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PERSPECTIVE

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European Cancer Organisation Essential Requirements for Quality Cancer Care: Hematological malignancies

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European Cancer Organisation Essential Requirements for Quality Cancer Care (ERQCCs) are primarily organizational recommendations, giving politicians, managers, oncology teams, patients, and patient advocacy groups a non-technical overview of the elements needed to provide high-quality care throughout the patient journey. They are not clinical guidelines, but define the actions necessary to deliver high-quality care to patients with specific cancer types, here applied to hematological malignancies in Europe.

The recommendations set out an aspirational but realistic standard that should be within reach for most countries, given adequate resourcing. They include the need for (1) fast and easy access to accurate diagnostic tests; (2) clearly established pathways for referral

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to specialist centers; (3) services to be centralized; (4) continuous monitoring of patient well-being; (5) treatment strategies to be agreed by a core multidisciplinary team; and (6) patients and their families to be involved at all stages of decision-making.

The foundation of ERQCCs is quality. This has become increasingly important in all aspects of healthcare as new and complex treatments come into use and pressure grows on resources. Improving quality means delivering cancer care that is timely, safe, effective, and efficient; that puts the patient at the center; and that gives all people in Europe equal access to high-quality services.

Variations in cancer outcomes and disparities in management and funding across Europe make quality frameworks essential.[1] The European Guide on Quality Improvement in Comprehensive Cancer Control (2017) underscored this fact, recommending comprehensive cancer centers and integrated care networks.[2] However, while some progress has been made in concentrating expertise for specific tumor types such as breast and prostate cancers, dedicated multidisciplinary units are lacking for most cancers, including hematological malignancies. Recent initiatives such as Europe's Beating Cancer Plan have added a new momentum to quality initiatives, emphasizing multidisciplinary collaboration and timely access to quality treatment, aligning closely with ERQCC principles.

KEY FACTS ON HEMATOLOGICAL MALIGNANCIES

Hematological malignancies (blood cancers) are the fifth most common cancer group in economically developed regions. They include leukemias, lymphomas, and myelomas, with over 100 clinically meaningful subtypes defined by the World Health Organization's Classification of Tumours of Haematopoietic and Lymphoid Tissues and the International Consensus Classification.[3–6] The European Society for Medical Oncology (ESMO) and the European Hematology Association (EHA) have issued clinical practice guidelines for many of the subtypes and these are regularly updated.

The European-Commission-funded HAEMACARE project has produced crude, age-specific, and age-standardized incidence rates for hematological malignancies in Europe, categorized according to morphological subtype.[7] These were derived from data on 66,371 diagnosed lymphoid malignancies and 21,796 myeloid malignancies recorded between 2000 and 2002 by 44 European cancer registries.

The age-standardized incidence rates were 24.5 (per 100,000) for lymphoid malignancies and 7.55 for myeloid malignancies. Among lymphoid malignancies, the most prevalent subtypes were plasma cell neoplasms (4.62), small B-cell lymphocytic lymphoma/chronic lymphatic leukemia (3.79), diffuse B-cell lymphoma (3.13), and Hodgkin lymphoma (2.41). Meanwhile, the most common myeloid malignancies included acute myeloid leukemia (2.96), other myeloproliferative neoplasms (1.76), and myelodysplastic syndromes (1.24). Lymphoid malignancies with unknown morphology were most prevalent in Northern Europe (7.53), whereas unknown morphology myeloid malignancies were the most common in Southern Europe (0.73).

Overall, the incidence of hematological malignancies was the lowest in Eastern Europe, with lower rates observed in women. Southern Europe showed the highest incidence for most lymphoid malignancies, while the United Kingdom and Ireland showed the highest incidence for myeloid malignancies. Variations in diagnostic and registration criteria significantly contribute to disparities in incidence, alongside differences in the distribution of hematological malignancy risk factors.

HEMATOLOGICAL MALIGNANCIES: KEY CHALLENGES

Classification

Classification is complicated, and two different classifications are currently in use.[8] An integrative approach to disease definition based on clinical, pathologic, and genetic features was introduced by the Revised European-American (REAL) classification of lymphoid neoplasms.[9] This approach has been expanded in successive editions of the WHO classification of tumors of the hematopoietic and lymphoid tissue and more recently by the International Consensus Classification (ICC).[5,6,10,11] Current recommendations for diagnostic reporting are based on the 5th Edition of the WHO classification.[12] The recommendation of the Society for Hematopathology in the USA and of the European Association for Haematopathology is to use both classifications for routine diagnosis, especially in those cases where the classifications differ.

Late diagnosis

Identification of hematological malignancies in primary care can be challenging due to their diverse and non-specific symptoms, such as fatigue and bone pain (myeloma) and swollen glands (lymphoma). This can result in diagnostic delays, leading to patient dissatisfaction, frequent GP consultations, and more emergency presentations before diagnosis compared with other cancers. Multiple myeloma patients typically endure three misdiagnoses and a three-month delay before receiving a correct diagnosis.[13] This impacts treatment, survival, and quality of life.[14]

Prompt diagnosis relies on primary care physicians recognizing potential malignancies and conducting appropriate tests, followed by diagnosis confirmation by hematopathologists within specialized multidisciplinary teams (MDTs). These teams play a crucial role in educating non-hematological healthcare providers about hematological malignancies, to reduce late diagnosis.

Maintaining quality of life

Maintaining quality of life is paramount for hematological malignancy patients. Many will survive for long periods with their disease. Therefore, maintaining self-esteem and a sense of control, along with accurate assessments of physical and mental functioning, are vital.[15] Quality of life considerations may thus take precedence over other clinical endpoints in some cases.

To maintain quality of life, it is essential to properly measure and manage treatment toxicity. As with other cancers, fatigue can have a significant impact and needs to be addressed according to current ESMO clinical practice guidelines.[16] Increasing efforts are being made to assess, record, and report quality of life using patient-reported outcome assessments.

Therapy adherence

Addressing issues of long-term adherence to treatments is becoming increasingly important, given the growing use of oral therapies over extended periods. Research has shown that adherence is poor in one fifth of chronic myeloid leukemia patients.[17] Adherence can be promoted through specialized nursing support and pharmacist monitoring within multidisciplinary follow-up clinics at specialist centers. This may be especially useful with older patients, who may be taking multiple medications for comorbidities.

Psychosocial challenges

Psychosocial challenges are prevalent among hematological malignancy patients and require comprehensive support services. Anxiety affects 45% of newly diagnosed lymphoma patients.[18] Fear of recurrence, isolation, being a burden to others, and death are common.[19] Distress disorder affects up to 27% of survivors and 44% of their partners, while clinical depressive symptoms afflict 12% to 33% of hematological malignancy patients.[20,21] Notably, depressive symptoms at diagnosis have been linked to lower survival rates.[22]

Inequalities

Treatment of hematological malignancies can be financially burdensome due to prolonged treatment periods and the use of novel, often expensive, agents. This leads to reimbursement difficulties and inequalities in care access. Disparities in access are particularly notable in Central and Eastern European nations.[23]

Age-related inequalities also exist. Older patients with conditions like acute myeloid leukemia can face significantly poorer outcomes compared to younger counterparts. This can only in part be attributed to higher comorbidity rates in older people.

ESSENTIAL REQUIREMENTS: ORGANIZATION OF CARE

Essential requirements for the organization of quality care for people with hematological malignancies are summarized in Table 1.

Diagnosis

Efficient and rapid access to diagnostics, high-quality testing, and rapid turnover of test results to clinicians and patients are all essential. Different tests and different samples are required for the diagnosis of different hematological malignancies. Blood and bone marrow morphological analysis is usually required for most hematological malignancies, which is further analyzed by flow cytometry and/or used for genetic tests, including cytogenetics and mutational analyses. Lymph node biopsy material is typically required for lymphomas, either by surgical excision or core biopsy by interventional radiologists. These tests are needed to make the correct diagnosis and the most appropriate choice of treatment and response monitoring. Different types of imaging can be added to provide additional information.

Errors and delays at this stage can significantly impact patient outcomes, so there is a need for quality diagnostics overseen by specialist hematopathologists. The ideal is that clinicians will together be able to work from an "integrated report," pulling together histology, flow cytometry, cytogenetics, and molecular testing into a single diagnosis.

There are important recommendations on hematological malignancy diagnostics and monitoring from ESMO, EHA, the European Leukemia Net (ELN), and the European Myeloma Network (EMN).[24–27] Useful recommendations have also been produced by health technology assessment programs in European countries. In the UK, for example, the National Institute for Health and Care Excellence recommends that specialist-integrated hematological malignancy diagnostic services should have a predefined diagnostic pathway that is followed for each specimen type or clinical problem.[28]

TABLE 1 Essential requirements for care organization in hematological malignancies.

- Fast access to accurate diagnosis and a second expert opinion if required.
- Timely treatment at all stages following diagnosis.
- Effective and continuing care and survivorship planning centered on a multidisciplinary approach.
- Care pathways that cover the entire patient journey.
- Care in specialized centers that treat sufficient patients on a daily basis to provide quality of care.
- High-quality supportive and palliative care spanning the entire patient journey.
- A patient-centered approach, with patients provided with information and involved in shared decision-making at every stage.
- Referral to patient/caregiver/advocacy organizations for information and practical and emotional support.

Care pathways and timelines

Establishing clear referral pathways to specialist centers is essential if treatment for suspected hematological malignancies is to be started promptly. There are well-established guidelines on the diagnosis and management of hematological malignancies from ESMO and EHA.[24,25] Services in different countries may have distinct qualities and different guidelines, but the need for rapid referral mechanisms is universal.

Units and centers

There are two models of care for hematological malignancies: either services centralized into larger centers (sometimes at the center of a "hub and spoke" arrangement, with smaller referring units) or more widely distributed smaller centers, closer to the patient. This expert panel recommends a centralized approach because of the relative rarity of many hematological malignancy subtypes and the need for specialized expertise and resources, including modern molecular diagnostics. It is particularly important to treat acute leukemias in larger referral centers. Other hematological malignancies may be managed at smaller local centers but with input from a wider MDT, which may be required to provide specialized services such as stem cell transplantation and immune effector cell therapy.

Psychosocial planning

Integrating psychosocial support into routine care is crucial.[29] Specialist psychological support should be readily available within treatment centers and the community. All MDT members should receive basic training in psycho-oncology and be proactive in identifying cancer distress and offering support.[30] The ESMO clinical practice guideline on anxiety and depression in adult cancer patients provides an evidence-based approach.[31] Research has shown that clinical interaction with a psycho-oncology-trained professional is key to helping patients feel informed and empowered in a complex and threatening environment.[32]

Distress screening is critical because it identifies individuals in need of psychological care.[33,34] Subgroups of hematological malignancy patients should be closely monitored for suicidal ideation and actively treated if necessary.[35,36] The Impact of Events Scale is a reliable tool for assessing post-traumatic stress in hematological malignancy patients.[37]

Supportive and palliative care planning

The majority of hematological malignancies are treated with curative intent or the expectation of long remission. Diseases such as

myeloma remain incurable and the treatment goal is to prolong life and quality of life. Although relapse is often associated with poor prognosis, salvage therapy is sometimes offered with curative intent, for example, after stem cell transplant or chimeric antigen receptor T (CAR-T) cell approaches.

For patients whose hematological malignancy is incurable, modern active (and well-tolerated) treatments are now available to improve duration and quality of life. This form of palliative care will be managed by hematologists, oncologists, and other members of the MDT.

All patients with severe symptoms or life expectancy of under a year should be introduced to the specialist palliative care team including physicians and specialist nurses. For end-of-life care, the team will work with social workers, chaplains, psychotherapists, physiotherapists, occupational therapists, dieticians, pain specialists, and psycho-oncologists. Planning for end-of-life care should prioritize dignity and comprehensive support.

The multidisciplinary team

Once a diagnosis is made, timely referral to a hematological malignancy MDT is essential. MDTs are crucial for achieving the best outcomes for patients and are a core component of good-quality cancer care.[38,39] Cancer management requires diverse health expertise and collaboration between specialists. Unlike reactive, referral-based approaches, an MDT approach involves making shared decisions all along the treatment pathway that is best for the individual patient, from initial assessment, through relapses to palliative care.[40,41]

Treatment strategies for hematological malignancy patients should be planned on the basis of consensus in the core MDT. MDT composition may vary according to the resource availability, but a standardized network, used globally, is desirable. Surgical oncologists are not part of the core MDT in hematological malignancies, but they may be required for diagnosis by surgical excision and if the initial referral is to a surgeon for diagnostic biopsy.

Here, we outline recommended core MDT members and their essential skill requirements.

ESSENTIAL REQUIREMENTS FOR THE MDT MEMBERS

The core multidisciplinary team should include representation from the following areas.

Hematology/medical oncology

Hematologists and medical oncologists are the primary healthcare professionals responsible for ordering diagnostics and providing treatment for hematological malignancy patients. They typically undergo extensive medical training, beginning with a foundation in internal medicine, and go on to specialize in hematology and/or medical oncology, allowing them to develop expertise in the diagnosis, treatment, and management of blood disorders and cancers. Many hematologists and oncologists further refine their expertise by focusing on specific subfields.

Their day-to-day responsibilities can vary significantly depending on the country or healthcare institution in which they practice. Some may be more involved in clinical research or teaching; others may primarily focus on patient care. They work in close collaboration with pathologists, radiologists, and surgeons to develop comprehensive treatment plans for patients. These specialists play an increasing and crucial role in managing complex therapies such as chemotherapy, immunotherapy, bone marrow transplants, and CAR-T cells. Their role is central to the multidisciplinary approach required for effective hematological malignancy care (Table 2).

TABLE 2 Essential requirements for hematologists/medical oncologists.

- Basic proficiency in medical domains such as infection medicine, endocrinology, gastroenterology, pulmonology, nephrology, rheumatology, immunology, cardiology, geriatrics, and genetics.
- Competence in diagnostics, differential diagnosis, prognosis assessment, management and treatment strategies, and follow-up of patients with hematological malignancies.
- Knowledge of when to refer patients for specialized treatments such as stem cell transplantation.
- Proficiency in interpreting imaging findings.
- Proficiency in performing procedures such as bone marrow biopsy, cerebrospinal sampling, ascites, pleural effusion, and lymph nodes biopsy.
- Ability to perform, report, and interpret special laboratory tests, including immunological and molecular diagnostics.
- Ability to administer systemic drug treatments, and recognize and manage their side effects.
- Knowledge of indications for surgical, radiotherapeutic, and interventional procedures and ability to assess their potential outcome.
- Ability to apply supportive measures, including prophylaxis and treatment of infections, pain management, nutrition, and dietetics.
- Skill in patient communication and addressing psychosocial aspects.
- Access to stem cell transplant and CAR-T cell therapy.

TABLE 3 Essential requirements for hematopathologists.

- At least one year of formal hematopathology training and several years of experience.
- Access to comprehensive clinical records, including patient clinical history, laboratory results, clinical diagnosis, previous biopsies, and information of any prior or ongoing treatment.
- Access to an immunohistochemical laboratory with a broad panel of antibodies needed for accurate diagnosis, FISH analysis with the most frequently used probes, ISH, and molecular laboratory for clonality analysis (access to flow cytometry testing is also recommended).
- Ability to establish a correct diagnosis of a specific disease entity listed in current classifications and supply a synoptic diagnostic report with a complete list and results of the ancillary tests performed.
- Engagement in quality assessments (often national) to ensure accurate reporting.
- Access to an accredited laboratory for molecular testing on site or as a referral.

Pathology

Hematopathology provides the accurate and timely hematological malignancy diagnoses that are required for clinical decision-making. They play a central role in the MDT and participate in clinical decision-making based on a histopathological diagnosis for each patient at MDT meetings.

Although the roles of diagnostic hematologists and hematopathologists may differ from country to country, a fundamental component is always specialized expertise in accurately diagnosing hematological malignancies. This is a labor-intensive process and requires ancillary techniques, including immunohistochemistry, in situ hybridization, fluorescence in situ hybridization, flow cytometry, and clonality analysis of T-cell receptor genes and/or immunoglobulin heavy- and light-chain genes. Genetic analysis has become increasingly important for accurate diagnosis of myeloid and lymphoid neoplasms.

The need for cytogenetics and molecular testing (gene mutations, gene fusions, chromosomal numerical aberrations) is becoming mandatory to provide diagnosis and prognosis information.[42,43] Next-generation sequencing is increasingly being used to assess mutations in hematological malignancies, often using targeted gene panels set up to cover the majority of mutations seen in individual diseases Table 3.

TABLE 4 Essential requirements for imaging specialists.

- Be proficient in tailoring imaging techniques to different hematological malignancies.
- Adhere to disease-specific imaging guidelines, such as Lugano for lymphoma and IMWG for myeloma.
- Be familiar with response assessment criteria, including the Deauville score for 18F-FDG-PET and MY-RADS MRI criteria for myeloma.[49]
- Collaborate with clinicians to address contraindications and discuss biopsy requests.
- Provide image-directed biopsies (in the case of interventional radiologists) for diagnosis and assessment of treatment response.

Diagnostic imaging

Imaging can reveal non-palpable thoracic or abdominopelvic lymphadenopathy as well as extranodal lesions in lymphoid malignancies that cannot be assessed by physical examination. Biopsies required for pathology workup are frequently performed by interventional radiologists under image guidance, especially using ultrasound and CT.

To assess the extent of disease before treatment, cross-sectional imaging with CT, MRI, or 18F-FDG-PET is the standard of care for lymphoma and myeloma. In leukemia, imaging is mainly used to assess complications such as pneumonia before and during treatment. The choice of the imaging technique in lymphoma and myeloma depends on histology.[44–46]

For treatment response assessment, 18F-FDG-PET/CT or contrast-enhanced CT is the standard of care in most lymphoma subtypes as well as in multiple myeloma.[47] For central nervous system lymphoma, contrast-enhanced MRI is the standard of care for initial assessment and post-treatment follow-up.[48]

For PET, hybrid PET/CT is the standard technique. PET/MRI has shown similar or better performance than PET/CT in a number of studies and may therefore be used as an alternative. 1.5. or 3.0 Tesla scanners are the standard of care for MRI. Up-to-date quality-assurance protocols must be in place for all imaging modalities. For PET/CT devices, EARL accreditation by the European Association of Nuclear Medicine is recommended.

Communication with other clinicians is extremely important. To enable correct interpretation of imaging findings, clinicians must inform imaging specialists about the exact type of hematological malignancy (e.g., lymphoma subtype, precursor, or symptomatic myeloma), treatment history (e.g., type of therapy, prior radiation), and other relevant information (e.g., granulomatous disease or other cancers). Requests for image-guided biopsies must be directly discussed between clinicians and imaging specialists Table 4.

Radiation oncology

Radiotherapy plays a significant role in several aspects of treatment. It can serve as primary treatment for early-stage indolent lymphoma. It is crucial in alleviating symptoms or managing emergencies such as imminent cord compression. It is also an essential component in combined modality treatments for early-stage Hodgkin lymphoma and aggressive lymphoma. In cases of advanced aggressive lymphoma, radiotherapy may act as a consolidation therapy to improve outcomes. For refractory/recurrent disease, radiotherapy is often used as a therapeutic strategy.

Furthermore, palliative radiotherapy offers relief to patients with advanced or incurable conditions. It also serves as a conditioning treatment for bone marrow transplantation: however, this requires specialist training and should only be delivered in centers that treat sufficient numbers of patients to ensure safety and effectiveness.

To ensure optimal outcomes with minimal late toxicities, radiation oncologists should prioritize modern techniques and take meticulous care in defining target volumes, optimizing dose, and minimizing long-term side effects (Table 5).

Radiation oncologists define appropriate indications and oversee the radiotherapy care pathway from the start, including (1) image acquisition in the treatment position; (2) defining the target volume and organs at risk; (3) evaluating the treatment plan; (4) assuring quality of treatment delivery, including image-guidance and motion management; and (5) assessing the need for adaptive radiotherapy and follow-up (Table 6).

Nursing

Nurses caring for hematological malignancy patients must possess specialized skills to handle the complexities of aseptic protocols, chemotherapy administration, and identifying and managing complications such as neutropenic sepsis. Essential nursing requirements involve proficiency in specialized care procedures, chemotherapy administration, and supporting patients through treatment-related side effects.

The psychosocial well-being of patients remains at the center of all decisions and management plans. The onus of educating patients falls largely on the nursing staff. Increasingly, there is demand for clinical nurse specialists and nurses trained to carry out expanded roles, including physical assessments and prescribing and managing late effects (Table 7).

TABLE 5 Essential requirements for radiation oncology departments treating hematological malignancies.

- Have access to up-to-date radiotherapy technology and techniques such as IMRT and IGRT, motion management, and adaptive radiotherapy.
- Be able to refer to proton beam treatment centers if necessary.
- Use multimodal imaging, including a CT in treatment position and/or a PET/CT scan to define disease extension at staging, response to systemic treatment, and target volume definition.

TABLE 6 Essential requirements for radiation oncologists.

- Know the radiotherapy indications in different hematological malignancies, as well as expected efficacy and potential side-effects of radiotherapy in multidisciplinary treatment options.
- Have a special interest and expertise in hematology in order to select the optimal treatment for each patient.
- Work with a team of radiation therapists, dosimetrists, and medical physicists with specific expertise in hematological malignancies.
- Be aware of ongoing clinical trials and updated specific clinical guidelines such as those from the International Lymphoma Radiation Oncology Group.[50]
- Follow up patients to act on early and late toxicity and be part of a survivorship team.

TABLE 7 Essential requirements for nurses.

- Be trained to care for patients with the appropriate additional precautions.
- Be trained in the delivery of chemotherapy.
- In specialized centers, be trained in the delivery of stem cells, gene modified cells, including CAR-T cells, and other advanced therapy medicinal products.
- Be aware of the side-effect profiles of treatment regimens and the signs and symptoms of hematological emergencies,
- Build strong relationships with patients to promote open communication about quality of life, response to treatment, and side effects.

Oncology pharmacy

The role of the oncology pharmacist is to liaise with the hematologist/medical oncologist about treatments and management of adverse effects to help ensure effective and safe treatment. The pharmacist supervises the preparation of oncology drugs and works with the nurses to manage therapy. Another important role is to counsel patients about their drug treatment, especially for initiation of oral targeted drugs (Table 8).

Endocrinology

Endocrinologists in hematological malignancy primarily address treatment side effects like glucocorticoid-induced diabetes and adrenal insufficiency. They also oversee fertility preservation efforts, which should be available for all patients undergoing treatment[51] (Table 9).

Nutrition and metabolism

Nutritional support plays a crucial role in managing malnutrition and cachexia in hematological malignancy patients. Screening, professional dietary counseling, and access to oral supplements or alternative feeding methods are all essential. To minimize the risk of ignoring malnutrition, international guidelines from ESMO and the European Society of Clinical Nutrition and Metabolism recommend screening all patients with malignant diseases repeatedly. Assessment aims to diagnose treatable deficits and quantify nutritional status to allow the effects of planned nutritional support to be monitored. Patients at risk of malnutrition should receive professional dietary counseling and, if necessary, psychological support (Table 10).

TABLE 8 Essential requirements for oncology pharmacists.

- Have experience with antineoplastic treatments, targeted drugs, and supportive care; interactions between drugs; drug dose adjustments based on age, liver and kidney function, body mass index, and toxicity profile; utilization and monitoring of pharmacotherapy and therapeutic drug monitoring; and patient counseling and pharmacovigilance.
- Have knowledge of complementary and alternative medicines.
- Comply with the European Quality Standard for the Oncology Pharmacy Service and complete a continuing education program in oncology pharmacy at the national or European level.
- Provide personalized information for patients on their drug therapy to support adherence and help medical oncologists monitor side effects.
- Work with hematologists on clinical cancer trials.

TABLE 9 Essential requirements for endocrinologists.

- Have expertise in glucocorticoid-induced diabetes and adrenal insufficiency.
- Have expertise in drug-induced endocrine side effects and optimal treatments.
- Have expertise in assisted medical procreation.

TABLE 10 Essential requirements for nutritional support.

- Offered as a component of multi-professional supportive care.
- Includes repeated professional dietary counseling.
- Includes access to oral nutritional supplements and, if necessary, tube or intravenous feeding, ensuring provision of adequate amounts of energy and nutrients, particularly protein and micronutrients, according to international guidelines.
- Always accompanied by muscle training, including endurance and strength exercises.

TABLE 11 Essential requirements for palliative care specialists.

- Be responsible for specialist palliative care and make recommendations to other specialists about symptom control and other conditions.
- Identify patients who need palliative care through the systematic assessment of distressing physical, psychosocial, and spiritual problems.
- Treat disease- and treatment-related symptoms and offer psychosocial and spiritual care.
- Incorporate support for family members.
- Provide early integrated palliative care in conjunction with cancer-specific treatments.
- Provide end-of-life care working with primary care palliative care providers.

Palliative care

Specialist palliative care teams should be involved early in the care of hematological malignancy patients with severe symptoms or limited life expectancy, providing comprehensive symptom management and psychosocial support (Table 11).

OTHER ESSENTIAL REQUIREMENTS

Patient involvement

Data from international surveys indicate that, at diagnosis, most patients are still not offered support (written information, referral to psychological support or patient groups), do not have the opportunity to discuss treatment options, and wish that they had more help with concerns about treatment.[52]

Patients and their families should be actively involved in all facets, and at all stages, of the decision-making process regarding treatment and care. As part of shared decision-making, healthcare professionals should provide relevant, easily understood, and reliable information and allow time for detailed discussion and questions.

It is crucial to ensure that hematological malignancy patients must have access to information, diagnostic results, and test outcomes. Hematologists/medical oncologists should support patient involvement in decision-making, providing tailored information and choices aligned with the patients' disease, circumstances, and preferences. Additionally, patients should be supported to take control of areas that could enhance their quality of life and influence the course of the disease, such as making dietary changes.

Clinicians must empower patients with the knowledge and resources needed to identify and manage side effects from medication and chemotherapy. Furthermore, healthcare professionals should recognize that receiving treatment in outpatient settings may limit patient opportunities to voice concerns. They should bear in mind that while survival is important to all patients, there are significant variations in individual perspectives. Research has shown that healthcare professionals often focus more on survival, while many hematological patients place more importance on quality of life.[53]

Patients report that the most important information for treatment decision-making relates to treatment effectiveness (e.g., overall survival benefit, likelihood treatment will work, time until disease returns) and then treatment tolerability and quality of life.[54]

Patient-reported outcome tools covering quality of life and symptoms should be used in clinical practice. Some are disease-specific, such as the Myeloma Patient Outcome Scale.[55] Others, such as HM-PRO, are generic to hematological malignancies.[56]

Patient organizations

Patient advocacy organizations can support patients and their families by providing information in simple language and in the patient's

mother tongue. Furthermore, they can help patients better understand the disease, treatment options, and available clinical trials. Emotional support can be provided face to face, in the hospital, online, or via the telephone.

The hematology patient community is well organized and has a strong track record on working with the European Hematology Association, the European Patient Advocacy Group of EuroBloodNET, and research networks such as the Innovative Medicines Initiative HARMONY project. International studies suggest that when patients reach out to patient organizations, they feel supported and have access to the information that they need.[52]

Pathology reporting

Diagnostic workup of hematological malignancies requires the integration of data from multiple sources, including microscopic evaluation, special stains, immunohistochemistry, flow cytometry, cytogenetic analyses, and molecular testing. These are considered the diagnostic data elements within a synoptic report, which is a template for an "integrated report," incorporating all diagnostic elements necessary to achieve a definitive hematological malignancies classification.

The College of American Pathologists (CAP) has established protocols by adopting synoptic report principles as key elements. The International Collaboration on Cancer Reporting also produces international and validated evidence-based pathology data sets for cancer reporting.

However, no data set for hematological malignancies has been published to date. The most recent hematological malignancy recommendations are described on the CAP "Cancer Protocol Templates" web page.[57] The protocols are based on widely accepted classification schemes such as the 2008 and 2017 WHO classification.[11,58] The various groups of hematological malignancy should be structured in a "layered" reporting format, where layer 1 is the final classification of the integrated diagnosis (incorporating histopathologic and ancillary findings); layer 2 provides the histological assessment (providing macroscopic and microscopic descriptions of the biopsy); and layer 3 provides ancillary and biomarker studies (such as immunohistochemistry, fluorescence in situ hybridization, clonality, and genetic analyses).

Performance, quality, and audit

The ERQCC expert group recommends that centers treating hematological malignancy patients should implement performance measurement, quality indicators, and robust data management systems that align with the essential requirements outlined in this paper. Decision-making and quality improvement initiatives should be driven by patient-reported outcomes, ensuring that the patient voice is central to shaping care.

Operational policies must be in place to ensure coordinated clinical pathways that adhere to published guidelines, promoting consistency and best practice. Systems should be established to guarantee safe and high-quality patient care and an excellent patient experience, with clear accountability within governance processes. Effective data management and reporting systems are crucial for monitoring and improving care. Additionally, meaningful engagement with patients, caregivers, and support groups is vital to ensure accurate reporting of outcomes and experiences, enabling continuous enhancement of care delivery.

Clinical, process, and patient-reported outcomes should be measured and collected in databases. These approaches can be developed in the context of quality management systems depending on the health economy of an individual country.

Centers should audit their performance using comparisons with previous years and national averages, also comparing MDTs' plans with delivery. Performance of individual professions can be audited according to European guidelines.

Assessing the overall quality of care of individual patients, patient views of care, and their quality of life against expectation is important and deserves greater attention than currently received. Collecting patient-reported outcome data is a vital part of this, and there needs to be more emphasis on bringing patient-reported outcome information back to MDTs to inform decision-making.

Accreditation

Accreditation is the means by which a center can demonstrate that it is performing to a required level of practice in accordance with agreed standards of excellence. Accreditation systems vary among institutions and between countries. For example, in the field of hematopoietic stem cell transplantation and cellular therapy (such as CAR-T cells), there is the Joint Accreditation Committee ISCT-Europe & EBMT (JACIE). This expert group strongly recommends participation in national or international accreditation programs such as those run by the Organisation of European Cancer Institutes and European Cancer Centres.

ESMO's Designated Centres of Integrated Oncology and Palliative Care accreditation program bestows special recognition for effectively integrating medical oncology and palliative care.[59]

Knowledge sharing

The European Reference Networks (ERNs) are virtual networks bringing together healthcare providers to tackle complex or rare medical conditions that require highly specialized treatment and a concentration of knowledge. EuroBloodNet, the ERN in rare hematological malignancies, plays an important role, promoting telemedicine and strengthening knowledge sharing between hematology specialist centers and cancer care in the field. Hematology specialist centers should make the most of the opportunities that the ERN provides to share expertise and drive excellence.

Education and training

National societies and, at the international level, the World Organization of Family Doctors, EHA, and the European School of Haematology provide education and training opportunities. EHA offers the European Hematology Exam, which standardizes knowledge and capabilities across Europe. The European Association for Haematopathology organizes continuing education courses and webinars.

Registries and research

Research drives excellence. It spreads learning beyond the large specialist hematology clinics, where most research takes place, down to the community hematologist level. Clinical research and clinical care are closely linked, so it is important that there are strong connections between the large specialist hematology clinics and hematology care in community settings.

Hematological malignancy centers need to be involved in national or international studies. There is a need for research obtaining quality of life data in hematology, given that many hematological diseases transform into long-term chronic conditions.

CONCLUSION

The information presented in this paper provides a comprehensive description of the essential requirements for establishing a high-quality service for hematological cancers. The ERQCC expert group is aware that it is not possible to propose a "one size fits all" system for all countries, but its recommendations aim to set out a realistic standard of quality that is within reach.

In summary, the main recommendations are that

- Patients must have fast and easy access to accurate diagnostic tests because quality of diagnostics influences both treatment outcomes and the overall patient experience.
- There should be clearly established referral pathways to specialist centers when a hematological malignancy is suspected, ensuring timely access to expertise.
- Services should be organized according to a centralized model, which facilitates high throughput and ensures the level of experience required to treat rare cancers effectively.
- Continuous monitoring of patient well-being and treatment effects is essential, with supportive care provided appropriately throughout.
- Treatment strategies should be planned and agreed by a core multidisciplinary team, which will determine the optimal treatment pathway for the patient from point of entry, through relapses and to palliative care if necessary.
- Members of the multidisciplinary team must be proactive in identifying signs of patient distress and offering support.
- Patients and their families should be involved in decision-making at every stage, ensuring that their perspectives and preferences are considered in the treatment plan.

AUTHOR CONTRIBUTIONS

All authors were part of a working group planning content of the paper, and then submitting individual contributions based on their own interests and speciality. In addition, John G. Gribben and Leticia Quintanilla-Martinez co-chaired the group and supervised the writing of the paper, which was completed by medical writer Simon Crompton. All authors assessed and commented on successive drafts of the paper.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no data sets were generated or analyzed during the current study.

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