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Measurement of the major ignored burden of multiple myeloma, pernicious anaemia and of other haematological conditions on partners and family members: A cross-sectional study

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Abstract

Background: Having a haematological condition can adversely affect the quality of life (QoL) of family members/partners of patients. It is important to measure this often ignored burden in order to implement appropriate supportive interventions.

Objective: To measure current impact of haematological conditions on the QoL of family members/partners of patients, using the Family Reported Outcome Measure-16 (FROM-16).

Methods: A cross-sectional study, recruited online through patient support groups, involved UK family members/partners of people with haematological conditions completing the FROM-16.

Results: 183 family members/partners (mean age = 60.5 years, SD = 13.2; females = 62.8%) of patients (mean age = 64.1, SD = 12.8; females = 46.4%) with 12 haematological conditions completed the FROM-16. The FROM-16 mean total score was 14.0 (SD = 7.2), meaning 'a moderate effect on QoL'. The mean FROM-16 scores of family members of people with multiple myeloma (mean = 15.8, SD = 6.3, $n = 99$) and other haematological malignancies (mean = 13.9, SD = 7.8, $n = 29$) were higher than of people with pernicious anaemia (mean = 10.7, SD = 7.5, $n = 47$) and other non-malignant conditions (mean = 11, SD = 7.4, n = 56, $p < .01$). Over one third (36.1%, $n = 183$) of family members experienced a 'very large effect' (FROM-16 score>16) on their quality of life.

Conclusions: Haematological conditions, in particular those of malignant type, impact the QoL of family members/partners of patients. Healthcare professionals can now, using FROM-16, identify those most affected and should consider how to provide appropriate holistic support within routine practice.

KEYWORDS

family impact haematology, family members/partners, FROM-16, haematology secondary burden, quality of life

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Novelty statement

What is the new aspect of your work?

This study measures the hidden burden of haematological conditions on the quality of life of partners/family members of patients, using the validated Family Reported Outcome Measure FROM-16.

What is the central finding of your work?

Haematological conditions, in particular malignant diseases, negatively impact the quality of life of family members/partners of patients.

What is (or could be) the specific clinical relevance of your work?

The FROM-16, a brief comprehensive generic family QoL instrument with established score meanings for ease of interpretation, could be used to measure this impact in clinical practice to identify and support impacted family members, which could contribute to holistic patient care.

1 | INTRODUCTION

Haematological conditions can have a great impact on the quality of life (QoL) of those affected,[1–4] but little is known about the impact on patients' partners and family members.[5] It is important to understand this impact because of the extensive involvement of family members in the day-to-day care of someone with such debilitating conditions and the ways this impacts the dynamic of a family unit.[6,7]

The distress of knowing the diagnosis of conditions such as leukaemias, lymphomas, and multiple myeloma, and the intensity of their treatment, can negatively impact the physical and psychosocial health of patients, affecting their daily activities such as work, household duties and parenting. This may also impact family members and partners who may have to rethink their working hours, manage additional responsibilities related to household duties and support their loved ones. Haematological malignancies are the fifth most common cancers in the developed countries. Most (60%) are incurable, follow an unpredictable trajectory of relapses and remissions and require varying treatments.[8] Patients may require sudden and prolonged hospital stays for diagnosis and treatment and ongoing regular admissions for therapy. All this can contribute to significant pressure on family members, impacting their QoL. Furthermore, with newer therapies, many patients are living longer,[9] implying extended morbidity and impact on QoL of both patients and their family members/partners. It is important to recognise and measure this impact in order to implement appropriate supportive interventions. Therefore, the purpose of this study was to measure the impact of haematological conditions on QoL of family members/partners of patients, using a generic measure, the Family Reported Outcome Measure (FROM-16), that allows comparison with the impact of other health conditions.[10]

2 | METHODS

2.1 | Study design and participant recruitment

The data used in this study came from a large online cross-sectional study of family members/partners of people with a wide range of medical conditions.[11] In this study, people with haematological conditions and their partners/family members were recruited online through Myeloma UK, Lymphoma Action, MDS, Pernicious Anaemia support group, Genetic Alliance UK and Healthwise Wales (HWW).

2.2 | Ethical considerations

Ethical approval was given by the Cardiff University School of Medicine Research Ethics Committee (SREC reference: 21/19), which conforms to the principles embodied in the Declaration of Helsinki. Convenience sampling was used for recruitment of the study participants. The study was open to UK family members/partners of patients, aged ≥18 years and capable of operating an electronic device. The exclusion criteria included family members of deceased patients, family members <18 years, not capable of using electronic devices and family members not living in the United Kingdom. The family members/partners chose whether to participate in the study after reading the participant information sheet embedded in the online questionnaire.

2.3 | Measurement of family QoL

The impact on Family members/partner was measured using the FROM-16, a generic family QoL instrument, which measures the impact of any disease on the QoL of adult family members or

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partners of patients of any age.[10] The FROM-16 comprises 16 items, each with three response options: 'Not at All' (scoring 0), 'A Little' (scoring 1) and 'A Lot' (scoring 2). The 16 items are divided into two categories (domains): Emotional (comprising six items, maximum score of 12) and Personal and Social Life (comprising 10 items, maximum score of 20). The lowest possible score of the FROM-16 is 0, and the highest is 32. The higher the total score, the greater the unfavourable effect on the family member's QoL. The interpretation of scores is described using validated score meaning bands.[11] The FROM-16 has been mapped to EQ-5D[12] and could potentially be used to convert QoL scores into utility values, thus allowing inclusion of disease impact of family members in health economic analysis.

2.4 | Procedure

The online study was carried out using the Jisc academic survey platform,[13] which is General Data Protection Regulation (GDPR) compliant. The online study questionnaire had two sections; in section one, patients completed some basic information (sex, age, occupation, health condition, and country of residence) about themselves and chose and allowed their family member/partner to take part in the study. Section two was completed by the family member/partner of the patient and comprised of some basic demographic questions (sex, age, occupation, and relationship to patient) and FROM-16.

The online questionnaire was available in two formats: Patient and family member (FM) questionnaire or FM-only questionnaire. The Patient and FM questionnaire was directed to patients registered with various haematology patient support groups (Myeloma UK, Lymphoma Action, MDS, Pernicious Anaemia support group and Genetic Alliance UK). The FM-only questionnaire was directed to the family members of patients registered with HWW. In the FM-only questionnaire, patient demographic information was completed by the family member.

Prior to the start of the study, a pilot was carried out with the Acute Leukaemia Advocate Network (ALAN) to test the online study questionnaire. 15 family members of leukaemia patients registered with ALAN took part in this pilot in order to refine wording for clarity, to ensure ease of use and to identify and resolve technical and practical issues.

Patient and public involvement: Two patients and one family member were involved in the study as research partners. They were actively involved at all stages of the study design, participated in research team meetings, and reviewed all study material.

2.5 | Data analysis

Descriptive analysis was carried out and included calculating mean, median, standard deviation and interquartile range of quantitative variables, and frequency and proportion for categorical variables. Independent samples t-test/Mann Whitney U-test was used to compare between groups. Descriptive banding was assigned to the FROM-16 scores to describe severity of the impact on family members/partners across different haematological conditions. Data were analysed using IBM SPSS Statistics for Windows, version 27.

3 | RESULTS

A total of 183 family members/partners (mean age = 60.5 years, SD = 13.2; females = 62.8%) of patients (mean age = 64.1, SD = 12.8; females = 46.4%) mostly from England (67.2%) and Wales (21.3%) with 12 different haematological conditions completed the FROM-16 instrument (Table 1). The study was carried out between April and November 2021 during the COVID-19 pandemic. Half of the family members/partners were retired, 30.6% in paid jobs and 6.6% in part-time jobs (Table 1). Family members were mostly spouses/partners of the patients (79.8%) or sons and daughters (14.2%) (Table 1).

The FROM-16 mean total score was 13.96 (SD = 7.23, range = 0-31, median = 14, IQR = 10), with a mean score for emotional domain = 6.30 (SD = 3.06) and for personal and social domain = 7.66 (SD = 4.90). As for the individual FROM-16 items, 'being worried' had the highest mean score of 1.52 (SD = 0.59), followed by 'feeling sad' (mean = 1.30, SD = 0.67); 'family activities', 'holiday', 'being frustrated', 'effect on sleep' and 'sex life' had the next highest mean scores (Table 2). There was no significant difference in FROM-16 mean total scores between male and female family members, however for individual items, females experienced more impact across 'sadness', 'frustration', 'time for self', 'effect on holiday' and 'sleep' due to their relative's haematological condition (Table S1).

Most reported impact on family members/partners QoL included feeling worried (95.1%; A little = 38.3%, A lot = 56.8%), feeling sad (87.9%; A little = 46.4%, A lot = 41.5%), impact on family activities (79.2%; A little = 42.6%, A lot = 36.6%), feeling frustrated (78.7; A little = 48.1%, A lot = 30.6%), and impact on sleep (73.2%; A little = 40.4%, A lot = 32.8%) (Figure 1).

The FROM-16 mean total score varied across haematological conditions. For multiple myeloma the mean FROM-16 score = 15.8 ($n = 99$), for other malignant haematological conditions = 13.9 ($n = 29$), for pernicious anaemia = 10.7 ($n = 47$) and for non-malignant haematological conditions = 11 ($n = 8$). The lowest FROM-16 mean score was reported for haemachromatosis = 6.7 ($n = 3$) (Table 3).

The FROM-16 mean total score differed depending on the relationship of the family member to the patient. Parents had a higher score (mean = 16.44, median = 12, SD = 6.54, range = 10–27, IQR = 12) compared to other relations (spouse/partners: mean = 13.86, median = 14, SD = 7.26, range = 1–31, IQR = 10; son/daughter: mean = 14.04, median = 15, SD = 7.54, range = 2–30, IQR = 12; sibling: mean = 9.00, median = 9, SD = 0, range = 9–9, IQR = 0) (Table S2), however these differences in means were not statistically significant (Table S3). Multiple Linear regression confirmed that FROM-16 mean scores of parents, son/daughter and siblings were not significantly different from that of spouse /partners (Table S4).

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TABLE 1 Descriptive and sociodemographic characteristics.

Characteristics		Mean (SD) or *N* (%)
Patient		
Age (years)	Mean (SD)	64.11 (12.83)
	Median	66
	Range	25–95
Sex	Male	98 (53.6%)
	Female	85 (46.4%)
Occupation	In paid work	51 (27.9%)
	Part-time job	9 (4.9%)
	Unemployed	4 (2.2%)
	In unpaid work	1 (0.5%)
	Education/training	2 (1.1%)
	Homemaker	5 (2.7%)
	Retired	109 (59.6%)
	Rather not say	2 (1.1%)
Country of residence in the United Kingdom	England	123 (67.2%)
	Northern Ireland	5 (2.7%)
	Scotland	16 (8.7%)
	Wales	39 (21.3%)
Haematological conditions	*Multiple myeloma*	99 (54.1%)
	Other malignant haematological conditions	29 (15.8%)
	Acute lymphoblastic leukaemia (ALL)	1 (0.5%)
	Chronic lymphocytic leukaemia (CLL)	2 (1.1%)
	Hodgkin lymphoma (HL)	7 (3.8%)
	Non-Hodgkin lymphoma (NHL)	11 (6.0%)
	Myelodysplastic syndromes (MDS)	8 (4.4%)
	Pernicious anaemia	47 (25.7%)
	Other non-malignant haematological conditions	8 (4.4%)
	Haemochromatosis	3 (1.6%)
	Blood clotting disorder	2 (1.1%)
	Haemophilia	1 (0.5%)
	Thalassaemia beta major	1 (0.5%)
	Thrombocytopenia	1 (0.5%)
Family member		
Age (years)	Mean (SD)	60.51 (13.19)
	Median	63
	Range	20–80
Sex	Male	68 (37.2%)
	Female	115 (62.8%)
Occupation	In paid work	56 (30.6%)
	Part-time job	12 (6.6%)
	In unpaid work	1 (0.5%)
	Education/training	4 (2.2%)
	Homemaker	9 (4.9%)
	Retired	99 (54.1%)
	Rather not say	2 (1.1%)

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TABLE 1 (Continued)

Characteristics		Mean (SD) or *N* (%)
Relationship	Spouse/partner	146 (79.8%)
	Son/daughter	26 (14.2%)
	Parent	9 (4.9%)
	Siblings	2 (1.1%)

TABLE 2 Mean scores of FROM-16 for family members/partners of people with haematological conditions (n = 183).

FROM-16	Description	Mean (SD)	Median	Range	IQR
Total FROM-16 mean score	Overall	13.96 (7.23)	14	0 – 31	10
Domain score	Emotional domain	6.30 (3.06)	6	0 – 12	5
	Personal and social domain	7.66 (4.90)	8	0 – 20	7
FROM-16 individual items score	Worried	1.52 (0.59)	2	0 – 2	1
	Angry	0.69 (0.75)	1	0 – 2	1
	Sad	1.30 (0.67)	1	0 – 2	1
	Frustrated	1.09 (0.72)	1	0 – 2	1
	Talking about thoughts	0.91 (0.83)	1	0 – 2	2
	Difficulty caring	0.80 (0.70)	1	0 – 2	1
	Time for self	0.77 (0.69)	1	0 – 2	1
	Everyday travel	0.44 (0.68)	0	0 – 2	1
	Eating habits	0.48 (0.69)	0	0 – 2	1
	Family activities	1.16 (0.74)	1	0 – 2	1
	Holiday	1.11 (0.86)	1	0 – 2	2
	Sex life	1.05 (0.86)	1	0 – 2	2
	Work or study	0.44 (0.63)	0	0 – 2	1
	Family relationships	0.62 (0.73)	0	0 – 2	1
	Family expenses	0.54 (0.72)	0	0 – 2	1
	Sleep	1.06 (0.77)	1	0 – 2	2

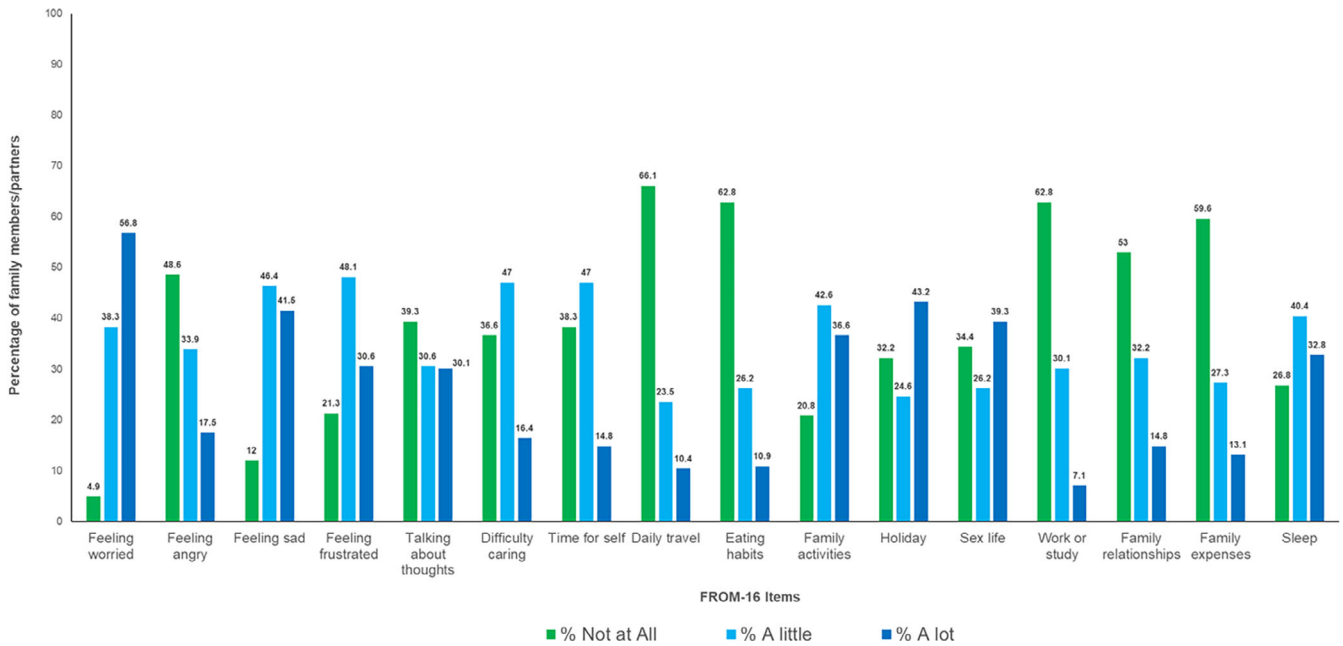


FIGURE 1 Impact of relative's haematological condition on family members/partners across 16 items of FROM-16.

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TABLE 3 Mean FROM-16 and domain scores across haematological conditions.

Haematological conditions (HCs)	Mean FROM-16	SD	Mean FROM-16 domain score	
			Emotional	Personal and social
Multiple myeloma (*n* = 99)	15.8	6.3	7.0	8.8
Other malignant HCs (*n* = 29)	13.9	7.8	6.1	7.8
Acute lymphoblastic leukaemia (n = 1)	13.0		4.0	9.00
Chronic lymphocytic leukaemia (n = 2)	12.5	0.7	5.5	7.00
Hodgkin lymphoma (n = 8)	13.6	7 .3	6.0	7.6
Myelodysplastic syndromes (n = 7)	14.8	7.5	7.3	7.5
Non Hodgkin lymphoma (n = 11)	13.7	9.9	5.5	8.2
Pernicious anaemia (*n* = 47)	10.7	7.5	5.3	5.4
Other non – malignant HCs (*n* = 8)	11.0	7.5	4.8	6.2
Haemachromatosis (n = 3)	6.7	6.1	2.7	4.00
Blood clotting disorders (n = 2)	14.5	13.4	5.0	9.50
Haemophilia (n = 1)	9.0		6.0	3.00
Thalassaemia beta major (n = 1)	18.0		8.0	10.0
Thrombocytopenia (n = 1)	12.0		6.0	6.0B

Abbreviations: HCs, Haematological conditions; SD, Standard deviation.

The mean FROM-16 scores of family members of people with multiple myeloma (mean = 15.8, SD = 6.3, $n = 99$) and other haematological malignancies (mean = 13.9, SD = 7.8, $n = 29$) were higher than that of people with pernicious anaemia (mean = 10.7, SD = 7.5, $n = 47$) and other non-malignant conditions (mean = 11, SD = 7.4, $n = 56$, $p < .01$) (Table 3), indicating the greater burden experienced by family members of people with haematological malignancies. Although the mean FROM-16 scores of family members of people with multiple myeloma was higher than for those with other haematological malignancies, however, the difference was not significant ($p = .174$) (Table S5). There was a significant difference between the mean FROM-16 scores of family members of people with multiple myeloma and those with pernicious anaemia ($p = .001$) (Table S6). The study also explored the degree of severity of impact experienced by the family members/partners[11]: 36% had a mean FROM-16 score greater than 16, indicating 'a very large impact' on the QoL of these family members. Only 4.4% of family members experienced 'no impact' (Table 4).

Further analysis of severity of impact indicated that family members of people with multiple myeloma (42.4% having FROM-16 scores >16) and other haematological malignancies (37.9% FROM-16 scores >16) were more impacted than the family members of people with pernicious anaemia (23.4% FROM-16 scores >16) and other non-malignant haematological conditions (25% FROM-16 scores >16) (Figure 2).

TABLE 4 FROM-16 score banding describing the impact on quality of life of family members/partners ($n = 183$).[11]

FROM-16 score banding	Number of family members	% of family members
No effect (0–1)	8	4.4
A small effect (2–8)	34	18.6
A moderate effect (9–16)	75	41.0
A very large effect (17–25)	56	30.6
An extremely large effect (26–32)	10	5.5
Total	183	100

4 | DISCUSSION

This unique study examined the experience and impact on QoL of family members/partners of people with haematological conditions, using a validated generic family specific measure, FROM-16, with validated score bands to interpret the meaning of scores.[11] While the impact was observed across all conditions, family members of people with haematological malignancies were impacted more than family members of those with non-malignant haematological conditions. The QoL of family members of multiple myeloma was more impacted than that of family members/partners of people with other malignant haematological conditions but this difference in impact was not significant ($p = .174$). However, family members of people with multiple myeloma experienced a significant impact on their sex life ($p = .04$) and difficulty in caring for their relative ($p = .019$) compared to family members of people with other haematological malignancies (Table S5).

There was a significant difference between the mean FROM-16 scores of family members of people with multiple myeloma and pernicious anaemia ($p < .001$). There was also significant difference between mean FROM-16 scores of family members of people with pernicious anaemia and other non-malignant haematological conditions ($p = .04$). Compared to family members of people with

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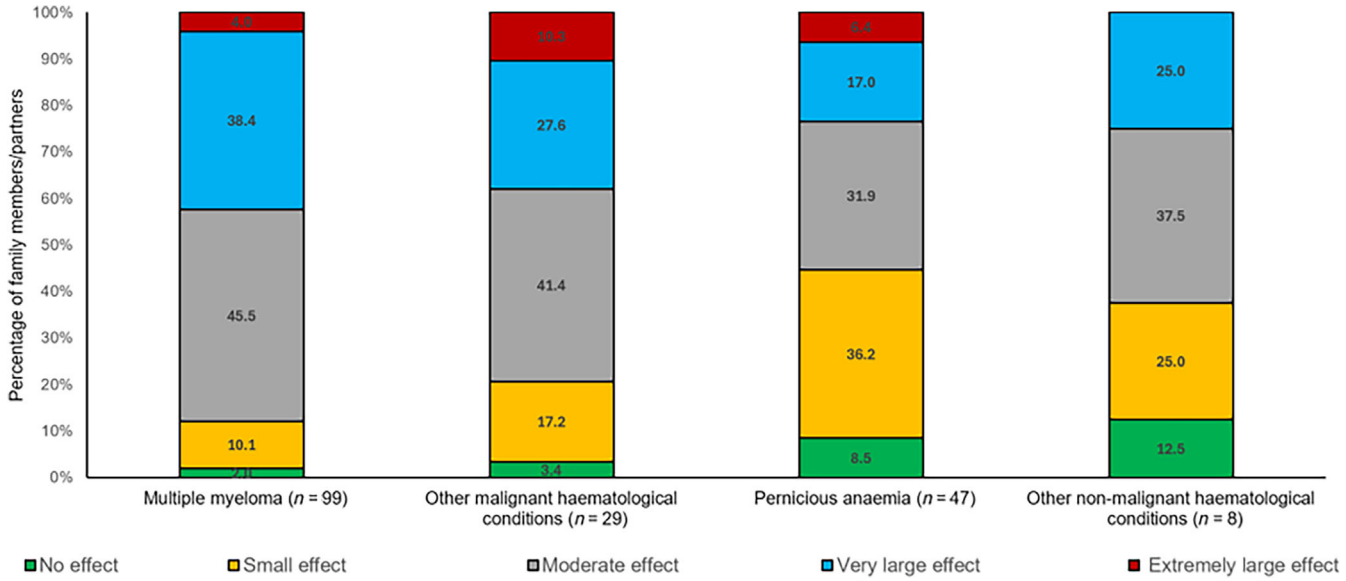


FIGURE 2 Comparison of the severity of impact on quality of life of family members in Multiple myeloma and other malignant haematological condition and in Pernicious anaemia and other non-malignant haematological conditions.

pernicious anaemia, family members living or caring for people with multiple myeloma were more worried ($p = .008$), sad ($p < .001$), experienced greater difficulty to find someone to talk to about their thoughts ($p = .001$) and had less time for self ($p < .001$). They also, experienced more impact on family activities ($p = .003$), eating habits ($p = .005$), holidays ($p = .001$) and sleep ($p < .001$) (Table S6).

The FROM-16 mean total score across all 12 conditions included in this study was 13.96. However, 36% of family members/partners had total FROM-16 scores >16, indicating a very large impact on their QoL. Having a relative with a haematological condition impacted family members'/partners' emotional health, with most feeling worried, sad and frustrated. These results are consistent with the findings of Rhee et al.[14] where family caregivers who felt burdened had six times the risk of experiencing elevated depressive symptoms compared with caregivers who did not feel burdened. A study conducted by the University of Florida on the long-term impact of cancer treatment on the QoL of partners of blood and bone marrow transplant recipients revealed that partners of these patients were over three times more likely to be clinically depressed than healthy peers, with some caregivers experiencing levels of clinical depression similar to the survivor.[15] In another study[16] conducted on patients with multiple myeloma and their caregivers, 44% of caregivers had symptoms of clinical anxiety, 16% had symptoms of depression, and 24% had symptoms of post-traumatic stress disorder (PTSD), with caregivers reporting higher levels of clinical anxiety than the patients. This could be attributed to the effects of treatments such as chemotherapy which not only take a physical toll on patients but can also place a huge emotional and financial burden on family members. In our study, 45.5% of family members/partners of multiple myeloma patients experienced a 'moderate impact' while 42.4% experienced a 'high' to 'extremely high' impact on their QoL. Other studies have also reported high levels of emotional distress in family members of patients with haematological malignancies.[5,17]

In our study, 73.2% of family members and partners of people with haematological conditions reported an impact on sleep. Impact on sleep has also been reported by other studies.[5,18,19] Disturbance of sleep can negatively affect QoL[20,21] and may contribute to immune system suppression.[22] Hoppe et al.[5] and Kurtin et al.[20] reported that haematological conditions impacted sleep of both patients and their family members. A Japanese study demonstrated that family members of patients with haematological malignancies suffered from higher rates of insomnia than the patients.[21]

Our study shows that the family members/partners of patients with haematologic conditions experienced considerable impact on their family activities. In an Indian study, 83% of parents of children with acute lymphoblastic leukaemia (ALL) and 86% of parents of children with Hodgkin lymphoma reported disruption of family routine.[23] Parents of children with ALL (61%) and with Hodgkin lymphoma (71%) experienced disruption of family leisure time and impact on family interactions.[23] These parents experienced moderate or severe burden despite the patient being in remission, indicating that caring for a sick child with a haematological malignancy remains stressful for families regardless of the disease activity. In our study, the people with Hodgkin's lymphoma ($n = 8$) were all adults with a mean FROM-16 score = 13.6 ('a moderate effect' on their QoL). One explanation may be that there is less involvement of family member/partners in the day-to-day care of adults compared to that of children with such conditions. In our study, 67% of family members/partners reported impact on their holidays due to their relative's haematological condition. This impact could partly have resulted from the protective isolation of haematological patients, as this study was conducted during the COVID-19 pandemic.

In our study 65.5% of family members/partners experienced problems with their sex-life. This is consistent with the findings of Yoo et al.[24] who reported sexual dysfunction in 62% of hematopoietic stem cell transplantation survivors and their partners. These authors

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found that about 80% of women and 57% of men experienced sexual dysfunction and this affected the highest percentage (81%) of people between the ages of 52–71 years.[24] Polomeni et al.[25] studied the impact of allogeneic-hematopoietic stem cell transplantation (allo-HSCT) on partners and reported that they face negative effects of HSCT in their own, as well as their spouse's sexual, family, professional and social lives. These authors reported that partners' QoL, including psychological health and social wellbeing, was worse than that of patients.[25] Richards et al.[26] have attributed sexual dysfunction in myeloma patients to multiple physical and psychological factors, including comorbidities, medical treatments, lack of psychological well-being, altered body image, and cultural and societal influences. Therefore, encouraging open communication between patients, partners and healthcare providers is essential in managing the underlying cause of the problem.[26]

Studies from the developing world reveal huge financial distress among family members of cancer patients.[23,27] Nevertheless, a diagnosis of cancer can lead to a high level of financial distress for both cancer patients and their family members even in the developed countries,[28–30] although the magnitude of this distress varies between countries.[31] In our study, 40% of family members experienced an increase in family expenses, with 13% reporting a major impact on family expenses due to their relative's haematological condition.

The study found that family members/partners of patients with multiple myeloma and other haematological malignancies were significantly impacted more than those with pernicious anaemia and other non-malignant conditions (Figure 2). Forty-two percent of family members/partners of people with multiple myeloma and 37% of the family members/partners of people with other haematological malignancies had FROM-16 scores >16, indicating a very large effect on the QoL of family members. This is comparable to the FROM-16 scores reported by family members of people with oncological conditions, where 40% of family members had FROM-16 scores >16 ($n = 241$) in a study conducted with family members of patients across 27 medical specialities.[32] However, the FROM-16 scores of family members of people with multiple myeloma and other malignant haematological conditions in this study are lower than that reported by the family members of people with neurological conditions (55% with FROM-16 score >16; $n = 1620$), and psychiatric conditions (48% with FROM-16 score >16; $n = 325$).[32]

In another Portuguese study, 35.5% of caregivers reported moderate burden and 4.1% reported a high burden of caring for person with multiple myeloma with the burden significantly higher in caregivers of patients with two or more lines of treatment ($p = .042$) and caregivers >60 years of age experienced greater financial burden.[33] In our study, though it did not specifically measure 'burden' but QoL impact, 48.5% of family members of multiple myeloma experienced moderate effect on their QoL while 38.4% and 4% experienced very high and extremely high effect on their QoL, respectively. A study from India reported that haematological malignancies in children had a negative impact on the psychological, social, vocational, economic, and spiritual aspects of parents' lives, and that there was a major decrease in the QoL of parents following the diagnosis of haematological malignancies in their children.[34] Although in our study parents of adult patients compared to other relationships seemed to have experienced more impact on their QoL, this difference in impact was not significant.

In order to understand better the meaning of FROM-16 scores and the comparative impact between haematological and other conditions, it is useful to give data from other studies. These studies were carried out before the COVID-19 pandemic, whereas the current study was carried out online during the pandemic. A general study on the impact on family members of patients' chronic disease across 26 medical specialities had a mean FROM-16 score of 12.4 (Emotional domain = 5.6; Personal and Social domain = 6.7).[35] A study on the impact on family members/partners of cancer patients reported a mean FROM-16 score of 11.8 (Emotional domain = 4.7; Personal and Social domain = 7.1).[36] The mean score for that study was lower than for our current study, indicating a greater impact on the QoL of family members/partners of people with haematological conditions. However, two FROM-16 studies conducted during the COVID-19 pandemic reported greater impairment of QoL than in the current study. For example, a global study on family members/partners of COVID-19 survivors had a mean FROM-16 score of 15.0 (Emotional domain = 6.12; Personal and Social domain = 8.88),[37] a study about family members of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) reported a mean score of 19.9 (Emotional = 8.8, Personal and social = 11.1)[38] and another global study on ME/CFS reported a mean FROM-16 score of 17.9 (Emotional = 7.6 and Personal and social life = 10.3).[39] These studies indicated that family members of people having MS/CFS and COVID-19 experienced a much greater impact than family member/partners of people with haematological conditions.

4.1 | Study limitations

Our study has some limitations. First, this study was conducted after the second wave of COVID-19 in the UK, indicating that the impact of haematological conditions on family members/partners could have been exaggerated. Second, although family members/partners of different haematological conditions were included, most (145/183) of them were family members/partners of people with multiple myeloma ($n = 99$) or pernicious anaemia ($n = 46$). Although this study also included the family impact of 10 other haematological conditions described as two groups ('other malignant haematological conditions' and 'other non-malignant haematological conditions'), the study findings may be more generalizable to family members of people with multiple myeloma and pernicious anaemia. Third, selection bias is possible as this study was conducted online with patient support groups. Therefore, only those family members of patients who were registered with patient support groups and able to use electronic devices could have participated. Fourth, the study did not ask questions on ethnicity, so we cannot comment on the diversity of the sample.

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4.2 | Implication for practice

Family members/partners of patients may experience a huge impact on their physical, social and psychosocial well-being,[6,7] which is often ignored and is excluded from healthcare policy and planning.[40] Our results are consistent with previous findings,[5,15–17,24–26,29] related to the family burden of haematological conditions, particularly haematological malignancies, demanding action that would support family centred care. Although the World Health Organisation advocates patient and family centred care, structured needs assessments of family members/partners of patients are usually not practiced. The FROM-16,[41] a brief comprehensive generic family QoL instrument with established score meanings for ease of interpretation[11] and responsiveness to change[42] could potentially be used to measure this impact in clinical practice to support impacted family members. It is important to measure this impact in routine clinical practice alongside patient-reported outcomes to arrive at shared decision-making and understanding as well as responding to the needs of family members/partners. This will in turn, improve patient outcomes and reduce the financial toll of providing long-term care for the patient.[43]

5 | CONCLUSIONS

To conclude, this study demonstrates that haematological conditions, and in particular malignant conditions, have a great impact on the QoL of family members/partners of patients. There is a need to identify and then provide support and care to impacted family members/partners as a part of routine holistic practice.

AUTHOR CONTRIBUTIONS

RS primarily carried out the study including data collection, analysis and interpretation, wrote the first draft and revised all documentation. SS and AYF equally contributed to the design, interpretation and supervision of the study and revised all study documentation and the manuscript. JRI, KO and SJN provided advice during the study and helped revise study documentation. HA, SJN and MN were involved in designing and reviewing the study protocol, drafting the study materials, reviewing the manuscript and providing suggestions from the patient and family perspectives. AYF, SS, KO, JRI, FMA, SJN, HA, and MN reviewed the manuscript and agreed on the final submitted version of the manuscript.

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There was no external funding for this Cardiff University study.

CONFLICT OF INTEREST STATEMENT

RS, KO, HA, MN and SJN declared no competing interest; FMA is employed by Cardiff University: Cardiff University receives royalties from some uses of FROM-16; AYF reports personal fees from Novartis Lecture honorarium, personal fees from Medscape Podcast honorarium, personal fees from Eli Lilly Lecture honorarium, outside the submitted work; MSS and AYF are joint copyright owner of the FROM-16 for which Cardiff University receives royalties for its commercial use, and they receive a share under standard university policy. JRI receives a stipend as Editor-in-Chief of the British Journal of Dermatology and an authorship honorarium from UpToDate. He is a consultant for Abbvie, Boehringer Ingelheim, ChemoCentryx, Citryll, Novartis and UCB Pharma and has served on advisory boards for Insmed, Kymera Therapeutics and Viela Bio. He is co-copyright holder of HiSQOL, Investigator Global Assessment and Patient Global Assessment instruments for HS. His department receives income from royalties for the use of the Dermatology Life Quality Index (DLQI), Family Reported Outcome Measure (FROM-16) and related instruments.

DATA AVAILABILITY STATEMENT

The data are available from the authors on reasonable request according to Cardiff University regulations.

CONSENT STATEMENT

All patients and family members gave their electronic informed consent.

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SUPPORTING INFORMATION

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