COVID & me

an EBMT webinar for patients and caregivers

EBMT online webinar April 3rd 2020

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Bregje Verhoeven, MSc

Role: EBMT Patient Advocacy Committee – Chair

International patient advocate for Foundation Hematon, the Dutch organization for lymphoma and blood cancer patients

“We can find comfort in beauty, knowledge and the support of others”
European Society for Blood and Marrow Transplantation (EBMT)

- EBMT is a non-profit organisation composed of scientists and health care providers.
- After consent, it collects anonymized data on diagnosis, treatments, procedures, complications and outcomes.
- This data is registered (Registry) and secured.
- Data is used for research on bone marrow transplantation and cellular therapies & can lead to:
  - Development of new technics
  - Changes in clinical practices
  - Improvements in patient care
  - Better outcome for patients
EBMT Patient Advocacy Committee (PAC)

Patient representatives, patient organization leaders, and patient advocates from Europe

Representing patients through these objectives:

• Ensure that patients’ meaningful concerns are well integrated in all of EBMT activities and organizations
• Ensure that patient perspectives are integrated in scientific activities
• Build an educational program during EBMT Annual Meeting (Patient Family Donor Day & Patient Advocacy Sessions)
• Build and maintain a Network of patients & patient advocates organizations in Europe

Interested in our activities? Email to leadership@ebmt.org
Hélène Schoemans, MD, PhD

Hematologist and Stem Cell Transplantation Physician

EBMT Late Complications Sub-committee Chair (Transplant Complications Working Party)

EBMT Patient Engagement Task Force

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Disclosures

No relevant disclosures for this presentation

*Because of the rapidly evolving knowledge about COVID, the information presented today will need to be re-evaluated in the near future based on the evolution of our understanding of the disease.*
Learning objectives
Our aim is to inform patients and care-givers the current state of knowledge regarding the COVID pandemic and its impact on stem cell transplantation and cell therapy as of April 3rd 2020.

- What is our current understanding of the impact of COVID on stem cell transplantation and cell therapy?
- Where can you find good sources of medical information & support?
- What can you do as patient/care-giver to get through the COVID pandemic?
- What is EBMT doing to help during the COVID pandemic?
Introduction
Vocabulary

CoV = Corona Virus

SARS-CoV-2 = Severe Acute Respiratory Syndrome - related Corona Virus

COVID-19 = Corona Virus Disease 2019

COVID is mainly an adult disease

Based on n= 44 672 confirmed cases in China

Zunyou & McGoogan JAMA. Published online February 24th, 2020
Li et al, Science, March 16th 2020
COVID is very often a mild disease

- Mild: 81%
- Severe: 14%
- Critical: 5%

n= 44 672 confirmed cases in China

Zunyou and McGoogan JAMA. Published online February 24th, 2020
Livingston & Bucher JAMA. Published online March 17th, 2020
Li et al, Science, March 16th 2020
The major problem with COVID-19 is more at the society’s level than at the individual level.
COVID clogs up the health care system

Influx of COVID patients in the hospital means

- less hospital and intensive care beds for other diseases and interventions
- need for dedicated care pathways to avoid cross-contamination
- constant fear of contamination

↓ access to standard care
↑ need for self-management
Data from COVID Hospitalisations in Belgium

% Hospitalized COVID patients in Belgium as of March 26th 2020 (n = 1286)

- Cardiovascular Disease: 28.5%
- High Blood Pressure: 35.5%
- Diabetes: 19.6%
- Chronic Lung Disease: 16.3%
- Chronic Kidney Disease: 11.4%
- Chronic Neuro Disease: 11.9%
- Tumor: 7.1%
- Disease of the immune system, including HIV: 4.3%
- Hematological Cancer, such as leukemia: 1.7%
- Chronic Liver Disease: 2.3%
- None: 26.5%

Underlying medical condition

risk of COVID with cancer?

In the Department of Radiation and Medical Oncology, University Hospital of Wuhan during the first two months of the outbreak, the COVID infection rate was:

0.79% (about 12 COVID+ cases out of 1500 cancer patients)

vs.

0.37% (about 41 000 COVID+ cases out of 11 000 000 from the general population)
Limited published information about cancer & COVID

- Huang, Lancet 2020: 1 (41 patients)
- Chen, Lancet 2020: 1 (99 patients)
- Wan, J Med Vir 2020: 4 (135 patients)
- Liang, Lancet 2020: 18 (1579 patients)
- Guan, NEJM 2020: 2 (30 patients)

Huang et al Lancet Feb 2020; 395; 497-506
Chen et al Lancet Feb 2020; 395; 507-513
Liang et al Lancet Oncol. 2020 Mar;21(3):335-337
Guan et al, NEJM Feb 28th 2020
↑ risk of severe event with cancer?

All cancers lumped together (1/3 lung cancer, only 1 lymphoma).

Patients with cancer were significantly older and had a higher rate of smoking history than non-cancer patients.

Liang et al Lancet Oncol. 2020 Mar;21(3):335-337
Xia et al Lancet Oncol. Mar 23rd 2020
Wang et al Lancet Oncol. Mar 3rd 2020
Too early to be sure…

Very limited published information

Cancer prevalence & care is likely to differ from country to country

... we are learning on the job ...
COVID & Cell Therapy
COVID & Transplantation/Cell therapy

There is currently **NO published DATA** to support formal recommendations

→ **use common sense**

Other medical issues (heart, lung, …)
Dysfunctional immune system
Impact on your transplant care - BEFORE

Overload due to COVID can reduce access to care

Transplantation/Cell therapy = complex chain of events…
- The donor / patient can get infected
- The supply chain can be delayed
- Transfusion product / Medication shortages can occur
- Clinical studies can be put on hold

➔ Your team will adapt depending on the local context

? Delay non-urgent transplantation / cell therapy
? Freezing cells for urgent transplantations

EBMT guidelines / ASTCT guidelines, March 30th 2020
Fred Hutchinson Cancer Research Center COVID-19 guidelines, March 17th 2020
Rose C, NEJM March 18th 2020
Impact on your transplant care - AFTER

41% of COVID infections in Wuhan

Many **non-urgent follow-up appointments** after transplantation / cell therapy can be **postponed** or replaced by **telephone contacts**

Know where to call if you have a issue

EBMT guidelines / ASTCT guidelines, March 30th 2020
Fred Hutchinson Cancer Research Center COVID-19 guidelines, March 17th 2020
Rose C, NEJM March 18th 2020
COVID & you
COVID is contagious

- Each patient spreads the infection to 2-3 people (! droplets)

- It is unclear whether the virus can be stable in air, but it can probably stay on plastic/stainless steel (72h) + cardboard (48h)

- Incubation (time infection → symptoms) is 1-14 days, median 5 days

Guan W et al. NEJM Feb 28th 2020
van Doremalen et al. NEJM March 17th 2020
Desai & Patel JAMA. Published online March 20th 2020
Li et al, Science, March 16th 2020
Avoiding COVID infection

✓ Wash your hands with soap/water for 20 sec
✓ Practice social distancing (! Closed spaces)
✓ Cancel all travel + non-essential appointments
✓ Exercise
✓ Sleep
✓ Eat healthy

Desai & Patel JAMA. Published online March 20th, 2020
Recommendations of Dr El-Jawahri and Dr Letourneau
BMT infonet webinar March 20th 2020
Fang et al Lancet, April 2020
Please do not…

✗ Touch your face with your hands

✗ Stop your current medication

✗ Buy / Start new medication based on what you read in the media

✗ Panic 😊
What about masks ?!? 

There is a **global shortage** on masks.

The majority of masks **do not offer adequate protection** against virus but they can serve as **physical barrier** against droplets.

Desai & Mehrotra JAMA. Published online March 6th 2020
Recommendations of Dr El-Jawahri and Dr Letourneau
BMT infonet webinar March 20th 2020
Mask etiquette

If you decide to wear a mask…

✓ Put it on/off correctly
✓ Do not continuously touch your face to adjust it!!

Face masks should only be used by
- Individuals with symptoms of respiratory infection such as coughing, sneezing, and sometimes fever
- Health care workers
- Persons taking care of or in close contact with someone with a respiratory infection

How do I use a face mask?
1. Wash hands for at least 20 seconds prior to putting on a face mask.
2. Place face mask over nose and mouth. Ensure a tight seal with no gaps and secure elastics or straps.
3. Avoid touching the front of the face mask. If you do, wash hands for at least 20 seconds.
4. Remove the face mask without touching the front. Discard in a closed bin.
5. Wash hands again for at least 20 seconds.
What can you feel when COVID starts?

- Fever
- (Dry) cough
- Shortness of breath
- Muscle pain
- Sore throat / runny nose
- Change in smell or taste (?)
- (fatigue)
- (diarrhea)

Zunyou & McGoogan JAMA. Published online February 24th 2020
Guan et al, NEJM Feb 28th 2020
Giacomelli et al, CID March 2020
Mo et al, CID March 2020
Zhang et al, Allergy Feb 19th 2020
What if you get a COVID diagnosis?

Make sure that your Transplantation/Cell Therapy team knows about it

1. Tell them about your COVID diagnosis
2. Make sure other transplantation issues have been taken into account
3. Ask what to do with your medication
How to cope with anxiety?

Keep **contact** virtually / with a distance

Notice the **solidarity** around you

Reserve some time to **think about something else**

- Exercise
- Read books
- Watch movies
- Use online links (museum tours, online concerts, …)
- Meditate?
COVID & EBMT
What is EBMT doing about COVID?

Guidelines
Helpful links
Webinars 😊
Collect data about COVID cases

https://www.ebmt.org/covid-19-and-bmt
As of April 2\textsuperscript{nd} 2020, there have been 84 cases reported to the EBMT registry (Italy 25; Spain 22; France 11; Belgium 6; UK 4; Sweden 3; Switzerland 3; Germany 3; Denmark 2; the Netherlands 2; Iran 2; Greece 1).

Median age 55 years (range: 4 - 77)

66 allo-Tx, 17 auto-Tx, 0 CAR-T; 1 unknown

Collection of follow-up data is ongoing.

Information is limited since most patients have been reported the last 10 days.
Your transplantation team can register COVID cases in the EBMT database

Your story can help us better understand this disease and how to help other transplantation patients!

Thank you for helping us!
Thanks!

All information will be available at
https://www.ebmt.org/covid-19-and-bmt
https://www.ebmt.org/information-patients-donors
https://www.ebmt.org/patient-advocacy-committee