Assessing the needs for support in MDS patients

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INTRODUCTION

Myelodysplastic syndromes (MDS) comprise a group of hematological malignancies that prevail in elderly patients. The management of MDS can impact patients' quality of life (QoL). MDS patients require regular monitoring and personalised active treatment or supportive care, which is generally not curative. Access to specialized MDS centers is warranted.

In the UK, the level of support to improve quality of care and QoL for such patients is poorly understood. Review of literature suggests that no specific study has investigated patient experience among UK MDS patients.

AIMS

- To better understand the impact of MDS on QoL.
- To evaluate the level of satisfaction with current care in the UK and unmet needs.
- To improve the support and care provided to UK MDS patients

METHODOLOGY

- A paper based survey was conducted in the UK of MDS patients referring to the MDS UK Patient Support Group. Survey was developed and revised to ensure content validity and reliability. Protocol and ethics approval was sought from King's College London Ethics Committee.
- Survey covered 139 items on demographics, referrals, access to health care, financial impact, disease information, treatment and patient reported outcomes (PRO), including the MDS-specific QoL instrument QOL-E.[1]
- Total of 962 questionnaires were distributed (862 by newsletter; 100 posted to a random set of MDS UK members). Patients willing to take part sent back the completed survey by prepaid envelope.
- Responses to the survey were analysed using descriptive statistics, univariate and multivariate analysis where $p<0.05$ was considered statistically significant.

RESULTS - Demographics

171 patients of mean age 69 ± 10 years (95 males, 76 females), mainly British Caucasians, completed the survey. Characteristics of patients are shown in Table 1.

Table 1.

Characteristics N=171	
Age, median (range)	70 (41-93)
Gender (Male/Female), N (%)	95 (56); 76 (44)
Years from MDS diagnosis, median (IQR)	3 (1-5)
Level of Education, N (%)	
Secondary School	51 (30)
College/University Degree	118 (70)
Level of income, N (%)	
<£15,000	22 (13)
£15,000-£50,000	85 (51)
≥£50,000	33 (20)
Employment Status, N (%)	
Retired	133 (78)
Not retired	38 (22)
Region, N (%)	
Rural	55 (34)
Urban	109 (67)
Additional health issues, N (%)	
Hearing/Visual impairment	36 (22)
Mental health condition	6 (4)
Long standing illness	96 (56)
IPSS Score, N (%)	
Low risk-Intermediate 1	56 (35)
Intermediate 2-High risk	11 (7)
Active MDS treatment, N (%)	
Azacitidine	21 (13)
Lenalidomide	9 (5.4)
Chemotherapy	27 (16)
Supportive Care, N (%)	
Transfusions	102 (62)
Growth Factors	65 (39)

RESULTS – Symptoms and Patient referrals

112 patients (66%) recalled symptoms before diagnosis (Figure 1). 65% of 120 cases judged their general practitioners as not familiar with MDS. Greater familiarity with MDS was significantly associated with time to referral to hematologists ($p<0.0001$). Most patients were referred to hematologists within 8 weeks (Figure 2). For GPs unfamiliar with MDS, 1/3 of patients took more than 3 visits to be referred, which resulted in a delay of diagnosis of ≥8 weeks in 50% of those patients ($p=0.003$).

Figure 1. Most reported symptoms by patients prior to diagnosis.

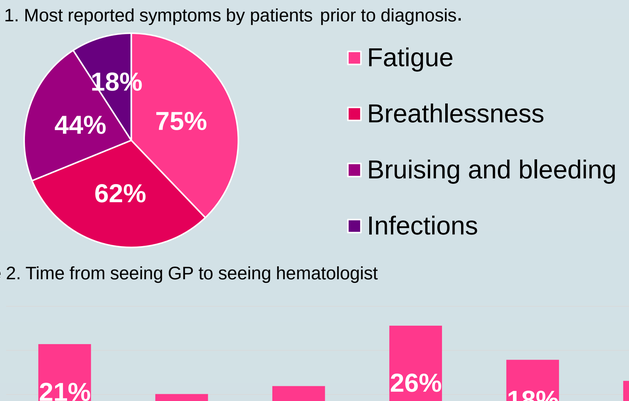
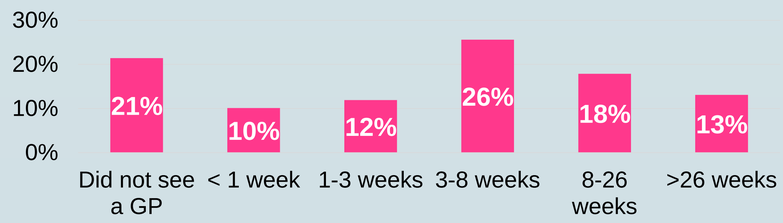


Figure 2. Time from seeing GP to seeing hematologist



RESULTS – Knowledge of MDS

One third of patients do not know or recall their initial diagnosis and 38 continue not to know their MDS subtype. Knowledge of disease type and prognosis was poorer in those with lower incomes ($p=0.048$).

The explanation of MDS diagnosis by staff was heterogeneous (Figure 3). Verbal information was considered sufficient by 39% of patients and this perception was associated with income (Figure 4).

Figure 3. Description of MDS at the time of diagnosis

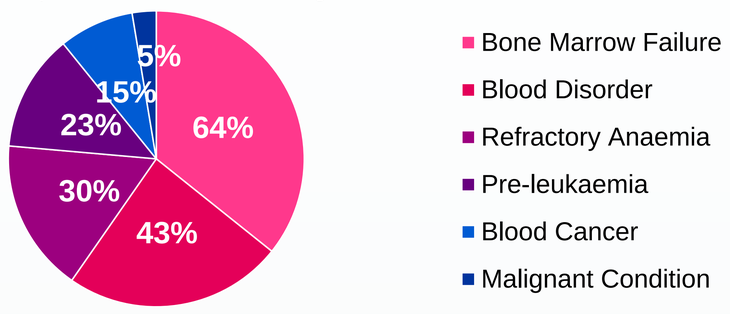
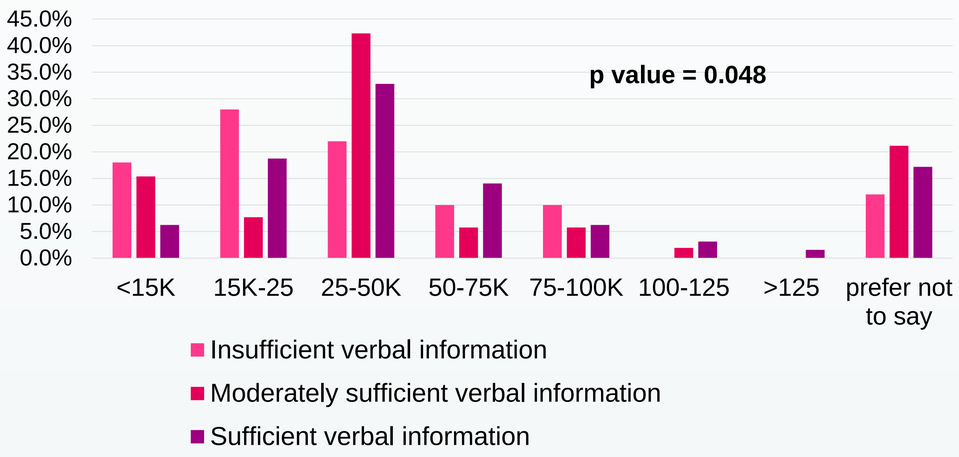


Figure 4. Association between income and levels of verbal information provided at time of diagnosis



RESULTS – Change of employment

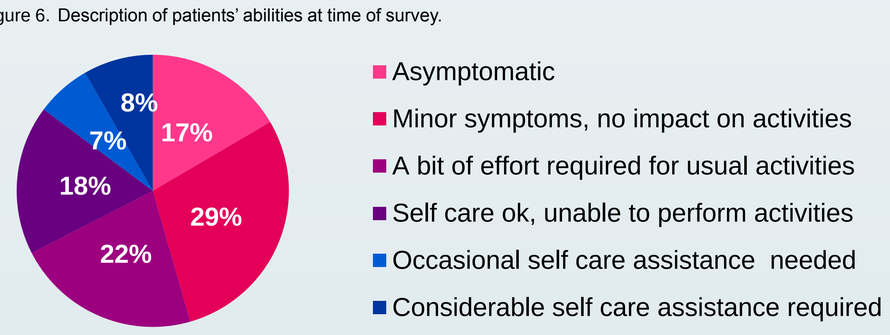
48 (31%) patients were of working age. Amongst these, the diagnosis necessitated a change in employment for 24 (50%) (Figure 5)

Figure 5. Change in employment as a result of MDS

RESULTS – Transfusions, Therapy and Patient Reported Outcomes

At the time of the survey, almost half of the patients referred absence of symptoms or only mild symptoms that did not impact on abilities while 14% required assistance (Figure 6).

Figure 6. Description of patients' abilities at time of survey.



Treatments were growth factors (38%), erythropoiesis stimulating agents (67%), lenalidomide (5%) and iron chelation (17%). High risk MDS treatment was given in 29% of patients.

Ninety seven patients (60%) had received red blood cell (RBC) transfusions and 60 were RBC transfusion dependent (TD) at the time of the survey. Abilities were compromised in 78% compared to 40% of the RBC transfusion free (TF) patients ($p<0.0001$) (Figure 7a). Further, RBC-TD patients were spending more time worrying about MDS compared to RBC-TF ($p=0.007$) with a higher emotional burden ($p=0.004$) (Figure 7b).

Figure 7a. Differences in abilities of RBC-TD and RBC-TF patients at time of survey.

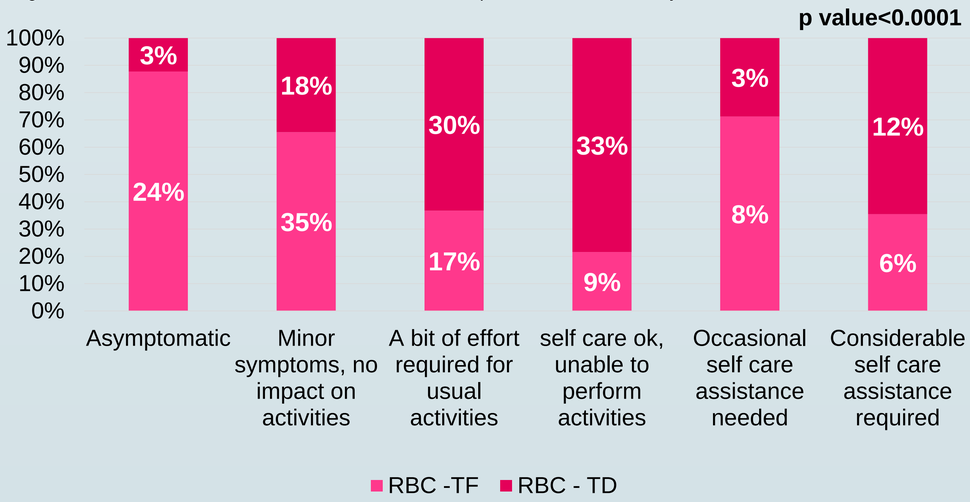
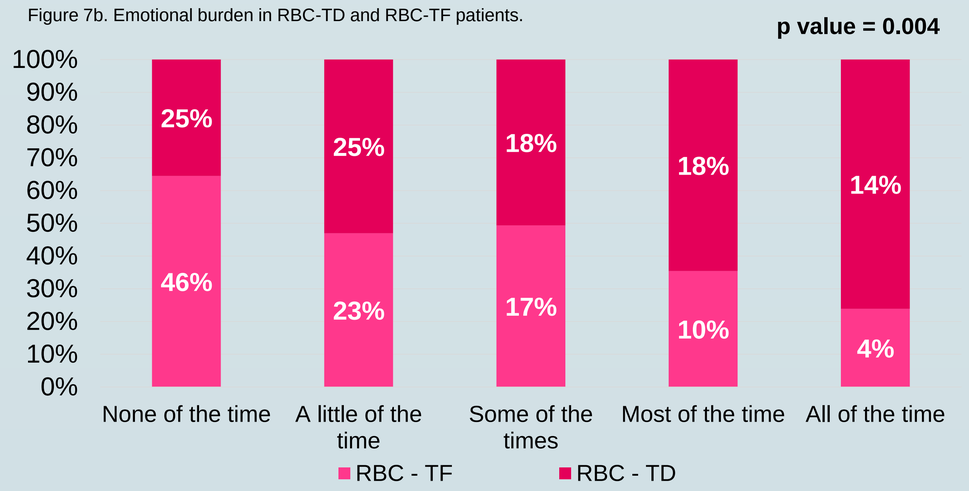


Figure 7b. Emotional burden in RBC-TD and RBC-TF patients.

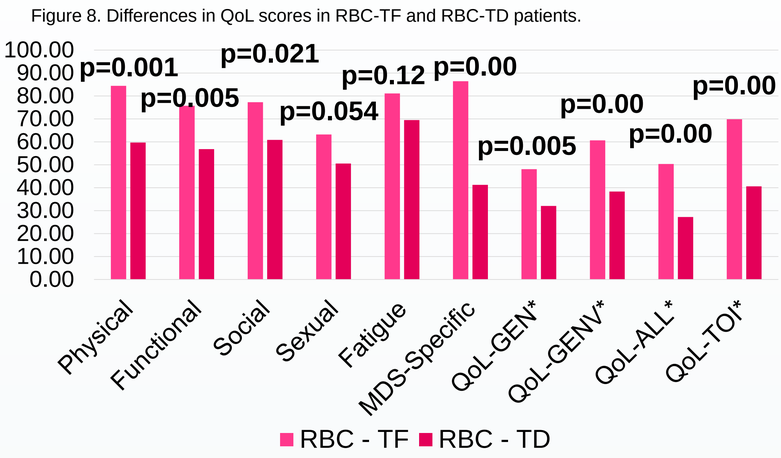


RESULTS – Differences in QoL between RBC-TF and RBC-TD patients

QOL-E showed good reliability in all domains (Cronbach alfa >0.7), except sexual domain. Duration of MDS correlated with QOL-E functional well-being ($p=0.01$). Physical issues caused by MDS (a separate item in the survey), as perceived by patients, strongly correlated with all QOL-E domains ($p<0.0001$).

Scores were significantly lower (worse QoL) in RBC-TD patients in all domains (Figure 8), and the independent impact on QoL was maintained on multivariate analysis.

Figure 8. Differences in QoL scores in RBC-TF and RBC-TD patients.



QoL-GEN = all domains except MDS-Specific; QoL-GENV = all domains except MDS-Specific and sexual domain, QoL-ALL = QoL-GEN+MDS-Specific; TOI = Treatment Outcome Index

DISCUSSION

Patients with lower household income have less knowledge and may seek less advice, compromising treatment and access to clinical trials which goes against multiple recommendations.[2,3]This is often compounded in hospitals unable to offer a dedicated Clinical Nurse Specialist and/or if the patient does not have a good support network. Change of employment further reduces income, which together with fatigue, can further limit treatment options at more distant centers. As other research has already stated, without additional support and information, patient outcomes and survival can be affected.[4]

Differences among hematologists in conveying information on MDS may cause increased confusion and distress in both patients and families, leading to a need for lengthier than necessary consultations with clinical staff in order to clarify diagnosis. In those unable or unwilling to vocalize their emotions to clinical staff, these differences in terminology can increase the burden of living with MDS.

The burden of transfusion dependence is perceived by patients through compromised self-care and distress.[5] Impact of fatigue is still under-recognised due to lack of appropriate evaluations, and insufficient patient communication, resulting in a poorer QoL in a portion of patients, as well as their families/carers. There is an over-reliance on patients themselves to request additional care options and insufficient sign-posting to additional support sources to empower those patients at a disadvantage from outset. Lifestyle, together with hemoglobin levels and pre-MDS symptoms should always be investigated, to avoid simply caring for patients according to the "perceived burden of chronological age".

CONCLUSIONS

- This is the largest UK MDS-specific survey ever conducted focusing on needs, experiences and QoL of MDS patients. Age group of respondents was truly representative of the median age at diagnosis.[6]
- Emotional and psychological support should be offered at the earliest stage to patients as also recommended in multiple guidelines.[3,4]
- MDS diagnosis vocabulary and its description used by clinical staff need to be consistent and harmonized to avoid confusion and additional worry for patients.[4,8]
- Further to survival data related to timing of GP referrals in rare hematological malignancies, our survey shows that unfamiliarity of MDS amongst GPs can result in delay investigating symptoms and referral to hematologist.
- RBC transfusion is a major determinant of MDS patients' perception of well-being with a significant impact on all of the domains of QoL: emotional, physical, functional and social.[4,9]

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DISCLOSURES

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