

Autologous Hematopoietic Stem Cell Transplantation for MS

The Dutch Experience of Patients going Abroad

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Introduction

Autologous hematopoietic stem cell transplantation (aHSCT) for MS¹ is not provided in the Netherlands, resulting in numerous Dutch people with MS going abroad at their own expense to fee for service clinics. As of May 2022, 151 Dutch people with MS were treated in Russia, 78 in Mexico, > 6 in India and > 15 were treated elsewhere.

Aim

To gain insight into the number of people, their MS-type, and experiences that underwent and those who are interested in pursuing aHSCT abroad.

Methods

Via (social) media and the Dutch MS society, people with MS were requested to fill out a questionnaire about aHSCT abroad.

Results

481 patients responded to the call (386 female, 80%). Of these, 135 (28,1%) had undergone aHSCT (treated group) and 346 (71,9%) considered treatment (planned group).

Of the planned group, 10.9% ultimately decided not to undergo aHSCT, and 176 (51.9%) patients indicated that they are waiting to make their final decision until aHSCT in the Netherlands has been approved.

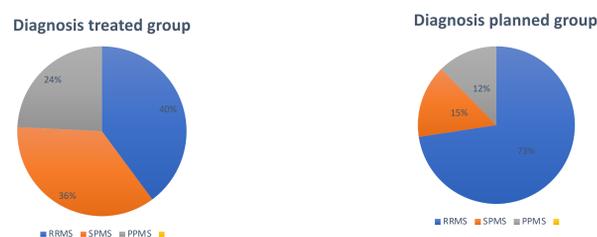


Fig. 1: MS subtype of the already transplanted group (left image) and of the planned group (right image)

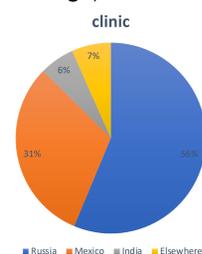


Fig. 2: Distribution of different clinics where patients travel to for HSCT

Treated group:

- Most patients rely on social media to choose a clinic.
- 77% decided for aHSCT regardless of their treating neurologist's opinion,
- 2 patients died during treatment (India),
- 2 underwent euthanasia in a later stage after aHSCT

- 125 (93%) patients indicated that, in hindsight, they would make the same decision,
- 4 indicated that aHSCT was too recent to answer this question.
- 2 patients regretted their decision,
- 84% reported no new disease activity since aHSCT and
- 57% improvement in disability.
- In none of the cases the health insurance contributed to financing the treatment.

Conclusion

Many Dutch MS patients seek aHSCT treatment abroad, usually regardless of the advice of their treating physician. While in the past years, more than half of the patients that went for aHSCT had progressive MS, in recent years, there seems to be a shift towards RRMS.

Expert coaching with attention to pre and aftercare of people going abroad for this high-risk treatment could improve safety. A centralized registry is needed for the registration of side effects. The ultimate goal would be Dutch standardization of aHSCT-treatment for MS and reimbursement for selected cases.

Disclosures

This study was not sponsored.

E.P.A. Kramer is a member of the medical advisory committee of the Dutch MS society and is involved in the reimbursement application for aHSCT in The Netherlands. G.J. Hengstman gives paid and unpaid, asked, and not-asked advice to several MS patient support groups and all pharmaceutical companies with licensed medications for MS. E. Hoitsma is chair of the Dutch MS Workgroup and involved in the reimbursement application for aHSCT in The Netherlands. C.W. Choi, T Berkx and B. Platel have nothing to disclose related to this poster.

References

- 1) Sharrack, B., Saccardi, R., Alexander, T. et al. Autologous haematopoietic stem cell transplantation and other cellular therapy in multiple sclerosis and immune-mediated neurological diseases: updated guidelines and recommendations from the EBMT Autoimmune Diseases Working Party (ADWP) and the Joint Accreditation Committee of EBMT and ISCT (JACIE). *Bone Marrow Transplant* 55, 283-306 (2020). <https://doi.org/10.1038/s41409-019-0684-0>