

BACKGROUND

- Chronic graft-versus-host disease (cGvHD) affects roughly 20–50% of transplant patients and significantly impacts outcomes such as morbidity, mortality, and quality of life.¹
- Managing the symptoms of cGvHD often requires multiple lines of therapy (LOT).²
 - Despite the impact on daily life, research on health-related quality of life (HRQoL) is lacking.
- Compounding this issue is the heterogeneous nature of cGvHD, encompassing various organ manifestations and degrees of severity.³
- The present study explores the experiences of patients managing cGvHD after multiple treatment failures, including how cGvHD impacts their HRQoL.

METHODS

- Adult patients/carers of adult patients with moderate or severe cGvHD, experiencing ongoing symptoms and having received ≥ 2 LOT, were invited to participate in a virtual, in-depth interview.
- Following screening, structured interviews were conducted with the patient alone (1 hour duration) or with the patient and their carer (1.5 hour duration).
- The aim of each interview was to evaluate and understand the impact of cGvHD on HRQoL in patients undergoing multiple LOT, encompassing the physical, emotional, social, and financial/educational burden of this condition.

RESULTS

Participant characteristics

- Ten UK-based participants were enrolled in the study (eight patients and two carers).
 - Participant characteristics are summarised in **Table 1**.

Table 1. Participant characteristics

Parameter	Respondents, N=10
Respondent type, n	
Patient	8
Carer	2
Sex, n	
Female	6
Male	4
	Patients, n=8
Age, n	
≤ 40 years	3
41–50 years	1
51–60 years	3
≥ 61 years	1
Location, n	
England	7
Wales	1
Previous conditions, n	
AML	3
MDS	3
Myelofibrosis	1
ALL	1

AML, acute myelogenous leukaemia; ALL, acute lymphoblastic leukaemia; MDS, myelodysplastic syndromes.

Impact of cGvHD on HRQoL

- Survey responses indicate that cGvHD imposes restrictions on the lives of patients and carers, affecting mobility, independence, appearance, relationships, hobbies, exercise, diet, and sleep.

Physical impact

- Participants reported that cGvHD symptoms impacted their daily life and wellbeing (see **Figure 1**).
 - The severity of symptoms varied between patients and affected numerous organs.

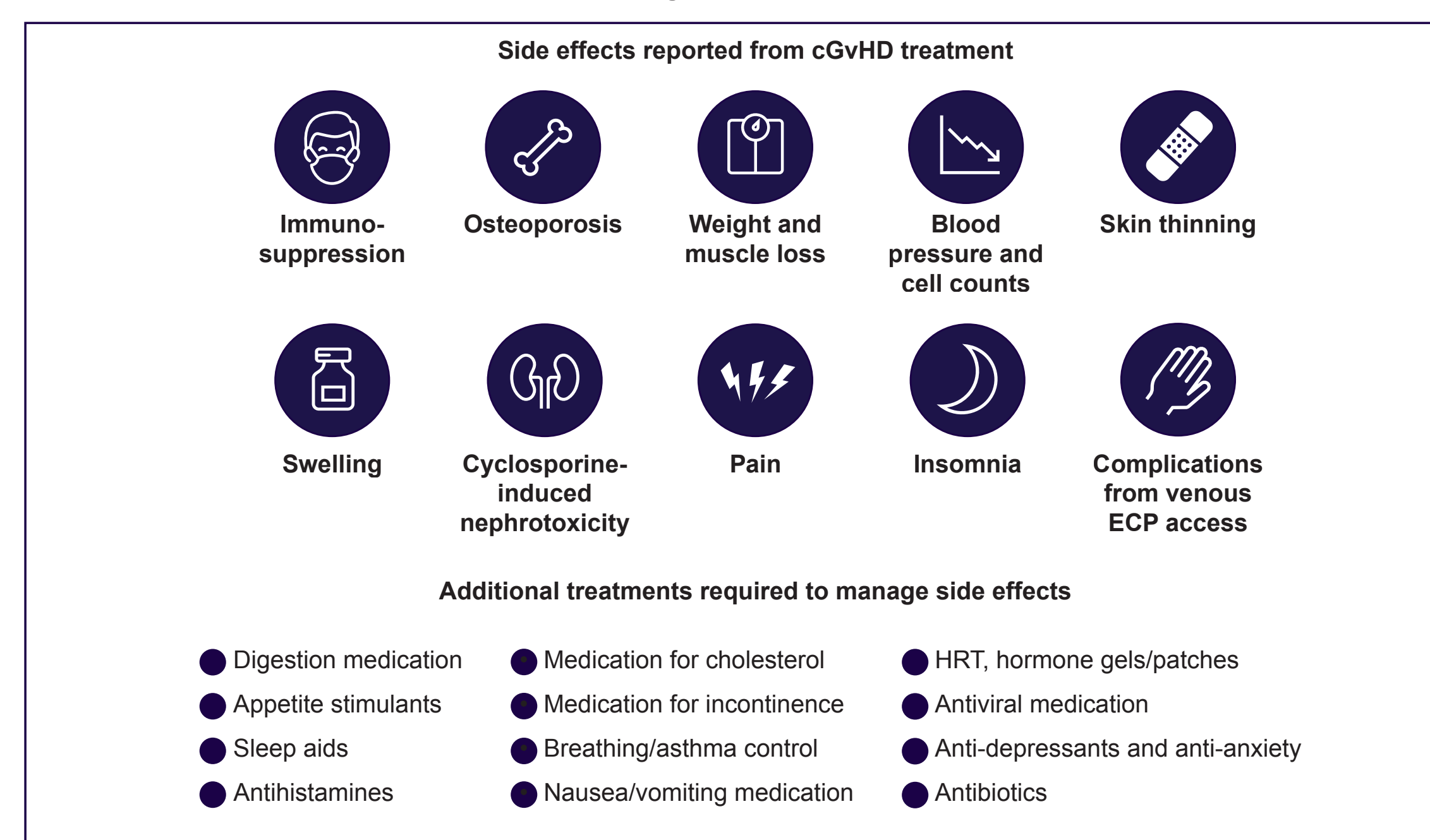
Figure 1. Patients describe the impact of cGvHD symptoms on their quality of life



c, chronic; GvHD, graft-versus-host disease.

- Patients and carers considered the treatment burden associated with cGvHD to be significant.
 - Patients reported taking a range of different treatments depending on their symptoms.
- Treatments for cGvHD lead to side effects/complications, resulting in further treatments with side effects, summarised in **Figure 2**.

Figure 2. Treatment burden experienced by patients with cGvHD

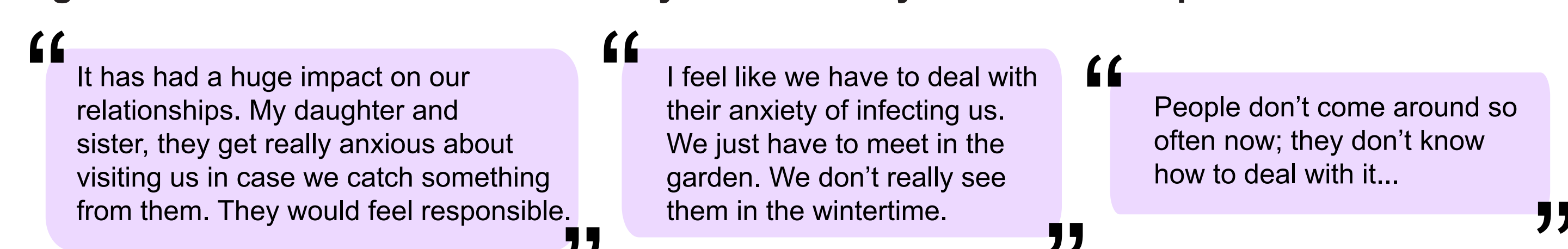


cGvHD, chronic graft-versus-host disease; ECP, extracorporeal photopheresis; HRT, hormone replacement therapy.

Emotional and social impact

- cGvHD imposes limitations on the lives of patients and carers, with psychological implications such as heightened anxiety, and a hindered ability to enjoy hobbies/interests, maintain friendships, relationships, and a sense of confidence.
- Patients initially felt positive following their stem cell transplantation; however, a cGvHD diagnosis, progressive symptoms, and a lack of treatment options left patients feeling disappointed.
 - This led to some patients feeling apathetic towards tracking their disease management.
- Seeing a range of specialists and managing multiple, regular appointments can cause notable burden and frustration.
- Increased infection risk due to immunosuppressive therapy caused patients and carers to experience isolation and elevated health anxiety.
 - Some patients became housebound due to fear of infection when leaving the house.
 - This anxiety extended to friends and family who shared concerns about transmitting infections to the patient (see **Figure 3**).

Figure 3. Infection risk creates anxiety for the family and friends of patients with cGvHD

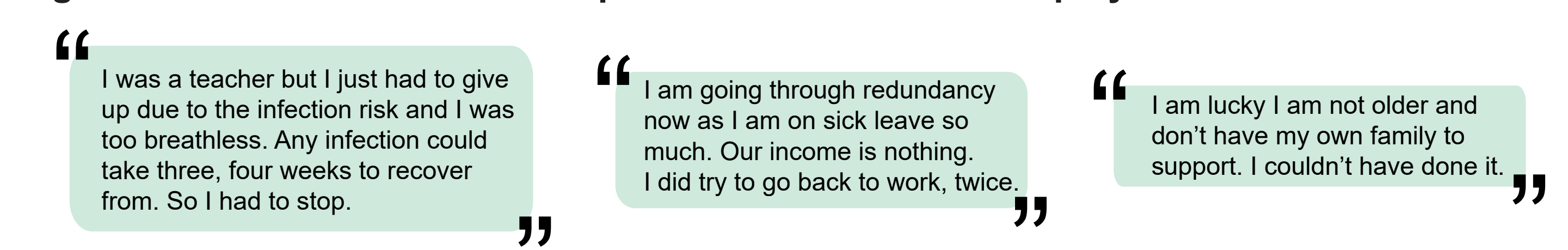


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Financial/educational impact

- Some patients and carers experienced a financial impact associated with cGvHD, including reduced income and increased financial pressure due to leaving their jobs (see **Figure 4**).

Figure 4. Patients describe the impact of cGvHD on their employment and finances



c, chronic; GvHD, graft-versus-host disease.

- cGvHD prevented patients and carers from pursuing their goals.
 - Only a minority of patients were still hopeful that they would be able to return to their goals, work, or education in the future.
- Hidden costs associated with cGvHD, such as travel expenses, new dietary needs, and non-prescription medications, contributed to financial burden.

CONCLUSIONS

- This study demonstrates that cGvHD notably affects the HRQoL of patients who have experienced multiple treatment failures.
- Patient experiences of cGvHD are unique and varied, but typically include a high and unpredictable burden of symptoms and treatment.
- Managing multiple symptoms and treatment-related side effects can create a compounding, continuous cycle, increasing the adverse emotional load and health anxiety experienced by patients and carers.
- As well as impacting physical and emotional aspects of HRQoL, cGvHD also has social and financial implications for patients and carers.

References

1. Lee SJ, et al. Haematologica 2018;103:1535–41; 2. Lee SJ, et al. Biol Blood Marrow Transplant 2018;24:555–62; 3. Mohty B & Mohty M. Blood Cancer J 2011;1:e16.

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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.