

# Dalle linee guida alla qualità di vita e alle cure palliative precoci e simultanee:

*come la storia delle leucemie mieloidi acute sta cambiando*



**Roma, 2 febbraio 2024** – Starhotels Metropole

## **Verso un nuovo modello di cure palliative precoci e simultanee**

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Modena

# EARLY PALLIATIVE CARE IN AML

1

Better QoL

2

Adaptive Coping

El Jawahri AR et al. JAMA Oncol. 2020;316(20):2094-2103.



# EARLY PALLIATIVE CARE IN AML

Nelson AM et al. Cancer 2021;127(24):4702-4710.



Better QoL

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Adaptive Coping

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Less Depression  
PTSD

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Adaptive Coping

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Less Depression  
PTSD

4

Enhance Medical





# EARLY PALLIATIVE CARE IN AML

Potenza L *et al.* *BMJ Supportive & Palliative Care* doi:10.1136/ bmjspcare-2021-002898

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Less Depression  
PTSD

4

Enhance Medical  
Assistance

5

Improve End



# EARLY PALLIATIVE CARE IN AML

5

Improve End  
Of Life Care

Potenza L *et al.* *BMJ Supportive & Palliative Care* doi:10.1136/ bmjspcare-2021-002898



# What are the **ELEMENTS/COMPONENTS** of EPC in AML?



1

**Clinicians may  
Implement**

2

**Patients may  
Benefit**

**Complete Description  
Of Interventions**

3

**Researches may  
Replicate**

Hoffman TC *et al.* BMJ 2014;348:g1687 doi: 10.1136/bmj.g1687





# Template for Intervention Description and Replication (TIDieR)

Hoffman TC *et al.* BMJ 2014;348:g1687 doi: 10.1136/bmj.g1687



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What

What

How



# CASE REPORT

**Paolo** is a **75-year-old** Caucasian man who was diagnosed with acute myeloid leukemia (**AML**) in Nov 2022

The next generation sequencing analysis identified mutations of TP53 and CNV of EZH2, ETV6, KRAS.

**Myelodysplasia-related AML (WHO 2022)**

**AML with Mutated TP53**





# CASE REPORT

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**Myelodysplasia-related AML  
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**AML with Mutated TP53  
(ICC 2022)**

**Adverse risk (ELN)**

His medical history revealed  
prostatic cancer, in hormone  
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stenosis and hypertension



# CASE REPORT

(WHO 2022)

AML with Mutated TP53

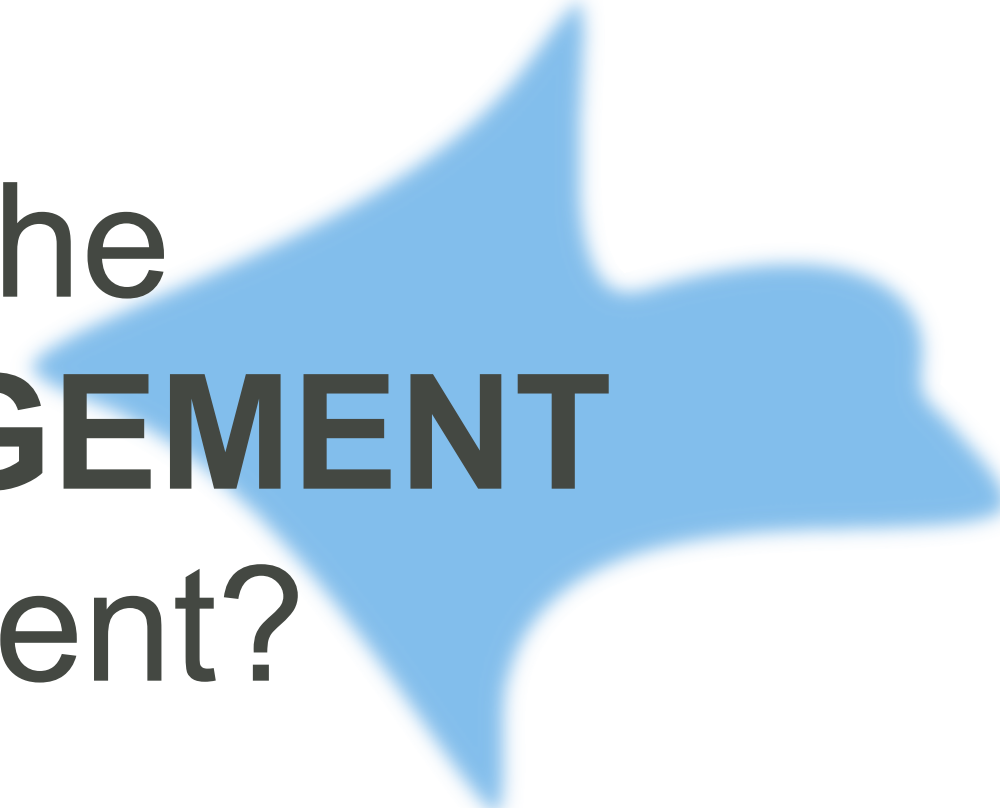
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His medical history revealed **prostatic cancer**, in hormone therapy, **severe aortic valve stenosis** and **hypertension**



# What's the **BEST MANAGEMENT** of our patient?



## Best Management of our Patient



**VENETOCLAX +  
5-AZACYTIDINE**

Di Nardo CD et al. NEJM . 2020;383:617-629.



**VENETOCLAX +  
5-AZACYTIDINE +  
EPC**

El Jawahri AR et al. JAMA Oncol. 2020;316(20):2094-2103.





2

**Feelings about  
a shocking  
diagnosis**

3

**High Indicators  
of intense healthcare  
utilization even at  
EOL**

**AML**

**Unmet Palliative Needs**

1

**High Symptoms  
Burden**

Shaulov A et al. Br J Haematol: 07 June 2022, DOI: (10.1111/bjh.18286)



Best Management  
of our Patient



**Integrating PC concurrently with  
disease-directed care for this patient  
has strong potential to **improve** several  
outcomes .**

El Jawahri AR et al. JAMA Oncol. 2020;316(20):2094-2103.

Potenza L et al. BMJ Supportive & Palliative Care doi:10.1136/ bmjspcare-2021-002898

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# 1<sup>st</sup> EPC Encounter

at the 7<sup>th</sup> day of the first  
venetoclax-5-azacytidine course

Dr. S explained the  
**function of EPC** as an  
**extra layer of support** and  
they started **talking about  
Paolo**

Paolo was a **retired renowned  
business executive** who was  
running a charitable nonprofit  
at the time. He **lived** with his  
**wife and daughter** and their  
numerous pets in the  
countryside, **60 km from the  
hospital**



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They **assessed** the situation and transfusion need. **Opioids** were prescribed and **follow-up** dates were **agreed** based on Paolo's needs and requests.



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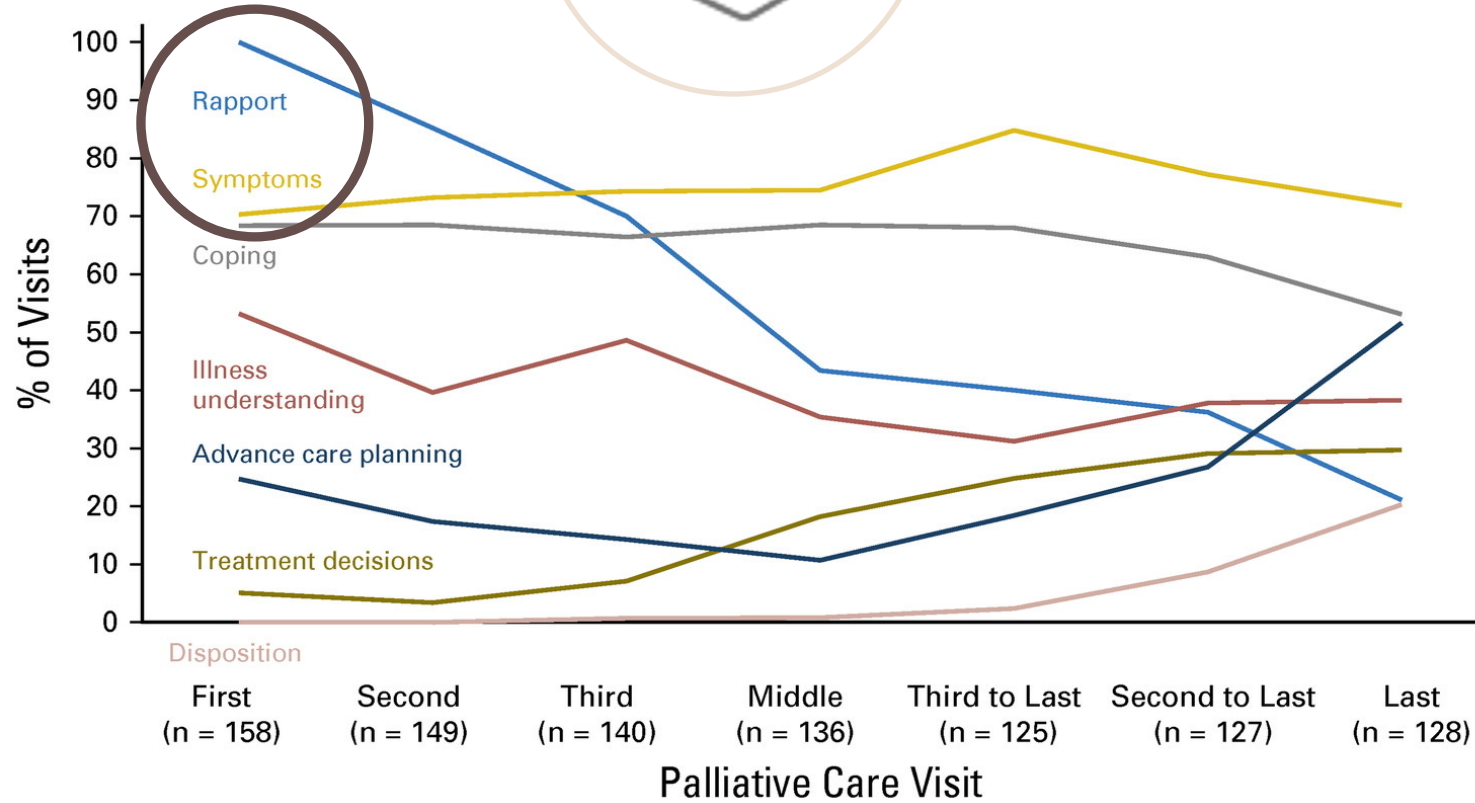
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# What are the **MAIN GOALS** of First EPC Visits?



# Main Goals Of First EPC Visits



Hoerger M et al *Journal of Clinical Oncology* 2018 36:1096-1102.



Building Rapport  
Managing Symptoms

# 4 Major Effects

01

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**IMPROVE  
QUALITY OF  
LIFE**

02

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**ESTABLISHING  
A RELATIONSHIP**

03

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**GIVE MORE  
EMPOWEREMENT**

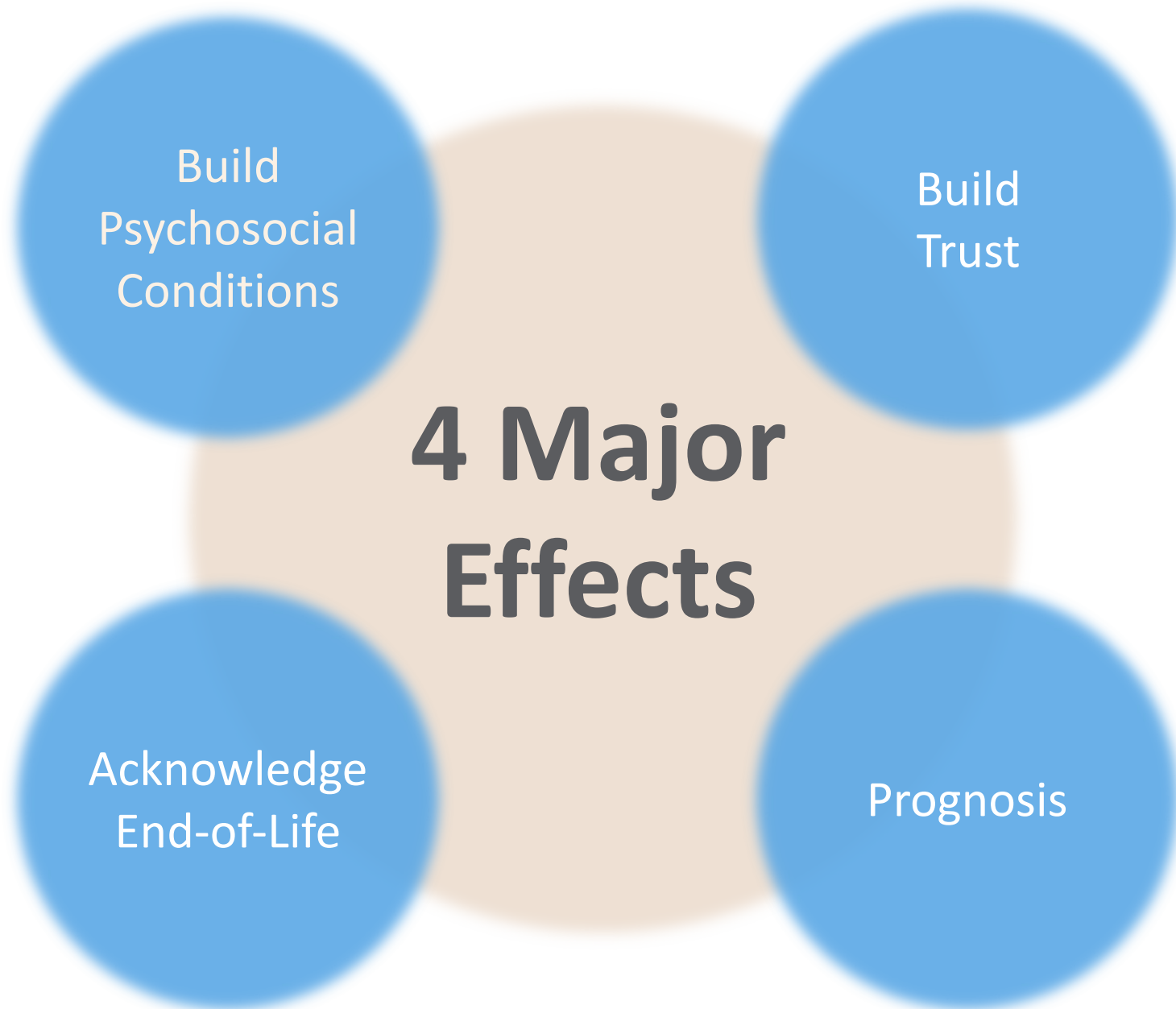
04

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**LET THE  
COPING BEGIN**

*Borelli E. et al. The Oncologist 2021;26:e2274–e2287*







# Subsequent EPC Encounters

1<sup>st</sup> day of next three venetoclax-5-azacytidine courses

After the first course, **Paolo achieved CRi.**

He felt better. The **pain** had **improved**, and **fatigue** became **milder**, as he received periodic **transfusion**, kept working at the charity association and engaged **mild physical activities.**

Dr. S. moved on to explore **Paolo's** and his **wife expectations** of the **treatment process** and their **understanding of prognosis.**



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Paolo **hoped to be cured**, but also to **live as long and as well as possible** by continuing to do his job. He said that he was not worried because he completely **trusted the medical team**.



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Dr. S aligned Paolo's **hope** and started to **explore** the Paolo's meaning of **living well with the cancer**. The upcoming Easter holidays represented a particular period in which Paolo would have liked to feel well in order to be able to give his contribution to the



# Subsequent EPC Encounters

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# What are the **MAIN GOALS** of **SUBSEQUENT EPC** Visits?





EPC Middle Visits

# MAIN GOALS

**447**

Visits

**221**

Coping Strategies

**177**

Redirecting Hopes

Nipp R er et al *Journal of Clinical Oncology* 2017, 35: 2551.





Expanding the Range of Hopes  
Living well with Illness

# 3 Major Effects

Back AL et al. J Palliative Med 2014; 17: 1244

01

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**IMPROVE  
QUALITY OF  
LIFE**

03

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**DOOR  
TO DEEPEN  
PROGNOSTIC  
AWARENESS**

02

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**REDUCE  
PSYCHOLOGICAL  
SYMPTOMS**

*Borelli E. et al. The Oncologist 2021;26:e2274–e2287*



# Final EPC Encounters

At day +4 of the fifth venetoclax-5-azacitidine course, **Paolo** developed **pneumonia** and **required intubation**. After one week, he **partially recovered** and was **extubated**.

The PC specialist was called by hematologic colleagues because it was necessary to define an advanced care planning with Paolo in case



# Final EPC Encounters

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The PC specialist was called by hematologic colleagues because it was necessary to **define an advanced care planning** with Paolo in case intubation was necessary again.

Dr. S knew that Paolo had built several coping skills, but his prognostic awareness was only partial, and he was not yet ready to acknowledge the EOL.



# Final EPC Encounters

to define an advanced care  
planning with Paolo in case  
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again.

Dr. S knew that **Paolo** had built  
**several coping skills**, but his  
**prognostic awareness** was only  
**partial**, and he was **not** yet  
ready to **acknowledge the EOL**.  
However, the sudden **decline**  
of clinical condition **required**  
such a **conversation**.

The patient's **goals**, shared by  
his family, resulted "**to live as  
good and as long as possible**"  
and "**to do whatever was  
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# Final EPC Encounters

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The patient's **goals**, shared by his family, resulted "**to live as good and as long as possible**" and "**to do whatever was necessary**". At the same time Paolo would like to **avoid prolonged hospitalization** and being dependent from machines

These **objectives** were aligned by agreeing a treatment plan including to **avoid resuscitation maneuvers/intubation, to evaluate**





# Final EPC Encounters

Paolo would like to avoid prolonged hospitalization and being dependent from machines

These **objectives** were **aligned** by agreeing a treatment plan including to **avoid resuscitation maneuvers/intubation**, to evaluate **discharge to home**, but also to **consider resuming treatment** with venetoclax-5-azacitidine if the condition improved.





# What are the **MAIN GOALS** of **FINAL EPC** Visits?



Final EPC Visits

# MAIN GOALS

01

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## RECEIVE TREATMENT

Aligning with  
**Preferences, Values  
and Priorities**

02

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## EOL PLANNING

Jacobsen J et al. New York: Oxford University Press, 2021.



EOL PLANNING



It is a **TIME-DEPENDENT**  
**PROCESS**



Jacobsen J et al. New York: Oxford University Press, 2021.



EOL PLANNING



May occur  
After **SEVERAL VISITS**



Back AL et al. J Palliative Med 2014; 17: 1244





# Because of deepening **PROGNOSTIC AWARENESS**



Jackson VA et al. J Palliat Med 2013;16:894-900



EOL PLANNING



Patients refer **HARD**  
the idea  
of an **INEVITABLE DEATH**



*Borelli E. et al. The Oncologist 2021;26:e2274–e2287*







# Patients report **PERIODIC CONVERSATIONS** **FAVOR** the **PROCESS**

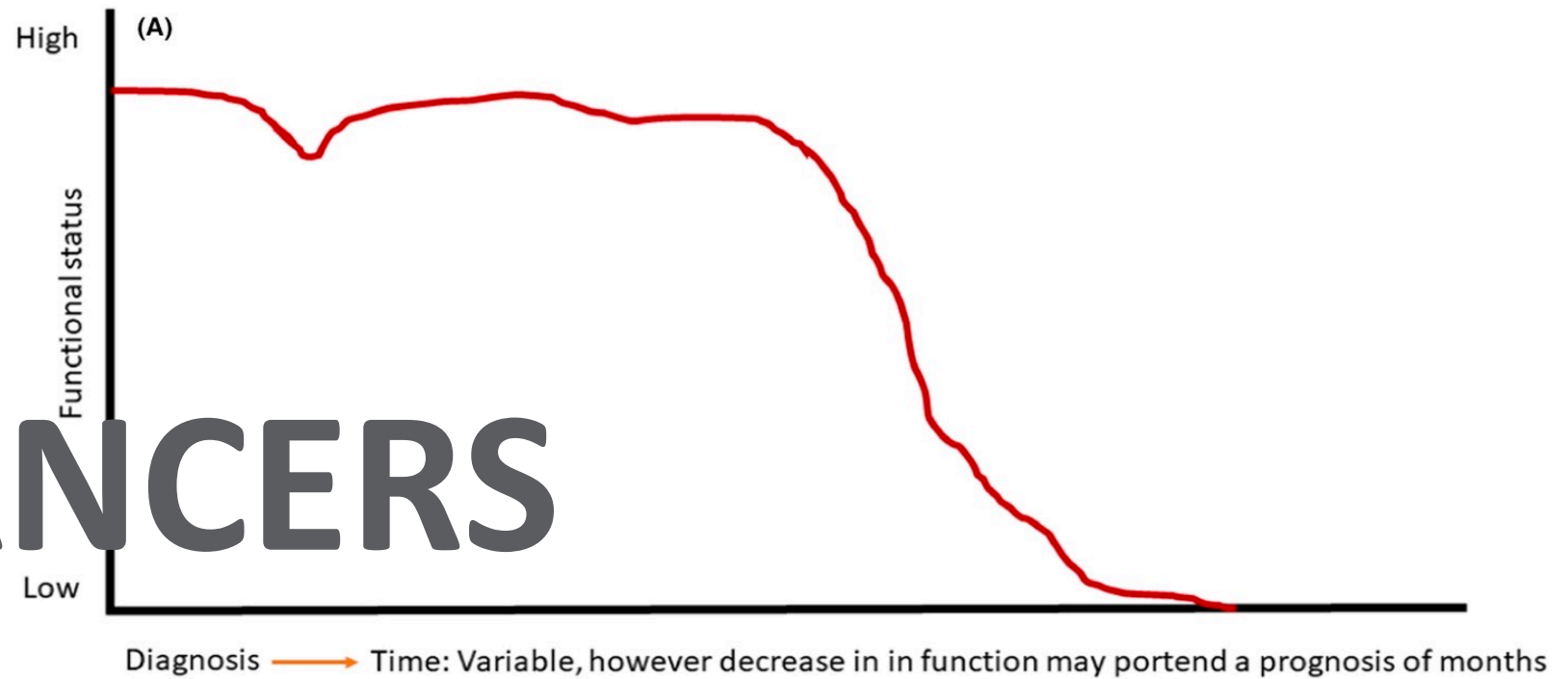


*Borelli E. et al. The Oncologist 2021;26:e2274–e2287*



# Illness Trajectory

# SOLID CANCERS



# Illness Trajectory

# Acute Myeloid Leukemia



Shaulov A et al. Br J Haematol: 07 June 2022, DOI: (10.1111/bjh.18286)



Conclusions

## EPC IN AML



**HELP Patients**  
to **LIVE** and **DIE WELL**



Conclusions

## EPC IN AML



# ALLEVIATES SYMPTOMS



Conclusions

# EPC IN AML



# BUILDS TRUST





Conclusions

**EPC IN AML**



# FACILITATES COPING



Conclusions

**EPC IN AML**



**CULTIVATES  
PROGNOSTIC AWARENESS**



Conclusions

## EPC IN AML



**Patients can make  
informed choices consistent  
with their values**



Conclusions

## EPC IN AML



In **AML**, **EPC** clinicians should be prepared to plan **EOL** even when **prognostic awareness is not complete.**



# Acknowledgement

01

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03

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04

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