Università degli Studi di Ferrara
Dipartimento di Neuroscienze e Riabilitazione

SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA
Azienda Unità Sanitaria Locale di Ferrara

Le cure palliative nelle persone affette da patologie mentali severe

Luigi Grassi

Istituto di Pischiatria, Dipartimento di Neuroscienze e Riabilitazione, Università di Ferrara
Unità Operativa Complessa di Psichiatria Ospedaliera
Dipartimento Attività Integrata di Salute Mentale - AUSL Ferrara

Faculty Disclosure

	No, nothing to disclose
X	Yes, please specify:

Company Name	*Honoraria/ Expenses*	*Consulting/ Advisory Board*	*Funded Research*	*Royalties/ Patent*	*Stock Options*	*Ownership/ Equity Position*	*Employee*	*Other (please specify)*
Oxford University Press				x				
Wiley				x				
Springer				x				
University of Ferrara			x					
Scientific consultancy	x							

I temi di oggi

- Generalità sul problema della salute fisica nelle persone con disturbi psichiatrici severi (SMI)
- I bisogni pluridimensionali delle persone con SMI e implicazioni per le cure palliatve
  - Tema dello stigma (esemplificazione clinica)
  - Tema dignità
- Prospettive di intervento

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Salute Mentale nel Mondo – Top 5

Numeri totali

- **300 milioni** → d. depressivo
- **285 milioni** → d. d'ansia
- **180 milioni** → d. da uso di sostanze

Numeri totali

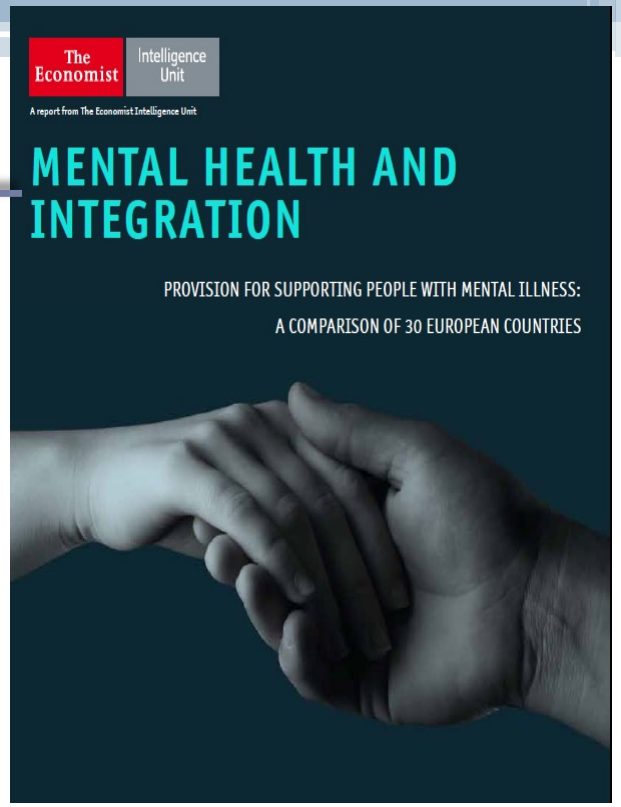
- **60 milioni** → d. bipolare
- **26 milioni** → d. spettro schizofrenico
- **????** → PTSD (da stress)

Lancet Psychiatry 2022; 9: 137–50

Global, regional, and national burden of 12 mental disorders in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019

*GBD 2019 Mental Disorders Collaborators**

Salute Mentale in Europa



- Circa il **38%** dei residenti nella UE (165 milioni) sono affetti da un disturbo psichico
- **75%** hanno esordio **prima dei 25 anni**
- **Solo UN QUARTO (25%)** dei pazienti riceve cure e **solo** nel **10%** queste sono appropriate
- Il disturbo psichico è considerato come la **SFIDA del XXI secolo** sia per l'impatto individuale e sociale sia per le difficoltà di prevenzione

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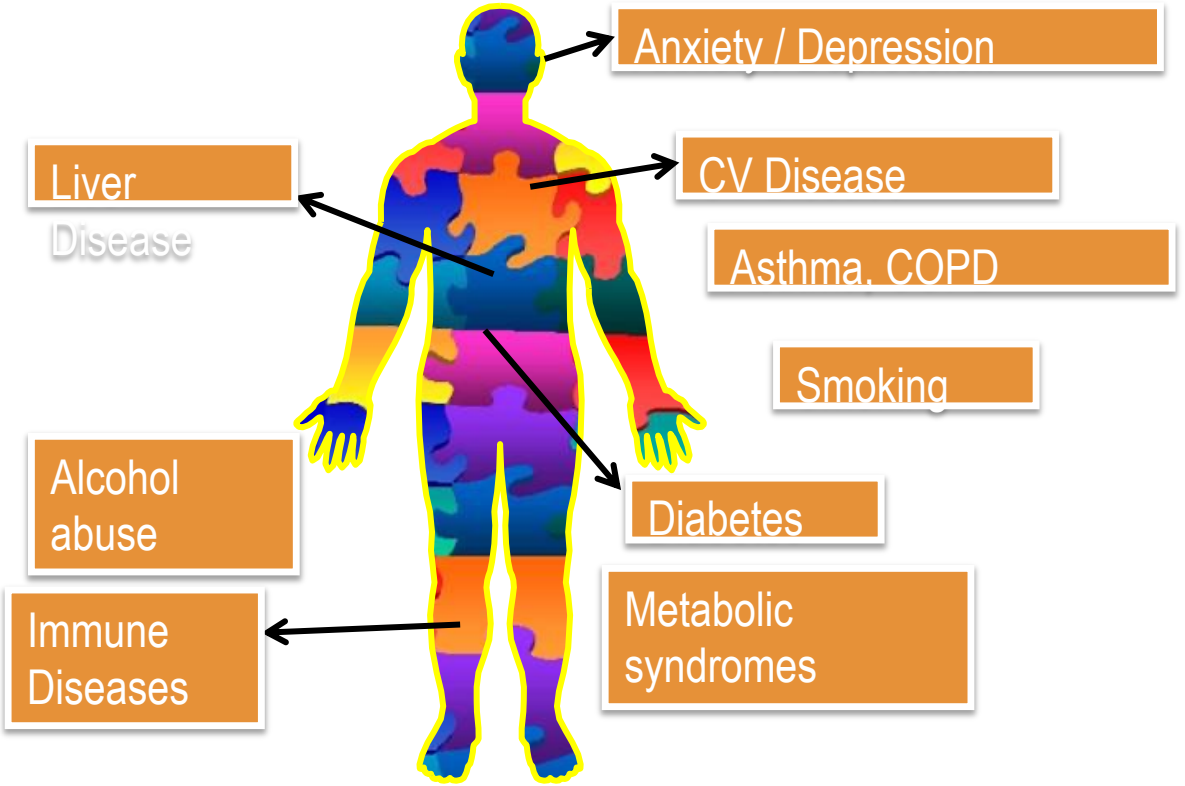
SMI: Multiple Physical Comorbidities

WPA EDUCATIONAL MODULE (World Psychiatry 2011;10:52-77)

Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care

Marc De Hert[1], Christoph U. Correll[2], Julio Bobes[3], Marcelo Cetkovich-Bakmas[4], Dan Cohen[5], Itsuo Asai[6], Johan Detraux[1], Shiv Gautam[7], Hans-Jurgen Möller[8], David M. Ndetei[9], John W. Newcomer[10], Richard Uwakwe[11], Stefan Leucht[12]



People with SPMI suffer from

- more chronic diseases
- greater severity of chronic disease
- late diagnosis
- fewer medical treatments
- Poorer quality care
- Premature death from medical illness (15-20 years shorter life extectancy)
- less likely to receive palliative care

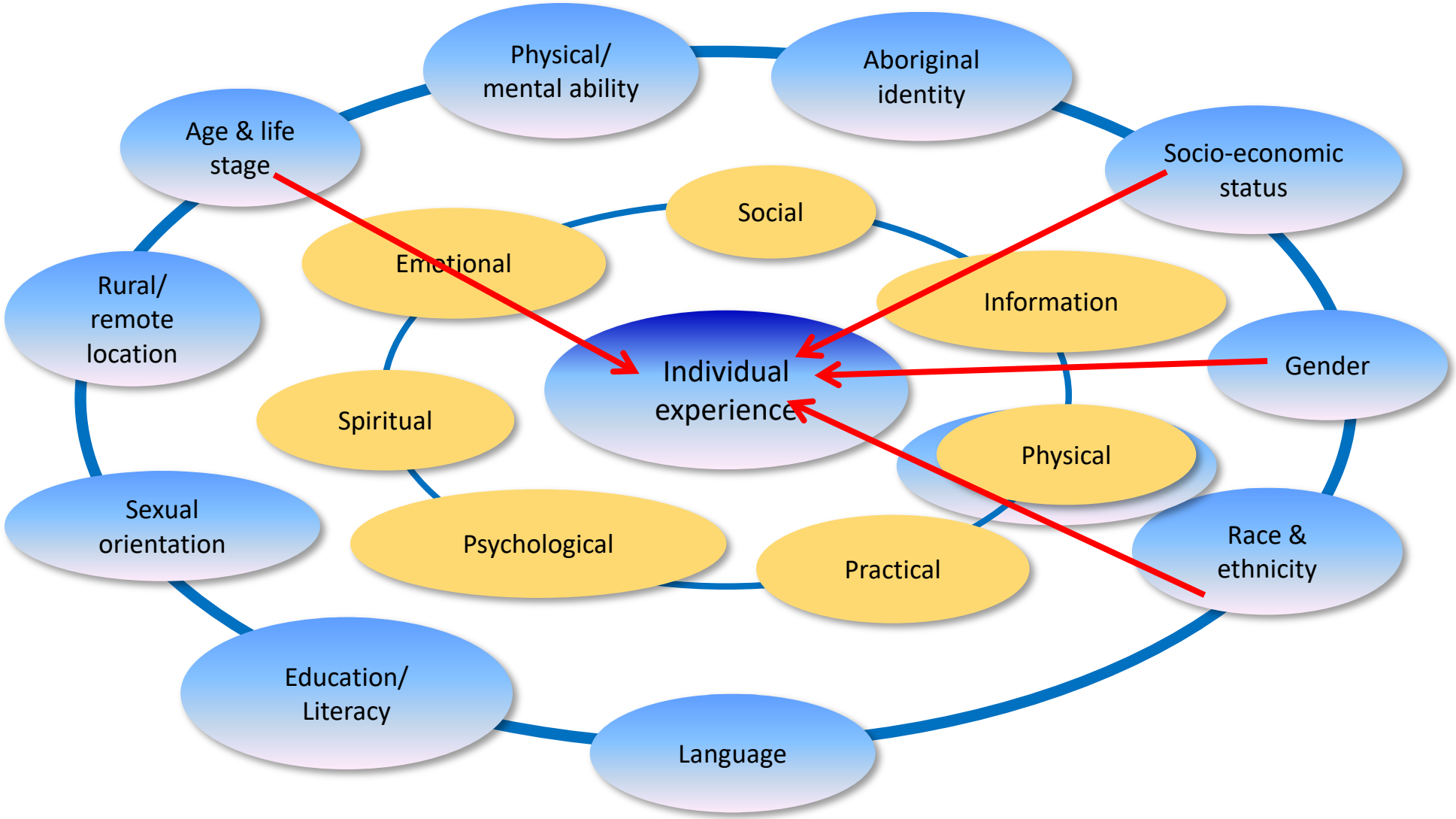
L'importanza del problema nelle persone con SMI

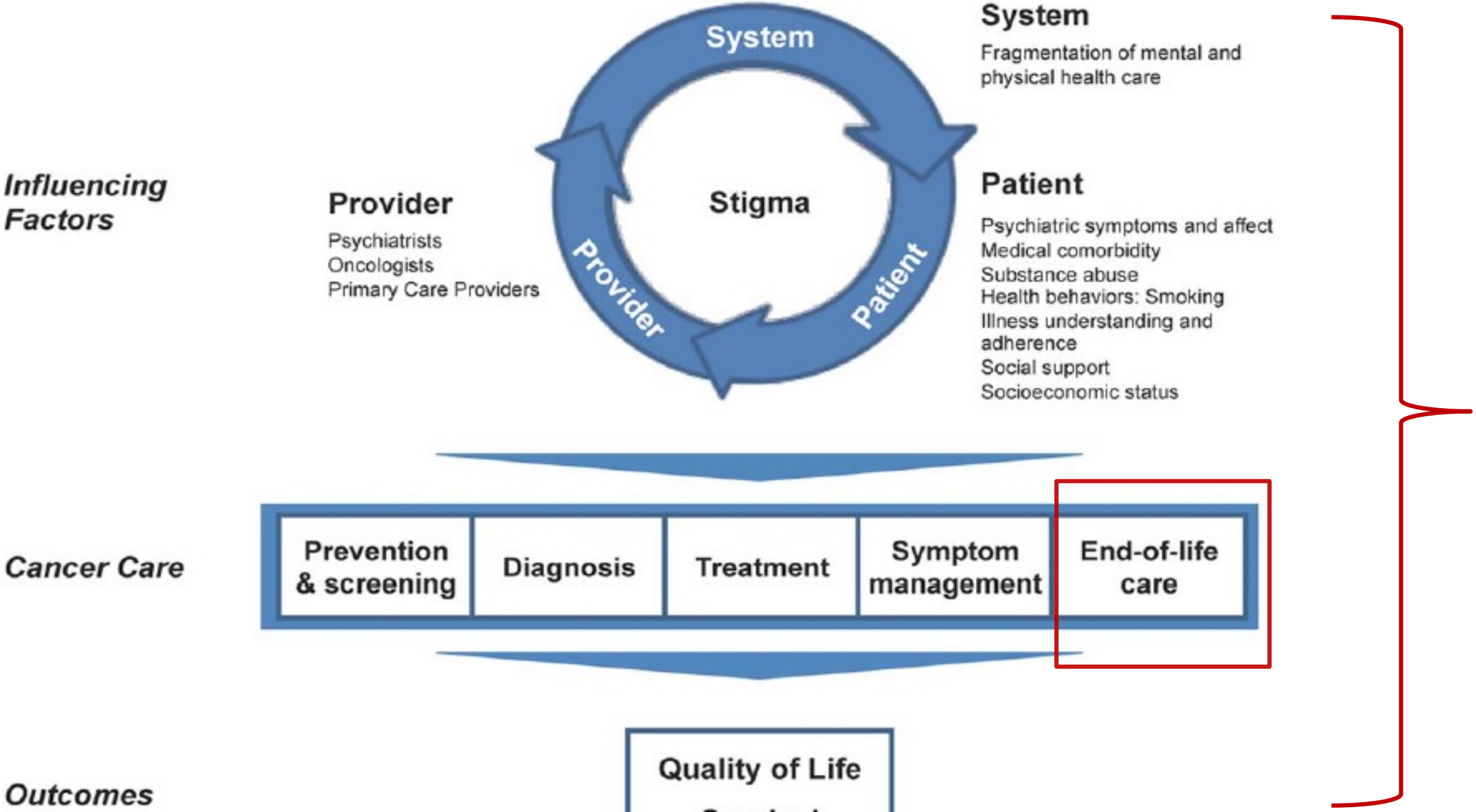
World Health Organization

Key facts

- **Cancer Incidence**: **18.1 million** new cases and **9.6 million** deaths just in 2018.
- **By 2030** the number of new cancer cases is expected to **increase 40%** (high-income countries) > 80% (low-income countries) [10 -11 million cancer cases diagnosed each year].
- Both **survival and mortality** from cancer are projected to **increase** → long survivors worldwide about **43.8 million** and number of deaths **> 13 million** just in 2030

I bisogni delle persone in PC




Influencing Factors
Provider
Psychiatrists
Oncologists
Primary Care Providers
System
Stigma
Provider
Patient
System
Fragmentation of mental and physical health care
Patient
Psychiatric symptoms and affect
Medical comorbidity
Substance abuse
Health behaviors: Smoking
Illness understanding and adherence
Social support
Socioeconomic status
Cancer Care
Prevention & screening
Diagnosis
Treatment
Symptom management
End-of-life care
Outcomes
Quality of Life
Survival

Cancer Mortality

The Breast 40 (2018) 170–176

Impact of schizophrenia and related disorders on mortality from breast cancer: A population-based cohort study in Denmark, 1995–2011

Susanne Oksbjerg Dalton [a, *], Nis Palm Suppli [a], Marianne Ewertz [b], Niels Kroman [c], Luigi Grassi [d, e], Christoffer Johansen [a, f]

Subjects

56,152 women with early-stage breast cancer diagnosed in 1995-2011, of whom 499 women with schizophrenia or related disorders (SMI).

Results

- **Survival** significantly **worse** than that of women without SMI
- Patients with SMI **less likely** to be allocated to guideline treatment
- Among those allocated to guideline treatment **mortality** from both breast cancer and other causes is **increased**.

Psycho-Oncology. 2021;30:2039–2051.

Mortality from cancer in people with severe mental disorders in Emilia Romagna Region, Italy

Luigi Grassi[1] | Elisa Stivanello[2] | Martino Belvederi Murri[1] | Vincenza Perlangeli[2] | Paolo Pandolfi[2] | Fabio Carnevali[1] | Rosangela Caruso[1] | Alessio Saponaro[3] | Mila Ferri[3] | Michele Sanza[4] | Angelo Fioritti[5] | Elena Meggiolaro[6] | Federica Ruffilli[6] | Maria Giulia Nanni[1] | Maria Ferrara[1,7,8] | Paola Carozza[9] | Luigi Zerbinati[1] | Tommaso Toffanin[1] | Marco Menchetti[10] | Domenico Berardi[10]

ER Regional Mental Health Registry during a 10-year period (2008–2017).

→ **12,385** patients suffering from SMI (2/3 schizophrenia spectrum; 1/3 bipolar spectrum disorders), **24% died of cancer.**

→ In comparison with the general regional population, the **mortality for cancer was about 50% higher among patients with SMI**, irrespective if affected by schizophrenia or bipolar disorders.

Can J Psychiatry 2008;53(11):725–736

Palliative Care for People With Severe Persistent Mental Illness: A Review of the Literature

Anne Woods, MD, CCFP[1]; Kathleen Willison, RN, CHPCNC[2]; Cindy Kington, RN, CPMHNC[3]; Alan Gavin, MSW, RSW[4]

Special Issue: Palliative Care in Minority Populations

Help Me Understand: Providing Palliative Care to Individuals With Serious Mental Illness

Kate L. M. Hinrichs, PhD[1,2], Cindy B. Woolverton, PhD[1,2,3], and Jordana L. Meyerson, MD, MSc[4,5,6]

NIHR | National Institute for Health Research

Health and Social Care Delivery Research

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End-of-life care for people with severe mental illness: the MENLOC evidence synthesis

Ben Hannigan, Deborah Edwards, Sally Anstey, Michael Coffey, Paul Gill, Mala Mann and Alan Meudell

Psycho-Oncology. 2021;30:1997–2001.

Disparities and inequalities in cancer care and outcomes in patients with severe mental illness: Call to action

Luigi Grassi[1,2,3]

Michelle B. Riba[4,5]

End of life care

Schizophrenia Research 141 (2012) 241–246

Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada

Harvey M. Chochinov [a,b,*], Patricia J. Martens [c,d], Heather J. Prior [c], Maia S. Kredentser [a]

Conclusions

End-of-life care is lacking for patients with schizophrenia. Compared to their matched cohor → much more likely to die in nursing homes, less likely to see specialists (other than psychiatrists), less likely to be prescribed analgesics, and less likely to receive palliative care.

End of life care

Received: 12 September 2023 | Revised: 9 January 2024 | Accepted: 21 January 2024
DOI: 10.1111/acps.13666

ORIGINAL ARTICLE

Acta Psychiatrica Scandinavica WILEY

Patients with both cancer and psychosis—to what extent do they receive specialized palliative care

Jenny Bergqvist[1,2] | Stina Hedskog[2] | Christel Hedman[3,4] | Torbjörn Schultz[4] | Peter Strang[4,5,6]

Methods: Stockholm Regional Council: 23,056 patients aged >18 years → 320 patients had a concomitant diagnosis of psychosis

Results: Patients with cancer and psychosis were less likely to receive SPC compared to patients with cancer only; four and a half years younger at the time of death; more likely to reside in nursing and a higher prevalence of low area-based socioeconomic status

Tabella S7.9 Ostacoli nella gestione delle persone con patologie psichiatriche gravi (Severe Mental Illness, SMI) e possibili interventi

Fattori legati al paziente	Fattori legati al contesto di cura	Fattori socioculturali
Sintomi psicotici cronici (ad es. *sintomi positivi*: deliri, allucinazioni; *sintomi disorganizzati*: comportamento bizzarro, alterazione della forma del pensiero)	Sistemi sanitari isolati tra lo	Mancanza di risorse sociali
Sequele cognitive della patologia psichiatrica	Mancanza di *expertise* interdisciplinare	Difficile accesso a figure che hanno procura sulla salute della persona con SMI
Sintomi negativi: apatia, abulia, ritiro sociale, alogia	Stigma verso la malattia mentale	

Stigma and Dignity

TYPES OF STIGMA

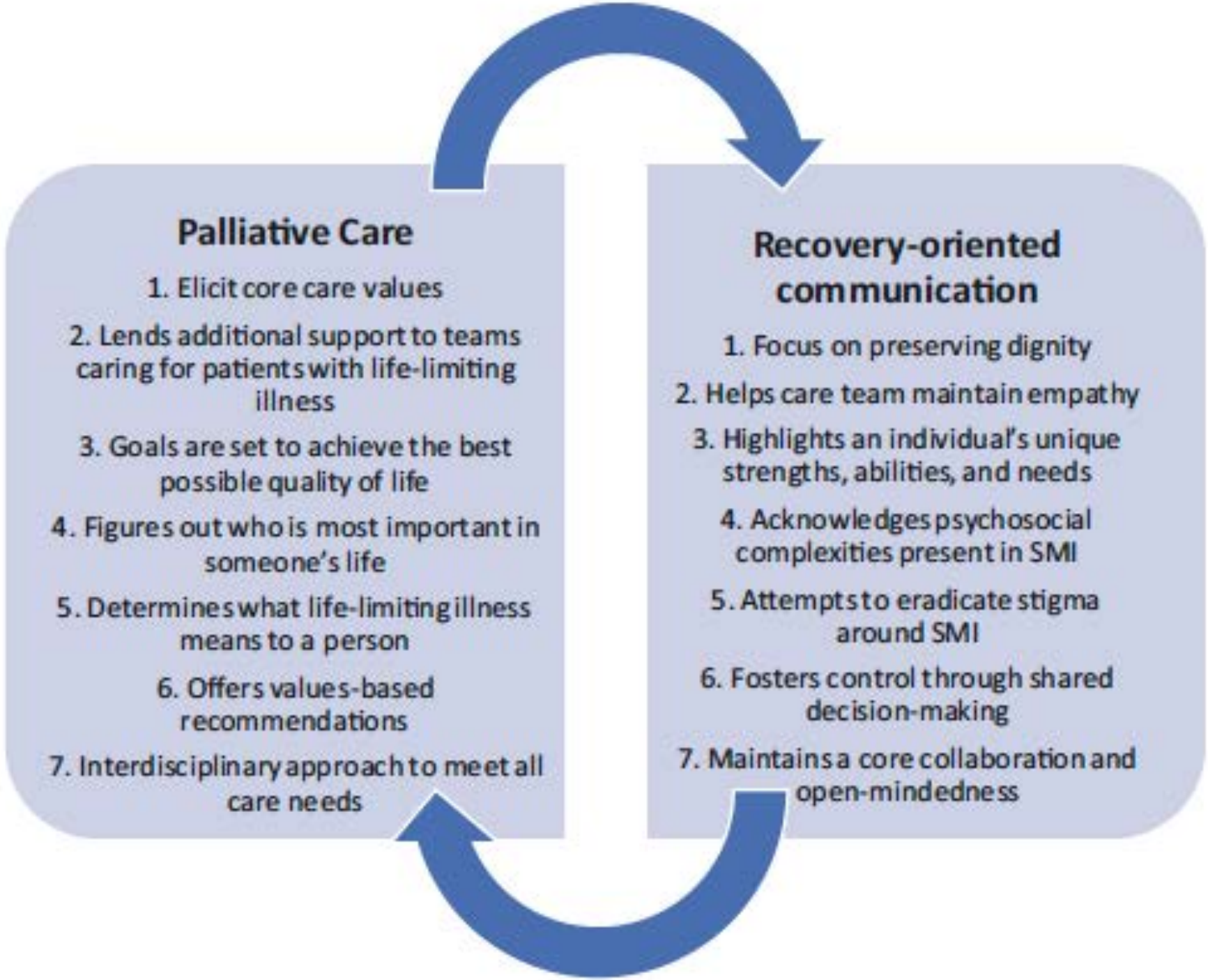
Action-oriented view
Public stigma
Structural stigma
Courtesy stigma
Provider-based stigma
Self-stigma

Experiential perspective
Perceived
Endorsed
Anticipated
Received
Enacted

- Personal Stigma ***(Self-stigma)***
- Public Stigma (***Social stigma)*** *[Stereotype, Prejudice, Discrimination]*

- Personal Dignity (***dignity of self)***
- Social Dignity ***(dignity in relation)***

Grassi, in press ; Grassi & Chochinov, 2024


Palliative Care
1. Elicit core care values
2. Lends additional support to teams caring for patients with life-limiting illness
3. Goals are set to achieve the best possible quality of life
4. Figures out who is most important in someone's life
5. Determines what life-limiting illness means to a person
6. Offers values-based recommendations
7. Interdisciplinary approach to meet all care needs
Recovery-oriented communication
1. Focus on preserving dignity
2. Helps care team maintain empathy
3. Highlights an individual's unique strengths, abilities, and needs
4. Acknowledges psychosocial complexities present in SMI
5. Attempts to eradicate stigma around SMI
6. Fosters control through shared decision-making
7. Maintains a core collaboration and open-mindedness

Raccomandazioni

- **Accesso al sistema di cure garantito** → integrazione tra i servizi (salute mentale, cure palliative, medicina generale, servizi sociali) e garanzia di continuità delle cure, interdisciplinarietà e lavoro di team multispecialistico
- **Formazione interdisciplinare** tra medicina palliativa e psichiatria è priorità
- **Integrare i principi dell'hospice** nelle cure di fine vita per le persone con SMI
- **Rivedere e sviluppare linee-guida** dedicate ai bisogni di questa fascia della popolazione

Interventi per il paziente

- Assicurare la continuità delle cure psichiatriche mantenendo e aggiustando il dosaggio dei farmaci, monitorando le interazioni tra farmaci, garantendo supporto

- Incoraggiare le capacità di valutazione caso per caso basandosi sul pregiudizio che tutte le persone con SMI siano incapaci di prendere decisioni
- Dare sostegno all'équipe nel comunicare la situazione medica in maniera concreta, centrata sulle abilità comunicative e cognitive della persona

- Istruire l'équipe sanitaria sul significato dei sintomi negativi
- Contrastare convinzioni errate che questi significhino disinteresse per la cura
- Assistere e sostenere i pazienti nel fare domande e nel comunicare con efficacia

Interventi per il team

- Rendere espliciti i problemi tra il team oncologico e quello psichiatrico per facilitare la comunicazione tra gli specialisti e incoraggiare l'adozione di una cura medica e psichiatrica sulla base dei bisogni dei pazienti
- Effettuare training interdisciplinari tra specialisti dell'oncologia e della salute mentale
- Aiutare l'équipe a evitare errori, quali attribuzione errata di sintomi fisici alla malattia mentale, affinché i pazienti con SMI ricevano terapie mediche appropriate e tempestive

Da Grassi L.: Cure psicosociali in medicina palliativa, Poletto ed., Milano,. 2022

Interventi per il team

- Integrare la valutazione dei bisogni sociali all'interno dell'assistenza medica al fine di affrontare eventuali difficoltà (ad es. isolamento sociale, problemi abitativi) che possano impedire l'erogazione di cure ottimali di fine vita

- Agganciare il paziente anticipatamente al progetto di cura fornendo guida e assistenza all'équipe di salute mentale e di cure palliative sulle discussioni di fine vita

Da Grassi L.: Cure psicosociali in medicina palliativa, Poletto ed., Milano,. 2022

Box 1. Topics covered in the mental health workshops for palliative care workers

- Description of schizophrenia, bipolar affective disorder, major depression
- South Australian Mental Health Act 2009
- Mental state examination and mental health assessment
- Medications used to manage the above diseases and implications for end-of-life care
- How to initiate community referrals to mental health services
- Consumer (a person who lives with a mental illness) personal story

Box 2. Topics covered during the palliative care workshops for mental health workers

- Terminology: palliative care, a palliative approach, end-of-life care, terminal care
- Referral process to the specialist palliative care services
- Legal orders: advance care planning and advance care directives
- Disease trajectories: cancer, organ failure, dementia
- Common symptom issues
- Case presentations to illustrate the above information

Barrier	Strategy
Identification	
Inconsistent mental illness documentation	Screen new oncology appointments for SMI (psychiatric diagnosis) and medications (antipsychotics, mood stabilizers)
Fragmentation of cancer and mental health care	Develop partnerships with oncology and community-based clinicians to facilitate referrals

Barrier	Strategy
Consent	
Cognitive deficits	Use verbal consent process, concrete language, and repetition
Paranoia, mistrust	Avoid complicated written documents
Need protection from coercion	Assess patients' capacity to consent with validated tool and process that promotes understanding of risks and benefits

Barrier	Strategy
Retention	
Complex care delivery system	Visit patients in multiple care and residential settings (outpatient clinic, hospital, and community)
Social isolation, poverty	Identify and engage caregiver (broad definition of caregiver), address social determinants of health
High burden of medical and psychiatric symptoms	Link study visits to oncology care and allow patients to complete assessments in person, by phone, or email

WPA – IPOS Global Initiative

- To build a network of people interested in the field of cancer / PC and SMI
- To work together on common projects as a part of global group to
  - Gather data on a national level
  - Conduct research projects
  - Create guidelines and recommendations
  - Create modules to train both oncologists and mental helath proessionals in the care of people with SMI affected by cancer

WORLD PSYCHIATRIC ASSOCIATION

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Grazie per l'attenzione

luigi.grassi@unife.it