

# The Dutch experience

Patients going abroad for HSCT, Ellen Kramer





# Background

- In the Netherlands, an unknown number of patients go abroad to fee for service clinics for HSCT for transplantation of non-hematological diseases
- Because many patients go abroad on their own initiative, data on numbers, indication, but also complications are lacking



# Motivation and background

- Death of patient after HSCT in India
- In this IRB approved study, we gather information about patients that went abroad and how it affected their health care



# Method

- Patients that went abroad for stem cell transplantation on their own initiative for any kind of disease were invited to fill out a survey (or have finalized plans to go)
- Patients were recruited through (social) media like Facebook, television and newspapers



# Method-2

The survey consisted of 3 parts:

1. Questions about their stem cell transplantation
2. EORTC30
3. NeuroQoL54



# Results after 12 months

- Registered patients: 51
- Forms completed: 30
- Here we report on the results of 24 patients that underwent aHSCT treatment abroad for MS and completed the survey.

3 did not yet undergo treatment

3 were treated for a different disease (Lyme, hearts disease CVA)



# 24 MS patients treated with aHSCT

- 50% women, 50 % men
- Mean age 46 (SD, 9,7)
- Mean disease duration 8 years (SD 6,1, range 0-23y)



# Course of MS

- PPMS: 10 (42%)
- SPMS: 7 (29%)
- RRMS: 7 (29%)





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Many self referred patients undergo high-risk treatment for non-evidence-based indications (like progressive MS)



# Transplant centre

- Russia: 10
- Mexico: 8
- India: 3
- Other: 3



# Centre selection

- All except for one patient chose for their center based on “*own research*” or “*success stories from other patients*”.
- None of the patients were referred by their physician.
- 3 were advised in their decision for a specific clinic by their neurologist. None of the participants was treated as part of an RCT.

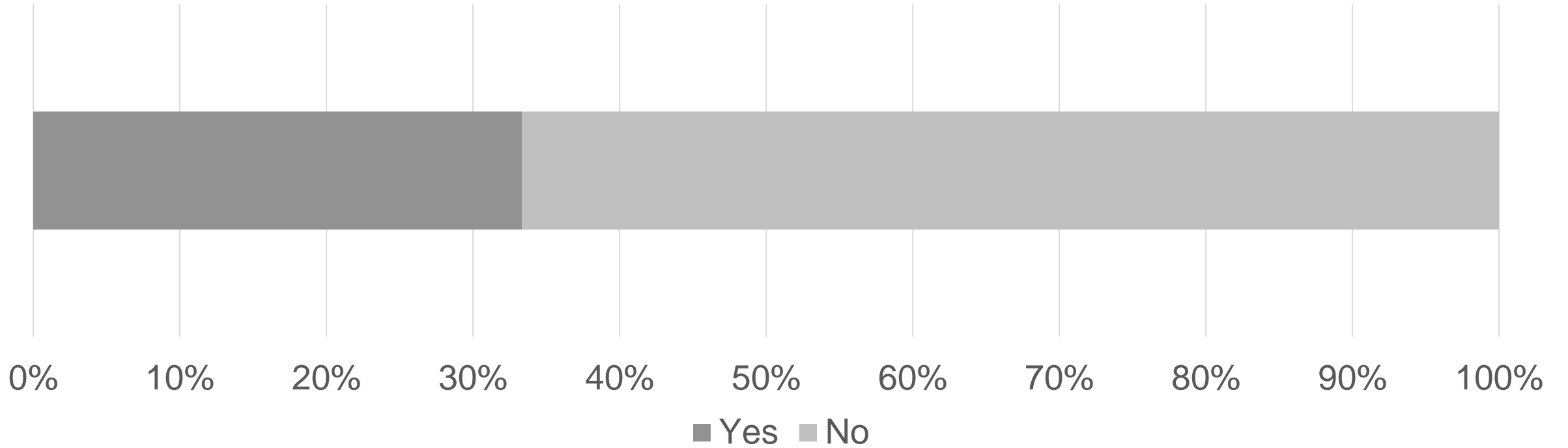


# Follow up

- 13 hematologist (3 were advised so by their neurologist)
- 5 GP
- **6 have not had any medical aftercare**

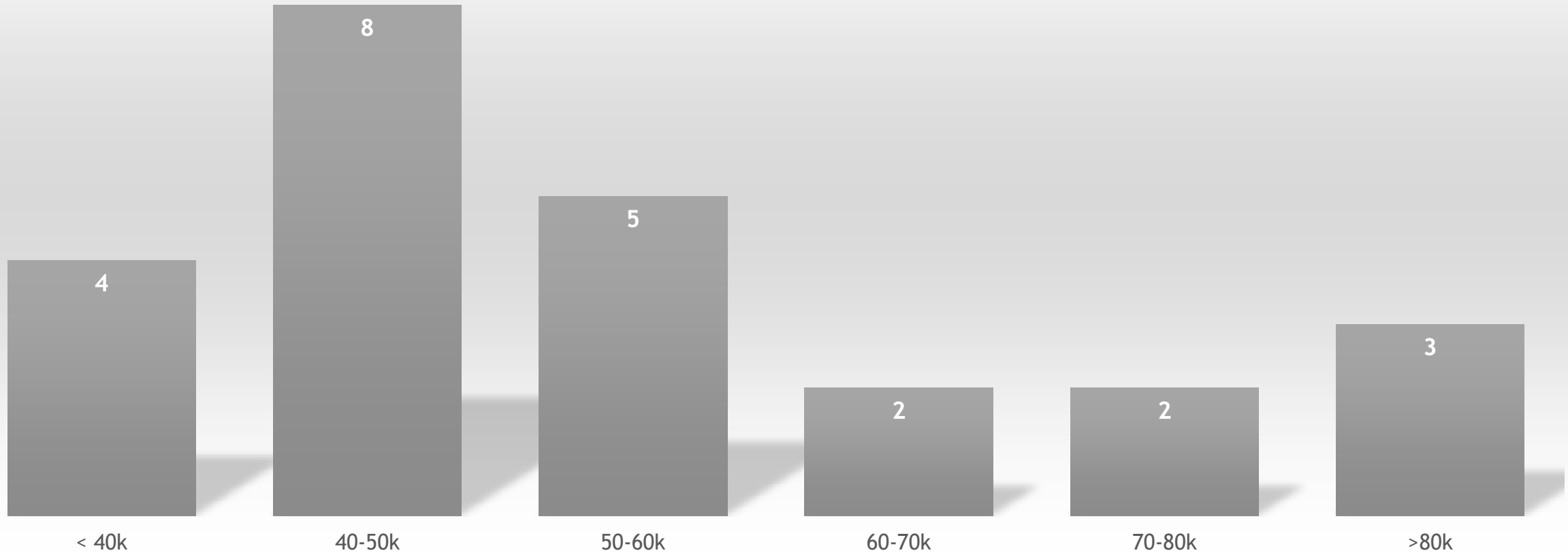


## Did you feel supported by you treating physician





# Treatment Cost





# Financing the treatment

## aHSCT

- Crowd funding 16/24
- Own means 8/24
- Health insurance 0/24

## Aftercare

- Health insurance 21/24



# Conclusion

- Central registration of people going abroad for this high-risk treatment could contribute to better safety with the ultimate goal to organize reimbursement for selected cases and attention to aftercare.





# Limitatons of this study

- At the start of our study there was quite a lot of resistance. It took a while for people willing to participate. The influence of social media is important here.
- Our study provides an underreport of the number of people who actually went abroad.
- At the end of 2019 the flow of patients who went to Russia for HSCT increased enormously. Before we could start recruiting, the Russian transplant centre was closed due to COVID



# Life after COVID

- To get an idea of the actual figures, we contacted the transplant centers in Mexico and Moscow in August 2021
- Mexico: 53 Dutch MS patients
- Moskou: 114 Dutch patients, 27 of them in 2021 and 27 more to come
- So our study was truly under reporting (total: 167)



# Gaining trust

- Because at first we encountered quite a lot of resistance from the patients in our own study, we asked them to work with us
- we asked the patients to develop a questionnaire themselves



# Second questionnaire

- Took 2 months to develop a questionnaire
- 14 question

## Topics:

- how do you decide whether or not to go abroad for HSCT
- how does it affect the relationship with your HCP?
- how many patients are still in the process of decision making



# Preliminary results

- Questionnaire was sent out by the end of september
- 2 reminders were sent
- We used social media: Facebookgroup, website Msinbeeld, website MSweb



## Preliminary results -2-

- Within 24 hours we had over 200 responses
- Last week: 310 responses
- Questionnaire will close december 1

### First results:

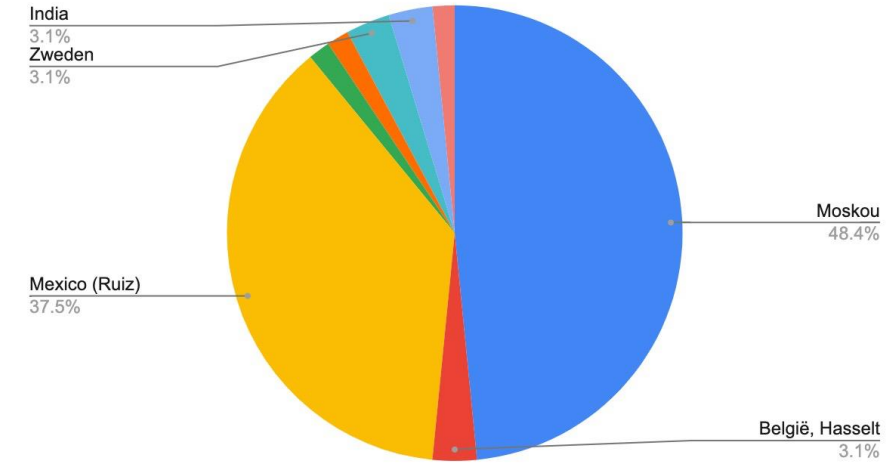
- 64/310 underwent aHSCT: still under reporting
- The remaining 246 not yet



## Preliminary results -3-

- Again: over 50% of patients SPMS and PPMS
- Moscow and Mexico are the most important centres
- Only 4% based their opinion on the advice of the neurologist
- Rising number of hematologists refuses after care

In welk centrum heb je de transplantatie ondergaan?





## Not yet transplanted (246)

- Over 46% of responding patients are waiting for reimbursement in the Netherlands
- Over 11% of patients are somewhere in the proces





# In conclusion

- The flow of patients going abroad for HSCT continues and increases
- Aftercare deteriorates
- Adequate information and follow-up upon return are important
- Central registration of people going abroad for this high-risk treatment could contribute to better safety with the ultimate goal to organize reimbursement for selected cases and attention to aftercare.



# Current situation

- HSCT for MS is not yet available in the Netherlands
- Reimbursement request is pending for selected cases but the prospects are uncertain
- Other indications (not MS) are still unknown, patients have often signed a confidentiality agreement