

Addressing the management of MDS in elderly patients: *a time for change*

Introduction

There is a growing body of evidence suggesting cancer is under treated in elderly people living in the UK.¹ An example of this are the Myelodysplastic Syndromes (MDS) – a group of blood cancers that predominantly affect patients over 60, where there is still an unmet need in patient care.

To help address this issue, the following Call to Action and subsequent recommendations were developed and discussed by a UK taskforce of 10 experts, in the field of haematology and geriatric medicine, brought together at a 2013 round table discussion.

These recommendations, which call for improved patient care in this area, were based on clinical practice experience and subsequent expert consensus.

Some members of the taskforce also played a role in developing the recent 2013 *British Committee for Standards in Haematology* (BCSH) MDS guidelines whose recommendations are also echoed in the conclusions detailed overleaf.²



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Setting the scene

Our population is ageing, and treatment of elderly patients could be improved.³ This is particularly apparent in cancer care, with under treatment of patients over 75 being one of a number of factors contributing to around 14,000 avoidable deaths each year in the UK.¹

MDS are a group of cancers where the production of blood cells is disrupted, often leading to infections and bleeding.⁴ Every year around 2,000 people in the UK are diagnosed⁵ and 40% of cases eventually progress to the life-threatening disease acute myeloid leukaemia (AML).⁴ MDS typically

affect people over the age of 60.⁵ Therefore, as our population ages, it is inevitable that the number of MDS cases will rise.

While MDS is incurable for the vast majority of patients, for those who receive the right treatment the disease progression can be slowed.^{6,7} Unfortunately, the evidence suggesting cancer is under treated in elderly people is growing. This is unacceptable and any obstacles preventing patients from receiving the quality of care they deserve needs to be addressed now.

Key recommendations

The issues and subsequent recommendations discussed at the roundtable meeting, reflect the MDS management and diagnosis guidelines recently published in the *British Journal of Haematology*.²

The importance of collaborative working and increased engagement with geriatricians

- Patient care should be managed by a team of experts, each with a dedicated area of knowledge aligned with the needs of the patient they are treating. An MDS multidisciplinary team (MDT) should comprise of a haematologist, geriatrician and additional specialists, should they be required⁸
- Since a variety of specialisms are required in MDS treatment, care can become fragmented. If members of the MDT are located at different hospital sites, this can lead to critical information not being shared between them⁸
- Despite the fact that geriatricians are experts in the clinical management of the elderly, they are often absent from discussions around their care. Since complex comorbidities and geriatric conditions may present a barrier to treatment if they are not managed optimally, greater engagement of geriatricians should be employed to help improve MDS outcomes for older patients⁸

The need for physician education around MDS and more clinical data on MDS

- Many healthcare professionals (HCPs) are unfamiliar with MDS and have minimal experience with the disease⁸
- Clinical data for MDS is limited due to the rarity of the condition and does not always accurately reflect MDS management in the clinical setting⁸
- As many haematologists and oncologists are insufficiently familiar with MDS, all HCPs treating

MDS patients should be trained in geriatrics to ensure patients receive the optimal care⁸

Individual patient characteristics are being overlooked due to lack of assessment

- Understanding a patient’s perception of their age and their morbidity is essential⁸
- Complications associated with age mean some older patients have different needs to others. When patients are not treated as individuals this presents a barrier to optimal care⁸

Practical and social support

- Additional support, such as transport to hospital or access to specialists, should extend to all patients with MDS. However, it is not always available to the extent required⁸
- Elderly patients might need access to supplementary treatments or therapies, such as physiotherapy, for their condition to be properly managed⁸

The classification of MDS

- MDS is recognised as a cancer by haematologists who treat it, but the lack of specific diagnostic testing for patients with mild disease has led to a reluctance for some HCPs to describe it as cancer to all patients due to the psychological impact⁸
- HCPs have a responsibility to tell patients the correct classification of their condition. However, many need support on how to communicate the diagnosis while explaining the differences between MDS and other forms of cancer⁸

Call to Action

The UK taskforce has identified the barriers to optimal management of MDS and are recommending seven straightforward steps, based on their experience, to ensure patients receive an accurate, timely diagnosis, personalised care, and education on their condition. These steps can be introduced into existing MDS MDTs immediately. Experts in the field of haematology are now calling for geriatricians, haematologists, GP’s, hospital managers, MDT coordinators and haematology nurses to take the following steps to address the unmet need in the current standard of elderly MDS care:

1. Ensure effective communication between haematologists, GPs and geriatricians⁸
2. Offer assessment by an expert haematologist wherever possible⁸
3. Report all MDS cases to a centralised database like the National Cancer Intelligence Network for registration⁸
4. Standardise treatment pathways for optimal care⁸
5. Follow the recommendations in the BCSH guidelines to ensure that patients are assessed prior to treatment and base recommendations on their individual needs and bone marrow analysis where appropriate^{2,8}
6. Offer MDS-specific education and training to patients and HCPs respectively⁸
7. Work towards developing a comprehensive single test to diagnose MDS⁸

The UK taskforce is calling for all of those working in the field of MDS to take action and implement the recommendations outlined in this Call to Action and the recent BCSH guidelines to improve patient care.



“This Call to Action highlights another example of the inequalities of cancer care experienced by elderly patients. It has highlighted some key considerations in the area of MDS and it is important that cancer specialists from all disciplines work together to address the disparities in elderly cancer care. It is vital that medical professionals involved at each stage of patient care ensure that elderly patients are being properly managed and treated with the care, consideration and attention they deserve.”

Sean Duffy, National Clinical Director for Cancer, NHS England

“Every week, our organisations receive phone calls from patients and carers highlighting inadequate care of these elderly MDS patients. We know these are just a small snapshot of the issues faced by older MDS patients. We could overcome these issues and improve the lives of MDS patients and their families by following basic guidelines and recommendations that allow for better and more cost-effective care to be put in place.”

MDS UK Patient Support Group and Leukaemia CARE

About MDS UK Patient Support Group and Leukaemia CARE

Leukaemia CARE is a UK charity dedicated to supporting patients and their families affected by blood cancer. For more information please visit: www.leukaemiacare.org.uk

MDS UK Patient Support Group supports patients with Myelodysplastic Syndromes (MDS). For more information please visit: www.mdspatientsupport.org.uk



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8. Celgene Elderly Care Round Table Meeting - UK-CELG130071



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