

PATIENT HEALTH ENGAGEMENT AND SOURCES OF INFORMATION ON MYELOPROLIFERATIVE NEOPLASMS: A SURVEY CONDUCTED BY THE ITALIAN PATIENT ASSOCIATION (AIPAMM)

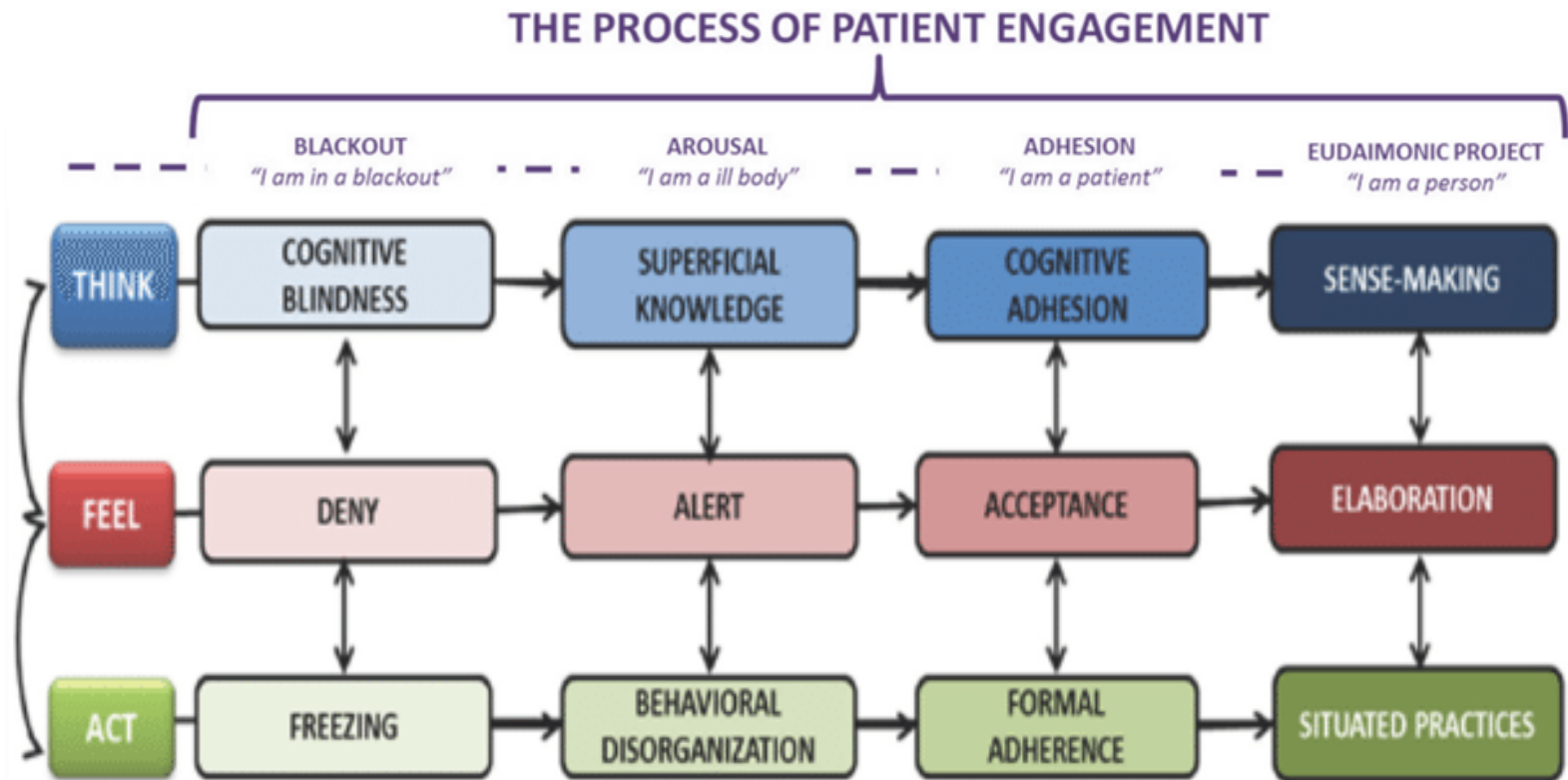
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Self-care_Aipamm Research Study Group

AIPAMM, ITALY



Background



- ✓ AIPAMM seeks to promote patient engagement by sharing understandable, relevant, and reliable information on MPN

The Patient Health Engagement model by Graffigna et al. (2015)



Aim

- ✓ To describe **the level of health engagement** in MPN patients and the most trusted **sources of information**.

Methods

- ✓ A **multicentric cross-sectional study** promoted by AIPAMM in Italy since November 2021, still ongoing.
- ✓ MPN patients were asked to complete a **paper-and-pencil questionnaire** to collect data anonymously about health engagement, sources of information, and other study variables.



Instrument:
The Patient Health Engagement (PHE) Scale

WHEN I THINK ABOUT MY DISEASE ...

I feel in blackout	<input type="radio"/>	<input type="radio"/>	I am in alarm	<input type="radio"/>	<input type="radio"/>	I am aware	<input checked="" type="radio"/>	<input type="radio"/>	I feel positive	<input type="radio"/>
I feel dazed	<input type="radio"/>	<input type="radio"/>	I am in trouble	<input type="radio"/>	<input type="radio"/>	I am conscious	<input type="radio"/>	<input type="radio"/>	I feel serene	<input checked="" type="radio"/>
When I think about my illness I feel overwhelmed by emotions	<input type="radio"/>	<input type="radio"/>	I feel anxious every time a new symptom arises	<input type="radio"/>	<input checked="" type="radio"/>	I got used to my illness condition	<input type="radio"/>	<input type="radio"/>	Despite my illness I perceive coherence and continuity in my life	<input type="radio"/>
I am very discouraged due to my illness	<input type="radio"/>	<input type="radio"/>	I feel anxious when I try to manage my illness	<input type="radio"/>	<input type="radio"/>	I feel I adjusted to my illness	<input type="radio"/>	<input checked="" type="radio"/>	I am generally optimist about my future and my health condition	<input type="radio"/>
I feel totally oppressed by my illness	<input type="radio"/>	<input type="radio"/>	I am upset when a new symptom arises	<input type="radio"/>	<input type="radio"/>	I feel I have accepted my illness	<input checked="" type="radio"/>	<input type="radio"/>	I can give sense to my life despite my illness condition	<input type="radio"/>





Implementation

Sample n = 375

Preliminary data n = 201

9 Italian centres

+



Patients for
each centre

n = 30

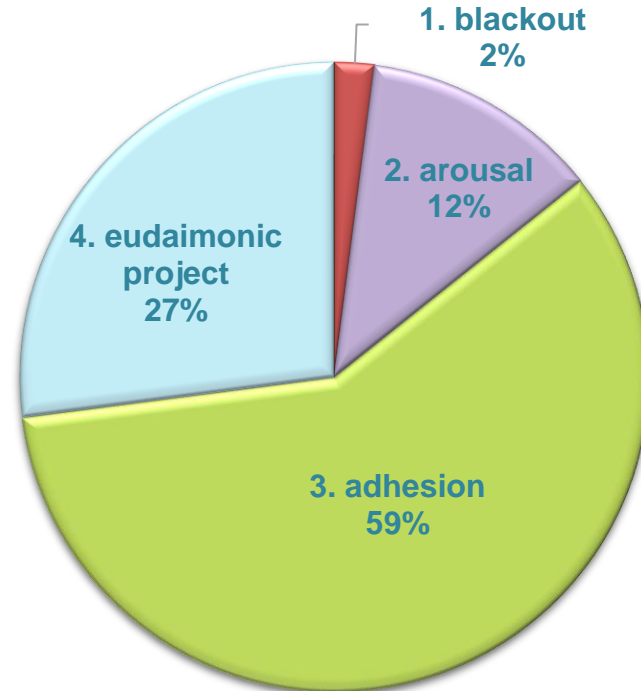
10 ET
10 PV
10 MF

✓ The Ethics Committee of each centre approved the Study



Results:

- ✓ Preliminary data from **201** patients (56% male; mean age = 60; SD = 14)
- ✓ Diagnoses → overt MF (33%), prefibrotic MF (13%), PV (26%), ET (28%)

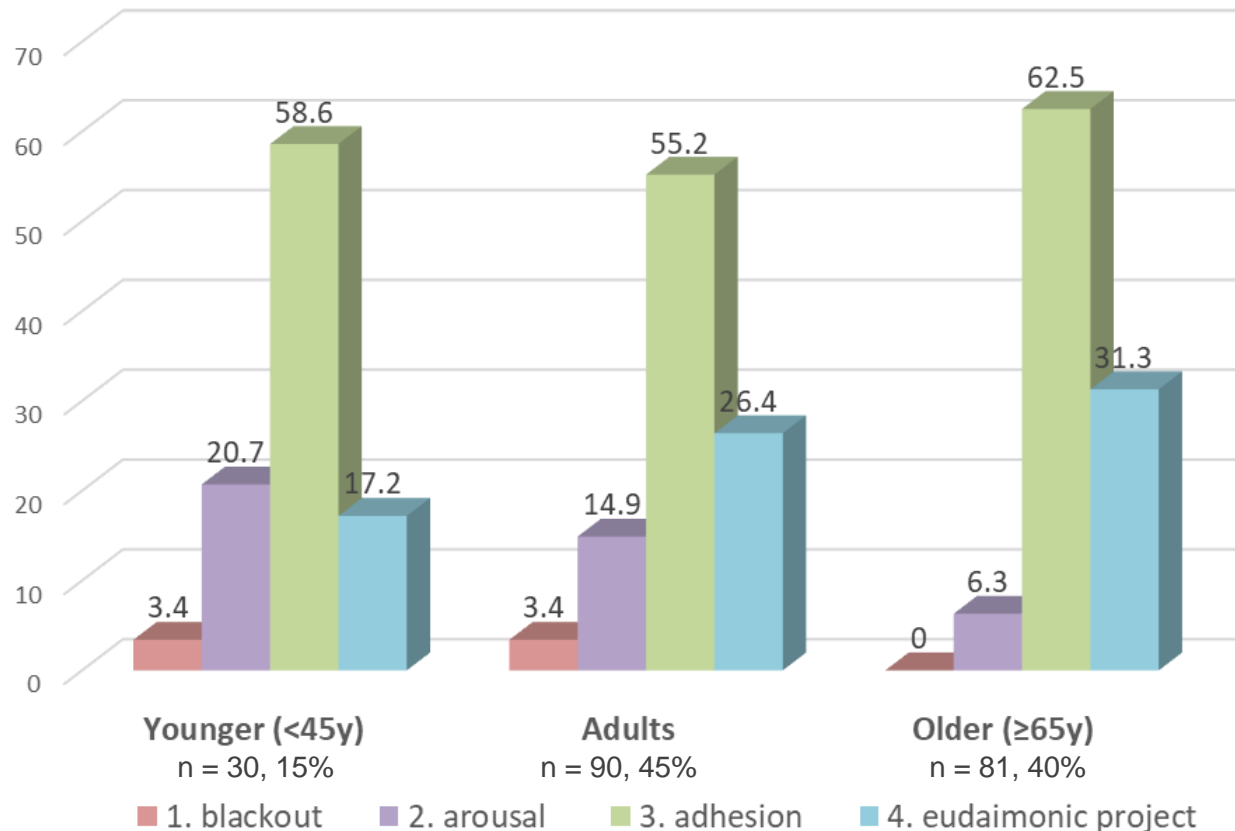


Patient Health Engagement score

- ✓ Patients were in the **third engagement stage** → **adhesion** (mean = 3.1, SD = 0.6; range 1-4)



Results:



Patient Health Engagement score by age

✓ **Age was positively associated with Patient Health Engagement, controlling for time since diagnosis ($\beta = .213$; $p < .003$)**



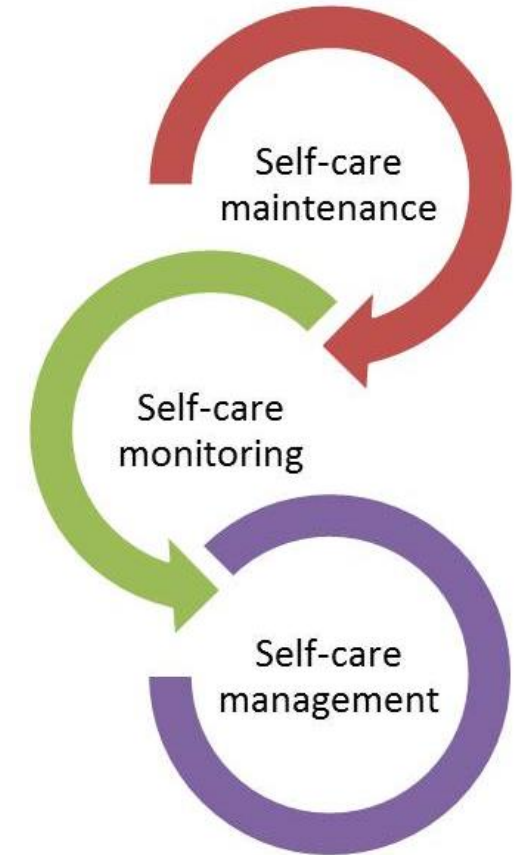
Results:

- ✓ Most of participants were **aware** (59%) and **conscious** (66%) about their health status.
- ✓ They perceived **coherence and continuity in their life** despite their illness (44%), and they felt they **adjusted** to their illness (58%) and **accepted it** (47%).
- ✓ The most trusted source of information was the **haematologist** (mean = 9.1, SD = 1.7).
- ✓ The more the haematologist was **clear in telling patients what to do in their daily life**, the more patients showed health engagement ($r = 0.22$, $p = 0.002$).



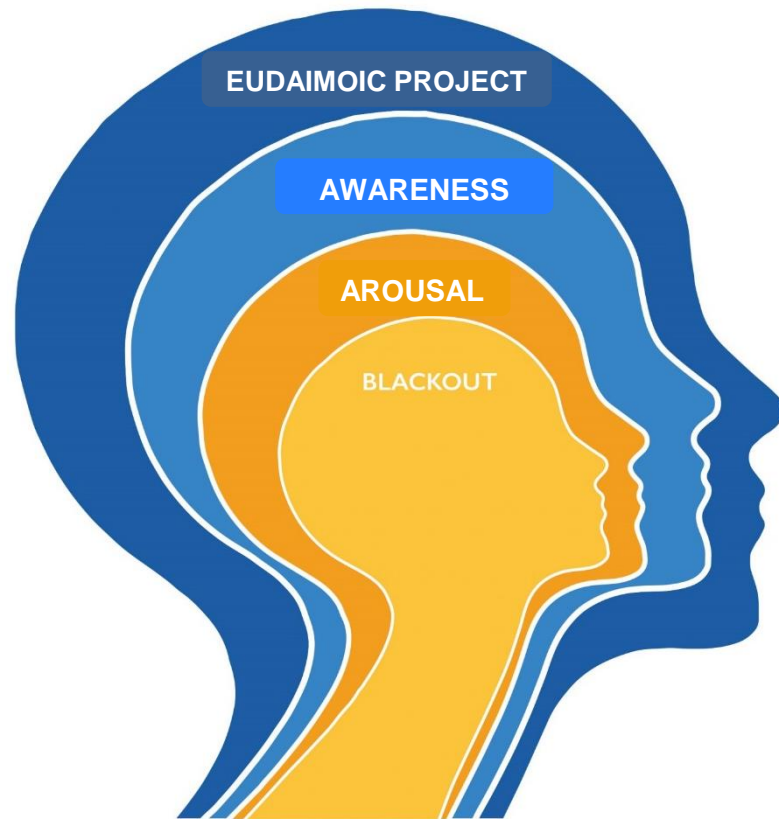
Impact:

- ✓ Haematologists should be aware of the importance of being **clear, honest, and kind** in providing information both on medications and **daily life activities**
- ✓ To support patients in engaging in **health management**



Recommendation:

- ✓ Greater efforts should be made to enhance the role of the **patient association** as a source of appropriate **information and support**
- ✓ To promote **emotional elaboration** and adjustment
- ✓ To foster **patient engagement**, especially in younger patients
- ✓ To **encourage research**



MPN Horizons

Understanding the
New Complexity of MPNs

13-15 October
Zagreb, Croatia

2023



AIPAMM - OdV
Associazione Italiana Pazienti
con Malattie Mieloproliferative



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