



## Self-perception of symptoms of anemia and fatigue before and after blood transfusions in patients with myelodysplastic syndromes



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### A B S T R A C T

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**Purpose:** Myelodysplastic syndromes (MDS) constitute a heterogeneous group of clonal bone marrow disorders characterized by chronic refractory anemia. Many patients with MDS are dependent on regular blood transfusions. The study aimed to investigate symptoms of anemia and fatigue in patients with MDS immediately before and after blood transfusion and to capture patients' descriptions of their symptoms. **Methods:** Sixteen transfusion-dependent MDS patients with a median age of 74 years (range 67–91) were included. Data were collected longitudinally using the *Functional Assessment of Cancer Therapy Anemia* (FACT-An) questionnaire, which measured anemia and fatigue symptoms before and after one blood transfusion (day 0–4 and 7). In addition, each patient was interviewed about his or her symptoms. **Results:** The median total score on FACT-An increased after blood transfusion from 50 to 58 (day 0–7,  $p = 0.016$ ), indicating decreased symptom burden. A positive correlation was found between increments in the FACT-An score and hemoglobin value ( $r_s 0.66$ ,  $p = 0.02$ ). One of seven items measuring symptoms of anemia (shortness of breath) and two of 13 symptoms of fatigue (feeling fatigue and weakness) changed significantly for the better from day 0 to day 7. The interviews confirmed the FACT-An results and revealed that patients experienced severe fatigue that negatively affected the maintenance of interpersonal relationships.

**Conclusions:** After blood transfusion, symptoms of anemia and fatigue decreased in patients with MDS. The patients felt their symptoms had a negative impact on social life. Providing psychosocial support may contribute to improve the care of patients with transfusion-dependent MDS.

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### Introduction

Myelodysplastic syndromes (MDS), a heterogeneous group of chronic clonal bone marrow disorders, are more common in people over 60 years of age (median age 72 years). MDS is a rare disease, with an incidence of about 4/100 000 per year (Bowen et al., 2003). MDS is characterized by chronic refractory anemia, which is present in more than 85% of patients with MDS (Heaney and Golde, 1999; Jansen et al., 2003) of whom many (40%) are dependent on regular blood transfusions (Bowen et al., 2003; Hellstrom-Lindberg and Malcovati, 2008). First line treatment for lower-risk MDS with anemia is erythropoietin (EPO) (Malcovati et al., 2013). Patients with a moderate transfusion need and an S-EPO <500 U/l have a

high probability of response and a median response duration of over 2 years. However, a number of patients experience a relapse of anemia and are then confined to regular transfusion therapy (Hellstrom-Lindberg et al., 2003; Stenke et al., 1993). In addition, immunomodulators (lenalidomid) may be an option for patients with EPO-refractory transfusion-dependent MDS with isolated 5q aberration (List et al., 2006).

The time between blood transfusions generally varies from once a week to every three months. Hemoglobin (Hb) increase after blood transfusion is not long-lasting. The Hb level decreases approximately one week after the transfusion, and consequently, the condition of anemia can change from mild to severe in a short space of time (Ludwig, 2002). To our knowledge, scientific research on how patients experience the outcomes immediately after blood transfusions is scarce.

Anemia in cancer patients is associated with greater symptom burden (e.g., lack of appetite, heart palpitation, headache, dyspnea, dizziness, weakness and difficulties sleeping) and reduced health-

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related quality of life (HRQoL) (Cella, 2002; Thomas, 1998). Even mild anemia (i.e. an Hb value between 100 and 120 g/L) can have a devastating effect on HRQoL (Cella, 1998, 2002). Several studies have investigated whether there is an association between Hb value and level of HRQoL in MDS patients: findings have been conflicting, with some studies reporting a correlation and others reporting no correlation (Platzbecker et al., 2012).

Numerous studies have shown that patients with MDS experience poor HRQoL, largely because of excessive fatigue (Hellstrom-Lindberg et al., 2003; Jansen et al., 2003; Pinchon et al., 2009; Steensma et al., 2008; Thomas, 1998, 2007). MDS patients who are dependent on regular blood transfusions even seem to report poorer functional, physical and social HRQoL than MDS patients without the need of transfusions (Oliva et al., 2012). A recent study using focus group interviews to explore how MDS impacts HRQoL found that numerous patients felt MDS had little impact on physical well-being, whereas the social, functional and emotional well-being of these individuals appeared to be more adversely impaired (Thomas, 2012). The uncertainty to live with the knowledge that MDS is a chronic disease, fear of future complications and the risk of progression to acute myeloid leukemia may influence the overall HRQoL negatively (Heptinstall and Myelodysplastic Syndromes Foundation, 2008; Thomas, 2012).

Fatigue is a multidimensional concept that includes psychological and social environmental dimensions (Thomas, 1998). Many patients with malignancies experience fatigue as a primary symptom, and if anemia is present, fatigue tends to increase even more (Cella, 2002; Ludwig, 2002). That fatigue is the most common symptom in MDS patients was reported from a large online survey of MDS patients in which 89% experienced excessive fatigue. This excessive fatigue was associated with significant impairment of HRQoL and diminished ability to work or to participate in desired activities (Steensma et al., 2008). Fatigue may be associated with lower self-esteem and reduced capability to take part in social relations, which could lead to a risk of withdrawing from daily life (Cella, 2002).

Blood transfusion is a well-established treatment for MDS and has a positive impact on its symptoms (Jansen et al., 2003; Nilsson-Ehle et al., 2011). Although we know a good deal about anemia and fatigue in this patient population, little is known about how MDS patients perceive symptoms of anemia and fatigue immediately after blood transfusion. The aim of this study was therefore to investigate self-reported symptoms of anemia and fatigue in MDS patients before and after blood transfusion. In addition, this study sought to explore how MDS patients describe their symptoms.

## Material and methods

### Design

This longitudinal study involves the use of quantitative and qualitative data collection methods. Quantitative data were collected using a questionnaire before (day 0) and after (day 1, 2, 3, 4 and 7) one blood transfusion with two units of packed red blood cells. Qualitative data were collected using unstructured and semi-structure interviews. Each patient was interviewed twice.

### Sample

Patients with MDS that were referred to the Division of Hematology, Karolinska University Hospital aged 18 years and older with a duration of blood transfusion need of >6 months and a minimum transfusion regularity of once monthly were asked to participate in the study. Patients treated with EPO or granulocyte colony stimulating factor (G-CSF) in the previous 6 months were excluded to

avoid the influence of such treatment on the evaluation of how symptoms were perceived before and after blood transfusion. Patients with creatinine levels >90 were also excluded to prevent bias from renal anemia due to renal insufficiency. Furthermore, patients who had an Eastern Cooperative Oncology Group (ECOG) score equal to 4 and patients not able to read or speak the Swedish language were not eligible. Sixteen (eight men and eight women with a median age of 74 years) of 26 eligible patients were included. Of the 10 eligible patients who did not participate, eight declined participation, one patient died and one moved to another town. Fifteen of the 16 patients included in the study responded to the questionnaires and 12 of these were subsequently interviewed. Patient characteristics are presented in Table 1. The study was approved by the Regional Ethics Board in Stockholm and all patients gave their written informed consent before inclusion in the study.

### Data collection

The *Functional Assessment of Cancer Therapy Anemia (FACT-An)*, a cancer-specific questionnaire containing 20 items, was used to measure self-reported fatigue (13 items) and anemia (7 items). FACT-An was chosen because the instrument includes items on both anemia and fatigue and is supposed to provide a broad assessment of anemia symptoms (Yellen et al., 1997). The instrument has demonstrated satisfactory validity and reliability for conceptual validity, internal consistency and test-retest reliability (Yellen et al., 1997). In this study the FACT-An was applied to assess patient symptoms before and after blood transfusion. Participants were asked to respond to each item on a five-point scale from 0 ("not at all") to 4 ("very much"). The total score on FACT-An ranges

**Table 1**  
Patient demographics and clinical and laboratory parameters at inclusion in the study ( $n = 16$ ).

Sex (n)	
Men/women	8/8
Age, years	
Median (range)	74 (67–91)
MDS according to the International Prognostic Scoring System (IPSS)	
Low	3
Intermediate – I	8
Intermediate – II	3
High	2
Marital status	
Married	10
Single	1
Widow/widower	5
ECOG <sup>a</sup>	
0	1
1	10
2	4
3	1
4	0
Hemoglobin value g/L median (range)	
Day 0 <sup>b</sup>	90 (64–114)
Day 2 <sup>b</sup>	106 (92–146)
Day 4 <sup>c</sup>	103 (87–144)
Day 7 <sup>c</sup>	97 (79–137)
Treatment with iron chelators	
Deferasirox	3
Deferoxamin	2
Deferipron	1
None	10
Treated with blood transfusions, in months	
Median (range)	41 (6–168)

<sup>a</sup> ECOG = Performance status.

<sup>b</sup> Missing,  $n = 1$ .

<sup>c</sup> Missing,  $n = 2$ .

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