

# Early palliative care in haematological malignancies

Leonardo Potenza <sup>1</sup>, Mario Luppi <sup>1</sup>,  
Camilla Zimmermann <sup>2</sup>, Elena Bandieri<sup>3</sup>

Early palliative care (EPC) has demonstrated benefits in patients with advanced solid tumours, and components of EPC that may influence outcomes have also been reported in this population.<sup>1 2</sup> Although benefits of EPC have also been shown in patients with haematological malignancies (HMs), the key elements of EPC have not yet been described for these patients.<sup>3–6</sup> Here, we offer a detailed description of EPC integration in the HM setting to characterise key steps that may allow other centres to implement this model or to use it in clinical trials.<sup>7</sup>

1. Joseph was a 73-year-old man, diagnosed with high-risk myelodysplastic syndrome (HR-MDS), after presenting with pancytopenia.<sup>8</sup> His medical history revealed hormone therapy for prostate cancer, severe aortic stenosis, and hypertension.

## WHAT IS THE BEST MANAGEMENT OF OUR PATIENT?

Patients with high-risk myelodysplastic syndrome have a median

overall survival of 1.7 years.<sup>8</sup> The standard of care to prolong survival is the hypomethylating agent 5-azacytidine. 50% of patients are unresponsive, and most responders progress within 2 years.<sup>8</sup> Moreover, patients typically have several symptoms.<sup>9</sup>

Integrating PC concurrently with disease-directed care for this patient would have a strong potential to improve several outcomes, including alleviating suffering, improving quality of life and reducing aggressiveness at the end of life (EOL).<sup>3–6</sup> In our experience, HM patients benefit from outpatient EPC, for a minimum of three visits, at monthly intervals.<sup>5 6</sup>

The patient was started on 5-azacytidine, integrated with specialist palliative care.

2. The PC specialist met Joseph during the first 5-azacytidine course, for the first visit. Dr. S explained EPC as an extra layer of support and they started talking about Joseph, who was a interventional orthopedic radiologist, spending many hours on his feet while working, and lived with his family in the countryside.

Dr. S noted that Joseph demonstrated moderate symptoms and poor quality of life (QoL). They talked about symptoms, mainly fatigue and back pain, which prevented Joseph from working, as well as pain and erythema at the site of the 5-azacytidine infusion.

They assessed the situation, agreed on an opioid prescription and arranged

follow-up visits at Joseph's convenience.

## WHAT ARE THE MAIN GOALS OF THE FIRST EPC ENCOUNTERS?

The goals of the initial EPC visits are to build rapport and allow for a detailed assessment of symptoms (table 1).<sup>1 2 10</sup> Relieving symptoms has four major effects: improving quality of life, establishing a therapeutic relationship, giving patients enhanced problem-solving skills and greater self-awareness and facilitating coping.<sup>1 2 10</sup> These effects help in building the conditions and trust necessary to introduce additional challenging topics, such as discussing prognosis and EOL planning (figure 1).

3. The subsequent EPC visits took place on the 1st day of the next three 5-azacytidine courses.

Joseph felt better; his pain had improved, and his fatigue had lessened, as he received periodic transfusions, kept working, and engaged in light-intensity physical activities.

Dr. S. moved on to explore Joseph's and his wife expectations of the treatment process and their understanding of prognosis. Joseph hoped to be cured, but also to live as long and as well as possible. He said that he was not worried because he completely trusted the medical team. Dr. S aligned hopes and began to explore Joseph's meaning of living well with cancer. A particular event emerged that Joseph was very keen to attend. So, they began to brainstorm how Joseph could attend that event.

## WHAT ARE THE MAIN GOALS OF THE SUBSEQUENT EPC ENCOUNTERS?

As soon as symptoms are under control, it is time to evaluate patients' prognostic awareness (table 1). The fact that our patient is not acknowledging any concerns suggests that he is not yet ready for such conversations. These middle

<sup>1</sup>Early Palliative Care Clinic, Hematology Unit and Chair, Azienda Ospedaliera Universitaria di Modena, Department of Medical and Surgical Sciences, University of Modena and Reggio Emilia, Modena, Italy

<sup>2</sup>Department of Supportive Care and Department of Medicine, Princess Margaret Cancer Centre, University Health Network and University of Toronto, Toronto, Ontario, Canada

<sup>3</sup>Early Palliative Care Clinic and Medical Oncology, Civil Hospital Carpi, Local Health Agency (USL), Carpi (MO), Italy

**Correspondence to** Professor Leonardo Potenza, Department of Medical and Surgical Sciences, University of Modena and Reggio Emilia, Modena 41124, Italy; leonardo.potenza@unimore.it

**Table 1** Patients' challenges and physicians' tasks according to EPC phases in the setting of haematological malignancies (HMs)

| EPC phase     | Patients' challenges   | Palliative care specialists' tasks  |
|---------------|--|---|
| First visits  | <b>Absorbing the shock of diagnosis</b><br><b>Maintaining emotional equilibrium</b><br><b>Adapting to the diagnosis</b><br><b>Adapting to changes in life</b>  | <b>Building partnership</b><br><b>Reviewing and managing physical and psychosocial symptoms</b><br><b>Psychosocial assessment</b><br><b>Assessing illness and prognostic understanding</b><br><b>Exploring concerns about the future</b>  |
| Middle visits | Adjusting to the diagnosis<br>Adapting to several changes in life<br><b>Living as well as possible with HM</b><br><b>Expanding hopes</b><br><b>Deepening prognostic awareness</b>  | Building partnership<br>Reviewing and managing physical and psychosocial symptoms<br><b>Exploring hopes and worries</b><br><b>Expanding hopes</b><br><b>Assessing prognostic understanding</b><br><b>Assisting with coping</b><br><b>Cultivating prognostic awareness</b><br><b>Advance care planning</b> |
| Final visits  | Living as well as possible with HM<br>Expanding hopes<br>Deepening prognostic awareness<br><b>Recognising priorities and values</b><br><b>Making informed choices</b><br><b>Acknowledging end of life</b><br><b>Dying well</b> | Building partnership<br>Reviewing and managing symptoms<br>Assisting with coping<br>Cultivating prognostic awareness<br><b>Leading goals of care conversations</b><br><b>Shared decision-making</b><br><b>Advance care planning</b><br><b>End-of-life planning</b>  |

Patients' challenges and physicians' tasks in bold are those that are most specific to that phase of EPC. Palliative care specialists may engage patients in several tasks in one visit and the same task may be undertaken across multiple visits.

EPC, early palliative care.

EPC visits serve as the time to start working on expanding the range of hopes and living well with the illness, because coping may further improve QoL, reduce psychological symptoms and open the door

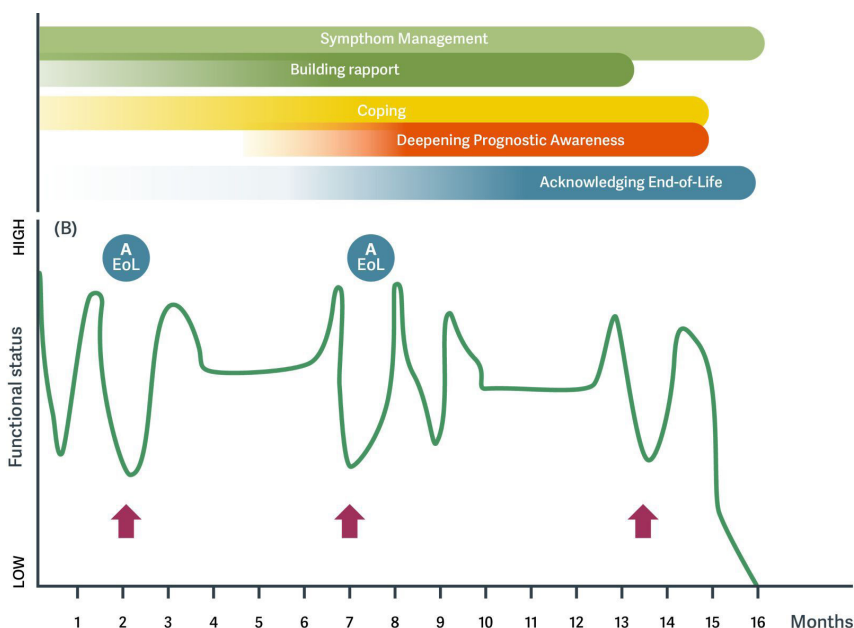
to deepening prognostic awareness (figure 1).<sup>1 2 10</sup>

4. At day+4 of the fifth course, Joseph developed pneumonia and required intubation.

After one week, he partially recovered and was extubated. The PC specialist was called because it was necessary to define an advanced care plan in case intubation was again necessary.

Dr. S knew that Joseph 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 his clinical condition required such a conversation.

The patient's goals, shared by his family, were "to live as well and as long as possible" and "to do whatever is necessary". At the same time, Joseph wanted to avoid prolonged hospitalization and being dependent on machines. These objectives were aligned by agreeing on a treatment plan that involved not only avoiding resuscitation maneuvers and intubation, prioritizing discharge home, but also considering further treatment with 5-azacitidine if the condition improved.



**Figure 1** Elements of early palliative care across the illness trajectory of high-risk myelodysplastic syndrome. Figure 1 was adapted, with permission, from Shaulov *et al.*<sup>4</sup> Red arrows indicate risk of sudden death during treatment. AEoL, acknowledging end of life.

## THE MAIN GOALS OF FINAL EPC VISITS

The goal of the final EPC visits is EOL planning. This is an individualised, time-dependent process, which may occur after several visits when prognostic awareness deepens (table 1).<sup>2</sup> Although many of our patients find it challenging to come to terms with their own inevitable death, they report that periodic conversations about the topic favour this process.<sup>10</sup> The disease trajectory of solid tumours is typically more predictable than that of HM, allowing for more time to prepare patients.<sup>4</sup> Patients with HM tend to have a steep trajectory of decline and a rapid death.<sup>4</sup> Thus, PC specialists should be prepared for difficult and sudden conversations, which are of paramount importance to alleviate family distress and reduce aggressiveness of care at EOL (figure 1).<sup>5</sup>

## CONCLUSIONS

In HM, the goal of EPC is to help patients to live and die well by means of alleviating symptoms, building trust, facilitating coping with the illness and increasing patients' understanding of their prognosis so that they can make informed choices consistent with their values. Because of the inherent characteristics of HM, EPC clinicians should be prepared to plan proactively for EOL, even when prognostic awareness is not complete.

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### ORCID iDs

Leonardo Potenza <http://orcid.org/0000-0002-2738-6105>

Mario Luppi <http://orcid.org/0000-0002-0373-1154>

Camilla Zimmermann <http://orcid.org/0000-0003-4889-0244>

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