*)

7. PROVISION OF INFORMATION

SIGN N.118/2010

7.1 Informazioni necessarie al paziente e ai suoi assistenti:

- l'informazione** deve essere **predisposta sulla base dei bisogni informativi** del paziente e dei suoi assistenti verificando la relativa comprensione ed assicurando chiarezza, ripetendo il processo informativo finché è appropriato/utile/necessario
(Grado A)

7. PROVISION OF INFORMATION

SIGN N.118/2010

7.1 Informazioni necessarie al paziente e ai suoi assistenti:

- **l'informazione** deve essere **predisposta sulla base dei bisogni informativi e visivi** del singolo paziente e dei suoi assistenti. I pazienti **afasici** devono essere provvisti di materiale accessibile e facile da leggere, devono avere un tempo sufficiente per la relativa assimilazione ed essere seguiti da professionisti sanitari per garantire la comprensione.
(Grado D)

7. PROVISION OF INFORMATION

SIGN N.118/2010

7.1 Informazioni necessarie al paziente e ai suoi assistenti:

- le necessità di **informazione** devono essere monitorate e l'informazione deve essere fornita al **tempo giusto** durante la traiettoria del recupero; le **necessità di informazioni cambiano** con lo scorrere del tempo.
(Grado A)

Strumenti per l'educazione dell'utenza



Realizzati con
il contributo di



***“Il tempo dedicato
all’informazione, alla
comunicazione ed alla
relazione, è tempo di cura”***

Carta di Firenze, 2005



L'empowerment in Riabilitazione è davvero una...



Mission impossible ?

CENTRO MEDICINA RIABILITATIVA "SAN GIORGIO"
Centro "HUB" Regionale per la Riabilitazione delle Gravi Cerebrolesioni

GRAZIE



**Cattedra di Medicina Fisica e
Riabilitativa**



Dipartimento Interaziendale di Neuroscienze e Riabilitazione, AOU e AUSL di Ferrara