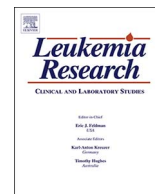




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Research paper

Living with the burden of relapse in multiple myeloma from the patient and physician perspective



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ABSTRACT

Multiple myeloma (MM) is a progressive plasma cell malignancy, with a range of clinical features including bone lesions, renal insufficiency, anaemia, and hypercalcaemia. Novel agents have significantly improved patient survival, however most patients will suffer multiple relapses. Although clinical challenges and economic costs of relapse are recognised, the psychological impact of relapse is not fully appreciated. Additionally, there is little information on how physicians perceive the impact of relapse on their patients' emotional state and how this might affect patient management.

Through face-to-face interviews with 50 relapsed and/or refractory MM patients and 30 haematologists across ten countries, we have used real-world evidence to explore and characterise the burden of living with MM, particularly the impact of relapsed disease.

This exploratory study illustrates the impact of the disease on friends and family, and the physical and emotional burden experienced by the patient resulting from both MM and its treatment. Haematologists feel poorly equipped to deal with the emotional aspects of patient relapse, lacking the time and resources to adequately deal with these issues.

Focused educational and support tools/resources targeted at both physicians and patients are required to facilitate physician–patient communication to help reduce the emotional burden of living with MM.

1. Introduction

Multiple myeloma (MM) is a plasma cell malignancy, characterised by a range of clinical features including bone lesions, renal insufficiency, anaemia, and hypercalcaemia [1]. For many years, there were limited treatment options [1]. The position of MM has shifted over recent years with improved survival related to the introduction of autologous stem cell transplantation and the novel agents thalidomide,

lenalidomide, and bortezomib, and more recently, pomalidomide and carfilzomib [1,2]. However, MM cannot yet be considered “curable”, and most patients suffer relapse, with some experiencing multiple relapses until the disease becomes refractory [1].

Whereas the clinical challenges and the economic cost of relapse are recognised [1,3–5], its psychological impact is poorly appreciated. There is an increasing awareness of the importance of patient-related factors in long-term disease management [6]. Various studies have

Abbreviations: EBMT, European group for blood and marrow transplantation; MM, multiple myeloma; PRO, patient-reported outcome; QoL, quality of life; RRMM, relapsed and/or refractory multiple myeloma; VRS, verbal rating scales

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Table 1
Patient demographics.

Demographics	France (n = 10)	Germany (n = 10)	Italy (n = 10)	Spain (n = 10)	UK (n = 10)	Total (n = 50)
Age, years, median (range)	67.5 (60–79)	74.0 (65–85)	73.0 (70–78)	68.5 (51–81)	68.0 (55–80)	71.0 (51–85)
Female, n (%)	3 (30)	2 (20)	9 (90)	3 (30)	5 (50)	22 (44)
Marital status, n (%)						
Single	0 (0)	0 (0)	2 (20)	1 (10)	0 (0)	3 (6)
Married	9 (90)	7 (70)	3 (30)	7 (70)	5 (50)	31 (62)
Living with partner	0 (0)	1 (10)	0 (0)	1 (10)	0 (0)	2 (4)
Separated	1 (10)	0 (0)	1 (10)	0 (0)	1 (10)	3 (6)
Widowed	0 (0)	2 (20)	2 (20)	1 (10)	2 (20)	7 (14)
Other	0 (0)	0 (0)	2 (20)	0 (0)	2 (20)	4 (8)
Employment status, n (%)						
Employed	1 (10)	0 (0)	0 (0)	1 (10)	1 (10)	3 (6)
Retired	9 (90)	9 (90)	7 (70)	8 (80)	6 (60)	39 (78)
Not working	0 (0)	1 (10)	3 (30)	1 (10)	1 (10)	6 (12)
Other	0 (0)	0 (0)	0 (0)	0 (0)	2 (20)	2 (4)
Number of relapses, median (range)	2.0 (1–3)	1.0 (1–3)	1.0 (1)	2.5 (1–5)	1.0 (1–5)	1.0 (1–5)
Previous therapy, n (%)						
Lenalidomide	9 (90)	1 (10)	3 (30)	6 (60)	3 (30)	22 (44)
Bortezomib	9 (90)	1 (10)	3 (30)	6 (60)	3 (30)	22 (44)
Thalidomide	9 (90)	1 (10)	3 (30)	6 (60)	3 (30)	22 (44)
Current therapy, n (%)						
Lenalidomide	8 (80)	0 (0)	0 (0)	5 (50)	3 (30)	16 (32)
Bortezomib	0 (0)	3 (30)	3 (30)	1 (10)	1 (10)	8 (16)
Thalidomide	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

looked at the impact of MM treatment on patients' quality of life (QoL) [7–10]; however there are fewer studies focusing on the day-to-day burden of living with the disease and its impact on patients.

A limited number of qualitative, interview-based studies have highlighted the significant burden of living with MM and its impact on family, social, and work-related areas of patients' everyday lives [11–16]. One key aspect identified by these studies is the high emotional impact of uncertainty and the fear of relapse; however, there is a paucity of data on the impact of relapse itself. Furthermore, although patients with MM place great importance on support from the health services [6,13,14], there is little information on how physicians perceive the impact of relapse on their patients' emotional status. Given that relapse is a fact of life for most MM patients, such insights are essential to better understand patient needs with the goal to improve long-term management.

The focus of this exploratory study was to expand the current knowledge on how relapse affects both patients and physicians.

2. Methods

In-depth, semi-structured face-to-face interviews were conducted with patients with relapsed and/or refractory MM (RRMM) and their haematologists in the UK, France, Germany, Italy, and Spain.

Haematologists who had treated at least ten patients with MM in the previous month and at least five symptomatic RRMM patients in the previous year were eligible for the study. They were asked to identify and nominate patients with RRMM who would be willing to participate. Haematologists used their own judgement when nominating patients for inclusion in the study, but were provided with criteria from the European Group for Blood and Marrow Transplantation (EBMT) for guidance [17]. These criteria include: an increase, or reappearance, of paraprotein in serum or urine; $\geq 5\%$ plasma cells in bone marrow; increased size of residual bone lesions or presence of new lesions; and hypercalcaemia.

2.1. Questionnaires

Patient questionnaires were developed in consultation with Myeloma UK, a registered UK charity (Supplementary material). The majority of the questions were open-ended and designed to explore: the personal emotional and physical impacts (e.g. daily activities, relationships, QoL) of MM overall and at relapse; the burden of treatment; and the support received by the patient from their family and their physician. In addition, verbal rating scales (VRS) were used to assess the patient's perception of the extent of change in physical, psychological, financial, and logistic factors from the time the patient felt their disease was stable until their latest relapse or disease progression (Supplementary material). In preparation for the interviews, patients were asked to draw graphical diagrams illustrating changes in their emotional and physical well-being over time, starting from the time of diagnosis. Haematologists were also asked to draw similar graphical diagrams prior to interview – one for a non-relapsed MM patient and one for an RRMM patient – illustrating their perception of changes in patients' emotional well-being from diagnosis onwards. Haematologist interviews were similarly guided using questionnaires (Supplementary material).

2.2. Interviews

All the interviews (60 min each) were carried out in 2013 by trained and experienced interviewers. Written informed consent for inclusion in the study and publication of the study results was obtained from all participants.

3. Results

3.1. Sample characteristics

A total of 50 individual patient interviews (ten per country) were conducted. The median age of patients was 71 (range, 51–85) years, and patients had experienced a median of 1.0 (range, 1–5) relapses (Table 1).

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