Understanding Cytomegalovirus Symptom Management, Quality of Life, and Care Coordination in Transplant Recipients Through Patient and Care Partner Experiences

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INTRODUCTION

- Cytomegalovirus (CMV) infection is a common viral infection, with an incidence rate of 8-75% in solid organ transplant (SOT) recipients, depending on the type of organ transplanted, and 5-30% in hematopoietic cell transplant (HCT) recipients.[1]
- It is important for transplant recipients to track symptoms such as fever, chills, fatigue, and muscle ache post-transplant as symptoms of CMV infection tend to start 1–4 months after transplant; transplant recipients and care partners might not know to identify these as CMV or what to do regarding treatment once CMV has been identified.
- Thus, there is a need to identify the knowledge gaps that transplant recipients and their care partners have regarding treatment practices related to post-transplant CMV.

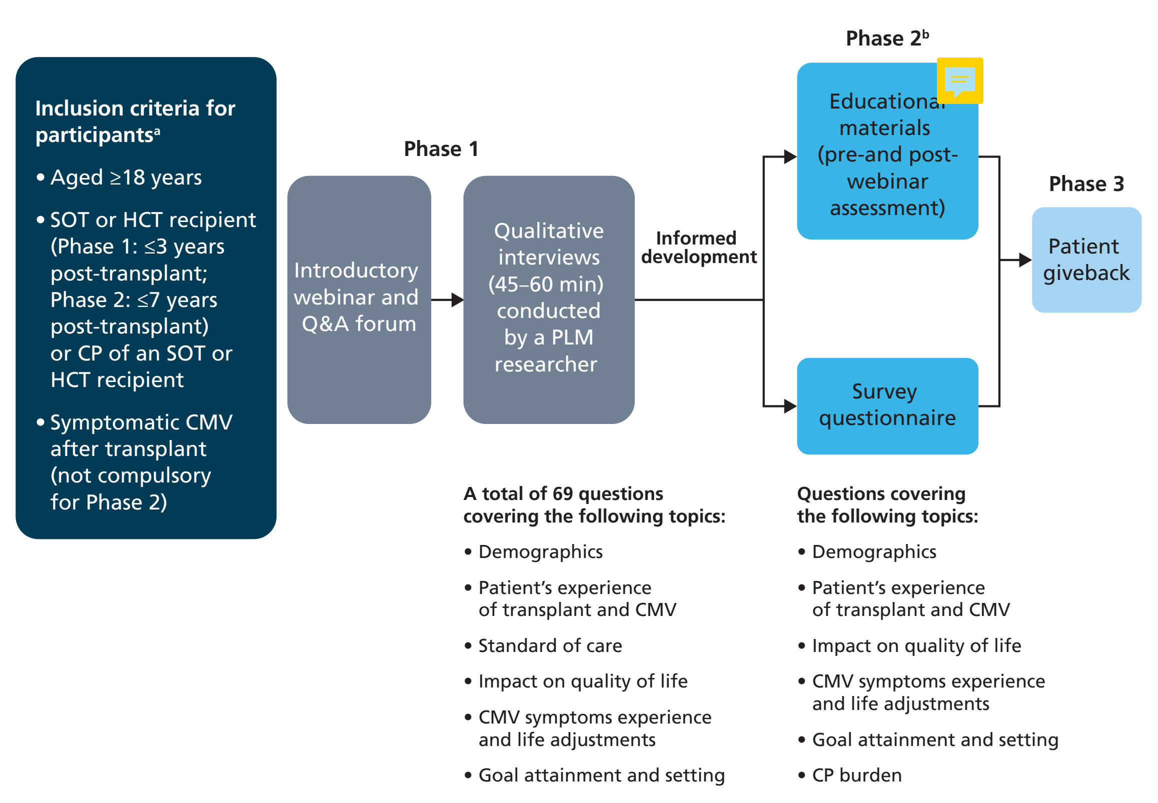
OBJECTIVE

- To better understand patient and care partner knowledge of CMV and their post-transplant (SOT and HCT) experience, and to identify knowledge gaps and opportunities to educate transplant recipients and care partners.

METHODS

- This was a mixed-method study conducted through the PatientsLikeMe (PLM) platform, which is an online community (>860,000 members) that enables members to monitor symptoms of their condition(s), share their disease experiences and treatment outcomes, and learn how to improve their care through peer-to-peer interactions.
- For inclusion, participants had to be 18 years or older, and a transplant recipient or care partner of a patient who had received an SOT or HCT (**Figure 1**).
  - For Phase 1 only, participants also had to have experienced symptomatic CMV or be a care partner of a transplant recipient who had experienced symptomatic CMV.
- Transplant recipients were recruited via the PLM website, email, and social media (Facebook, Twitter, Instagram, or LinkedIn).

Figure 1. Study design



Inclusion criteria for participants[a]

- Aged ≥18 years
- SOT or HCT recipient (Phase 1: ≤3 years post-transplant; Phase 2: ≤7 years post-transplant) or CP of an SOT or HCT recipient
- Symptomatic CMV after transplant (not compulsory for Phase 2)

Phase 1

Introductory webinar and Q&A forum

Qualitative interviews (45–60 min) conducted by a PLM researcher

Informed development

Phase 2[b]

Educational materials (pre-and post-webinar assessment)

Survey questionnaire

Phase 3

Patient giveback

A total of 69 questions covering the following topics:

- Demographics
- Patient's experience of transplant and CMV
- Standard of care
- Impact on quality of life
- CMV symptoms experience and life adjustments
- Goal attainment and setting

Questions covering the following topics:

- Demographics
- Patient's experience of transplant and CMV
- Impact on quality of life
- CMV symptoms experience and life adjustments
- Goal attainment and setting
- CP burden

[a]Particpants were recruited from PLM website, email, or social media, including Facebook, Twitter, Instagram, or LinkedIn.
[b]Results enriched with retrospective data summary from data linkage.
CMV, cytomegalovirus; CP, care partner; HCT, hematopoietic cell transplant; PLM, PatientsLikeMe; SOT, solid organ transplant.

- The study included two research phases and a giveback phase:
  - Phase 1 included a webinar followed by a Q&A forum and post-webinar qualitative interviews.
    - The Phase 1 webinar and Q&A forum were available on the PLM platform for the general PLM community.
    - Only participants who met the inclusion criteria were invited to participate in the post-webinar qualitative interviews.
  - Phase 2 included an educational webinar (including a 5-question assessment pre- and post-webinar on participants' knowledge regarding CMV, as well as a pre- and post-webinar confidence rating) and a quantitative survey on transplant recipients' lived experiences with CMV.
  - Transplant recipients were also invited to link their electronic health record to supplement survey data in Phase 2.
  - Phase 3 includes a patient education giveback in which aggregate-level learnings were shared with the transplant recipients and their care partners.
- To protect participants' confidentiality, no direct participant identifiers were included, and indirect participant identifiers were presented with summary statistics only.
- This poster presents results from Phases 1 and 2 (March 2022–March 2023).

Data analysis

- Themes arising from free-text responses to the qualitative interviews were evaluated using a directed content analysis approach.
- Demographics and clinical baseline characteristics for the quantitative survey respondents were summarized and described for all transplant recipients using descriptive statistics, including frequencies and proportions for categorical variables and means, standard deviations (SD), and medians for continuous variables.
- Statistical significance was defined based on an alpha of 0.05.

RESULTS

Phase 1 (Qualitative analysis)

- In total, 5 participants (4 SOT recipients, 1 care partner) were interviewed.
  - All participants except one were unaware of CMV or their CMV status prior to transplant, none knew their donor's CMV status prior to transplant, and none could specify the extent of CMV monitoring by their care team.
  - Two participants reported financial complications from CMV treatment, and four participants indicated receiving no CMV-specific support and/or education about their CMV treatment.

Phase 2 (Quantitative analysis)

Webinar

- In total, 33 participants (31 transplant recipients, 2 care partners) completed the webinar.
  - The key demographics for the transplant recipients were: mean age: 48.3 (SD: 13.6) years; female sex: 11 (35.5%); had single organ transplant: 28 (90.3%); had CMV post-transplant: 15 (48.4%). Only one patient had received HCT.
- Responses to the pre- and post-webinar questions indicated a significant improvement in understanding of CMV after the webinar as compared with before ($p < 0.05$; t-test statistic).
- Participants also reported higher confidence in their ability to recognize the CMV symptoms post-webinar (**Table 1**).

Survey

- In total, 29 participants (28 transplant recipients, 1 care partner) completed the survey.
  - The key demographics for the transplant recipients were: mean age 48.1 (SD: 13.6) years; female sex: 9 (32.1%); had single organ transplant: 25 (90.3%); had CMV post-transplant: 14 (50.0%).

Table 1. Participants' self-reported confidence rating pre- and post-webinar in Phase 1

How confident are you in your ability to recognize the symptoms of cytomegalovirus (CMV) infection after transplant?	Confidence rating Pre-webinar (n=33[a])	 Post-webinar (n=33[a])
Not at all confident	16	0
Somewhat confident	5	2
Moderately confident	10	12
Very confident	2	12
Completely confident	0	7

[a]Included 31 transplant recipients and 2 care partners.

- More than half of the transplant recipients were unaware of their or their donor's CMV status prior to transplant; however, 50% developed CMV post-transplant (**Table 2**).

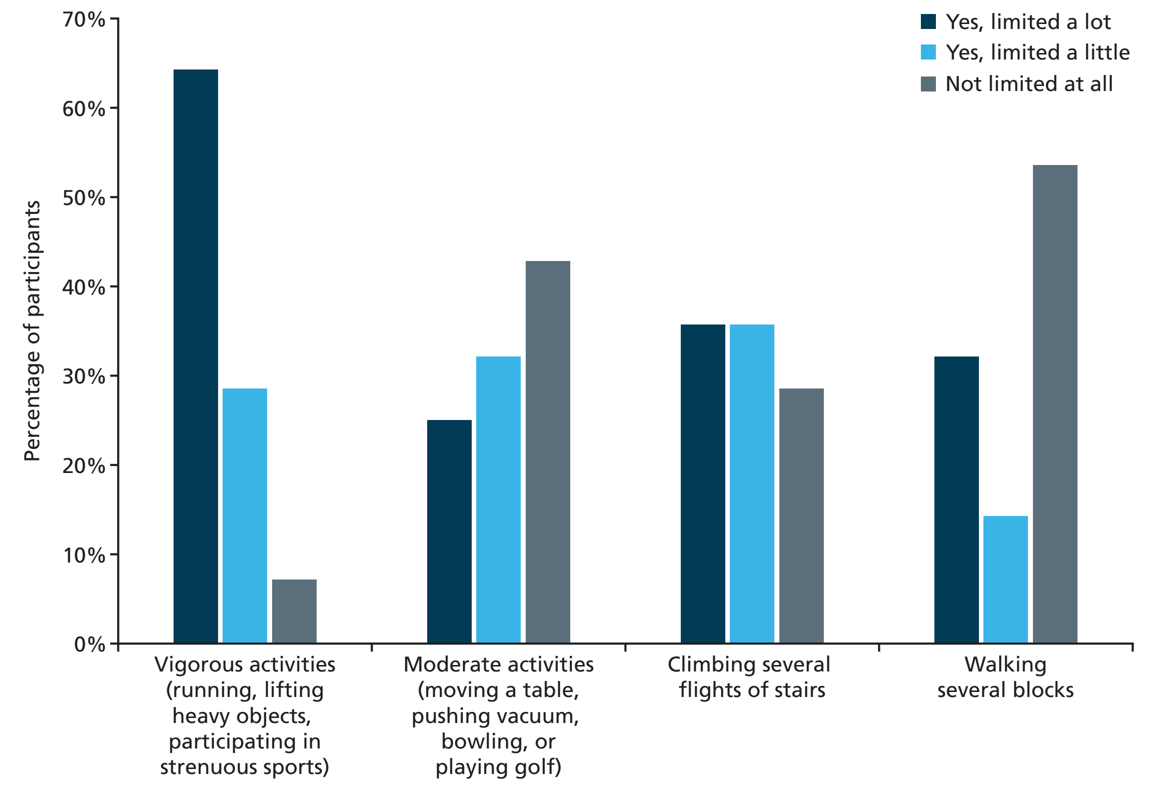
Table 2. Patient responses to Phase 2 quantitative interview questions on lived experience with CMV

Characteristics	Participants (n=28)
CMV diagnosis post-transplant	
Yes	14
No	12
Don't know	2
Aware of CMV status prior to transplant	
Yes	12
No	16
CMV treatment	
Pre-emptive only	3
Prophylaxis only	10
Both (pre-emptive and prophylaxis)	2
None	7
Don't know	6
CMV symptoms	n=14[a]
Yes	7
Diagnosed from lab work	6
Don't know	1
CMV medication switches	n=14[a]
Yes	3
Once	1
Twice	2
No	11
CMV medication dose change	n=14[a]
Yes	5
Once	3
Multiple times	2
No	9
CMV hospitalizations	n=14[a]
Yes	10
Once	7
Multiple times	3
No	4
CMV education in hospital (before discharge)	n=28
Yes	13
No	11
Don't know	4
Top 3 challenges with CMV treatment	n=14[a,b]
Remembering to take medication(s) as prescribed	9
Burden of clinic visits and monitoring the impact of side effects	7
Coordinating various medications and supplements	7
Top 3 most contacted care team members for CMV	n=7[c]
Transplant surgeon	5
Nurse specialist	1
Internal medicine physician	1
Top 3 useful sources of information on CMV treatment	n=14[a,b]
Internet searches	12
My care team	8
Patient guides and handbooks	5

[a]Participants who underwent transplant surgery and received a CMV diagnosis post-transplant.
[b]Participants could select more than one response, so the total could exceed the number of participants.
[c]Participants who underwent transplant surgery, received a CMV diagnosis post-transplant, and were symptomatic.

- Most (27/28) transplant recipients reported a positive experience with their care team post-transplant. Half of the transplant recipients set goals with their care team or were provided with resources to track their goals post-transplant.
- Transplant recipients reported challenges with limitations to their physical health (**Figure 2**), taking a large number of medications, and having to take multiple pills.
- Transplant recipients primarily contacted their surgeon about CMV and sought information on the internet.

Figure 2. Participants' responses to limits of physical health experienced



CONCLUSIONS

- **CMV education resulted in a significant ($p<0.05$) improvement in patient knowledge and an increase in confidence regarding recognizing CMV symptoms post-transplant.**
- **Most transplant recipients reported a positive experience with their care team post-transplant surgery. However, participants felt they were not well-informed about CMV infection post-transplant and felt the most challenging aspects of the post-transplant journey were remembering to take their medications as prescribed, the burden of clinic visits, monitoring the impact of side effects, and coordinating their various medications and supplements.**
- **The post-transplant care journey could be improved by better preparing and educating transplant recipients and care partners about CMV and its management.**
- **Limitations of this real-world evidence study include the potential for recall bias as the study comprised participant perceptions, the small number of participants, and underrepresentation of HCT recipient and care partner populations; thus, the results cannot be generalized to the larger community of people affected by CMV.**

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DISCLOSURES:
DS, MCB, SR are employees of PatientsLikeMe. ERM is an employee of and owns stock in PatientsLikeMe. MR {Please provide}. GP is an advisor/consultant for and has received grant/research support from Merck and Takeda; is an advisor/consultant for Astellas, Cidara, CSL Behring, MSD, Partners Rx, and SymBio; is an advisor/consultant and EAC member for Octapharma; and serves on a DSMC for AlloVir, Amplyx, and Vera. MLL is an advisor/consultant for Takeda. MM is an employee of Takeda. MG is an employee of and owns stock in Takeda. DG is an employee of Takeda and owns stock in Abbott Laboratories, Ionis Pharmaceuticals, Johnson & Johnson, NovoNordisk, Pfizer, Regenxbio, Takeda, and Vertex Pharmaceuticals.

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This poster is intended for healthcare providers.