IL PAZIENTE CHE INVECCHIA

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SITE SOCIETA' ITALIANA TALASSEMIE ED EMOGLOBINOPATIE

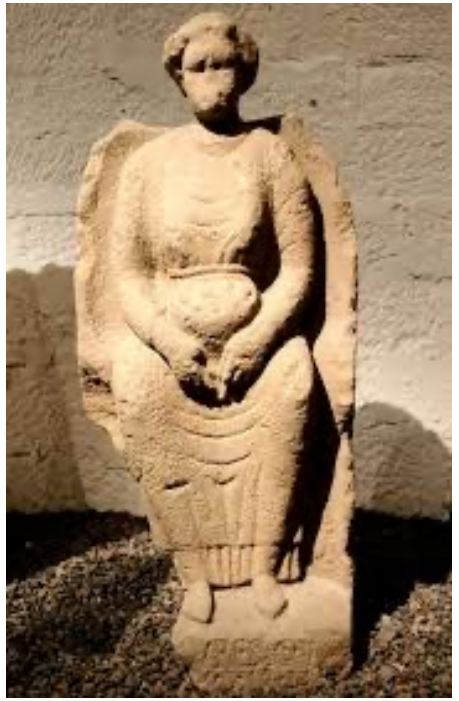
XIV CONGRESSO NAZIONALE SITE

Roma, 11-13 Settembre 2025

Pontificia Università Urbaniana

Il ruolo dell’infermiere nella gestione del paziente cronico con malattie rare

- **Assistere**
- **Prendersi cura**



Nella mitologia Romana

Cura era la Dea dell’inquietudine.

Il mito racconta che, un giorno, nell’attraversare un fiume, Cura sia stata attratta dal fango argilloso.

Pensosa, senza bene rendersi conto di quello che stava facendo, Cura si mise a modellare la figura di un uomo.

La Dea chiese a Giove di soffiare lo spirito vitale nella scultura da lei plasmata, cosa a cui Giove acconsentì con facilità.

Fu così che nacque questo essere a cui bisognava dare un nome.

Ne nacque un litigio su chi avrebbe dovuto dargli il nome tra Giove, che gli aveva infuso la vita, Cura che lo aveva plasmato e Terra che aveva fornito il materiale da plasmare.

Per risolvere la controversia fu chiamato a pronunciarsi Saturno il cui giudizio distribuì le rivendicazioni:

Giove, che aveva infuso lo spirito sarebbe toccato, alla morte, di rientrare in possesso dell'anima;

Terra, della cui materia l'essere era composto, sarebbe tornato il corpo dopo la morte;

MA

a possederlo durante tutta la vita,

ad accompagnarlo e a garantirne la salute

sarebbe toccato a CURA la Dea dell’Inquietudine, la prima a plasmarlo.

Cura Dea dell'INQUIETUDINE

Patologie Ereditarie
CRONICHE e DEGENERATIVE

PROBLEMI CHE INSORGONO:

ACCESSI VENOSI DIFFICILI

ANSIA

INSODDISFAZIONE

PAURA

IMPAZIENZA

INSOPPORTAZIONE (puntura, tempo trascorso in ospedale)

COSA POSSIMO FARE:

ACCESSI VENOSI STABILI come PAC

CONSOLARE

RASSICURARE

CURARE

Prendersi carico del paziente

Prendersi CURA

Prendersi CURA

Ascoltare, Consigliare, Sostenere, Essere empatici, Comunicativi

Non è solo curare

Spesso è difficile e frustrante, inquieta anche noi operatori

Ma è la nostra professione

Dobbiamo cercare di farla sempre al meglio

IL CORPO CHE RESISTE…

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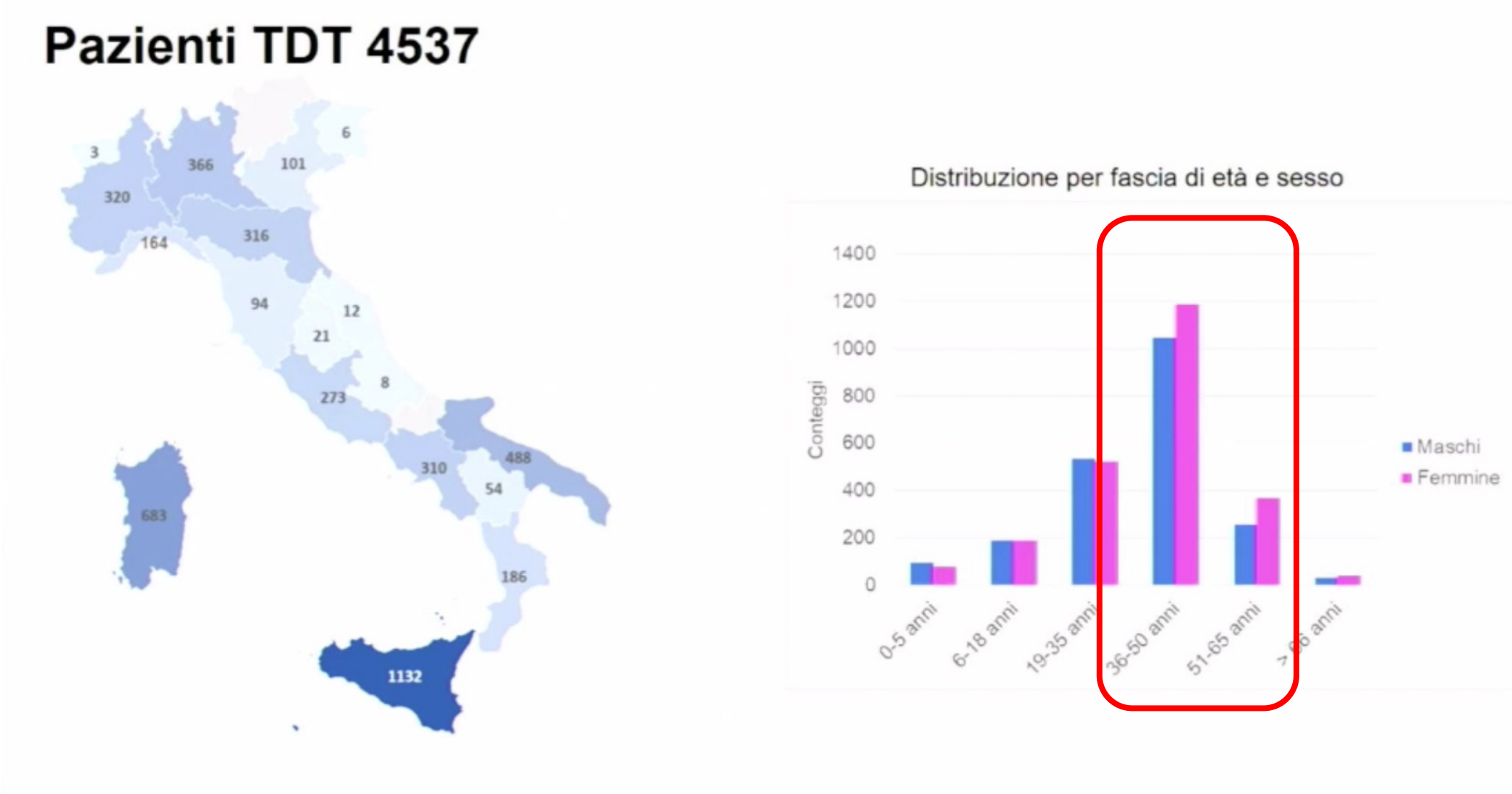
Disclosures of Name Surname

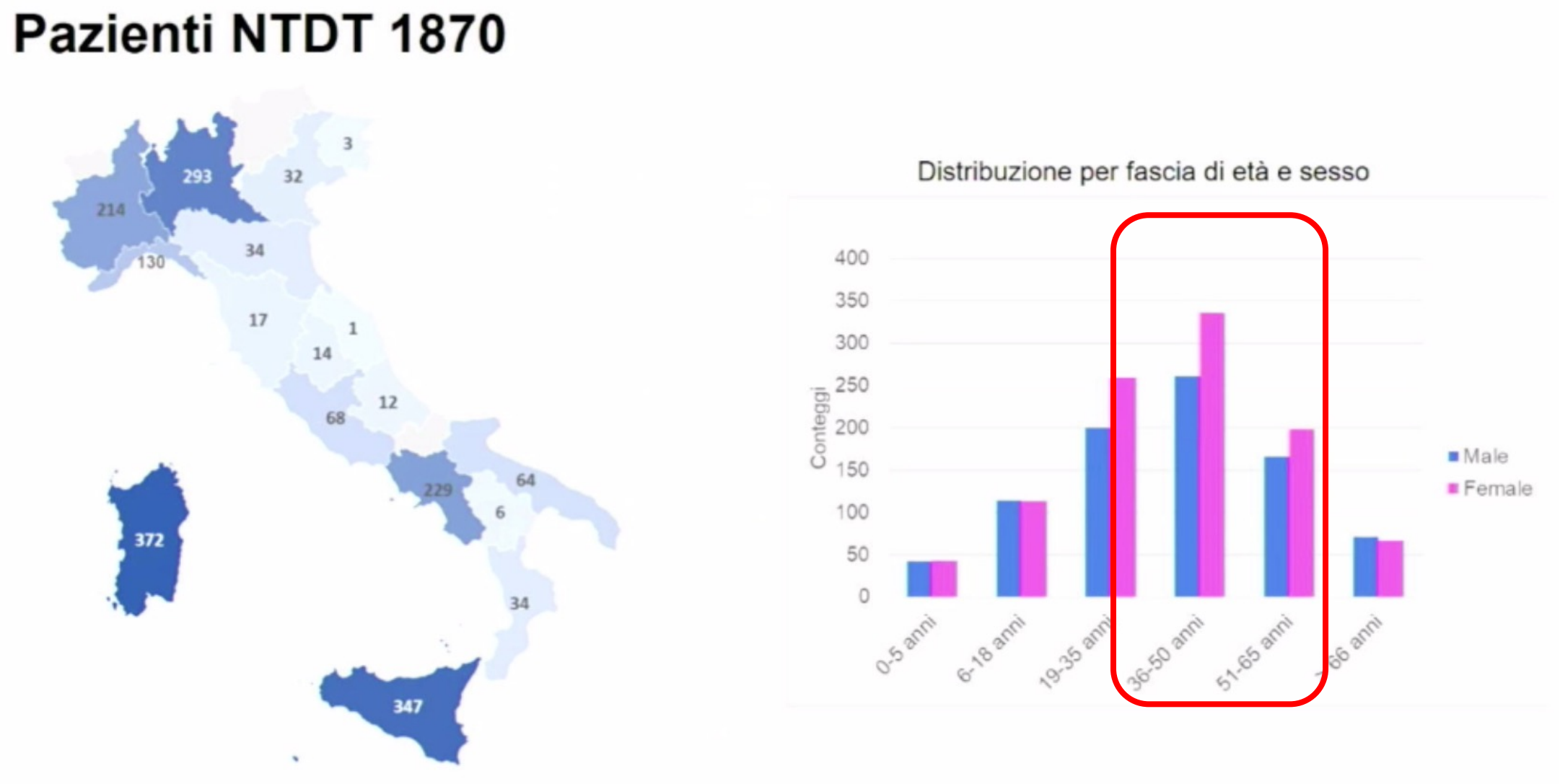
Company name	Research support	Employee	Consultant	Stockholder	Speakers bureau	Advisory board	Other
Nothing to disclose							

AGING IN THALASSEMIA



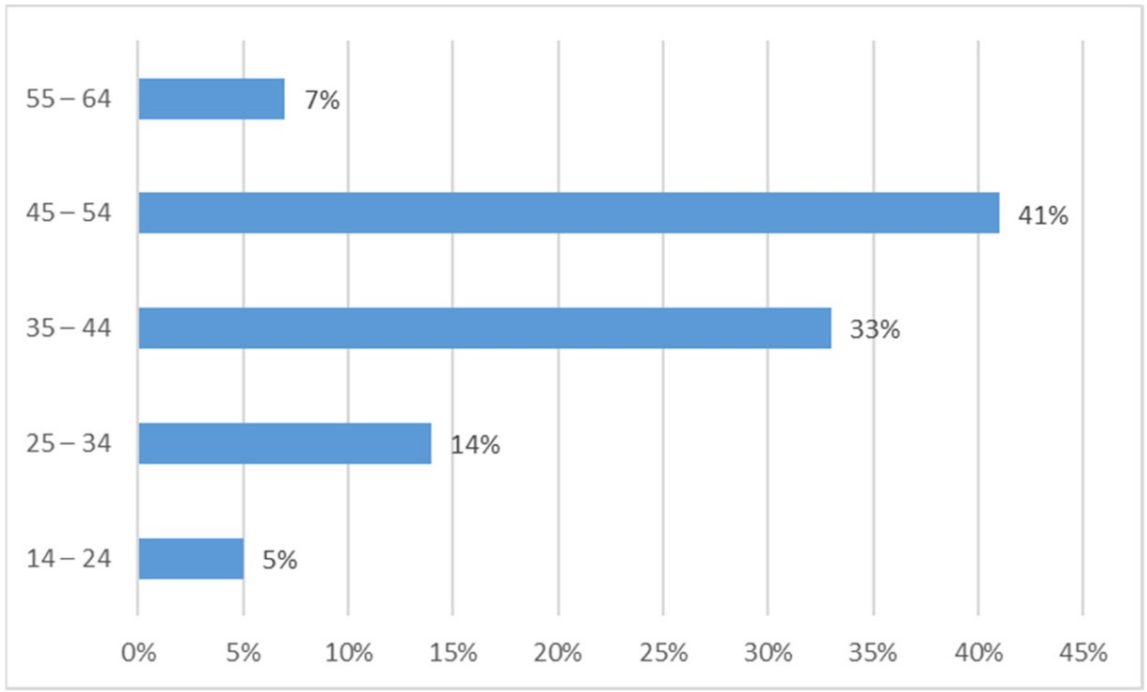
Censimento SITE 2019, Forni GL Congresso SITE 2020

AGING IN THALASSEMIA

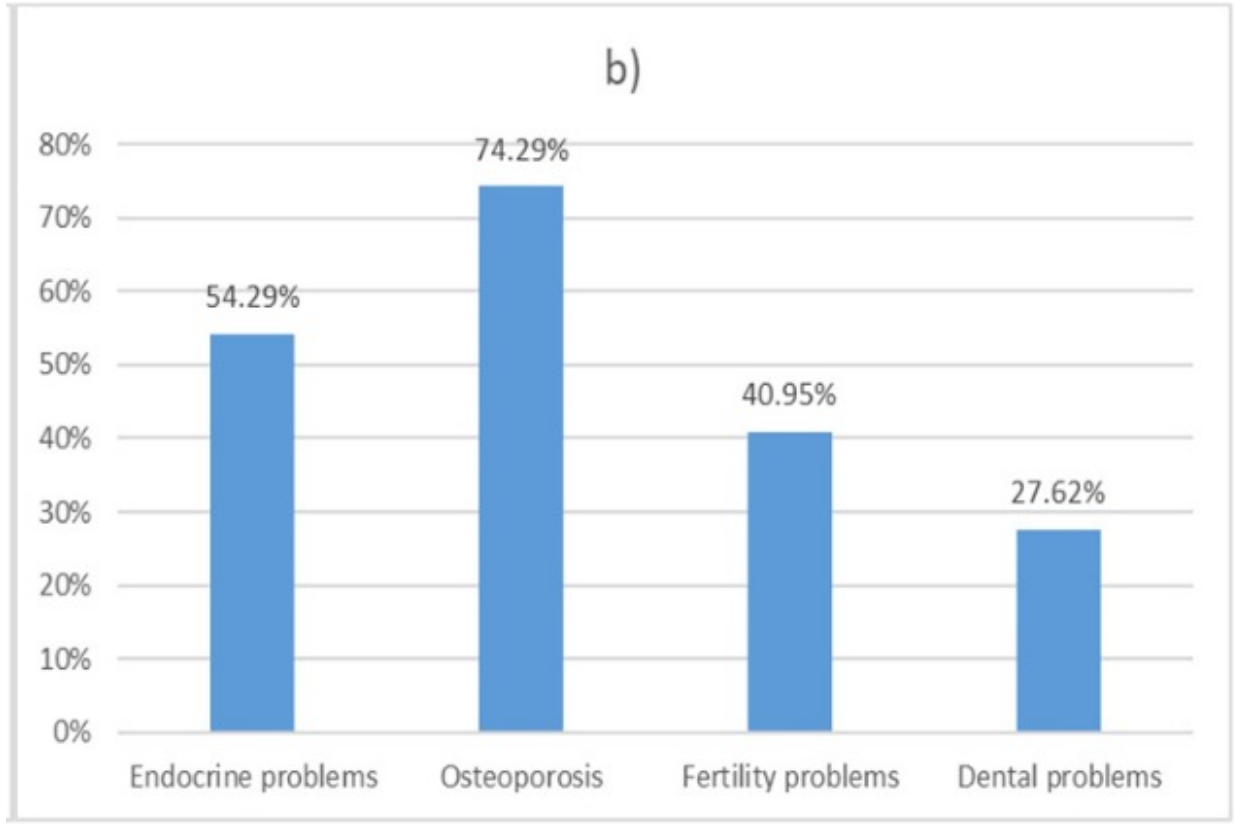


Censimento SITE 2019, Forni GL Congresso SITE 2020

AGING IN THALASSEMIA -QOL-



167 TDT, 105 responder
42.4 ± 9.16 (14-64)



Tedon F et al. J. Clin. Med. 2022, 11-15

AGING IN THALASSEMIA -QOL-

Trigger point

Lower overall psychological well-being and a significantly lower level of well- being in the general health and vitality domains

Burden of disease high in terms of time spent for transfusions (time, chelation treatment, for non-transfusion activities (managing specialists visits, blood tests, therapy complications) and family management (time subtracted to family activities, babysitting, organizing work permissions).

AGING IN THALASSEMIA

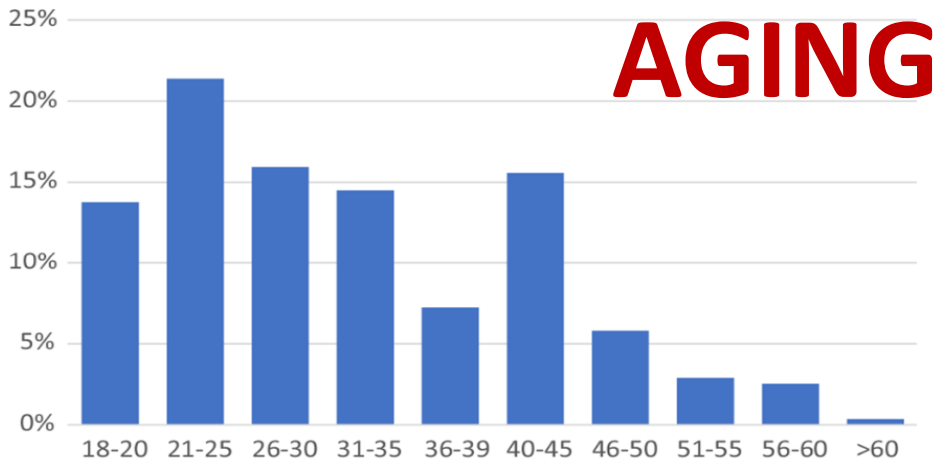


Fig 1.
Age distribution of adult study participants with thalassaemia in the CDC Consortium.

Table II.

Socioeconomic demographics of younger and older adults with thalassaemia.

	Age 18–39		Age ≥40		Chi-square *P* values 18–39 vs ≥40
	No.	%	No.	%	
Education					0·2401
Other	13	6·5	5	6·7	
≤High school	43	21·4	10	13·3	
Some college	68	33·8	22	29·3	
Bachelor's degree	56	27·9	28	37·3	
Master or doctoral	21	10·4	10	13·3	
Employment					0·3311
Employed full-time	72	35·8	35	46·7	
Employed part-time	31	15·4	11	14·7	
Not employed	89	44·3	28	37·3	
Marital status					<0·0001
Single	149	74·1	29	38·7	
Married/partnered	43	21·4	41	54·7	
Separated/divorced/widowed	0	0	4	5·3	
Health insurance					0·0021
Other	46	22·9	12	16	
Commercial	99	49·3	47	62·7	
Medicaid	45	22·4	5	6·7	
Medicare	9	4·5	10	13·3	
Uninsured	2	1	1	1·3	
All	201	100	75	100	

Table IV.

Transfusion and iron overload: cardiac, liver and serum iron values.

	Age 18–39			Age ≥40			
Cardiac, liver and serum iron values	*n*	Mean	SD	*n*	Mean	SD	*t*-test *P* values
Age, years	201	27·2	6·1	75	47	6	
Serum ferritin, last 12 months	181	2434	2342	71	1251	1554	<0·0001
Serum ferritin by diagnosis							
Beta thalassaemia major	130	2395	2083	53	1415	1749	0·003
Beta thalassaemia intermedia	13	2171	2580	17	740·6	510·8	0·007
HbH-Constant Spring	13	2029	2992	1	1215	0	
Cardiac iron, MRI T2	124	24·5	13·5	48	30·4	9·2	0·001
Liver iron content							
Liver dry weight (mg iron per gram liver weight); MRI or liver biopsy *	128	10·6	10·5	46	4·5	5·7	<0·0001
Liver wet weight (mg iron per gram liver weight): SQUID †	17	4·8	7	6	1·4	0·7	0·06

MRI, magnetic resonance imaging; SD, standard deviation; SQUID, Superconducting Quantum Interfering Device.

*Liver iron content (mg iron per gram liver dry weight) measured by MRI ($n = 126$) and by liver biopsy ($n = 3$; one liver biopsy result not available for analysis) in $n = 128$ younger adults and by MRI in $n = 46$ older adults.

†Liver iron content wet weight measured by SQUID in $n = 7$ younger adults and $n = 6$ older adults.

Chapin J et al. Br J Haematol, 2022; 196(2): 380–389.

AGING IN THALASSEMIA

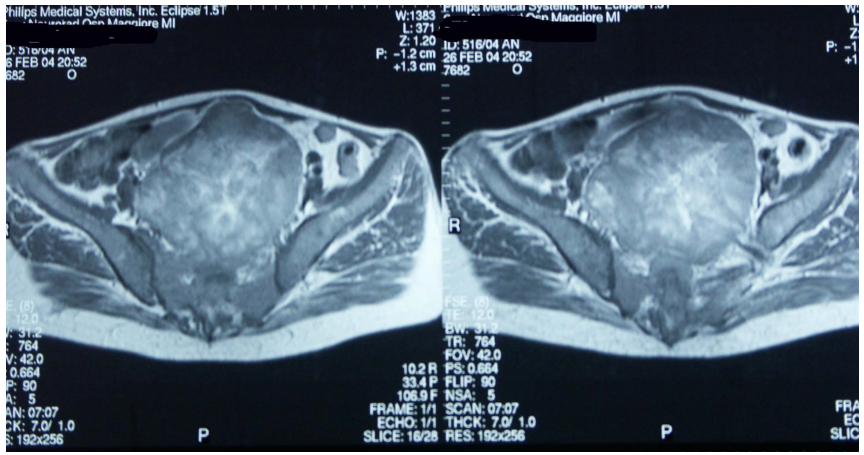
Table 1. Age-related complications in thalassemia. CMR: cardiac magnetic resonance; ECG: electrocardiography; DOACs: direct oral anticoagulants; CPET: cardiopulmonary exercise testing; CTEPH: Chronic Thromboembolic Pulmonary Hypertension; US: ultrasound; dw: dry weight; LIC: liver iron concentration; DFX: deferasirox.

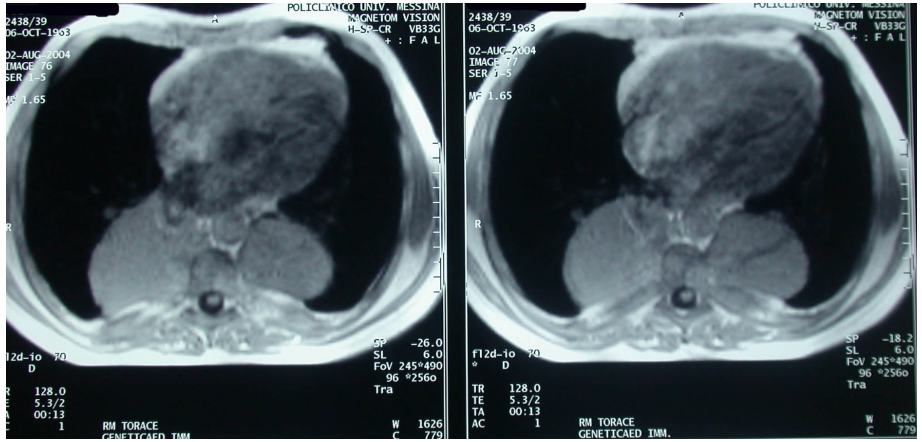
Complication	Diagnosis	Treatment	Future perspective
Heart failure	Echocardiography and CMR T2* annually [40].	Anemia and iron overload management. Treatment for heart failure as in general population, with particular attention to blood pressure	Studies about prevalence in older patients.
Arrhythmias	ECG every three-four months; 24 hours Holter-ECG annually.	As in general population; the need for anticoagulation should be patient-tailored.	Recommendations on DOACs
Pulmonary hypertension	NTDT: proBNP measurement and echocardiography annually or biannually [40]. CPET can be considered.§	Warfarin for CTEPH. For group 5 PH, consider regular transfusion regimen and specific therapies in selected cases	Recommendations on RHC
Adrenal insufficiency	Basal adrenal function evaluation (serum ACTH and cortisol). If borderline values stimulation test with Synachten [40].	Chronic replacement therapy for clinical adrenal insufficiency. For partial/subclinical adrenal insufficiency replacement therapy during stressful events	Studies about prevalence in older patients.
Bone disease	Biochemical markers of bone turnover [40], femoral and spine DXA every 18–24 months, bone X-ray.§	Vitamin D and calcium supplementation if needed, bisphosphonates therapy. In selected cases therapy with denosumab/teriparatide.	Recommendations on denosumab and teriparatide
Cancer	As in general population according to suspected origin and localization (Bi)annual abdominal US in patients with HCV and/or HBV infection, NTDT with LIC ≥5 mg Fe/g dw, TDT with LIC ≥7 mg Fe/g dw, advanced cirrhosis [40] and in all those aged over 40 years.§	As in general population (according to grade, stage and performance status)	Epidemiological studies
Renal disease	TDT: Renal function monthly [40]. NTDT: According to renal function and therapy 24-hours urinary creatinine, protein and calcium annually [40],§ patients on DFX: protein and creatinine on single urine sample monthly.§ Abdominal US annually [40]	As in general population, according to stage Optimize medication through targeted deprescribing	Pathophysiology of renal disease and role of iron chelators.

§From authors' experience.

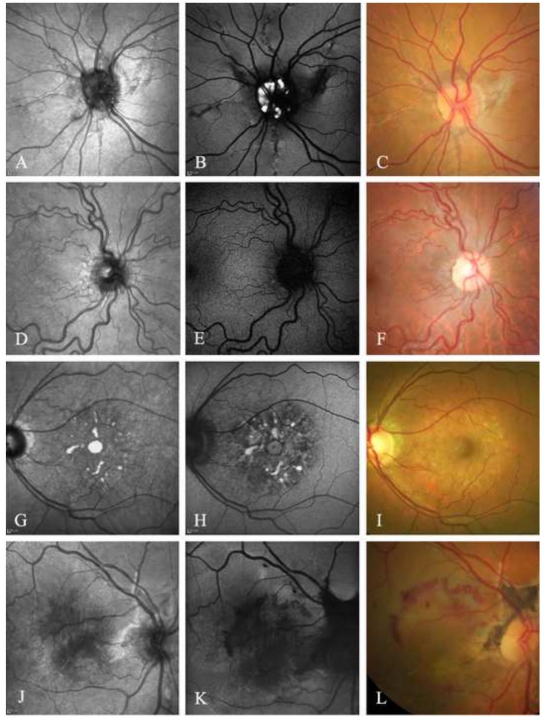
Motta I, Expert Review of Hematology, 2020, 13:1, 85-94

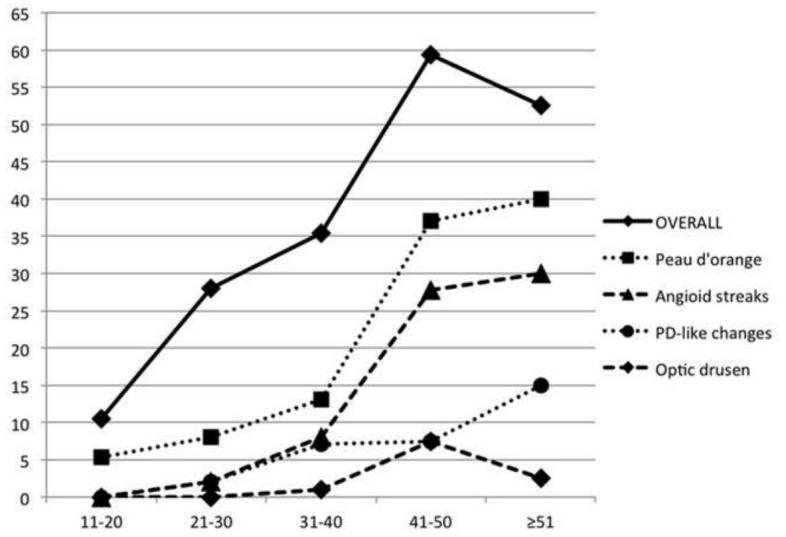
AGING IN THALASSEMIA





Meo A, Int J Lab Hematol. 2008 Oct;30(5):425-31





Barteselli G, Ophthalmology, 2014, Vol 121 (3); 709-718.

Mean age of patients with relevant lens opacification affecting their vision: 53.5 years

Akitridou F, HIPPOKRATIA 2021, 25, 2: 79-82

AGING IN THALASSEMIA

Caregiver
Prima genitori, ora figli

Terapie multiple

Farmaci innovativi

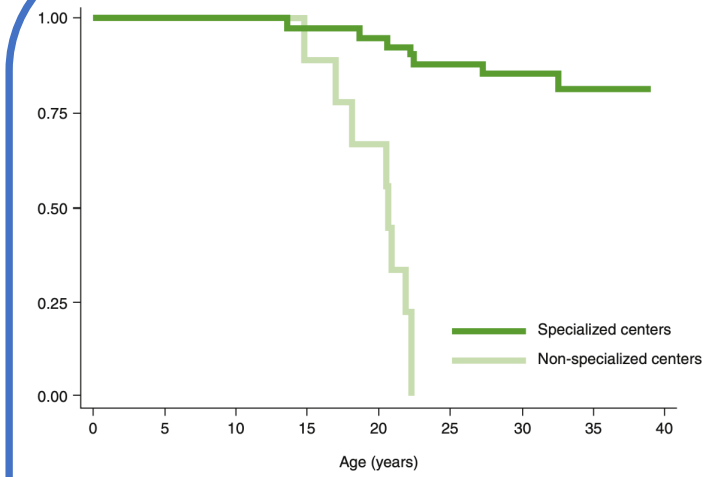
Terapie «psichiatriche»

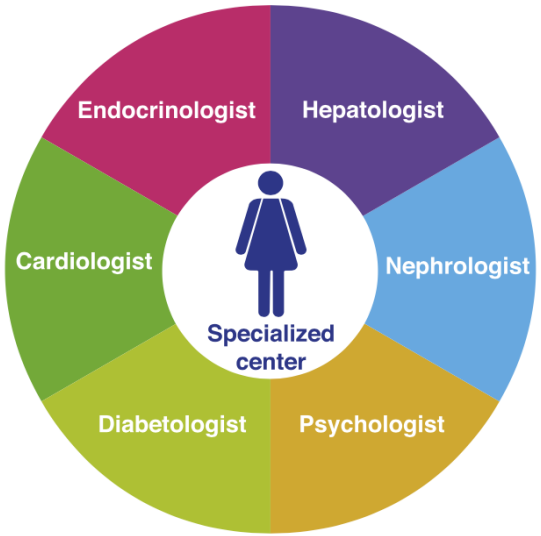
Protocolli ricerca nuovi farmaci

Compliance

Controllo di tutte le comorbidità con :
- Carico psicologico
- Carico «controlli»
- Trasfusione dipendenza

Nuove figure:
- Neurologo
- Geriatra
- Fisiatra

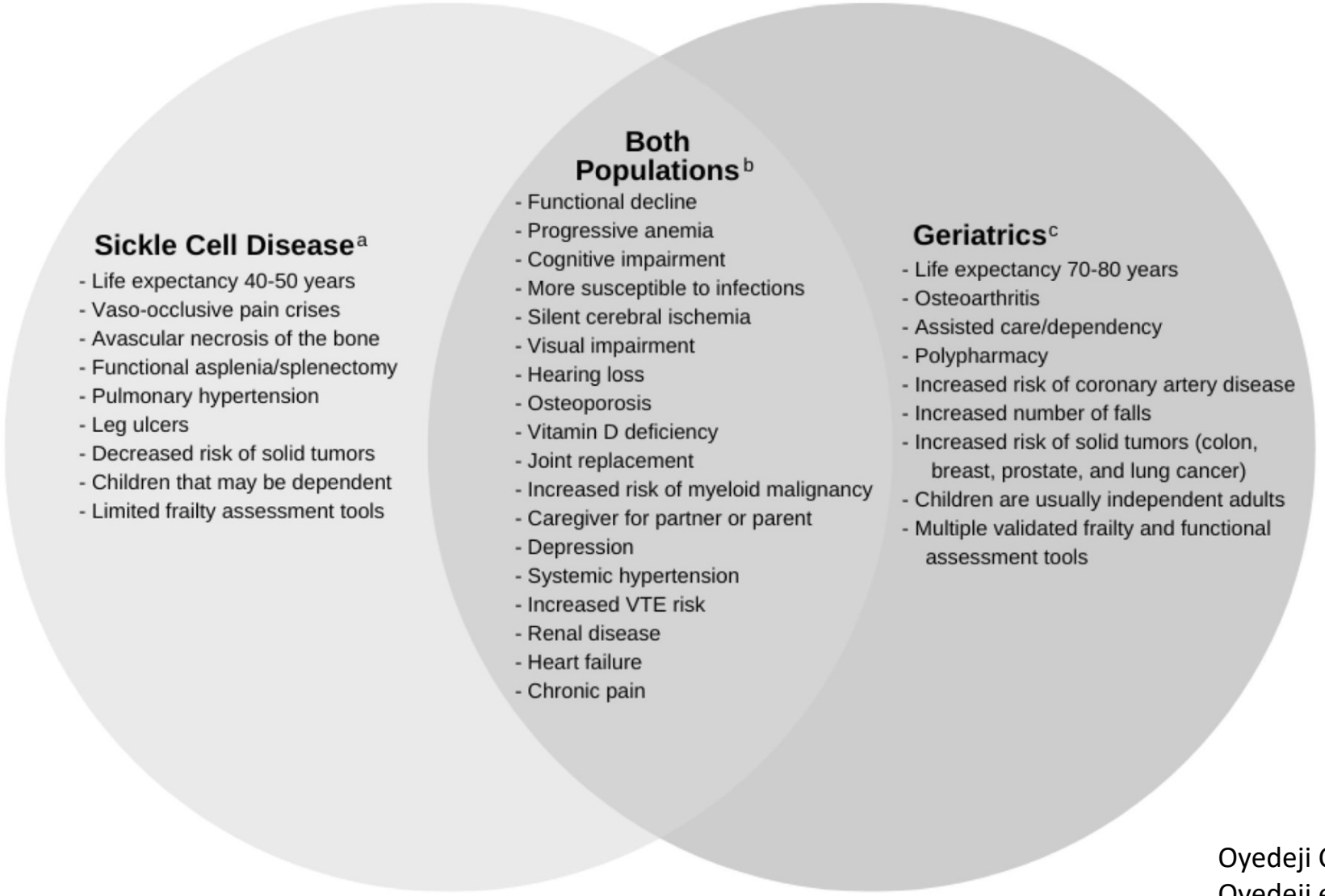




Blood Bank, Radiologist, Transplantation Team, Gynecologist, General Surgeon, Oculist

Pinto VM, Blood Reviews 2019; 38, 100594

AGING IN SCD



Oyedeji CI et al. Drugs Aging, 2023; 40(4): 317–334
Oyedeji et al. Pilot and Feasibility Studies (2020) 6:131

AGING IN SCD

Table 1

Current sickle cell therapies and potential issues in older adults

Therapy	Mechanism	Clinical trial in adults and age of treatment group	Potential issues in older adults
Hydroxyurea[26]	-Increases fetal hemoglobin, thereby reducing polymerization of HbS - Reduces leukocytes and number of adherent reticulocytes - Reduces frequency of vaso-occlusive events and acute chest syndrome	Multicenter Study of Hydroxyurea (MSH) Mean age 30.5, 10% over age 40	Renal clearance May cause: • Reversible, dose-dependent myelosuppression due to age-related decline in hematopoietic stem cells • Decreased drug clearance as eGFR declines, requiring dose reduction
Opioids[31,32]	Agonist or mixed agonist/ antagonists of Mu-opioid receptor	Weight-based vs patient-specific opioid dosing in acute setting Median age 27.0 (IQR 23.0-32.5)	Hepatic (first pass) and renal clearance May cause: • Excess sedation, confusion, respiratory depression • Opioid-induced constipation • Increased falls • Cognitive impairment • Decreased muscle strength • Osteoporosis • Hypogonadism • Dental Issues
Transfusion Therapy[33,34]	Increases total hemoglobin and reduces hemoglobin S%	The Preoperative Transfusion in Sickle Cell Disease Study 0-9 years 40% 10-19 years 35% ≥ 20 years 25% The Transfusion Alternatives Preoperatively in Sickle Cell Disease (TAPS) study Median age 13.4 (IQR 6.4-26.5)	Reticuloendothelial system clearance May cause: • Volume overload • Iron overload • Alloimmunization to minor red blood cell antigens
Iron Chelation Therapy Deferoxamine[35] Deferiprone[36] Deferasirox[37]	Removal of excess iron from tissues	Barriers to adherence to Deferoxamine Mean age 12.1 (range 5-17) Deferasirox in Sickle Cell Trial Median age 15 (range 3-54) Ferriprox in Patients with Iron Overload in Sickle Cell Disease Trial (FIRST) Mean age 16.9 ± 9.6 (range 3-59)	Deferoxamine • Urine and fecal excretion • May cause hearing loss, visual disturbances, and osteoporosis Deferiprone • Urine excretion • May cause agranulocytosis and arthropathy Deferasirox • Fecal excretion • Can be nephrotoxic so should be avoided when eGFR is < 40 mL/minute/1.73m^2[38] • May cause acute liver injury

DRUGS USE

DRUGS INTERACTIONS

Oyedeji CI et al. Drugs Aging, 2023; 40(4): 317–334
Oyedeji et al. Pilot and Feasibility Studies (2020) 6:131

AGING IN SCD -TREATMENTS-

Clinical trials for current and emerging therapies have had little or no representation from older adults (age ≥ 40 years) and individuals with severe end organ damage or fragilty.

More real-world data are needed to determine safety and effectivness of sickle cell therapies in older adults.

Management of older adults: focus on both disease and age-related conditions

Consideration for the impact of physiological changes: decline in renal and hepatic function and increased sensitivity to psychoactive medications.

Oyedeji CI et al. Drugs Aging, 2023; 40(4): 317–334
Oyedeji et al. Pilot and Feasibility Studies (2020) 6:131

AGING IN SCD

Table 1. Demographics and social history of study participants.

Characteristics	Participant (n = 19)
Mean age, years (range)	58 (50-71)
	n (%)
Female	9 (47%)
Race	
Black/African American	18 (95%)
Other, Israeli	1 (5%)
Household Income/year	
< $10 000	2 (11%)
$10 000-$50 000	8 (42%)
> $50 001	8 (42%)
Refused to answer	1 (5%)
Employment status	
Working	9 (47%)
Unemployed	1 (5%)
Disabled	6 (32%)
Retired	2 (11%)
Other	1 (5%)
Education level	
High school graduate or less	5 (21%)
Some college/associates/technical school	7 (37%)
Bachelor's degree	5 (26%)
Advanced degree	3 (16%)
Household size	
1	4 (21%)
2	9 (47%)
3	4 (21%)
≥ 4	2 (11%)
Marital status	
Married/domestic partner	12 (63%)
Single/never married	3 (16%)
Divorced/separated	4 (21%)

Table 2. Disease characteristics and therapeutics for participants.

Disease characteristics	(n = 19)
	n (%)
SCD genotype	
Hb SS	10 (53%)
Hb Sβ$^+$	2 (11%)
Hb SC	7 (37%)
Avascular necrosis	15 (79%)
Joint surgeries	6 (32%)
Retinopathy	11 (58%)
Chronic kidney disease	9 (47%)
Pulmonary hypertension	5 (26%)
Heart failure	3 (16%)
Stroke	2 (11%)
Cutaneous leg ulcers	3 (16%)
Hypertension	7 (37%)
Diabetes mellitus	1 (5%)
Percentage hospitalized in the last year	9 (47%)
Percentage with severe pain crises at home not requiring medical attention/6 months	14 (74%)
	Median (interquartile range)
Hb (g/dL)	8.9 (6.5-11.1)
Fetal Hb (%)	4.9 (0.9-15.7)
Therapeutics/medications	
	n (%)
Hydroxyurea	11 (58%)
Chronic transfusion therapy	3 (16%)
Folic acid	14 (74%)
Iron chelation therapy	3 (16%)
Short-acting opioids	16 (84%)
Long-acting opioids	7 (37%)

Journal of Sickle Cell Disease, 2025, 2(1), yoaf017
https://doi.org/10.1093/jscdis/yoaf017
Advance Access Publication Date: 25 April 2025
Research Article

THE FOUNDATION FOR SICKLE CELL DISEASE RESEARCH — CHANGE THE CONVERSATION. RESHAPE THE FUTURE.

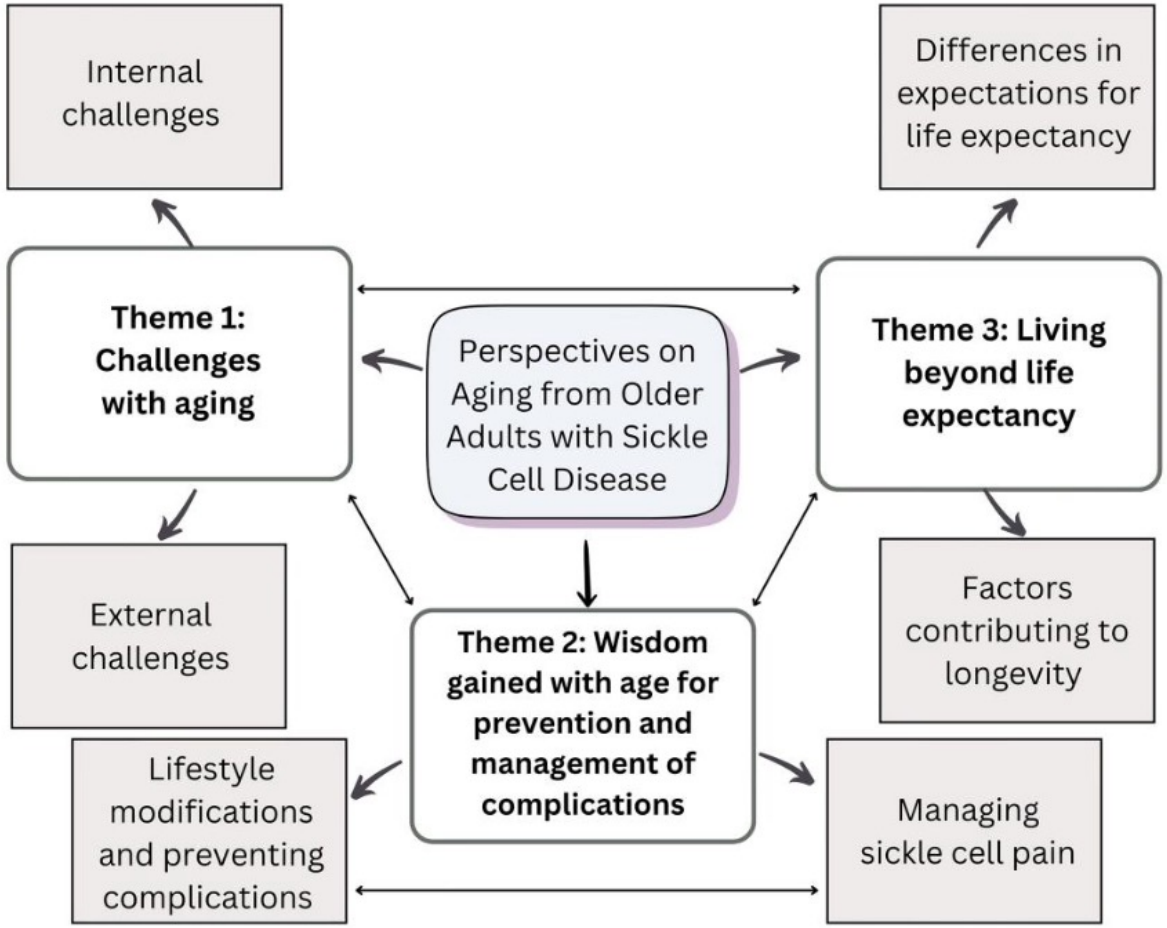
OXFORD

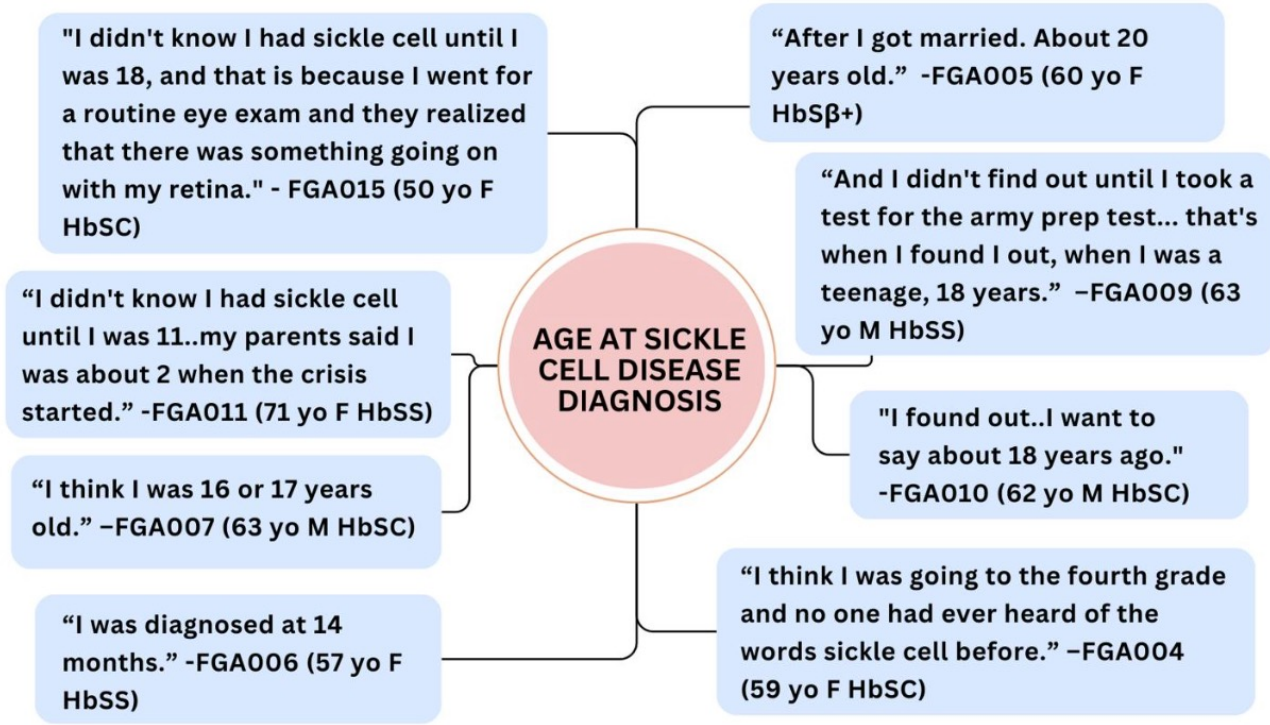
"I can't let it stop me": perspectives on aging from older adults with sickle cell disease

Charity I. Oyedeji MD[1,2,3,*], Tolu O. Oyesanya RN, PhD[4], Rania Mohamed BS[1], Stephanie Padrick BSN[1], Reena Ravi BS[1], Teagan Callaway BS[1], John J. Strouse MD, PhD[1,2,3,5]

Oyedeji CI et al. Journal of Sickle Cell Disease, 2025, 2(1)

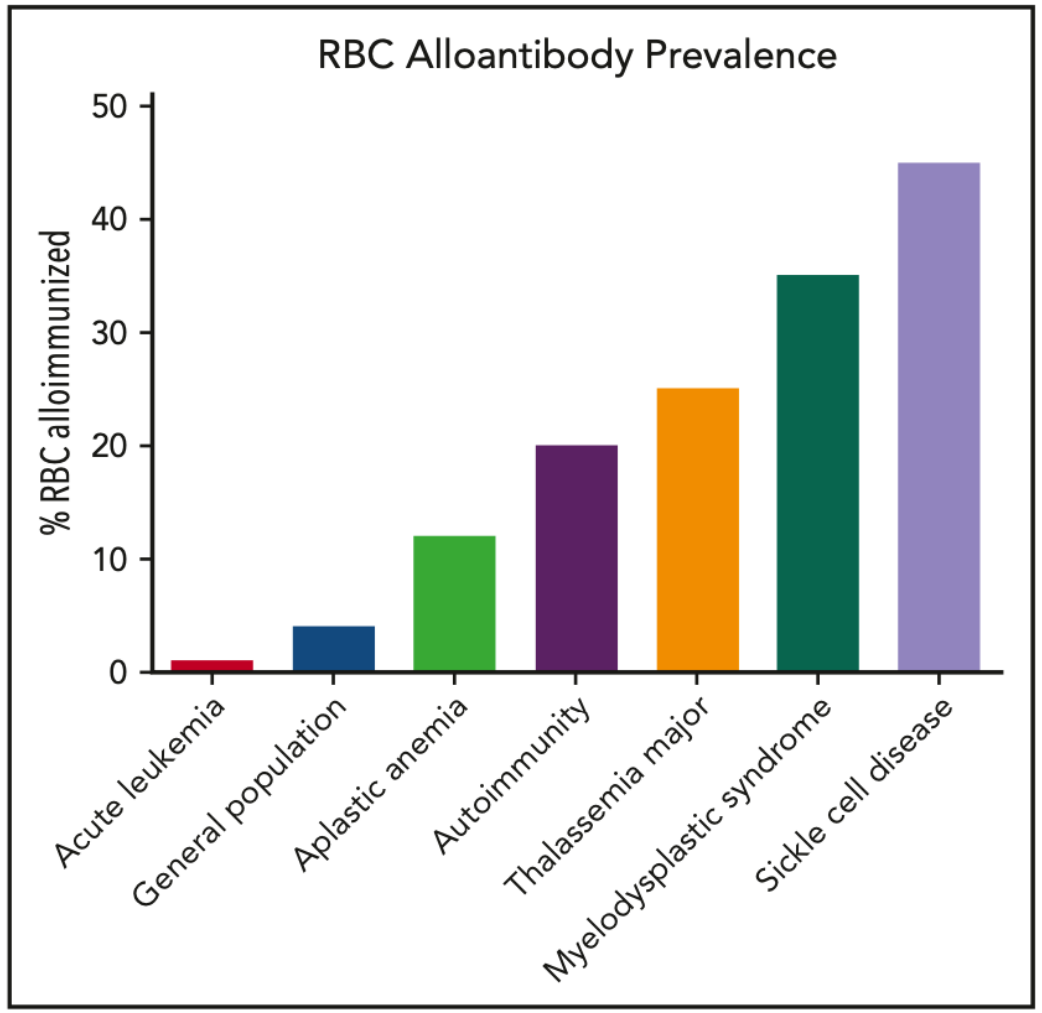
AGING IN SCD





Oyedeji CI et al. Journal of Sickle Cell Disease, 2025, 2(1)

ALLOIMMUNIZATION



Patients with SCD : the highest rates of RBC alloimmunization of any population.

- high transfusion burden
- number of Rh variants (of D, E/e, or C/c) known in patients of African descent

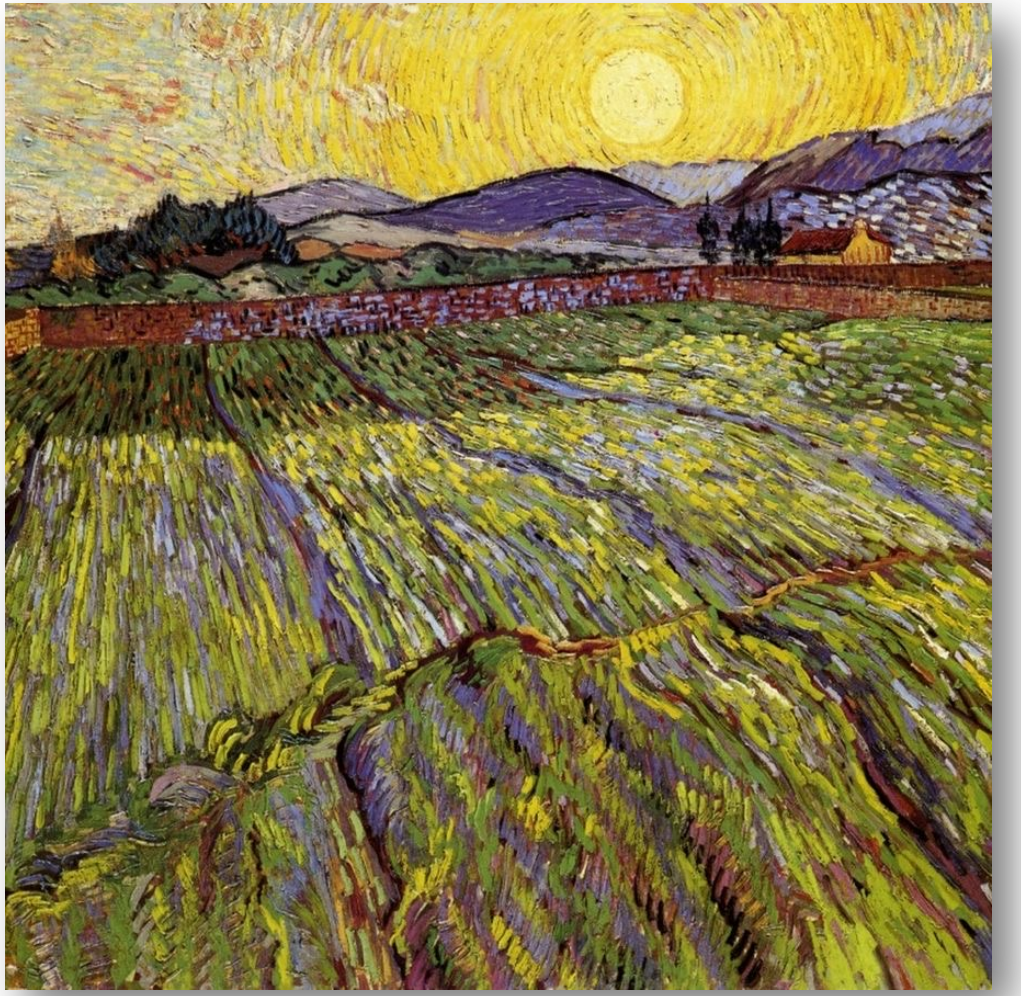
Patients with thalassemia: higher alloimmunization rates than the general transfused population

Patients transfused in infancy or early childhood: lower rates of alloimmunization than those intermittently transfused.

Tormey CA et al. Blood. 2019;133(17):1821-1830
Chou ST et al. Blood. 2013; 122(6):1062-1071
Azarkeivan A et al. Pediatr Hematol Oncol. 2011;28(6):479-485
Spanos T et al. Vox Sang. 1990;58(1):50-55

I GIORNI NON PREVISTI:

la psicologia di una mente che resiste



Campo chiuso con sole nascente" (1889), Vincent van Gogh

Simone Maggio - Ospedale Policlinico Maggiore Milano
Psicologo e Psicoterapeuta

Disclosures of Name Surname

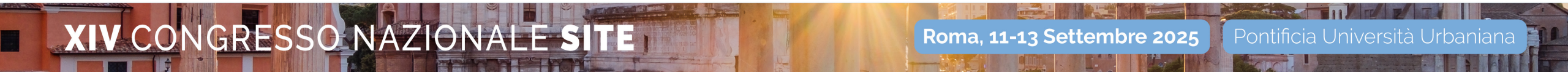
Company name	Research support	Employee	Consultant	Stockholder	Speakers bureau	Advisory board	Other
Vertex Pharmaceuticals			x			x	

TRE DOMANDE CHIAVE:

Cosa significa per i nostri pazienti “**invecchiare**”?

Qual è **l’impatto psicologico** con cui si confrontano?

In che modo possiamo aiutarli ad affrontare questa **nuova fase della vita**?



MODELLO DELLO SVILUPPO PSICOSOCIALE

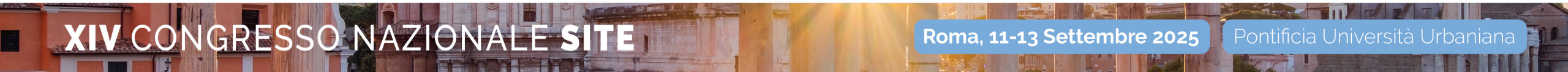
Il ciclo della vita vede susseguire 8 fasi, ognuna si presenta come una crisi/sfida. L'ultima fase (8a) dai 65+ ha come obiettivo: **giungere a una visione d'insieme della propria esistenza [Erikson, 1950].**

Integrità dell'Io vs Disperazione

Integrazione della storia di vita, accettazione della finitudine, coerenza narrativa.	vs	Rimpianto, rigidità mentale e chiusura emotiva, irritabilità, cinisimo, umore depresso, angoscia della morte

Cosa significa per i nostri pazienti “invecchiare”?

La fine è nell’inizio....



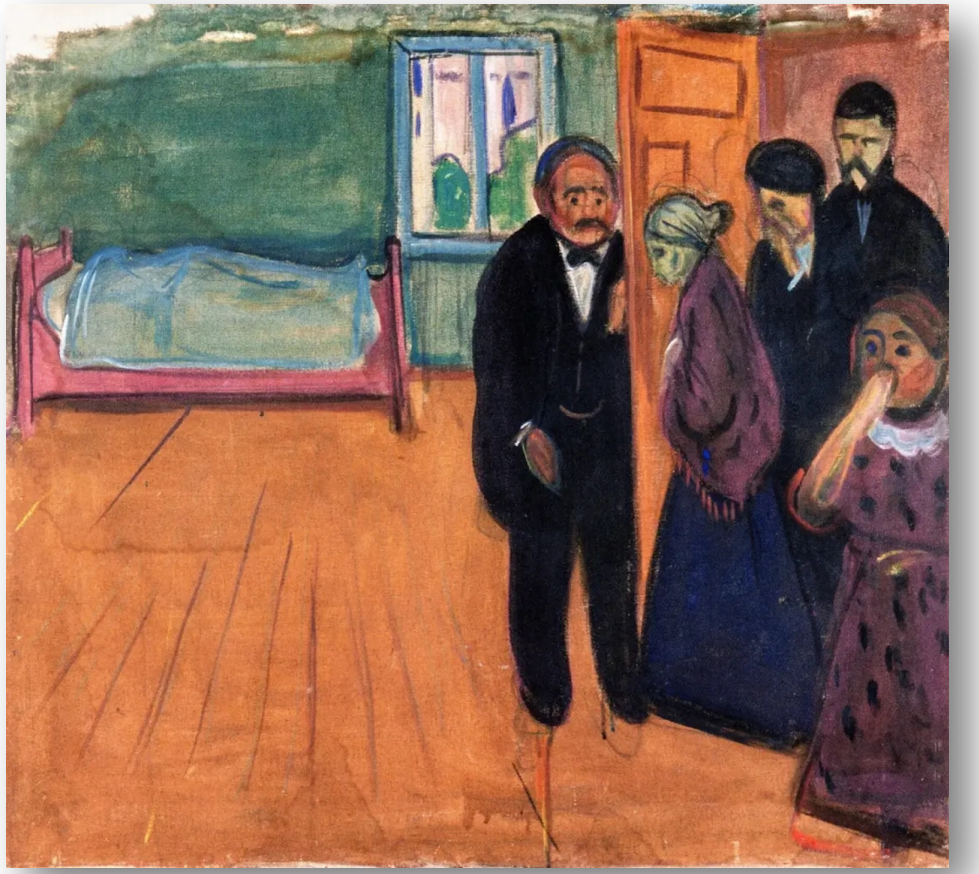
VISSUTI E ASPETTI RICORRENTI

- **Invecchiare:** traguardo difficile se non impossibile
- **Comunicazione dell'aspettativa di vita/aspettativa di morte:** percepita come una vera e propria "sentenza di morte".
- Ambienti sanitari meno favorevoli e accesso alle cure limitato
- Maggiore stigma sociale
- Effetto cumulativo dello stress cronico dovuto al carico psicosociale prolungato

Un'esistenza trascorsa per molti pazienti con un costante senso di precarietà e incertezza per il futuro dove si sono alternati speranza e angoscia della morte.

LE QUATTRO PREOCCUPAZIONI ULTIME DELL'ESISTENZA UMANA

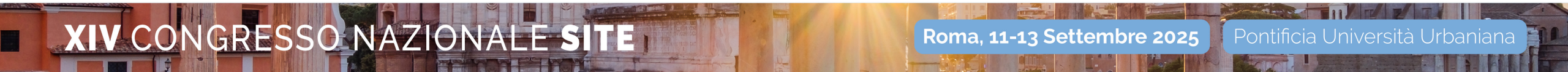
[Yalom, 1980; Schnipke, B., & MacKay, M., 2023]



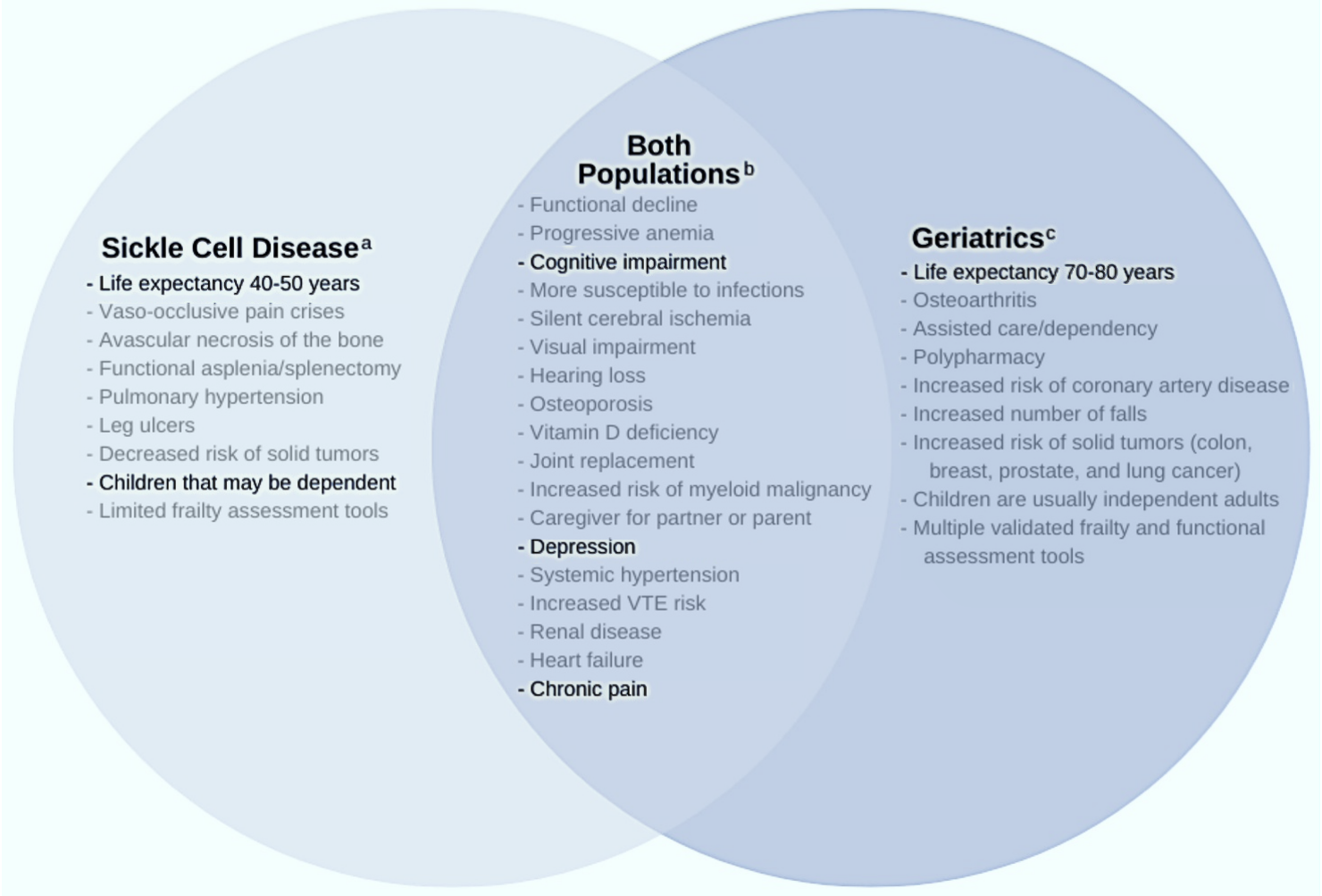
Odore di morte, Edvard Munch 1895

- **Isolamento esistenziale**: "nucleo ultimo" di solitudine per ognuno. Amplificato dallo stigma invisibile ("*nessuno capisce davvero la mia condizione*"), dal ridotto numero di pari e, con l'età, dalla perdita progressiva di legami.
- **Mancanza di significato**: la sopravvivenza inattesa può generare smarrimento ("*non pensavo di arrivare fin qui, e ora*?").
- **Libertà/responsabilità**: tensione tra dipendenza dalle cure e bisogno di autonomia.
- **Angoscia della morte**: il fatto stesso di vivere oltre le aspettative li pone davanti a una morte "*che non era prevista ma che ora incombe*".

Qual è l'impatto psicologico con cui si confrontano i nostri pazienti invecchiando?



CARATTERISTICHE E LE COMPLICAZIONI CONDIVISE TRA PAZIENTI SCD E GERIATRICI (Oyedeji et al., 2023)



PAZIENTI SCD

- La depressione diagnosticata nel 35,2% dei pazienti adulti con SCD [4,4% popolazione generale] ed è stata fortemente associata a **peggiori risultati** in termini di **qualità della vita fisica e mentale**.
  [Adam et al., 2017]

- Una revisione sistematica di Doglioni et al. del 2021 parla di una prevalenza di depressione fino al 85%.
  I pazienti anziani soffrono maggiormente ansia/depressione rispetto a quelli più giovani.
  [McClish et al., 2017]

- I pazienti più anziani hanno punteggi fisici e mentali più bassi nella scale della qualità della vita; **crisi vaso occlusive e ricoveri li riducevano ulteriormente** (SF-36/HRQoL).
  [Yaya et al., 2024]

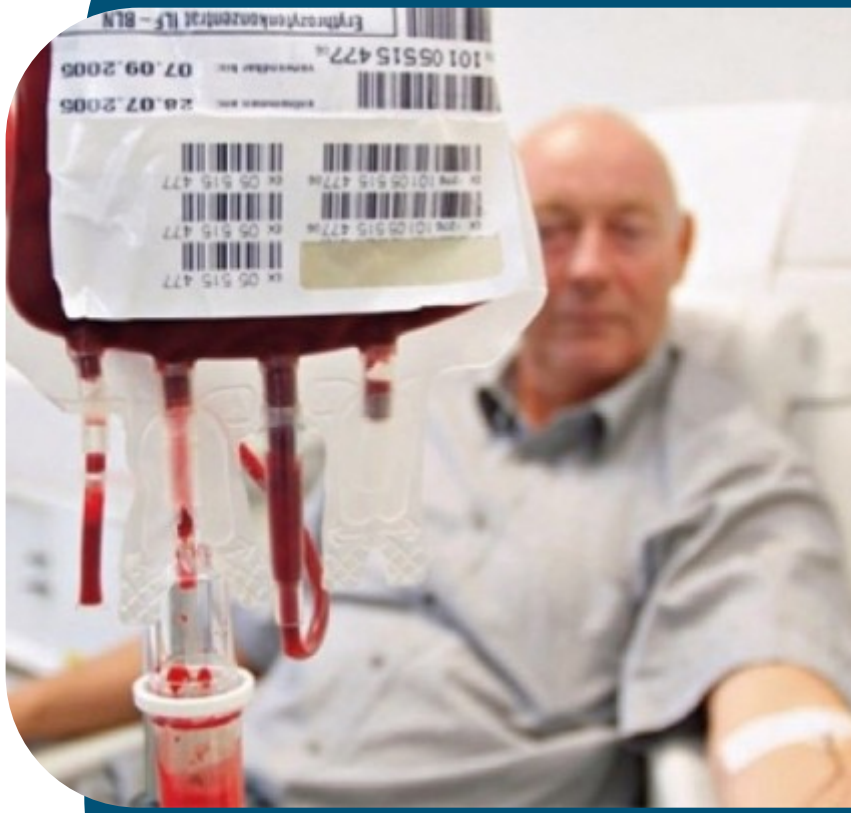
- **Deterioramento precoce** delle funzioni cognitive.
  [Oyedeji et al., 2020]

PAZIENTI TDT e NTDT

- **L'età** è indipendentemente associata a una **ridotta qualità della vita**.
  [Sobota et al., 2011; Panepinto, 2012; Amid et al., 2016; Klonizakis et al., 2024]

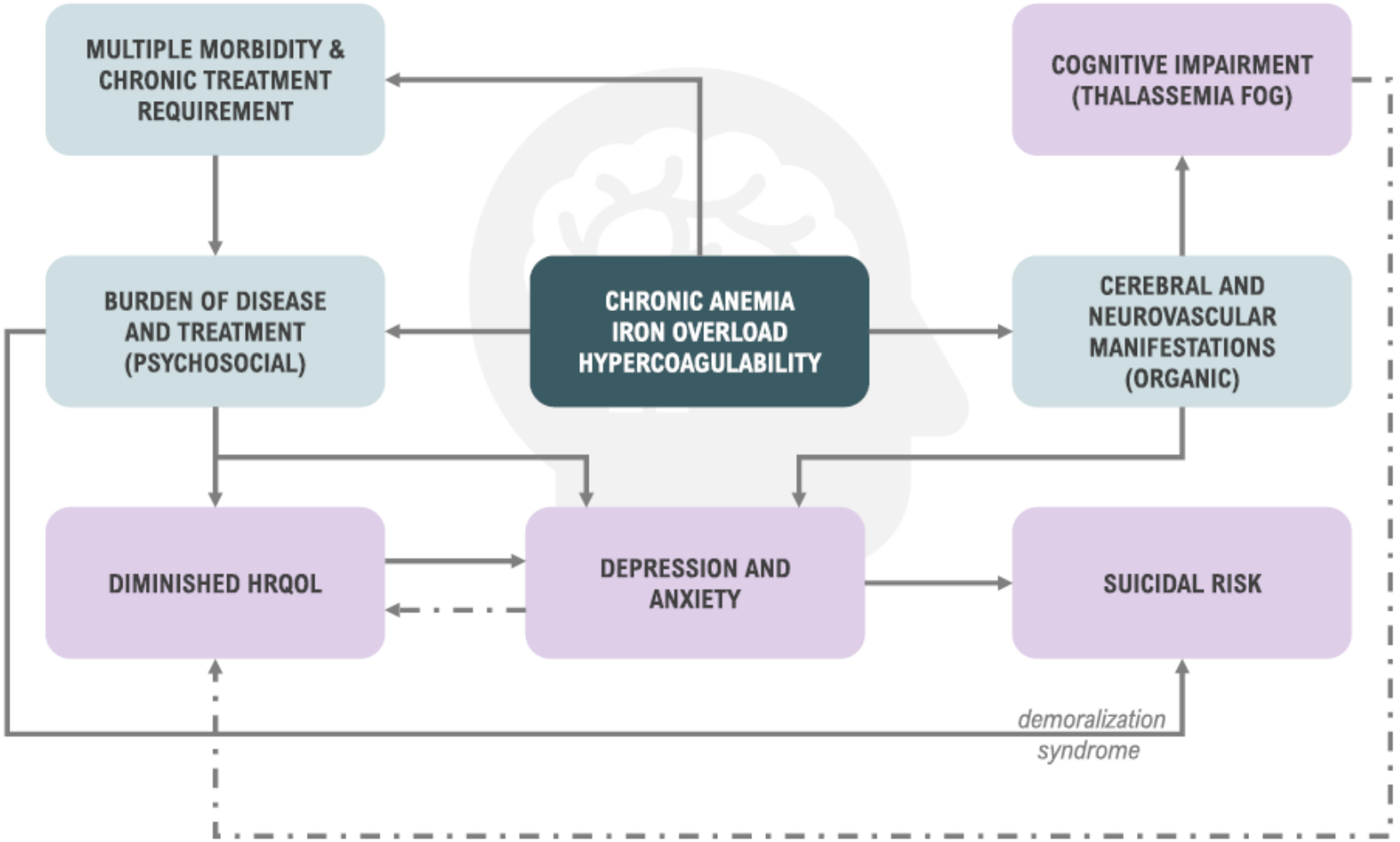
- **Maggiori livelli di ansia/disturbi dell'umore (depressione),** somatizzazione mentre il supporto sociale percepito diminuisce
  [Mednick et al., 2010; Khani et al., 2012; Maheri et al., 2018; Elbeh et al., 2024; Bizri et al.2024]

- **Maggiore rischio di deterioramento cognitivo** (+1,6 x 10 anni di età) e **demenza** [Chen et al., 2015; Kung et al., 2021; Limpawattana et al., 2022] con deficit di attenzione, memoria, funzioni esecutive. [Bizri et al., 2024]

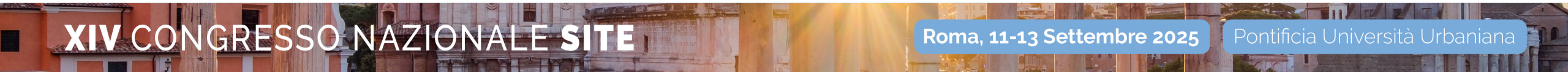


DETERMINANTI DELLA QUALITÀ DELLA VITA CORRELATA ALLA SALUTE (HRQOL), DISTURBI DELL'UMORE E DETERIORAMENTO COGNITIVO NEGLI ADULTI CON B-TALASSEMIA

[Review, Bizri et al., 2024]



In che modo possiamo aiutarli ad affrontare questa nuova fase della vita?



RACCOMANDAZIONI CLINICHE PER L'EQUIPE CURANTE

- Dare priorità e importanza alla **dimensione emotiva del paziente**

- **Valutazione sintomi** di compromissione cognitiva o disturbi psichiatrici e favorire invio a neurologo/psichiatria/psicologo

- **Screening regolare** con strumenti dedicati come:
  1. TranQol (Transfusion-dependent QoL questionnaire):salute fisica, salute emotiva, funzionamento familiare e funzionamento scolastico e professionale, attività sessuale.
  2. Valutazione SCD-GA (inclusi indicatori di QoL) dedicato a ≥50/post-ricovero, per cogliere declini funzionali e cognitivi che abbassano la QoL. [Oyedeji et al., 2020]

- **Promuovere i fattori protettivi** come supporto sociale e alfabetizzazione sanitaria, psicoeducazione e formazione tecniche di gestione del dolore e stress (es. mindfulness, training autogeno, stili di vita sani, ipnosi medica)

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Uno dei modo più efficaci per affrontare l'angoscia della morte....

è con il piacere della vita!

Irvin D. Yalom

GRAZIE