

BACKGROUND

- Chronic graft-versus-host disease (cGvHD) is a multisystemic condition that affects 20–50% of post-hematopoietic stem cell transplantation patients and is associated with long-term morbidity and mortality.¹
- Patients with cGvHD frequently suffer with skin, eye, and musculoskeletal symptoms, often leading to physical debilitation and in severe cases, death.
 - These effects are further exacerbated by adverse effects of multiple lines of therapy (LOTs).^{2,3}
- In the UK, there is a lack of health-related quality of life (HRQoL) data that describes the physical and emotional impact of cGvHD on both patient and carers.
- The objective of this study was to understand the experiences of patients and carers managing cGvHD after multiple treatment failures, including how cGvHD impacts their HRQoL.

METHODS

- Patients/carers of patients with a diagnosis of cGvHD who had received ≥ 2 LOTs and had ongoing symptoms were included in this study; these patients were invited to complete a 25-minute online survey in September 2022.
- Survey questions covered areas pertinent to the physical, psychological, and social/economic impact of cGvHD.

RESULTS

Respondent characteristics

- In total, 27 participants (17 patients; 8 current carers; 2 previous carers) were enrolled in the study.
- Demographics and characteristics varied between the patient and carer groups and are summarised in **Table 1**.

Table 1. Participant demographics and characteristics

	Patient* n=27	Carer n=10
Gender, n (%)		
Male	21 (78)	3 (30)
Female	6 (22)	7 (70)
Ethnicity, n (%)		
White	26 (96)	10 (100)
Asian/Asian British	1 (4)	0 (0)
Employment status, n (%)		
Working full-time	5 (19)	3 (30)
Working part-time	2 (7)	3 (30)
Retired	8 (30)	2 (20)
Unable to work due to illness	10 (37)	1 (10)
Student	1 (4)	0 (0)
Unemployed	1 (4)	0 (0)
Stay at home parent/carer	0 (0)	1 (10)

*Calculation based on responses from 17 patients and 10 carers who were asked about the patients they care for

Physical symptoms experienced by cGvHD patients

- Commonly reported symptoms experienced by patients included skin symptoms (100%), fatigue (93%), and eye symptoms (81%).
- Most symptoms presented daily or frequently, with skin (78%), eye (63%), and joint (67%) symptoms being most prevalent.
- In general, symptoms with the highest incidence in cGvHD patients (eye, skin, lung, and infection symptoms) had the highest impact on daily life.

Treatment of cGvHD

- Many patients (61%) had undergone ≥ 3 LOTs and were taking 5.3 different cGvHD treatments at the time of survey participation, indicating a significant treatment burden.
 - 81% of participants indicated they had used other systemic treatments, including intravenous drips or oral tablets at some point.
- Many patients reported needing additional treatments to control cGvHD symptoms and side effects.
 - 74% reported using antibiotics and 67% antivirals.
 - Medication for digestion, breathing, nausea, osteoporosis, and depression/anxiety were also common.

Treatment-related side effects

- The majority (92%) of patients reported experiencing treatment-related side effects.
- A significant proportion (78%) of patients encountered general and gastrointestinal side effects, including fatigue (67%), moon-face (56%), oedema (44%), weight gain (41%), constipation (37%), and diarrhoea (33%).
- Less than 50% of patients experienced sensory systems side effects; however, the impact on daily life was high.

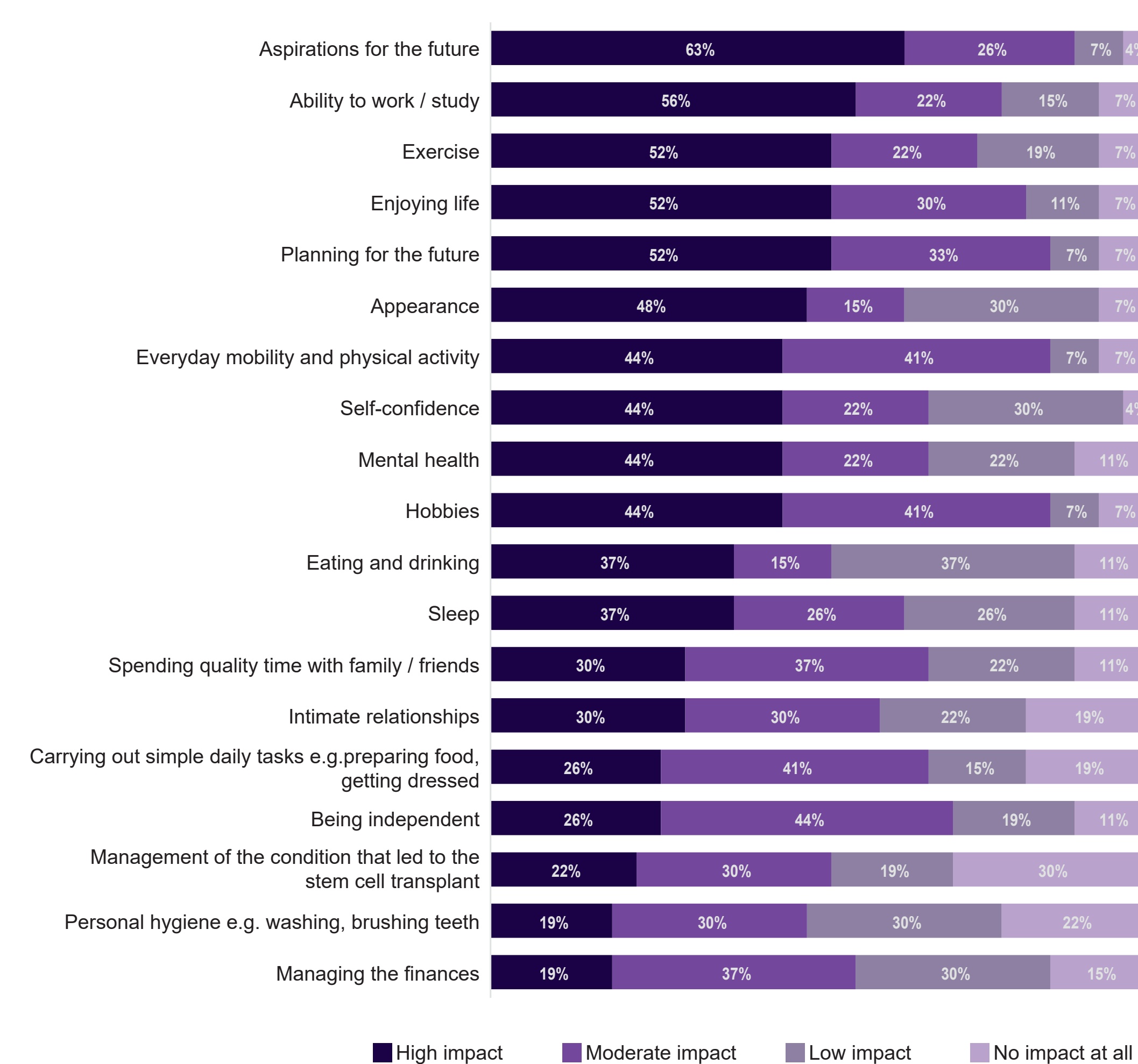
Medical appointments

- Medical appointments represented a substantial burden for respondents; 48% of patients attended appointments at least once a month while 26% of patients attended once a week; 37% had unplanned hospital visits once a month or a few times a year.
- Survey respondents have typically seen a mean of five different healthcare professionals (HCPs) in relation to their cGvHD, including hematologists (89%), dermatologists (70%) and ophthalmologists (59%).
- Most patients (66%) expressed the need for improved communication between HCPs that manage their cGvHD and 48% preferred the use of one doctor to manage their cGvHD.

The impact of cGvHD on HRQoL

- The greatest impact of cGvHD on patient HRQoL was on aspirations for the future (89% reported a moderate to high impact).
- More than 50% of respondents reported that cGvHD had a high impact on patients' ability to work, exercise, enjoy life, and plan for the future (**Figure 1**).

Figure 1. The impact of cGvHD on patient HRQoL

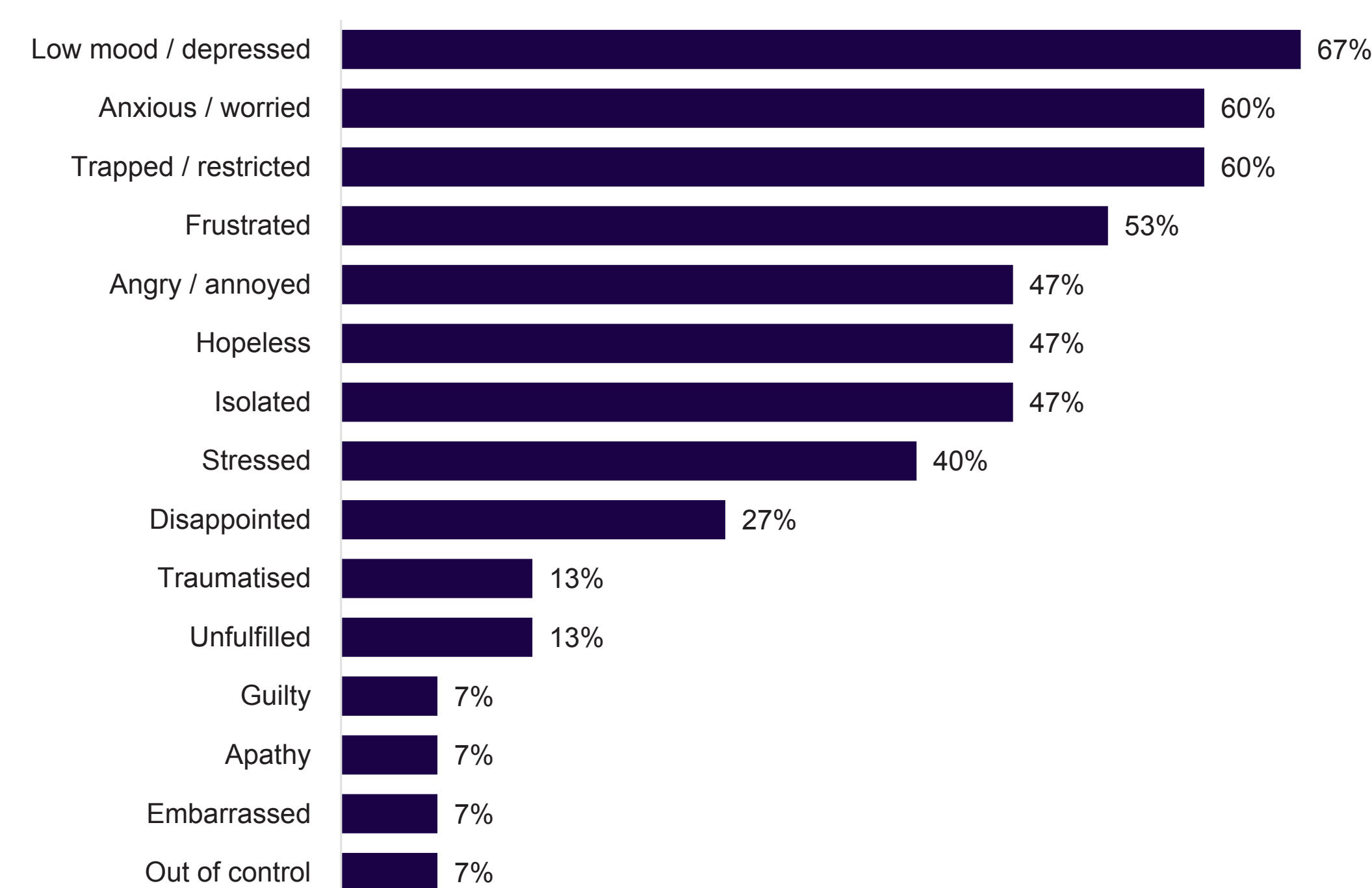


Survey respondents: n=27 (17 patients, 10 carers); Q9: Please tell us how much impact chronic GvHD has on each of these aspects of your daily life / please tell us how much impact chronic GvHD has on each of these aspects of the daily life of the person you care(d) for.
 cGvHD, chronic graft-versus-host disease; HRQoL, health-related quality of life.

Mental health challenges associated with cGvHD

- Many patients (69%) reported that cGvHD impacted their mental health, and 78% felt they were a burden to others due to their condition. The challenges associated with mental health are summarised in **Figure 2**.
- Only 35% of patients were offered and accepted mental health support, while 35% were not offered any mental health support; many patients and carers (74%) feel that people with cGvHD need more emotional support than is currently available.

Figure 2. Emotions expressed by patients in connection with cGvHD



Survey respondents: n=15 patients, 4 participants chose to skip this portion of the survey; Q10: Which of the following emotions, if any, have you experienced in connection with your chronic GvHD?
 cGvHD, chronic graft-versus-host disease.

Carer QoL

- The majority of carers (90%) felt that caring for someone with cGvHD impacted their ability to plan for the future or work/study and 60% said their finances were affected.
- All carers reported feeling anxious or worried when caring for someone with cGvHD and expressed the need for more emotional support.

CONCLUSIONS

- The treatment burden, side effects, medical appointments, impacts on daily life, and mental health challenges associated with cGvHD can all contribute to a diminished HRQoL for patients and carers.
- Addressing these factors and providing support for individuals according to their needs is crucial to improve HRQoL and alleviate the multifaceted burden of cGvHD.

References

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Disclosures

Sanofi has paid Anthony Nolan a fee for service to provide consultancy and communications support to assist recruitment for market research on quality of life of people with cGvHD. In return, Anthony Nolan will be given access to the final data report.