

Association between health literacy, communication and psychological distress among myelodysplastic syndromes patients



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ABSTRACT

MDS is a complex and potentially severe disease which can trigger psychological distress. A lack of information received and understood about MDS may also arouse feelings of distress. Low health literacy (HL) might play a role particularly among older patients. Our aim was to assess MDS-related distress and to study the factors associated with it, including medical and non-medical factors such as HL.

A self-administered questionnaire was mailed to all members of French and Australian patients’ national MDS associations. Data of 280 patients were analysed.

A majority of patient (59.5%) reported low functional HL and 50% reported regular difficulties in asking physicians questions. Distress was not modified by gender, awareness of increased risk of developing leukaemia or MDS characteristics. French patients had a higher mean IES score (adjusted $\beta = 5.9$, $p = 0.004$) compared to Australian patients. Poor satisfaction with information provided about MDS, lower functional HL and difficulties in asking physician’s questions were also independently associated with distress.

MDS-related distress seems more related to HL and communication with physicians than to MDS characteristics. More efforts are needed to improve health literacy, tailor information for MDS patients and support them psychologically in order to improve their emotional well-being.

1. Introduction

A diagnosis of myelodysplastic syndrome (MDS), i.e. a cancerous disease with a variable risk of evolution into acute myeloid leukaemia [1] can trigger different emotions, particularly, psychological distress [2], as MDS can potentially be a life-threatening disease without any curative treatment except stem-cell transplant, which is not applicable for most patients [3]. Among lower-risk patients watchful waiting or symptomatic treatment might also generate distress because of the lack of MDS-focused treatment. In the context of these heterogeneous potentially life-threatening syndromes, difficulty understanding the

disease and the aim of treatment [4] might also be associated with more distress.

Despite the growing interest in patient-reported outcomes (PROs) and their association with overall survival [5,6], to our knowledge only a few studies focused on MDS patients [7–11]. Most of these studies investigated quality of life (QoL) of MDS patients [8,9,5,6] and one study highlighted that emotional problems were ranked as one of the most important domain [10]. More specifically, a previous small survey ($n = 47$) on MDS patients showed that one in three patients reported anxiety/depression problems [7]. A larger QoL study confirmed the frequent report of anxiety/depression problems (37.9%) to a higher

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level than among age- and sex- matched peers [9]. However, to our knowledge only one study has specifically evaluated MDS-related distress and the clinical factors associated with it [5].

Among the non-medical factors potentially associated with increased psychological distress among patients with MDS, health literacy (HL) and other communication barriers such as language might play a role [12]. HL has been defined as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make basic health decisions” [13]. Among cancer patients, lower functional HL has been shown to be associated with poorer health-related quality of life and increased anxiety and depression levels [14]. In addition, MDS patients who prefer an active role in decision-making have a better QoL [15]. However, involvement in decision-making needs adequate access and understanding of medical information, i.e. an adequate level of HL. As MDS patients are frequently older they are more likely to have a lower level of functional HL [16]. However HL is clearly multidimensional [17,18] and communicative aspects might potentiate or mitigate the effect of functional HL. To our knowledge no previous study has focused on the relationships between HL and distress among onco-haematological patients in general and MDS patients in particular.

Our aim was therefore to assess MDS-related distress and to study the factors associated with it, including medical and non-medical factors such as HL.

2. Materials and methods

2.1. Design and sample

A cross-sectional survey was conducted with a broader objective of developing a question prompt list (QPL) to reduce the unmet information needs of MDS patients [19]. A self-administered questionnaire was mailed to all members of two national patients' association: the Leukaemia Foundation of Australia and *Connaître et Combattre les Myélodysplasies* in France. Respectively, 147 (19.4%) and 245 (53.0%) members of the Australian and French associations responded (Fig. 1). The overall response rate (calculated using the declared number of members of both associations) was 32.1%. Of respondents,

301 were MDS patients and 53 were family caregivers (who could also participate if they were members of one of the two participating associations). However, the responses of family caregivers were not included in this analysis focusing on psychological distress. The final sample analysed here includes 280 patients (154 French and 126 Australian patients) who answered at least seven of the fifteen items on the IES scale (93%) (Fig. 1).

2.2. Measures

2.2.1. General characteristics

Collected variables included socio-demographics (age, gender, education level, current financial difficulties and country) and MDS general characteristics (year from MDS diagnosis, latest treatment considered as a proxy of the severity of the MDS, and awareness of leukaemia risk induced by MDS diagnosis [20]).

2.2.2. Functional health literacy and difficulties in asking physicians questions

Functional HL level was evaluated using the Single Item Literacy Screener (SILS) asking “How often do you have someone help you read hospital materials?” [21]. As previously suggested [22], response categories were merged into 3 categories: never (adequate HL), rarely (marginal HL) and at least sometimes (inadequate HL).

As in this aged population with a complex disease the source of information is expected to be mainly physicians, and because communication is a potentially modifiable factor [19], we also focused on patients' self-perceived ability to ask questions using the following item: “Do you usually find asking your doctor questions difficult?”. Responses were merged to obtain the same 3 categories: never (No difficulties), rarely (rare difficulties) and at least sometimes (regular difficulties). Furthermore, we hypothesised that the absence of difficulty in asking questions is a proxy of communicative HL and could mitigate the impact of a low level of functional HL.

2.2.3. Preferences for information and involvement in decision-making

Patients' preferences for information and involvement were evaluated using Cassileth's Information Styles Questionnaire. Patients were

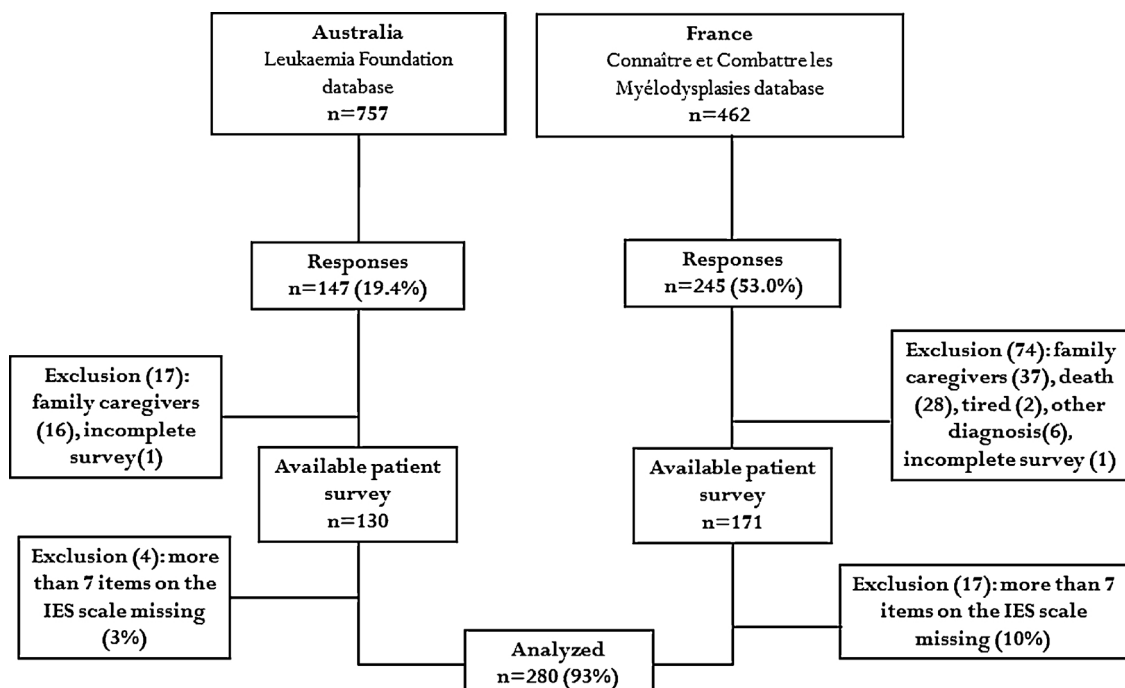


Fig. 1. Participants' flow chart.

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