An ecosystem for managing frailty in people living with dementia and their informal caregiver

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YOUNG EPIDEMIOLOGISTS SIGG yes

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2015 World Report Ageing and Health

Over 60

1 bilion in 2019
1.4 bilion in 2030
2.1 bilion in 2050

Health systems need to be realigned to needs of older population «Systems must be capable of providing older person centred and integrated care, and focus on maintaining capacities as people age»

Healthy aging: «the process of maintainig the functional ability that enable well-being in older age»
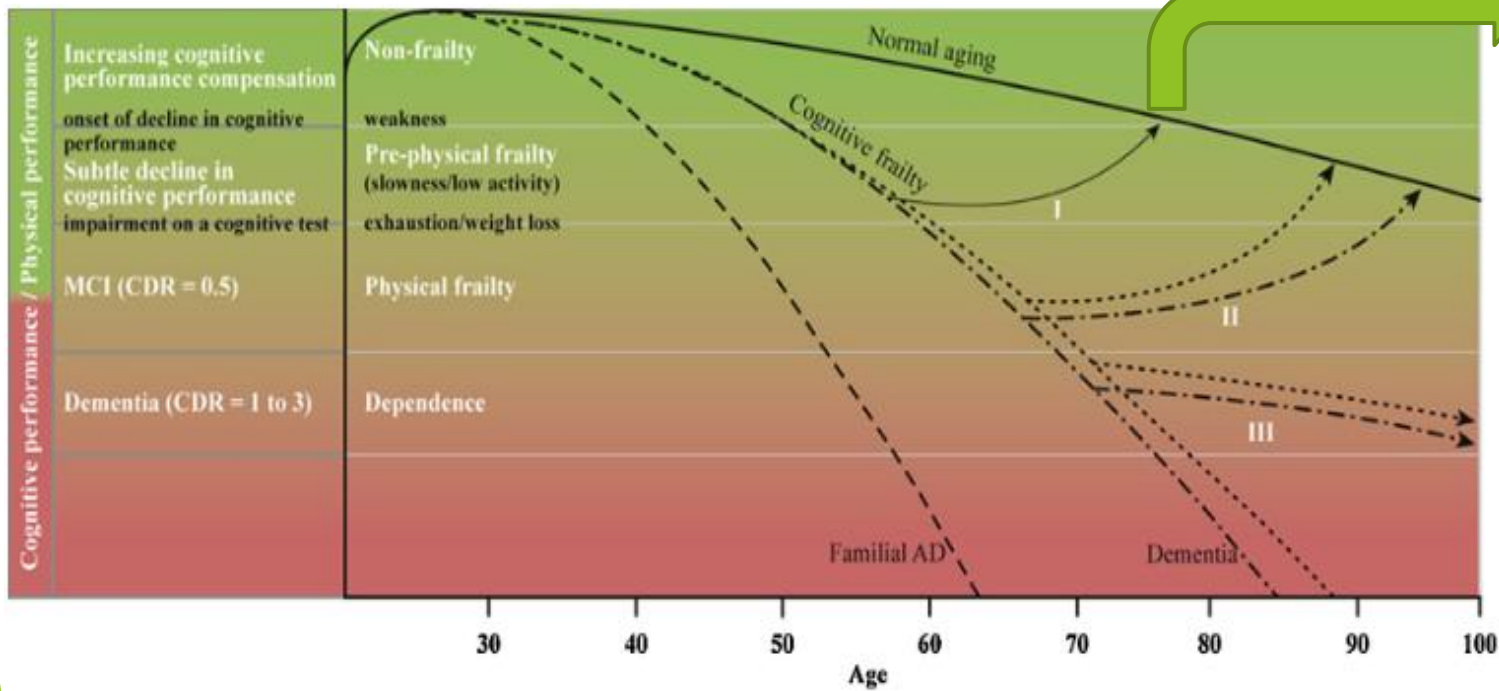
Frailty and cognition
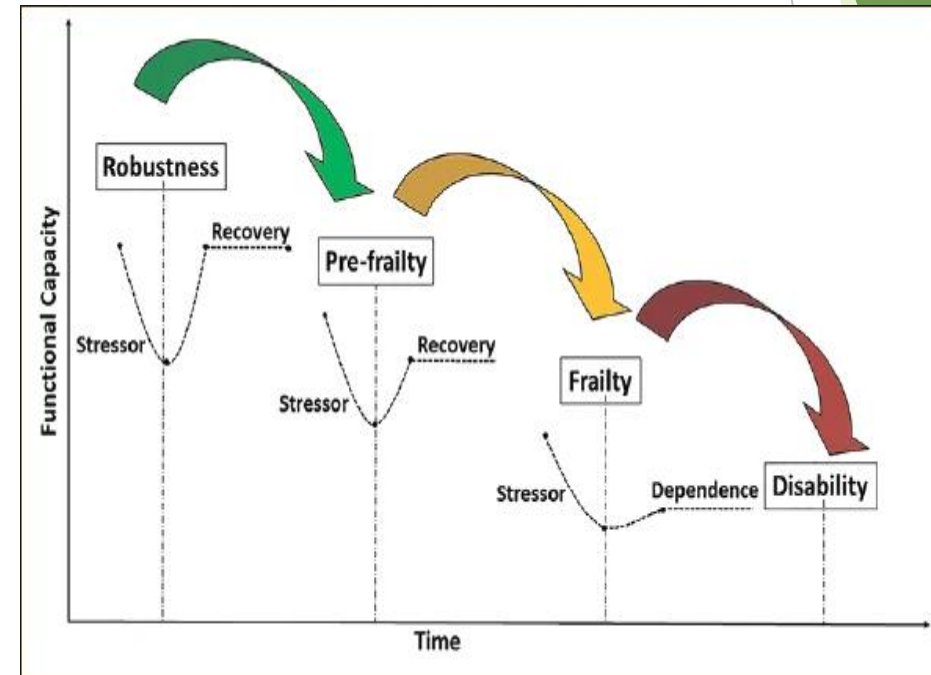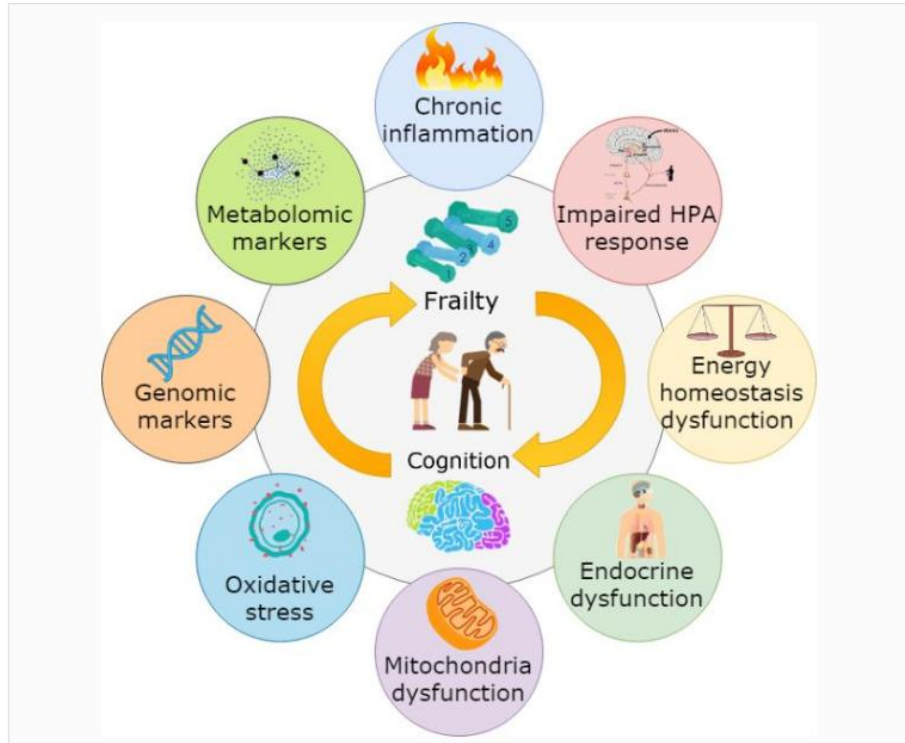
Cognitive frailty trajectories and possible modifiable factors

Dementia prevention, intervention, and care: 2024 report of the *Lancet* standing Commission
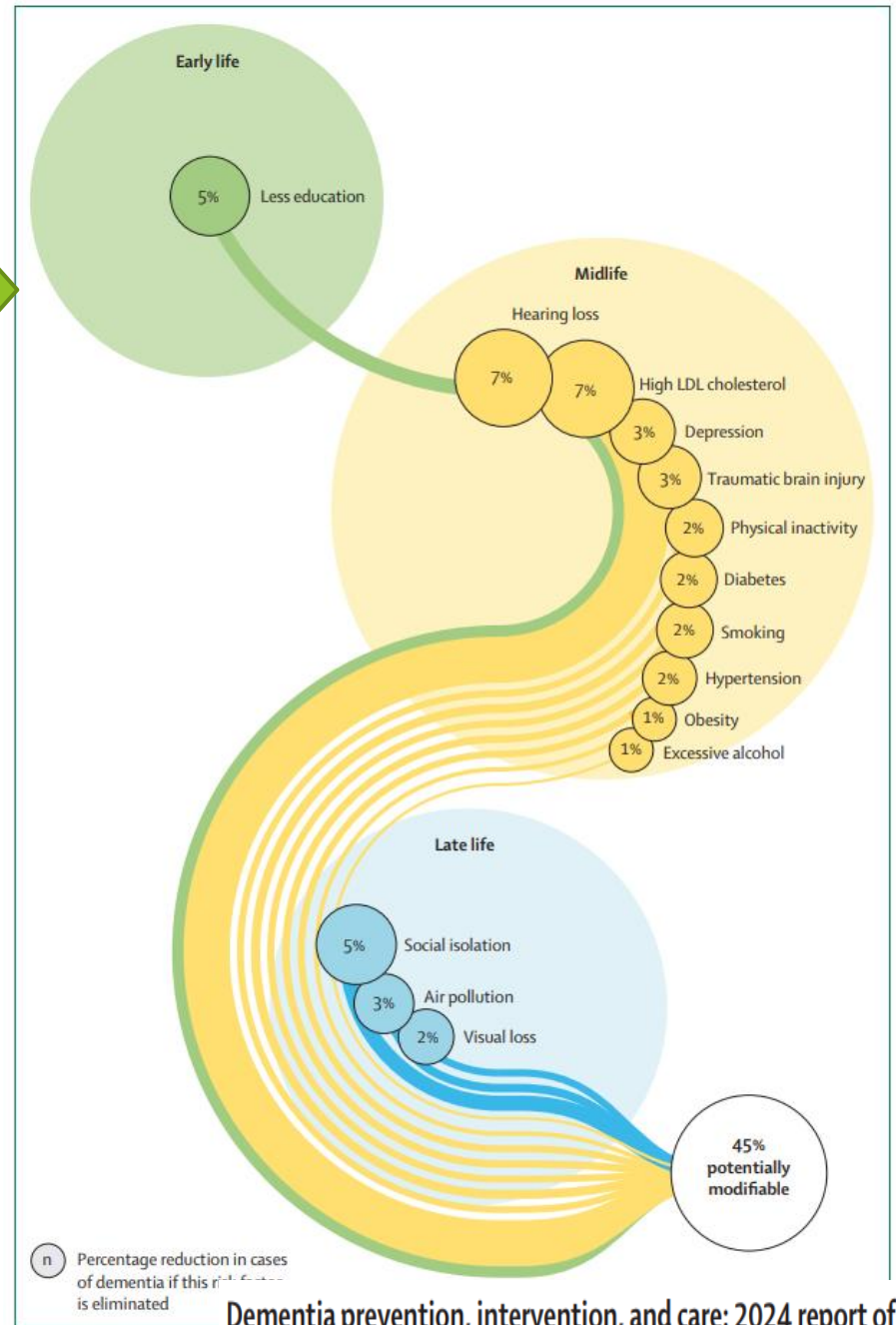
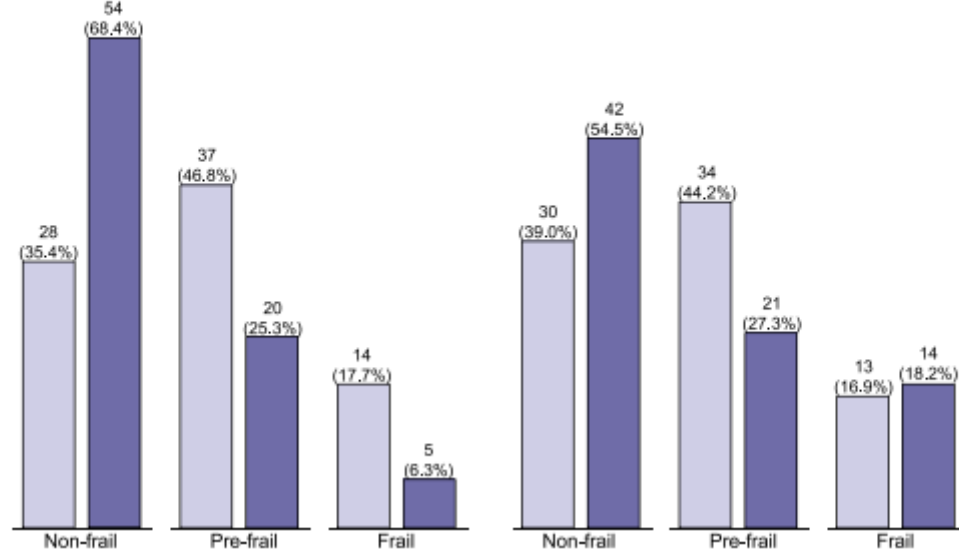# Frailty and dementia risk: health promotion and risk reduction

The intervention group was significantly less frail than control at three months (P = 0.011)

Baseline
3 months

Frailty status (SHARE Frailty Instrument)
Intervention group (n=79)   Control group (n=77)

Non-frail: 28 (35.4%), 54 (68.4%)
Pre-frail: 37 (46.8%), 20 (25.3%)
Frail: 14 (17.7%), 5 (6.3%)

Non-frail: 30 (39.0%), 42 (54.5%)
Pre-frail: 34 (44.2%), 21 (27.3%)
Frail: 13 (16.9%), 14 (18.2%)

Primary multidimensional strategies mitigate onset of frailty

Low neuropathology   Intermediate neuropathology   High neuropathology

Clinical diagnosis
Intermediate cognition
Mild cognitive impairment
Dementia

Frailty tertiles
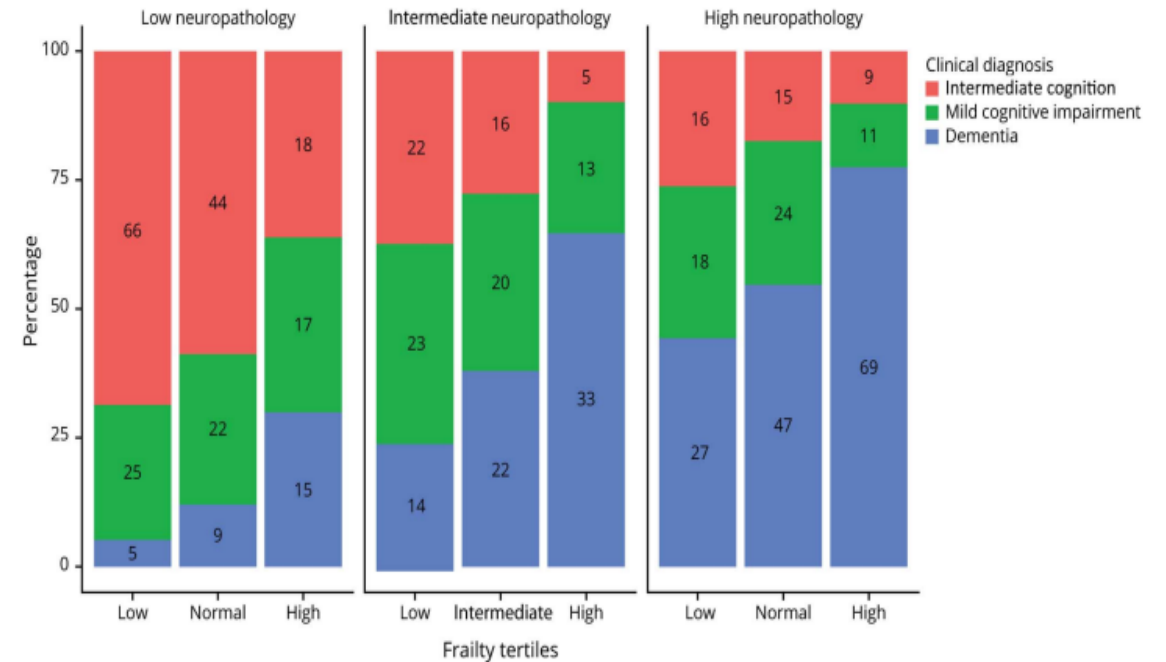
Frailty reduces cognitive decline's expression

From deficits to resilience: The novel concept of intrinsic capacity

Handbook
Guidance on person-centred assessment and pathways in primary care

- ✓ In 2017, "Integrated care for older people: Guidelines on community-level interventions to manage declines in intrinsic capacity
- ✓ 13 evidence-based recommendations
- Targeted at healthcare and social professionals
- Purpose: to help develop and implement integrated, person-centered care for the elderly.
- Level of intervention: community-dwelling.
- The focus of the integrated care approach for older people (ICOPE): to optimize intrinsic capacity and functional ability to ensure healthy aging.

An ecosystem for managing frailty

- A technological ecosystem to manage, detect, monitoring and treatment of frailty

- From hospital to community care

- To involve all actors:
  - older people
  - informal caregivers
  - Primary care
  - Social services

An ecosystem for managing frailty
Technical characteristics

- Synchronus vs asynchronus
- Partecipatory and usability
- Scalability
  - Modular
  - Pluggable
  - Portable
- Affordable
- Interoperability
- Sustainability
  - Socio-economical impact
  - Enviromental

An ecosystem for managing frailty

- ✓ Early detection system in population at risk
- ✓ Personalized integrated care plan to manage both disease and social issues
- ✓ Preferential attention to enviromental aspects
- ✓ Alerts and communications tools

- ▪ Solutions eclusively based in the disease
- ▪ Lack of communications and physical accessibility
- ▪ Privacy issue
- ▪ Technical problems
- ▪ Lack of CG training
- ▪ Trust in machine learning?

An ecosystem for managing frailty
Some European examples:

- IN-LIFE project (2015-2018) : prolong and support indipendent living in Person with cognitive impairment
- SMART4MD (2017-2020): support monitoring and Reminder technology for Mild Dementia patients and caregiver quality of life
- Vivifrail project (2017-2020): exercise program on functional capacity of physically pre-frail/frail older individuals diagnosed with MCI/mild dementia.

An ecosystem for managing frailty

The caregiver perspective

Caregiver burden:

- Lack of support network
- Not using informal or formal services due to different barriers
- Problems behaviour of the PwD
- Insufficient coping skills

Available interventions for informal caregivers:

- Respite
- Psychosocial interventions
- Informant and communications technology (ICTs) support

An ecosystem for managing frailty
The caregiver perspective

- ✓ Digital mental health tools for informal caregivers should be used as an intervention, support, means of education, and training, that could provide set of skills necessary for an individual to maintain health and well-being while fulfilling the role of a caregiver

- ✓ combining the digital tools can lead to creating a useful mixed tool for addressing the caregiver's mental health, burden, and stress at the more general level regardless of the limitations or illness of the care recipient

- ▪ there is a clear lack of practical approach in creating digital mental health tools, content, and interventions, by simply involving caregivers in the creation of technology intended for them. In

Our clinical practice

► In the clinic, treatments are provided using digital rehabilitative software for various types of patients (neurological, with neurodegenerative diseases, geriatric, with psychiatric conditions, pediatric).

► The rehabilitative options in use include computerized rehabilitation packages (software that provides a wide range of rehabilitative exercises, divided by the main cognitive functions).

► In experimental research projects, the goal is to validate new rehabilitation software for specific cognitive domains (e.g., for attentional and visuospatial deficits) or with new interaction methods (e.g., telerehabilitation).

► <u>Strenghts and weakness</u>

➕ Use of exercises focused on the specific difficulties of each patient

➕ Difficulty levels adaptable to the patient's performance

➕ Ability to reach patients who are unable to go to the hospital and continuity of the rehabilitation path post-discharge (TELE)

➖ Digital divide, lack of knowledge of technology

➖ Exercises are not very ecological

The patient's perspective

► Before starting the treatment, it is necessary to teach the patient some basic digital skills (e.g., turning on the device, adjusting the volume, managing the touchscreen).

► The patient expresses mistrust towards digital tools and their rehabilitative potential. At times, this mistrust turns into fear regarding the digitalization process..

► To justify the mistakes made, the patient blames the digital tools.

► Example 1: The patient shows impulsive traits and starts the digital exercise without reading the instructions, making several mistakes. She then blames the tool for her errors, claiming that the instructions were not presented clearly.

► Example 2: The patient blames the digital exercise for being too fast/too slow, without understanding that the speed setting has a rehabilitative purpose.

The patient's perspective

CASE 2: Patient with mild cognitive decline, IADL=8, 70 years old, good digital skills (daily use of smartphone, email, and internet for personal use).

▶ The patient expresses trust and curiosity towards the digital treatment. This leads to active engagement and good motivation, which has a positive impact on the therapeutic process.

▶ The patient appreciates the flexibility offered by digital tools, particularly because it reduces the need to travel and ensures access to the therapeutic process without the need for hospitalization. It can also be integrated with daily and work commitments.

▶ Example: Following the therapist's guidance, the patient can perform rehabilitative activities independently, even outside the therapist's working hours, thereby increasing the intensity of the treatment.

▶ At the end of the rehabilitation process, the patient asks for suggestions on how to continue doing digital exercises independently.

Caregiver's perspective

CASE 1: Patient with dementia (IADL=4), 82 years old, poor prior digital skills.

The caregiver:

- He is involved daily in the rehabilitation process and assists the patient in managing devices and complex situations (e.g., internet connection, use of the charger).

- He learns new ways of interacting with the patient, listens to, and puts into practice the therapists' advice to apply in the daily context.

- He positively assesses the possibility of following a consistent rehabilitation path without having to accompany the patient to the clinic.

Caregiver's perspective

CASE 2: Patient with mild cognitive decline, IADL=8, 70 years old, good digital skills (daily use of smartphone, email, and internet for personal use).

The caregiver:

▶ Thanks to the ability to observe the digital rehabilitation activities, he gains a greater awareness of the patient's cognitive difficulties and seeks a discussion with the therapist.

▶ He learns different cognitive stimulation techniques, which can be applied to daily life contexts.

▶ He positively evaluates the time and cost savings of digital treatment.

▶ He reports cognitive improvements after the exercise therapy, greater confidence, and an enhancement in the patient's mood.